



American Brain Tumor Association

## END OF LIFE CARE

Although it can be difficult, discussing options related to death and dying can help ease some of the anxiety that may accompany this time. The following organizations offer information, support and/or services that can help you and your family address these concerns. The organization list is followed by a bibliography of resource books that may also be of assistance.

### ORGANIZATIONS

#### AGING WITH DIGNITY

888-594-7437

[www.agingwithdignity.org](http://www.agingwithdignity.org)

Non-profit organization dedicated to promoting better care of the dying. Publishes the *Five Wishes*, a living will that helps a patient define their medical, emotional and spiritual wishes. It is now available in the following languages: Chinese traditional, Chinese simplified, Arabic, Haitian Creole, Portuguese, Somali, Hmong, Korean, French, Polish, Spanish, Russian, Ilocano, Taglog, Vietnamese, Albanian, Bengali, Hindi, Urdu, Japanese, Gujarati, and Croatian. They also offer a DVD on how to best use the *Five Wishes*. They have also developed *My Wishes* a similar document to be used with children. There is a five dollar charge per copy.

#### AMERICAN BRAIN TUMOR ASSOCIATION

800-886-2282

[www.abta.org](http://www.abta.org)

Offers *Bridges* a pen pal program to connect family members and friends to other who have lost a loved one to a brain tumor. Also maintains a listing of bereavement support groups by state, online bereavement support resources and a bereavement bibliography.

#### AMERICAN HOSPICE FOUNDATION

800-347-1413

[www.americanhospice.org](http://www.americanhospice.org)

Assists caregivers with end-of-life decision-making and locating a hospice in their area. Provides resources for professionals in the area of dying and bereavement.

## BRAIN TUMOR HOSPICE CARE

[www.brainhospice.com](http://www.brainhospice.com)

This site was created so that caregivers approaching this important new junction may recognize and understand end-stage events that are likely to happen, as well as find support in providing the best of loving care during this critical time.

## CARING CONNECTIONS

800-658-8898

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

A service of the National Hospice and Palliative Care Organization for consumers. Provides information on hospice and palliative care, pain, grief, financial planning, and patient advocacy. Offers downloadable state-specific living wills and healthcare power of attorney. Offers Spanish helpline as well at 877-658-8896.

## CHILDREN'S HOSPICE INTERNATIONAL

800-242-4453

[www.chionline.org](http://www.chionline.org)

Provides information and referral services for child and family counseling, support groups and hospices.

## COMPASSIONATE FRIENDS

877-969-0010

[www.compassionatefriends.org](http://www.compassionatefriends.org)

National, non-profit, support organization that offers friendship understanding and emotional support to those who have lost a child. Web site offers various articles on bereavement and links to support groups.

## GET PALLIATIVE CARE.ORG

415-863-3045

[www.getpalliativecare.org](http://www.getpalliativecare.org)

Website provides information on what palliative care is, understanding if it is right for you, how to get it and a search option to help locate providers in your area.

## GROWTH HOUSE, INC.

415-863-3045

[www.growthhouse.org](http://www.growthhouse.org)

International gateway to resources for life threatening illness and end-of-life care.

## HOSPICE EDUCATION INSTITUTE

800-331-1620

[www.hospiceworld.org](http://www.hospiceworld.org)

Maintains a computerized directory of hospices and palliative care services nationwide.

## NATIONAL ASSOCIATION FOR HOME CARE AND HOSPICE

202-547-7424

[www.nahc.org](http://www.nahc.org)

Offers home care and hospice database that is searchable by your zip code. Will also let you know if the provider is licensed or certified.

## NATIONAL ASSOCIATION FOR THE TERMINALLY ILL

866-668-1724

[www.terminallyill.org](http://www.terminallyill.org)

Provides financial assistance for day-to-day living expenses such as rent, groceries or utilities, to children and their families who have a life expectancy of two years or less.

## NATIONAL INSTITUTE FOR JEWISH HOSPICE

800-446-4448

[www.nijh.org](http://www.nijh.org)

Resource center for patients and family members. Provides information 24 hours a day regarding traditional Jewish views on death, dying, and managing the loss of a loved one. Also offers help locating a hospice.

## END OF LIFE AND BEREAVEMENT BIBLIOGRAPHY

### BOOKS FOR ADULTS

***Angel Catcher: A Journal of Loss and Remembrance.*** Kathy and Amy Eldon. An invaluable resource for anyone who is coming to terms with the death of a loved one. A guided journal, filled with thoughtful quotations, prompts to encourage memories, and illustrations, but mostly it offers space to record thoughts, paste photos and clippings, or express any feeling or remembrance of someone greatly missed. Chronicle Books, San Francisco, CA. 2007

***The Complete Bedside Companion.*** Rodger McFarlane and Philip Bashe. Provides practical advice on how to care for an ailing loved one. Draws on the experience of dozens of people who have cared for friends and relatives. Simon and Schuster, New York, NY. 1998. (hardcover).

***The Family Handbook of Hospice Care.*** Fairview Health Service. A comprehensive resource book for individuals and families seeking practical hospice information and emotional support. Covers topics such as: how hospice can help, pain control, financial concerns and grief issues. Also includes a complete bibliography offering books and organizations that can offer assistance. Fairview Press, Minneapolis, MN. 1999. (paper).

***Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying.*** Maggie Callanan and Patricia Kelley. This book is a comforting instruction manual on what happens, what to do, and what not to do. It begins with information about what happens to the body when it is in the process of dying, then moves into experiences the authors have had in dealing with people who are dying, or whose loved ones are dying. They have helpful information throughout the book about what to say or do. Bantam Press, New York, NY. 1997. (paper).

***Garden of Memories-A Written Remembrance.*** Ellyn Nadeau. A keepsake that allows family members and friends to write memories shared with a lost loved one. Grief Recovery Group, Fort Smith, MT. 1999.

***Grief, Dying and Death.*** Therese Rando. A sensitive but realistic approach to the difficult issues to be faced in the dying process. Offers many practical suggestions for the caregiver. Research Press, Champaign, IL. 1984. (paper).

***A Guide to Understanding Guilt During Bereavement.*** Robert Baugher, PhD. Guilt is a common part of the bereavement process and the topic is explored through description of behaviors and examples and suggestions for coping. Caring People Press, Newcastle, WA. 1997. (paper).

***The Helper's Journey: Working With People Facing Grief, Loss, and Life-Threatening Illness.*** Dale G. Larson. A helpful guide offering renewed strength, inspiration and useful skills for medical professionals or grief support group leaders. Research Press, Champaign, IL. 1993. (paper).

***Holiday Hope: Remembering Loved Ones during Special Times of the Year.*** Fairview Press. A collection of activities, stories, poems and music for coping with grief during the holidays and other times throughout the year including birthdays and anniversaries. A variety of professionals including: social workers, clergy and counselors as well as lay people have contributed their personal and professional accounts to this moving book. Fairview Press, Minneapolis, MN. 1998. (paper).

***In Sickness and In Health: One Women's Story of Love, Loss, and Healing.*** Gail Lynch. Personal journey of a woman whose husband was diagnosed with a brain tumor and her journey through his illness, death and her life later. Fairview Press, Minneapolis, MN. 2002.

***Learning to Fall: The Blessings of an Imperfect Life.*** Philip Simmons. A compilation of essays written by the author during the last years of his life. A book that offers insights and spiritual reflections on life, loss, hope and finding meaning in the face of death. Companion Journal with same title also available. Bantam Books, New York, NY. 2003.

***Losing a Parent: Passage to a New Way of Living.*** Alexandra Kennedy. Offers readers an array of suggestions and techniques that will enable them to deal effectively with the grief a parent's death causes. HarperCollins, San Francisco, CA. 1991. (paper).

***Morrie: In His Own Words.*** Morrie Schwartz. A short easy to read book of life affirming insights from Morrie Schwartz, who died of ALS in 1995. The book was written by Morrie as he was experiencing the physical losses caused by his disease and with keen awareness of his impending death from it. It covers such topics as living with physical limitations, grieving your losses, dealing with your emotions and reaching acceptance. Walker and Company, New York, NY. 2008.

***The Mourning Handbook: The Most Comprehensive Resource Offering Practical and Compassionate Advice on Coping with all Aspects of Death and Dying.*** Helen Fitzgerald. A comprehensive resource book that offers practical strategies for coping with the loss of a loved one. It sensitively addresses handling the holidays and other special occasions, and suggests ways to cope with your feelings. Includes useful sections on anticipatory grief and funeral preparations, as well as bibliography and resource sections. Simon and Schuster, New York, NY. 1995. (paper).

***On Death and Dying.*** Elizabeth Kubler-Ross. The author's classic book describing the five stages of coping with the diagnosis of a terminal illness. Simon and Schuster, New York, NY. 1997.

***Remembering with Love: Messages of Hope for the First Year of Grieving and Beyond.*** Elizabeth Levang, PhD and Sherokee Ilse. Over three hundred short stories and poems fill this book with little lessons on remembering our loved one. The book is arranged chronologically, but a reader's guide in the front of the book helps locate particular topics that will be most helpful on a certain day. Fairview Press, Minneapolis, MN. 1996. (paper).

***A Travel Guide to Heaven.*** Anthony DeStefano. Uses a mixture of scripture and imagination to envision a place more amazing than one could ever imagine. If you can't imagine, he remedies that by giving folks in the here and now a guided tour of the by and by. The author's belief is that heaven will be the same as earth, only better. His vision of heaven is lovely. No matter what your personal beliefs are, anyone can enjoy this fun and fast-paced tour of heaven. And while his basic take on heaven as a place conforms to Christian teaching, he is loose in his interpretation and lets his and our imagination run wild. DoubleDay, New York, NY. 2005. (paper).

***What Dying People Want to Know: Practical Wisdom for the End of Life.*** David Kuhl, MD. Written by a palliative care physician, this book explores the psychological and spiritual issues encountered at the end of life. Based on stories of those who knew they were dying and offering insights into how to express difficult feelings, sensitive listening, pain management, forgiving self and others, and doing a life review. Designed to be read by those who are dying, their loved ones and professionals who would like a clearer understanding of the social and emotional aspects of the dying process. HarperCollins, Pittsburgh, PA. 2003. (paper).

***When Men Grieve: Why Men Grieve Differently and How You Can Help.*** Elizabeth Levang, PhD. Informative book giving insight on men and how they grieve. This book will help women to understand men in grief and how to comfort them. Fairview Press, Minneapolis, MN. 1998. (paper).

## BOOKS FOR PARENTS

***Home Care for Seriously Ill Children.*** Stacy Orloff, Ed.D, LCSW, Susan Huff, MSN. A manual that serves as a guide and support to parents who, faced with their child's life-threatening illness, choose to or must care for their child at home. Available from Children's Hospice International, Alexandria, VA, [www.chionline.org](http://www.chionline.org) or 800-242-4453. 2003. (paper).

***Shelter from the Storm: Caring for a Child with a Life-Threatening Condition.*** Joanne Hilden, MD and Daniel Tobin, MD. A sensitively worded book that gently walks parents through the complex maze of feelings and decisions they face when their child is seriously ill. Offers insight and support on topics ranging from parents' fears, coming to terms with death, preparation, spirituality and peace. Perseus Publishing, Cambridge, MA. 2002.

***Ya Can't Let Cancer Ruin Your Day.*** Syd Birrell and Tom Hanks. A book of emails, the James emails, about James, a young boy with a rare childhood cancer, neuroblastoma. This story inspires us to find the joy in every day and in every way. James teaches us how to live. The terrible tragedy of his death is as heart wrenching as his story is inspirational. You will get to know the whole family, and share in the emotions. Syd Birrell's effort to find a cure is inspiring. Essence Publishing, Onatrio, Canada. 2006.

## BOOKS FOR CHILDREN

***The Fall of Freddie the Leaf.*** Leo Buscaglia. As Freddie experiences the changing seasons along with his companion leaves, he learns about the delicate balance between life and death. Henry Holt and Company, New York, NY. 2002.

***Help Me Say Goodbye: Activities for Helping Kids Cope when a Special Person Dies.*** Janis Silverman. An art therapy and activity book for children coping with the death of someone they love. Exercises address questions children may have during this emotional time. Children are encouraged to put in pictures what they may not be able to express in words. Fairview Press, Minneapolis, MN. 1999. (paper).

***Lifetimes: The Beautiful Way to Explain Death to Children.*** Bryan Mellonie. Photographs by Robert Ingpen. A simple and sensitively written book that helps children understand death by talking about the lifetimes of all living things. This book is short enough to be read in one sitting. Bantam Books, Inc., New York, NY. 1983. (paper).

***Nana Upstairs and Nana Downstairs.*** Tomie DePaola. Tommy has a grandmother and a great-grandmother. When Nana Upstairs dies, he feels sad but remembers her with love. G.P. Putnam Sons, New York, NY. 2000.

***The Next Place.*** Warren Hanson. A short, beautifully illustrated children's book that addresses death and the afterlife, without subscribing to one particular belief system. Adults too will appreciate the gentle rhythm of the verse and the soothing pictures throughout. Waldman House Press, Minneapolis, MN. 1997.

***What's Heaven?*** Maria Shriver. Based on actual questions asked by her own daughter after the death of her great-grandmother. This book delivers a simple, traditional definition of heaven and other aspects associated with funerals and death. The short length and beautiful illustrations make it a book that can be read even to the youngest of children. Golden Books, New York, NY. 2007.

***When Someone Very Special Dies: Children Can Learn to Cope with Grief.*** Marge Heegaard. It provides a healthy message and positive means for helping children work through an experience with grief. Children need help to grieve and grow in healthy ways. This book provides children with a positive healing experience, and the ability to know that life can be okay again. Woodland Press, Minneapolis, MN. 1988.

## ADVANCE DIRECTIVES

***Be Prepared: The Complete Financial, Legal, and Practical Guide for Living With Cancer, AIDS and Other Life-Challenging Conditions.*** David S. Landay. This comprehensive book provides information to work through financial, tax, and other practical issues that arise when you are confronted with a life-threatening condition. St. Martin's Press, New York, NY. 2000.

***Final Choices - Seeking the Good Death.*** Michael Vitez. Chronicles the experiences of patients as they make the best end-of-life decisions. Also discusses living wills and medical powers of attorney. Camino Books, Philadelphia, PA. 1998.

***The Other Mid-Life Crisis: Everything You Need to Know About Wills, Hospitals, Life-and-Death Decisions and Final Matters (but were never taught).*** Adeline Rosemire. Easy-to-understand answers to difficult questions. Includes pages of resources. Meridian Publishing, Inc., San Jose, California. 1994. (paper).

***Ready to Live Prepared to Die.*** Amy Harwell. The author discusses not only the spiritual and emotional elements of preparing for death but also the details of advanced directives, life-sustaining treatments and funeral arrangements. Waterbrook Press, Colorado Springs, CO. 2000.

***What Dying People Want to Know: Practical Wisdom for the End of Life.*** David Kuhl, MD. Written by a palliative care physician, this book explores the psychological and spiritual issues encountered at the end of life. Based on stories of those who knew they were dying and offering insights into how to express difficult feelings, sensitive listening, pain management, forgiving self and others, and doing a life review. Designed to be read by those who are dying, their loved ones and professionals who would like a clearer understanding of the social and emotional aspects of the dying process. HarperCollins, Pittsburgh, PA. 2003. (paper).

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information. The American Brain Tumor Association does not endorse any of the organizations listed or guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

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