

# Alzheimer's and Parkinson's Diseases

## ➤ Books for Patients

Coste, J. K., & Butler, R. N. (2004). Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease. New York: Mariner Books.

Another important resource in the Alzheimer's care giving literature, this book provides valuable advice for family members and professionals on how to communicate with those who have Alzheimer's Disease.

Friedman, J. H. (2008). Making the Connection Between Brain and Behavior: Coping with Parkinson's Disease. New York: Demos Medical Publishing.

This book describes the behavioral symptoms associated with Parkinson's Disease. Dr. Friedman uses case vignettes to illustrate common problems. Written in a clear and easy to understand style, the book is intended as a source of practical information for people with Parkinson's Disease and those who care for them.

Mace, N. L., & Rabins, P. V. (2006). The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life (3rd Edition). New York: Warner Books.

For many years, this book has been considered "the bible" for families affected by dementia disorders. The guide provides practical information on the many aspects of caring for someone with dementia.

# Bereavement Support and Palliative Care

## ➤ Books and Websites for Patients

### *Grief in General*

Colgrove, M., Bloomfield, H., and McWilliams, P. (1976). How to Survive the Loss of a Love. New York: Bantam Books.

Small book with lots of practical suggestions that provide road maps for surviving grief.

Grollman, E. (1997). Living When a Loved One Has Died. Boston: Beacon Press.

Written to both inspire and inform the succinct thoughts on each page are resonant and comforting.

Grollman, E. (editor) (1981). What Helped Me When My Loved One Died. Boston: Beacon Press.

This collection of personal stories of bereaved parents, spouses, children, and friends creates a moving portrayal of the landscape of grief.

Kushner, H. (1981). When Bad Things Happen To Good People. New York: Schocken Books.

The death of the author's son provoked this search for an understanding of suffering and tragedy.

Lewis, C.S. (1961). A Grief Observed. New York: Seabury Press.

The famous writer's vivid account of his grieving following his wife's death from cancer has become a classic.

Rando, T. (1988) Grieving: How to Go On Living When Someone You Love Dies. Lexington, MA.: Lexington Books.

A comprehensive and compassionate guide written by a distinguished psychologist and death educator.

Tatelbaum, J. (1980). The Courage to Grieve. New York: Harper and Row.

Written to describe grief as a normal life experience, this sensitive book offers the possibility of growth as a meaningful bereavement outcome.

## ***Recommended Grief Information Websites***

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

*This site, sponsored by the National Hospice & Palliative Care Organization, provides simple and clear answers to various questions about grief, such as, “What is grief?, What does grief feel like?, How long does grief last?, and How will I know when I’m ‘done grieving?’”*

### **<http://dying.about.com>**

*Look up “bereavement” on this site that provides simple as well as somewhat more complex and expanded definitions of grief and mourning; reviews myths about grief; addresses normal responses to loss; and identifies the difference between grief and depression.*

### **[www.journeyofhearts.org](http://www.journeyofhearts.org)**

*This site provides good clinical information about grief interlaced with poetry, quotes and photos of nature that attempt to capture the experience of grief.*

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

*This Hospice Foundation of America site provides a clear and sensitive one-page informative piece about grief as well as a very worthwhile one-page piece by Ken Doka (well-known in the field of bereavement) titled, “Evaluating Advice and Information About Grief.”*

### **<http://grief.com>**

*The site is maintained by David Kessler, who is well-known in the fields of end-of-life care and bereavement and who collaborated with Elisabeth Kubler-Ross. Mr. Kessler provides information about grief and bereavement, including common misunderstandings about Ms. Kubler-Ross’s “Five Stages” and evolving thought about those stages over the past thirty years.*

### **[www.icfa.org](http://www.icfa.org)**

*A funeral planning site that provides good information about “How I Can Deal With The Death of a Loved One,” as well as “Five Assumptions That May Complicate Grief.”*

## ***More Interactive Bereavement Sites To Consider***

### **[www.GriefNet.org](http://www.GriefNet.org)**

*“An internet community of persons dealing with grief, death, and major loss.” The site provides many resources, including 50 email support groups, access to creating on-line memorials, and information.*

### **[www.virtual-memorials.com](http://www.virtual-memorials.com)**

### **[www.memory-of.com](http://www.memory-of.com)**

### **[www.remembered-forever.com](http://www.remembered-forever.com)**

## Bereavement Support and Palliative Care

### ➤ Titles for Professionals Interested in End of Life Care and Bereavement

Albom, Mitch, (1997). Tuesdays With Morrie. New York: Doubleday.

Bowlby, J. (1999). Attachment and Loss. New York: Basic Books.

Byock, Ira, (1997). Dying Well: The Prospect for Growth at the End of Life. New York: Riverhead Books.

Callanan, M. and Kelley, P. (1992). Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying. New York: Bantam Books.

Frankl, Viktor E. (1964). Man's Search for Meaning. London: Hodder & Stoughton.

Grollman, Earl (1995). Bereaved Children and Teens: A Support Guide for Parents and Professionals. Boston: Beacon Press.

Klass, D., Silverman, P., and Nickman, S. (editors) (1996). Continuing Bonds: New Understandings of Grief. Levittown, PA: Taylor & Francis.

Lynn, J., Harrold, J., and The Center to Improve Care of the Dying (1999). Handbook for Mortals: Guidance for People Facing Serious Illness. London: Oxford University Press.

Neimeyer, Robert (editor), (2001). Meaning Reconstruction and the Experience of Loss. Washington: American Psychological Association (APA).

Silverman, Phyllis, R. (2000). Never Too Young To Know: Death in Children's Lives. London: Oxford University Press.

Wogrin, Carol, (2001). Matters of Life and Death: Finding the Words to Say Goodbye. New York: Broadway Books.

# Cancer

## ➤ Books for Patients

Hill Schnipper, Hester, LICSW (2003,2006). After Breast Cancer, A Common-Sense Guide to Life After Treatment – Updated Edition. New York: Bantam Dell, Division of Random House, Inc.

This guide, written by a two-time breast cancer survivor, helps prepare women for life after treatment. The author covers a wide range of topics which include: chemotherapy and managing its side effects, changes in hormonal treatment, coping with financial and work place issues, and how to move beyond the fear of recurrence and rediscover the joy in life.

Harpham, Wendy Schlessel, MD (1998). Diagnosis: Cancer – Revised and Updated. New York: W.W. Norton and Company.

Wendy S. Harpham, MD, doctor and cancer survivor, writes about her experiences with cancer from diagnosis to remission in a question and answer format. Topics include medical, emotional, and health care insights gained during her fight against lymphoma.

# Pregnancy Loss

## ➤ Books for Patients

### *Miscarriage*

Allen, Marie and Marks, Shelly (1993) Miscarriage: Women Sharing from the Heart. New York: Wiley.

Davis, Deborah L. (1991). Empty Cradle, Broken Heart: Surviving the Death of Your Baby. Golden, Colorado: Fulcrum Publishing.

Diamond, Kathleen (1991). Motherhood and Miscarriage. Holbrook, MA.: Adams Media Corporation.

Faldet, Rachel and Fitton, Karen (1997). Our Stories of Miscarriage. Minneapolis: Fairview Press

Friedman, Rochelle and Gradstein, Bonnie (1996). Surviving Pregnancy Loss: A Complete Sourcebook for Women and their Families. New York: Citadel Press.

Ilse, Sherokee, (1996). Empty Arms: Coping with Miscarriage, Stillbirth and Infant Death. Maple Plain, MN: Wintergreen Press

Kluger-Bell, Kim (1998). Unspeakable Losses: Understanding the Experience of Pregnancy Loss, Miscarriage, and Abortion. New York: W.W. Norton and Co., Inc.

Miscarriage. Centering Corporation

Panuthos, Claudia and Romeo, Catherine (1984). Ended Beginnings: Healing Childbearing Losses. South Hadley, MA: Bergin and Garvey Publishers.

## ***Stillbirth***

The titles listed above also are recommended for individuals who have suffered a stillbirth. In addition, the following may be helpful:

Kohn, Ingrid and Moffit, Perry-Lynn (2000). A Silent Sorrow: Pregnancy Loss: Guidance and Support for you and your Family. New York: Routledge Books.

McCraken, Elizabeth (2009). An Exact Replica of a Figment of My Imagination: A Memoir. New York: Little, Brown and Co.

Peppers, Larry and Knapp, Ronald (1985). How to Go on Living After the Death of a Baby. Atlanta: Peachtree Publishers.

Schiff, Harriet (1978). The Bereaved Parent. New York: Viking Press.

## ***For Dads***

\*The Rocking Horse Is Lonely

\*Miscarriage: A Man's Book

+Strong and Tender

+Unspeakable Losses... See full bibliography above.

Chapter 5: "Lost Fathers: Men's Experience of Pregnancy Loss and Abortion"

## ***For Grandparents***

+A Grandparent's Sorrow

## ***Interrupting A Pregnancy***

\*A Time to Decide, A Time to Heal.

Pineapple Press

PO Box 312

St. Johns, MI 48879

Surviving Pregnancy Loss... See full bibliography above.

Chapter 5: "Prenatal Testing- When a Problem is Discovered"

Unspeakable Losses... See full bibliography above.

Chapter 4: "The Dilemma of Choice: Abortion - Elective, Genetic, and Multifetal Reduction"

## ***For Parents Who Know A Baby Is Not Going To Survive***

Kuebelbeck, Amy (2003) Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life. Chicago: Loyola Press.

## ***For Siblings***

\* Sibling Grief. Centering Corporation

Deborah L. Davis' book Empty Cradle, Broken Heart...has an excellent chapter on sibling grief.

Friedman and Gradstein's book, Surviving Pregnancy Loss...has a chapter on sibling grief.

Grollman, Earl, (1969). Explaining Death to Children. Boston: Beacon Press.

\*Gryte, Marilyn, (1988). No New Baby. Centering Corporation

Heegard, Marge, When Someone Very Special Dies: Children Can Learn to Cope with Grief. Minneapolis, MN: Woodland Press. (612-926-2665).

\*Johnson, Joy et al. Where's Jess? Centering Corporation

O'Toole, Donna (1988). Aarvy Aardvark Finds Hope. Compassion Books

+Tapp, Kathy Kennedy. No Smile Cookies Today.

### ***Pregnancy After Loss***

Kohn and Moffitt's book, Silent Sorrow includes material on coping with pregnancy after loss.

Friedman and Gradstein's book, Surviving Pregnancy Loss includes coping with pregnancy after loss.

\*Schwiebert, P. and Kirk, P. (1989). Still To Be Born. Centering Corporation

### ***Pregnancy Loss Organizations//Explanation of markers:***

\* Centering Corporation  
P.O. Box 4600  
1531 N. Saddle Creek Rd.  
Omaha, NE 68104  
Phone: 402-553-1200  
Fax: 402-553-0507  
Website: [www.Centering.Org](http://www.Centering.Org)

+Pregnancy and Infant Loss Center  
1421 East Wayzata Blvd.  
Suite 30  
Wayzata, MN 55391  
Phone: 952-473-9372  
Fax: 952-473-8978

### ***Pregnancy Loss and Support Information***

#### **➤ On the World Wide Web**

Losing a pregnancy at any stage is a difficult and often overwhelming experience. The following is a partial listing of Internet Websites that other families have found supportive, informative and helpful as they coped with their loss. Many of the sites have links to other helpful information.

- ❖ **The Compassionate Friends**  
<http://www.compassionatefriends.org>
- ❖ **HAND - Santa Clara County**  
<http://www.handonline.org>
- ❖ **Hygeia**  
<http://www.hygeia.org>

- ❖ **A Heartbreaking Choice**  
<http://www.aheartbreakingchoice.com>
- ❖ **Subsequent Pregnancy after a Loss Support**  
<http://www.spals.com>
- ❖ **WISSP –Wisconsin Stillbirth Service Program**  
<http://www.wisc.edu/wissp>
- ❖ **CLIMB - Center for Loss in Multiple Birth, Inc**  
<http://www.climb-support.org>
- ❖ **Yahoo Groups:** You will find multiple sites for support around loss in multiple birth pregnancy. Many of our parents who have a loss involving multiples in pregnancy have found it helpful to “chat” with and gain support and empathy from others who have experienced similar losses. They have recommended these sites and we want to pass them along to you.
  - Go to: Yahoo Groups; health & wellness; support; mourning & loss; loss of child. Scroll to site of choice. Includes:

**eLIMBO- (electronic) Loss in Multiple Birth Outreach**

For parents who have lost one or more babies in multiple pregnancy

**LAMBS- Loss of All Multiple Births**

*Please note that this list is not complete and may not be up to date as websites change frequently.*