

Dying Well— The Final Stage of Survivorship

Practical Resources and Guidance for
Cancer Survivors and Their Loved Ones



A *Cancer Survival Toolbox*® audio program designed to help you and your family choose the best path during the last stages of life.

- Stories from survivors and caregivers
- Information about your choices and resources
- Guidance to manage hope and expectations

"I worked through my dying to go on with my living. I believe that once we have prepared to die, we are really freed to live in whatever time we have left."

—Amy Harwell, cancer survivor and author



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Introduction

Dying Well—The Final Stage of Survivorship is part of the *Cancer Survival Toolbox*[®], which was created by the National Coalition for Cancer Survivorship (NCCS), along with cancer survivors and leading cancer organizations, to help you and your loved ones deal with a cancer diagnosis no matter where you are in your journey.

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

Resources for Dying Well— The Final Stage of Survivorship

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 *Cancer Survival Toolbox*, *Basic Skills* programs—communicating, finding information, decision-making, problem-solving, negotiating, and standing up for your rights—can be used at every step of the journey and are available free of charge from NCCS. The resources listed here may be helpful for people with advanced illness.

Alphabetical List of Support Organizations and Other Resources

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

Use this key to help you identify which organizations/resources may be of most use to you at this time.

-  Pain and Palliative Care
-  Older Persons
-  Caregivers
-  Support Groups/One-on-One Support/Staying Connected
-  End of Life

AARP (American Association of Retired Persons)   

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

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.

Aging With Dignity and Five Wishes®  

888-5-WISHES (888-594-7437)

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* uses everyday language to help 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. Available in several languages.

American Academy of Hospice and Palliative Medicine * ○ + ✿ ☼

847-375-4712

www.palliativedoctors.org

Provides resources and guidance on palliative care, hospice, and legal and insurance issues relevant to people facing a serious illness.

American Association for Geriatric Psychiatry *

301-654-7850

www.aagpgpa.org

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

American Cancer Society * ○ + ✿

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

www.cancer.org

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.

American Childhood Cancer Organization ✿

(formerly Candlelighters Childhood Cancer Foundation)

800-366-CCCCF (800-366-2223)

www.acco.org

Provides a network of support groups for children, parents, and caregivers.

American Chronic Pain Association *

800-533-3231

www.theacpa.org

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.

***American Pain Foundation* ***

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

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

***American Pain Society* ***

847-375-4715
www.ampainsoc.org

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

***Association of Oncology Social Work (AOSW)* * ○ + ✦**

215-599-6093
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.

***Blogger.com* +**

www.blogger.com

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

***C3: Colorectal Cancer Coalition* +**

877-4CRC-111 (877-427-2111) or 703-548-1225
www.fightcolorectalcancer.org

A national nonprofit advocacy organization whose mission is to win the fight against colorectal cancer through research, empowerment, and access. Provides information about colorectal cancer and clinical trials.

CancerCare * ○ + ✦

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

www.cancercares.org

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.

Cancer.Net * ○ + ✦

888-651-3038

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

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

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/

Offers free, personalized websites that connect family and friends during a serious health event.

***Caring Connections* + ☸**

800-658-8898

caringinfo.org

As the consumer site of the National Hospice and Palliative Care Organization, provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

***Caring Conversations*® ☸**

Center for Practical Bioethics

800-344-3829

www.practicalbioethics.org

Offers a step-by-step workbook to document wishes about end-of-life care, including personal, emotional, and spiritual needs as well as medical wishes. Also provides forms for durable power of attorney and advance treatment directive. Provides separate resources for young adults, veterans, and Spanish speakers.

***Center to Advance Palliative Care* ***

www.getpalliativecare.org

Offers information about how palliative care can relieve suffering and help people achieve the best possible quality of life when facing pain, symptoms, and stresses of a serious illness.

Children's Hospice and Palliative Care Coalition * 🌻

831-763-3070

www.childrenshospice.org

Provides training and support to hospice teams to better meet the medical, emotional, and spiritual needs of the dying child and the family. Promotes policies and all-inclusive care programs that meet the complex medical, emotional, social, and practical needs of families who are experiencing great loss.

Circle of Sharing™ +

circleofsharing.cancer.org/

An American Cancer Society resource that helps cancer patients and their caregivers get personalized information about the disease, and share that information with family and friends.

The Compassionate Friends * 🌻

877-969-0010

www.compassionatefriends.org

Assists families toward the positive resolution of grief following the death of a child of any age and provides information to help others be supportive.

Eldercare Locator ○

800-677-1116

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.

Elisabeth Kübler-Ross Foundation * 🌻

www.ekrfoundation.org

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

Family Caregiver Alliance +

800-445-8106

www.caregiver.org

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

Gerontological Society of America ○

202-842-1275

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, publications, and a list of online resources useful to older persons with cancer and their caregivers.

Good Grief ✦ 🌀

908-522-1999

www.good-grief.org

Provides direct services for children and adults coping with loss due to death.

Health Insurance Counseling and Advocacy Program (HICAP) ○

800-434-0222

www.aging.ca.gov/information_on/hicap.asp

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.

Hospice and Palliative Nurses Foundation * ○ + ✦ 🌀

412-787-9301

www.hpnf.org

Provides funding for research and nursing education related to pain and symptom management at the end of life.

Hospice Foundation of America * ○ + ✦ ⦿

800-854-3402

www.hospicefoundation.org

Provides general information about hospices and will assist you in locating a hospice near you. Available on their website is *The Dying Process: A Guide for Caregivers*, a free booklet that discusses both the physical symptoms of dying and the psychological issues that accompany the dying process. Also offers free videos, webinars, and fact sheets on hospice, end-of-life care, and the Medicare Hospice Benefit. Provides a public service program called Ask HFA, where experts can answer questions on end-of-life issues.

Lance Armstrong Foundation/LIVESTRONG ✦

866-467-7205 or 866-673-7205

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

Provides support services, including local support groups and financial assistance to persons with leukemia, lymphoma, and multiple myeloma. Information about LLS resources is available in English, Spanish, Portuguese, and French.

MyLifeLine ✦

www.MyLifeLine.org

Offers free, customizable websites to empower cancer patients and caregivers to build an online community of friends and family.

National Academy of Elder Law Attorneys ○

703-942-5711
www.naela.com

Offers *Questions and Answers When Looking for an Elder Law Attorney*, a pamphlet that covers issues such as where to find an attorney, what questions to ask, how to discuss fees, and more, available either online at www.naela.org/About_QandA.aspx or by sending a stamped self-addressed business-sized envelope to:

NAELA Q & A
1577 Spring Hill Road, Suite 220
Vienna, VA 22182

National Association of Social Workers (NASW) ✦ 🌟

202-408-8600

www.socialworkers.org

www.helpstartshere.org—Offers many resources, including “Understanding End of Life Care.”

www.naswweb.org—Provides online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals.

www.helppro.com/nasw/Default.aspx—Offers assistance in finding licensed social workers through the National Social Worker Finder.

National Cancer Institute (NCI) * ○ +

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

www.cancer.gov

Offers many educational resources for cancer survivors, including information on coping with advanced cancer, end-of-life issues, and hospice. Last Days of Life (PDQ®) is an expert-reviewed summary about care during the last days to last hours of life.

National Center for Grieving Children & Families (The Dougy Center) 🌻

866-775-5683

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

Advocates for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves. Its free programs include the *Cancer Survival Toolbox*, an audio program using patient stories to help people develop the essential skills to meet the challenges of their illness. Includes individual programs such as Communicating, Making Decisions, Standing Up for Your Rights, Topics for Older Persons, and Living Beyond Cancer, in addition to Dying Well—the Final Stage of Survivorship. Offers pamphlets including *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor* and *You Have a Right to Be Hopeful*, available in English and Spanish.

National Family Caregivers Association 🌻

800-896-3650

www.nfcacares.org

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

National Hospice and Palliative Care Organization * 🌈 🌻

800-658-8898

www.nhpco.org

www.caringinfo.org (consumer site)

Offers assistance in finding a hospice; also provides consumer-oriented materials. Offers resources on pediatrics, legal issues, communication, caregiving, hospice, and grief. Materials are available in Spanish and Mandarin Chinese.

On Our Own Terms: Moyers on Dying 🌀

800-257-5126

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.

OncoLink * +

www.oncolink.upenn.edu

A website managed by the Abramson Cancer Center of the University of Pennsylvania that provides a range of cancer-related information, including articles on the final stage of life.

Pathways: Education & Consultation in End of Life Care ✦ 🌀

520-400-0274

www.pathwayseol.com

Provides resources designed to help improve end-of-life care.

Physician Orders for Life-Sustaining Treatment (POLST) Paradigm 🌀

www.ohsu.edu/polst/

Provides templates of available physician orders, which provide direction and documentation of patient preferences regarding a range of medical interventions. Designed to improve quality of care at end of life through effective communication of patient wishes and documentation of medical orders. Includes a list of states with recognized POLST Paradigm programs.

U.S. Department of Veterans Affairs + ✦

800-827-1000

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

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.

Survivorship Tools

Distress 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 healthcare team.

From the *NCCN Clinical Practice Guidelines in Oncology™: Distress Management (V.1.2011)* Jenkintown, PA: National Comprehensive Cancer Network; January 2010. To view the most recent and complete version of the guideline, visit www.nccn.org.

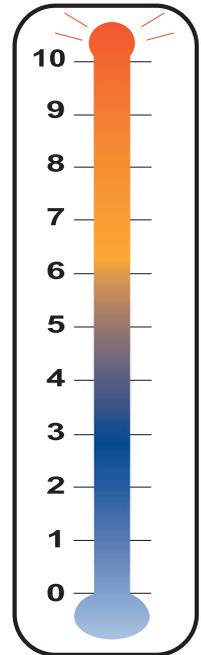
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Clinical Practice Guidelines
in Oncology – V.1.2011

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.

Extreme distress



No distress

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 Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

Family Problems

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

Spiritual/Religious Concerns

Yes No Physical Problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Tingling in hands/feet

Other Problems: _____

Books Related to End-of-Life Concerns

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

Byock I. (1997). *Dying Well: The Prospect of Growth at the End of Life*. New York, NY: The Berkley Publishing Group. Available at www.dyingwell.org.

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

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

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.

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

Mintz S. (2007). *A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard*. Herndon, VA: Capital Books.

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Notes

The *Cancer Survival Toolbox* is provided free of charge and used each year by thousands of people in cancer centers, hospitals, support groups, corporate wellness programs, community organizations, and professional societies. Please help make the program available by donating online at www.canceradvocacy.org/donate.

The *Cancer Survival Toolbox* programs are designed to support all cancer survivors. A set of 12 self-learning audio programs—as well as several additional programs for specific cancer types—are available FREE from the National Coalition for Cancer Survivorship (NCCS). These include *Basic Skills* programs and *Special Topics* that may be of interest to you.

Basic Skills
(available in English and Spanish)

- Communicating
- Finding Information
- Making Decisions
- Solving Problems
- Negotiating
- Standing Up for Your Rights

Special Topics
(available in English and Spanish)

- First Steps for the Newly Diagnosed
- Topics for Older Persons
- Finding Ways to Pay for Care
- Caring for the Caregiver
- Living Beyond Cancer
- Dying Well—The Final Stage of Survivorship

Other Cancer Survival Toolbox Programs

- Living With Blood and Marrow Transplant
- Living With Chronic Lymphocytic Leukemia
- Living With Chronic Myelogenous Leukemia
- Living With Multiple Myeloma
- Living With Non-Hodgkin Lymphoma (available in English and Spanish)

To obtain a copy of these FREE programs, call 877-NCCS-YES (877-622-7937) or visit www.canceradvocacy.org/toolbox.



The First Step to Cancer Survival™



Content Development Partners



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NOT FOR SALE

The Toolbox is provided as a free program thanks to the generous support of our partners.

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