



APPENDICES

To die will be an awfully big adventure
J. M. Barrie



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(BCHPCA 2008) (Updated 2015)**



Glossary of Terms

Advance Care Planning:	The process of planning, in advance, for personal and financial care should one be unable to make decisions on their own behalf.
Activities of Daily Living (ADLs):	A term that refers to daily activities such as bathing, dressing, eating, toileting, transferring out of a bed or chair, and walking. Ability to do ADLs is one of the criteria used in assessing for residential and community-based care.
Alzheimer's Disease:	A progressive, neurological disease that affects brain functions including language, short-term memory, ability to reason, and the ability to care for oneself.
Anticipatory Grief:	A grief reaction that occurs in anticipation of an impending death. While this term is usually used in connection with spouses, other people and even the dying can experience anticipatory grief themselves. Anticipatory grief can be just as painful as the actual death of the person.
Aphasia:	Aphasia is a language difficulty. As a rule, people who have aphasia know what they want to say, but have trouble communicating their thoughts and ideas. Individuals with aphasia may have trouble speaking, understanding the speech of others, reading and writing.
Assisted Living:	Assisted living residences provide housing and a range of supportive services, including personalized assistance, for seniors and people with disabilities who can live independently but require regular unscheduled help with day-to-day activities.
BCHPCA:	The British Columbia Hospice Palliative Care Association. BCHPCA is an umbrella organization whose mission is to provide a leadership role for its member organizations and individuals to ensure quality of care for British Columbians faced with a life-threatening illness, death and bereavement.
Bereavement:	the period after a loss during which grief is experienced and mourning occurs.
Care Plan:	An individualized action plan that takes into account the client's unique needs and the goals of care.



Glossary of Terms

Compassion Fatigue:	A term that refers to a gradual lessening of compassion over time. Compassion fatigue may occur when, due to over-exposure to the experiences of people who are undergoing loss and grief, the volunteer develops a resistance to these experiences. As the impact of these messages lessens, their ability or willingness to respond empathically declines.
Dementia:	The medical term for a group of symptoms that describe a loss of intellectual ability, including loss of vocabulary, abstract thinking, judgment, memory, and physical coordination.
Delirium:	Is a reversible, acute condition where there are delusions, illusions, sleep disturbances, disorientation to time, place or person and memory impairment. Delirium is different from dementia in that it is a temporary state lasting a short time, whereas dementia is often permanent.
Depression:	A reversible psychological state characterized by an inability to concentrate, difficulty sleeping, feelings of hopelessness, fatigue, the “blues” and guilt.
DNR:	A Do Not Resuscitate Order (DNR) is a legal document instructing medical professionals not to revive a patient in a condition, such as cardiac or pulmonary failure, who cannot be saved without invasive and continuous medical treatment. It is put in place only if there is no reasonable probability of recovery from the illness.
End-of-Life Care:	The term used for the range of clinical and support services appropriate for dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families.
Home Care:	A range of supportive services in the home, from intensive medical support to assistance with activities of daily living to housekeeping. Home care can include nurses, social workers, occupational therapists, physical therapists and other rehabilitation services.
Hospice:	Hospice services involve palliative rather than curative treatments that aim to comfort the person who is dying and their family. It involves professional medical care, advanced pain and symptom relief, and emotional, spiritual and practical support based on the patient’s wishes and family’s needs. The term hospice is also often used to refer to a home-like place where people go in the last few weeks of life.



Glossary of Terms

Long-Term Care Facility:	Often referred to as Complex Care or Extended Care Homes, provide a higher level of care and supervision than Assisted Living Residences. Designed for those who require ongoing 24-hour supervision, personal nursing care and/or treatment by skilled nursing staff.
Mourning:	in the simplest sense synonymous with grief over the death of someone. The word is also used to describe a cultural complex of behaviours in which the bereaved participate or are expected to participate. Customs vary between different cultures and evolve over time, though many core behaviors remain constant.
Occupational Therapist:	A rehabilitation professional who assists individuals to learn skills and techniques needed to perform activities of daily living.
Palliative Care:	The specialized care for people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term “palliative care” is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.
Patient-Controlled analgesia (PCA)	Pain medication given through an IV, or epidural catheter. Patients control the dose of medication they take, depending on how much is needed to control the pain. PCA is usually used for chronic pain such as that due to cancer.
Physiotherapist:	A rehabilitation specialist who assists individuals in maximizing mobility and restoring strength and body movement.

Power of Attorney: A power of attorney is a document that appoints a person, called an “attorney,” to make financial and legal decisions for another. An enduring power of attorney allows the “attorney” to make the necessary financial and legal decisions for another in case of mental incapacity because of age, accident or illness.



Glossary of Terms

Representation Agreement:	<p>The Representation Agreement Act allows a person to appoint someone as their legal representative to handle financial, legal, personal care and health care decisions, if the appointee is unable to make them on their own. The document is called a representation agreement, and it creates a contract between the person and their representative.</p> <p>There are two types. One is known as a Section 7 limited agreement – to cover straightforward, everyday decisions.</p> <p>The other is a Section 9 general agreement – to deal with complex legal, personal care and health care matters.</p>
Residential Care Facility:	<p>A residential care facility provides care and supervision for seven or more persons. Residential care homes provide care and supervision for 3-6 persons. Family homes that provide care for 1-2 persons do not require a community care facility licence.</p>
Respite Care:	<p>Services that provide a break, a temporary relief for caregivers. These can be delivered in the home or in a short-stay facility. Respite Care enables caregivers to achieve respite.</p>
Retirement Home:	<p>Is a place of residence where older adults can live independently, with minimal assistance. There are often recreational activities, common areas and other amenities.</p>
Wellness:	<p>A dimension of health that goes beyond the absence of illness, disease and/or disability. It includes social, emotional and spiritual aspects of health that are central to a person's quality of life.</p>

WEBSITES, BOOKS AND VIDEOS OF INTEREST TO FACILITATORS AND VOLUNTEERS

WEBSITES

BC Hospice Palliative Care Association.	www.hospicebc.org
Canadian Hospice Palliative Care Association.	www.chpca.net
Hospice Net (USA).	www.hospicenet.org
National Hospice Palliative Care Organization (USA).	www.nhpco.org
International Association for Hospice & Palliative Care.	www.hospicecare.com
"Virtual Hospice." Interactive network	www.virtualhospice.ca
Griefworks BC. Support for children, teens and adults	www.griefworksbc.com
Vancouver Island Health Authority volunteer resources	www.viha.ca/volunteer_resources/

BOOKS

1. A Caregiver's Guide: a Handbook About End-of-Life Care. Macmillan, Karen, Jacquie Peden, Jane Hopkinson, and Dennie Hycha. Ottawa: The Military and Hospitallers Order of Saint John Lazarus of Jerusalem and the Canadian Hospice Palliative Care Association, 2004.
2. Alberta Palliative Care Resource. Pereira, Jose, and Eduardo Bruera, comps. Edmonton: The Alberta Cancer Board, 2001.
3. The American Book of the Dying: Lessons in Healing Spiritual Pain. Groves, Richard. Ten Speed Press, 2005.
4. Approaching Death: Improving Care At the End of Life. Field, MJ, and CK Cassels. Washington, DC: National Academy, 1997.
5. At the Will of the Body. Frank, Arthur W. Houghton Mifflin, 1991.
6. The Caring Community. Rothstein, Jerry, and Miriam Rothstein, eds. Burnaby: BC Hospice Palliative Care Association, 1997.
7. Caring for Dying People of Different Faiths. Neuberger, Rabbi Julia. 2004.
8. The Courage to Laugh: Humour in Death and Dying. Klein, Allen. Tarcher/Putnam, 1998.
9. Cross Cultural Caring for Health Care Professionals in Western Canada. Waxler-Morrison, Nancy, Joan Anderson, Elizabeth Richardson, and Natalie Chambers, eds. UBC Press, 1990.
10. Death and Bereavement Across Cultures. Parkes, Colin Murray, Laungani, Pittu & Young, Bill. Routledge, 1997.
11. Don't Take My Grief Away. Manning, Doug. Harper Collins, 2005.
12. The Empty Chair. Zonnebelt-Smeenge, Susan, and Robert Devries. Simon & Schuster, 2000.
13. Facing Death Embracing Life. Kuhl, David. Doubleday Canada, 2006.

BOOKS cont'd

14. Facing Death & Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying. Longaker, Christine. Doubleday, 1997.
15. Family Hospice Care: Pre-Planning & Care Guide. Van Bommell, Harry. Scarborough: Resources Supporting Family and Community Legacies Inc., 1999.
16. Final Gifts: Understanding the Special Needs and Communications of the Dying. Callanan, Maggie, and Patricia Kelley. Random House, 1992.
17. Good Grief. Westberg, Granger. Fortress, 1979.
18. Grieving: a Beginner's Guide. Hull, Jerusha. Delta, Longman & Todd, 2005.
19. A Guide for Caregivers. Ottawa: Canadian Hospice Palliative Care Association, 2002.
20. A Guide to End-of-Life Care for Seniors. Fisher, R, Mm Ross, and MJ MacLean.
21. Guidelines for Social Work in Hospice. Alexandria, VA: The National Hospice and Palliative Care Organization, 1994.
22. Healing Through the Dark Emotions. Greenspan, Miriam. Shambhala, 2003.
23. How Can I Help? Dass, Ram & Gorman, Paul. Alfred Knopf, 1985.
24. How, Then, Shall We Live? Muller, Wayne. Bantam, 1996.
25. How to be a Help Instead of a Nuisance. Wegela, Karen Kissel. Shambhala, 1996.
26. How to Go on Living When Someone You Love Dies. Rando, Therese. Bantam, 1988.
27. How to Survive the Loss of a Loved One. Bloomfield, Melba, Harold Bloomfield, and Peter McWilliams Colgrove, 1976.
28. How We Die: Reflections on Life's Final Chapter. Sherwin B. Nuland. Random House, 1995. Also available in abridged audiobook. Random House, 2007.
29. The Illustrated Tibetan Book of the Dead. Hodge, Stephen. Sterling, 1999 (or any edition).
30. Improving Palliative Care for Cancer. Foley, Km, and H Gelband. National Academy, 2001.
31. Intimate Death. De Hennezel, Marie. Alfred Knopf, 1997.
32. Kitchen Table Wisdom: Stories that Heal. Remen, Rachel Naomi. Riverhead Books, 1996.
33. Lessons from the Dying. Smith, Rodney. Wisdom, 1998
34. Letting Go: Morrie's Reflections on Living While Dying. Schwartz, Morrie.. Dell, Delta Books, 1997

BOOKS cont'd

35. Life After Loss. Delts, Bob. De Capo, 2004.
36. Living When a Loved One Has Died. Grollman, Earl. Beacon, 1995.
37. A Long-Shadowed Grief: Suicide and Its Aftermath. Smith, Harold I. Cowley, 2007.
38. The Lost Art of Listening. Nichols, Michael P. New York: Guilford, 1995.
39. Men Don't Cry... Women Do: Transcending Gender Stereotypes of Grief. Martin, Terry & Doka, Kenneth. Brunner/Mazel, 2000.
40. Meeting Death. Robertson, Heather. McClelland & Stewart, 2000.
41. A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ferris, Frank D., Heather M. Balfour, Karen Brown, Justine Farley, Marsha Hardwick, Claude Lamontagne, Marilyn Lundy, Anne Syme, and Pamela J. West. Ottawa: Canadian Hospice Palliative Care Association, 2004.
42. The Mourner's Dance. Ashenburg, Katherine. Macfarlane, Walter and Ross, 2002.
43. Multicultural Palliative Care Guidelines. Taylor, A, and M Box. Palliative Care Council of South Australia, 1999.
44. My Grandfather's Blessings: Stories of Strength, Refuge and Belonging. Remen, Rachel Naomi. Riverhead Books, 2000
45. The Needs of the Dying. Kessler, David. Harper Collins, 1997.
46. On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families. Kubler-Ross, Elisabeth. (Chap. 3-7, re: The Five Stages of Grief) MacMillan, 1969.
47. Our Journey: First Nations Experience in Navigating Cancer Care. Loppie, PhD, Charlotte, and Fred Wien, PhD. Halifax: Cancer Care Nova Scotia, 2005.
48. Oxford Textbook of Palliative Medicine. Doyle, D; GWC Hanks, and N Macdonald. Oxford University Press, 1998.
49. A Path Through Loss: a Guide to Writing Your Healing and Growth. Reeves, Dr. Nancy. Northstone, 1999.
50. Praying Our Goodbyes. Rupp, Joyce. (Order of the Servants of Mary, "Servites"). Ave Maria, 1988.
51. The Seasons of Change. McClelland, Carol L. Conari, 1998.
52. Sorrow's Journey: Words of Comfort to Heal the Grieving Heart. Fisher, Twyla. Fell, 2005.
53. Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care. Victoria Hospice Society & Cairns, Moira, Thompson, Marney & Wainright, Wendy. 2003.

BOOKS cont'd

54. Transitions: Making Sense of Life's Changes. Bridges, William. Perseus, 1980
55. Understanding Your Grief. Wolfelt, Alan. Companion, 2004.
56. What Dying People Want. Kuhl, David. Anchor Canada, 2003.
57. When Men Grieve: Why Men Grieve Differently and How to Help Them. Levang, Elizabeth. Fairview, 1998.
58. When Things Fall Apart: Heart Advice for Difficult Times. Chodron, Pema. Shambhala, 1997
59. Who Dies? An Investigation of Conscious Living and Conscious Dying. Levine, Stephen. Anchor-Doubleday, 1982
60. When a Loved One Dies: Meditations for the Journey Through Grief. Williams, Philip. OK Books, 2001.
61. The Year of Magical Thinking. Didion, Joan. Random House, 2005.

BOOKS FOR CHILDREN

1. Lifetimes: the Beautiful Way to Explain Death to Children. Mellonie, Bryan. Bantam P, 1983.
2. Sad Isn't Bad: a Good Grief Guide for Kids Dealing with Loss. Mundy, Michaelene. 1998.
3. Tear Soup: a Recipe for Healing After Loss. DeKlyen, Chuck, and Pat Schweibert. 2005.
4. The Next Place. Hanson, Warren. Waltman, 1997.
5. The Tenth Good Things About Barney. Viorst, Judith. New York: Simon & Schuster, 1971.
6. Waterbugs and Dragonflies: Explaining Death to Young Children. Stickney, Doris. Pilgrim P, 2004.
7. What is Death? Boritger, Etan. Veronica Lane Books.
8. When Dinosaurs Die: a Guide to Understanding Death. Brown, Laurie. Laurie, Krasner & Brown, 1996.

BOOKS FOR TEENS

1. The Grieving Teen: a Guide for Teenagers and Their Friends. Fitzgerald, Helen. New York: Fireside, 2000.
2. Straight Talk About Death for Teenagers. Grollman, Earl A. 1993.
3. When a Friend Dies: a Book for Teens About Grieving and Healing. Gootman, Marilyn E. Free.Spirit, 2005.

DVD/VIDEO/AUDIO

Being With Dying. Roshi Joan Halifax. Sounds TrueAudio Learning Course. Order from:
www.soundstrue.com

Death, A Love Story. Michelle LeBrun. Order from:
www.amazon.ca/Death-Love-Story-Michelle-LeBrun/dp/B000168A96

Pioneers of Hospice: Changing the Face of Dying. Madison-Dean Initiative, 2002.
About Dame Cecily Saunders, Elizabeth Kubler Ross, Florence Wald and Balfour Mount. Order
on-line at www.pioneersofhospice.org or call 1-866-293-8200.

Journeys: An Educational Video Describing Hospice Palliative Care. British Columbia Hospice
Palliative Care Association. Order form on-line at www.bchpca.org. Click on
BCHPCA Resources under Resources & Links.

My Healing Journey: Seven Years With Cancer. Joseph Vismeg. National Film Board 1998. Order
on line at www.nfb.ca/boutique.

Fanlight Productions. Several videos on Death and Dying and Grief and Recovery.
<http://www.fanlight.com/catalog/subjects/death.php>
http://www.fanlight.com/catalog/films/245_gia.php