

# Living With Blood and Marrow Transplant Resource Booklet



A Companion Booklet to  
the *Cancer Survival Toolbox*®  
Transplant Audio Resource Program



*"Lots of good information on both physical and emotional things related to transplantation."*

—John T.



*"This program showed me what I could do to help get the best possible outcomes."*

—Kathy S.



*"Full of practical tips and tools that helped me cope. This program made a huge difference."*

—Javier L.

## The *Cancer Survival Toolbox*<sup>®</sup> Program: Blood and Marrow Transplant

The award-winning *Cancer Survival Toolbox* is a self-learning audio program created by the National Coalition for Cancer Survivorship (NCCS), along with cancer survivors and leading cancer organizations, to help you develop practical skills that you can use on a day-to-day basis as you deal with a cancer diagnosis and treatment for yourself or a loved one. To order additional copies of this FREE program, please contact the National Coalition for Cancer Survivorship at 877-NCCS-YES (877-622-7937) or [www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox).

The audio program that comes with this booklet focuses on transplantation of blood and marrow stem cells for the treatment of various forms of cancer that affect adults. The goal of this program is to provide people who are considering transplant as a treatment option—and their caregivers, family, and friends—with tools that can improve their abilities to cope during and after this form of treatment. This program, written by cancer survivors and health care professionals, can be used on its own or along with the other Toolbox programs.

Contact information for all organizations and websites mentioned in the audio program is provided.

This Resource Booklet supports information offered in the audio portion of the “Living With Blood and Marrow Transplant” program of the *Cancer Survival Toolbox*. While far from all-inclusive, it offers a place to begin the search for information and understanding about the complex processes of blood and marrow transplantation in the treatment of blood cancers. Enough information is provided to prepare potential transplant donors, recipients, and family caregivers to formulate and ask questions and communicate well with health care and transplant team members. Voices of people considering transplant as a treatment option, and others who are transplant recipients and survivors, are testament to shared concerns, fears, and hopes that arise from the notion of blood and marrow transplantation. If you, a family member, or a friend need to consider transplant, ask every question that comes to mind. Look for a member of the transplant team who is most likely to be able to answer your questions. The glossary at the end of this booklet will help you learn the language of transplant so that you can understand other members of the transplant team—and they can understand you. Use the list of resources at the end of the booklet to search for more in-depth information that is specific to your needs. The 6 *Basic Skills* programs of the *Cancer Survival Toolbox* (Communicating, Finding Information, Making Decisions, Solving Problems, Negotiating, and Standing Up for Your Rights) are, after all, generic life skills that anyone can use. Applying these basic skills to the more difficult and complex issues of transplantation can help potential transplant recipients and their caregivers face the challenges ahead, knowing how to find and use any and all available sources of support, information, and guidance.

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## **Using the Internet to Find Information**

On the Internet, people affected by cancer and cancer survivors can get information available throughout the world, all at the touch of a few keystrokes on a computer in their homes, libraries, and community centers. It can be hard to find your way around the Internet at first. You may need to ask for help. A word of caution: There is a great deal of very helpful, reliable, factual information available on the Internet, but there is also a lot of misinformation. It is important to be sure your sources are reliable and to check information further. The most reliable medical information will come from well-known cancer organizations, research facilities, hospitals, libraries, government agencies, and professional journals.

There are many good books to help you get comfortable with using the Internet. Also, many companies that provide Internet access offer free classes to help beginners learn to use the Internet. Community colleges, senior centers, information specialists in community or hospital libraries, or the cancer information specialist in a cancer resource center may be able to provide the help you need to get started.

# What Is Transplantation?

The Leukemia & Lymphoma Society (LLS) defines transplantation as “a procedure that replaces unhealthy blood-forming cells with healthy ones.” Transplantation is an option sometimes offered to people with certain types of blood cancers (see Table 1). About 50,000 transplants are done worldwide each year. A transplant is not usually the first treatment used; instead, radiation, chemotherapy, and/or immunotherapy may be offered. If these therapies don’t work, or if the cancer responds but then comes back (recurs), a transplant may then become an option.

*Table 1. Blood Cancers That May Be Treated With Transplantation\**

Allogeneic Transplant	
Acute lymphocytic leukemia	Hodgkin disease
Acute myelogenous leukemia	Multiple myeloma†
Chronic lymphocytic leukemia	Myelodysplastic syndrome
Chronic myelogenous leukemia	Non-Hodgkin lymphoma
Autologous Transplant	
Multiple myeloma	Hodgkin disease
Non-Hodgkin lymphoma	Acute myelogenous leukemia

\* This list is not all-inclusive.

† Investigational.

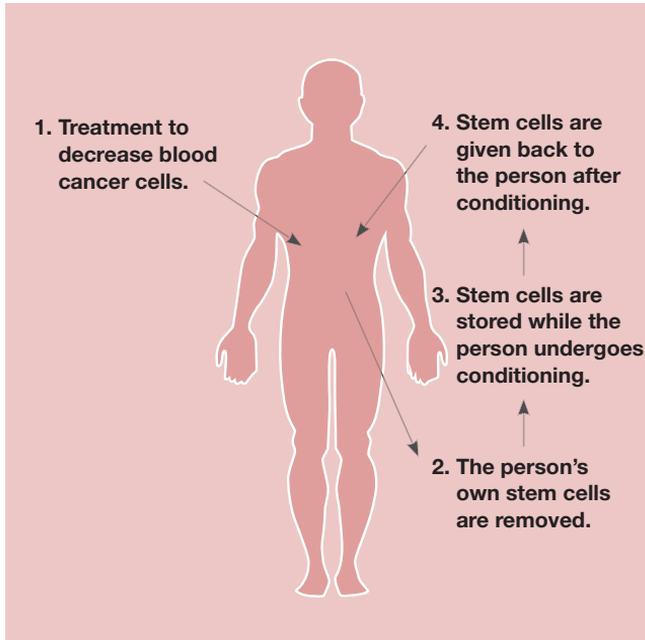
Adapted from Ezzone SA. Table 18-1: Hematologic and Nonhematologic Conditions Treated With HSCT. In: Yarbro CH, Wujcik D, Gobel BH, eds. *Cancer Nursing: Principles and Practice*; 2011:506.

## Types of Transplantation

The types of transplantation are named according to the source of healthy cells:

- **Autologous Transplantation (also called autologous stem cell infusion)**—A person’s stem cells (the cells from which all blood cells develop) are removed and stored while the person undergoes conditioning (the preparation process that rids the body of disease). Then, these cells are given back to the same person. Since the patient’s own cells are transplanted, risks associated with donor cells are largely avoided (See Figure 1).

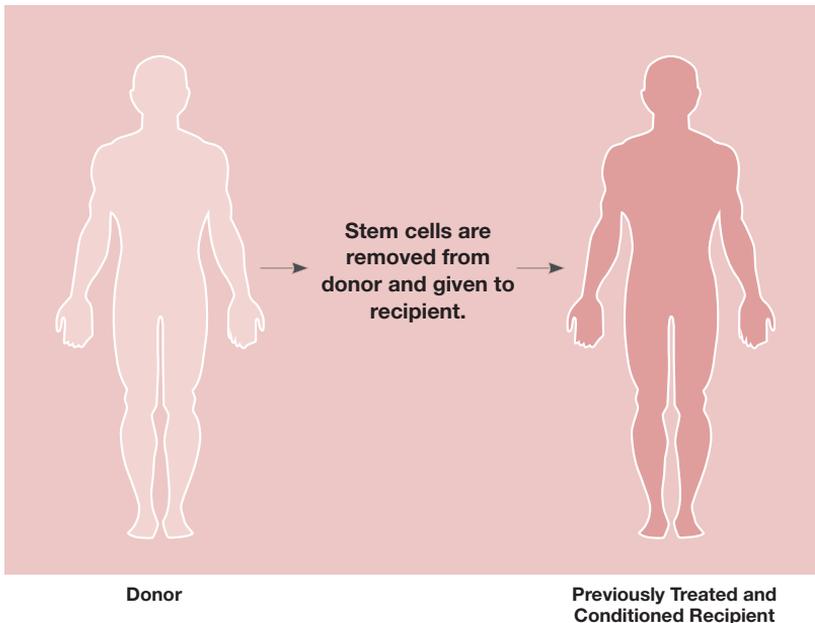
*Figure 1. Autologous Transplantation*



Adapted from *Blood and Marrow Stem Cell Transplantation*, The Leukemia & Lymphoma Society, 2011, and available online at <http://www.lls.org/#/resourcecenter/freeeducationmaterials/treatment/bloodmarrowstemcelltransplant>. Reprinted with permission of The Leukemia & Lymphoma Society.

- **Allogeneic Transplantation**—A person undergoes conditioning and then receives stem cells from a genetically similar donor. This is often a sister or brother, but could be an unrelated donor whose stem cells are a close match. Stem cells from umbilical cord blood may also be used. Possible complications include rejection of the donor stem cells by the recipient (host-vs-graft effect), or a donor cell reaction to the recipient (graft-vs-host disease, or GVHD) (See Figure 2).

*Figure 2. Allogeneic Transplantation*



Adapted from *Blood and Marrow Stem Cell Transplantation*, The Leukemia & Lymphoma Society, 2011, and available online at <http://www.lls.org/#/resourcecenter/freeeducationmaterials/treatment/bloodmarrowstemcelltransplant>. Reprinted with permission of The Leukemia & Lymphoma Society.

- **Syngeneic Transplantation**—Use of an identical twin sibling donor.
- **Reduced-Intensity Allogeneic Transplantation (also called nonmyeloablative transplantation)**—Similar to an allogeneic transplant, but during conditioning the person's bone marrow is not totally destroyed. Although reduced-intensity transplantation does carry some of the same risks as standard allogeneic transplantation, it may be an option for patients who are older, have major organ complications, or are otherwise not healthy or strong enough to undergo standard allogeneic transplantation.

## Transplantation Treatment Goals

The primary goals of transplantation are to increase the length of disease-free survival and, for many people, offer hope for a cure.

## Conditioning

As mentioned above, before a person receives a transplant, they undergo conditioning. Conditioning is done to (1) rid the body of disease, (2) stop cancer cell production, and (3) suppress the immune system (make it so it doesn't work as well), so that the transplant is more likely to succeed.

During conditioning, the recipient gets high doses of chemotherapy, total body radiation therapy, or both. Side effects can include nausea, vomiting, diarrhea, sores in the mouth and throat, hair loss, infection, and extreme fatigue. Other side effects can also occur. Medicines can be used to prevent or minimize nausea, vomiting, and diarrhea. Platelet and/or red blood cell transfusions may also be needed. Side effects in people receiving reduced-intensity allogeneic transplantation are usually not as bad and go away more quickly. Your transplant team can help you learn about what side effects you are likely to have and how to make these side effects easier to deal with.

## Supportive Care Before, During, and After Transplantation

Because of the intense nature of transplantation, recipients are given specialty care throughout the transplantation process. Short-term (acute) and longer-term (chronic) complications, or problems, can occur (See Table 2). These can be related to the disease itself, the conditioning treatment, GVHD, and/or side effects from medications. Assessment for and management of long-term complications can last for years after transplant.

*Table 2: Potential Complications to Be Aware of—and What Recipients and Caregivers Can Do to Help*

<b>Infection</b>	<p>It is important to take steps to prevent infection, or, if it does occur, to catch it early.</p> <p><b>What you can do to help:</b></p> <p>Frequent, careful, and thorough hand washing is key to preventing infection. Recipients and family members may want to remind doctors, nurses, vascular access team members, respiratory therapists, and other staff members who touch the patient in any way to wash their hands before and after patient care tasks.</p> <p>A recipient's personal cleanliness is also important in minimizing germs on the skin and in the mouth.</p> <p>Infection is easiest to treat when found early. Ask your health care team what the signs of infection are, and notify them immediately if you notice any of those signs.</p>
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## *Graft-vs-Host Disease (GVHD)*

GVHD is one of the most common and serious side effects that can happen with allogeneic transplantation. It occurs when donor cells (the graft) attack the recipient (the host). Careful donor selection and human leukocyte antigen (HLA) matching can help prevent GVHD. Medication—usually started 1 to 2 days before the transplant and continued for several months—may also help.

There are 2 types of GVHD: acute GVHD (aGVHD) and chronic GVHD (cGVHD).

**Acute GVHD** (aGVHD) occurs within 100 days of transplantation, often within 2 to 5 weeks. It is usually first noticed as an itchy or painful rash on the hands and feet, but it can start anywhere. The gastrointestinal (GI) system, liver, and other organs can also be affected. Things that increase the risk of having aGVHD include an unrelated donor, HLA mismatch, older age of donor and recipient, gender mismatch, higher dose of total body irradiation (greater than 12 Gy), and no T-cell depletion.

A staging system is often used to describe how bad a person's aGVHD is and help doctors decide about treatment. Grade I aGVHD is mild and goes away on its own. Grade II aGVHD involves several organs and requires therapy to stop the disease from advancing. Grade III is considered severe, and may lead to grade IV, which is life-threatening.

**Chronic GVHD** (cGVHD) usually develops 100 or more days after transplantation—usually within the first 2 years, but sometimes sooner and sometimes years later. Treatment can involve medication to suppress the immune system, as well as steroids. Because cGVHD can be complicated by infection, medication to prevent infection may also be used.

### **What you can do to help:**

Be aware of the signs and symptoms of GVHD and alert your transplant team to any concerns.

## *Gastrointestinal Problems*

The conditioning before transplantation, certain side effects from medication, and infection can all affect the gastrointestinal (GI) system (the mouth, throat, stomach, intestines, etc). Symptoms that can indicate GI damage include redness inside the mouth, sores (which can become infected), bleeding, pain, difficulty talking and swallowing, nausea, vomiting, abdominal cramps, and diarrhea.

Mouth and throat sores can be a symptom of mucositis—a condition where the entire digestive system is inflamed. These sores are extremely painful and require strong pain medicines. Mouth rinses may also be used.

### **What you can do to help:**

Whether or not you currently have any GI issues, ask your transplant team members about oral care (including mouth rinses), how to recognize signs of infection, and directions to follow if infection is suspected.

### *Liver Problems*

Liver problems can occur after transplantation. The most common include hepatic (liver) veno-occlusive disease (VOD) or sinusoidal obstruction syndrome (SOS), aGVHD, infection, and injury caused by medications.

SOS, which can occur after either an allogeneic or an autologous transplant, usually develops by day 35 after transplantation. It leads to less blood flow in the liver and can be fatal. Symptoms include unexplained weight gain, liver enlargement, and yellowing of the skin and eyes (jaundice). Some chemotherapy medicines increase the risk of SOS, including busulfan, a common conditioning agent. SOS is more likely to occur in people who are unable to do routine daily tasks, who are 20 years of age or older, or who have a history of liver disease, fungal infection, or intense conditioning treatment.

#### **What you can do to help:**

Promptly alert your transplant team to any symptoms you may have.

<p><i>Lung Problems</i></p>	<p>Late-onset lung problems affect about 15% to 20% of transplant recipients. The most common problems include pneumonia and those related to side effects of medications.</p> <p>Bronchiolitis obliterans organizing pneumonia (BOOP) is a lung disease in which the tiny air sacs in the lungs become plugged. It is often associated with cGVHD, infection, and immunosuppression. Early symptoms of BOOP are vague but often include rapid onset of fever, cough, shortness of breath, wheezing, bronchospasms, and general fatigue. Symptoms can progress to respiratory failure. Treatment could be a “wait and see” approach, or steroids may be given.</p> <p><b>What you can do to help:</b></p> <p>Promptly alert your transplant team to any symptoms you may have.</p>
<p><i>Eye Problems</i></p>	<p>Ocular (involving the eye) GVHD and cataracts are common late effects seen among transplant recipients.</p> <p>Development of cataracts, usually within a year of transplant, can occur as a result of whole body and cranial radiation therapy, high-dose chemotherapy, and/or long-term steroid use. Treatment consists of standard cataract removal and lens replacement.</p> <p>Ocular GVHD affects about half of all long-term allogeneic transplant recipients. The main symptom is eye dryness, caused by damaged tear ducts. Ocular GVHD can be treated with eye drops. Antibiotics may also be used to prevent infection.</p> <p><b>What you can do to help:</b></p> <p>Transplant recipients and caregivers should ask their transplant team about observing eye changes and reporting visual changes.</p>

*Other Problems*

Other complications related to transplantation can affect the nervous system, heart, and kidneys.

**What you can do to help:**

Ask your transplant team about any specific concerns you may have.

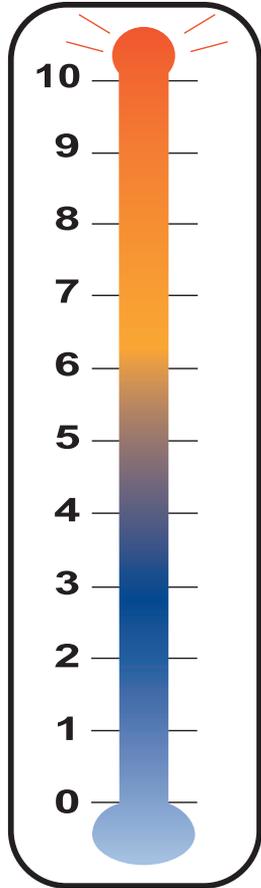
Remember that your transplant team can provide information about potential complications, as well as help recipients and caregivers become involved and effective team members. Prevention, early recognition, and treatment of complications are crucial to decreasing the unwanted effects that often occur throughout the transplantation process.

## Emotional Issues

Although transplants can be lifesaving, they can also be very difficult to deal with emotionally. This is true for the recipient, as well as for caregivers, family, and friends. Be sure to talk with your transplant team about any specific concerns.

It can be helpful to understand and keep track of the amount of distress a person is feeling. The “Distress Thermometer” is a useful tool for this. To use, circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today, and share this information with your health care team. You may also want to try some of the suggestions listed at the top of page 17.

**Extreme distress**



**No distress**

### ***Things That Can Help With the Emotional Aspects of Transplantation:***

- Prescribed antidepressant medication
- Participation in support groups
- Social support (strong social support can be a key factor in emotional recovery after transplant)
- Complementary therapies (diet, meditation, exercise, massage)
- Cognitive and behavioral therapy
- Use of relaxation techniques
- Education about depression and treatments, and counseling on communication with health care professionals

### **Caring for the Caregiver**

Informal caregivers—most often a husband or wife, family member, friend, or neighbor—provide hours and hours of unpaid help to transplant recipients. Caregiving can be a positive experience, but it can also be physically and emotionally difficult. Caregivers may need help finding time for themselves, as well as managing physical and emotional stress and/or balancing work and family responsibilities.

Some transplant centers provide programs that can help caregivers to:

- Learn more about the disease
- Identify community resources
- Develop problem-solving and coping skills
- Obtain referrals to psychotherapy
- Integrate health-promoting self-care behaviors into caregiving

Your transplant team can help you find caregiving education and support programs in your community. Another resource that's great for caregivers is a special *Cancer Survival Toolbox* program called "Caring for the Caregiver."

## Clinical Trials

People in need of a transplant may be interested in taking part in a clinical trial. You can learn about clinical trials from members of your cancer care team. They may have people undergoing transplants already enrolled in various trials. The resources listed below can help people who are considering a transplant and their doctors find clinical trials that match the needs of people who need this type of treatment.

The clinical trial process for potential new treatment methods involves 4 phases. In phase 1 trials, the goal is to discover harmful side effects. Researchers also try to learn the best way to give new treatments and decide the correct dose. Most phase 1 trials include a small number of people: usually fewer than 50 participants. Phase 2 trials usually include fewer than 100 people and are designed to test whether the new treatment is effective against one type of cancer. If the phase 2 trial has good results, the treatment method can be tested in phase 3 trials, which compare the new treatment method to the best treatment that is now in use against that one type of cancer. Phase 3 trials can enroll hundreds and even thousands of people, who will get either the new treatment or the best existing or standard form of treatment. After new treatment methods have been proven to have benefits over the best standard treatment, the new treatment can be approved by the U.S. Food and Drug Administration (FDA) for general use. Usually, newly FDA-approved treatments are followed in phase 4 trials, also called post-marketing trials, in which problems or concerns with the drug are reported to the FDA and the drug undergoes more testing to assure its effects and overall safety.

The Coalition of Cancer Cooperative Groups suggests asking your doctor these 10 questions if you are thinking of taking part in a clinical trial:

1. Why would this trial be important for me? What is the aim of the study?
2. What are the potential risks and benefits to me compared to other treatment options I have?
3. What are the eligibility requirements?
4. Who will monitor my care and safety?
5. What are the trial's tests and treatments? Will I need to be in the hospital, and if so, how often and for how long?
6. How do the possible side effects of the study treatment compare to side effects of the standard treatment option?
7. What support will be there for me and my caregivers during the trial? Can I talk to someone if I have questions?
8. Will my insurance, Medicaid, Medicare, or managed care plan cover costs of the trial? Who will help me answer these coverage questions?
9. What are my responsibilities and out-of-pocket costs?
10. What is the long-term follow-up care?

## **Clinical Trial Resources**

### *Coalition of Cancer Cooperative Groups (CCCCG)*

877-227-8451

[www.cancertrialshelp.org](http://www.cancertrialshelp.org)

Offers clinical trial–matching services. Resources include:

- Patient and Caregiver Toolkit—a package of practical information and publications you can use to learn about cancer clinical trials. Access this resource at [www.cancertrialshelp.org](http://www.cancertrialshelp.org).
- A search engine (database) of cancer-related clinical trials. Access this resource at [www.cancertrialshelp.org/trialcheck](http://www.cancertrialshelp.org/trialcheck).

### *Education Network to Advance Cancer Clinical Trials (ENACCT)*

240-482-4730

[www.enacct.org](http://www.enacct.org)

Seeks to ensure that everyone affected by cancer is educated about cancer clinical trials.

### *Leukemia & Lymphoma Society—TrialCheck®*

800-955-4572

[www.lls.org/diseaseinformation/managingyourcancer/clinicaltrials/](http://www.lls.org/diseaseinformation/managingyourcancer/clinicaltrials/)

Provides a clinical trial search service that offers patients and caregivers immediate access to listings of all blood cancer clinical trials.

*Lymphoma Research Foundation (LRF)*

800-500-9976

[www.lymphoma.org](http://www.lymphoma.org)

Provides a Clinical Trials Information Service to increase awareness about investigational treatments for lymphoma that are being evaluated at cancer treatment centers nationwide.

*National Cancer Institute (NCI)*

800-4-CANCER (800-422-6237)

[www.cancer.gov](http://www.cancer.gov)

Provides information on cancer trials available from their Cancer Information Service (CIS).

## Coping With Disease and Treatment

These resources may be helpful for people looking for ways to cope with the challenges of undergoing a transplant.

### *Association of Cancer Online Resources (ACOR)*

[www.acor.org](http://www.acor.org)

Provides a supportive online community where transplant survivors and their families can share ideas, problems, and solutions.

### *Association of Oncology Social Work (AOSW)*

215-599-6093

[www.aosw.org](http://www.aosw.org)

An organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

### *BMT Support*

866-340-3567

[www.bmtsupport.org](http://www.bmtsupport.org)

An interactive organization that offers support, education, and awareness to anyone involved in blood and marrow transplantation.

### *CancerCare*

800-813-HOPE (800-813-4673)

[www.cancercares.org](http://www.cancercares.org)

Provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Programs—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers free of charge. Also offers free telephone workshops, called CancerCare Connect, for people living with different types of cancer.

### *Cancer Support Community (includes The Wellness Community and Gilda's Club)*

888-793-WELL (888-793-9355)

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

A national nonprofit organization dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones. Through participation in professionally led support groups, educational workshops, and mind/body programs utilizing the Patient Active Concept, people affected by cancer can learn vital skills to regain control, reduce feelings of isolation, and restore hope—regardless of the stage of disease. All programs are free of charge.

### *Leukemia & Lymphoma Society*

800-955-4572

[www.lls.org](http://www.lls.org)

Provides fact sheets on sexuality and intimacy, fatigue, fertility, nutrition, and complementary therapies. Also offers *Understanding Drug Therapy and Managing Side Effects*, a booklet that helps patients understand their drug therapy and how to manage side effects.

### *National Family Caregivers Association (NFCA)*

800-896-3650

[nfcacares.org](http://nfcacares.org)

Educates, supports, empowers, and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships, and life stages to help transform family caregivers' lives by removing barriers to health and well being.

# Pain Management

If you are in pain, seek help. No one needs to suffer unnecessarily. The resources below can help you learn more about pain and pain management.

## *American Chronic Pain Association (ACPA)*

800-533-3231

[www.theacpa.org](http://www.theacpa.org)

Provides support for persons dealing with chronic pain through more than 800 local chapters. Find the one closest to you by calling their central number.

## *American Pain Foundation (APF)*

888-615-PAIN (888-615-7246)

[www.painfoundation.org](http://www.painfoundation.org)

Dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

## *American Pain Society (APS)*

847-375-4715

[www.ampainsoc.org](http://www.ampainsoc.org)

Provides a directory of more than 500 pain treatment centers in the United States.

## *National Cancer Institute (NCI)*

800-4-CANCER (800-422-6237)

[www.cancer.gov/cancertopics/paincontrol.pdf](http://www.cancer.gov/cancertopics/paincontrol.pdf)

Provides *Pain Control: Support for People With Cancer* (NIH Publication #10-6287), a brochure that discusses pain control medicines and other methods to help manage pain, as well as addresses the physical and emotional effects of pain. Includes questions to ask your health care team, a sample pain control record, a list of resources, and a glossary of terms to know.

## Laws Pertaining to Health Insurance

**COBRA**, the **Consolidated Omnibus Budget Reconciliation Act**, gives some workers the right to keep their health insurance coverage for a limited period of time after they leave their jobs. The booklet *An Employee's Guide to Health Benefits Under COBRA* contains detailed information about COBRA and is available at [www.dol.gov/ebsa/pdf/cobraemployee.pdf](http://www.dol.gov/ebsa/pdf/cobraemployee.pdf) or 866-444-EBSA (866-444-3272) toll free.

The **Americans with Disabilities Act**, often called the "**ADA**," was passed in 1990 and protects workers from job discrimination based on disability or disease. To file a complaint under the ADA, call the Equal Employment Opportunity Commission (EEOC) toll free at 800-669-4000 or 800-669-6820 (TTY) to obtain the location of your regional EEOC office. For additional information visit [www.ada.gov](http://www.ada.gov).

**ERISA**, the federal **Employee Retirement Income Security Act**, is the nation's major pension law and provides rights and protections for private pension and health benefit plan participants and their beneficiaries. ERISA prohibits an employer from discriminating against an employee for the purposes of preventing the employee from collecting benefits under an employee benefit plan. For more information, visit [www.dol.gov/ebsa/compliance\\_assistance.html](http://www.dol.gov/ebsa/compliance_assistance.html).

The **Family and Medical Leave Act** requires an employer to provide an employee with the same or a similar job in the event the employee needs to take an unpaid leave of absence. This law lets eligible employees take up to 12 weeks of leave for certain family or medical reasons. Employers with 50 or more employees within 75 miles of the workplace are covered by the Act. To file a complaint under the Family and Medical Leave Act, contact the Employment Standards Administration, Wage and Hour Division, of the U.S. Department of Labor. A regional office will be listed in your local telephone book under "United States Government." For more information, visit [www.dol.gov/dol/topic/benefits-leave/fmla.htm](http://www.dol.gov/dol/topic/benefits-leave/fmla.htm).

The **Health Insurance Portability and Accountability Act (HIPAA)** was passed by Congress in 1996. This legislation protects many workers from discrimination based on preexisting medical conditions and other health-related factors. This law protects employees from losing their insurance when they change jobs or move to a different state. The HIPAA helps some employees keep their health insurance when they change jobs. It does not prevent increases in premiums associated with a new group plan or when the insured person moves to a new location. For more information, visit [www.hhs.gov/ocr/privacy/hipaa/understanding/index.html](http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html).

The **Patient Protection and Affordable Care Act (PPACA)** was passed into law in 2010. According to the White House, it “puts in place comprehensive health insurance reforms that will hold insurance companies more accountable, lower health care costs, guarantee more health care choices, and enhance the quality of health care for all Americans.” Insurance companies are now prohibited from denying coverage due to preexisting conditions in policies covering children, and in 2014 the same will be true for adults. Premiums can still be calculated based on differences in age, sex, and geographic region. More information can be found at [www.healthcare.gov](http://www.healthcare.gov).

## Paying for Care

If you don't have insurance, get help through a social worker and/or a financial counselor at your local hospital or cancer treatment center. The case manager will contact you and begin working with you to ensure that your questions are answered and your needs are met. Ask your case manager for his or her direct-dial telephone extension so you can avoid time-consuming menu selections and recordings when you call the case manager in the future.

For more financial assistance options, you can also refer to the *Cancer Survival Toolbox* program "Finding Ways to Pay for Care." In addition, please refer to The Wellness Community resource *Frankly Speaking About Cancer: Coping With the Cost of Care*. The Patient Advocate Foundation website, [patientadvocate.org](http://patientadvocate.org), and the CancerCare website, [www.cancercares.org](http://www.cancercares.org), also offer information and assistance.

## Relationships, Fertility & Sexuality

### *American Association of Sexuality Educators, Counselors, and Therapists (AASECT)*

202-449-1099  
[www.aasect.org](http://www.aasect.org)

Devoted to the promotion of sexual health by the development and advancement of the fields of sex therapy, counseling, and education. Their website can help you locate a sexuality educator, counselor, or therapist in your area.

### *Fertile Hope*

866-965-7205  
[www.fertilehope.org](http://www.fertilehope.org)

A LIVESTRONG initiative (see Lance Armstrong Foundation) dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility. Focuses on research, awareness, education, financial assistance, and support.

### *Impotence Specialists.com*

[www.impotencespecialists.com](http://www.impotencespecialists.com)

This website can help you find a physician in your area and offers information about treatment options.

### *OncoFertility.org*

866-708-FERT (866-708-3378)  
[www.myoncofertility.org](http://www.myoncofertility.org)

This website is devoted to answering common questions and providing information about ways to preserve fertility, and offers advice about being your own advocate for fertility preservation.

## Reading Materials

Fincannon J, Bruss K. (2002). *Couples Confronting Cancer: Keeping Your Relationship Strong*. Atlanta, GA: American Cancer Society.

Katz A. (2009). *Man Cancer Sex*. Pittsburgh, PA: Hygeia Media, an imprint of the Oncology Nursing Society. Explores how men are affected by a diagnosis of cancer and how they can seek help. Written for men and the women and men who love them and live with them through the cancer experience. Explores issues ranging from loss of libido to communication with a partner and problems and concerns in between.

Katz A. (2009). *Woman Cancer Sex*. Pittsburgh, PA: Hygeia Media, an imprint of the Oncology Nursing Society. Explains the changes that many women with cancer experience and offers practical and compassionate advice on how to handle these changes.

Kydd S, Rowett D. (2006). *Intimacy After Cancer: A Woman's Guide*. Seattle, WA: Big Think Media, Inc.

## End of Life

While the resources below may be helpful for people with advanced illness, everyone will eventually need information and support surrounding the final stage of survival.

### *Aging With Dignity and Five Wishes®*

888-5WISHES (888-594-7437)

[www.agingwithdignity.org](http://www.agingwithdignity.org)

Affirms and safeguards the human dignity of individuals as they age and promotes better care for those near the end of life. *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It deals with all of a person's needs: medical, personal, emotional, and spiritual.

### *The Compassionate Friends*

877-969-0010

[www.compassionatefriends.org](http://www.compassionatefriends.org)

A nonprofit, self-help support organization for families who are grieving the death of a child of any age, from any cause.

### *Hospice Foundation of America*

800-854-3402

[www.hospicefoundation.org](http://www.hospicefoundation.org)

Provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. health care system and the role of hospice within it. Also, will assist you in locating a hospice near you.

*National Association of Social Workers (NASW)*

202-408-8600

[www.socialworkers.org](http://www.socialworkers.org)

[www.helpstartshere.org](http://www.helpstartshere.org)—Offers many resources, including “Understanding End of Life Care.”

[www.naswweb.org](http://www.naswweb.org)—Provides online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals.

[www.helppro.com/nasw/Default.aspx](http://www.helppro.com/nasw/Default.aspx)—Offers assistance in finding licensed social workers through the National Social Worker Finder.

*National Coalition for Cancer Survivorship (NCCS)*

877-NCCS-YES (877-622-7937)

[www.canceradvocacy.org/toolbox/](http://www.canceradvocacy.org/toolbox/)

Offers an audio program titled “Dying Well—The Final Stage of Survivorship” in the *Cancer Survival Toolbox*.

*National Hospice and Palliative Care Organization (NHPCO)*

800-658-8898

[www.nhpco.org](http://www.nhpco.org)

[www.caringconnections.org](http://www.caringconnections.org)

Offers assistance in finding a hospice; also provides consumer-oriented materials. Printed materials can be ordered by calling the number above.

## Suggested Reading Materials

The following is a list of materials designed to help cancer survivors, including people who have received blood and marrow transplants.

### Caregivers Support

Houts PS, Bucher JA. (2001). *Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home*. Atlanta, GA: American Cancer Society. Revised Edition.

NCCS. (2011). "Caring for the Caregiver." In: *Cancer Survival Toolbox*. Silver Spring, MD: National Coalition for Cancer Survivorship. Third Edition. Available in English and Spanish.

The following publications are available from the National Cancer Institute (NCI) at 800-4-CANCER (800-422-6237) or at the individual websites listed below:

NCI. (2007). *Caring for the Caregiver: Support for Cancer Caregivers*. Bethesda, MD: National Institutes of Health. NIH Publication #07-6219. Available at [www.cancer.gov/cancertopics/caring-for-the-caregiver.pdf](http://www.cancer.gov/cancertopics/caring-for-the-caregiver.pdf).

NCI. (2009). *Taking Time: Support for People With Cancer and the People Who Care About Them*. Bethesda, MD: National Institutes of Health. NIH Publication #09-2059. Available at [www.cancer.gov/cancertopics/takingtime.pdf](http://www.cancer.gov/cancertopics/takingtime.pdf).

NCI. (2005). *When Someone You Love Is Being Treated for Cancer*. Bethesda, MD: National Institutes of Health. NIH Publication #05-5726. Available at [www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated.PDF](http://www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated.PDF).

### General Information

Ackermann A, Ackermann A. (2002). *Our Mom Has Cancer*. Atlanta, GA: American Cancer Society.

*Coping*® With Cancer Magazine  
615-790-2400  
[copingmag.com/cwc/index.php](http://copingmag.com/cwc/index.php)

CURE: Cancer Updates, Research, & Education Magazine  
800-210-CURE (800-210-2873)  
www.curetoday.com

Feuerstein M, Findley P. (2006). *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer*. New York, NY: Marlowe & Company.

Gruman J. (2007). *After Shock: What to Do When the Doctor Gives You—or Someone You Love—A Devastating Diagnosis*. New York, NY: Walker & Company.

Harpham WS. (2005). *Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor*. New York, NY: W. W. Norton & Company.

Harpham WS. (2004). *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY: HarperCollins.

Haylock PJ, Mitchell SA, Cox T, et al. (2007). *The prescription for living plan*. Abstracted from: The cancer survivor's prescription for living. *AJN, American Journal of Nursing*, vol 107, no 4, pgs 58-70. Available at [www.nursingcenter.com/library/static.asp?pageid=721732](http://www.nursingcenter.com/library/static.asp?pageid=721732).

### **National Coalition for Cancer Survivorship (NCCS) Resources**

The following resources are available from NCCS at [www.canceradvocacy.org](http://www.canceradvocacy.org) or 877-NCCS-YES (877-622-7937):

Calder KJ, Pollitz K. (2006). *What Cancer Survivors Need to Know About Health Insurance*. Silver Spring, MD: National Coalition for Cancer Survivorship. Sixth Edition. Available in English and Spanish.

Clark EJ (ed). (2010). *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available in English and Spanish.

Clark EJ. (2008). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. Available in English and Spanish.

Hoffman B (ed). (2008). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Ninth Edition. Available in English and Spanish.

*Journey Forward* is a survivorship care plan that provides a concise but comprehensive record of the treatment a patient has received and outlines clear steps for care and monitoring of follow-up treatment. This free software program helps the provider create a custom-made care plan and includes a survivorship library, which offers specific patient-centered articles on survivorship care. Additionally, *Journey Forward* has an electronic *Medical History Builder*, which enables patients to enter their medical history so that it can be accessible to multiple providers. It is available at [www.journeyforward.org](http://www.journeyforward.org).

Scherr SL. (2009). *Self-Advocacy: A Cancer Survivor's Handbook*. Silver Spring, MD: National Coalition for Cancer Survivorship. Second Edition. Available in English.

# Transplantation Resources & Advocacy Organizations

Important resources mentioned throughout the entire Toolbox audio program are listed below. For additional resources, please visit the Toolbox website at [www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox).

Resources specific to transplantation are highlighted in yellow

## *AARP (American Association of Retired Persons)*

888-OUR-AARP (888-687-2277)

[www.aarp.org/relationships/caregiving/](http://www.aarp.org/relationships/caregiving/)

Provides various resources on issues of caregiving, such as long-term financing, home care, housing options, video and written resources, and an online weekly caregiver support group.

## *American Association for Geriatric Psychiatry (AAGP)*

301-654-7850

[www.aagponline.org/](http://www.aagponline.org/)

Provides referrals for geriatric psychiatrists. Also offers written materials for patients, family members, and caregivers.

## *American Association of Sexuality Educators, Counselors, and Therapists (AASECT)*

202-449-1099

[www.aasect.org](http://www.aasect.org)

Devoted to the promotion of sexual health by the development and advancement of the fields of sex therapy, counseling, and education. Their website can help you locate a sexuality educator, counselor, or therapist in your area.

### *American Cancer Society (ACS)*

800-ACS-2345 (800-227-2345)

[www.cancer.org](http://www.cancer.org)

Provides written information about cancer, cancer research, and treatment options. Also has information on sexuality. Call to locate a chapter near you and learn about what programs and resources are being offered, including the Patient Navigator and the Look Good...Feel Better programs.

### *American Pain Foundation (APF)*

888-615-PAIN (888-615-7246)

[www.painfoundation.org](http://www.painfoundation.org)

Dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

### *American Pain Society (APS)*

847-375-4715

[www.ampainsoc.org](http://www.ampainsoc.org)

Provides a directory of more than 500 pain-treatment centers in the United States.

### *American Society of Hematology (ASH)*

202-776-0544

[www.hematology.org](http://www.hematology.org)

The world's largest professional society concerned with the causes and treatments of blood disorders. The mission of the Society is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

### *America's Health Insurance Plans (AHIP)*

202-778-3200

[www.ahip.org](http://www.ahip.org)

A national association representing nearly 1,300 member companies providing

health insurance coverage. Their website provides consumer information about private insurance, managed care, getting coverage, and answers to frequently asked questions. Access health plan offerings on their comprehensive, national directory (locator).

*Association of Oncology Social Work (AOSW)*

215-599-6093

[www.aosw.org](http://www.aosw.org)

An organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

*BBB Wise Giving Alliance*

703-276-0100

[www.bbb.org/us/charity/](http://www.bbb.org/us/charity/)

A service of the Better Business Bureau, offering information on legitimate charities and causes.

*Be The Match®*

888-999-6743

[www.bethematch.org/patient](http://www.bethematch.org/patient)

Helps patients with leukemia, lymphoma, and other diseases who need a marrow or umbilical cord blood transplant. Offers patients and their families support and resources before, during, and after transplant. People can join the Be The Match Registry®—the largest listing of potential marrow donors and donated cord blood units—and can contribute financially and volunteer. Be The Match is operated by the National Marrow Donor Program® (NMDP).

*Be The Match Foundation®*

800-507-5427

[www.bethematchfoundation.org](http://www.bethematchfoundation.org)

Raises funds to help provide marrow and umbilical cord blood transplants to patients with leukemia, lymphoma, and other diseases as well as to deliver tangible relief to patients through financial grants and to contribute to new research discoveries. Helps underwrite recruiting of new potential donors to the Be The Match Registry® and expanding the ranks of its hands-on and financial volunteers.

### *Blogger.com*

[www.blogger.com](http://www.blogger.com)

A way to share your thoughts, photos, and more with your friends and the world.

### *Blood & Marrow Transplant Information Network (BMT InfoNet)*

[www.bmtinfo.net](http://www.bmtinfo.net)

Dedicated to providing transplant patients, survivors, and their loved ones with emotional support and high-quality, easy-to-understand information about bone marrow, peripheral blood stem cell, and cord blood transplants.

### *Bone Marrow Foundation*

800-365-1336

[www.bonemarrow.org](http://www.bonemarrow.org)

Provides financial aid, education, and support programs to transplant patients and families.

### *Cancer.Net*

888-651-3038

[www.cancer.net](http://www.cancer.net)

A patient education website from the American Society of Clinical Oncology (ASCO) that provides information on more than 50 types of cancer and their treatments, clinical trials, side effects, and coping. Also includes live chats, message boards, and links to support groups.

### *Caregiver Media Group*

800-829-2734

[www.caregiver.com](http://www.caregiver.com)

Provides an online newsletter, workshops, audiotapes, and information on caregivers and the work force, caregiver tips, and other topics.

### *Family Caregiver Alliance (FCA)*

800-445-8106  
[www.caregiver.org](http://www.caregiver.org)

Provides a clearinghouse that covers current medical, social, public policy, and caregiving issues related to brain impairments of adults, including brain tumors. Information is also available in Spanish and Chinese.

### *Fertile Hope*

866-965-7205  
[www.fertilehope.org](http://www.fertilehope.org)

A LIVESTRONG initiative (see Lance Armstrong Foundation) dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility. Focuses on research, awareness, education, financial assistance, and support.

### *Health Insurance Counseling and Advocacy Program (HICAP)*

800-434-0222  
[www.aging.ca.gov/hicap/default.aspx](http://www.aging.ca.gov/hicap/default.aspx)

A Medicare assistance program for the elderly and disabled. HICAP helps people learn about Medicare benefits including Medicare HMOs, long-term care, Medicare supplemental or long-term care insurance, and other important changes in Medicare.

### *Impotence Specialists.com*

[www.impotencespecialists.com](http://www.impotencespecialists.com)

This website can help you find a physician in your area and offers information about treatment options.

### *International Myeloma Foundation (IMF)*

800-452-CURE (800-452-2873)  
[www.myeloma.org](http://www.myeloma.org)

Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure. It also serves patients and families with a hotline, a multilingual website, educational materials, and global support groups.

### *Intercultural Cancer Council (ICC)*

713-798-4614

[www.iccnetwork.org](http://www.iccnetwork.org)

Works to eliminate the unequal burden of cancer in racial and ethnic minorities and medically underserved populations. Offers a wide variety of educational programs.

### *Journey Forward*

707-636-5900

[www.journeyforward.org](http://www.journeyforward.org)

A survivorship care plan that provides a concise but comprehensive record of the treatment a patient has received and outlines clear steps for care and monitoring of follow-up treatment. This free software program helps the provider create a custom-made care plan and includes a survivorship library, which offers specific patient-centered articles on survivorship care. Additionally, *Journey Forward* has an electronic *Medical History Builder*, which enables patients to enter their medical history so that it can be accessible to multiple providers.

### *Lance Armstrong Foundation (LAF)/LIVESTRONG*

877-236-8820/855-220-7777 or 866-673-7205

[www.livestrong.org/Get-Help](http://www.livestrong.org/Get-Help)

Seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. The site features survivors discussing their experiences as well as links to more information.

### *Leukemia & Lymphoma Society (LLS)*

800-955-4572

[www.lls.org/](http://www.lls.org/)

Provides information about blood cancers, including diagnosis, staging, treatment, and clinical trials, sexuality and intimacy, as well as support services, including telephone/web education programs, local support groups, peer-to-peer telephone support, and financial assistance, to persons with leukemia, lymphoma, multiple myeloma, and non-Hodgkin lymphoma. This site also provides general information about transplants and dealing with the treatment.

### *Life Insurance Settlement Association*

407-894-3797

[www.thevoiceoftheindustry.com](http://www.thevoiceoftheindustry.com)

Provides a list of viatical companies that will buy your life insurance policies under certain conditions.

### *Lymphoma Research Foundation (LRF)*

800-500-9976

[www.lymphoma.org](http://www.lymphoma.org)

The nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and health care professionals with critical information on the disease. Its mission is to eradicate lymphoma and serve those touched by this disease. Also offers webcasts and podcasts for lymphoma patients, survivors, and loved ones.

### *Medicare*

800-MEDICARE (800-633-4227) or 877-486-2048 (TTY/TDD)

[www.medicare.gov](http://www.medicare.gov)

U.S. government agency that provides various services (in English and Spanish), including publications on Medicare health plans and Medicare managed care choices. Some publications are also available in Braille or audio format for the visually impaired.

### *Multiple Myeloma Research Foundation (MMRF)*

203-229-0464

[www.multiplemyeloma.org](http://www.multiplemyeloma.org)

Serves to urgently and aggressively fund research that will lead to the development of new treatments for multiple myeloma.

### *National Association of Community Health Centers (NACHC)*

301-347-0400

[www.nachc.com](http://www.nachc.com)

Provides a listing of local nonprofit, community-owned health care programs serving low income and medically underserved urban and rural communities.

### *National Association of Social Workers (NASW)*

[www.socialworkers.org](http://www.socialworkers.org)

[www.helpstartshere.org](http://www.helpstartshere.org)

NASW, the largest membership association of social workers nationwide, provides a consumer website with information and advice regarding health, mental health, cancer, and other illnesses, as well as a way to find a social worker near you through their National Social Worker Finder, available at [www.helppro.com/nasw/Default.aspx](http://www.helppro.com/nasw/Default.aspx).

### *National Bone Marrow Transplant Link (nbmtLINK)*

800-LINK-BMT (800-546-5268)

[www.nbmtLINK.org](http://www.nbmtLINK.org)

A nonprofit organization dedicated to serving individuals before, during, and after a bone marrow or stem cell transplant. Provides supportive and information resources, as well as links to other resources. Explains the transplantation process and covers practical issues and emotional concerns. Also provides a web portal called *ExploreBMT* where survivors can browse resources and services from many transplant organizations. Offers numerous helpful publications, including their *Resource Guide for Stem Cell Transplant, Including Bone Marrow, Peripheral Blood, and Cord Blood: Friends Helping Friends*, which lists addresses and phone numbers for support networks, donor information, and financial resources.

### *National Cancer Institute (NCI)*

800-4-CANCER (800-422-6237)

[www.cancer.gov](http://www.cancer.gov)

Offers many educational resources for cancer survivors, including the Cancer Information Service (CIS), a network of regional offices providing easy-to-understand information in English and Spanish on cancer treatment, research, and local cancer-related services and community resources, along with a list of organizations that provide financial assistance. Specifically provides information about transplants available from their CIS under “Types of Treatments.”

### *National Coalition for Cancer Survivorship (NCCS)*

877-NCCS-YES (877-622-7937)

[www.canceradvocacy.org](http://www.canceradvocacy.org)

[www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox)

Advocates on the federal level for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves. Its free publications and resources include the award-winning *Cancer Survival Toolbox*, a self-learning audio program created by leading cancer organizations to help people develop essential skills to meet the challenges of their illness.

### *National Comprehensive Cancer Network (NCCN)*

215-690-0300

[www.nccn.com](http://www.nccn.com)

Provides information about non-Hodgkin lymphoma (chronic lymphocytic leukemia/small lymphocytic lymphoma) and its treatment, including stem cell transplantation, and side effects..

### *National Family Caregivers Association (NFCA)*

800-896-3650

[www.nfcacares.org](http://www.nfcacares.org)

Advocates on behalf of caregivers. Services include education, information, support, public awareness, and advocacy.

### *National Hospice and Palliative Care Organization (NHPCO)*

800-658-8898  
[www.nhpco.org](http://www.nhpco.org)

Offers assistance in finding a hospice; also provides consumer-oriented materials. Printed materials can be ordered by calling the number above.

### *National Marrow Donor Program (NMDP)*

800-MARROW-2 (800-627-7692)  
[www.marrow.org](http://www.marrow.org)

Works to ensure that every patient has the best possible chance to receive the transplant he or she needs. Operates the Be The Match Foundation® and Be The Match Registry®.

### *NeedyMeds*

[www.needymeds.org](http://www.needymeds.org)

A clearinghouse for information about getting medications from pharmaceutical companies. There is no charge for the service.

### *Office of Minority Health Resource Center (OMHRC)*

800-444-6472  
[minorityhealth.hhs.gov](http://minorityhealth.hhs.gov)

Provides health information regarding Native American, Alaska Native, African American, Asian American, Native Hawaiian/Pacific Islander, and Hispanic/Latino populations.

### *OncoLink*

[www.oncolink.org](http://www.oncolink.org)

A website managed by the Abramson Cancer Center of the University of Pennsylvania that provides a wide range of cancer-related information. Also includes information on clinical trials, reimbursement assistance programs, and a caregiver education course.

### *Oncology Nursing Society (ONS)*

866-257-4ONS (866-257-4667)

[www.ons.org](http://www.ons.org)

A national organization composed of more than 37,000 registered nurses and other health care providers who work with persons who have cancer. Their website has a special section for patient information and educational resources.

### *Partnership for Prescription Assistance*

888-4PPA-NOW (888-477-2669)

[www.pparx.org](http://www.pparx.org)

Helps qualifying patients who lack prescription coverage to access public and/or private programs. Information is available in English and Spanish.

### *Social Security Administration (SSA)*

800-772-1213 or 800-325-0778 (TTY)

[www.ssa.gov](http://www.ssa.gov)

An agency of the federal government that manages Social Security, Supplemental Security Income, Medicare, and parts of Medicaid. Information is available in English, Spanish, and many other languages.

### *U.S. Department of Veterans Affairs (VA)*

800-827-1000

[www.va.gov](http://www.va.gov)

Veterans can consult with a VA benefits counselor at any VA Medical Center, or call the Department of Federal Benefits.

### *Well Spouse Association*

800-838-0879

[www.wellspouse.org](http://www.wellspouse.org)

Provides a quarterly newsletter, pamphlets, mutual aid support groups in many areas, letter-writing support groups, an annual conference, and regional and weekend meetings around the country for caregivers.

## Glossary of Common Terms

**Absolute neutrophil count (ANC):** A measure of the total number of neutrophils (a type of white blood cell that fights against infection) present in the blood to help measure the progress of treatment.

**Acute:** A condition that develops quickly or in a short period of time. Its opposite is *chronic*.

**Acute leukemia:** A leukemia that is rapidly progressing and affects cells that are unformed or not yet fully developed.

**Allogeneic:** Refers to stem cells from the blood, bone marrow, or other tissue that are transferred from one person to another.

**Allogeneic bone marrow or blood stem cell transplantation:** A procedure in which a person receives blood-forming stem cells (cells from which all blood cells develop) from a genetically similar, but not identical, donor; this is often a sister or brother, but could be an unrelated donor. See *Unrelated bone marrow or blood stem cell transplantation*.

**Anemia:** A condition in which the number of red blood cells is below normal.

**Antibody:** A protein found in the blood that recognizes and binds to other substances. Helpful antibodies, such as those to viruses or bacteria, neutralize or destroy the target and prevent infection. Auto- or self-antibodies that work against a person's own red blood cells or platelets may destroy these important blood components and cause disease.

**Antigen:** Any substance that causes the body to stimulate the immune system. These substances could be toxins, bacteria, foreign blood cells, or the cells of transplanted organs.

**Apheresis:** A procedure in which the blood of a donor or patient is passed through a blood cell separator that collects one specific type of cell, such as plasma, platelets, or stem cells. The remainder of the blood is returned to the donor.

**Autologous:** Refers to blood or other tissue derived from a person's own body.

**Autologous bone marrow or blood stem cell transplantation:** A procedure in which a person's stem cells (cells from which all blood cells develop) are removed, stored, and later given back to the same person.

**Biological therapy:** Treatment to boost or restore the ability of the immune system to fight cancer, infections, and other diseases and to lessen certain side effects that may be caused by some cancer treatments. Also called *immunotherapy*, *biotherapy*, or *biological response modifier therapy (BRM therapy)*. Agents used in biological therapy include monoclonal antibodies, growth factors, and vaccines; these agents may also have a direct antitumor effect.

**Biopsy:** A procedure where a piece of tissue or fluid (a group of cells) is taken from a person's body and examined with a microscope to see if the cells are normal or not; a biopsy is a common way of determining if a person has cancer and, if so, what type it is.

**Blood cancer:** A condition (also known as a *hematologic malignancy*) that may affect the blood, bone marrow, or lymph nodes. Normal blood production and function are typically interrupted by the uncontrolled growth of an abnormal type of blood cell.

**Blood transfusion:** The administration of blood or blood products into a blood vessel.

**Bone marrow:** The soft, spongy center of bones that produces white blood cells, red blood cells, and platelets.

**Bone and marrow transplant (BMT):** The transfer of healthy bone marrow cells into a person whose bone marrow is defective or has been damaged by chemotherapy or radiation.

**Cancer:** An abnormal and uncontrolled growth of cells.

**Central venous catheter:** Also called a *central line*, this thin, flexible, silicone tube is used to take blood and give chemotherapy and other drugs during treatment for cancer. It is surgically inserted into a large vein, usually in your chest, and left there during your treatment.

**Chemotherapy:** The treatment of cancer with a drug or combination of drugs that kill cancer cells and prepare patients for transplant.

**Chronic leukemia:** A leukemia that progresses slowly and limits development of normal blood cells that provide protection against infection.

**Clinical trial:** A research study that involves human volunteers and is conducted to evaluate new ways to prevent, diagnose, manage, or treat medical problems or diseases.

**Conditioning:** Treatments used to prepare a patient for a stem cell transplant. These may include chemotherapy with or without radiation to the entire body. This intensive treatment kills both cancer and immune cells and makes room in the patient's bone marrow for new blood stem cells to grow. See *Preparative regimen*.

**Congenital:** Refers to a condition that is present at or before birth.

**Cord blood:** See *Umbilical cord blood stem cells*.

**DNA (deoxyribonucleic acid):** A self-replicating material present in nearly all living organisms that is responsible for the transmission of hereditary characteristics from parents to offspring.

**Engraftment:** The process by which the transplanted or transfused blood-forming cells begin to grow and produce healthy new blood stem cells.

**Erythrocyte:** Another term for *red blood cell*, the most common cell in the blood. Its main role is to carry hemoglobin, bringing oxygen from the lungs to the rest of the body.

**Erythropoietin:** A hormone made by the kidneys that controls the production of red blood cells (erythrocytes).

**Graft-vs-host disease (GVHD):** A condition in which the newly transplanted (or transfused) marrow or blood cells (the graft) attack the patient's own cells (the host). Symptoms can range from minor skin rashes to life-threatening conditions.

**Granulocyte:** A type of white blood cell that includes neutrophils, eosinophils, and basophils.

**Hematocrit (Hct):** The percentage of the whole blood volume that is made up of red blood cells.

**Hematologic cancer:** A cancer affecting blood-forming cells in the bone marrow, such as leukemia and non-Hodgkin lymphoma. Also called *blood cancer*.

**Hematologic malignancy:** A disease (also known as a *blood cancer*) affecting the blood, bone marrow, or lymph nodes. Normal blood production and function are altered by uncontrolled growth of an abnormal type of blood cell.

**Hematologist:** A physician who specializes in researching, diagnosing, and treating blood disorders.

**Hematology:** The study of blood and blood-forming tissues.

**Hematopoiesis:** The body process of forming new blood cells.

**Hematopoietic cell transplantation (HCT):** A procedure by which stem cells are collected from an individual donor and transferred into a patient who has defective bone marrow. This term is used universally to describe any transplantation of the stem cells, regardless of the donor source.

**Hematopoietic stem cell (HSC):** A cell that can become any type of blood cell, including red blood cells, white blood cells, and platelets.

**Hemoglobin (Hgb or Hb):** A protein in red blood cells that carries oxygen to other cells in the body.

**Histocompatibility:** Degree of compatibility between the cells of a donor and that of the transplant recipient. Determines whether an organ transplant will be tolerated. See *Human leukocyte antigen (HLA)*, *HLA testing*.

**HLA testing (typing):** Used to match patients and donors for marrow or blood stem cell transplants. Testing is done to diminish the likelihood of rejection after transplantation and to avoid or decrease the severity of graft-vs-host disease (GVHD). See *Human leukocyte antigen (HLA)*.

**Hodgkin lymphoma:** A cancer of the immune system that is marked by the presence of a type of cell called the *Reed-Sternberg cell*.

**Human leukocyte antigen (HLA):** A protein located on the surface of white blood cells that plays an important role in the body's immune response and helps determine the degree of tissue compatibility between transplant donors and recipients.

**Immune system:** The network of cells, tissues, and organs that defend the body against infection and disease.

**Immunotherapy:** Stimulation of the body's own immune system to slow or stop the growth and spread of cancer.

**Leukemia:** A cancer found in blood and bone marrow that is caused by the production of abnormal white blood cells (leukocytes).

**Leukocyte:** Another term for *white blood cell (WBC)*, the cells that protect the body from infection. There are 5 major types of white blood cells: basophils, eosinophils, lymphocytes, monocytes, and neutrophils.

**Lymphocyte:** A type of white blood cell that plays a role in the immune system. There are 2 main types of lymphocytes: T lymphocytes, which help regulate the function of other immune cells and attack infected cells and tumors, and B lymphocytes, which make antibodies.

**Lymphocytic:** Refers to diseases of abnormal growth of the white blood cells called *lymphocytes*.

**Lymphoma:** A blood cancer that occurs when abnormal lymphocytes multiply and collect in the lymph nodes and other tissues, impairing function of the immune system.

**Malignant:** Refers to a cancerous growth or disease that can spread, or metastasize, to other parts of the body.

**Match:** How similar the donor's tissue type is to the patient's tissue type, specifically looking at the human leukocyte antigen (HLA). The goal is to obtain as close a match of HLA as possible. See *Histocompatibility, Human leukocyte antigen (HLA), HLA typing*.

**Monocyte:** A white blood cell that destroys bacteria and foreign particles.

**Molecular HLA typing:** The same as DNA-based typing, done at the molecular level and with more precise results.

**Myelogenous:** Refers to a disease of blood-forming cells in the bone marrow.

**Myeloma:** A blood cancer that affects plasma cells, white blood cells that produce disease- and infection-fighting antibodies.

**Neutropenia:** A condition in which the number of granulocytes (white blood cells that fight infection) is below normal.

**Neutrophil:** The most common type of white blood cell, which helps the body fight infection.

**Nonmyeloablative transplantation:** A type of conditioning regimen that uses lower doses of chemotherapy and/or radiation to prepare a patient for transplantation. It is used for patients with limited treatment options or who are unable to tolerate full doses. Also known as a *low-intensity, reduced-intensity, or mini transplant regimen*. See *Conditioning*.

**Peripheral blood:** Blood in the bloodstream that is flowing through the vessels and heart.

**Peripheral blood stem cell (PBSC):** A type of cell in the peripheral blood that can develop into other types of cells; these cells may be used in stem cell transplantation.

**Peripheral blood stem cell (PBSC) donation:** The method by which stem cells and other blood-forming cells are collected for transplantation through the process of apheresis (similar to donating platelets or plasma). Blood is removed from a vein in one arm and passed through tubing into a blood cell separator machine. Stem cells or blood-forming cells are saved, while plasma and other blood cells are returned to the donor through a vein in the other arm.

**Plasma:** The liquid component of blood that transports blood cells throughout the body, along with nutrients, waste products, antibodies, proteins, and chemical messengers such as hormones.

**Plasma cell:** A type of cell that produces disease- and infection-fighting antibodies.

**Platelet:** Fragments of larger cells that are produced in the bone marrow, are disk-shaped, and are involved in the process of blood clotting. Also called *thrombocyte*.

**Preparative regimen:** Treatments used to prepare a patient for a stem cell transplant. These may include chemotherapy with or without radiation to the entire body. This intensive treatment kills both cancer and immune cells and makes room in the patient's bone marrow for new blood stem cells to grow. Also known as *conditioning*.

**Prognosis:** A prediction of what might happen in a specific case of a disease.

**Prognostic indicators:** A situation, condition, or characteristic that can be used to estimate the chance of recovery from a disease or the chance of the disease recurring (coming back).

**Protocol:** A specific plan for treatment of a disease, or a blueprint for a scientific research study or trial. It describes the types of patients who are eligible, the number of patients required to complete the trial, the type of care they will receive, and all information specific to the treatment plan.

**Red blood cell (RBC):** The most common blood cell in the bloodstream. It carries the protein hemoglobin, which transports oxygen from the lungs to the rest of the body. Also known as *erythrocyte*.

**Relapse:** The return of a disease following a remission. See *Remission*.

**Remission:** The complete disappearance of the signs and symptoms of cancer. It does not necessarily mean the individual has been cured, but that the disease is under control.

**Stem cell:** A cell that has the unique property of self-renewal as well as the ability to develop into other types of specialized cells, such as blood cells.

**Stem cell transplantation:** A method of replacing immature blood-forming cells that were destroyed by cancer treatment. Stem cells are given to the person after cancer treatment to help the bone marrow recover and continue producing healthy blood cells.

**Stage (staging):** A system used to define the extent of spread of a cancer.

**Syngeneic transplantation:** Use of an identical twin sibling donor—a perfect HLA match for the other identical twin brother or sister recipient.

**T cell:** A type of white blood cell that matures in the thymus. T cells target infections and trigger greater immune response. Also called *T lymphocyte*.

**T lymphocyte:** A type of white blood cell (also known as a *T cell*) that helps protect the body against infection and cancer. Some T cells can also release substances to attract other white blood cells and can regulate the activity of other immune cells.

**Umbilical cord blood stem cells:** Stem cells from the umbilical cord, collected from the placenta after a baby is born, that have the unique property of self-renewal as well as the ability to develop into other types of cells; they may be used in stem cell transplants.

**Unrelated bone marrow or blood stem cell transplantation:** A transplant procedure in which the donor is not related to the patient. See *Allogeneic bone marrow or blood stem cell transplantation*.

**Vein:** A vessel that carries blood low in oxygen away from the body's organs and back to the heart.

**White blood cell:** A type of blood cell (also known as a *leukocyte*) that is primarily responsible for protecting the body from infection. There are 5 major types of white blood cells (basophils, eosinophils, lymphocytes, monocytes, and neutrophils), each with special properties and functions.

**White blood cell count (WBC):** A blood test that measures the number of white blood cells to help detect problems in the body's immune system.



# Notes

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