

# Living With Chronic Lymphocytic Leukemia (CLL) Resource Booklet



A Resource Booklet for  
the *Cancer Survival Toolbox*®

Living With Chronic  
Lymphocytic Leukemia  
Audio Program

With Information on:

- Coping With Therapy
- Clinical Trials
- Advocacy Organizations and Resources
- Glossary of Terms



*"This information has meant so much to me and my family. It's put together and presented better than anything else I've come across."*

—Steve S.\*



*"This program helped me to feel more in control of complex health issues. I know where to start and don't feel so alone."*

—Mary N.\*



*"The most helpful and realistic resource I've found."*

—Mark R.\*

## The *Cancer Survival Toolbox*® Program: Chronic Lymphocytic Leukemia

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 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 one type of cancer: chronic lymphocytic leukemia (CLL). The goal of this program is to provide people with CLL—and their caregivers, family, and friends—with tools that can improve their abilities to cope with this form of blood cancer and its treatment. This program, written by cancer survivors and healthcare professionals, can help people newly diagnosed with CLL and those at other stages of this illness as well. It can be used on its own or along with the other Toolbox programs.

The aim of this program is to increase your knowledge about:

- Chronic lymphocytic leukemia and its current treatment options
- Common side effects and symptoms, and their management
- Ways to cope with the change brought on by this illness
- Being a caregiver to someone with CLL

This booklet is a supplement to the CLL audio program. Contact information for all organizations and websites mentioned in the audio program is provided. Note: Although the resources in this booklet can be helpful to people with cancer, those specific to people with CLL are highlighted in yellow.

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## Using the Internet to Find Information

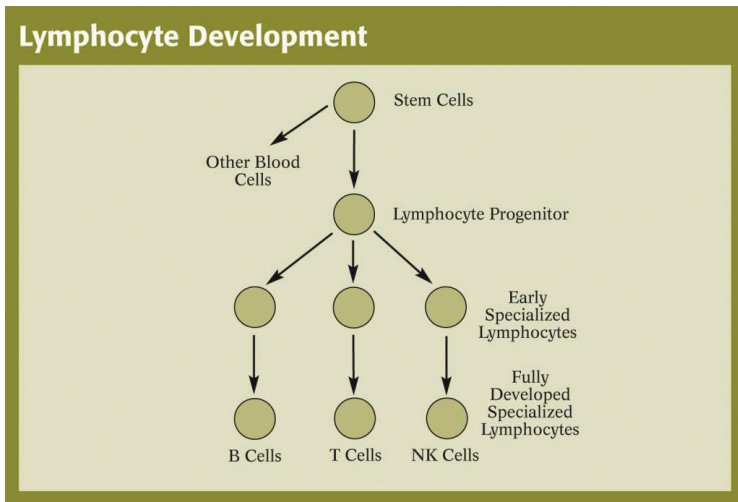
On the Internet, cancer survivors can get information available throughout the world, all at the touch of a few keystrokes on a computer in their home, library, or community center. It can be hard to find your way around the Internet at first. You may need to ask for help. A word of caution: There is a great deal of 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 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 also be able to provide some beginning instruction to help you get started.

# What Is Chronic Lymphocytic Leukemia?

Chronic lymphocytic leukemia (CLL) is a blood cancer or leukemia that starts in lymphocytes, white blood cells that are normally found in lymph nodes, lymph channels, and the spleen. Each of 3 major types of lymphocytes performs special tasks that defend us against bacteria, fungus, and viral infections. B lymphocytes (B cells) produce antibodies to fight infections caused by bacteria, viruses, and fungi; T lymphocytes (T cells) help B cells make antibodies and also ingest and destroy bacteria and viruses; natural killer cells (NK cells) attack cells that are infected by viruses. Figure 1 depicts the process of normal lymphocyte development.

*Figure 1. Blood Cells Maturing From Stem Cells*



Reprinted with permission from The Leukemia & Lymphoma Society.



For the most part, the causes of CLL are not known. However, in 2002, the U.S. National Academy of Sciences Institute of Medicine reported an association between CLL and exposure to herbicides used during the Vietnam war. You may access information about Agent Orange exposure at the Department of Veterans Affairs website [www.publichealth.va.gov/exposures/agentorange](http://www.publichealth.va.gov/exposures/agentorange) or by calling them toll free at 800-749-8387, menu choice 3.

CLL begins with a change or mutation in the DNA of a single lymphocyte. A mutation can occur in any of the 3 forms of lymphocytes, though it most often affects B cells. Chronic forms of leukemia advance slowly, often over 2 to 5 years. The slow course of the disease allows for growth of cells that appear to be mature but which cannot function as they should. Each year, about 15,000 people are diagnosed with CLL, making this the most common form of leukemia.

### **Signs and symptoms of CLL**

Signs and symptoms of CLL relate to the types and growth rates of the involved lymphocytes. Abnormal lymphocytes multiply and replace normal lymphocytes in bone marrow and lymph nodes. Most people are diagnosed before symptoms occur, as a result of blood tests done as part of a routine physical exam or test for another health problem. Sooner or later, CLL cells displace normal cells enough to impair normal cell functions. When this happens, symptoms of CLL can appear. The more common symptoms include frequent and repeated infections, anemia, tiredness, and lymph node swelling that disrupts normal organ function in the digestive and urinary systems.

## Diagnosis and staging of CLL

A person's diagnosis may be referred to as CLL or small lymphocytic lymphoma (SLL). The diagnosis of SLL is used when the disease affects mostly lymph nodes; the diagnosis of CLL is made when mostly bone marrow and blood are affected. Sometimes, the diagnosis is both SLL *and* CLL (SLL/CLL), meaning that lymph nodes *and* bone marrow and blood are involved. CLL and SLL are really the same disease, and they are managed in the same ways. For this reason, we use the term *CLL* through the rest of this program.

The 2 most common staging systems used in the United States are the Rai (pronounced *rye*) and Binet (pronounced *bin-ay'*) staging systems (Table 1). A third staging system, created by an International Workshop on CLL, combines the Binet and Rai systems but is not widely used in the United States. Staging systems describe the extent of disease and provide clues to potential survival time. The staging process combines physical exam findings and laboratory tests to arrive at a grouping or stage for each person with CLL. The Rai system places patients in categories of risk ranging from low risk (0) to intermediate risk (I/II) to high risk (III/IV). A person who has stage 0 CLL has the longest predicted survival time, and a person with stage IV would be predicted to have the shortest survival time. The Binet system uses lettered categories of risk: stage A is similar to Rai stage 0; stage B is like Rai stage I or II; and stage C is similar to Rai stage III or IV.

**Table 1. Staging Systems for Chronic Lymphocytic Leukemia**

Staging System	Prognosis (Stage and Signs at Diagnosis)		
	Good	Intermediate	Poor
<b>Rai</b>	<b>Low risk – 0</b>  Increased number of lymphocytes in bloodstream and bone marrow	<b>Intermediate risk – I &amp; II</b>  Increased number of lymphocytes in bloodstream and bone marrow, plus enlarged lymph nodes (I)  <i>or</i>  Increased number of lymphocytes in bloodstream and bone marrow, plus enlarged spleen and/or liver, with or without enlarged lymph nodes (II)	<b>High risk – III &amp; IV</b>  Increased number of lymphocytes in bloodstream and bone marrow, plus anemia (too few red blood cells), with or without enlarged lymph nodes, spleen, and/or liver (III)  <i>or</i>  Increased number of lymphocytes in bloodstream and bone marrow, plus thrombocytopenia (too few blood platelets), with or without anemia, enlarged lymph nodes, spleen, and/or liver
<b>Binet</b>	<b>A</b>  < 3 areas of enlarged lymph tissue, no anemia (too few red blood cells), no thrombocytopenia (too few blood platelets)	<b>B</b>  ≥ 3 areas of enlarged lymph tissue, no anemia, no thrombocytopenia	<b>C</b>  ≥ 3 areas of enlarged lymph tissue, plus anemia and/or thrombocytopenia

Adapted from *NCCN Clinical Practice Guidelines in Oncology: Non-Hodgkin's Lymphomas*, v.1.2011 (2010); and American Cancer Society *Detailed Guide: Non-Hodgkin Lymphoma—early detection, diagnosis, and staging: how is non-Hodgkin lymphoma staged?*

You can find more detailed information about the stages of CLL at the Leukemia & Lymphoma Society (LLS) website ([www.lls.org](http://www.lls.org)) or by calling the LLS call center at 800-955-4572.

## Chronic Lymphocytic Leukemia Resources

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

Other resources specific to people with CLL are highlighted in yellow throughout this booklet.

### *American Cancer Society (ACS)*

800-ACS-2345

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

A nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering through research, education, advocacy, and service. Provides a detailed guide about CLL.

### *CancerCare*

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

[www.cancercare.org](http://www.cancercare.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.Net*

571-483-1780 or 888-651-3038

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

Brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians, to people living with cancer and those who care for and care about them. Information on different types of cancer, including CLL, is available.

*Leukemia & Lymphoma Society (LLS)*

800-955-4572

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

The world's largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. Its mission is to cure leukemia, lymphoma, Hodgkin disease, and myeloma and to improve the quality of life of patients and their families.

*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 healthcare 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.

*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.

## Clinical Trials

People with CLL 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 with CLL and other forms of cancer already enrolled in various trials. The resources listed below can help people with CLL and their doctors find clinical trials that match the needs of people with this illness.

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 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 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:

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](http://www.cancertrialshelp.org).
2. 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/all\\_page?item\\_id=8348#trialcheck](http://www.lls.org/all_page?item_id=8348#trialcheck)

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/site/pp.asp?c=chKOI6PEImE&b=1573731](http://www.lymphoma.org/site/pp.asp?c=chKOI6PEImE&b=1573731)

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 Therapy

These resources may be helpful for people looking for ways to cope with therapy for CLL.

### *American Cancer Society (ACS)*

[www.cancer.org/docroot/MIT/MIT\\_7\\_1x\\_SexualityforMenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforMenandTheirPartners.asp)  
[www.cancer.org/Treatment/TreatmentsandSideEffects/PhysicalSideEffects/SexualSideEffectsinWomen/SexandWomenwithCancer/index](http://www.cancer.org/Treatment/TreatmentsandSideEffects/PhysicalSideEffects/SexualSideEffectsinWomen/SexandWomenwithCancer/index)

Offers online guides for men and women with cancer—"Sex and Men With Cancer" and "Sex and Women With Cancer"—that provide pertinent information about sex, sexuality, and the impact of a cancer diagnosis.

### *Association of Cancer Online Resources*

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

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

### *Chronic Lymphocytic Leukemia Information Group (CIG)*

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

Provides disease-specific information to CLL patients and caregivers, to increase awareness about the disease and gain increased visibility in order to achieve greater support from the medical community.

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.

#### *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 Cancer Institute (NCI)*

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

[www.cancer.gov/cancertopics/wyntk/leukemia.pdf](http://www.cancer.gov/cancertopics/wyntk/leukemia.pdf)—Offers *What You Need to Know About Leukemia* (NIH Publication #08-3775), a brochure to help leukemia patients understand their disease.

[www.cancer.gov/cancertopics/chemotherapy-and-you.pdf](http://www.cancer.gov/cancertopics/chemotherapy-and-you.pdf)—Offers *Chemotherapy and You: Support for People With Cancer* (NIH Publication #10-7156), a booklet that explains chemotherapy and how it affects patients with cancer.

# 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 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.

## *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 healthcare 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. 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](http://www.dol.gov/ebsa/pdf/cobraemployee.pdf) or by calling 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.

**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 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 US Department of Labor. A regional office will be listed in your local telephone book under “United States Government.”

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.

## 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.cancercare.org](http://www.cancercare.org), also offer information and assistance.

## Special Resources for Older Persons

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

### *American Geriatrics Society*

212-308-1414

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

An organization of health professionals devoted to improving the health, independence, and quality of life of all older people.

### *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, how to discuss fees, and more. To obtain a copy, send a self-addressed, stamped envelope (legal size) to the address below:

National Academy of Elder Law Attorneys

1604 North Country Club Road

Tucson, AZ 85716

520-881-4005

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

## 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®*

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.

### *CancerCare*

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

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

A national organization that provides a toll-free counseling line and educational materials include *Caregiving at the End of Life*, *Advance Care Planning*, and *Sharing Memories, Values, and Hope*.

### *Elisabeth Kübler-Ross Foundation*

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

Provides information and resources related to end-of-life care and for those who are grieving.



### *Hospice Foundation of America (HFA)*

800-854-3402

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

Provides general information about hospices and 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.

### *National Cancer Institute (NCI)*

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

Offers a booklet called *Last Days of Life* that includes making end-of-life plans, palliative care at end of life, and hospice care.

### *National Center for Grieving Children and Families (The Dougy Center)*

866-775-5683

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

Provides support and training to individuals and organizations seeking to assist children in grief.

### *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*.

### *On Our Own Terms: Moyers on Dying*

800-257-5126

[www.pbs.org/wnet/onourownterms](http://www.pbs.org/wnet/onourownterms)

Videotapes of this 4-part, 6-hour PBS series on end-of-life issues may be ordered by calling Films of the Humanities at the number above.

## Suggested Reading Materials

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

### **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). (2011). *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). (2010). *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 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](http://www.journeyforward.org).

NCCS. (2011). *Cancer Survival Toolbox*. Silver Spring, MD: National Coalition for Cancer Survivorship. Third Edition. Available in English and Spanish. Includes information about communicating, finding information, making decisions, solving problems, negotiating, standing up for your rights, first steps for the newly diagnosed, finding ways to pay for care, caring for the caregiver, living beyond cancer, and the final stage of survivorship.

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

### **National Cancer Institute (NCI) Resources**

The following publications are available from 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*. 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. (2003). *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](http://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.

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

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. (2003). *Diagnosis, Cancer: Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W. W. Norton & Company. Third Edition.

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

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## 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 & 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 phone numbers 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](http://www.canceradvocacy.org/toolbox) or visit [www.canceradvocacy.org/resources/guide](http://www.canceradvocacy.org/resources/guide).

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

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

[www.aarp.org/families/caregiving](http://www.aarp.org/families/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.aagpgpa.org](http://www.aagpgpa.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.

### *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.

### *Blogger.com*

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

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

### *CancerCare*

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

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

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.

### *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.

### *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.

### *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.

### *CaringBridge*

651-789-2300

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

Offers free, personalized website that connects family and friends during a serious health event.

### *Caring Connections*

800-658-8898 or 877-658-8896 (multilingual)

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

Provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

### *Consumer Action*

415-777-9635

[www.consumer-action.org](http://www.consumer-action.org)

Provides a downloadable 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. Available in English and Spanish, this brochure advises people currently on Medicare about changes taking place in Medicare and what they mean.

### *Eldercare Locator*

800-677-1116

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

A nationwide, directory-assistance service designed to help older persons and caregivers locate local support resources. 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



### *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.

### *Gerontological Society of America (GSA)*

202-842-1275

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

An organization for professionals in the field of aging that focuses on promoting the scientific study of aging. Provides reports, bibliographic searches (\$5 per keyword), publications, and a list of online resources useful to older persons with cancer and their caregivers.

### *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.

### *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 (9 AM-5 PM, PST/PDT)

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

*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*.

### *Lance Armstrong Foundation/LIVESTRONG*

866-467-7205 or 866-673-7205

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

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.leukemia.org/hm\\_lls](http://www.leukemia.org/hm_lls)

Provides information about blood cancers, including diagnosis, staging, treatment, and clinical trials, 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. The site also has information on sexuality and intimacy.

### *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 healthcare 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.

### *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 healthcare 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 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. The NCI website features information about CLL, treatments, side effects, and clinical trials in a section called “Cancer Topics: Coping with Cancer” and *Facing Forward: Life After Cancer Treatment; Facing Forward: Ways You Can Make a Difference in Cancer; Taking Time: Support for People With Cancer and the People Who Care About Them; When Someone You Love Is Being Treated for Cancer; and When Somebody in Your Family Has Cancer.*

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

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

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

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

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

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.

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

215-690-0300

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

Provides information about CLL, and its treatment and side effects. Clinical guidelines for treating CLL are available to registered users and can be found on the NCCN website under non-Hodgkin lymphoma, chronic lymphocytic leukemia/small lymphocytic lymphoma.

### *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 Marrow Donor Program (NMDP)*

800-MARROW-2 (800-627-7692)

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

Provides treatment basics on transplant clinical trials, questions to ask your doctor plus facts about the diseases treated with transplant.

### *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

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

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

### *OncoLink*

[www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)

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 healthcare 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.

### *Patient Advocate Foundation*

800-532-5274

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

Assists patients with medical debt crisis insurance access issues and job retention issues.

### *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*

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

**Acute leukemia:** A leukemia that is rapidly progressing and affects cells that are unformed 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 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).



## Notes

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The First Step to Cancer Survival™

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