“This program helped me figure out where to go for information and help at a time when I was feeling totally overwhelmed.”
—John S.*

“Made me feel like I wasn’t so alone. I loved the hope and the ongoing survival attitude.”
—Carol S.*

“An excellent source of information. I wish this had been offered to me when I was first diagnosed; it would have been very useful at the first stage of treatment.”
—Michael N.*
The Cancer Survival Toolbox® Program: Multiple Myeloma

The Cancer Survival Toolbox (CST) is a FREE set of self-learning audio programs developed by the National Coalition for Cancer Survivorship (NCCS), along with leading cancer organizations. NCCS is the oldest survivor-led cancer advocacy organization in the United States, advocating for quality cancer care for all Americans and empowering cancer survivors to advocate for themselves. To order copies of the Cancer Survival Toolbox, call 877-NCCS-YES (877-622-7937) or visit our website at www.canceradvocacy.org/toolbox.

The audio program that accompanies this booklet is focused on one type of cancer: multiple myeloma. The goal of this program is to provide you as a person diagnosed with multiple myeloma—as well as your caregivers, family, and friends—with practical tools you can use in your daily life as you deal with your cancer diagnosis and treatment. This program, which was written by cancer survivors and healthcare professionals, can be helpful both to individuals newly diagnosed with multiple myeloma, as well as to anyone at any other stage of this illness. It can be used on its own or along with the other CST programs.

This module addresses:

- Multiple myeloma diagnosis and basic treatment options
- Side effects and symptom management
- Coping with change
- Information for caregivers

This booklet is offered as a supplement to the multiple myeloma audio program. Contact information for all organizations and websites mentioned in the audio program are provided. Note: Although all resources in this booklet can be helpful to people with cancer, resources developed specifically for people with multiple myeloma are highlighted in yellow.

The Living With Multiple Myeloma program is also available via PhoneCast by calling 866-382-3479. Other Cancer Survival Toolbox programs may also be available by phone in the near future.
Using the Internet to Find Information

In this booklet, a number of Internet resources (websites) are provided. The Internet allows cancer survivors to get information at the touch of a few keystrokes on a computer in their home, library, or community center.

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 helpful, reliable, factual information available, 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 comes from well-known cancer organizations, research facilities, hospitals, libraries, government agencies, and professional journals. Some of the best sources of information are listed in this booklet.

There are many good books to help you get comfortable with using the Internet. Also, many of the companies that provide Internet access offer free classes to help beginners learn how 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 some beginning instruction to help you get started.
What Is Multiple Myeloma?

Imagine your bones as long, hollow tubes—hard on the outside, with space for a more liquid or spongy substance, called bone marrow, on the inside. All blood cells begin in the bone marrow as stem cells. These stem cells turn into red cells, white cells, and platelets.

White cells fight infection and are where multiple myeloma begins. White cells make different types of cells, one of which is called B lymphocytes. In healthy bone, as seen on the left side of this diagram, B lymphocytes turn into plasma cells, which then produce substances that fight disease and infection.

If the B lymphocytes are genetically damaged, as seen on the right side of this diagram, they can turn healthy plasma cells into malignant multiple myeloma cells that are unable to fight infection. These abnormal cells reproduce and make large amounts of protein, thus taking up space and crowding out normal cells in the bone marrow. The abnormal cells can then attack and weaken the solid part of the bone, causing soft spots, or “osteolytic lesions.”
In healthy bone marrow (A), blood-producing stem cells produce all types of blood cells, including lymphocytes, types of white blood cells that help fight off infection. One type of lymphocyte is called a B-cell, which develops into normal plasma cells when foreign substances (antigens) enter the body. Normally, plasma cells make up less than 1% of the cells in the bone marrow, and these plasma cells are capable of making a large variety of different antibodies necessary to fight infection. In multiple myeloma (B), genetic damage to a developing B lymphocyte transforms the normal plasma cell into a malignant cell (multiple myeloma cell). The malignant cell multiplies, leaving less space for normal blood cells in the bone marrow, and produces large quantities of M protein.

Fracture caused by lesion. Lesions.

Figure 2. Myeloma cells in the bone marrow cause osteolytic lesions, which appear as “holes” on an x-ray. Weakened bones increase the risk of fractures, as shown in this x-ray of a forearm. DeVita Jr VT, Hellman S, Rosenberg SA, eds. Cancer: Principles and Practice of Oncology. 5th ed. 1997:2350. Adapted with permission from Lippincott Williams & Wilkins.

Introduction

This booklet is designed primarily to help individuals with newly diagnosed multiple myeloma and their friends and families better understand this disease. The information provided here offers an overview of myeloma as a supplement to the information provided by your doctor. Learning as much as possible about multiple myeloma will help you be more involved in making decisions about treatment.

The booklet explains what myeloma is and how it develops within the body. Words that may be unfamiliar are bolded throughout the text and defined in the Glossary (page 24). A separate booklet produced by the Multiple Myeloma Research Foundation (MMRF), Multiple Myeloma: Treatment Overview, explains current standard therapy and emerging treatment options being tested in clinical trials. Please read that booklet to learn more about specific treatment choices.

The information in this booklet is not intended to replace the services of trained healthcare professionals (or to be a substitute for medical advice). Please consult with your healthcare professional regarding specific questions relating to your health, especially questions about diagnosis or treatment. To get copies of this booklet or the other MMRF booklets for yourself, your doctor’s office or cancer center, or your support group, contact the MMRF at 203-229-0464 or info@themmrf.org.

What Is Multiple Myeloma?

Multiple myeloma (also known as myeloma or plasma cell myeloma) is a blood cancer that develops in the bone marrow. One type of cell in bone marrow is the plasma cell, which produces antibodies (also known as immunoglobulins [Igs]), proteins that help fight disease and infection. In myeloma, normal plasma cells transform into malignant cells, which multiply and interfere with the production of all types of blood cells. These cancer cells, or myeloma cells, produce large quantities of one antibody called monoclonal (M) protein. Myeloma cells crowd out and inhibit the production of normal blood cells and all other antibodies in the bone marrow, except for M protein. In addition, groups of myeloma cells cause other cells in the bone marrow to remove the solid part of the bone and cause osteolytic lesions, or soft spots in the bone (Figure 1). These lesions are the hallmark of multiple myeloma and occur throughout much of the skeleton; however, not all individuals with myeloma will have these lesions or other signs of bone loss (Figure 2).

Multiple Myeloma Disease Overview. Norwalk, CT: Multiple Myeloma Research Foundation (MMRF); 2008.
Multiple Myeloma Resources

Below are some resources that may be especially helpful to people with multiple myeloma.

**CancerCare**
This national nonprofit organization 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.
800-813-HOPE (800-813-4673)
www.cancercare.org
(click on “Find Services by Cancer Type” and select “Multiple Myeloma”)

**International Myeloma Foundation (IMF)**
IMF is 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.
800-452-CURE (800-452-2873)
www.myeloma.org

**The Leukemia & Lymphoma Society (LLS)**
LLS is the world’s largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. The mission of LLS is to cure leukemia, lymphoma, Hodgkin’s disease, and myeloma and to improve the quality of life of patients and their families.
800-955-4572
www.lls.org

**The Multiple Myeloma Research Foundation (MMRF)**
MMRF serves to urgently and aggressively fund research that will lead to the development of new treatments for multiple myeloma.
203-229-0464
www.multiplemyeloma.org
There are a number of medical centers throughout the United States that specialize in the treatment of multiple myeloma. These centers often have doctors who are multiple myeloma specialists and often have ongoing multiple myeloma clinical trials.

**Dana Farber Cancer Institute**
44 Binney Street
Boston, MA 02115
617-632-3000
Link to Hematologic Center:
www.dana-farber.org/pat/adult/
hematologic-oncology/multiple-myeloma.html

**Mayo Clinic—Rochester, MN**
200 First Street, SW
Rochester, MN 55905
507-284-2511
Link to Hematologic Center:
www.mayoclinic.org/multiple-myeloma/

**Mayo Clinic—Scottsdale, AZ**
13400 East Shea Boulevard
Scottsdale, AZ 85259
480-301-8000
Link to Hematologic Center:
www.mayoclinic.org/multiple-myeloma/scttreatment.html

**H. Lee Moffitt Cancer Center**
University of South Florida
12902 Magnolia Drive
Tampa, FL 33612
888-MOFFITT (888-663-3488)

**Johns Hopkins Hospital**
600 N Wolfe Street
Baltimore, MD 21287
410-955-5000

**University of Texas M. D. Anderson Cancer Center**
1515 Holcombe Blvd
Houston, TX 77030
800-392-1611
Link to Hematologic Center:
www.mdanderson.org/patient-and-cancer-information/cancer-information/
cancer-types/multiple-myeloma/index.html

**Stanford University Hospital**
875 Blake Wilbur Drive
Stanford, CA 94305
650-723-4000
Link to Hematologic Center:
cancer.stanford.edu/blood/
Clinical Trials

People with multiple myeloma may be interested in participating in clinical trials. You can get information about clinical trials from members of your cancer care team. They may have individuals already taking part in various trials. The resources listed below also can help people with myeloma and their doctors identify clinical trials that may be of interest.

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. Phase 2 trials are designed to test whether the new treatment is effective against a specific 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 this particular type of cancer. After new treatment methods have been proven to have benefits over the best standard treatment, the new treatment can be approved by the US Food and Drug Administration (FDA) for general use. Usually, newly FDA-approved treatments are followed in phase 4 trials, also called postmarketing 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 (see below) 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?
Coalition of Cancer Cooperative Groups (CCCG)

CCCG offers clinical trial–matching services. Resources include:

1. 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.


Education Network to Advance Cancer Clinical Trials (ENACCT)

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

301-562-2774
www.enacct.org

Multiple Myeloma Research Foundation (MMRF)

MMRF works with EmergingMed to offer a free, confidential, and personalized service to help you locate multiple myeloma clinical trials. This service is designed to help you quickly search for clinical trial options that match your specific diagnosis and treatment history. MMRF encourages you to identify your clinical trial options (and review them with your doctor) each time you have to make a treatment decision.

www.myeloma.trialx.com/

National Cancer Institute (NCI)

Information on cancer trials is available from the NCI.

NCI’s Cancer Information Service (CIS): 800-4-CANCER (800-422-6237)
www.cancer.gov
Coping With Therapy

These resources may be helpful for people looking for ways to cope with their multiple myeloma therapy.

**The Understanding Series**
The International Myeloma Foundation (IMF) is committed to making information on myeloma treatments available in a form that is easy to understand. The *Understanding* series offers 14 booklets that explain each chemotherapy drug used in myeloma therapy. Access this resource at:
myeloma.org/Main.action
800-452-CURE (800-452-2873)

**The Myeloma Manager™**
This tool was created by IMF to help patients and caregivers deal with the growing glut of information and constantly increasing complexity of myeloma treatment programs. The *Myeloma Manager™* is a program that runs on the user’s computer and stores all personal data there. It provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. Access this resource at:
myeloma.org/ArticlePage.action?tabId=1&menuId=199&articleId=2316&aTab=-1

**Understanding Drug Therapy and Managing Side Effects**
This booklet from the Leukemia & Lymphoma Society helps patients understand their drug therapy and how to manage side effects. Access this resource at:
www.lls.org/content/nationalcontent/resourcecenter/freeeducationmaterials/treatments/pdf/understandingdrugtherapy

**What You Need to Know About™ Multiple Myeloma**
The National Cancer Institute offers this brochure to help patients with multiple myeloma understand their disease. Access this resource at:
800-4-CANCER (800-422-6237)

**Chemotherapy and You: Support for People With Cancer**
This booklet from the National Cancer Institute explains chemotherapy and how it affects patients with cancer. Access this resource at:
800-4-CANCER (800-422-6237)
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)**
ACPA provides support for persons dealing with chronic pain. There are more than 800 chapters. Find the one closest to you by calling their central number.
800-533-3231
www.theacpa.org

**American Pain Foundation (APF)**
APF is 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.
888-615-PAIN (888-615-7246)
www.painfoundation.org

**American Pain Society (APS)**
APS provides a directory of more than 500 pain treatment centers in the United States.
847-375-4715
www.ampainsoc.org

**National Hospice and Palliative Care Organization (NHPCO)**
NHPCO’s Caring Connections program offers information on understanding pain and guidelines for pain management. Access this resource at:

**National Cancer Institute (NCI)**
NCI 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 healthcare team, a sample pain control record, a list of resources, and a glossary of terms to know.
800-4-CANCER (800-422-6237)
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. A booklet entitled Health Benefits Under the Consolidated Omnibus Budget Reconciliation Act contains detailed information about COBRA and is available online at www.dol.gov/ebsa/pdf/cobraemployee.pdf or by calling 866-444-EBSA (866-444-3272).

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.

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.

The Family and Medical Leave Act requires an employer to provide an employee with the same or similar job in the event the employee needs to take an unpaid leave of absence. This law lets eligible employees take up 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 US Department of Labor. A regional office will be listed in your telephone book under “United States Government.”

The Health Insurance Portability and Accountability Act (HIPAA) 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. 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.
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.” The Patient Advocate Foundation website, patientadvocate.org, also offers information and assistance.
Special Resources for Older Persons

The following resources may be of interest to older persons dealing with multiple myeloma.

**American Geriatrics Society**
The Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118
212-308-1414
www.americangeriatrics.org

**Questions and Answers When Looking for an Elder Law Attorney**
This pamphlet covers issues such as where to find an attorney, what questions to ask, and how to discuss fees and more. To obtain a copy, send a self-addressed, stamped envelope (legal size) to:

National Academy of Elder Law Attorneys
1604 North Country Club Road
Tucson, AZ 85716
520-881-4005
www.naela.com

**Shape Your Health Care Future with Health Care Advance Directives**
This pamphlet is available through the American Bar Association (ABA) website. Access this resource at:

www.abanet.org/aging/publications/docs/shape_your.pdf
202-662-1000 or 800-285-2221
Death and Dying

Unlike 20 years ago, when cancer and grief were both kept hidden, there is now a great deal of information to help you and your loved ones learn about your choices and resources. The Basic Skills of the Toolbox—communicating, finding information, decision-making, problem-solving, negotiating, and standing up for your rights—can be used at every step of the journey.

The resources listed below may be helpful for people with advanced illness.

Aging With Dignity and Five Wishes®
PO Box 1661
Tallahassee, FL 32302-1661
888-5WISHES (888-594-7437)
www.agingwithdignity.org

American Pain Foundation (APF)
www.painfoundation.org

Association of Oncology Social Work (AOSW)
www.aosw.org

CancerCare
A national organization that provides a toll-free counseling line and educational materials, including Caregiving at the End of Life, Advance Care Planning, and Sharing Memories, Values, and Hope.
800-813-HOPE (800-813-4673)
www.cancercare.org

Elisabeth Kübler Ross (EKR) Foundation
Provides information and resources related to end-of-life care and for those who are grieving.
www.elisabethkublerross.com

Hospice and Palliative Nurses Foundation (HPNF)
www.hpnf.org
Death and Dying

Hospice Foundation of America (HFA)
www.hospicefoundation.org

National Association of Social Workers (NASW)
202-408-8600
www.socialworkers.org
www.helpstartshere.org – Offers many resources, including “Understanding End of Life Care.”
www.naswwebed.org – Provides online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals.

National Cancer Institute (NCI)
Offers a booklet called Last Days of Life that includes making end-of-life plans, palliative care at end of life, and hospice care.
www.cancer.gov/cancertopics/support

National Center for Grieving Children and Families (The Dougy Center)
www.grievingchild.org

National Coalition for Cancer Survivorship (NCCS)
Offers an audio program titled “Dying Well—The Final Stage of Survivorship” in the Cancer Survival Toolbox.
877-NCCS-YES (877-622-7937)
www.canceradvocacy.org/toolbox/

On Our Own Terms: Moyers on Dying
www.pbs.org/wnet/onourownterms

Reflections: A Guide to End of Life Issues for You and Your Family
Written by Roger C. Bone, MD, a physician dying from renal cancer, this 60-page booklet covers many important issues about planning for end-of-life care. It is available free and can be downloaded from the Kidney Cancer Association’s website below.
800-850-9132
kidneycancer.org
Suggested Reading Materials

The following is a list of materials designed to help cancer survivors, including people with multiple myeloma.

Support for Cancer Survivors

Materials published by the National Coalition for Cancer Survivorship are available at www.canceradvocacy.org.


Coping® With Cancer magazine. Available at copingmag.com/cwc/index.php/

CURE: Cancer Updates, Research, & Education magazine. Available at www.curetoday.com or 800-210-CURE (800-210-2873).


Suggested Reading Materials


*Journey Forward* is a program that helps cancer survivors collaborate with their physicians to create treatment summaries and follow-up care plans that provide clear steps for care and monitoring after cancer treatment. The program offers a Survivorship Toolkit for both patients and professionals. It also provides the *Survivorship Care Plan Builder*, free software that helps you create a custom-made care plan, as well as an electronic *Medical History Builder*. Both are available at www.journeyforward.org.


Advocacy Organizations & Other Sources of Information

The National Cancer Institute’s Cancer Information Service (CIS), nongovernmental organizations such as the American Cancer Society, and cancer type–specific organizations like the Leukemia and Lymphoma Society provide up-to-date information and connections to other people with the same kind of cancer. Some grassroots advocacy groups also facilitate support.

Important telephone numbers, mailing addresses, and Internet addresses mentioned throughout the entire Toolbox audio program are listed below. For additional resources, please visit the Toolbox website at www.canceradvocacy.org/toolbox, or visit www.canceradvocacy.org/resources/guide.

**AARP**
This organization 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.
888-OUR-AARP (888-687-2277)
www.aarp.org/families/caregiving

**Alliance for Aging Research**
The Alliance promotes research to improve quality of life for a growing population of older persons. It also provides educational programs for consumers and professionals.
202-293-2856
www.agingresearch.org

**American Association for Geriatric Psychiatry (AAGP)**
AAGP provides referrals for geriatric psychiatrists. Written materials for patients, family members, and caregivers may also be obtained.
301-654-7850
www.aagpgpa.org
American Association of Sexuality Educators, Counselors, and Therapists (AASECT)

AASECT is 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.
202-449-1099
www.aasect.org

American Cancer Society (ACS)

ACS provides written information about multiple myeloma, other cancers, cancer research, and treatment options. Call to locate a chapter near you and learn about what programs and resources are being offered, including the Patient Navigator Program.
800-ACS-2345 (800-227-2345)
www.cancer.org

American Chronic Pain Association (ACPA)

ACPA provides support for persons dealing with chronic pain. There are more than 800 chapters, and you may find the one closest to you by calling their central number.
800-533-3231
www.theacpa.org

American Pain Foundation (APF)

APF is 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.
888-615-PAIN (888-615-7246)
www.painfoundation.org

American Pain Society (APS)

APS provides a directory of more than 500 pain-treatment centers in the United States.
847-375-4715
www.ampainsoc.org
Advocacy Organizations & Other Sources of Information

*America's Health Insurance Plans (AHIP)*
AHIP is the national association representing nearly 1,300 member companies providing health insurance coverage to more than 200 million Americans. Their website provides consumer information about private insurance, managed care, getting coverage, and answers to frequently asked questions.
202-778-3200
www.ahip.org

*Association of Oncology Social Work (AOSW)*
AOSW is 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.
215-599-6093
www.aosw.org

*BBB Wise Giving Alliance*
This group, a service of the Better Business Bureau, offers information on legitimate charities and causes.
703-276-0100
www.give.org

*Blogger.com*
This website provides a way to share your thoughts, photos, and more with your friends and the world.
www.blogger.com

*CancerCare*
This is a national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are also available in Spanish. All services are free of charge.
800-813-HOPE (800-813-4673)
www.cancercare.org
Cancer.net
This patient education website from the American Society of Clinical Oncology (ASCO) provides information on more than 50 types of cancer, including multiple myeloma, and their treatments, clinical trials, side effects, and coping. It also includes live chats, message boards, and links to support groups.
888-651-3038
www.cancer.net

Cancer Support Community (includes The Wellness Community and Gilda’s Club)
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.
888-793-WELL (888-793-9355)
www.cancersupportcommunity.org
www.thewellnesscommunity.org

Caregivers Media Group
This organization provides an online newsletter, workshops, audiotapes, and information on caregivers and the work force, caregiver tips, and other topics.
800-829-2734
www.caregiver.com

CaringBridge
This online resource offers free, personalized websites that connect family and friends during a serious health event.
651-789-2300
www.caringbridge.org

Caring Connections
This organization provides free resources and information to help people make decisions about end-of-life care and services before a crisis.
800-658-8898 or 877-658-8896 (multilingual)
www.caringinfo.org
Advocacy Organizations & Other Sources of Information

**Consumer Action**
You may download a 30-page booklet, *It’s Your Choice: Are Medicare HMOs right for you?*, written with assistance from the Gray Panthers and the National Consumers League. The brochure, available in English and Spanish, advises people currently on Medicare about changes taking place in Medicare and what they mean.
415-777-9635  
www.consumer-action.org

**Eldercare Locator**
This nationwide, directory-assistance service is designed to help older persons and caregivers locate local support resources. Eldercare Locator links you with state and local area agencies on aging, where you can get information about services such as transportation, meals, home care, housing alternatives, legal issues, and social activities. You may visit their website or call the toll-free number weekdays from 9 AM until 8 PM eastern time.
800-677-1116  
www.eldercare.gov

**Family Caregiver Alliance (FCA)**
FCA 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.
800-445-8106  
www.caregiver.org

**Fertile Hope**
This organization is dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility. Fertile Hope focuses on research, awareness, education, financial assistance, and support.
866-965-7205  
www.fertilehope.org
Gerontological Society of America (GSA)

GSA is an organization for professionals in the field of aging. GSA focuses on promoting the scientific study of aging. It provides reports, bibliographic searches ($5 per keyword), publications, and a list of online resources useful to older persons with cancer and their caregivers.
202-842-1275
www.geron.org

Health Insurance Counseling and Advocacy Program (HICAP)

HICAP is 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.
800-434-0222
www.aging.ca.gov/information_on/hicap.asp

Health Privacy Project (HPP)

HPP is a nonprofit organization that was founded to raise public awareness of the importance of ensuring health privacy to improve health care quality and access.
www.cdt.org/issue/health-privacy

Hospice Foundation of America (HFA)

HFA provides general information about hospices and will assist you in locating a hospice near you.
800-854-3402
www.hospicefoundation.org

Impotence Specialists.com

This website can help you find a physician in your area and offers information about treatment options.
www.impotencespecialists.com
Advocacy Organizations & Other Sources of Information

**Intercultural Cancer Council (ICC)**
ICC works to eliminate the unequal burden of cancer in racial and ethnic minorities and medically underserved populations. This organization offers a wide variety of educational programs.
713-798-4614
www.iccnetwork.org

**Journey Forward**
*Journey Forward* is a program that helps cancer survivors collaborate with their physicians to create treatment summaries and follow-up care plans that provide clear steps for care and monitoring after cancer treatment. The program offers a Survivorship Toolkit for both patients and professionals. It also provides the *Survivorship Care Plan Builder*, free software that helps you create a custom-made care plan, as well as an electronic *Medical History Builder*.
707-636-5900 (9 AM-5 PM, PST/PDT)
www.journeyforward.org

**Lance Armstrong Foundation/LIVESTRONG**
LIVESTRONG seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. It also focuses on the physical, emotional, and practical issues that you may encounter after completing active treatment for cancer. The site features survivors discussing their experiences as well as links to more information.
866-673-7205
www.livestrong.org
Leukemia & Lymphoma Society (LLS)

LLS provides support services, including local support groups and financial assistance, to persons with leukemia, lymphoma, and multiple myeloma.

800-955-4LSA (800-955-4572)
www.lls.org

Life Insurance Settlement Association

This association can provide you with a list of viatical companies that will buy your life insurance policies under certain conditions.

407-894-3797
www.thevoiceoftheindustry.com/

Medicare

This US government agency 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.

800-MEDICARE (800-633-4227) or 877-486-2048 (TTY/TDD)
www.medicare.gov

National Association of Community Health Centers, Inc. (NACHC)

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

301-347-0400
www.nachc.com

National Association of Social Workers (NASW)

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.

202-408-8600
www.socialworkers.org
www.helpstartshere.org
Advocacy Organizations & Other Sources of Information

**National Cancer Institute (NCI)**

NCI 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. The NCI website features information about clinical trials as well as *Facing Forward Series: Life After Cancer Treatment*.

800-4-CANCER (800-422-6237)
www.cancer.gov

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

NCCS advocates for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves. Founded by and for cancer survivors in 1987, NCCS created the widely accepted definition of survivorship and considers someone a cancer survivor from the time of their diagnosis through the rest of their lives. 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.

877-NCCS-YES (877-622-7937)
www.canceradvocacy.org
www.canceradvocacy.org/toolbox
www.canceradvocacynow.org

**National Family Caregivers Association (NFCA)**

NFCA advocates on behalf of caregivers. Their services include education, information, support, public awareness, and advocacy.

800-896-3650
www.nfcacares.org
NHPCO can assist you in finding a hospice; it also provides consumer-oriented materials through its consumer-focused website, Caring Connections.

800-658-8898  
www.nhpco.org  
www.caringinfo.org

National Institute on Aging (NIA)
NIA is dedicated to research, education, training, information, and referral. This organization provides a broad range of written materials on various topics.

800-222-2225 or 800-222-4225 (TTY)  
www.nia.nih.gov

National Marrow Donor Program (NMDP)
NMDP works to ensure that every patient has the best possible chance to receive the transplant he or she needs.

800-MARROW2 (800-627-7692)  
www.marrow.org

National Comprehensive Cancer Network (NCCN)
NCCN provides information about multiple myeloma, and its treatment and side effects.


Needy Meds, Inc.
This is a clearinghouse for information about getting medications from pharmaceutical companies. There is no charge for the service.

www.needymeds.org

Office of Minority Health Resource Center (OMHRC)
OMHRC provides health information regarding Native American, Alaska Native, African American, Asian American, Pacific Islander, and Hispanic/Latino populations.

800-444-6472  
www.omhrc.gov
Advocacy Organizations & Other Sources of Information

**OncoLink**

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

www.oncolink.upenn.edu

**Oncology Nursing Society (ONS)**

This national organization is 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.

866-257-4ONS (866-257-4667)
www.ons.org

**Partnership for Prescription Assistance (PPA)**

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

888-4PPA-NOW (888-477-2669)
www.pparx.org

**Patient Advocate Foundation (PAF)**

PAF’s Patient Services provides patients with arbitration, mediation, and negotiation to settle issues with access to care, medical debt, and job retention related to their illness.

800-532-5274
www.patientadvocate.org

**Social Security Administration (SSA)**


800-772-1213 or 800-325-0778 (TTY)
www.ssa.gov
You may order a free copy of a publication, *Protect Your Pension: A Quick Reference Guide*, that provides information about safeguarding your pension plan.

866-444-3272 or 877-889-5627 (TTY)
www.dol.gov/ebsa

**Veterans Affairs**

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

800-827-1000
www.va.gov

**Well Spouse Association**

This association 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.

800-838-0879
www.wellspouse.org
Glossary of Common Terms

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

**Allogeneic 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.

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

**Autologous 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.

**B cell**: A white blood cell that comes from bone marrow. As part of the immune system, B cells make antibodies and help fight infections. Also called B lymphocyte.

**B-cell lymphoma**: A term used to describe a type of lymphoma involving white blood cells known as B cells.

**Benign**: A term used to describe a swelling or growth that is not cancerous, that does not spread from one part of the body to another, and which is usually not life-threatening.

**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 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.

**Chronic leukemia**: A leukemia that progresses slowly and limits development of normal blood cells that provide protection against infection.
Grade (grading): A system used to categorize how quickly a tumor is likely to grow and spread. The grade of a tumor depends on how abnormal the cancer cells look under a microscope. Grading systems are different for each type of cancer.

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

Immune system: The complex group of cells and organs that defend the body against infection and disease.

Leukemia: Cancers affecting the bone marrow and white blood cells.

Malignant: A term used to describe a type of tumor that is cancerous.

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).

Site of origin: The part of the body where a cancer started.

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.

T cells: White blood cells that mature in the thymus. T cells target infections and trigger greater immune response. Also called T lymphocytes.

White blood cells: Infection-fighting cells, including neutrophils, monocytes (which ingest germs), and lymphocytes (which produce antibodies as an immune response to an infection).
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NOT FOR SALE
The Toolbox is provided as a free program thanks to the generous support of our partners.