

END OF LIFE

General End of Life Resources	111
Grief and Loss Resources for Adults	112
Grief and Loss Resources for Children	112
Community Programs	113



This symbol indicates resources specifically for Young Women with Breast Cancer.

GENERAL END OF LIFE RESOURCES

Advance Directive and End of Life Decisions

(Caring Connections)
(800) 658-8898 (Helpline)

This booklet answers many questions about living wills, medical power of attorney, appointing health care agents, and advance directives.



Before I Say Goodbye: Recollections and Observations from One Woman's Final Year

Ruth Picardie (Owl Books, 1998, \$13)
(646) 307-5095 or www.henryholt.com

Through the author's columns for London's Observer Life, correspondence from readers, emails to her friends, letters to her children and reflections by her husband and sister, this book chronicles her struggle and death from breast cancer at age 33.

Cardiopulmonary Resuscitation, Do-Not Resuscitate Orders and End of Life Decisions

(Caring Connections)
(800) 658-8898 (Helpline)

This booklet answers frequently asked questions about Do-Not-Resuscitate Orders.

Caring Connections

National Hospice and Palliative Care Organization (NHPCO)

1700 Diagonal Road, Suite 625
Alexandria, VA 22314
(800) 658-8898 (Helpline)
(877) 658-8896 (Spanish helpline)
www.caringinfo.org

Caring Connections, a program 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, helps people connect with the resources they need, when they need them, and brings together community, state and national partners working to improve end-of-life care.

Dying at Home

(Caring Connections)
(800) 658-8898 (Helpline)

This booklet addresses the concerns and questions about dying at home.

Dying Well: Peace and Possibilities at the End of Life

Ira Byock, M.D. (Riverhead Trade, 1998, \$16)

This book brings us to the homes and bedsides of families with whom the author has worked. It is a companion for families, showing them how to deal with doctors, talk to loved ones and make the end of life as meaningful and enriching as the beginning of life.

Grace and Grit: Spirituality and Healing in the Life and Death of Treya Kilam Wilber

Ken Wilber (Shambhala, 2001, \$19.95)

An account of a couple's struggle with cancer and their journey to spiritual healing; it is the story of the five-year journey of Ken Wilber and his wife Treya Killam Wilber through Treya's illness, treatment, and, finally, death.

Hospice Foundation of America

1621 Connecticut Ave NW, Suite 300
Washington DC, 20009
(800) 854-3402
hfaoffice@hospicefoundation.org
www.hospicefoundation.org

Hospice Foundation of America provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the American health care system and the role of hospice within it. They provide a number of resources, as well as a local hospice directory.

National Hospice and Palliative Care Organization (NHPCO)

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(800) 658-8898 or www.nhpco.org

The organization is committed to improving end of life

care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

On Death and Dying

Elisabeth Kubler-Ross (Scribner, 1997, \$14.95)

In this book, the author first explored the now-famous five stages of death: denial and isolation, anger, bargaining, depression and acceptance. Through interviews and conversations, the book provides a better understanding of how imminent death affects the patient, the professionals who serve the patient and the patient's family.

GRIEF AND LOSS RESOURCES FOR ADULTS

GriefNet.org

www.griefnet.org

An internet community of persons dealing with grief, death, and major loss. Their more than fifty email support groups and the integrated approach to on-line grief support provides help to people working through loss and grief issues of many kinds.

YoungWidow.org

www.youngwidow.org

A useful online resource for young widows and widowers, including an active bulletin board and resources for those who have children at home.

GRIEF AND LOSS RESOURCES FOR CHILDREN

A Life and Loss: A Guide to Help Grieving Children

Linda Goldman (Brunner-Routledge, 1999, \$28.95)

This book provides an overview of the issues that children may face when coping with loss, including resources that are available.

A Matter of Time

Roni Schotter (1979, \$7.95)

A 16-year-old girl develops her sense of self while coping with the grief over her mother's lung cancer diagnosis and subsequent death.

Barklay and Eve

www.barklayandeve.com

A series of coloring and activity books to help support children of all ages through the grieving process.

Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies

Janis Silverman (Fairview Press, 1999, \$9.95)

Although not cancer specific, this book, written by an art teacher for children ages 4 to 12, offers children and parents tools for coping with loss and grief through art.

Helping Children Live with Death and Loss

Diana Seibert, et al. (SIU Press, 2003)

www.siu.edu/~siupress

This is designed for parents, caregivers, and other adults who will be responding to children who have experienced loss. It is written sensitively and empathically in order to help the adult deal with the child's feelings about loss.

KidsAid

P.O. Box 3272

Ann Arbor, MI 48106-3272

www.kidsaid.com

An internet site for child and teen grief support and kid to kid grief support, where children and teens can safely express themselves in support groups and through sharing their experiences.

Learning to Say Good-bye: When a Child's Parent Dies

Eda LeShan (Avon, 1978)

In simple, direct language, this book discusses the questions, fears and fantasies you may have about the parent who has died and the people who are still alive. Helps you to understand the different stages of mourning human beings

need to go through. But most important, you will learn not just about death and grieving, but about life itself.

Motherless Daughters: The Legacy of Loss

Hope Edelman (DaCapo Press, 2006, \$15.95)

Edelman shares her own story of loss in this informative account of the psychological and spiritual effects that the death of a mother might have on the life and well-being of her daughter.

Never Too Young To Know: Death in Children's Lives

Phyllis R. Silverman (Oxford University Press, 1999, \$22.5)

Using stories of children's own experiences, supported by data from a large research study, Silverman explains the wide range of effects of loss upon children, the challenges they face as they grieve, and ways of supporting them as they change and grow in the bereavement process.

When Someone Very Special Dies: Children Can Learn To Cope With Grief

Marge Heegaard (Woodland Press, 1988, \$9.95)
(952) 926-2665

This book is presented in a practical format for allowing children to understand the concept of death and develop coping skills for life.

You Shouldn't Have to Say Goodbye

Patricia Hermes (Scholastic, 1984, \$1.95)

This is a touching story of a young girl's struggle to deal with her mother's imminent death and of their interactions with each other.

COMMUNITY-BASED PROGRAMS FOR CHILDREN

Barr-Harris Children's Grief Center

122 S. Michigan Ave., Suite 1300
Chicago, IL 60603
(312) 922-7474 or www.barrharris.org

The Center provides services to children who have lost a parent through death, divorce or abandonment. The Center has programs at several Chicago area locations. Counseling

fees are available on a sliding scale and no family will be denied treatment because of its financial situation.

Brooke's Place: For Grieving Young People

50 East 91st Street, Suite 103
Indianapolis, IN 46240
(317) 705-9650 or www.brookesplace.org

Provides support and services to grieving children (age 3 to 20+) who have experienced the death of a parent, grandparent, aunt, uncle, cousin, sibling, friend or loved one, and their families in an understanding environment, in the belief that hope for tomorrow begins today.

Center for Grief and Healing

(978) 774-7566
www.hns.org/tabid/89/Default.aspx

Provides comprehensive support for individuals and families dealing with life-threatening illnesses, including expert care, support, consultation, and education for those affected by life-limiting illness, death and loss.

Comfort Zone Camp

2101-A Westmoreland Street
Richmond, VA 23230
(866) 488-5679 or (804) 377-3430
www.comfortzonecamp.org

Offers free weekend camps for 7 to 17 year olds who have experienced the death of a close loved one.

The Alcove Center for Grieving Children and Families

950 Tilton Road, Suite 108
Northfield, NJ 08255
(609) 484-1133 or info@thealcove.org
www.thealcove.org

The Alcove Center for Grieving Children facilitates free activity-based bereavement support groups for children and their families residing in Southern New Jersey between the ages of 3 to 18 who have experienced the loss of a loved one.

The Children’s Room Center for Grieving Children and Teenagers

1210 Massachusetts Ave
Arlington, MA 02476
(781) 641-4741 or info@childrensroom.org
www.childrensroom.org

The Children’s Room provides bereavement support for children, teens and their families after the death of someone close to them.

The Dougy Center for Grieving Children & Families

3909 SE 52nd Ave.
Portland, OR 97206
(503) 775-5683 or (866) 775-5683
help@dougy.org
www.dougy.org

Provides support in a safe place where children, teens and their families grieving a death can share their experiences as they move through their grief process. Website offers an excellent online bookstore.

The Family Center of Brooklyn

584 Nostrand Avenue
Brooklyn, NY 11216
(718) 230-1379 or www.thefamilycenter.org

The Family Center works to create a more secure present and future for children whose parents have a life-threatening illness by providing comprehensive legal and social services, education and research. The Center offers youth programs, counseling and legal services for end-of-life planning.

The Front Porch of Atlanta Center for Grieving Children

PO Box 2908
Decatur, GA 30031-2908
(770) 730-5858 or info@thefrontporch.org
www.thefrontporch.org

The Front Porch of Atlanta, Inc. is a nonprofit center that supports the grief process by providing a place of gathering, promoting an environment of healing, and offering services free of charge. Modeled after other effective children’s grief programs throughout the country, the center offers support for children and their families as they move through the healing process. Age-specific groups of children (ages 3 to 18) and their families gather and share their issues surrounding loss.

The Link Counseling Center

348 Mt. Vernon Highway NE
Atlanta, GA 30328
(404) 256-9797 or www.thelink.org

Serves all ages and offers counseling and psychotherapy for individuals, couples, families and groups. Grief support for children and adolescents also available.

Touched By Cancer Kids Camp

6612 Dixie Highway
Florence, KY 41042
(859) 647-2200

This is a one-day camp for children ages 6 through 12 whose lives have been touched by cancer. It is a fun and safe place for children to express their feelings and learn more about their experiences with cancer.

DYING WELL

A natural outgrowth of the patient advocacy movement has been a focus on maximizing survivors' quality of life, a concept that extends through the final moments of life, even when they arrive far too soon. In recent years, a growing movement to improve the care and quality of patients' end-of-life has benefited women with breast cancer. Each patient has a right to good "palliative," or pain-free care in her final years, months and days. Making progress, patient advocates now challenge us to add to palliative care, the right to a dignified, high-quality, well-planned end-of-life, designed to be reflective of the individual's personality, culture and wishes.

An important tool is an advance directive document. Advance Directives are documents that outline what kind of care a person would want at the end of life. They are available for adults to complete in all 50 states. Most states call these documents Living Wills and Health Care Powers of Attorney. The Living Will is not about finances or material possessions. (A "last will and testament" addresses those issues.) The Living Will specifies whether one would want to be on life support systems if they were terminally ill and unable to express themselves or were permanently unconscious. It allows a person to make choices and outline them so that they are carried out by the medical team.

A Health Care Power of Attorney is a document that allows you to name another person whom you trust to make health care decisions for you anytime you are unable to make these decisions for yourself. Most states allow any adult, 18 years of age and older, to complete these documents. These are important for everyone to consider having in order to safeguard your medical treatment wishes. For more information on this subject, go to www.caringinfo.org

Advance care planning is the process of considering your care options, making your preferences known, and consulting with your health care team. The documents can assist this process, yet the conversation is really the most important part. One solution to managing your Advance Directives is the U.S. Living Will Registry, visit www.uslivingwillregistry.com.

A recent study of quality end-of-life care, as defined by terminally ill patients, identified these major determinants of quality care:

- Receiving adequate pain and symptom management
- Relieving burdens placed on family members
- Avoiding inappropriate prolongation of dying
- Strengthening relationships with loved ones
- Achieving a sense of control

The resources listed in this section will be helpful for patients, survivors, family members and professionals. The organizations listed can lead to other, more extensive resources, as well.

Revised 2008, YSC - This information was originally developed and published by the National Alliance of Breast Cancer Organizations (NABCO) and made available by agreement with NABCO prior to its closing in June 2004.