Bone Marrow/Stem Cell Transplant Frequently Asked Questions

Helpful information for patients, caregivers, and families

This booklet is dedicated to the growing population of bone marrow/stem cell transplant patients, survivors, their caregivers, and families. The National Bone Marrow Transplant Link (nbmtLINK) hopes that this booklet will provide you with helpful information, encouragement, and hope. We wish all of you a successful journey!

Founded in 1992, the nbmtLINK is an independent, nonprofit organization funded entirely through the generosity of individuals, corporations, and foundations. Tax deductible contributions are welcomed and enable us to create and sustain programs and services.

The mission of the National Bone Marrow Transplant Link is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

The information in this booklet should not be a substitute for medical advice, and the listed resources are not intended to be endorsements. Please consult with your physician regarding your medical decisions and treatment.

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Introduction

This booklet is intended for patients, caregivers, and families as they prepare for and enter the world of bone marrow/stem cell transplant. It was written as a helpful resource to give patients and families tools, information, encouragement, and support during their transplant journey. The term “patient” is used in this booklet to refer to the person receiving the transplant. We encourage you to use this booklet as a guide to enhance the recommendations of your physician and health care team. It is not meant to be a substitute for medical advice or an endorsement for a particular procedure. Remember that there is no “right” way or “wrong” way to go through a transplant. We hope that the information and suggestions in this booklet lead you to ask additional questions and to make the choices that are right for you and your family.

Question 1:
What diseases are typically treated with bone marrow/stem cell transplant?

Bone marrow/stem cell transplants are generally used to treat diseases of the blood, the immune system, or genetic disorders. A transplant can replace unhealthy blood-forming cells with healthy ones, or it can replenish blood-forming cells if chemotherapy and radiation destroy them. The diseases and disorders treated with bone marrow, peripheral blood, or cord blood transplantation include:

Leukemias
- Acute myelogenous leukemia (AML), acute lymphoblastic leukemia (ALL), chronic myelogenous leukemia (CML), chronic lymphocytic leukemia (CLL), juvenile myelomonocytic leukemia (JMML)

Lymphomas
- Hodgkin and non-Hodgkin lymphoma

Multiple myeloma and other plasma cell disorders

Severe aplastic anemia and other marrow failure states including:
- Severe aplastic anemia, Fanconi anemia, paroxysmal nocturnal hemoglobinuria (PNH), pure red cell aplasia, and amegakaryocytosis / congenital thrombocytopenia

Inherited immune system disorders including:
- Severe combined immunodeficiency (SCID) and Wiskott-Aldrich syndrome

Hemoglobinopathies including:
- Beta thalassemia major and sickle cell disease

Inherited metabolic disorders including:
- Hurler's syndrome (MPS-IH), adrenoleukodystrophy, and metachromatic leukodystrophy
Myelodysplastic and myeloproliferative disorders including:

- Refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, refractory cytopenias with multilineage dysplasia, polycythemia vera with fibrosis, essential thrombocythemia with fibrosis, chronic myelomonocytic leukemia, and agnogenic myeloid metaplasia (myelofibrosis)

Familial erythrophagocytic lymphohistiocytosis and other histiocytic disorders

Other conditions are also treated with bone marrow/ stem cell transplant, often through clinical trials. (See Question 18)

**Question 2:**

*How can I decide if a transplant is right for me or my child?*

Becoming informed about treatment options is the first step in making a decision about whether or not to proceed with a transplant. This means speaking to your physicians about treatment options, getting second opinions, discussing the risks and benefits of each option, and understanding the quality of life issues associated with each treatment plan. It is important to weigh all treatment options in order to determine what treatment is best for you or your child. Some diseases may warrant a more urgent consultation with a transplant specialist while others may not. If your physician suggests a transplant consultation, the transplant physician and the oncologist can work together to coordinate a treatment plan that is best for you or your child.

Often patients considering a transplant get second opinions from a number of specialists, including other transplant specialists. A second opinion provides additional information and can confirm a treatment recommendation, or it can bring to light information which may result in changes to the proposed treatment plan. It is important that the transplant physician receive the complete disease and treatment history, as well as any other information about health issues, before your appointment so that he/she will have enough time to go over your health information.

Effective communication requires effort on your part. Come to appointments prepared with questions you would like to ask. Giving accurate and complete health information to your doctors will help them better assess your situation and provide you with the information you need to decide on the right treatment for you. The risks and benefits of a transplant vary significantly from person to person, depending on the type of disease, health history, and current health. Therefore, it is important to communicate effectively with all of your physicians. Be sure to explain any difficulties or complications you or your child has experienced with prior treatments. Bring a list of all current medications, including the doses, frequency, and the reason for taking them.

It is a good idea to bring along a second person that you trust and have him/her take notes for you to help you remember what was said during the visit. Get to know who else, besides your doctor, works in the clinic. In some cases, having your questions answered may mean approaching other individuals who work in the medical office, such as a social worker, nurse, clinic manager, or finance person.
Question 3: What is a bone marrow/stem cell transplant?

A transplant, at its most basic level, is a procedure where an individual receives healthy stem cells to replace stem cells that were damaged either because of disease or treatment. Stem cells are the source of the different types of blood cells in our body, including the white blood cells, which fight infection. As such, stem cells play a key role in the functioning of our immune system. Stem cells also give rise to the red blood cells, which carry oxygen, and the platelets, which aid in blood clotting.

Stem cells are found in the spongy center of our bones but can be collected from different places in the body. The type of transplant a person receives depends in part on where the stem cells are collected.

- If the stem cells are collected from the bone marrow, which is the spongy tissue found in the cavities of the body’s bones, the procedure is referred to as a **bone marrow transplant**.
- If the stem cells are collected from the circulating blood, instead of from the bone marrow, the procedure is referred to as a **peripheral blood stem cell (PBSC) transplant**.
- If the stem cells are collected from the umbilical cord of a baby immediately after it is born, the procedure is referred to as a **cord blood transplant**.

The type of transplant also depends on who donates the stem cells:

- In an **autologous transplant**, the patient donates his/her own stem cells prior to treatment for reinfusion later.
- In an **allogeneic related transplant**, the person donating the stem cells is a biologically-related family member (usually a brother or sister).
- In an **allogeneic unrelated transplant**, the person donating the stem cells is not related to the patient but has been adequately tissue-matched.
- In a **syngeneic transplant**, the person donating the stem cells is an identical twin.

**Overview of the Transplantation Process**

**Autologous transplant**—The autologous transplant is not necessarily performed because there is something wrong with the bone marrow or stem cells. It is performed because the dose of chemotherapy and radiation needed to treat the cancer in the body is so high that it will destroy the patient’s existing stem cells in the bone marrow. And without stem cells, the body cannot produce blood cells or an immune system. So, in cases where the patient’s stem cells are healthy, they are collected prior to the high dose chemotherapy/radiation and are stored for safekeeping. After receiving high doses of chemotherapy and/or radiation to treat the cancer, the stem cells are then re-infused into the patient’s body through a vein, just as in the case of a blood transfusion. The patient’s own cells thus “rescue” or restore blood cell production and the immune system.

In most cases, it is recommended that the patient be in a full remission for the autologous transplant to be successful. However, in the case of some malignancies, patients with minimal disease can also be transplanted with their own stem cells. The
chemotherapy given for transplant often destroys any remaining diseased cells.

Even when the patient is in remission, it’s possible for some cancer cells to remain in the bone marrow or peripheral blood. In order to deal with this, some transplant centers have developed methods of purging or cleansing the stem cell product in an attempt to remove any remaining cancerous cells. The goal is to destroy enough diseased cells so that the body’s defense system will be able to destroy them after re-infusion. Purging is done differently from center to center, and many centers don’t do it at all. Bring up any questions you have about this procedure and the different methods used at different hospitals with your doctor and other medical professionals.

**Allogeneic transplant**—An allogeneic transplant is usually done when a patient has a disease or condition that affects their stem cells, such as leukemia or aplastic anemia or some genetic conditions. In these cases, the healthy stem cells of a donor are used to replace the patient’s damaged stem cells. Donors are all carefully screened to make sure that they are a good genetic match. Donors can be identical twins, siblings, or unrelated strangers.

Once infused into the patient’s body, the new healthy stem cells from the donor will then migrate to the spongy tissue in the bone and generate new blood cells, including a new immune system. This can be important in preventing relapse after transplant because the donor’s immune cells can destroy any remaining cancer cells in the patient, thus reducing the risk of relapse. This is referred to as *graft-versus-tumor (GVT)* or *graft-versus-leukemia (GVL)* effect. This graft-versus-tumor effect is one of the important treatment benefits of allogeneic stem cell transplantation.

To prepare for an **allogeneic transplant**, patients receive a **conditioning treatment** which involves chemotherapy with or without radiation. The purpose of conditioning treatment is to destroy any remaining cancerous cells in the body and also to weaken the patient’s immune system so that the new donor cells are not rejected and can grow and reproduce in the body. The duration and intensity of the conditioning treatment varies depending on the disease being treated and the age of the patient. Patients who are older or who have certain immune deficiencies may not require as intensive a conditioning regimen prior to transplant.

- **Myeloablative transplant**: In cases where the conditioning treatment involves high doses of chemotherapy and/or radiation and destroys the stem cells in the body, the process is referred to as **myeloablative** (marrow destroying). In this type of transplant, the patient receives high doses of chemotherapy and/or radiation that will destroy the host immune system along with as many remaining cancer cells as possible. The process of destroying the stem cells in the marrow creates “marrow space” for the new donor stem cells to grow in. This type of transplant is associated with greater side effects because of the high-dose chemotherapy and/or radiation. However, it can lead to a lower risk of relapse (the cancer coming back).

- **Non-myeloablative transplant/reduced intensity transplant**: In cases where the conditioning is less intensive and only weakens the immune system, the conditioning treatment is called **non-myeloablative** (non-marrow destroying). In this type of transplant, the patient receives lower doses of chemotherapy and/or radiation that will not destroy his or her marrow completely. Instead, the treatment weakens the
patient’s immune system just enough so that the donor’s stem cells are not rejected by the existing immune system. After this type of transplant, both the donor’s stem cells and the patient’s own stem cells can coexist (also called “mixed chimerism”). In a successful transplant, the donor cells will gradually fight off the patient’s blood and immune cells and establish a new donor immune system.

**Graft versus Host Disease (GVHD)**

In addition to the treatment benefits of high-dose chemotherapy and radiation therapy, allogeneic transplantation can provide the additional benefit of a strong, new immune system. However that new donor immune system can also attack the patient’s healthy tissues and organs, including the skin, gut, and liver. This reaction is called graft versus host disease (GVHD). The medical team will try to control the severity of GVHD through the use of immunosuppressant medications that will allow the new donor immune system to accommodate to its new environment in the patient’s body. Over time, the new immune system will learn to recognize the patient as “self” and will develop tolerance to the genetic differences in the tissues of its new environment. However, for the first several years after an allogeneic transplant, many patients do experience signs and symptoms of acute and then chronic GVHD. This can include symptoms such as dry eyes and mouth, discoloration in the skin, rashes, and fatigue, among others.

However, graft versus host disease can also be beneficial and reduce the risk of recurrence through the “graft versus malignancy” effect discussed earlier.

For additional information about graft versus host disease, please see webcasts: “Chronic Graft versus Host Disease in Adults” and “Graft versus Host Disease in Children and Adolescents” available at www.nbmtlink.org. Or call the nbmtLINK at 800-LINK-BMT (800-546-5268) or e-mail info@nbmtlink.org for additional information and resources.

**Question 4:**

**How are the stem cells used in transplant collected?**

The stem cells used in transplant are collected from one of three sources:

**Bone Marrow**

Stem cells are collected from the patient’s or donor’s bone marrow. Historically, this was the way that all stem cells were collected for transplantation, hence the common usage of the term “bone marrow transplantation.” The bone marrow collection is performed under general or spinal anesthesia. As such, the donor or patient doesn’t feel significant pain or discomfort during the marrow collection. This is an outpatient procedure, and the donor (or patient, in the case of an autologous transplant) usually goes home the same day. However, some soreness can be expected in the lower back after the procedure for a few days or longer. This discomfort can be well-controlled with oral pain medication.

The doctors use large, hollow needles to withdraw the liquid marrow from the back of the pelvic bone. The hip bones in the pelvis are used as a collection site because in the adult they are marrow-rich and contain the stem cells.
When the collection is complete, the donor or patient will be given instructions about icing, a prescription for pain medication if needed, and other recommendations for care. The amount of marrow taken in each case varies depending on the size of the transplant recipient. More marrow is needed for a large adult compared to a child. 

In general, the amount of marrow removed from the donor’s body will replenish itself within four to six weeks. In some cases, marrow donors will have a unit of their red blood cells collected in advance for transfusion during or after the harvest procedure. This would minimize the anemia (from blood loss) that may occur after the procedure. Don’t hesitate to discuss any of these procedures with the BMT physician or nurse coordinator prior to donation.

**Peripheral Blood**

When stem cells are collected from the circulating blood, the procedure is more like a blood or platelet 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 under normal circumstances. So before collecting the cells, medications (called 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. Most growth factors are administered as injections under the skin for approximately five days. The duration of growth factor administration and the number of collection procedures will depend on the number of stem cells collected. Ask the collection center staff for guidance.

The donor should not stop taking the growth factor unless advised. It is important that the correct dose of growth factor be administered around the same time each day. Physicians should be contacted immediately if any side effects occur.

Once these stem cells are released into the blood, they are collected in one or more sessions. During this procedure, blood is removed through a needle in the donor’s vein. Each session normally takes four to six hours. Stem cell collections are performed as outpatient procedures. Donors should plan to spend most of the day at the collection center on the day of collection. In this procedure, called **apheresis**, the blood circulates through a machine called a cell separator that removes the peripheral blood stem cells and returns the rest of the blood to the body.

For autologous bone marrow transplants, the stem cells are then stored and frozen until the time of the transplant. In an allogeneic transplant, stem cells are commonly infused fresh. However, in some circumstances, the cells from a related donor are frozen and stored prior to infusion.

**Cord Blood**

Since the first cord blood transplant in 1988, tremendous strides have been made in this field. Umbilical cord blood can be donated by parents when a child is born. Umbilical cord blood is rich in stem cells, and an increasing number of hospitals have the ability to collect the blood from the umbilical cord using special kits.

Cord blood plays an important role in transplant today. The use of cord blood transplants has increased for both children and adults. Cord blood is used more often in children
because a cord blood unit has a limited amount of blood-forming cells. Smaller patients need fewer cells, and larger patients may need two cord blood units combined.

Because cord blood cells are less immunologically mature compared to cells collected from adult donors, they can be used for transplantation even when there is a greater degree of human leukocyte antigen (HLA) mismatching between the patient and the cord blood unit. A close HLA match reduces the risk that your immune cells will attack the donor's cells or that the donor's cells will attack your body. As such, cord blood may offer a chance for transplant for patients who otherwise do not have any suitably matched adult donors.

There are potential advantages and disadvantages of using cord blood for a transplant. In some studies, patients who receive a cord blood transplant experienced less severe GVHD. However, a cord blood transplant may also carry a higher risk of graft failure, slower blood count recovery, and infection. As always, it is important to discuss the benefits and risks of a cord blood transplant with your doctor.

**Question 5:**

_How does the search for a donor get started?_

If you are having an allogeneic transplant, your center will initiate a donor search. In particular, they will look for someone who has a matching human leukocyte antigen (HLA) type. Human leukocyte antigens are proteins on the surface of your white blood cells, which serve as a kind of “fingerprint” and play an important role in your immune system’s ability to distinguish between “self” and “other.” There are several pairs of antigens that are considered important in determining the degree of fit between you and your donor. The transplant team will look for a donor who is a match at 6, 8, 10, or even 12 antigens. The transplant team might say that they are looking for a “10/10 match.” The more closely matched the donor and recipient are, the more likely it is that the new immune system will recognize the host’s body as “self,” and the less likely it is that the recipient will experience GVHD.

Blood type is not the same as HLA type – a well-matched donor may not have the same blood type as you. After the transplant, the patient will acquire the blood type of the donor.

Before initiating a national donor search, the transplant team will first check to see if any of your siblings are a match. Each full brother or sister has a 25% chance of being a match. An identical twin is a perfect match. If potential matches are not found through this preliminary search, a formal search is initiated. This part of the search usually takes weeks, if not months, and there are costs involved, so insurance approval will be sought first. Once potential donors are identified, they will be contacted to see if they are still able to donate. Each potential donor will need to undergo a physical exam to make sure it is safe for him/her to donate stem cells. Often friends and family members are enthusiastic to donate their stem cells, but it is unlikely that they would be a match. They can be referred to the Be the Match Registry. (See Resource Listing)
Question 6:
How does one become a bone marrow donor or donate cord blood?

Friends, coworkers, and others interested in becoming a volunteer bone marrow donor may either contact a local donor center or visit Be the Match at www.bethematch.org to learn more about local donor drives or about joining online. (See Resource Listing)

The criteria for becoming a volunteer donor include being between the ages of 18 and 60, meeting the health guidelines, and being willing to donate to any patient in need. Those who will not be able to serve as marrow or PBSC donors include people with a history of severe heart problems, cancer, hepatitis, insulin-dependent diabetes, or HIV infection. 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.

Donating umbilical cord blood poses no danger to the mother or newborn’s health, has no associated costs, and may save a life someday. Interested parents should speak with their obstetrician about this option in advance of their delivery. Public cord blood banks have staff dedicated to guiding potential donors through the process. Individuals may also be interested in options for private/family banking of cord blood for future use by the baby it came from or by immediate relatives. In this case, the family covers the cost of annual storage fees, but the parents retain ownership of the cord blood unit.

Question 7:
Where can I find information about survival rates?

This is a common question with a complex answer. Survival rates are numbers that are statistical estimates. Although statistics cannot predict outcomes for any particular individual, they are very useful for making treatment decisions and in understanding how a large group of people with a certain condition will fare over time.

There are many factors that influence how well someone will do, including age, disease, overall health, and previous treatments. Given recent advances, an increasing number of older individuals are receiving transplants now. When looking at survival statistics, it is important to remember that the existing data reflect statistics that are several years old and may not reflect your situation. Survival rate information is often presented in a complex way, geared to an audience of health professionals. A good resource for understanding survival data is Understanding Survival Outcomes Data on the Be the Match website. (See Resource Listing)

Keep in mind when looking at information on treatment outcomes for a particular disease or for a type of transplant, it is important to consider factors such as the age of the patients in the study, the type of disease being treated, and the number of people in the study. The results of a study that was done that looked at outcomes for people in their twenties and thirties, for example, will not be applicable to a person in their sixties.
Similarly, the results of a study on a group of people undergoing a transplant from a related donor may not be applicable to a person who is getting a transplant from an unrelated donor.

It will be helpful to share any information you gather with your health professionals, as they can help you interpret the data and its relevance to your situation.

Keep in mind that the patient, family members, and friends all deal with the stress of transplant differently. While one person may cope by gathering every available piece of information on treatment and survival statistics, another might feel overwhelmed and may choose not to look at journal articles, graphs, and charts or may allocate this task to a trusted friend or relative. This is also a perfectly acceptable way of coping.

**Question 8:**

*How much does a transplant cost? And how will I pay for all of this?*

Understandably, the prospect of a transplant is stressful enough without worrying about finances as well. The reality is that transplants are costly. Aside from medical costs, there may be additional out-of-pocket expenses. Being informed about the expenses can help you plan for and better manage the expenses that arise.

The entire transplant procedure (including donor search costs and post-transplant costs such as prescriptions and lodging) is expensive, and insurance plans vary widely on how much they cover. It is possible that much of your transplant, if not the entire cost, will be covered.

General ranges for an autologous transplant (using the patient’s own cells) can cost from $75,000–$150,000 or more. An allogeneic transplant (using donor cells, either related or unrelated) can range from $150,000–$300,000 or more. Call your insurer to learn about your health insurance coverage and what your transplant center choices are, or have your transplant center make the call on your behalf. If your insurer refuses to cover expenses, be persistent and consider speaking with legal counsel or someone with expertise in the insurance field. Consider getting second opinions at transplant centers covered by your insurance.

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, you can request a general estimate for the cost of your transplant and what your insurance plan will pay to determine your out-of-pocket expenses. This is especially important if your insurance coverage is limited.

It is difficult to predict your expenses after the transplant. Much will depend on your recovery time, which may range from six months to a year or longer. 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.

Be the Match offers a free financial guide for transplant patients called Mapping the Maze. This guide can help you plan for the costs of transplant. (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 transplant center to direct you to appropriate resources and organizations. Check with nonprofit organizations affiliated with your disease. Certain organizations help cover mileage, lodging, and even some prescriptions. See the Resource Listing for organizations that help with finances, while keeping in mind that the aid the organizations provide may vary from year to year and may be restricted geographically. Being persistent and resourceful in finding resources can be very helpful. Some patients contact different airlines to see if they can get discounted flights. Others call local relief agencies affiliated with their religion, and yet others may find financial help through their local social services agencies.

If the transplant is for a child under the age of 18, 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. 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.

Please call the nbmtLINK at 800-LINK-BMT (800-546-5268) or e-mail info@nbmtlink.org for additional information. If you need a transplant and have no resources to cover it, you may be eligible to enroll in a clinical trial without insurance. 800-4-CANCER is a national line that can help answer your questions.

Question 9:

Will my insurance cover the transplant?

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 bone marrow/stem cell transplant, ask for a written explanation and 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 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)

Navigating health insurance can be a complex process, and you will likely have specific questions about your coverage. If your questions are outside the scope of your treatment
center, or if you are not getting the answers you need from your insurance company, please refer to the resources listed under Financial and Fundraising, Insurance and Prescriptions, and Legal Rights and Workplace Issues in the Resource Listing. It is also helpful to consult with a social worker to provide guidance on navigating the system. You may also consider enlisting the help of a friend or family member to assist you in addressing the many details associated with health insurance and reimbursement for your treatments and health care.

**Question 10:**

*How do I choose a transplant center?*

Selecting a transplant center will be a big decision. Talk to your doctor and check with your insurance company to learn about your coverage. Factors such as living arrangements, proximity to family, and follow up care may influence your choice of whether to select a transplant center close to home or further away.

Signing on to stem cell transplant bulletin boards or newsgroups on the Internet can be another useful way to get information from other patients who have had their transplants at different centers. 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.

Visiting the transplant center before the transplant to familiarize yourself with the transplant setting and its staff is often useful. While you are at the center, you might inquire if you can speak to patients who have undergone transplants to get their impressions, feedback, and tips.

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. For example:

1. How many transplants has the center completed for people with your specific condition? Ideally, you should undergo a transplant at a center that has done at least 20 transplants of the type that you need. In general, the more transplants a center performs, the more experienced the staff typically is. In pediatrics, a moderately sized transplant center does around 20 transplants per year.

2. Are you going to have the same staff treating you throughout the transplant? Most transplant centers have doctors, nurse practitioners, physician assistants, etc. who rotate on a regular basis.

3. Will you have access to a social worker or counselor during the transplant?

4. What is the average amount of time that the nurses have worked in the BMT unit?

5. How experienced are the physicians at the center, and are there specialists (such as pulmonary and infectious diseases) available to handle complications should they arise?

6. Is there a support group for patients or their families?

7. What is the survival rate for patients with your condition in your age group undergoing your type of transplant?
8. Could someone who has undergone a transplant at the center contact you to tell you about their experience?

9. What is the visitor policy? How flexible is it? (Having your caregiver stay at the hospital overnight can be very comforting). Are children allowed to visit?

10. What living arrangements can be made for you and your family if you need to move away from your home to the transplant center? How much can your family expect to pay for living expenses?

11. Can the center provide any assistance to defray some of the family’s expenses?

12. Does the center have a long-term follow-up clinic that is easily accessible and will respond to questions once you leave the transplant center? This is particularly important if the oncologists near your home have very little experience with transplants.

13. Individuals undergoing a transplant from an unrelated donor should also inquire whether the center has a donor search coordinator and a quality tissue typing facility.

14. In addition, you may want to make a list of questions that are personally important to you. For example, “Will I be allowed to go outside, walk in the halls, or will I be confined to my room?” “Can the hospital accommodate my dietary needs?” “Can I ask for food at any time of the day, or do I have to order it a day in advance?” “Am I allowed to eat raw fruits and vegetables?” (Sometimes certain foods are restricted to reduce the risk of infection after transplant. Having a flexible eating schedule can be helpful as you may be nauseated at times and may not want to eat during conventional mealtimes.)

There are distinct advantages to having the transplant at an experienced medical center with an excellent track record. If there is no center near your home, or if you have concerns about the reported outcomes or the degree of experience at the center near you, you might consider moving your care to a larger more well-regarded center farther from home. Weighing the advantages of staying close to home where you have an extensive support network versus moving to a larger transplant center is difficult.

Be the Match has a Transplant Center Access Directory which has information about all U.S. transplant centers that perform allogeneic transplants. This information includes the number and type of transplants performed at each center, as well as some statistics about survival rates. Additionally, BMT InfoNet offers a comprehensive listing of transplant centers on their website, and the website of the Health Resources and Services Administration (HRSA) also offers comprehensive information. (See Resource Listing)

Please call the nbmtLINK at 800-LINK-BMT (800-546-5268) or e-mail info@nbmtlink.org for additional information.
Question 11:  
How do I tell my children about my transplant?

Communication is vital to all aspects of transplant. Children need to receive information that is appropriate to their age and stage of development. Teaching children about your 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.

Some cancer centers have a Pediatric Social Worker or Child Life Specialist with whom you can consult. These professionals have special training in age-appropriate communication with children and in family dynamics. You may also find it helpful to consult with the social worker at your center and review written materials about communicating with your child. Some useful resources about communicating with your child can be found in the Resource Listing.

Question 12:  
What do I tell my child about his/her transplant?

Children often do better when they have appropriate expectations. Describing some of the daily routines and some of the procedures in advance can be helpful. For example, saying “We will have a special way to brush your teeth” or “We will all have to wash our hands very often to keep you safe from bacteria” is useful. Letting them know that they will be admitted to the hospital for a month or longer is important. Explaining that they will receive medicines that may not be pleasant but that will make them better is often useful. When preparing your child for certain procedures, it is important to be as truthful as possible (so that they feel that they can trust what you say) while at the same time being positive and protecting them. For example, a parent might say, “The chemotherapy medicine is a very powerful medicine that will destroy the sick cells in your body so that you can get better and go back to school and play with your friends. But, chemotherapy can also make you feel sick and throw up. I want you to know that I will always be here with you and that if you feel sick, I will hold you and hug you. We will do this together, even though sometimes it will be hard. And when you are done with the chemotherapy, we will have a little celebration and some treats.”

It is sometimes helpful to describe the transplant as a second birthday, and many children enjoy looking forward to the ‘party’ after the chemotherapy and/or radiation. Many pediatric centers have creative ways to encourage children during this process. Help your child to understand that the transplant is a way to get better and get back to playing with friends and being at school.

Developing a plan to have a caregiver with the child throughout the transplant is
important. Most of the time, family members and/or friends will need to take shifts, as this may be too tiring for one individual. Helping the child to know that there will be someone there with them and that they are not alone provides comfort. For older children, finding ways to communicate with friends through the Internet or phone may be useful. Finally, many children will mirror the feelings that they perceive from those closest to them. As scary as it is to think of your child undergoing a transplant, it is important to convey to them that you will be supporting them throughout the process and that this is something that you all have the strength to manage. Try to be hopeful, yet open to all feelings that your child may have and may want to discuss. This may mean dealing compassionately and with understanding to anger, sadness, frustration, and questions about life and death. These are all normal responses to the life-changing experience of undergoing a transplant.

**Question 13:**

*What can I do to prepare myself mentally, physically, and emotionally for the transplant?*

Getting yourself and your family prepared to meet the transplant challenge can feel like a full time job. It takes a great deal of energy and effort. On an emotional level, preparing for a transplant may entail spending time with friends and family, rallying social support, and taking time out to be alone to experience one’s feelings. Counseling may also be helpful in coping with difficult emotions and making important decisions. On a physical level, this may mean eating a healthy 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.

Put together a notebook or binder to record information from your health care 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. Discussions between hospital staff and family will be helpful. Also, 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.
Question 14:
What can I expect before and during the transplant?

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. 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 if you are feeling pain or other symptoms. Be a good communicator. Conversations with your health care team are particularly important at this time.

The chemotherapy and/or radiation will also destroy the stem cells in your bone marrow and severely weaken your immune system. This is a time when you will be very immune-compromised, which means that you’ll be susceptible to infection. During this time, you’ll have to be very vigilant about guarding against bacterial, viral, and fungal infections. This entails staying away from sick people, washing hands frequently, keeping good oral hygiene with frequent mouth rinses, and eating food that has been meticulously prepared.

The bone marrow/stem cell transplant is a surprisingly simple procedure, very much like a blood transfusion. 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. You will be monitored frequently for any reaction to the infusion, but in most cases the process is uneventful. 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 are used, this generally occurs somewhat more quickly than with bone marrow or cord blood.

As your new stem cells establish themselves and start to reproduce (engraft), your risk of infection will start to go down. The time it takes for the new immune system to rebuild itself and become fully functional varies from patient to patient and may take from six months to a year or more. As the new immune system becomes established, the risk of infection declines.

Question 15:
What are the emotional considerations while undergoing transplant?

For some, going through the transplant is extremely difficult emotionally, whereas others find it easier than they expected. Some people are relatively alert and active during the transplant whereas others suffer greatly. Giving up control and losing one’s independence and privacy can be a very big adjustment. In some cases, the medications you will take may affect your mood. It is common to feel alternating emotions, such as worry, hope, anger,
fear, or even self-pity. Some patients find that while going through the transplant they lash
out at the people who are closest and dearest to them. Dealing with a changed status and
new role in the family may be difficult. You may find that other people are suddenly too
protective or, in other cases, not as understanding as you wish. Taking it one day at a time
and remembering to be gentle with yourself and others is helpful.

Learning about the anticipated course of treatment during hospitalization and possible
complications is important, although it can also cause anxiety for patients and their
relatives. Most transplant centers provide handouts about what to expect and possible
complications. Many people find that having the information helps them adjust their
expectations and gives them a sense of control.

A very important part of coping is communicating your needs and preferences to those
around you—your family and your doctors and nurses. Things that may seem obvious to you
may not be obvious to others. Let people know what you would like—what kind of food, what
kind of schedule, what kind of care. Ask what your options are and find out what services are
available to you.

Your caregiver or a social worker can also serve as your advocate. All transplant centers
should have a social worker who can meet with you to discuss your concerns and help you
manage your stress. Remember to ask for help when you need it. Professional counseling
can also positively impact your emotional well-being. Although there are many different
ways of coping, you might find the following suggestions helpful:

• Acknowledge the full range of your feelings, both positive and negative. Be honest
about how you feel, and then begin to plan out first steps in coping with your difficult
situation.

• Be kind to yourself. Take time for activities that bring you joy. Laughter and a good
attitude can be powerful sources of support and healing. Clearly, if you are not feeling
well, this can be quite a challenge. To the extent possible, try to incorporate some fun
into your days. Rent some funny movies or ask friends and family to send you videos.
Try to incorporate a few things you enjoy into your day.

• Communicate your needs! Often people will not know how best to support you unless
you tell them. Be specific. You might want to create a list of tasks that would be
helpful. Or have a friend coordinate the help that you need.

• If possible, try to arrange to have many different caregivers so that the burden is
shared and is lighter for everyone. Some caregivers may be able to visit in the hospital,
whereas others can help with rides to and from the doctor, as patients are not able to
drive on their own for several weeks.

• Focus on the issues that bring meaning to your life—your religion, spirituality,
interests, or passions.

• Exercise on a daily basis to improve your mood, promote health and maintain muscle
strength.

• Use guided imagery and meditation to reduce stress. (See Resource Listing under
Alternative, Complementary and Integrative Medicine.)

Often patients and families facing a transplant appreciate talking with someone who
has been through the transplant experience, a BMT survivor or caregiver. The National
Bone Marrow Transplant Link’s Volunteer Peer Support On Call Program links up trained volunteers with patients, survivors, or caregivers. Whether by phone, e-mail, or written correspondence, being “linked” to a peer support volunteer can be very helpful. Hearing how someone has coped with a difficult situation can often better prepare you emotionally for your own journey and lets you know that you are not alone. It is equally helpful for caregivers to talk to others in similar circumstances.

**Question 16:**

**How do I choose a caregiver?**

When you are referred for a bone marrow or cord blood transplant, your transplant center coordinator will ask you to identify a responsible family member or friend who can provide physical care and emotional support during and after your transplant. 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. In many cases, the choice of a primary caregiver is obvious: a spouse or partner, a parent, or an adult child. In others, the choice is less clear. Some people have several family members or friends who may be able to work together as a caregiving team. In some situations, you may have to think “outside the box.” For example, a religious or service group may take turns caring for a transplant patient in their community.

You may want to consider the following before asking someone to be your caregiver:

- Your caregiver may have to be away from his or her work for weeks or even months. Is your caregiver able to take a leave (Family Medical Leave Act — FMLA) or an extended absence from work? Does he or she have a good means of support that will allow for unpaid time off?

- Your caregiver will often be your escort. Will he or she have the time and the transportation to take you to your medical appointments?

- You may have to be at the hospital for long periods of time. Is this person comfortable in the hospital setting?

**Question 17:**

**What are the responsibilities of a caregiver?**

Ideally, 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 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.

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. 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 other 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:

- Providing emotional support
- Providing physical care during and after hospitalization
- Caring for the central line (catheter in a vein in the chest)
- Helping administer 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.

Please call the nbmtLINK at 800-LINK-BMT (800-546-5268) or e-mail info@nbmtlink.org for additional information.

**Question 18:**

**What is a clinical trial?**

According to the U.S. Department of Health and Human Services, a clinical trial is “a research study conducted to evaluate a medical procedure or medical product, such as a drug.” New treatment approaches for transplant-related side-effects and complications are also being tested through clinical trials.
Clinical trials have three phases:
• Phase 1: Determines whether the treatment is safe, the best way to give the treatment and the right dose that causes the fewest side effects
• Phase 2: Determines the effectiveness of treatment and whether there are less common side effects which may appear when more patients receive the treatment
• Phase 3: Compares/contrasts the new treatment with standard treatment

Benefits of a clinical trial may include lower treatment costs, additional monitoring and follow-up above the standard of care, and potential availability of newer treatments not currently available to treat your malignancy. Drawbacks may include unknown side-effects and insurance issues.

Discuss the pros and cons of participating in a clinical trial with your doctor. For information on Clinical Trials, see Resource Listing under National Cancer Institute and National Institutes of Health.

Question 19:

How long does recovery take?

Recovery from a bone marrow, peripheral blood, or cord blood transplant is highly variable and can take from several months to a year or more. As a general rule, autologous transplant recipients recover more quickly than allogeneic transplant recipients. By one year after transplant, many transplant survivors are able to take part in some of their usual activities, such as work or school. For others, it may take two or more years to recover their strength and energy. And there are also individuals who never fully regain their health and struggle with fatigue and other chronic health issues for years to come.

Many factors, such as the development of infections or graft versus host disease (GVHD), will impact the recovery period. In chronic GVHD, the new immune system can attack different parts of the body. Areas that are commonly affected include the skin, eyes, mouth, digestive tract, joints, lungs, and liver. In addition to damaging organs, GVHD and its treatment may also cause immunosuppression and fatigue and can make you more vulnerable to infection.

Your treatment team will monitor you closely, and you may be given antimicrobial medications to prevent the most common post-transplant infections. It is very important to have a comprehensive discussion with your doctor and other members of your health care team before the transplant and during your post transplant care. Dealing with infections, staying away from crowds, limitations on traveling, the importance of good hygiene, and the management of GVHD through immunosuppressive medication are all important topics to cover. The nbmtLINK offers a series of GVHD telephone/education support groups and helpful webcasts, including: “Understanding and Coping with Chronic Graft versus Host Disease,” “Chronic Graft versus Host Disease in Adults,” and “Graft versus Host Disease in Children and Adolescents” available at www.nbmtlink.org. Additionally, Be the Match offers guidelines for evaluation and management of GVHD and other late effects. (See Resource Listing)
Question 20:

Are there any survivorship resources?

There are a growing number of available transplant survivorship resources. As a starting point, go to the National Bone Marrow Transplant Link's website at www.nbmtlink.org where you will find information on survivorship programs as well as publications, such as the *Survivorship Guide for Bone Marrow/Stem Cell Transplant, Coping with Late Effects*. This booklet includes a listing of many other survivorship resources, in addition to practical advice from 2, 5, 10, and 15+ year survivors. You will also find helpful links to other advocacy organizations.

Detailed guidelines for follow-up care are summarized in two helpful guides from Be the Match and the CIBMTR, *A Guide to Protecting Your Health After Transplant, Recommended Tests and Procedures* (for Autologous and for Allogeneic patients) and a handout for clinicians entitled *Clinician’s Quick Reference Guidelines: Transplant Consultation and Post-Transplant Care*. The Lance Armstrong Foundation also offers information on improving rehabilitation and managing issues of survivorship. In this booklet you will find a listing of many other helpful resources, but your best source of medical information is your physician and other health care professionals. If you have additional questions that were not addressed in this booklet, please contact the nbmtLINC by phone 800-546-5268 or email info@nbmtlink.org.

We would like to hear from you.
Please take our five minute online survey at:

http://www.zoomerang.com/Survey/WEB22FR8MBW4RS

You may also call 800-546-5268 for a print version of the survey or for any questions that you may have.
The National Bone Marrow Transplant Link provides a number of services and resources designed to meet the needs of patients, survivors, caregivers, and health care professionals, including:

- Survivorship Programs & Publications
- Information & Referral
- Peer Support On Call
- Celebrating Second Birthdays
- Informative Webcasts & Podcasts
- Emmy Award-winning DVD
- Chronic Graft versus Host Disease (cGvHD) Telephone Education/Support Groups

Visit us online at www.nbmtlink.org or call 1-800-LINK-BMT.
Resource Listing

The following list of resources may be helpful to BMT survivors, their caregivers, and families. They are not intended to be endorsements. While the internet may be a valuable tool, it may also contain misleading or inaccurate information. Remember, the best source of medical advice is your physician and other health care professionals. Additional information and resources may be found on the National Bone Marrow Transplant Link web site at www.nbmtlink.org.

**Bone Marrow/Stem Cell Transplant Information and Support**

**Be The Match**
Patient Services 888-999-6743 or 612-362-3410
www.bethematch.org/patient
www.exploreBMT.org

**National Bone Marrow Transplant Link (nbmtLINK)**
800-LINK-BMT (800-546-5268) or 248-358-1886
www.nbmtlink.org

**Blood & Marrow Transplant Information Network (BMT InfoNET)**
888-597-7674 or 847-433-3313
www.bmtinfonet.org

**BMTSupport.org**
www.bmtsupport.org

**The Bone Marrow Foundation**
800-365-1336 or 212-838-3029
www.bonemarrow.org

**American Society for Blood and Marrow Transplantation (ASBMT)**
847-427-0224
www.asbmt.org

**Center for International Blood & Marrow Transplant Research (CIBMTR)**
414-805-0700
www.cibmtr.org

**Health Resources and Services Administration**
C.W. Bill Young Cell Transplantation Program
http://bloodcell.transplant.hrsa.gov

**Bone Marrow Donor Information**

**Be the Match Registry**
Operated by the National Marrow Donor Program
800-MARROW2 (800-627-7692)
www.bethematch.org
Asians for Miracle Marrow Matches (A3M)  
888-A3M-HOPE (888-236-4673)  
www.asianmarrow.org

Bone Marrow Donors Worldwide  
www.bmdw.org

The Caitlin Raymond International Registry  
800-726-2824 or 508-334-8969  
www.crir.org

DKMS Americas  
866-340-3567  
www.dkmsamericas.org

Gift of Life Bone Marrow Foundation  
800-9MARROW or 561-982-2900  
www.giftoflife.org

ALTERNATIVE, COMPLEMENTARY AND INTEGRATIVE MEDICINE

Complementary/Integrative Medicine Education Resources  
MD Anderson Cancer Center  
877-MDA-6789 (877-632-6789)  
www.mdanderson.org/departments/CIMER/

Integrative Medicine – About Herbs, Botanicals and Other Products  
Memorial Sloan-Kettering Cancer Center  
212-639-2000  
www.mskcc.org/mskcc/html/11570.cfm

MayoClinic.com – Drugs and Supplements  
Mayo Clinic  
507-284-2511  
www.mayoclinic.com/health/drug-information/DrugHerbIndex

National Center for Complementary and Alternative Medicine  
888-644-6226  
www.nccam.nih.gov

National Institutes of Health Office of Dietary Supplements  
301-435-2920  
http://ods.od.nih.gov

National Cancer Institute Office of Cancer Complementary and Alternative Medicine  
301-435-7980  
www.cancer.gov/cam/index.html
CANCER, MULTISERVICE

American Cancer Society
800-ACS-2345 (800-227-2345)
www.cancer.org

CancerCare, Inc.
800-813-HOPE (800-813-4673)
www.cancercare.org

National Cancer Institute
Cancer Information Service
800-4-CANCER
www.cancer.gov

CAREGIVER SUPPORT

Family Caregiver Alliance
800-445-8106 or 415-434-3388
www.caregiver.org

National Alliance for Caregiving
301-718-8444
www.caregiving.org

National Family Caregivers Association
800-896-3650 or 301-942-6430
www.thefamilycaregiver.org

Rosalynn Carter Institute for Caregiving
Georgia Southwestern State University
229-928-1234
www.rosalynncarter.org

Well Spouse Association
800-838-0879 or 732-577-8899
www.wellsppouse.org

Young (Cancer) Spouses
www.youngcancerspouses.org

CHILDREN, ADOLESCENTS, YOUNG ADULTS

Beyond the Cure
(National Children’s Cancer Society)
800-5-FAMILY (800-532-6459)
www.beyondthecure.org
Cancer Survivors’ Fund
281-437-7142
www.cancersurvivorsfund.org

American Childhood Cancer Organization (formerly Candlelighters)
800-366-2223 or 301-962-3520
www.acco.org

CureSearch for Children’s Cancer
Children’s Oncology Group
800-458-6223
www.curesearch.org
www.survivorshipguidelines.org

I’m Too Young for This! Cancer Foundation
877-735-4673
www.i2y.org

Planet Cancer
512-452-9010
www.planetcancer.org

Ronald McDonald House Charities
630-623-7048
www.rmhc.org

The SAMFund for Young Adult Survivors of Cancer
866-439-9365 or 617-938-3484
www.thesamfund.org

SuperSibs!
888-417-4704 or 847-462-4742
www.supersibs.org

Teens Living with Cancer
585-563-6221
www.teenslivingwithcancer.org

The Ulman Cancer Fund for Young Adults
888-393-3863 or 410-964-0202
www.ulmanfund.org
Clinical Trials

Cancer.gov (National Cancer Institute)
888-624-1937
www.cancer.gov/clinicaltrials

CenterWatch Clinical Trials Listing Service
www.centerwatch.com

Coalition of Cancer Cooperative Groups, Inc.
www.cancertrialshelp.org

EmergingMed
877-601-8601
www.emergingmed.com

National Institutes of Health
www.clinicaltrials.gov

Disease Related Information

American Sickle Cell Anemia Association
216-229-8600
www.ascca.org

Aplastic Anemia & MDS International Foundation, Inc.
800-747-2820 or 301-279-7202
www.aamds.org

Fanconi Anemia Research Fund, Inc.
888-326-2664 or 541-687-4658
www.fanconi.org

American Brain Tumor Association
800-886-2282 or 773-577-8750
www.abta.org

National Brain Tumor Society
800-770-8287
www.braintumor.org

National Comprehensive Cancer Network
215-690-0300
www.nccn.com

Immune Deficiency Foundation
800-296-4433
www.primaryimmune.org
National Organization for Rare Disorders
800-999-6673 or 203-744-0100
www.rarediseases.org

The Leukemia & Lymphoma Society
800-955-4572 or 914-949-5213
www.lls.org

Leukemia Research Foundation
(Illinois residents and Chicago vicinity)
888-558-5385 or 847-424-0600
www.leukemia-research.org

Lymphoma Research Foundation
800-500-9976 or 212-349-2910
www.lymphoma.org

International Myeloma Foundation
800-452-2873 or 818-487-7455
www.myeloma.org

Multiple Myeloma Research Foundation
203-229-0464
www.themmrf.org

Fertility, Sexuality, and Intimacy

The American Association of Sex Educators, Counselors, and Therapists
202-449-1099
www.aasect.org

American Society for Reproductive Medicine
205-978-5000
www.asrm.org

Female Sexual Medicine Program
650-723-7243
http://womenshealth.stanford.edu/fsm/

Fertile Hope (LIVESTRONG)
855-220-7777
www.fertilehope.org

Genetics and IVF Institute
800-552-4363 or 703-698-7355
www.givf.com
Frequently Asked Questions

The Oncofertility Consortium at Northwestern University
866-708-3378
http://myoncofertility.org

Resolve: The National Infertility Association
703-556-7172
www.resolve.org

FINANCIAL AND FUNDRAISING

Cancer Financial Assistance Coalition
www.cancerfac.org

The Max Foundation
888-462-9368 or 425-778-8660
www.themaxfoundation.org

National Association of Hospital Hospitality Houses
800-542-9730
www.nahhh.org

National Foundation for Transplants
800-489-3863 or 901-684-1697
www.transplants.org

HelpHOPELive (Formerly National Transplant Assistance Fund)
800-642-8399
www.HelpHOPELive.org

Patient Access Network Foundation
866-316-7263
www.panfoundation.org

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

INSURANCE AND PRESCRIPTIONS

Foundation for Health Coverage Education
800-234-1317
www.coverageforall.org

Medicare
800-MEDICARE (800-633-4227)
www.medicare.gov

Medicare Rights Center
800-333-4114
www.medicarerights.org
NeedyMeds, Inc.
www.needymeds.org

Partnership for Prescription Assistance
888-477-2669
www.pparx.org

LEGAL RIGHTS AND WORKPLACE ISSUES

American Bar Association
800-285-2221
www.americanbar.org

Americans with Disabilities Act
800-514-0301
www.ada.gov

Cancer and Careers
646-929-8032
www.cancerandcareers.org

Cancer Legal Resource Center
866-843-2572 or 213-736-1455
www.cancerlegalresourcecenter.org

Equal Employment Opportunity Commission
800-669-4000
www.eeoc.gov

National Cancer Legal Services Network
www.NCLSN.org

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

MANAGING SIDE EFFECTS

American Pain Society
847-375-4715
www.ampainsoc.org

Boston Foundation for Sight
781-726-7337
www.bostonsight.org

Cancer Symptoms (Oncology Nursing Society)
866-257-4667
www.cancersymptoms.org
National Bone Marrow Transplant Link
Coping with Chronic GVHD Telephone Education/Support Group and Webcasts
800-LINK-BMT (800-546-5268) or 248-358-1886
www.nbmtlink.org

National Lymphedema Network
800-541-3259 or 415-908-3681
www.lymphnet.org

National Sleep Foundation
703-243-1697
www.sleepfoundation.org

The Neuropathy Association
212-692-0662
www.neuropathy.org

Nutrition

American Institute for Cancer Research
800-843-8114 or 202-328-7744
www.aicr.org

Food and Nutrition Information Center
www.nutrition.gov

Survivorship

Association of Cancer Online Resources (ACOR)
212-226-5525
www.acor.org
BMT Talk: http://listserv.acor.org/SCRIPTS/WA-ACOR.EXE?A0=bmt-talk
GvHD: http://listserv.acor.org/SCRIPTS/WA-ACOR.EXE?A0=GVHD

R.A. Bloch Cancer Foundation, Inc.
800-433-0464 or 816-854-5050
www.blochcancer.org

Cancer.Net (American Society of Clinical Oncology)
888-651-3038 or 571-483-1780
www.cancer.net

Cancer Hope Network
800-552-4366 or 908-879-4039
www.cancerhopenetwork.org

Cancer Support Community (Formerly Gilda’s Club and the Wellness Community)
888-793-9355
www.cancersupportcommunity.org
Cancervive
cancervivr@aol.com
www.cancervive.org

Journey Forward
707-636-5900
www.journeyforward.org

LIVESTRONG Lance Armstrong Foundation
855-220-7777
www.livestrong.org

National Cancer Survivors Day Foundation
615-794-3006
www.ncsd.org

National Coalition for Cancer Survivorship
877-622-7937 or 301-650-9127
www.canceradvocacy.org

Oncolink
Abramson Cancer Center of the University of Pennsylvania
www.oncolink.org

Vital Options International
818-508-5657
www.vitaloptions.org

Transportation

Air Care Alliance
888-260-9707
www.aircareall.org

Air Charity Network
877-621-7177
www.aircharitynetwork.org

Corporate Angel Network
866-328-1313 or 914-328-1313
www.corpangelnetwork.org

National Patient Travel Center
800-296-1217
www.patienttravel.org

Patient AirLift Services
888-818-1231
www.palservices.org
CD’s / DVD’s / Videos

Coping with Chronic GVHD in Adults and Meeting the Challenges of Chronic GVHD in Children & Adolescents, National Bone Marrow Transplant Link, 2009

Decisions. Support. Possibilities. Transplant as an Option When You are 50 and Older, Be The Match, 2011

Guided Visualization Working with the Healing Power of Your Immune System, Aquarius Health Care Media, 2003

The Healing Attitude: The Empowered Patient, Aquarius Health Care Media, 2007

Insights: Experiencing Transplant as a Young Adult, Be The Match, 2011

The New Normal: Life after Bone Marrow/Stem Cell Transplant, National Bone Marrow Transplant Link, 2001

Stress Relief Healing with Dr. Russ Greenfield, Aquarius Health Care Media, 2006

Super Sam versus the Marrow Monsters. A Guide to Bone Marrow Transplant for Children and their Families, Be The Match, 2011


Books and Magazines


100 Questions & Answers about Cancer and Fertility, by Kutluk H. Oktay, 2008

After the Diagnosis: How to Look Out for Yourself or a Loved One, by Donna L. Pikula, DDS, 2006


American Cancer Society Complete Guide to Nutrition for Cancer Survivors: Eating Well, Staying Well, 2010

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

Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration, by Norman Cousins, 2005

Anticancer: A New Way of Life, by David Servan-Schreiber, 2009

The Art of Conversation Through Serious Illness: Lessons for Caregivers, by Richard P. McQuellon, 2010

Breaking the Silence: Inspirational Stories of Black Cancer Survivors, by Karin L. Stanford, PhD, 2005


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 National Coalition for Cancer Survivorship, edited by Barbara Hoffman, 2004


Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives, National Bone Marrow Transplant Link, 2007


Crazy Sexy Cancer Tips, by Kris Carr, 2007

Creative Visualization: Use the Power of Your Imagination to Create What You Want in Life, by Shakti Gawain, 2009

Chronic Graft Versus Host Disease: Interdisciplinary Management, by Georgia B. Vogelsang, MD and Steven Z. Pavletic, MD, 2009

Coping with Cancer Magazine, www.copingmag.com

Coping with Prednisone (and other cortisone-related medicines), by Eugenia Zukeman and Julie R. Inglefinger, MD, revised and updated 2007

CURE Magazine, www.curetoday.com

Diagnosis: Cancer, by Wendy Schlessel Harpham, 2003

Eating Well Through Cancer; by Holly Clegg & Gerald Miletello, MD, 2008

Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and their Families, by Ernest Rosenbaum, MD and Isadora Rosenbaum, 2005


Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness, by Jon Kabat-Zinn, PhD, 2009

Handbook of Cancer Survivorship, by Michael Feuerstein, PhD, 2007


Kitchen Table Wisdom: Stories That Heal, by Rachel Naomi Remen, MD, 2006


Men Cancer Sex, by Anne Katz, 2010

Nutritional Issues in Cancer, edited by Valerie J. Kogut, MA, RD, LDN, 2005

One Bite at a Time Nourishing Recipes for Cancer Survivors and Their Friends, by Rebecca Katz with Mat Edelson, 2nd edition, 2008

Out of Nowhere, by Esther M.R. Hougham, 2011


Picking Up the Pieces: Moving Forward after Surviving Cancer, by Sherri Magee and Kathy Scalzo, 2007

Resource Guide for Bone Marrow/Stem Cell Transplant: Including Bone Marrow, Peripheral Blood, and Cord Blood, National Bone Marrow Transplant Link, 2006 (Online only at www.nbmtlink.org)

Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner, American Cancer Society, 2005

Stumbling Toward Heaven: Mike Hamel on Cancer, Crashes and Questions, by Mike Hamel, 2011

Survivorship Guide for Bone Marrow/Stem Cell Transplant: Coping with Late Effects, by Keren Stronach, National Bone Marrow Transplant Link, 2010
Understanding Cancer Therapies, by Helen S.L. Chan, 2007

Voices of Hope & Healing For Bone Marrow/Stem Cell Transplant; Offering Inspiration, Support & Hope to Patients, Survivors & Their Caregivers, National Bone Marrow Transplant Link, 2011


When Bad Things Happen to Good People, by Harold S. Kushner, 2004

Woman Cancer Sex, by Anne Katz, 2009

You Can Conquer Cancer: Prevention and Management, by Ian Grawler, 2005

You the Smart Patient: An Insider’s Handbook for Getting the Best Treatment, by Michael F. Roizen, MD and Mehmet C. OZ, MD with the Joint Commission, 2006

Your Brain After Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus, by Diana Dyer, 2010


We would like to hear from you.
Please take our five minute online survey at:

http://www.zoomerang.com/Survey/WEB22FR8MBW4RS

You may also call 800-546-5268 for a print version of the survey or for any questions that you may have.