



## Cancer Survival Toolbox

An audio resource program

REVISED AND UPDATED

1. Communicating
2. Finding Information
3. Making Decisions
4. Solving Problems
5. Negotiating
6. Standing Up for Your Rights
7. First Steps for the Newly Diagnosed
8. Topics for Older Persons
9. Finding Ways to Pay for Care
10. Caring for the Caregiver
11. Living Beyond Cancer
12. Dying Well—The Final Stage of Survivorship

©2009 National Coalition for Cancer Survivorship (NCCS)  
 877-NCCS-YES (877-622-7937)  
 Fax: 301-565-9670  
 e-mail: [info@canceradvocacy.org](mailto:info@canceradvocacy.org)  
[www.canceradvocacy.org](http://www.canceradvocacy.org)  
[www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox)



This project was made possible by unrestricted educational grants from the Amgen Foundation, the Bayer Foundation, Genentech BioOncology, the Lilly Foundation, Novartis Pharmaceuticals, and the sanofi-aventis Foundation.

NOT FOR SALE  
 The toolbox is provided  
 as a free service.



## The *Cancer Survival Toolbox*® Is an Award-Winning Program

The *Cancer Survival Toolbox*® is designed to support all cancer survivors. If you find the Toolbox helpful, we encourage you to pass it on, when you no longer need it, to a friend or to your local library, community center, or house of worship, so that others may benefit from this information.

### National Cancer Institute Cancer Patient Education Network (CPEN) Gold Star Award, 2000

The CPEN Gold Star Award recognizes organizations or groups that have made outstanding contributions to cancer patient education. The 2000 National Cancer Institute CPEN Gold Star Award was given to the four organizations that produced the *Cancer Survival Toolbox*: NCCS, AOSW, ONS, and Genentech® BioOncology.

### Public Relations Society of America Silver Anvil Award of Excellence, 2000

The *Cancer Survival Toolbox* won an Award of Excellence in the Corporate/Nonprofit Partnerships category of the Silver Anvil awards sponsored by the Public Relations Society of America. The Silver Anvil is the highest honor a public awareness campaign can achieve.

### American Society of Association Executives (ASAE) Award of Excellence, 2000

The *Cancer Survival Toolbox* received honors in the ASAE Associations Advance America Awards. This award recognizes associations that propel America forward with innovative educational projects. The Toolbox received recognition in the category of Business and Social Innovation.

### Women Executives in Public Relations (WEPR) Foundation Crystal Obelisk Award for Social Responsibility, 2000

The *Cancer Survival Toolbox* received the coveted Crystal Obelisk Award from the WEPR Foundation. The Crystal Obelisk is the only public relations industry award given solely for social responsibility.

## Contributors

### *National Coalition for Cancer Survivorship*

Pamela J. Haylock, RN, MA  
Susan A. Leigh, RN, BSN  
Ellen L. Stovall  
Debra Thaler-DeMers, BSN, RN, OCN

### *Oncology Nursing Society*

Ruth Van Gerpen, RN, MS, AOCNS

### *Association of Oncology Social Work*

Carol P. Marcusen, LCSW, BCD  
Katherine Walsh, PhD, MSW

### *National Association of Social Workers*

Elizabeth J. Clark, PhD, ACSW, MPH  
Yvette Colón, DSW  
Rebecca Myers, MSW  
Karyn Walsh, MSW

### *Area Specialists*

Tani Bahti  
Dean H. Gesme, Jr, MD  
Barbara Hoffman, JD  
Elmer Huerta, MD, MPH  
Marie Kennedy, BA  
Roxanne Koepke, RN, BSN  
Ruth Zu-Kei Lin, RN, MS, AOCN  
Kerry A. McGinn, MA, MS, RN, NP  
Lynn Nye, PhD  
Naomi Stearns, MSW  
Margarita Tobar  
Lucy Young, MA

Did you find this program useful? Your feedback will help us provide the best information to other cancer survivors. Please take the enclosed survey, fill it out online at <http://www.canceradvocacy.org/toolbox/survey>, or call 877-TOOLS-4-U.

# Table of Contents

An Introduction to the <i>Cancer Survival Toolbox</i> ® Programs.....	2
<i>The Basic Skills Program</i> .....	2
<i>Programs on Special Topics</i> .....	2
PROGRAM 1: Communicating.....	3
PROGRAM 2: Finding Information.....	3
PROGRAM 3: Making Decisions .....	4
PROGRAM 4: Solving Problems .....	4
PROGRAM 5: Negotiating.....	5
PROGRAM 6: Standing Up for Your Rights .....	5
PROGRAM 7: First Steps for the Newly Diagnosed.....	6
PROGRAM 8: Topics for Older Persons .....	6
PROGRAM 9: Finding Ways to Pay for Care .....	7
PROGRAM 10: Caring for the Caregiver .....	8
PROGRAM 11: Living Beyond Cancer .....	8
PROGRAM 12: Dying Well—The Final Stage of Survivorship.....	9
Finding Information on the Internet.....	10
Treatment Options and Decision-Making Tools.....	10
<i>Treatment Guidelines</i> .....	10
<i>Decision-Making Tools</i> .....	10
Laws Pertaining to Health Insurance .....	11
<i>Health Insurance and Financial Resources</i> .....	12
Help With Paying for Care.....	13
<i>Cancer Institutions and Organizations</i> .....	13
Guide to Clinical Trials.....	13
<i>Designation of Types of Cancer Treatment Centers</i> .....	13
<i>Description of Clinical Trials</i> .....	13
<i>Specific Resources for Clinical Trials</i> .....	14
Suggested Reading Materials and Resources .....	15
<i>Support for Cancer Survivors</i> .....	15
<i>Support for Caregivers</i> .....	16
<i>Coping With Cancer Therapy</i> .....	16
<i>Special Resources for Older Persons</i> .....	16
<i>Death and Dying Resources</i> .....	17
Advocacy Organizations and Other Sources of Information.....	19
Distress Management Thermometer .....	28
Glossary of Common Terms .....	30
Contributors.....	33

## An Introduction to the *Cancer Survival Toolbox*® Programs

The *Cancer Survival Toolbox* is a FREE set of self-learning audio programs developed by leading cancer organizations. While it was originally designed to assist individuals newly diagnosed with cancer, it will also help anyone at any stage of illness who is facing hard decisions and changes in life because of cancer.

For the purpose of these programs, all persons diagnosed with cancer are, for the balance of their lives, *cancer survivors*.

The goal of the *Cancer Survival Toolbox* is to help you develop practical tools that you can use in your daily life as you deal with your cancer diagnosis and treatment. Family members and caregivers can also use the Toolbox on behalf of a child or anyone else with cancer.

Programs 1 through 6 cover *Basic Skills* that can help people with cancer meet the challenges of their illness. Programs 7 through 12 build on these skills and relate them to specific aspects of cancer survivorship.

The 6 *Basic Skills* audio programs and programs 8 through 11 are available in Spanish. A text version of the 6 *Basic Skills* is also available in Chinese.

### The *Basic Skills* Programs

*Program 1: Communicating*

*Program 2: Finding Information*

*Program 3: Making Decisions*

*Program 4: Solving Problems*

*Program 5: Negotiating*

*Program 6: Standing Up for Your Rights*

### Programs on Special Topics

One or more of the programs on special topics may be of interest to you. These programs were designed to accompany the *Basic Skills* programs and will probably be most useful if you listen to the *Basic Skills* programs first.

*Program 7: First Steps for the Newly Diagnosed* contains information designed especially for people who have recently been diagnosed with cancer.

*Program 8: Topics for Older Persons* was developed specifically to address issues that older persons with cancer might face.

*Program 9: Finding Ways to Pay for Care* is designed to help underinsured or uninsured people who are having difficulty finding and paying for care and medicines.

*Program 10: Caring for the Caregiver* was developed to provide resources and support for cancer caregivers to help them address the issues they face on an ongoing basis.

*Program 11: Living Beyond Cancer* was developed to help explore the day-to-day process of cancer survivorship. It discusses the physical and emotional effects of cancer and cancer treatment, sexuality, family communication, advance health directives, financial planning, employment rights, and living with hope.

*Program 12: Dying Well—The Final Stage of Survivorship* provides information to support survivors (and their families) as they enter the final stages of life.

You may choose to listen to these programs in order, or to cover only certain topics. You may also listen to the programs more than once, and you can practice the exercises that are provided as you need them.

To order additional copies of this FREE program, please contact us at 877-TOOLS-4-U (877-866-5748) or visit our web site at <http://www.canceradvocacy.org/toolbox>.

PROGRAM 1 30 minutes

## Communicating

*Communicating* means letting someone else know clearly what you think and feel and also learning what the other person thinks and feels.

After listening to this Toolbox program, you will be better prepared to:

- Assert yourself or state positively what you want and need
- Make “I” statements by saying “I think” or “I feel” instead of saying “you should”
- Listen actively and check the message. This means listening carefully, showing the other person you are listening, and checking to see if what you heard is what the person meant to say
- Match verbal with nonverbal communication, that is, match your words to your actions and facial expressions
- Express your feelings by letting others know how you feel as well as what you think

### References

Clark EJ (ed). (2006). *Teamwork: The Cancer Patient’s Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. Available at <http://www.canceradvocacy.org>.

Pollin I, Golant SK. (1994). *Taking Charge: Overcoming the Challenges of Long-Term Illness*. New York, NY: Times Books (Random House).

PROGRAM 2 27 minutes

## Finding Information

*Finding Information* means being able to use many of the different resources available to find information that will help you understand your kind of cancer and its treatment.

After listening to this Toolbox program, you will be better prepared to:

- Find good information on the kind of cancer you have and on the types of treatment that offer the best records for success
- Pick the experts you respect and trust to be part of your health care team
- Know when and how to seek a second opinion
- Look for what is new in the treatment of your kind of cancer
- Know that the decisions you have made about your cancer and its treatment are based on the right kind and right amount of information

### References

Buckman R. (1997). *What You Really Need to Know About Cancer: A Comprehensive Guide for Patients and Their Families*. Baltimore, MD: The Johns Hopkins University Press.

Coleman CN. (1998). *Understanding Cancer: A Patient’s Guide to Diagnosis, Prognosis, and Treatment*. Baltimore, MD: The Johns Hopkins University Press.

## Making Decisions

*Making Decisions* means being able to identify how you make decisions, how your style of decision making can work or be improved, and how you can weigh the pros and cons of deciding about cancer treatment.

After listening to this Toolbox program, you will be better prepared to:

- Identify how you prefer to make decisions about cancer and cancer treatment
- Find out the benefits of getting a second opinion to help you make decisions
- Identify how much time you have to make a decision
- Weigh the pros and cons in making a decision about cancer treatment
- Understand that you are an individual, NOT a cancer statistic

### References

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

Morra M, Potts E. (2003). *Choices*. New York, NY: HarperCollins. Fourth Edition.

Murphy GP, Morris LB, Lange D. (1997). *Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment and Recovery*. New York, NY: Viking.

## Solving Problems

*Solving Problems* means being able to follow the steps needed to solve a difficult situation in your life or daily activity.

After listening to this Toolbox program, you will be better prepared to:

- Identify and define the problem
- Gather information
- Plan your action
- Carry out your plan
- Evaluate your plan and make necessary changes

### References

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

Hoffman B (ed). (2004). *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship. Hoboken, NJ: John Wiley & Sons. Third Edition. Available at <http://www.canceradvocacy.org>.

## Negotiating

*Negotiating* means talking with people involved in your health care so that you can get what you need to have the best quality of life possible.

After listening to this Toolbox program, you will be better prepared to:

- Listen and communicate effectively
- Identify the values that are the principles and standards by which you live
- Set your personal limits—the boundaries of behavior that you will not cross
- Learn to set emotions aside when negotiating
- Visualize more than one solution to any problem

### References

Canfield J, Hansen MV. (1995). *The Aladdin Factor*. New York, NY: Berkley Publishing Group.

Donaldson MC, Donaldson M. (1996). *Negotiating for Dummies*. Foster City, CA: IDG Books Worldwide, Inc.

Hoffman B (ed). (2007). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Seventh Edition. Available at <http://www.canceradvocacy.org>.

## Standing Up for Your Rights

*Standing Up for Your Rights* means learning to actively do something in your own best interest. This is also known as *self-advocacy*.

After listening to this Toolbox program, you will be better prepared to:

- Feel more in control about your life
- Build confidence to face challenges that seem too difficult to overcome
- Reach out to others, such as asking to talk to someone who is in a similar situation as you are
- Feel hopeful rather than hopeless and helpless

### References

Clark EJ, Stovall E. (1996). Advocacy: The cornerstone of cancer survivorship. *Cancer Practice*, vol 4, pgs 239-244.

Zakarian B. (1996). *The Activist Cancer Patient: How to Take Charge of Your Treatment*. New York, NY: John Wiley & Sons, Inc.

Spingarn ND. (1999). *The New Cancer Survivors: Living With Grace, Fighting With Spirit*. Baltimore, MD: The Johns Hopkins University Press.

## First Steps for the Newly Diagnosed

*First Steps for the Newly Diagnosed* refers to the information that needs to be gathered and the decisions that need to be made in the initial days and weeks after you are diagnosed with cancer. In this program, we offer practical guidelines designed to help you take those first steps toward successfully meeting the challenges that a cancer diagnosis can impose.

After listening to this Toolbox program, you will be better prepared to:

- Select the members of your cancer care team
- Work with your team to gather the information needed to make informed decisions
- Decide on an initial treatment plan
- Learn what you need to know about your insurance policy (or where to go for help if you are underinsured or uninsured)
- Tell people about your diagnosis
- Identify and ask for the help and support you'll need

### References

Babcock EN. (1997). *When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients*. New York, NY: Bantam Books.

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

Healy B. (2007). *Living Time: Faith and Facts to Transform Your Cancer Journey*. New York, NY: Bantam Books.

Hoffman B (ed). (2004). *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship. Hoboken, NJ: John Wiley & Sons. Third Edition. Available at <http://www.canceradvocacy.org>.

Schwartz AL. (2004). *Cancer Fitness: Exercise Programs for Patients and Survivors*. New York, NY: Simon & Schuster.

Shapiro D. (2000). *Mom's Marijuana: Life, Love, and Beating the Odds*. New York, NY: Vintage Books.

## Topics for Older Persons

Cancer is a common problem for many older persons, but simply being older should not add to the burden of the disease. This audio program, *Topics for Older Persons*, focuses on issues that have specific meaning for older cancer survivors. Examples of these issues include finding quality cancer care despite your age and other health problems, getting help paying for medications you need, and standing up for your rights in a health care system that sometimes discriminates against the older person.

After listening to this Toolbox program, you will be better prepared to:

- Communicate about your condition
- Find information about your condition
- Make decisions
- Solve problems
- Negotiate about your treatment and care
- Stand up for your right to make informed decisions

### References

American Geriatrics Society. *Complete Guide to Aging and Health*. Available at <http://www.americangeriatrics.org>.

AARP, ABA, AMA. (1995). *Shape Your Health Care Future With Health Care Advance Directives*. Available at <http://www.abanet.org/aging>.

## Finding Ways to Pay for Care

People who have no health insurance or have problems with their insurance face special barriers to getting quality cancer care. But, while finding care when you do not have insurance coverage is difficult, it is not impossible. If you need help paying for your medications, there are several options available. First, your state may have a pharmaceutical assistance program that will help you pay for the drugs you need. Also, most of the large drug companies have what is called an "Indigent Drug Program." These programs help provide medications to people who cannot afford them. Individuals cannot apply directly for these programs. However, your doctor, nurse, or social worker can contact them and help get your drug costs covered. Contact your local or state department on aging to see if such a program is available in your state. In addition, contact *Needy Meds* (<http://www.needymeds.com>) for information about getting medications from pharmaceutical companies.

The stories you will hear in this program offer hope and encouragement that insurance problems need not stand in the way of finding and getting good cancer care.

After listening to this Toolbox program, you will better understand:

- The effect of insurance on cancer care
- What to do when you have no insurance
- Medicare benefits

- Hospice care and how to evaluate it
- Medicaid
- Veterans Affairs benefits
- Public and private community resources
- Your life insurance
- Private insurance and gaps in coverage
- Getting and paying for prescription medicines
- Federal laws and health care rights

### References

Annas GJ. (1997). Patients' rights in managed care—exit, voice, and choice. *New England Journal of Medicine*, vol 337, pgs 210-215.

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 at <http://www.canceradvocacy.org>.

Oncology Nursing Society. (1999). Oncology Nursing Society and Association of Oncology Social Work Joint Position on End-of-Life Care. *Oncology Nursing Forum*, vol 26, pg 15.

Stair J. (1998). Understanding the challenges for hospice: fundamentals for the future. *Oncology Issues*, March/April pgs 22-25.

## Caring for the Caregiver

*Caring for the Caregiver* was developed specifically to provide resources and support for cancer caregivers to help them address the issues they face on an ongoing basis.

As a caregiver, it is easy to be overwhelmed by caring for a cancer survivor. An important point to remember is that you, as a caregiver, are *also* a survivor because you, too, are surviving the challenges, responsibilities, and life-changing effects of this disease and its treatment. Throughout this self-help program, you will hear stories taken from real life and solutions that can provide you with the hope and options you need, while showing you ways to balance your own personal needs with those of the person you are caring for.

After listening to this Toolbox program, you will be better prepared to:

- Strengthen your skills and abilities while finding and using new resources
- Do a much better job of nurturing everyone involved—including yourself

## References

Carter R. (1994). *Helping Yourself Help Others: A Book for Caregivers*. New York, NY: New York Times Books.

National Family Caregivers Association. (1996). *The Resourceful Caregiver: Helping Family Caregivers Help Themselves*. St. Louis, MO: Mosby Lifeline.

## Living Beyond Cancer

Cancer survivorship is a day-to-day, ongoing process that begins with your diagnosis and continues through the rest of your life. *Living Beyond Cancer* discusses a number of important issues that are specific to life beyond the diagnosis and initial treatment of cancer.

Surviving cancer is more complicated than simply being sick or well, having cancer, or being cancer-free. Instead, it is a continual process that is constantly changing. There may be times when the joy you feel about survival far outweighs any anxieties you may have. Then, there will be times when your fears and uncertainties seem to take over your life, and you wonder if you will ever feel normal again.

This program will introduce you to skills to help you adapt to your life after cancer. The goal is to help you, a cancer survivor, be as healthy as possible within your personal circumstances.

After listening to this Toolbox program, you will better understand:

- Common physical effects of cancer and its treatment, and what kind of medical records you need to keep to maintain a personal health history
- How to address concerns about sexuality and fertility
- How to support family relationships that may have changed during treatment
- The emotional aspects of cancer, including anxiety, depression, grief, and distress

- Health directives, wills and trusts, power of attorney, and financial planning
- How to live with hope while dealing with uncertainty

A copy of the Distress Management Thermometer, an important component of this program, can be found at the end of this booklet.

## References

Frank AW. (2002). *At the Will of the Body: Reflections on Illness*. New York, NY: Houghton Mifflin.

Keene N, Hobbie W, Ruccione K. (2006). *Childhood Cancer Survivors: A Practical Guide to Your Future*. Sebastopol, CA: O'Reilly & Associates, Inc. Second Edition.

Hoffman B (ed). (2004). *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship. Hoboken, NJ: John Wiley & Sons, Inc. Third Edition. Available at <http://www.canceradvocacy.org>.

Nessim S, Ellis J. (2000). *Can Survive: Reclaiming Your Life After Cancer*. New York, NY: Houghton Mifflin. Second Edition.

## Dying Well—The Final Stage of Survivorship

Although death is an inevitable part of life, few of us know just what to do or say or how to find the support we need when we are nearing the end of our lives and saying our final goodbyes. *Dying Well—The Final Stage of Survivorship* is an informative, supportive, and reassuring program designed to teach you more about your choices and resources and what to expect during this last stage of survival.

After listening to this Toolbox program, you and your loved ones will be better prepared to:

- Communicate with the members of your cancer care team, as well as family, friends, employers, and coworkers
- Manage hopes and expectations
- Deal with any anxiety or depression that may arise
- Make decisions about symptom management (including controlling pain) and continuing or stopping treatment
- Recognize what is happening during the dying process
- Make informed decisions about hospice/palliative care
- Manage grief

## References

Bahti T. (2006). *Dying to Know: Straight Talk About Death and Dying*. Tucson, AZ: Pathways: Education & Consultation in End of Life Care. Available at <http://www.pathwayseol.com/products.html>.

Byock I. (1997). *Dying Well: The Prospect for Growth at the End of Life*. New York, NY: Putnam/Riverhead.

*Five Wishes*®. (2007). Tallahassee, FL: Aging With Dignity. Available at <http://www.agingwithdignity.org/>.

Harwell A. (2000). *Ready to Live: Prepared to Die—A Provocative Guide to the Rest of Your Life*. Wheaton, IL: Shaw Publishing.

Mullan F. (1985). Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine*, vol 313, pgs 270-273.

## Finding Information on the Internet

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.

The World Wide Web (also known as “www” or “the Web”) is the “point and click” graphic portion of the Internet. It is made up of millions of pages, thousands of which provide different kinds of cancer information. Each page can have “links” (a jump or connection from one site to another) to other web sites, enabling the user to branch off to another document for more information and then be able to return to the same location in the original document with ease.

There are many good books to help you get comfortable with using the Internet. Also, many of the companies that provide Internet access (called Internet Service Providers or “ISPs”) 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.

## Treatment Options and Decision-Making Tools

### Treatment Guidelines

The National Comprehensive Cancer Network (NCCN) and the American Cancer Society (ACS) worked together to develop the NCCN Clinical Practice Guidelines in Oncology™ which are available to clinicians and non-clinicians on the NCCN’s main site, [www.nccn.org](http://www.nccn.org). NCCN will also offer patient-friendly summaries based on these guidelines through a new consumer website, <http://www.nccn.com>. The online summaries will help patients understand treatment options for their disease and prepare them to talk to their doctors about the therapies that may be right for them. In addition to offering patient-friendly summaries based on the NCCN Guidelines, the new consumer website, [www.nccn.com](http://www.nccn.com), will provide information on living with cancer, paying for cancer treatment, cancer survivorship, and other topics.

### Decision-Making Tools

The American Cancer Society has information available at <http://www.cancer.org> to help you make treatment decisions about the following cancers:

- Bladder
- Breast
- Cervical
- Colorectal
- Hodgkin’s lymphoma
- Kidney
- Leukemia
- Lung
- Melanoma
- Multiple myeloma
- Non-Hodgkin’s lymphoma
- Oral
- Ovarian
- Pancreatic
- Prostate
- Testicular
- Uterine

## Laws Pertaining to Health Insurance

**COBRA**, the **Consolidated Omnibus Budget Reconciliation Act**, gives some workers the right to keep their health insurance coverage for a limited period of time after they leave their jobs. The booklet, *An Employee’s Guide to Health Benefits Under Cobra*, contains detailed information about COBRA and is available online at <http://www.dol.gov/ebsa/pdf/cobraemployee/pdf>, or by calling the toll-free number 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) to obtain the location of your regional EEOC office in order to file a complaint. The toll-free number is 800-669-4000.

**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 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 United States 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 pre-existing 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.

**Health Insurance and Financial Resources**

*It's Your Choice: Are Medicare HMOs right for you?*

This 30-page booklet was written by Consumer Action, with assistance from the Gray Panthers and the National Consumers League. The brochure, downloadable from their web site and available in English and Spanish, advises people currently on Medicare about changes taking place in Medicare and what they mean.

Consumer Action  
 Phone: 415-777-9635  
 Web Site Address:  
<http://www.consumer-action.org>

*The Managed Care Answer Guide*

This 35-page booklet, covering the terminology of managed care, is a consumer's guide to selecting an insurance plan and understanding the provisions of your plan. You may order a free copy by writing, calling the toll-free number, or visiting the web site.

Patient Advocate Foundation  
 700 Thimble Shoals Boulevard, Suite 200  
 Newport News, VA 23606  
 Phone: 800-532-5274  
 Web Site Address:  
<http://www.patientadvocate.org>

*Protect Your Pension: A Quick Reference Guide*

You may order a free copy of this publication with information on safeguarding your pension plan. It is also available on the USDOL/EBSA web site below.

U.S. Department of Labor  
 Employee Benefits Security Administration  
 200 Constitution Avenue, NW, Suite N-5625  
 Washington, DC 20210  
 Phone: 866-444-EBSA (866-444-3272)  
 Web Site Address: <http://www.dol.gov/ebsa>

*What Cancer Survivors Need to Know About Health Insurance*

This booklet includes new information about the Health Insurance Portability and Accountability Act (HIPAA). You may order a copy by phone or through the web site.

National Coalition for Cancer Survivorship  
 1010 Wayne Avenue, Suite 770  
 Silver Spring, MD 20910-5600  
 Phone: 877-NCCS-YES (877-622-7937)  
 Web Site Address:  
<http://www.canceradvocacy.org>

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 assure 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 Program 9 of the Toolbox, *Finding Ways to Pay for Care*. The Wellness Community web site, <http://www.thewellnesscommunity.org>, also offers information.

**Cancer Institutions and Organizations**

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, the National Colorectal Cancer Alliance, the National Prostate Cancer Coalition, and the Susan G. Komen Foundation provide up-to-date information and connections to other people with the same kind of cancer. Some of the grassroots advocacy groups also facilitate support. For example, the Pancreatic Cancer Action Network (PanCAN) helps connect pancreatic cancer survivors with others who have been more recently diagnosed. Check with an advocacy group that offers services to people with your form of cancer to see if they help connect survivors with one another. You will find a list of advocacy groups in the "Advocacy Organizations and Other Sources of Information" section of the Toolbox, and you can also use links to advocacy groups listed on the National Coalition for Cancer Survivorship web site, <http://www.canceradvocacy.org>.

**Designation of Types of Cancer Treatment Centers**

Desirable qualities in a cancer treatment facility can be found in many different settings, ranging from doctors' offices to hospital-based outpatient clinics to community cancer centers to the National Cancer Institute-designated and comprehensive cancer centers that do cancer research and provide clinical care and services to individuals with cancer. To find these designated cancer centers and learn more about them, use the National Cancer Institute's web site, <http://cancercenters.cancer.gov>.

There is also an organization, the R.A. Bloch Cancer Foundation, that lists places that offer multidisciplinary second opinions for cancer on their web site, <http://www.blochcancer.org>. The list is arranged by state and has a contact name and phone number for each cancer center. You can also call the Bloch Foundation's toll-free cancer hotline at 800-433-0464.

**Description of Clinical Trials**

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 less 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

## Suggested Reading Materials and Resources

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.

### Specific Resources for 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. Information on cancer trials is also available from the National Cancer Institute on the NCI web site listed in the Toolbox (<http://www.cancer.gov>). Information about clinical trials is also available toll-free from NCI's telephone-based Cancer Information Service (CIS) at 800-4-CANCER (800-422-6237). Several web sites offer clinical trial matching services. The Coalition of Cancer Cooperative Groups (CCCCG) has a web site (<http://www.cancertrials-help.org>) that offers the "Patient and Caregiver Toolkit"—a package of practical information and publications you can use to learn about cancer clinical trials. It also offers a search engine or database of cancer-related clinical trials (<http://www.cancertrials-help.org/trialcheck>).

The CCOG 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?

### Support for Cancer Survivors

Materials published by the National Coalition for Cancer Survivorship are available at <http://www.canceradvocacy.org>.

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

Blogger.com. Available at <http://www.blogger.com>.

BreastCancer.org. (2006). *Your Guide to the Breast Cancer Pathology Report*. Available at <http://www.breastcancer.org>.

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

Clark EJ (ed). (2006). *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. 58pp.

Clark EJ. (2007). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition.

*Coping® With Cancer* magazine. PO Box 682268, Franklin, TN 37068-2268.

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

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

Greenfield NR. (2004). *When Mommy Had a Mastectomy*. Savage, MD: Bartleby Press.

Gruman J. (2007). *After Shock: What to Do When the Doctor Gives You—or Someone You Love—A Devastating Diagnosis*. New York, NY: Walker and 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. (2004). *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY: HarperCollins.

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

Hoffman B (ed). (2007). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship.

Hoffman B (ed). (2004). *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship. Hoboken, NJ: John Wiley & Sons. Third Edition.

McGinn KA, Haylock PJ. (2002). *Women's Cancers*. Alameda, CA: Hunter House. Third Edition.

Schnipper H. (2003). *After Breast Cancer: A Common-Sense Guide to Life After Treatment*. New York, NY: Bantam.

*Self-Advocacy: A Cancer Survivor's Handbook.* (2003). Silver Spring, MD: National Coalition for Cancer Survivorship. First Edition. 26pp.

*The Prescription for Living Plan.* Available at <http://www.nursingcenter.com/ajncancersurvivors>.

### Support for Caregivers

*Taking Time: Support for People With Cancer and the People Who Care About Them.* (2003). National Institutes of Health, National Cancer Institute. Available at <http://www.cancer.gov> or 800-4-CANCER (800-422-6237).

*When Someone You Love Is Being Treated for Cancer.* (2005). National Institutes of Health, National Cancer Institute. Available at <http://www.cancer.gov> or 800-4-CANCER (800-422-6237).

### Coping With Cancer Therapy

Dodd MJ. (2001). *Managing the Side Effects of Chemotherapy & Radiation Therapy: A Guide for Patients and Their Families.* San Francisco, CA: Regents University of California School of Nursing. Second Edition.

### Special Resources for Older Persons

*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).

National Academy of Elder Law Attorneys  
1604 North Country Club Road  
Tucson, AZ 85716  
Phone: 520-881-4005  
Web Site Address: <http://www.naela.com>

### Death and Dying Resources

Unlike 20 years ago, when cancer and grief were both kept hidden, in the 21st Century there are many resources to help survivors and their family members with the questions and adjustments that have to be made before, during, and after a cancer diagnosis. 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.

A simple living will that helps persons make decisions about end-of-life care—for example, choosing a health care agent and exercising your rights—is available from:

*Aging With Dignity and Five Wishes®*

PO Box 1661  
Tallahassee, FL 32302-1661  
Phone: 888-5WISHES (888-594-7437)  
Web Site Address:  
<http://www.agingwithdignity.org>

Other specific resources on the topics covered in the *Dying Well* program of the Toolbox can be found at the organizations listed below:

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

Web Site Address: <http://www.aarp.org>

*American Foundation for Suicide Prevention*

Phone: 888-333-AFSP (888-333-2377)  
or 212-363-3500  
Web Site Address: <http://www.afsp.org>

*American Pain Foundation\**

Web Site Address:  
<http://www.painfoundation.org>

*Association of Oncology Social Work\**

Web Site Address: <http://www.aosw.org>

*CancerCare\**

Web Site Address: <http://www.cancercares.org>

*Candlelighters Childhood Cancer Foundation\**

Web Site Address: <http://www.candlelighters.org>

*Children's Hospice and Palliative Care Coalition*

Web Site Address:  
<http://www.childrenshospice.org>

*Compassion & Choices*

Web Site Address:  
<http://www.compassionandchoices.org>

*The Compassionate Friends*

Phone: 877-969-0010  
Web Site Address:  
<http://www.compassionatefriends.org>

*Elisabeth Kübler Ross Foundation*

Web Site Address:  
<http://www.elisabethkublerross.com>

*Good Grief Resources*

Web Site Address:  
<http://www.goodgriefresources.com>

*Hospice and Palliative Nurses Foundation*

Web Site Address: <http://www.hpnf.org>

\*See detailed description in the next section, "Advocacy Organizations and Other Sources of Information."

## Advocacy Organizations and Other Sources of Information

### *Hospice Foundation of America\**

Web Site Address:  
<http://www.hospicefoundation.org>

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

NASW online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals can be accessed at <http://www.naswwed.org>. NASW also offers "Understanding End of Life Care," an online course for individuals and their loved ones affected by death and dying. The course is available at [http://www.helpstartshere.org/health\\_and\\_wellness/death\\_and\\_dying/resources/understanding\\_end\\_of\\_life\\_care\\_course.html](http://www.helpstartshere.org/health_and_wellness/death_and_dying/resources/understanding_end_of_life_care_course.html).

Web Site Addresses:  
<http://www.socialworkers.org>  
<http://www.helpstartshere.org>

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

Web Site Address:  
<http://www.cancer.gov/cancertopics/support>

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

Web Site Address: <http://www.grievingchild.org>

### *National Hospice and Palliative Care Organization\**

Web Site Addresses:  
<http://www.nhpco.org>  
<http://www.caringconnections.org>

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

Available at:  
<http://www.pbs.org/wnet/onourown/terms>

### *Pathways: Education & Consultation in End of Life Care*

Phone: 520-400-0274  
Web Site Address: <http://www.pathwayseol.com>

### *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 web site below.

Kidney Cancer Association  
1234 Sherman Avenue, Suite 203  
Evanston, IL 60202-1375  
Phone: 800-850-9132  
Web Site Address: <http://kidneycancer.org>

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

### *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.

Phone: 888-OUR-AARP (888-687-2277)  
Web Site Address:  
<http://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.

Phone: 202-293-2856  
Web Site Address: <http://www.agingresearch.org>

### *American Association for Geriatric Psychiatry*

This organization provides referrals for geriatric psychiatrists. Written materials for patients, family members, and caregivers may also be obtained.

Phone: 301-654-7850  
Web Site Address: <http://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 web site can help you locate a sexuality educator, counselor, or therapist in your area.

Phone: 804-752-0026  
Web Site Address: <http://www.aasect.org>

### *American Cancer Society*

This organization provides written information about cancer, 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.

Phone: 800-ACS-2345 (800-227-2345)  
Web Site Address: <http://www.cancer.org>

### *American Chronic Pain Association*

This organization 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.

Phone: 800-533-3231 or 916-632-0922  
Web Site Address: <http://www.theacpa.org>

\*See detailed description in the next section, "Advocacy Organizations and Other Sources of Information."

#### *American Pain Foundation*

This organization 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.

Phone: 888-615-PAIN (888-615-7246)

Web Site Address:

<http://www.painfoundation.org>

#### *American Pain Society*

This group provides a directory of more than 500 pain-treatment centers in the United States.

Phone: 847-375-4715

Web Site Address: <http://www.ampainsoc.org>

#### *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 web site provides consumer information about private insurance, managed care, getting coverage, and answers to frequently asked questions.

601 Pennsylvania Avenue, NW

South Building, Suite 500

Washington, DC 20004

Phone: 202-778-3200

Web Site Address: <http://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.

100 North 20th Street, 4th Floor

Philadelphia, PA 19103

Phone: 215-599-6093

Web Site Address: <http://www.aosw.org>

#### *BBB Wise Giving Alliance*

This group, a service of the Better Business Bureau, offers information on legitimate charities and causes.

Phone: 703-276-0100

Web Site Address: <http://www.give.org>

#### *Breast Cancer Network of Strength*

Provides immediate emotional relief to anyone affected by breast cancer. This organization's mission is to ensure, through information, empowerment, and peer support, that no one faces breast cancer alone. Information is available in a number of languages, including English, Spanish, Chinese, and others.

Phone: 312-986-8338

Web Site Address:

<http://www.networkofstrength.org>

#### *CancerCare*

This is a national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are available in Spanish. All services are free of charge.

Phone: 800-813-HOPE (800-813-4673)

Web Site Address: <http://www.cancer.org>

#### *Cancer.Net*

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

Phone: 888-651-3038

Web Site Address: <http://cancer.net>

#### *Cancer Survivor's Treatment Record: Taking Care of Yourself for Life*

This booklet by Kathy Ruccione and Wendy Hobbie will help you keep track of your medical history with a summary of your cancer treatment and guidelines for health monitoring that may reduce your chances of medical problems in the future. Available for download at [http://www.patientcenters.com/survivors/treatment\\_record.pdf](http://www.patientcenters.com/survivors/treatment_record.pdf)

#### *Candlelighters Childhood Cancer Foundation*

This organization provides a network of support groups for children, parents, and caregivers.

Phone: 800-366-CCCCF (800-366-2223)

Web Site Address: <http://www.candlelighters.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.

Phone: 800-829-2734

Web Site Address: <http://www.caregiver.com>

#### *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.

221 Main Street, Suite 480

San Francisco, CA 94105

Phone: 415-777-9635

Web Site Address:

<http://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 web site or call the toll-free number weekdays from 9 AM until 8 PM eastern time.

Phone: 800-677-1116

Web Site Address: <http://www.eldercare.gov>

### *Family Caregiver Alliance*

This organization 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.

Phone: 415-434-3388

Web Site Address: <http://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.

Phone: 888-994-HOPE (888-994-4673)

Web Site Address: <http://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.

1220 L Street NW, Suite 901

Washington, DC 20005

Phone: 202-842-1275

Web Site Address: <http://www.geron.org>

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

HICAP is a national 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.

Web Site Address:

<http://www.inlandagency.org/hicap.html>

### *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.

Web Site Address: <http://www.healthprivacy.org>

### *Hospice Foundation of America*

This organization provides general information about hospices and will assist you in locating a hospice near you.

Phone: 800-854-3402

Web Site Address:

<http://www.hospicefoundation.org>

### *Impotence Specialists.com*

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

Web Site Address:

<http://www.impotencespecialists.com>

### *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.

Phone: 713-798-4617

Web Site Address: <http://www.iccnetwork.org>

### *Lance Armstrong Foundation (LAF)*

LAF seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. Livestrong.org, an additional web site created by LAF, focuses on the physical, emotional, and practical issues that you may encounter after completing active treatment for cancer. The site features real survivors discussing their experiences as well as links to more information.

Phone: 866-467-7205

Web Site Addresses:

<http://www.laf.org>

<http://www.livestrong.org>

### *Leukemia & Lymphoma Society of America*

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

Phone: 800-955-4LSA (800-955-4572)

Web Site Address:

<http://www.leukemia-lymphoma.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.

Phone: 407-894-3797

Web Site Address:

<http://www.thevoiceoftheindustry.com>

### *Lighthouse International*

This is a leading resource for persons with vision impairment. It enables those who are blind or partially sighted to lead independent and productive lives.

Phone: 800-829-0500 or 212-821-9713 (TTY)

Web Site Address: <http://www.lighthouse.org>

### *Medicare*

This U.S. 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.

Phone: 800-MEDICARE (800-633-4227)

Web Site Address: <http://www.medicare.gov>

### *National Association of Community Health Centers*

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

Phone: 301-347-0400

Web Site Address: <http://www.nachc.com>

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

NASW, the largest membership association of social workers nationwide, provides a consumer web site with information and advice regarding health, mental health, cancer and other illnesses, as well as a way to find a social worker near you.

750 First Street, NE, Suite 700  
Washington, DC 20002-4241  
Phone: 202-408-8600

Web Site Addresses:  
<http://www.socialworkers.org>  
<http://www.helpstartshere.org>

#### *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 web site features information about clinical trials as well as *Facing Forward Series: Life After Cancer Treatment*.

Phone: 800-4-CANCER (800-422-6237)  
Web Site Address: <http://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 1986, NCCS created the widely-accepted definition of survivorship and considers someone a cancer survivor from the time of diagnosis through the balance of life. 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.

1010 Wayne Avenue, Suite 770  
Silver Spring, MD 20910-5600  
Phone: 877-NCCS-YES (877-622-7937)

Web Site Addresses:  
<http://www.canceradvocacy.org>  
<http://www.canceradvocacynow.org>  
<http://www.canceradvocacy.org/toolbox>

#### *National Family Caregivers Association*

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

Phone: 800-896-3650  
Web Site Address: <http://www.nfcacares.org>

#### *National Hospice and Palliative Care Organization*

This organization can assist you in finding a hospice; it also provides consumer-oriented materials. Printed materials can be ordered by calling 800-646-6460.

Phone: 800-646-6460  
Web Site Address: <http://www.nhpco.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.

Phone: 800-222-2225 or 800-222-4225 (TTY)  
Web Site Address: <http://www.nia.nih.gov>

#### *National Self-Help Clearinghouse*

This organization provides information and referral for self-help support groups and for other community resources.

Phone: 212-817-1822  
Web Site Address: <http://www.selfhelpweb.org>

#### *Needy Meds, Inc.*

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

PO Box 219  
Gloucester, MA 01931  
Web Site Address: <http://www.needymeds.com>

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

This organization provides health information regarding Native American, Alaska Native, African American, Asian American, Pacific Islander, and Hispanic/Latino populations.

PO Box 37337  
Washington, DC 20013-7337  
Phone: 800-444-6472  
Web Site Address: <http://www.omhrc.gov>

#### *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.

Web Site Address:  
<http://www.oncolink.upenn.edu>

#### *Oncology Nursing Society (ONS)*

This national organization is composed of more than 35,000 registered nurses and other health care providers who work with persons who have cancer. Their web site has a special section for patient information and educational resources.

125 Enterprise Drive  
RIDC Park West  
Pittsburgh, PA 15275-1214  
Phone: 866-257-4ONS (866-257-4667)  
Web Site Address: <http://www.ons.org>

#### *Pancreatic Cancer Action Network (PanCAN)*

PanCAN helps connect pancreatic cancer survivors with others who have been more recently diagnosed.

Phone: 877-272-6226 (Patient and Liaison Services [PALS])

Web Site Address: <http://www.pancan.org>

#### *Partnership for Prescription Assistance (PPA)*

PPA helps qualifying patients who lack prescription coverage to access public and/or private programs.

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

Web Site Address: <http://www.pparx.org>

#### *ProLiteracy Worldwide*

This international network of more than 1,200 programs helps people learn how to read and use literacy skills.

Phone: 888-528-2224

Web Site Address: <http://www.proliteracy.org>

#### *Social Security Administration*

The Social Security Administration of the federal government manages Social Security, Supplemental Security Income, Medicare, and parts of Medicaid.

Phone: 800-772-1213

Web Site Address: <http://www.ssa.gov>

#### *Susan G. Komen Breast Cancer Foundation*

This organization provides information about breast health and breast cancer research, as well as a toll-free “Helpline” that is staffed by trained volunteers.

Phone: 800-IM-AWARE (800-462-9273)

Web Site Address: <http://www.komen.org>

#### *United Ostomy Associations of America, Inc. (UOAA)*

This volunteer-based health organization is dedicated to providing education, information, support, and advocacy for people who have intestinal or urinary diversions.

Phone: 800-826-0826

Web Site Address: <http://www.uoa.org>

#### *U.S. Department of Labor Employee Benefits Security Administration*

You may order a free copy of a publication, *Protect Your Pension: A Quick Reference Guide*, that provides information about safeguarding your pension plan.

200 Constitution Avenue, NW, Suite N-5625  
Washington, DC 20210

Phone: 866-444-3272 or 877-889-5627 (TTY)

Web Site Address: <http://www.dol.gov/ebsa>

#### *Us TOO International, Inc.*

This international network of chapters provides support and services to men with prostate cancer and their loved ones. For support group information or local chapters, call the toll-free number or visit their web site.

Phone: 800-80-US-TOO (800-808-7866)

Web Site Address: <http://www.ustoo.com>

#### *Veterans Affairs*

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

Phone: 800-827-1000

Web Site Address: <http://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.

Phone: 800-838-0879

Web Site Address: <http://www.wellspouse.org>

#### *The Wellness Community (TWC)*

TWC is 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.

Phone: 888-793-WELL (888-793-9355)

Web Site Address:

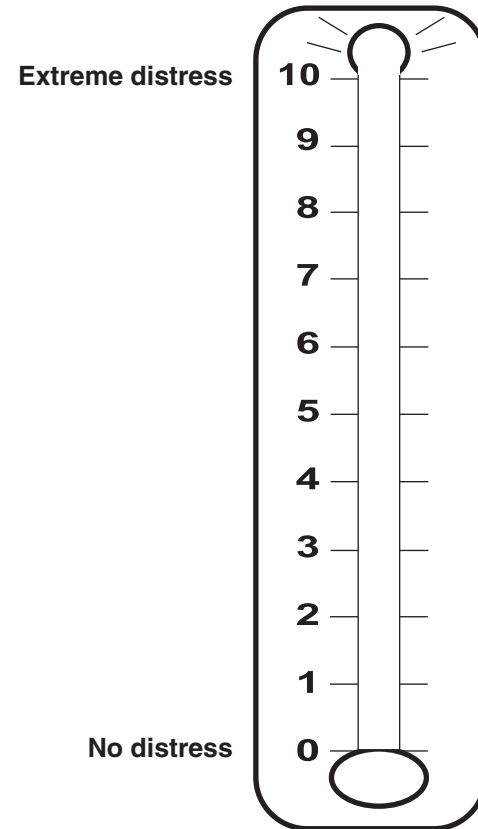
<http://www.thewellnesscommunity.org>

# Distress Management Thermometer

The emotional distress that cancer causes can take many forms; anxiety, anger, depression, and frustration are all quite common. Cancer specialists use the Distress Thermometer to help them measure the emotional impact of cancer on survivors. We have included a copy here for your reference. If you are experiencing emotional distress from your cancer, it is very important to know that help is available, and to go get the help you need. The Distress Thermometer may help you describe the way you are feeling to your health care team.

## Screening tools for measuring distress

**Instructions: First, please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.**



From the NCCN Distress Management Guidelines (V.1.2007), *The Complete Library of NCCN Clinical Practice Guidelines in Oncology™* [CD-ROM]. Jenkintown, Pennsylvania: National Comprehensive Cancer Network, August 2006. To view the most recent and complete version of the guideline, go online to [www.nccn.org](http://www.nccn.org).

## Distress Management

**Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.**

YES	NO	<u>Practical Problems</u>	YES	NO	<u>Physical Problems</u>
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
			<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
		<b><u>Family Problems</u></b>	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Fevers
		<b><u>Emotional Problems</u></b>	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Pain
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	<b><u>Spiritual/Religious Concerns</u></b>	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other problems: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Glossary of Common Terms

**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

**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

**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 multiple myeloma

**Lymphoma:** a type of cancer that starts in a lymph node

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

**Metastasis:** (a) the spread of cancer cells from the original tumor through the bloodstream and lymphatic system to another part of the body; (b) a secondary tumor caused by this movement of cancer cells

**Neoplasm:** a new growth of cells

**Prognosis:** a prediction of what might happen to an individual 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

**Solid tumor:** a firm, compact tumor made up of a cluster of cells

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

\*The stage of cancer is defined by 3 factors: (1) how large the tumor (T) itself is; (2) how much, if any, the tumor has spread to nearby lymph nodes (N); and (3) whether there is any known metastasis (M) or spread to distant organs. Stage 0 means an *in situ* carcinoma—a tumor that has not spread to nearby tissues and is unlikely to have migrated or metastasized to lymph nodes or other organs. The TNM status for an *in situ* carcinoma would be T0 N0 M0—a very small tumor, with no lymph node involvement and no evidence of metastasis. A non-small cell lung cancer that is larger than 3 centimeters (about 1½ inches) in diameter, with spread to the lymph nodes around the bronchus but none to other distant organs, would be staged as T2 N1 M0.

**Tumor margin:** the edge or border of the tissue removed in cancer surgery; described as negative or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed; described as positive or involved when the pathologist finds cancer cells at the edge of the tissue, suggesting that all of the cancer has not been removed.

