

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 or 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. Organizing personal affairs, and planning for high-quality last days is only possible when the patient and her healthcare team can communicate truthfully and openly when cure or remission is no longer a realistic goal.

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 January 2007, 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.)

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)

(703) 837-1500

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.

Hospice Foundation of America

12000 Biscayne Boulevard, #505


Miami, FL 33181

(800) 854-3402

info@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.

 **Before I Say Goodbye: Recollections and Observations from One Woman's Final Year**
by Ruth Picardie (Owl Books, 2000, \$13.00)

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.

Dying Well: Peace and Possibilities at the End of Life
by Ira Byock, MD (Riverhead Trade, 1998, \$16.00)

Dying Well 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 Killam Wilber
by Ken Wilber (Shambhala, 2001, \$19.95)

An account of one 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.

On Death and Dying
by 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 resources for adults

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 resources for children

There are many scholarships for children who have lost a parent to breast cancer or whose parent is a survivor of breast cancer. For a list of these resources, see scholarships page 104.

Life and Loss: A Guide to Help Grieving Children
by 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.

Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies
by 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 their parents tools for coping with loss and grief through art.

Helping Children Live with Death and Loss
by Diana Seibert, et al. (Southern Illinois University Press, 2003, \$24.95)

This book offers a practical guide for adults who will interact with children who have experienced loss.

Memories for Surviving Kids

2206 Shark Loop
Round Rock, TX 78664
www.mfsk.org

Started by an adult who lost both his parents as a child, this website provides an extensive listing of resources for grieving children.

Motherless Daughters: The Legacy of Loss

by 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

by Phyllis R. Silverman (Oxford University Press, 1999, \$22.50)

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

by Marge Heegaard (Woodland Press, 1988, \$9.95)

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

by 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 programs

The Front Porch of Atlanta Center for Grieving Children

PO Box 2908
Decatur, GA 30031-2908
(770) 730-5858

The Center supports the grief process by providing a place of gathering, promoting an environment of healing and offering services free of charge.

Barr-Harris Children's Grief Center

122 South Michigan Avenue, Suite 1300
Chicago, IL 60603
(312) 922-7474
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 circumstances.

The Children's Room Center for Grieving Children and Teenagers

1210 Arlington Avenue

Arlington, MA 02476

(781) 641-4741

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 Alcove Center for Grieving Children and Families

950 Tilton Road, Suite 108

Northfield, NJ 08255

(609) 484-1133

info@thealcove.org

www.thealcove.org

The Alcove Center for Grieving Children facilitates 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 Family Center of Manhattan

66 Reade Street

New York, NY 10007

(212) 766-4522

The Family Center of Brooklyn

584 Nostrand Avenue

Brooklyn, NY 11216

(718) 230-1379

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 Dougy Center for Grieving Children & Families

PO Box 86852

Portland, OR 97286

(866) 775-5683

(503) 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.

Comfort Zone Camp

2101-A Westmoreland Street

Richmond, VA 23230

(866) 488-5679

(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.