



## BookEnds

*In pursuit of information and perspectives.*

# On Matters Of Life & Death:

*Living and dying with a chronic or serious illness.*

A Selected Annotated Bibliography  
Compiled by Reva M. Greenberg, EdD

Download at: [www.cpcwestchester.org](http://www.cpcwestchester.org) [www.westchesterpartnership.org](http://www.westchesterpartnership.org)



*"Donald is such a fatalist—he's convinced he's going to grow old and die."*

© Barbara

Smaller/The New Yorker Collection/[www.cartoonbank.com](http://www.cartoonbank.com)

# ***The BookEnds***

**ACKNOWLEDGEMENTS....4**

**ARTICLES....7**

**NON-FICTION: FACT BASED WRITINGS ....12**

**PERSONAL REFLECTIONS: MEMOIRS....24**

**LITERATURE &THE ARTS ....30**

**CHILDREN'S BOOKS FOR KIDS OF ALL AGES....37**

**DATABASES, GUIDELINES, PUBLIC POLICY....38**

**BLOGS & OTHER WEB WISDOM....39**

**A WEBSITE LIST ....43**

***OTHERWISE: A POEM....49***

**This Annotated Bibliography documents a portion of the ideas, research, perspectives and genres that reflect the science, experience and mystery of living with a chronic and/or serious illness. It is not all-inclusive, somewhat idiosyncratic, but I hope that what is here is broad enough to give every interested reader something to think about.**

**Use this annotated bibliography to read complementary and contradictory ways of looking at an issue that challenge your thinking and invigorate the conversation. All web sites are hyperlinked making it particularly valuable as an electronic compilation.**

***Please forward this bibliography to colleagues in your respective organizations and associations  
and  
to your friends.***

**Whether a patient, family, friend, caregiver, health care provider, teacher, clergy or a fellow human being, we all benefit from the search for knowledge, the search for meaning, the search for personal and professional growth.**

*Reva M. Greenberg, EdD*  
2011

## ACKNOWLEDGEMENTS

Killimachos or Callimachus (circa 200 BCE), a renowned poet and head of the Alexandrian Library, compiled a catalogue of its holdings that he called *Pinakes* (tables or lists). Supposedly, extending up to 120 papyrus rolls, his catalogue amounted to a systematic survey of Greek literature up to his time. It represents the origins of the bibliography.

This compilation was a personal journey made possible with the help of others. I thank them all.

- Killimachos for his *Pinakes*.
- José Matthews, Senior Technical Support Specialist, RefWorks-Cos is a paragon of patience and a bottomless well of information and expertise. And think...I only know him through my multiple e-mails and his prompt replies.
- The Larchmont Public Library, Larchmont, NY, staff that, seemingly effortlessly, found books for me in other libraries both near and far.
- Karl Maruyama, Maruyama Designs, transformed my prosaic layouts into magical art. Karl also keeps me grounded in reality.
- Rabbi Jeffrey Sirkman, Larchmont Temple, Larchmont, NY, who introduced me to the excitement, and the joy of “the search,” the importance of asking questions and the necessity of continuing the conversations.
- My husband Josh, the family “spell checker,” scrupulously hunted down uninvited typos, unintelligible sentences and undisciplined commas.

## ABOUT THE AUTHOR

Reva M. Greenberg, EdD is an educational gerontologist with an expertise in program development. Active in Westchester County for over thirty-five years, her professional activities include:

- Executive Vice-Chair, Collaborative For Palliative Care-Westchester/NYS Southern Region
- Director, VOCAL - Voices of Community Action and Leadership for the Westchester County Department of Senior Programs and Services
- Director, The Open Book: An Intergenerational Literacy Program at the Westchester County Medical Center Out-Patient Pediatric Clinic, Valhalla, NY
- Director of Education, Mainstream at Westchester Community College, Valhalla, NY
- Co-Author with Judith Dobrof and Janna Heyman on *Building on Community Assets to Improve Palliative Care and End-of-Life Care*. In the Journal of Social Work in End-Of-Life Care, Special Issue, Partners in Palliative Care: Enhancing Ethics in Care at the End of Life. March 2011.
- Author of *Education for Older Adult Learning: A Selected Annotated Bibliography*. Westport, CT: Greenwood Press, 1993

### Education:

Vassar College, BA, 1958.

Columbia University Teachers College, EdD, Educational Gerontology, 1979.

***Every reader finds himself. The writer's work is merely a kind of optical instrument that makes it possible for the reader to discern what, without this book, he would perhaps never have seen in himself.***

**Marcel Proust**



## ARTICLES

- Afkhami, A. (2010, December 27, 2010). A doctor in Iraq, watches a faith healer at work. *New York Times*, Retrieved from [www.nytimes.com](http://www.nytimes.com)
- Mullah Eskandar is a faith healer in Iraq who had completed a 15-year apprenticeship with a renowned senior healer. He is a young, tanned, and bearded man in a flowing white dishdasha seated on a rug. Over 80% of his patients are women. Amir Afkhami, MD, a psychiatrist at George Washington University, watched Eskandar's treatment of a young woman from Kurdistan. She had come with her father and mother because she faints at the talk of marriage. In medical terms it sounds like "hysteria." The Mullah starts chanting a Koranic verse. He explains that the woman is possessed by an evil jinn. To banish the jinn Eskandar prescribes prayers, bathing and counsels the patient of the responsibilities of a daughter to marry. The patient and family leave comforted. It struck Dr. Afkhami that this approach is very similar to Western medicine support therapy and patient-centered care.
- Altilio, T. (2004). Pain and symptom management. An essential work. In J. Berzoff, & P. Silverman (Eds.), *Living and dying: A handbook for end-of-life healthcare professionals*. (pp. 380-408). New York: Columbia University Press. Terry Altilio's chapter discusses a comprehensive, individualized approach to pain and symptom management. She stresses that it must respect the impact of a person and the family's past experience, present realities and perceptions. Altilio emphasizes that interventions have the potential to affect mood, function and quality of life.
- Altilio, T. (2006). Pain and symptom management: Clinical, policy, and political perspectives. *Journal of Psychosocial Oncology*, 24(1), 65-79.
- During the last decade, the prevalence of cancer pain and the reality of under treatment have been documented in both adults and children. Terry Altilio calls for psychosocial clinicians to advocate, in an informed way, on the policy, legislative and political issues that flourish around the treatment of pain.
- Alvarez, J. (2009). On the southern front. Caring for elderly parents across the borders and cultures and languages. *Health Affairs*, 28(4), 1163-1170. Dominican/American author Julia Alvarez writes about the problems that arise when long distance caregiving becomes *Larga Distancia*. Joining 7 million other Americans in the same boat, she and her sisters ponder and eventually work out *¿Cómo vamos a cuidar a Mami y Papi? How are we going to care for Mami and Papi?*
- Barnes, B. (January 24, 2011). Unflinching end-of-life moments. *New York Times*, pp. C1-C5.
- This documentary follows Cody Curtis, a 54-year old mother of two who had for ten months, suffered from recurrent liver cancer. After Christmas 2009, she takes the prescribed barbiturate that ends her life. Director Peter Richardson examines the Oregon law that allows terminally ill patients of sound mind to take, with a doctor's prescription, enough Seconal to end their life. The film is compassionate and heartbreaking throughout but as her husband Stan Curtis said, "My wife understood the meaning of her own life. It seems like a story about dying but actually it is very much a story about living." HBO Documentary Films will run the film summer or fall 2011.
- Callahan, D. (2005). Death: "the distinguished thing." *Improving End of Life Care: Why has it been so difficult? A Hastings Center Special Report 35.*, (6), S5-S8.
- A core question for Daniel Callahan is "what is the appropriate relationship between the care of the dying and our stance toward death itself...." Starting with the premodern era, (covered by Philippe Aries in The Hour of Death) how people died and the meaning of death were inextricably blended. Callahan elegantly moves through the years to what he sees as the great schism in medicine in today. On one side is palliative care clinical practice that seeks to raise the relief of pain and suffering to one of the highest goals of medicine. On the other side is "an ever-expansive medical research drive, the sworn and well-financed enemy of death and illness of every stripe." Callahan leaves the question of resolution unanswered but on the way challenges society to respond to the issue since as Henry James wrote "So it has come at last, the distinguished thing."

*The caregiver quandary: Employees at work, caregivers at home, uncertain in both.*, 2010, from

<http://pb.com/images/30/thecaregiverquandary/FINAL.pdf>

A Pitney Bowes White Paper details the issues and challenges employed caregivers face providing care for loved ones facing serious illness and end-of-life. The paper suggests a need to increasing employer supports. The issue and the Pitney Bowes response was covered on a NPR report on *Morning Edition*, August 10, 2010 by Judy Martin, [Firms Help Workers Provide End-Of-Life Care](#). The website offers audio of the segment and a transcript at [www.npr.org/tablet/#story/?storyid=128485708](http://www.npr.org/tablet/#story/?storyid=128485708).

Csikai, E. Editor; Guest Editors., Morrissey, M. B., Jennings, B., Authors., Dobrof, J., Heyman, J., Greenberg, R., Morrissey, M. B., Stanley, P., Hurst, M., Bomba, P., Morrissey, M. B., Leven, D., Doka, K., & Bullock, K. (2011). Partners in palliative care: Enhancing ethics in care at the end of life. (selected contributions from fourth conference of collaborative for palliative care). *Journal of Social Work in End-of-Life & Palliative Care*, 7(1). Eight comprehensive articles and the Editor's and Guest Editors' introductions detail the richness and vast well of information presented to over five hundred participants at the Collaborative for Palliative Care/Westchester & NYS Southern Region Annual Conference in 2010. Contact the CPC at [www.cpcwestchester.org](http://www.cpcwestchester.org)

Daitz, B. (2011, January 24, 2011). With a poem, broaching the topic of death. *New York Times*, pp. D5-D6. The home-based care program at the Fort Defiance Indian Hospital in northeastern Arizona helps Navajos deal with the complex and confusing process of decision-making at the end of life. In Navajo culture, talking about death is thought to bring it about, so it is not discussed. A dead person's name is never spoken. Only designated tribal members are permitted to touch and bury the dead. The staff decided to use a poem to start the conversation: *When that time comes, when my last breath leaves me, I choose to die in peace to meet Shi' dy' in-the creator*. Written in both Navajo and English, it served to open a discussion about living wills and advance directives. "Using the poem and open-ended questions allows nuanced and respectful solutions to this problem because it gives people the opportunity to discuss end-of-life planning impersonally."

DeCamp, M., Walter, K., & Goold, S. (2011). Case study. Conjectural mixed motives. *Health Affairs*, 41(1), 11-12. The issue: AB is a seventy-four-old man with longstanding chronic kidney disease related to diabetes. AB developed acute back pain caused by a bacterial abscess near his spine. FB, his only son, is his primary caregiver. AB's living will, written 20 years ago when his wife was alive, said he preferred to "die with dignity." Citing this and his father's decline, FB asks for his father to stop dialysis and be transported to hospice. Matthew DeCamp, Jennifer Walter and Susan Goold offer commentaries on whether FB's caregiver burden undermines his legitimacy as a surrogate decision-maker.

Detering, K., Hancock, A., Reade, M., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomized controlled trail. *British Medical Journal*, 340 (March 25, 2010), 1345. doi:10. Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives. President Obama quoted this research in the preamble to the Medicare regulation of December 2010 that institutes advance care planning discussions.

Gawande, A. Letting go: What should medicine do when it can't save your life? *The New Yorker*, (August 2, 2010), 36-49.

Sara Thomas Monopoli was thirty-nine weeks pregnant with her first child when she was diagnosed with lung cancer. Treatments began but were ineffective. The scenario-treatment will no longer cure the illness. Gawande writes "Time was running out. This is the moment in Sara's story that poses a fundamental question for everyone living in the era of modern medicine. What do we want Sara and her doctors to do now?" The article forces patients and physicians to consider when to have the hard discussion within the context that "Death is the enemy. But the enemy has superior forces." The article is available on [The New Yorker](#) website. Dr. Gawande was interviewed by Terry Gross on her July 30, 2010 NPR program [Fresh Air](#) entitled [Dr. Atul Gawande: Make End of Life More Humane](#).

- Gawande, A. (5/1/2007). *The power of negative thinking*. Retrieved 12/1/2010, 2010, from <http://select.nytimes.com/2007/05/01/opinion/01gawande.html>  
Americans are true believers in the power of positive thinking (see Barbara Ehrenreich's book *Bright-Sided*). That said Atul Gawande, MD, general surgeon at Harvard Medical School writes "But the key, it seems to me, is actually negative thinking: looking for, and sometimes expecting, failure." Negative thinking can be painful but it having some may be exactly what we need to solve problems.
- Glassman, A., Gaziano, T., Buendia, C., & de Aguiar, F. (2010). Confronting the chronic disease burden in latin america and the caribbean. *Health Affairs*, 29(12), 2142-2148.  
The U.S. is not alone in facing increasing incidence and prevalence of chronic conditions (non-communicable diseases) as they contribute to poorer health and growing health care spending. Cardiovascular disease now constitutes a major burden in Latin America and the Caribbean. Add to the list diabetes, stroke, asthma, kidney, liver, lupus, depression, tooth decay, high cholesterol, childhood epilepsy, and rheumatoid illness. Successful interventions suggest that their applicability can be extended worldwide.
- Gupta, V. B., & Mukherjee, D. (2010). Case study: Conflicting beliefs. *The Hastings Center Report*, 40(4), 14-15.  
Vijay is a forty-eight year old man with profound mental retardation and cerebral palsy. He is rushed to the ER where doctors want to change his peripherally inserted central catheter (PICC line). His parents, who are Hindu, refuse to consent as they believe that Vijay's body is now trapping his spirit, keeping it from its onward journey. Gupta and Mukherjee offer commentaries on the case.
- Hardwig, J. (2009). Going to meet death. The art of dying in the early part of the twenty-first century. *Hastings Center Report*, 39(4), 37-45.  
Hardwig posits that current medical technology requires us to rethink how and when is the time to die. This thought-provoking, and probably controversial, article broadens the debate on end-of-life.
- Hastings Report*, 40(3), 32-38.  
There is a consensus, medically and legally, that palliative sedation to unconsciousness (PSU) is a medical treatment and is therefore not tantamount to active euthanasia. But PSU is subject to restrictions that are extraordinary in medicine. Joseph Berger's article lays out the issues and proposes revisions to the current guidelines. One change is that "PSU should be accepted for existential suffering..." for which all available and reasonable effective treatments are acceptable to the patient.
- Horton, J.; Indelicato, R. (2010). The advanced practice nurse. In Ferrel, B. Coyle, N. (Eds). *Oxford textbook of palliative nursing*, 3<sup>rd</sup> ed. (pp. 1121-1131). New York: Oxford University Press.  
This chapter defines the role of the advanced practice nurse in the provision of palliative care across care settings.
- Jobs, S. (2005). *Transcript of commencement speech at stanford given by steve jobs*.  
<http://www.americanrhetoric.com/speeches/stevejobsstanfordcommencement.htm>  
A memorable graduation speech by Steve Jobs at Stanford University, Palo Alto, CA is available on this website in print, audio and YouTube formats.
- Jochim, C. (2010). *Chinese beliefs*. Retrieved 12/22, 2010, from <http://www.deathreference.com/Ce-Da/Chinese-Beliefs.html>  
Here is an article that provides a broad overview of Chinese rites for the dead, conceptions of souls and ancestral existence and individual salvation from premodern to modern day China. There is a bibliography and opportunity to comment about the article, add new information and ask questions.

Kelley, A., & Meier, D. (2010). Palliative care -A shifting paradigm. *New England Journal of Medicine*, 363(August 19, 2010), 781-782.

Palliative care is covered within the Medicare hospice benefit and in nonhospice palliative care. Currently, nonhospice palliative care is offered simultaneously with life-prolonging and curative therapies. Hospice palliative is beneficial when introduced at time of diagnosis of a serious or life-limiting illness. Kelley and Meier conclude that we now have "the means and knowledge to "make palliative care an essential and routine component of evidence-based, high-quality care for the management of serious illness."

Kolata, G. (2010, December 18, 2010). Tests, detect Alzheimer's risks, but should the patient be told? *New York Times*, pp. A1-A14.

A bioethical question - there are new diagnostic tests for Alzheimer's but since there is no treatment or cure is it a good thing to tell people, years earlier, that they have this progressive degenerative brain disease or that they have a good chance of getting it? Should you even do the tests? Bioethicists are talking with scientists, the public and physicians about the right thing to do. The article lays out the issues and is a thought-provoking look at a topic that has no clear answers. New studies come out almost daily.

Kristof, N. (2010, June 6 2010). A scare, a scar, a silver lining. *New York Times*, pp. WK12. Retrieved from [www.newyorktimes.com](http://www.newyorktimes.com)

Nicholas Kristof vividly remembers the day his doctor broke the news that there was a tumor on his right kidney. What followed was a month of visits to a variety of doctors; a three hour operation; the loss of 10% of his kidney; and a six inch scar. Kristof was lucky. His biopsy result showed a benign tumor, an oncocytoma, . "So today I have an impressive scar, a bit less kidney, a big bellyache and a far more appreciation for the glory of life."

Levine, C., Halper, D., Peist, A., & Gould, D. (January 2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs*, 29(1), 116-135.

Abstract: Families are the bedrock of long-term care, but policymakers have traditionally considered them "informal" caregivers, as they are not part of the formal paid caregiving workforce. As chronic and long-term care systems have become more complex and as more demanding tasks have been shifted to families, this view is no longer sustainable. The care transition process offers a critical opportunity to treat family caregivers as important care partners. Enhancing their involvement, training, and support will contribute to reducing unnecessary rehospitalizations and improving patient outcomes. The contributions and experiences of family caregivers should be considered in gathering information to shape policies and practice; training health care professionals; developing programs; and reforming financing.

Levinson, W., Lesser, C., & Epstein, R. (July 2010). Developing physician communication skills for patient-centered care. *Health Affairs*, 29(7), 1310-1317.

Health care professionals, especially physicals, must become more comfortable and effective in discussing end-of-life concerns with their patients. As of today most would get a C-. Abstract: Growing enthusiasm about patient-centered medical homes, fueled by the Patient Protection and Affordable Care Act's emphasis on improved primary care, has intensified interest in how to deliver patient-centered care. Essential to the delivery of such care are patient-centered communication skills. These skills have a positive impact on patient satisfaction, treatment adherence, and self-management. They can be effectively taught at all levels of medical education and to practicing physicians. Yet most physicians receive limited training in communication skills. Policy makers and stakeholders can leverage training grants, payment incentives, certification requirements, and other mechanisms to develop and reward effective patient-centered communication.

- Miller, F., & Truog, R. (2008). Rethinking the ethics of vital organ donations. *Hastings Center Report*, 38(6), 38-46.  
When organ transplantation became possible, doctors needed dead donors whose bodies were still alive. It is thought permissible under the "dead donor rule" to retrieve vital organs. This raises the question, is "a brain dead" patient really dead? It is important to emphasize that our current practices of vital organ donation are inconsistent with the dead donor rule. The brain dead are not really dead, given the range of integrative organic functions that can be performed with continued life support." The authors present a range of views and issues and conclude with endorsement of life terminating acts of vital organ extraction prior to death provided that "they are tied to valid decisions to withdraw life support and to valid consent." The May-June 2009 issue of the Hastings Report has letters in response to the article.
- Moazam, F., Zaman, R., & Jafarey, J. (2009). Conversations with kidney vendors in Pakistan: An ethnographic study. *Hastings Center Report*, 39(3), 29-44. The growing concern about the shortage of kidneys available for transplantation has led to talk of "selling" organs through international organ trafficking. The authors address the issue in Pakistan, a country known as the largest "kidney bazaar." Their ethnographic study sheds light on the "vendors" who are typically economically disadvantaged people. Qualitative data shows that most vendors sell a kidney because of *majboori*- a word meaning lack of options, a situation over which one has no control-"in order to fulfill what they see as obligations toward immediate and extended family..."
- Ogg, M. (2011). Running out of time, money, and independence? *Health Affairs*, 30(1), 173-176. doi:10.1377/HLTHAFF.2010.0857.  
Retired Physics Professor Michael Ogg is fifty-six years old and has primary progressive multiple sclerosis (it started at age forty two). He lives alone. His morning and night "formal" or paid caregivers provide for all his care. Without Serge Michel and Nelita Dossous he could not live independently, which is what he wishes to do. Within a few years he will not have the money to afford personal care assistants and Ogg faces going on Medicaid and possibly becoming institutionalized. Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. World-wide, MS affects about 2.5 million people. Most do not write as well as Ogg.
- Pawlecki, J. B. (2010). End of life: A workplace issue. *Health Affairs*, 29(1), 141-145.  
Employers would be wise to place addressing end-of-life issues with their employees. Caregiver employees of parents, siblings and children plus their own personal health crises affect their productivity and emotional well-being. Estimated lost of productivity of working caregivers was \$17.1 billion to \$33.6 billion per year (2002/03). Employers cannot erase the caregiving challenges of their employees, but they can foster discussion and provide tools that will ease the burden. J. Brent Pawlecki is corporate medical director of Pitney Bowes, Stamford, CT.
- Puchalski, C., Ferrel, G., Virani, R., & et al. (2009). Improving the quality of spiritual care as a dimension of palliative care. *Journal of Palliative Medicine*, 12, 885-904.  
This Conference was based on the belief that spiritual care is a fundamental component of quality palliative care. In its report, practical recommendations are provided for the implementation of spiritual care in palliative, hospice, hospital, long-term, and other clinical settings. Board-certified chaplains would be included in the decision-making team.
- Schoen, C., Osborn, R., How, S., Doty, M., & Peugh, J. (2009). In chronic condition: Experiences of patients with complex health care needs, in eight countries, 2008. *Health Affairs Web Exclusives (Published Online 10 February 2009: 10.1377/hlthaff.28.2. w326)*, 28(1-2), w1-w16.  
There are growing challenges of caring for patients with chronic diseases in systems initially designed to respond to acute illnesses. Chronically ill adults in Australia, Canada, France Germany, the Netherlands, New Zealand, the United Kingdom and the United States show that chronically ill U.S. patients have the most negative access, coordination and safety experiences although there is room for improvement in all eight countries. "In an era of rising rates of chronic disease, public health initiatives as well as system innovations will be essential to enable all patients to achieve healthier, longer and more productive lives."

Veach, R. (2009). The evolution of death and dying controversies. *Hastings Center Report*, 39(3), 16-18.

While there is recognition that while dying is a process, death is a momentary event. This raises a Pandora's box of complex issues. Innumerable variations on the definition of death include religious and philosophical positions. brain-heart definitions and the foregoing of life support are controversial issues that need newer, more nuanced guidelines. Robert Veach has been a prominent member of the Hastings Center since it began in 1969.

Verghese, A. (2009). A touch of sense. patients and physicians connect through touch and trust. *Health Affairs*, 28(4), 1177-1182.

For the past two decades it seems that doctors touch patients less and connect to computers and images more. The skilled bedside examination of the patient "has diminished to where it is pure farce." Abraham Verghese, MD at Stanford University of Medicine sees a physical exam as being "about trust, about a sacred privilege." "We are, therefore, obliged to teach them the most skilled and thoughtful way we can." Hands-on is a powerful diagnostic tool and it must be the mission of medical schools to see that their students and hospital residents develop the bedside clinical competencies of touch. Dr. Verghese is the author of the novel Cutting For Stone (2010) that has been called "a lovely ode to the medical profession.

### **NON-FICTION: FACT BASED WRITINGS**

Ariès, P. (1982). *The hour of our death* [L'homme devant la mort] (H. Weaver Trans.). New York: Alfred A. Knopf.

Here is Philippe Ariès's landmark history of Western man's changing attitudes toward death from their roots in the Greco-Roman world to earliest Christian times and up to the twentieth century. The last sections cover the modern phenomenon of "The Invisible Death...Death Denied." Illustrations take us from the Appian Way in Rome to the Greenwood Cemetery in Brooklyn. A big book packed with fascinating information.

Bailey, S., & Flowers, S. (2009). *Grave expectation. Planning the end life like there's no tomorrow*. Kennebunkport, ME: Cider Mill Press.

Since so far there does not seem to be an alternative to dying, this book may interest you. It can be used to memorialize your life on your own terms while you are still around. You may laugh out loud but along the way you will do much serious thinking. Here is the opportunity to gather together all important legal documents, fill in the blanks for your options and wishes on rites of passage such as coffin choices, visitation, burial, body part donations, graveside services, funeral and memorial services, music, readings, eulogies, a memorial party, headstone inscriptions. Then there are burial choices: cemetery, in some states in your backyard or next to highways are allowed. And then there are cremation (UPS and FedEx will not accept cremated remains so use U.S. Postal Services), cryonics (deep-freezing), mummification, and burial at sea. The authors also include interesting blurbs of information on other cultures, religions, and events.

Becker, E. (1973). *The denial of death*. (Free Press Paperback Edition 1997 ed.). New York: Free Press.

When Ernest Becker published his Pulitzer Prize book in 1973 it was, and still is, considered a brilliant analysis of the psychology of death and the science of evil. Becker analyzes numerous philosophies that deal with man's fears and the notion of immortality to ensure our lives have meaning. He believed that awe, fear and anxiety are universal "natural accompaniments to our contemplating death." Humans can build a variety of defense mechanisms, try attempts at immortality but death is man's ultimate destiny. Our lives are subsumed by the paradox - we live and die at the same time. Humans have a life history but die, rot and decay like all other animals on the planet. Becker speaks of "awe-filled creatures trying to live in harmony with the rest of creation" to explain the possibility of man's meaningful survival. A courageous, thought-provoking book that may change the way you look at the world and at your life.

Blackman, S. (Ed.). (1997). *Graceful exits: How great beings die. Death stories of Hindu, Tibetan Buddhist, and Zen masters* (2005th ed.). Boston, MA: Shambhala Publications, Inc.

The focus is the Tibetan Buddhist, Zen Buddhist, and Hindu or Yogic traditions and the importance they place on dying. Sushila Blackman has compiled stories that reflect the feelings or attitudes of some of the great masters as they were dying (e.g. Dilgo Khyentse Rinpoche; Anandamayi Ma; Sai Baba of Shirdi; Rumi). In 1955, Blackman was diagnosed with lung cancer and received palliative brain radiation. She died peacefully and consciously in 1996, supported by her Gurumayi and the entire congregation at the Shree Mukhtanananda Ashram in South Fallsburg, NY.

Blake, R. (2007). *The day donny herbert woke up*. New York: Three Rivers Press.

A twenty-first century bio-ethics conundrum - when do you declare a person dead...beyond repair? The roof collapsed on Buffalo Fire Department fireman Donny Herbert on December 29, 1995. By the time the rescue team found him, Donny was unconscious, head forward at a 90 degree angle and not breathing. CPR brought back a pulse but weeks later Donny was diagnosed with a severe anoxic brain injury. Taken off the ventilator, he was breathing on his own but there was scant brain-wave activity. Is it a minimal conscious state or persistent vegetative state? Fast forward. Donny woke up in 2005 but was this wheelchair bound man the active, free-willing, thinking, feeling Donny? It's a question that concerns everyone but a question that is hard to answer. Donny died of pneumonia in 2006.

*The book of symbols. Reflections on archetypal images*. (2010). In Ronnberg A., Martin K. (Eds.), . Cologne, Germany: Taschen.

Fourteenth century theologian Meister Eckhart wrote "When the soul wants to experience something she throws out an image in front of her and steps into it." This beautiful book is big and heavy, but the images it presents express what cannot be said. Very readable essays accompany almost 800 full-color images that represent art from around the world and from every era since human beings first painted on rocks and cave walls. Of particular interest to this Bibliography are in the sections *Human World* and *Spirit World*. The book will appeal to psychotherapists, religious and spiritual searchers, writers, artists, students, and any curious about the power of archetypal [prime examples, prototype] images in art, literature, religion, life or dreams.

Brennan, M., Karpiak, R., Shippy, A., & Cantor, M. (Eds.). (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York: Nova Publishers.

From the Publisher: "The first decade of the HIV/AIDs epidemic was defined by young gay men dying and activism. The second decade saw people of color and women account for the majority of those with HIV, as well as the development of effective drugs and the hope that HIV could become treatable or even curable. In this third decade, HOV has evolved into a chronic manageable disease. Few would have thought that there would be large number of older adults living with HIV in our lifetimes...Research on Older Adults with HIV (ROAH), conducted by the AIDS Community Research Initiative of American (ACRIA), is the first step to begin to establish a valid comprehensive knowledge-base of the unique characteristics and needs of this growing population."

Brody, J. (2009). *Jane brody's guide to the great beyond*. New York: Random House.

A put-your-affairs-in-order road map authored by the well-known *New York Times* health columnist Jane Brody. In her informative, pragmatic style Brody addresses a topic many people want to avoid...preparing for end-of-life. Topics include emotional, spiritual and practical concerns from living to grieving. As usual, Brody covers a lot of territory, succinctly.

Byock, I. (1997). *Dying well. The prospect for growth at the end of life*. New York: Riverhead Books.

"Over the years I have learned that the actual range of human experience of dying is broad." The stories Byock has chosen represent the wide range of human potential to find meaning and value within the process of illness and dying. He believes that dying need not be agonizing and that no one should die in pain. Drawing on the experiences of people with whom he has worked in his family practice, Byock teaches us about the journey of life from birth to death. The Q & A appendix format suggests valuable approaches.

Byock, I. (2004). *The four things that matter most. A book about living*. New York: Free Press.

Please forgive me; I forgive you; Thank you; I love you. Ira Byock, MD introduces these "four powerful tools for reconciling the rifts that can divide us and restoring the closeness we innately desire." Drawing upon people's stories and his own insights, he illustrates the healing potential of simply said, heartfelt words. A book about living, these words present an extraordinary opportunity to use on any occasion that involves relationships that are important to you.

Callahan, D. (1993). *The troubled dream of life. Living with mortality*. New York: Simon and Schuster.

Distinguished medical ethicist Daniel Callahan talks about the way we view death, care of the dying and the critically ill in America today. Callahan poses many challenging questions central to the given that death is inescapable. He asks how can individuals and society become comfortable talking about the legal and moral issues surrounding it? No pat, reassuring answers here but stimulating thoughts for private and public discussions. One of those timeless books on a timeless subject.

Callanan, M. (2008). *Final journeys. A practical guide for bringing care and comfort at the end of life*. New York: Bantam Books.

When Maggie Callanan's father was dying, he asked her "But what does it *feel* like to die-not the physical pain, the *feeling part*. If no one gets out of this world alive, why don't we know these things? Why do we go in fear?" Callanan, a hospice nurse since 1981, wrote this book to offer other possibilities. The 40 personal stories are all true ones and her comments, responses of support to patients and families are what she learned from them. They teach that dying is hard work. It asks that we meet physical, emotional, spiritual and ethical challenges. There are also excellent Appendices. Callanan is the co-author of the classic Final Gifts.

Callanan, M., & Kelley, P. (1997). *Final gifts. Understanding the special awareness, needs, and communications of the dying*. New York: Bantam Books.

The title of hospice nurses Maggie Callanan and Patricia Kelley book reflects the comfort and teachings offered by the dying to those who hear their needs and to those who will grieve their death. According to the authors, dying messages fall into two categories: descriptions of what they are experiencing (such as the places they see, the presence of others no longer alive, or their knowledge of when death will occur) and requests for what the dying need for a peaceful death (a reconciliation, for instance, or the removal of some barrier to departure). To illustrate, Callanan and Kelley include numerous examples gathered from their years of caring for the dying. They offer practical advice not only to involved family members but also to professional caregivers on how to recognize, understand, and respond to a dying person's messages. No false cheerfulness here, but insightful observations and advice on a difficult topic. The book, now a classic, is published in ten languages.

Carter, B., & Levetown, M. (Eds.). (2004). *Palliative care for infants, children, and adolescents: A practical handbook*.

Maryland: Johns Hopkins University Press. Neurologist Brian Carter and pediatrician Marcia Levetown, gathered together physicians, nurses, parents, ethicists, social workers, and ministers to create this exceptional text. The forty-three contributors are leading researchers and practitioners from different disciplines. Case studies discuss the experiences and perspectives of parents. From the beginning the editors note that " We need to improve the way babies and children die in our care."

Cassell, E. J. (1991). *The nature of suffering and the goals of medicine*. (Second edition (2004 ed.)). New York: Oxford University Press.

To understand the patient (the one in need), the physician (the healer) must have time alone with the doctor's "private ear listening only to the patient." Eric Cassell, MD, attending physician at The New York-Presbyterian Hospital and member of the Hastings Center Board of Directors, firmly believes that to understand the patient's illness the doctor must understand the patient's entire story not just the MRI or blood test. In recent times, the treatment of pain has taken prominence over suffering but "suffering is an affliction of the *person*, not the body." The 2004 second edition of this medical classic includes a new preface and three additional chapters. Cassell's message however remains the same: while the importance of scientific medicine is crucial, the relief of suffering is the fundamental goal of medicine.

- Chen, P. (2008). *Final exam. A surgeon's reflection on mortality*. New York: Vintage Books.  
 "Our professional fear and aversion to dying is the most difficult—and most fundamental human-obstacle in changing end-of-life care." Pauline Chen, MD chronicles an insider's view of the key events through which medical students and residents learn about and encounter death that ultimately leads them to depersonalize it. Chen periodically writes articles for the *New York Times*.
- Colby, W. (2006). *Unplugged. Reclaiming our right to die in America*. New York: American Management Association.  
 Nancy Cruzan's lawyer, William Colby, recounts Terry Schiavo's wrenching last months. He asks why modern end-of-life medical, legal and ethical issues have become so challenging and posits that letting nature take its course is no longer always a good, or possible, option. Colby asks people of all ages "What would you want if you were in her [Terri Schiavo] shoes. Don't we all owe it to those we love to spend the time needed to face these questions head on before it's too late?"
- Coleman, P. (1997). *Corpses, coffins, and crypts. A history of burial*. New York: Henry Holt and Company.  
 A fascinating tour of the customs, rites, rituals, realities and mysteries of death and dying through various times and cultures. Photos and historical illustrations, an appended glossary and an excellent bibliography add to this intriguing subject. This readable book fills the niche between young adult and adult non-fiction.
- Dasgupta, S., & Hurst, M. (2007). *Stories of illness and healing: Women and their bodies. stories of illness and healing. Women and their bodies*. Kent, OH: Kent State Publishing.  
 A variety of women's illness narratives stand alongside analytic essays from prominent scholars in the field. The essays respond to the themes and issues raised by the narrative.
- Doka, K. (2009). *Counseling individuals with life threatening illness*. New York: Spring Publishing Company.  
 Life-threatening illness is a psychological, social, and spiritual crisis as well as a medical crisis. Serious illness affects the family and the patient. The book's two major principles are that care in life-threatening illness must be holistic, and it must be family centered. Kenneth Doka, PhD, MDiv presents an insightful, comprehensive guide for counselors, social workers and healthcare professionals.
- Doka, K., & Martin, T. (2010). *Grieving beyond gender: Understanding the ways men and women mourn* (2nd. edition. ed.). New York: Routledge.  
 The authors explore the different ways that individuals grieve, noting that gender is only one factor that affects an individual's style or pattern of grief. The book differentiates intuitive grievers, where the pattern is more affective, from instrumental grievers, who grieve in a more cognitive and behavioral way, while noting other patterns that might be more blended or dissonant. The model is firmly grounded in social science theory and research. A particular strength of the work is the emphasis placed on the clinical implications of the model on the ways that different types of grievers might best be supported through individual counseling or group support. Kenneth J. Doka, Ph.D., is a Professor of Gerontology at the Graduate School of The College of New Rochelle and Senior Consultant to the Hospice Foundation of America. Terry L. Martin, Ph.D., is Associate Professor of Psychology and Thanatology at Hood College, and maintains a private practice in Maryland.
- Doka, K., & Tucci, A. (Eds.). (2009). *Diversity and end of life care. (living with grief)*. Washington, D.C.: The Hospice Foundation of America.  
 This book examines the ways that cultural diversity influences end-of-life care. It presents a multifaceted view of diversity including race and ethnicity, social class, spirituality, sexual orientation and disabilities. Experts within the field author the seventeen chapters. The foreword is by Richard Payne, MD.

Doka, K., & Tucci, A. (Eds.). (2010). *Living with grief: Cancer*

This book in the *Living with Grief®* series reviews how a holistic plan of care can allow persons living with terminal cancer to live and die with dignity. It offers valuable information on treating cancer when the goal of care is palliative. From a historical context of cancer and illness to treatment options, psychosocial concerns, and prevailing cultural attitudes toward cancer,

These 14 chapters instruct professional and lay caregivers on how to help patients and families better assess their options as life ebbs and understand their grief during and after loss. The personal perspectives and case studies—written by both end-of-life professionals and laypersons—help temper the clinical instruction with real-world narratives of cancer and loss that highlight the need for quality end-of-life care. Chapters cover: Nature of Cancer; Treating Cancer; Psychosocial Aspects of Cancer Care; Grief and Cancer. Available in paperback.

Doka, K. J. (Ed.). (1989). *Disenfranchised grief. recognizing hidden sorrow*. Lexington, MA: Lexington Books.

Was it a best friend, a roommate, a cherished animal friend that died? Or was it an elected abortion, an adolescent and young adult relationship or extramarital breakup or a perinatal death? In these situations or a myriad of others where the event is forgotten, not socially sanctioned or publicly shared, when natural grief is minimized or ignored people the sufferer is denied the all-important "catharsis" that shared, socially sanctioned or publicly shared can bring. Kenneth Doka, professor, trailblazer in death education and a Lutheran Minister, brings together contributors from various disciplines to shed light on what is seen as an "appropriate" death and how to recognize, acknowledge, counsel and support the hidden sorrows. All loss involves the grieving process and Doka introduces the book with a line from the movie *Torch Song Trilogy* when Arnold, the gay protagonist, raises his mother's ire by saying kaddish for his dead lover. "How, she demands, can you compare your loss to mine?" Where can a conversation go from here?

Ehrenreich, B. (2009). *Bright-sides. How the relentless promotion of positive thinking has undermined America*. New York: Metropolitan Books.

Positive thinking can mean two things - the *positive thought* itself such as make lemonade out of lemons OR it can be the *actual practice or discipline of trying to think positively*. Barbara Ehrenreich returns to challenge the conventional wisdom of what she calls "the cult of cheerfulness." She starts off with people facing serious illness (she didn't want a pink teddy bear or pin. She was angry about having cancer). She continues on to workplace and her anger made her aware of a \$9.6 billion self-improvement business that "encourages us to deny reality, submit cheerfully to misfortune, and blame only ourselves for our fate." Ehrenreich claims her right to not be silenced and converts her anger into positive action to help with societal ills. Hanna Rosin in [The New York Times Book Review Section](#) wrote that she has waited a long time for someone to write a book like this and "that even when she did not agree with Ehrenreich's arguments, she felt less guilty about not sharing in our smiley culture." Reclaim your anger?; Consider Atul Gawande's view of the importance of negative thinking?; Walk only on the sunny side of the street? What's your choice?

*The ethics of organ transplants. The current debate* (1999). In Caplan A., Coelho D. (Eds.). Amherst, NY: Prometheus Books.

Nearly 100,000 people are on waiting lists for organ transplants in the U.S., but about a dozen of them will die each day because of a lack of organs. With more than thirty of the most important, influential, and up-to-date articles from leaders in ethics, medicine, philosophy, law, and politics, this book examines the numerous and tangled issues that surround organ procurement and distribution. Recently, rationing has been put on the table. Topics include: Sources, Policy, Commoditization, Allocation and Rationing and Value. In many cases, the editors have selected companion articles that illustrate contrasting viewpoints on a particular issue. [The Clinical Journal of the American Society of Phrenology](#) has more current articles but this does not tarnish the value of this book. Arthur Caplan, MD is an internationally recognized authority on bioethics and health policy director of the Center for Bioethics at the University of Pennsylvania and Daniel Coelho frequently writes on medical bioethics.

- Fadiman, A. (1997). *The spirit catches you and you fall down. A Hmong child, her American doctors, and the collisions of two cultures*. New York: Farrar, Straus and Giroux.  
*Qaug dab peg* (the spirit catches you and you fall). These three Hmong words are central to a belief in which there is no distinction between mental and physical ills. Everything is a spiritual problem. Juxtapose this with the culture of Western medicine. Profound differences in belief systems emerge. In 1982, Lia the three-month-old daughter of the Lee family (recent refugees from Laos) was diagnosed with severe epilepsy at Mered Community Medical Center (MCMC) in CA. The Lees see the condition as *qaug dab peg* and know that Lia needs healing spirits, *neeb*s, to restore her soul to her body. The doctors at MCMC know the condition as epilepsy and believe it can be kept under control with medications. Here are two different cultures on a collision course in which neither understands or trusts the other. Lia did not die, nor did she recover. The question is what is more important, the life or the soul? The answer is, it depends upon whom you ask. Anne Fadiman has written an engrossing, memorable book that is a must read, not only for health care professionals, but also for anyone concerned with cultural difference in our ever shrinking global world. Read this along with Colin Cotterill's mystery [The Coroner's Lunch](#) for a view of the Hmongs in Laos in 1976.
- Ferrell, B., & Coyle, N. (2008). *The nature of suffering and the goals of nursing*. New York: Oxford University Press.  
 A slim volume that gives voice to the suffering that patients, families, colleagues and nurses witness and their reactions. A critically acclaimed book that is relevant to a broad range of specialties and interests.
- Fins, J. (2006). *A palliative ethic of care: Clinical wisdom at life's end*. Sudbury, MA: Jones and Bartlett Publishers.  
 Joseph Fins, MD presents a monograph on ethics and a textbook to educate physicians-in-training. Fins is a practitioner and noted medical ethicist. The book ties the critical link of ethical theory to clinical practice when caring for the terminally ill patient. A structured method of goal setting to use in clinical work and research has been developed. The centerpiece of this method, *The Goals of Care Assessment Tool* (GCAT) is in the Appendix. "Not all deaths can be good ones but most can be better." "Each of us plays a part of a larger process."
- Glajchen, M., & Portenoy, R. (2005). *The caregiver resource directory*. (3rd. ed.). New York: Continuum Health Partners, Inc.  
 A comprehensive, reader-friendly guide for family caregivers and "...anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home." The Directory is available at the website of the Department of Pain Medicine & Palliative Care, Beth Israel Medical Center, New York. [www.StopPain.org/](http://www.StopPain.org/)
- Groopman, J. (2004). *The anatomy of hope*. New York: Random House.  
 Good books don't go out of style and Jerome Groopman, MD always has something to teach us. In his search for how patients find hope in the face of significant tragedy and/or diagnosis, he draws on his thirty year learning journey in clinical practice. "Hope is as vital to our lives as the very oxygen that we breathe" and health care professionals, families and patients should always remember this.
- Handbook of psychiatry in palliative medicine*. (2009). In Chochinove H., Breitbart W. (Eds.), (2nd. ed.). New York: Oxford University Press.  
 The two editors, major contributors to the original literature in the field, have written much of the material in this text. The book's twenty-eight chapters cover all the common psychiatric complications seen in the terminally ill. The text brings together up-to-date, comprehensive, and authoritative accounts covering a range of issues at the interface of psychiatry and palliative medicine.
- Hanks, G., Charny, N., Christakis, N., Fallon, M., Kassa, S., & Portenoy, R. (Eds.). (2009). *Oxford textbook of palliative medicine*. (4th edition ed.). New York: Oxford University Press.  
 This updated edition joins its predecessor as the definitive, gold standard textbook on palliative care. It is used worldwide by a wide range of professionals involved in the care of terminally ill patients, or chronic, progressive conditions. All of the editors are prominent leaders in their fields.

*Helping bereaved children. A handbook for practitioners.* In Boyd-Webb N. (Ed.), (3rd. ed.). New York: Guildford Press.  
A completely revised and updated 3rd edition of Nancy Boyd-Webb's (DSW, LCSW) best selling book will help practitioners and counselors in their work with bereaved children. The revision includes recent literature and new content about helping bereaved children following deaths in the family, school and the world. Kenneth Doka, PhD, MDiv. has written the forward.

Holloway, K. (2003). *Passed on. African-American mourning stories.* Durham, NC: Duke University Press.  
Karla Holloway writes, "black culture's stories of death and dying were inextricably linked to the ways in which the nation experienced, perceived and represented African-America." The book covers the collective cultural memory of how in the twentieth-century blacks die, "a color-coded death." It interweaves research, interviews, literature, film and music to show how untimely death (racial injustice, violence, medical neglect) cannot be disentangled from how black culture represents itself and is represented. Brian Reed wrote in the Journal of the American Medical Association, it "may help physicians today to understand why some African-Americans do not fully trust our present medical system."

Hyden, L. (2008). *Health, illness and culture. broken narratives.* New York: Routledge.  
These narratives are a varied collection of studies and essays on the interrelationship among illness, disability, health, society and culture. The narratives represent and add to this new multidisciplinary field.

Jacobs, M. (2010). *A clergy guide for end-of-life issues.* Cleveland, OH: Pilgrim Press.  
A 176-page guidebook through the dense maze of clinical and ethical issues that clergy face when ministering to patients and families who face death. Jacobs, an ordained minister and a certified hospital chaplain, covers topics from end-of-life, theological, pastoral, legal, medical issues to our own demons and miracle cures. The chapter *Focusing on Transformation* includes commentaries by several of her chaplain colleagues. The book's focus is from a Christian perspective but it covers subjects of interest to a wider readership. There is a wealth of materials and resources in the easy-to-use Appendices. Jacob's website is : [www.deathisnottheenemy.com](http://www.deathisnottheenemy.com)

Jacoby, S. (2011). *Never say die. The myth and marketing of the new old age.* New York: Pantheon Books.  
"Can you imagine old age? Of course you can't" - (Phillip Roth). Drawing on research, personal experience and anecdotes, Susan Jacoby offers a reality check for Americans enamored of the images of healthy, active seniors featured in advertisements. Some will find the book too pessimistic and negative. That said, the 70 million Americans who will be over sixty-five by 2030 need to read it. The eternal fountain of youth does not exist and many of us may live too long for both our own good and for the good of others. Unless you die young those living to be old-old, i.e. 85, 90, 100, will eventually have to accept the transition from being a caretaker to being a care recipient. This, despite how many vitamins you take and drinks you do not drink. Jacoby takes a realistic, tough look at aging and by reading it you may be in a better position to grow old with dignity.

Johnson, M. (2006). *The dead beat. Lost souls, lucky stiffs and the perverse pleasures of obituaries.* New York: HarperCollins.  
Obituaries are some of the best-read newspaper pages. Filled with the lives of the rich, the famous and everyday folks, a well-researched obit is not only a vital historical record but also first-rate reading. With a reverent level of humor, Marilyn Johnson reaffirms life as much as she talks about death. A wonderfully uplifting book to read before you turn to the obit pages of your newspaper to see - older than I am, younger than I am, the same age as me. Too bad we can't read our own obits since they would *really* be interesting.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition.* New York: Basic Books.  
This seminal work by Harvard Medical School psychiatrist and medical anthropologist, Arthur Kleinman, posits that doctors must consider the psychological and social aspects of chronic illness along with the medical conditions they treat. For Kleinman every illness is a personal story not just a list of pathologies. His set of eight questions is widely used in cross-cultural medicine. There is a need to reform today's medical-care system to better bridge the gap that too often exists between patient and doctor. Once again here is the crucial conversation.

- Koenig, H. (2007). *Spirituality in patient care. Why how, when and what.* (Revised and expanded second edition ed.). West Conshohocken, PA: Templeton Press.  
Addressing spiritual issues in patient care is an extension of patient-centered medicine writes Harold Koenig, MD, Duke University Medical Center. The landmark text includes sections for physicians, nurses, pastoral counselors, social workers and occupational and physical therapist i.e. the complete health care team. It includes health care information related to specific religious traditions as well as a model educational curriculum for use in medical schools. As William Osler, MD wrote "Ask not what disease a person has, but rather what person the disease has."
- Kubler-Ross, E. (1969). *On death and dying.* (1997th ed.). New York: Touchstone. The pioneer in the field of death and dying, Elizabeth Kubler-Ross, MD explores her now iconic five stages of death: denial and isolation, anger, bargaining, depression, and acceptance. Through sample interviews and conversations, she gives the reader an understanding of how imminent death affects the patient, the professionals who serve that patient and the patient's family.
- Kuschnier, H. (1981). *When bad things happen to good people.* New York: Anchor Books.  
When his son Aaron died at age 14 of progeria, rapid aging, Rabbi Harold Kuschnier struggled to understand the unfair distribution of suffering in the world or why bad things happen to good people. Can God prevent calamity? Misfortunes, Kuschnier concludes, "are caused by bad luck or bad people and are simply an inevitable consequence of our being mortal and living in a world of inflexible natural law." Turning to God can give us the strength to overcome loss and go on living positive and constructive lives. This book cannot go unread by anyone who has ever been troubled by the question, "Why me?"
- You don't know jack: The life and deaths of jack kevorkian.* Levinson, B. (Director). (2010).[Video/DVD] New York: HBO Home Video.  
The DVD of an HBO film which stars Al Pacino (Dr. Jack Kevorkian) and Susan Sarandon (Hemlock Society leader) takes a considered look at a controversial issue...euthanasia...and Kevorkian's right-to-die practice. Assisted suicide is one of those topics that raises many ethical concerns of our time and arouses strong emotions and discussion. The film received very favorable critical reviews.
- Martensen, R. (2008). *A life worth living. A doctor's reflections on illness in a high tech era.* New York: Farrar, Straus and Giroux.  
Physician, historian, bio-ethicist Robert Martensen details treatment scenarios, daily realities and ethical dimensions of today's medical care. He discusses ICUs, medical choices, sick children, people with limited innate capacity or serious mental illness and people living on the margins. Martensen tries to balance the reflections of patients, families and friends with his prescriptive advice on what is a life worth living.
- Meier, D., Isaacs, T., Hughes, R. (Ed.). (2010). *Palliative care. Transforming the care of serious illness.* (First edition.) San Francisco, CA: Jossey-Bass.  
A tour of the palliative care movement and the impact it currently has on the accrued high costs and quality of care given to individuals with serious illnesses. Palliative care entered the mainstream of medical practice when in 2006 more than half of U.S. hospitals reported having such a program. The first chapter, written exclusively for this book, by Dr. Meier, Director of the Center to Advance Palliative Care and a 2008 MacArthur Foundation 'Genius Grant' recipient, offers a comprehensive review of the field. Twenty-five reprints of some of the very best works that the field has to offer follow it. They include issues, coping with death, social, legal and ethical issues, pain and medical decision making, research, caregiving and issues and perspectives. Reading this book is a transformative experience in itself.

Miller, L. (2010). *Heaven. Our enduring fascination with the afterlife*. New York: HarperCollins.

Is there a heaven? Where is it? Who resides there? What do they do? How do you get there? How did the idea of heaven start and by whom? Lisa Miller, ([Newsweek's](#) Religion Editor), draws upon history, biblical research, everyday beliefs and popular culture to create a scholarly and readable study of the afterlife from Christian, Jewish and Muslim perspectives. The diversity of belief (or disbelief) "presents a problem for heaven, an idea-or reality, depending upon your view-that has never been characterized by conceptual consensus or clarity." A 2007 Gallup poll reported that 81 percent of Americans say they believe in heaven. Most looked up when asked where heaven is.

Mosca, A. (2008). *Green-wood cemetery. Images of America: new york*. New York: Arcadia Publishing.

Alexandra Mosca learned about Green-Wood Cemetery in Brooklyn when she worked for a funeral parlor. This is not only a guidebook, but also a history lesson and a great place to look for traditional baby names. On 478 acres the thousands of graves and mausoleums reside the remains of greats, plus others less known but equally as important in making New York the great city it is today. A working cemetery, and a national historic landmark since 2006, the book chronicles the cemetery's history and documents how its tradition as a park and a popular tourist attraction. It continues to attract 300,000 visitors annually. Alexandra Mosca has a Facebook page that includes lectures, tours and other events.

Moyers, B. (1993). *Healing and the mind*. New York: Doubleday.

This companion book to the PBS TV series features the intriguing Bill Moyers' dialogues with sixteen doctors and scientists about their views on the meaning of sickness, health and healing. Among those interviewed are physician Dean Ornish, who has reversed heart disease in patients with treatments combining meditation, stress-reduction exercises, group therapy, walking and vegetarian diet; neurobiologist David Felten, discoverer of nerve fibers that link the nervous system to the immune system; and Thomas Delbanco of Harvard Medical School who seeks ways to transform the doctor-patient relationship so that patients are more actively involved. Available as an audio download, DVD and VHS formats.

Mukherjee, S. (2010). *Emperor of all maladies. A biography of cancer*. New York: Scribner.

In 1971 Nixon declared "war on cancer." Oncologist, physician, researcher Siddhartha Mukherjee wrote this book because he could not answer a patient question "What am I battling?" This book brings us up to date: here's what we know, here's what we will do, here's what we didn't know is what will happen and where we will go from there. "We are getting a glimpse of what causes a cell to mutate to cancer but all cancers have their own personalities. Only, the abnormal growth of cells is their bottom line commonality." Mukherjee ties history with personal stories and scientific results.

Myers, M., & Fine, C. (2006). *Touched by suicide, hope and healing after loss*. New York: Gotham.

There are tens of thousands of suicides a year (which indirectly affect another five million Americans). By combining the experiences and perspectives of a leading clinician in the field, psychiatrist Myers, and survivor Fine we get a range of practical advice and guidance to the survivors and to those who work with them.

Nuland, S. (1994). *How we die. Reflections on life's final chapter*. New York: Alfred A. Knopf.

Sherwin Nuland, MD posits that the process of dying in our modern world hides death from view. None of us seems psychologically able to deal with the thought of permanent nothingness. By and large, death is a messy business and pursuing treatment in face of futility is a disservice to the patient and family. When nature has its job to do "The dignity that we seek in dying must be found in the dignity in which we lived our lives." Nuland, clinical professor of surgery at Yale University School of Medicine was a winner of the National Book Award for this book.

Nuland, S. (2010). *The soul of medicine. tales from the bedside*. New York: Kaplan Publishing.

How *do* doctors think? Sherwin Nuland, MD relates first person narratives as told to him by other doctors with the medical facts just as they happened. In this non-fiction book the commentaries he provides demonstrate aspects of medical ethics, technological advances and patient advocacy groups. As a clinical professor of surgery at Yale University School of Medicine and National Book Award winner for [How We Die](#) he is dedicated to the transactional, sacrosanct relationship between doctor and patient and how it which ultimately changes life for both of them. The conversation, the conversation.

*Oxford textbook of palliative medicine*. (2009). In Hanks G., Charny N., Christakis N., Fallon M., Kassa S. and Portenoy R. (Eds.), (4th ed.). 2009: Oxford University Press.

This updated edition joins its predecessor as the definitive, gold standard textbook on palliative care. It is used worldwide by a wide range of professionals involved in the care of terminally ill patients, or chronic, progressive conditions. All of the editors are prominent leaders in their fields.

Payson, R. (2006). *Autopsy: Learning from the dead. A Cleveland clinic guide*. Cleveland, OH: Cleveland Clinic Press.

Autopsies have been around for centuries and despite a recent decline their value is considerable. The principal aim of an autopsy is to determine the cause of death, the state of health of the person before he or she died, and whether any medical diagnosis and treatment before death was appropriate. This valuable illustrated guide provides indispensable information to families who face having to make the to do or not to do decision.

Puchalski, C., & Ferrell, B. (2010). *Making health care whole. Integrating spirituality into patient care*. West

Conshohocken, PA: Templeton Press. Working with people at the edge of life may change the perspective of highly technologically trained health care professionals and cause them to see spiritual path as an integral part of medical care (Rachel Naomi Remen, MD in the book's forward). Patients and family often struggle to find answers to profound questions about what their life has meant. Who am I? How will I be remembered? This Christina Puchalski, MD and Betty Ferrell, RN, PhD comprehensive book defines spirituality as "that which gives meaning and purpose to life..." While *spirituality* is sometimes used synonymously with *religion* is typically equated with organized systems of belief. The book provides the tools for how we can bring the spiritual dimension into the palliative care setting. In addition the work serves as a scholarly review, as well as a practical resource. There is a bibliography, terrific appendices, tables and figures (includes Puchalski's FICA spiritual history tool).

Reese, P., Caplan, C., Kesselheim, A., & Bloom, R. (2006). Creating a medical, ethical, and legal framework for complex living kidney donors. *Clinical Journal of the American Society of Nephrology*, 12, 1148-1153.

doi:10.1021/CJM.02180606

A special feature article by noted experts discusses the ever-increasing waiting times for deceased-donor kidneys. They focus attention on living donations as a useful way to increase the supply of organs for transplant candidates. Many renal transplant centers now routinely accept donors with risk factors for developing future kidney disease, a group of patients that we term "complex living donors." A lack of consensus about what constitutes an important risk factor and insufficient data about long-term outcomes for complex living donors have generated heated debate among transplant professionals over the ethics of allowing donations to proceed. A medical, ethical, and legal framework for protecting complex living donors therefore is important, given the diverse, sometimes conflicting pressures that transplant centers are under to accept living donors. The article is available online at [www.cjasn.org](http://www.cjasn.org)

Reiss, M. (2010). *Lessons in loss and living. Hope and guidance for confronting serious illness and grief*. New York: Hyperion.

"Having a life-threatening illness changes people. In fact, any face-to-face confrontation with possible extinction, whether via a serious illness, a near-miss accident, or a natural disaster is a powerful existential blow." Michele Reiss, PhD (UPMC St. Margaret Family Medicine Residency Program in Pittsburgh) shares some lessons she learned from people who faced illness, loss and grief (families, children, adolescents), sudden unexpected losses, loss of a child, caregiver's challenges. The book offers health care professionals a resource for new information plus a reminder to listen to patients. For clients, it awakens an awareness of "the positives that still exist despite coexisting negatives."

Remen, R. (2006). *Kitchen table wisdom. Stories that heal*. (10th Anniversary ed.). New York: Riverhead Trade.

People with life-threatening illnesses come to cancer physician, and Crohn's Disease survivor, Rachel Remen because they seek meaning in their lives. The simple, powerful stories of real-life cases can help heal despair and loneliness and connect us more deeply to life. Told with clarity and kitchen table style the wisdom that springs from the stories speaks to things we cannot measure and that may turn out to be just those that nourish and enhance our lives.

- Rinpoche, S. (2002). In Gaffney P., Harvey A. (Eds.), *The tibetan book of living and dying* (Revised and Update 2002 by Rigpa Fellowship ed.). New York: HarperOne.  
The world acclaimed bestseller of the ancient text of Tibetan Buddhist teachings, translated by Sogyal Rinpoche, serves as a guide for life and death, as a work of reference and as a source of sacred inspiration. This edition presents the tradition in ways relevant to the needs of modern men and women in the West and East. Rinpoche explores the four continuously interlinked realities (bardos): life, dying and death, after death and rebirth. The book is used in many colleges, and by nurses, doctors and other health care professionals. The Forward is by His Holiness the 14th Dalai Lama.
- Rodgers, A. (2008). *Alzheimer's disease. Unraveling the mystery*. Silver Spring, MD: NIH Publication Number: 08-3782.  
This book explains what Alzheimer's Disease (AD) is, describes the main areas in which researchers are working, and highlights families and friends care for people with AD. In color and with readable font, the topics covered include the basics of the healthy brain, what happens to the brain in AD and a glossary. The book is free. To order phone- 800-433-4380, Email- [adear@nia.nih.org](mailto:adear@nia.nih.org) or visit the Website [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers).
- Russell, J., & Rovere, A. (Eds.). (2009). *American cancer society complete guide to complementary & alternative cancer therapies*. (Second Edition ed.). Atlanta, GA: American Cancer Society/Health Promotion.  
This comprehensive guide provides clarity in the sea of information about complementary and alternative medicine. The goal is to help people decide what treatments are best for them and that is based upon accurate and reliable information so they can move forward with confidence in their decisions.
- Sacks, O. (2010). *The mind's eye*. New York: Alfred A. Knopf.  
The book's theme is vision but the collection of minutely observed case histories, and of his own cancer, is a testimony to the human capacity to find new ways to live and order their worlds. Oliver Sacks has been referred to as "the poet laureate of medicine." He is a practicing neurologist, professor and bestselling author. He is always attuned to the psychological and emotional adjustments patients make. For his reading audience, Sacks deconstructs neurological illnesses and the complex brain function theories in understandable prose. Readers learn about alexia (inability to read), prosopagnosia (failure to recognize faces), aphasia (loss of speech and language) and the science of visual imagery (seeing in one's mind an object as if it were right there, when in fact it is not). Finding himself on the patient side of the desk, Sacks follows the course of his ocular melanoma diagnosis (panic/ anger to being a "cancer victim") in a journal written from 2005 to 2010. Sacks readily admits that he is still working on adapting to his visual challenge.
- Saunders, C., & Clark, D. (2006). *Cicely saunders: Selected writings 1958-2004*. New York: Oxford University Press.  
In forty-four selected papers by the universally acclaimed pioneer of modern hospice care, Cicely Saunders charts the creation of a radical new approach to death and dying—hospice. Written for a multi-disciplinary audience the collection is a key reference for anyone interested in the history and practice of palliative care.
- Skloot, R. (2010). *The immortal life of henrietta laks*. New York: Crown Publishing.  
A quest by Rebecca Skloot to tell the true story about the woman whose cancerous cervical tissue became HeLa in 1951. HeLa is the first line of immortal human cells ever grown that have unstoppable intensity. Many of the most important scientific advances of the past and present would not have been possible without them. However, neither Henrietta nor her family was told about the use of her cells. Not only does this engrossing narrative talk about the struggles Henrietta Lak's family face, it also illuminates the issues involved in the ethics of tissue research. The issues range from consent and privacy to the profits made by product developers that rely on human biological materials. Do you know that all the snippets taken from your body for diagnostic procedures like mole biopsies or appendixes, fat and foreskins skin sit in bio-banks somewhere. "At this point no case law has fully clarified whether you own or have any right to control your tissues. This non-fiction book reads like a novel and was on the best-seller lists for months.

- Thernstrom, M. (2010). *The pain chronicles. Cures, myths, mysteries, prayers, diaries, brain scans, healing and the science of suffering*. New York: Farrar, Straus and Giroux.  
*Dolor dictat*-pain dictates. Pain has been recorded since ancient Mesopotamia and we still cannot fully explain it today. The mind-body debate continues: Are our behaviors due entirely to the action of the brain and nervous system or are they also due in some way the action of something like a mind or soul? Melanie Thernstrom weaves together history, neuroscience, philosophy, literature, her personal pain and investigative reporting to deconstruct this common human experience. Example: Acute pain is "like a well-functioning fire alarm signaling danger; it ends when the fire does," while chronic pain is a "broken alarm that continuously signals only its own brokenness." Current brain medical technology is exploring, and making progress, to understand how the whole brain works.
- Thomson, G. (2008). *I shot a man in reno. A history of death by murder, suicide, fire, flood, drugs, disease and general misadventure, as related in popular song*. New York: Continuum International Publishing Group.  
 Pop music may not be the first genre you think of when you feel the need to have visions of mortality. Graeme Thomson makes the case for popular music as he follows the musical journey from the nineteenth century to 2003 . This is a fascinating book with information you never thought of or thought anyone compiled. It includes a subject list of the *40 Greatest Death Records of All Time*. This book then, "is something to chew on for anybody who has ached to remain alive but who finds themselves drawn to the music made by those who can't help but imagining a time when singing stops for good." Try Dylan, Led Zeppelin, Metallica, U2, the Beatles, Dusty Springfield, Warren Zevon.
- Wanzer, S., & Glenmullen, J. (2007). *To die well. Your right to comfort, calm, and choice in the last days of life*. Philadelphia, PA: Da Capo Press.  
 Leaders in the right-to-die movement, these Harvard University doctors advocate measures that allow patients to control decisions about end-of-life treatment and ensure a peaceful death. Drawing on case histories, they argue that when someone is in uncontrollable pain with no hope of improvement, hastening death through large doses of morphine, refusal of fluids or inhaling helium should be an option. They define a patient's rights, including the right to refuse treatment, and provide information on appointing a health-care proxy.
- Webb, N. B., & Doka, K. F. (2010). *Helping bereaved children, third edition: A handbook for practitioners* (3rd. edition ed.). New York: The Guilford Press. "Grounded in developmental theory, the book provides detailed and phase-specific guidelines for assessing and helping bereaved children in a variety of contexts. Perhaps the most compelling characteristic of the book is the use of thorough case presentations that illustrate interventions such as sand play, art therapy, storytelling, role play, and puppetry, in individual, family, and group modalities. Webb concludes the volume with a much-needed section on self-care for those who engage in this rewarding and demanding work." It includes 11 reproducible assessment tools and handouts that can also be downloaded and printed from Guilford's website. Once again a Kenneth Doka, PhD Forward adds gravitas to the book.
- Weiner, W. (2010). *Long for this world. The strange science of immortality*. New York: HarperCollins.  
 The longevity quest from Gilgamesh and Descartes to Ponce de Leon has been hotly debated in religious and intellectual traditions over the centuries. It continues right down to Benjamin Button. The 2009 Pulitzer Prize science writer Jonathan Weiner's thought-provoking exploration of the "can", "when" and "what then" of scientific conquering of mortality is engagingly deconstructed. Weiner reports on the ideas of those who believe aging is a curable disease and those who say "no way." And then there is the questions raised by molecular biologist Jasher Lederberg (among others) who poses the question 'how much immortality do we want?' Or when is enough, enough already?
- When illness turns families into caregivers*. (2004). In Levine C. (Ed.), (2nd ed.). Nashville, TN: Vanderbilt University Press.  
 Powerful narrative experiences of caregiving spouses and children are translated into useful advice for anyone who ever is or will be a family caregiver. A former caregiver and current health care advocate, Carol Levine, authority on the topic and the other authors cover the essential dimensions of this rewarding, but isolating, challenging and stressful role. Policy and advocacy suggestions enrich the health-care debate.

Yalom, I. (2008). *Staring at the sun. Overcoming the terror of death*. San Francisco, CA: Jossey-Bass.

Our confrontation with death and the fear of death are at the heart of much of our anxiety posits Irwin D. Yalom, MD. Yalom, therapist, professor of Psychiatry and storyteller extraordinaire, draws on his own and his patients' lives, philosophers, writers, artists, lay people and therapists to explain his thesis. He conveys "the necessity and the feasibility of confronting and exploring all fears, even the darkest ones." Chapter 7 is directed at therapists and a Reader's Guide asks probing questions.

Zeisel, J. (2009). *I'm still here*. New York: Penguin Group.

John Zeisel, PhD, an innovator in the treatment of Alzheimer Disease with non-pharmacological approaches, advocates for building upon the uncompromised parts of the brain.

## **PERSONAL REFLECTIONS: MEMOIRS**

Albom, M. (1997). *Tuesdays with morrie. an old man, a young man, life's great lesson*. New York: Random House.

Morrie Schwartz (Albom's college professor and mentor) faces death from ALS (Lou Gehrig's Disease). Albom begins weekly visits that continue through his professor's final days. There is much to learn from Morrie's travels from diagnosis to serene death because the issues resonate so in each of us. Available in audio and DVD (a movie with Jack Lemon) formats.

Armstrong, L., & Jenkins, S. (2002). *It's not about the bike. my journey back to life*. New York: Berkley Books.

He's a world champion cycling to the top of his form when in September 1996 Lance Armstrong is diagnosed with third stage metastatic testicular cancer. There are 7,000 cases of this cancer a year in the U.S. and he was a statistic at age 25. Armstrong undergoes numerous surgeries, chemo and emerges as a survivor who asks "how do you slip back into the ordinary world?" He does return to competitive cycling in 1998 taking us breathlessly along through his struggles, pain and triumphs. "Every year that I get back on the bike and try to win another Tour de France is another year that I've survived the illness."

Atwell, D. (2009). *Somewhere towards the end*. New York: W.W. Norton & Company.

At 89, Diana Atwell decided to have a go at writing about the "inevitable end" and the experience of living during one's last years. She recounts with regret the many losses but celebrates those that have taught her to regret very little...events, lovers and friendships. It is the sobering reality of *times winged chariot hurrying near* that focuses her on the importance of trying to conduct her life "properly." Recently on October 10, 2010, Atwell wrote in *The New York Times* that she relocated to what she calls "an old person's home." "You gradually become aware of how liberating it is," Ms. Atwell said. "Not a single domestic worry do I have." Atwell, at 91, still tells it like it is.

Barnes, J. (2009). *Nothing to be frightened of*. New York: Alfred A. Knoff.

How does one deal with the basic fact of human mortality? Through humor and serious inquiry author Julian Barnes writes this elegant contemplation on death. He intersperses his own memories with those of writers, composers, theologians, scientists and businessmen to keep the debate open and vigorous. An atheist at twenty, an agnostic at sixty, Barnes' opening line is "I don't believe in God but I miss him." When asked by a friend how often he thinks about death, he replies "at least once each waking day, and then there are the intermittent nocturnal attacks." If he were to receive a death-warning diagnosis Barnes wonders "whether in the light of late-arriving information, this book needs an afterword." (By the way, he hasn't written one as yet).

Brinkler, N., & Rodgers, J. (2010). *Promise me. How a sister's love launched the global movement to end breast cancer*. New York: Crown Archtype.

Susan and Nancy were sisters. Susan was diagnosed with breast cancer in 1977. The chemotherapy was grueling and the disease was aggressive. Before Susan died, in 1980, she told Nancy that breast cancer has to be talked about, there must be research. It has to change. Promise me it will be better." Nancy kept the promise and Susan G. Komen for the Cure was born. Nancy was diagnosed with breast cancer in 1984 but she is well. She went on to make SGK into the most influential health charity in the world. What began with \$200 and a list of friends has to date contributed more than \$1.5 billion for research and community programs. This book is the journey of Nancy's promise to her sister Susan.

- Broyard, A., & Forward by Sacks, O. (1992). In Compiled and edited by Broyard, Alexandra. (Ed.), *Intoxicated by my illness and other writings on life and death*. New York: Fawcette Columbine.
- In 1989, sixty-nine year old Anatole Broyard was diagnosed with metastatic prostate cancer. He died fourteen months later. Essayist, reviewer and an editor of the *New York Times Book Review*, writing and books had always been a part of his life. He wrote to the end despite great pain. When cancer entered his life, Broyard realized for the first time that "I don't live forever." He knew that "every seriously ill person needs to develop a style for his illness." For him "...Storytelling seems to be a natural reaction to illness" ...Stories are antibodies against illness and pain." Through six beautiful essays, meditations on mortality, Broyard approaches the conditional nature of the human condition. The essays range from *The Patient Examines the Doctor* to *What the Cystoscope Said* (the bladder cancer that killed his father).
- Castaldo, J., & Levitt, L. (2010). *Uncommon wisdom. True tales of what our lives as doctors have taught us about love, faith, and healing*. New York: Rodale Books.
- It's all there - the ER, the calling "code," personal struggles, medical crises, high school sports. John Castaldo and Lawrence Levitt are practicing neurologists at Lehigh Valley Hospital in Allentown, PA. Their book puts the human side of medicine on view and spotlights the crucial doctor-patient relationship. In the sixteen fast-paced, riveting narrative medicine stories, the physicians take the reader through the steps of diagnosis, treatment plan, judgment calls, sorrows, courage and humility. They teach by example that even experienced doctors can miss the clues and patients should not always bow to medical "wisdom." The book should be required reading for medical students, healthcare providers of all stripes and those of us who are "the consumers" of healthcare.
- Clift, E. (2008). *Two weeks of life. A memoir of love, death ad politics*. New York: Basic Books.
- While her journalist husband Tom spent his last two weeks of life with home hospice, Terri Schiavo was dying with the nation watching her enter her final days. Same ending—very different experiences. Eleanor Clift writes about dying in America and the choices we make. Tom Clift wrote about his kidney cancer.
- Cohen, R. (2004). *Blindsided. Lifting a life above illness: A reluctant memoir*. New York: HarperCollins.
- Cancer and MS are not buddies" writes Richard Cohen, but by age 51 he had both. Diagnosed with multiple sclerosis at twenty-four he gradually lost strength in his legs and then vision in one eye (is now legally blind). A well known news journalist and television producer for CBS News and CNN, Cohen initially hid the illness from everyone (except the family) and fought fear, self-doubt and anger. Cohen writes "that serious sickness was a large sandwich for a skinny young man to swallow." Brutally honest writing includes how his illness affects his wife and three children and how he struggles to move beyond the guilt that his children must live with his problems. Coping for him is a work in progress. "Is forever an aspiration." The Cohen family has been identified with MS for three generations. In 2011 he will be 63.
- Cohen, R. (2008). *Strong at the broken places. Voices of illness, a chorus of hope*. New York: HarperCollins.
- And then there were five and Richard Cohen made six. They all came together as the voices of people who live on the front lines of a serious chronic illness. Cohen has multiple sclerosis; Denise has Crohn's disease; Larry has manic-depression (bipolar) disease; Denise has ALS; Buzz has non-Hodgkin's lymphoma; Ben has muscular dystrophy. Individual illnesses wreck havoc in different ways but they all "travel the same highway." The six met together with Harvard Medical students who needed to hear their future patient's voices and to understand that their mission is to treat whole people, not simply their disease. Ninety million Americans confront chronic illness every day. Read the stories of how these five taught the doctors-to-be, and Cohen, how to cope as they try to live a normal life. Contribute your story at [www.strongatbrokenplaces.com](http://www.strongatbrokenplaces.com)
- de Beauvoir, S. (1973). *A very easy death*. [Un mort tres douce.] (P. O'Brian Trans.). New York: Warner Paperback Library Edition.
- Daughter Simone de Beauvoir recounts the drama of her mother's cancer in a Paris nursing home in October 1963. We get a 1960's view of end-of-life pain and suffering before the days of palliative care and it is a raw account but reading Beauvoir where every word is important is an awakening. Beauvoir writes, its a "hard time dying when one loves life so much" her mother says yet continues to rebel against death even as a "skeleton clothed in damp blue skin." "There is no such thing as a natural death: nothing that happens to a man is ever natural, since his presence calls the word into question." Death is not easy.

DeBaggio, T. (2003). *Losing my mind: An intimate look at life with alzheimer's*. New York: Free Press.

In 1999, when he was 57 years old, Thomas DeBaggio was diagnosed with early-onset Alzheimer's disease. Shortly thereafter, he began this moving memoir. Herbalist and writer DeBaggio eloquently describes the terror evoked by the label "Alzheimer's disease." His book joins works of fiction, nonfiction and alleged nonfiction that portray their authors' struggles with the demon of dementia. "I must now wait for the silence to engulf me and take me to the place where there is no memory left and there remains no reflexive will to live. It is lonely here waiting for memory to stop and I am afraid and tired. Hug me, Joyce, and then let me sleep." Thomas DeBaggio died on February 21, 2011.

Didion, J. (2005). *The year of magical thinking*. New York: Alfred A. Knopf.

"Life changes fast. Life changes in the instant." In the middle of a conversation that Joan Didion and her husband of forty years were having, John Donne suffered a fatal coronary. Both of them had just returned from the hospital where their daughter was in a coma. (Quintana died four months later at age 30). Didion writes how painfully difficult it was to make sense of it all and keep on living and writing. "I know why we try to keep the dead alive: we try to keep them alive in order to keep them with us." The book is an intimate portrait of grief and memories. It won a National Book Award and was made into a play monologue starring Vanessa Redgrave. Didon latest book [Blue Nights](#), a memoir on aging, is due out in 2011.

Forman, V. (2009). *This lovely live. A memoir of premature motherhood*. New York: Houghton Mifflin Harcourt.

The start - "I learned about grief during this time." This is not a depressing book. Rather it is a book full of love, strength, vulnerability, honest feelings and struggle. On July 30, 2000 Vicki Forman gave birth to twins, Ellie and Evan, after twenty-three weeks of gestation. Each baby weighed one pound three ounces. Her request for a DNR was denied. Ellie lived four days and took two hours to die in her parents' arms. Evan survived in a variety of NICUs for six months where he underwent numerous medical interventions for his multiple disabilities - blindness, mental retardation, seizure disorder, congenital heart conditions. After six months Evan came home to his parents and four year old sister Josie. Evan learned to walk, respond and eat without a G-tube but with numerous medications and rushes to the hospital. Evan died of an acute intestinal blockage just six days shy of his eight birthday. Forman learned that there is a difference between living, existing and surviving and there are many responses to the dilemmas and challenges involved. Evan's-and-Ellie's "lives began too soon, and ended too quickly. But even a short life is a whole life: this I have learned." A book that will help bioethicists and neonatologists become better at what they do.

Jamison, K. (1995). *The unquiet mind. A memoir of moods and madness*. New York: Vintage Books.

Manic-depressive illness is a genetic disease that kills tens of thousands of young people every year. Kay Redfield Jamison, MD, writes how being manic-depressive affects her professional and personal lives. She has written a scientifically accurate, poetic, riveting book that will help others understand the disease (also called Bipolar Disorder) and ultimately save lives. Jamison is a healer and the healed. See also her new book [Nothing Was the Same](#).

Jamison, K. (2009). *Nothing was the same. A memoir*. New York: Alfred A. Knopf.

"When it came down to it, Richard and I simply enjoyed being together." They were for nearly twenty-years of marriage until Richard died. By writing this book, Kay Redfield Jamison was able to transform her continuing love and build upon a grief that taught her so much. Jamison is a Professor of Psychiatry at Johns Hopkins School of Medicine, an author (see [An Unquiet Mind](#)) and an expert on manic-depression, (bipolar disorder). She herself is a patient. Richard Wyatt was a renowned expert on schizophrenia. "He brought science, as well as humor, and love to bear on my problem with mood." Gradually after his death *la vie recommence* - life starts again. Grief taught what Ecclesiastes wrote "all die." Jamison will have to handle her illness without Richard.

Judt, T. (2010). *Night*. *New York Review of Books*, 57(1)

Tony Judt, born in 1948, died at age 62. *Night* was written on January 14, 2010 and he died on August 6, 2010. Judt had amyotrophic lateral sclerosis, ALS, Lou Gehrig's disease, which was diagnosed 16 months before his death. "A.L.S. constitutes progressive imprisonment without parole," Judt writes. Effectively a quadriplegic, he could not scratch an itch, adjust his spectacles or do all the dozens of things one does during a day. He was in no pain and his head was clear "a blessing-curse that left him acutely conscious of how his dwindling supply of days was destined to be spent." Nights are the worst so Judt tries to find solace in his own thoughts, fantasies, memories but it is "a lonely journey..." Judt has left us a memorable reflection of life with loss even though "loss is loss, and nothing is gained by calling it by a nicer name." Judt is considered a giant in the intellectual world, the founder and director of the Remarque Institute at NYU and the author of many books and essays.

Krementz, J. (1980). *How it feels to fight for your life*. Boston, MA: Little, Brown and Company.

Fourteen children ranging in age from seven to sixteen candidly talk about their medical issues, personal conflicts, struggles for independence and for their futures. The serious illnesses include cancer, epilepsy, spina bifida, diabetes, cystic fibrosis, kidney transplants, paralysis and burns. While the treatment regimes have changed since 1980, the emotions speak to us in the 21st century. The Kremmentz photographs bring the situations right onto the pages. Stewart Ugelow, burn patient (age 12:) "My life is a fight - against my fears and my future... For all I know, the scars will be for an eternity. But I feel that if I know somebody really well and they know me, my scars shouldn't be a barrier."

Kugel, J. (2011). *In the valley of the shadow: On the foundations of religious belief*. New York: Free Press.

At the age of 54, Harvard professor and Hebrew Bible scholar, James Kugel was told that he had cancer and had only a few years to live. Seven years later, with his cancer in remission, he began this book to explore how his encounter with death moved him to "the state of mind in which you intuit something on the order of God" i.e. what impressions, hints of God might feel like. As always, Kugel writes brilliantly, clearly and makes you think thorough the small universe right in front of "our own noses."

Laitmon, E., & Toll, T. (1961). *Our children, our hearts*. Tuckahoe, NY: Bereavement Center of Westchester.

Giving words to devastating sorrow was the inspiration for this book. It focuses on twenty-five children from the tender age of 28 days to forty-one years who died. Their parents and siblings find some comfort by writing about their beloveds. Coping with the untimely death of a child is "a process, an end, a beginning and above all, a lifelong journey of change." The stories are almost too much to read but only then you can appreciate the almost unbearable sorrow of the families.

Lewis, C. L. (1961). *A grief observed*. (1994th ed.). New York: Harper One.

Shattered with grief after the tragic death of his beloved wife Joy drives C. S. Lewis, the influential Christian writer and one of the intellectual giants of our times, to painfully asks "why?" "She is with God" was not consoling and mourning for his wife and become "like God, incomprehensible and unimaginable." Lewis becomes aware "of being an embarrassment to everyone I meet." People are uncomfortable with the reality of grief and death. As Lewis struggles to come to grips with life, death, faith and anguish he "gradually been coming to feel that the door [to God] is no longer shut and bolted." "Praise is due order; of Him as the giver, of her, as the gift." "Poi si tornò all'eterna Fontana. Then to Eternal Light she (Beatrice) turned once more." (Dante, *Paradiso*, XXXI, 93). If we could call the dead back, Lewis feels that Joy would say to the chaplain "I am at peace with God."

Lynch, T. (2009). *The undertaking. Life studies from the dismal trade*. New York: W.W. Norton & Company.

Funerals, after all, are for the living. The dead, Lynch reminds us, don't care. Poet, essayist, National Book Award Finalist, family funeral director in a small Michigan town, Thomas Lynch transforms the job of preparing the dead into a beautiful, comforting, life-affirming book through a combination of prose and poetry. The Lynch family believes that the rituals of a funeral are more than mere formalities, they are an undertaking. "To undertake is to bind oneself to the performance of a task, to pledge or promise to get it done." "A good funeral gets the dead where they need to go and the living where they need to be." "While the dead don't care, the dead matter. They matter to the living. Equally moving is the *Frontline* documentary based on the book at <http://www.pbs.org/wgbh/pages/frontline/undertaking/>

Mount, B. (1983). *Sightings in the valley of the shadow*. Downers Grove, IL: InterVarsity Press.

The author, Balfour Mount, MD, leader of Canada's work with terminal patients and founder of McGill Palliative Care Service in Montreal responds to his mother's tearful, urgent question "How do you prepare to die, Bal? How do you?" Mother was dying of bowel cancer. In response Mount wrote "On Learning to Trust," the first piece in this book. The following writings of the weeks that follow, although from a Christian perspective, speak to anyone of any tradition who is standing in the valley of death and is submerged in impending loss and grief. "Final. Final as her name cut in cold stone a granite slab lying in the grass, wet, stained, bearing her name. *Her name!*"

Oates, C. (January 2010, A widow's story. *The New Yorker*, (December 13, 2010), 70-79.

At 12:38 A.M. on February 15, 2008 she was a wife. At 1:21 she is a widow. Joyce Carol Oates, wife of Raymond Smith, Professor of the Humanities at Princeton University, and prolific author of short stories and novels, writes a personal history of the last week of a long marriage. Filled with grief and shock it is gripping, realistic writing. Her latest book *A Widow's Story: A Memoir* (2011) was first excerpted in *The New Yorker*.

Piper, D., & with Murphey, D. (2004). *90 minutes in heaven. A true story of death & life*. Grand Rapids, MI: Revell.

At age 38, husband, father of three, eminent Texas ordained minister Don Piper's car was crushed by a large truck. EMS personnel declared him dead. Ninety minutes after the wreck, while a minister friend who happened by prayed for him. Piper returned to life. He later recounts that during those minutes he was in heaven. Through months, years and 34 surgeries, often depressed and angry, Don Piper never doubted that God was with him. Whatever your beliefs this story of faith, serious injuries, pain and grueling, still ongoing recovery, is a riveting read. There have been 41 editions since 2004, on bestseller lists for years, and it is available in a childrens' edition, audio format and as a Kindle download.

Redgrave, L., & Clark, A. (Photographer). Introduction by Lerner, B. (2004). *Journal. A mother and daughter's recovery from breast cancer*. (Third printing ed.). New York: Editions.

Together with her daughter Annabel Clark (a photography student), acclaimed actress Lynn Redgrave create a compelling, heart-struggling, honest 2003 journey through Redgrave's breast cancer diagnosis, surgery, chemotherapy and radiation. Dr. Lerner provides information about the disease that complements the photos and Lynn Redgrave's journal entries. This beautiful book remains as a testimony to the strength of a mother-daughter relationship and the determination and commitment to recovery and life. It has much to offer patients, survivors and all women, their family and friends.

*Reflections on a life with diabetes. A memoir in many voices*. (2004). In Parker D., Mark R. (Eds.). College Station, TX: Virtualbookworm.com Publishing Inc.

At present, one in 10 Americans has diabetes. It affects both children and adults. This chronic, incurable and often debilitating illness costs the health care system \$174 billion a year. This book's stories tell the personal cost of diabetes. The tales are from friends, partners and family, young and old. They relate the ups and downs, coping, weight, nutrition. There are the calls to 911, the prick, the tests, pills, paper strips, injections and pumps. There is the courage to find meaning in life, the fears and for some "diabetes has been a wonderful teacher." Enlightening reading for the newly diagnosed, the long-term diabetic, for family, friends, professionals and the inquiring-minded uninformed.

Rieff, D. (2008). *Swimming in a sea of death. A son's memoir*. New York: Simon and Schuster.

This is dying and death in there here and now. David Rieff is by his mother's, Susan Sontag, side when she confronts the first cancer diagnosis in 1975 and through to her final days and death at seventy-one in 2004. Always the rigorous researcher, we get a glimpse into Sontag's thinking as she applies her fighting mantra "more is always better" to herself. *She will* survival against the odds. Rieff is with her as they seek out and try protocols and as she refuses to give up. Her son shares her suffering, anger and wrenching pain but adds to the list his own guilt because he could not do more to save her from dying. Like his mother Rieff is a marvelous writer.

Roiphe, A. (2008). *Epilogue: A memoir*. New York: Harper.

Not quite seventy, nearly 40 years of marriage and Anne Roiphe suddenly finds herself a widow living alone in

her NYC Upper West Side apartment. Brutally honest, unabashedly lonely and sad she moves between memories of H. (husband) and her pre-widowhood life and her current activities of everyday living. Thinking she needs male companionship she signs up on match.com and meets an alphabet soup of prospectives...L.D; P.J; M; DR.B; V; K; A; C. Roiphe's beautiful written book allows us to enter into her thoughts, loss, grief and eventually return to life. Like the owl who went to sea with the pussycat "she must dance by herself by the light of the moon."

Rosenblatt, R. (2010). *Making toast*. New York: Ecco - Imprint of HarperCollins Publisher.

When Elizabeth Rosenblatt Solomon, daughter, wife, mother of three young children, pediatrician, collapsed and died at age 38, her father Roger Rosenblatt could only say "It's impossible. It can't be." But, it was possible and it did happen. Expanding upon his New Yorker December 2008 article, Rosenblatt poignantly and realistically writes about his and his wife's attempts to fill the roles of grandparents, alongside Amy's husband. They become chauffeurs, playmates, tear dryers, listeners, homework helpers and, of course, make the toast for breakfast. Rosenblatt finds that he must train himself to deal with life as it is and to "value the passing of time."

Sanford, M. (2006). *Waking. A memoir of trauma and transcendence*. New York: Rodale.

The family car skidded on a snowy Iowa day. The accident killed the father and daughter, but Matt Stanford, age 13, survived with a spinal cord injury. He was paralyzed from the chest down and would be confined to a wheelchair for life. Sanford writes that what he has "actually lost was in my experience of myself is an inward connection to my body." From medical rehabilitation and subsequent surgeries, he searched for an alternative healing path. Sanford began to rebuild his mind-body integration through yoga and mindfulness. What he now knows "is that presence within the body can be approached from many directions." (In many languages, mind and heart are the same word). Sanford teaches yoga, specializing in adapting it for people living with disabilities. He spoke with Krista Tippett on NPRs Being (5/27/11) in a segment entitled "The Body's Grace." There he shared his insights on knowing the strength and grace of our bodies even in the face of illness, aging and death. <http://being.publicradio.org>

Schimmel, R., & with Eisenstock, A. (2008). *Cancer on \$5 a day (chemo not included). How humor got me through the toughest journey of my life*. Philadelphia, PA: Da Capo Press.

"So I'm sitting in a chair in my room at the Mayo Clinic waiting for the results." So we are introduced to Robert (Bob) Schimmel (Comedy Central comic) born January 16, 1950 as he enters into the world of stage III non-Hodgkin's lymphoma. All through the book we feel both his humor and his pain. Sometimes the book is funny, sometimes threatening but it is always honest about life as he sees it. It's not a book for everyone, but if you are up to it, it is compelling reading and behind the laughter lies a serious meaning. Schimmel died from injuries in a car accident on September 3, 2010.

Strauss, D. (2010). *Half a life*. San Francisco, CA: McSweeney's.

Darin Strauss, 18 years old, a senior at North Shore High School on Long Island, NY, was driving his car in May, 1988 when Celine Zilke, 16, was riding her bicycle. Celine swerved, was hit by the car and died. Dan Strauss opens the book with "Half my life ago, I killed a girl." Strauss is haunted by the death even though it was not his fault. "My accident was the deepest part of my life, and the second deepest was hiding it." In 2009, then a father of two sons, he decided to write this book and make it his bereavement therapy. He had to come to terms with his grief. This is a simply said, memorable book that asks a powerful question.... how does each of us deal with the hand we are dealt?

Whitehead, J. (2008). *A heart too good to die. A shocking story of sudden cardiac arrest*. Bangor, Maine: Booklocker.com, Inc.  
Newly married, Carolyn (47) and Jeremy emigrated from Australia to Boston in 2002. Six weeks later Carolyn has cardiac arrest at an IBM meeting in Dallas. Half a million people die each year of cardiac arrest. Carolyn is a lucky one. Although she will always be at risk for arrhythmia her Implantable Cardioverter Defibrillator has made it possible for her to reclaim her chance of life. Jeremy Whitehead tells the story as seen from the eyes of a spouse/caregiver. He describes the fear, the uncertainty, the need to understand the medical words and their implications. In the ICU Jeremy feels "like a stranger in a foreign land." The book is a short course on sudden cardiac arrest. It includes a glossary of medical terms and procedures, the importance of CPR and access to an automated external defibrillator. It is a gripping read for patients, friends, family professionals and the uninformed.

Williams, M., & Grobel, L. (2004). *Climbing higher*. New York: New American Library.  
Why me? How did I get this disease? Montel Williams, popular talk show host, after almost twenty years of symptoms, hears the words "you have MS." You know, the disease that Jerry Lewis was always raising money to defeat. Multiple sclerosis is a chronic, unpredictable, prime of life - 20-40 - disease of the central nervous system (the brain, optic nerves and spinal cord). Williams learned, went through periods of helplessness, anger, confusion and depression and then decided to pass on what he had learned. Today he is a dedicated spokesperson, advocate, fundraiser and guinea pig for MS research to find a cure and a treatment. In this memoir we travel the road with him. The book's Appendix asks ten doctors some questions. The diversity of their answers highlights what we don't know and why there is much more research to do. The Williams MS Foundation is at [www.montelms.org](http://www.montelms.org). Also active is the Nancy Davis Foundation Race to Erase MS at <http://erasems.org/>

## LITERATURE AND THE ARTS

Agee, J. (2008). *A death in the family*. New York: Penguin Books.  
First published in the United States in 1957, this iconic Pulitzer Prize autobiographical novel movingly depicts a family's loss and grief following the accidental death of the father at age 36. The story unfolds through the eyes of the six-year old son, Rufus. A classic to be read and reread.

Anka, P. (1969). *My way* [Comme d'habitude].  
Paul Anka wrote the English lyrics for "My Way" [Comme d'habitude] which is based on a French song composed by Francois and Revaux,. Frank Sinatra popularized it on his 1969 album of the same name. The lyrics recount one man's reflections on his past life now that "the end is near and so I face the final curtain..." He has few regrets because "And yes, I did it my way." A popular funeral musical and eulogy option, the song is available in multiple formats. You can listen to and view the Sinatra/Pavarotti duet on YouTube.

Arena, P., & Manuali, T. (2010). *Reflections of the breast. breast cancer in art through the centuries*. New York: Brick Tower Press.  
An art historian (Manuali) who is interested in the social meaning behind art and an oncologist (Arena) whose interest is breast cancer, come together to tell the history of the disease. The medical story is interwoven with images of artists such as Michelangelo, Rubens, Raphael, Eakins and the modern day artists (Currie Matuschka, Metzger). The journey begins in 1500 BC at the Temple of Imanhotep outside of Luxor, Egypt.

Ariyoshi, S. (1984). *The twilight years*. [Kkokotsu no Hito] (M. Tahara Trans.). Tokyo, Japan: Kodansha International.  
Some stories are timeless and caregiving is one of them. The cultural expectations and experience may be different but the feelings resonant. Faced with the care of his aged senile father, Shigezo delegates all the work to his wife Akiko. This is a timeless book with the universal theme of a woman caught between traditions, expectations, and personal realities.

*The art of losing. poems of grief and healing.* (2010). In Kevin Y. (Ed.), . New York: Bloomsbury Press.

"Poets may not run the world, but they are a special species who come closer to life's existential issues to enjoy beauty and salute life's fleeting moments" (Renee Leopold). In Kevin Young's latest anthology the prolific and acclaimed poet has gathered 150 poems about suffering and overcoming loss. Organized around the subjects Regret, Remembrance, Ritual, Recovery and Redemption, it includes poets both canonical and contemporary, with a larger selections of the latter. There are poems as diverse as the emotions of loss. While poetry cannot offer easy answers to grief, poetry can convincingly say, as Young does in *Burial [No Woman No Cry]*, "We held each other a long time/after and could not speak,/like you. Get up,/Stand up, we'll sing."

Polley, S. (Producer), & . (1999). *Away from her.* [Video/DVD] Santa Monica, CA: Lionsgate.

Fiona (Julie Christie) and Grant (Gordon Pinsett) are forced to face the reality that Fiona's forgetfulness is beyond normal slips of mind. Alzheimer's Disease has taken her over. We watch as Fiona decides to live out her life in a nursing home and how that decision affects both her and her husband. Olympia Dukakis's performance adds another riveting dimension. We are left with a wrenching but very memorable portrait of a marriage, an illness and an abiding love.

Bauby, J. (2007). *Diving bell and the butterfly.* [Le Scaphandre et le (Papillon)] (T. Leggatt Trans.). New York: Vintage International.

Imagine being "Paralyzed from head to toe, the patient, his mind intact, is imprisoned inside his own body, unable to speak or move. In my care, blinking my left eyelid is my only means of communication." So wrote Jean-Dominique Bauby after surviving a massive stroke at age 43. "You survive, but you survive with what is so aptly known as "locked-in syndrome." This former editor-in-chief of French Elle, husband and father of two, how overcomes mind-boggling obstacles to write this memoir. Working with a dedicated specialist he responds with a left eye blink to a special alphabet recited which is then recorded. The writing is trans-formative for Bauby transport us from our world to his inside his diving bell. A book you will not easily forget and will want others to read. it is available in DVD format. Bauby died in 1997 a few weeks before the book was published. Oliver Sacks, MD wrote "A book of surpassing beauty, a testament to the freedom and vitality and delight of the human mind."

Brabner, J., Pekar, H., & Stack, F. i. (1994). *Our cancer year.* Philadelphia, PA: Running Press.

Harvey Pekar was a legend in the comic book series world. In this first book-length graphic autobiography Pekar finds himself with lymphatic cancer. The Pekar/Brabner team tells the story of how he fought cancer and at the same time continue their involvement with the background events of that year-Cambodia, Middle East, Operation Desert Storm. Pekar died on July 2, 2010 at age 70. Pekar won the 1987 American Book Award for his autobiography comic book series American Splendor which was made into a movie. Our Cancer Year won the 1995 award for the best original graphic novel.

Caxton, W., & Seuse, H. (2010). In Comper F. (Ed.), *The book of the craft of dying, and other early english tracts concerning death (1917).* (Kessinger Publishing's Legacy Reprints ed.) Breingsville, PA.

Rescued from the shelves of the British Museum and Bodleian Libraries, The Craft of Dying, is a translation of the popular medieval work De Ars Moriendi, or the art of dying.. This work expresses the Middle Ages societal and ecclesiastical response to the grim reality of the plague. Over 100 editions were printed throughout Europe. Since death is inevitable, the Catholic Church suggested advice on procedures, protocols and prayers for dying. By the fifteen century there was even an illustrated version for the illiterate.

Cotterill, C. (2004). *The coroner's lunch.* New York: Soho Press.

Dr. Siri Paiboun, one of the last doctors left in Laos after the Communist takeover, is drafted as a coroner in 1976. This fiction mystery story provides a fascinating portrait of the Laos Hmong population and their spiritual practices and beliefs. This is the group that fought on the side of the Americans and after the war came to the U.S. and is the subject of Anne Fadiman's non-fiction account The Spirit Catches You and You Fall Down by Anne Fadiman.

- Dante, A. (1995). In Musa M. (Ed.), *The portable dante*. [La divina commedia] (M. Musa Trans.). New York: Penguin. In this lyrical translation by Mark Musa we experience Dante Alighieri's masterpiece The Divina Commedia/The Divine Comedy that is considered one of the greatest works of world literature in all its glory. Completed in 1314 allegory continues to intrigue, challenge and inspire readers today as much as it has over the centuries. A vision of the afterlife in the soul's journey toward God, Dante travels through Hell (*Inferno*), Purgatory (*Purgatorio*) with the Roman poet Virgil and through Heaven (*Paradiso*) guided by Beatrice, the ideal woman. Poetry, philosophy, politics combine as "in a flash of understanding, which he cannot express, Dante finally understands the mystery of Christ's divinity and humanity, and his soul becomes aligned with God's love" (Wikipedia).
- Dark, A. (1997). In the gloaming. In J. Updike (Ed.), *Best short stories of the century*. ( pp. 688-714). New York: Houghton Mifflin Harcourt. Throughout this quiet, beautiful compassionate short story by Alice Elliot Dark, a mother and her son share their favorite time of day knowing that for him the dark has already come. The son is dying of AIDS. The mother movingly cares for him as he dies.
- De Pascale, E. (2007). *Death and resurrection in art*. [Morte e resurrezione.] (A. Shugaar Trans.). Los Angeles, CA: Getty Publications. The theme of death is one of the oldest and most common in the history of art dating back to hunting scenes painted on the cave walls during the Paleolithic era. Experience wonderful, often sublime, sometimes surprising art along with the insights of individual brief introductory text, information about the artist, title, date, present location and subtitle details. Taken together these make for an aesthetic and informative encounter with which to supplement any discussion of death, grief and the afterlife or to just immerse yourself in art.
- Dickens, C. (2004). In Hearn M. (Ed.), *The annotated christmas carol: A Christmas carol in prose*. New York: W.W. Norton & Company. Read primarily during the Christmas season, A Christmas Carol is really one for all seasons. We meet the now famous, miserly curmudgeon Scrooge who hates goodwill, charity, puppies, kittens, employees and everything except money. As Scrooge is transported through time (past, present and future) it is the Ghost of Christmas Yet to Come that really shakes him. The quintessential skinflint comes face to face with his own death. He becomes aware of mortality and, well you know the rest. Death reminds us that existence cannot be postponed and there is still time for life. The wonderful Michael Patrick Hearn annotated edition is authoritative and entertaining. If you want a more popular edition try one of the teams of others available in print, film, DVD, theater, audio and probably other formats.
- Dove, R. (1986). *Thomas and beulah*. Pittsburgh, PA: Carnegie-Mellon University Press. In these poems, former U.S. Poet Laureate Rita Dove tells the story of a married black couple as seen from their two perspectives. The first, "Mandolin," consists of 23 poems giving Thomas's side, and "Canary in Bloom" gives Beulah's in 21 poems. Dove won a Pulitzer Prize for this beautiful book that paints portraits of beginnings and endings, of life and death. Beauty, moving and wonderful to read.
- Eagleman, D. (2009). *Sum. Forty tales from the afterlives*. New York: Vintage Books. We recognize that we are going to die some day. But what then? Neuroscientist, David Eagleman, PhD acknowledges our shared mortality by offering up forty brief vignettes on possible afterlives (or are they really comments on our daily lives and the human condition?) This "stunningly original" "dazzling", "gem of a book", is at times funny, at times provocative, at times unsettling, at times humbling but never dismissible.
- Edson, M. (1999). *Wit*. New York: Farber and Farber. Recently diagnosed with late-stage ovarian cancer, Vivian Bearing, PhD finds that the hospital doctors treat her body as a text. Hailed as one of the great plays of the decade, Wit is used to teach medical students about empathy and compassion at the end-of-life. It is a play you will not forget whether you see it, read it, hear it. See The Runaway Bunny.

Everyman. (1485). In *Everyman and other miracle & morality plays* (1995th ed., pp. 36-59). Mineola, NY: Dover Thrift Editions.

Guild craftsmen or professional actors, hired by towns and villages for the occasion, performed medieval miracle and morality plays that are rooted in the liturgy of the early Western Church. "Everyman" is an allegorical drama featuring *Helps*: Good-Deeds, Mercy, Perseverance, Fellowship, Beauty, Knowledge, Strength, Discretion and *Hindrances*: Goods, Vice that one encounters on the road to salvation. The main character Everyman is summoned by Death and must face final judgment on the strength of his good deeds.

Franzen, J. (2002). My father's brain. In *How to be alone essays*. (pp. 7-38). New York: Farrar, Straus and Giroux. Jonathan Franzen writes about his father Earl and his slide into Alzheimer's and the medical research on the disease. How do we remember and how do we forget? When first told about Earl's condition, Franzen pays little attention. Then "I can see my reluctance to apply the term "Alzheimer's" to my father as a way of protecting Earl Franzen from the generality of a nameable condition." We meet the entire family including his mother and his two brothers as they come to terms with the disease, the caregiving, the hospitalization and the death. Eventually Earl had stopped eating and then had stopped breathing. "There would be no new memories of him. The only stories we could tell now were the ones we already had." This compelling story is about people you don't know but become involved with and care about because Franzen is such a riveting writer. He won the 2002 National Magazine Award for this story which first appeared in *The New Yorker*, September 10, 2001, 80 - 91 [www.newyorker.com](http://www.newyorker.com)

Gilbert, S. (2006). *Death's door. modern dying and the ways we grieve*. New York: W.W. Norton & Company. Poet and critic Sandra Gilbert personally knows grief and she deals with it in the way she knows best. She draws upon works by scholars, poets, writers, artists and practices to offer a comprehensive, multidisciplinary contemplation of dying, death and mortality. Gilbert chose carefully and hones in on those who articulated their fears, hopes and memories surrounding death and how they confronted mortality. Living in a society, as we do, that does not like to discuss death, that is uncomfortable with grief expressed and increasingly distanced from death she reminds us that "death's door is always open."

Hall, D. (1998). *Without: Poems*. New York: Houghton Mifflin Harcourt. U.S. Poet Laureate Donald Hall expresses his love, loneliness, longing and grief in his collection of elegies for his wife Jane Kenyon who died of leukemia in 1995 at age 47. Hall was nineteen years her senior and traces his lonely pilgrimage to grief. From the first three words in the first poem "Her Long Illness" to the last poem "Can you hear me Jane?" in which he expresses his obsession with the concept of an afterlife, we hear him mourn for his loss and mourn for Jane and her shortened life.

Harding, P. (2008). *Tinkers*. New York: Bellevue Literary Press. There were eight days, 691,200 seconds and 192 hours before George Washington Crosby, clock repairer, died. During this time George puts together a collage of memories that recaptures his father Howard's life and George's own New England youth. In 191 pages, Paul Harding writes flowing descriptions of clocks, nature and generations of families and numerous characters. He illuminates how we struggle to understand what life is all about. The book won a 2011 Pulitzer Prize.

Ionesco, E. (1963). *Exit the king*. New York: Grove Press. Ionesco wrote the play in 1962 as a lesson in dying. "I told myself that one could learn to die, that I could learn to die, that one can also help other people to die, we're all of us dying men who refuse to die." At the start of the play when the King gets the diagnosis that he will die in one hour and a half (i.e. when the show ends) he replies...*in forty, fifty, three hundred years*. But, die he does. Curtain descends.

- Larson, T. (2010). *The saddest music ever written. The story of samuel barber's adagio for strings*. New York: Pegasus. The music is a gem and this book will lead you to numerous recordings, YouTube videos or perhaps help you recall hearing it at a funeral. Publishers Description: In the first book ever to explore Samuel Barber's "Adagio for Strings", music and literary critic Thomas Larson tells the story of the prodigal composer and his seminal masterpiece: from its composition in 1936, when Barber was just twenty-six, to its orchestral premiere two years later, led by the great Arturo Toscanini, and its fascinating history as America's secular hymn for grieving our dead. Older Americans know Adagio from the funerals and memorials for Presidents Roosevelt and Kennedy, Albert Einstein, and Grace Kelly. Younger Americans recall the work as the antiwar theme of the movie Platoon. Still others treasure the piece in its choral version under the name Agnus Dei. More recently, mourners heard "Adagio" played as a memorial to the victims of the 9/11 attacks. Barber's "Adagio" is truly the saddest music ever written, enrapturing listeners with its lyric beauty as few laments have.
- McDermott, A. (2004). Enough. In W. Martin (Ed.), *More stories we tell. The best contemporary stories by north american women*. (, pp. 231-238). New York: Pantheon. In seven pages, Alice McDermott's 2000 short story gives us the whole arc of one ordinary woman's life. The story is seen as a flashback by the mother and McDermott's luxurious writing encapsulates this life from 12 to over 90 years old. Here is a woman who could embrace life. There is much sorrow in the world so she savors the joy. Love, family, sensuous sensations, faith are what she values and yet life itself is such pleasure that there is never enough....just like eating a favorite like ice cream- never enough.
- O'Reilly, J., O'Reilly, S., & Sterling, R. (Eds.). (2002). *The ultimate journey. Inspiring stories of living and dying*. San Francisco, CA: Traveler's Tales. Travel across religious and geographic boundaries with short stories by authors who have experienced the death and loss of another or have had a near-death experience themselves. The forty-three stories attempt to illuminate the human condition of mortality. This book has an interesting recommended reading list but even more it inspires the reader to seek out additional short stories about the fragility and wonder of life.
- Picoult, J. (2009). *Handle with care. A novel*. New York: Atria. A family in turmoil, a five-year-old child with a brittle bone disease (osteogenesis imperfecta), flawed parents, an older child who feels neglected. Picoult gives no clear answers but does raise many questions. In this book, Willow's sickness deals with current medical ethics issues. For a sampling - faced with the knowledge that a fetus will be disabled, is it right for a parent to terminate the pregnancy and how disabled is disabled? The questions remain and they stay around for us to ponder.
- Poe, E., A. (2006). The masque of the red death. In G. Kennedy (Ed.), *The portable edgar allan poe* (, pp. 164). New York: Penguin Classics. An age-old theme that is as old as the medieval morality play Everyman is revisited by Edgar Allan Poe in this 1839 classic tale. Poe, the "the master of the macabre" deals with the inevitability of death. He reinforces the message that there is no use trying as no human being can escape death. To see this story and twelve others get a copy of the DVD Edgar Allen Poe's Tales of Mystery and Imagination distributed under exclusive license from Indigo Film & Television by American Home Treasures
- Rosenberg, J. (2005). Reassessing immortality: The *makropulas* case revisited. In R. Feldman, K. McDaniel, J. Raibley & M. Zimmerman (Eds.), *The good, the right, life, and death*. (, pp. 220-240). Adlershot, UK: Ashgate Publishing. The title refers to the play by Karel Capek of a woman named Elina Makropulas who took an elixir of life. At the time of the action Elina is 342 years old. Her unending life has come to a state of boredom, indifference, and coldness. Everything is joyless: "In the end it is all the same," she says, "singing and silence." She refuses to take the elixir again; she dies; and the formula is destroyed. Rosenberg, a philosopher, refutes philosopher Bernard Williams' well-known article about the play and who does not think that immortality is a good idea - death gives meaning to life. Rosenberg sees it differently. "What do I get, if I take the proffered drink and so opt for immortality? The obvious answer seems to me also to be the correct one. I get a possibility. I get the option of going on, of continuing to live, for as long as I continue to want to live. I get an open future" and can take action and choose to die. A challenging article but a fascinating one that stays with you. The *Makropulas Case* is also an opera by Janacek.

Roth, P. (2006). *Everyman* (2007th ed.). New York: Vintage International.

Known for his prodigious literary output (32 as of 2010), in this novella-length essay on mortality, Philip Roth ruminates or even obsesses on illness, aging and death. The unnamed "He", the universal archetype, Everyman, is haunted by a sense of mortality which started with his youthful encounters with death and continue up to his own death at seventy-one. Roth takes us into "the layers of his life" writing about the ordinary struggles with the human mortality we all face. He ponders, perhaps echoing our own thoughts- "I've got a deep-rooted fondness for survival." Roth does have a great gift for wit and deep insight.

Sartre, J. (1948). The wall. In *The wall (intimacy) and other stories*. [Le mur] (L. Alexander Trans.). (, pp. 1-17). New York: New Directions Paperback.

The Wall, the best know of Jean-Paul Sartre's five short stories is a story about death. Three political prisoners, Pablo Ibbieta (narrator), Juan Mirabel, Tom Steinbock contemplate their upcoming execution before "the wall" during the Spanish Civil War. The wall symbolizes the inevitability and unknowing of death. The three become corpse like. Pablo loses the illusion of the eternal - a godless universe where life has no value. "I tell myself there will be nothing afterwards. But I don't understand what it means." "I see my corpse...and think that I won't see anything any more and the world will go on for the others." The story expresses Sartre's existential sense of nothingness - death is definite. Given a death sentence, you cease to be.

Sebold, A. (2002). *The lovely bones*. New York: Little, Brown and Company.

"My name was Salmon, like the fish; first name Susie" begins the story. Susie is adjusting to her new home in heaven. Susie was murdered at fourteen. This acclaimed novel by Alice Sebold takes an unthinkable subject – the horror of losing a child through violence and turns it into a lyrical portrait of family love and healing. A book that never seems to leave the best seller lists.

Seuss, D. (1986). *You're only old once! A book for obsolete children*. New York: Random House.

"You're not feeling your best so here you are in the "Golden Years Clinic on Century Square for Spleen Readjustment and Muffler Repair." Any adult who has been subjected to a battery of medical tests will find Dr. Seuss's journey from being "properly pillled and properly billed" familiar. What a delightful way to lighten the aches and pains of growing older. Seuss wrote this one to celebrate his 82nd birthday. Give it to anyone over 50. They will relate.

Sontag, S. (1999). The way we live now. In J. Updike, & K. Kenison (Eds.), *The best American short stories of the century*. (, pp. 600-618). New York: Houghton Mifflin.

"Becoming seriously ill was something that happens to other people. "At first he was only loosing weight." Seen and quoted only through the words of his friends in the artistic community it is acknowledged "He" has "the Disease." As He gets sicker they, who frenetically and mournfully buzz around him, get yanked awake to the harsh reality of their life-styles in light of the yet to be named illness. With her signature masterful writing Sontag brings the encroachment of AIDS to America. The story was written in 1983.

Spark, M. (2000). *Memento mori*. New York: New Directions Classic. Written in 1959 the message rings true in this century. London old adults receive anonymous phone calls reminding them that "*remember you will die*" (*memento mori*). This novel is funny, insightful, poignant reading where old feathers are ruffled, old secrets are kicked up and reminders that "leaves one relishing life all the more." Memento mori rings true as a cautionary tale for us all. Perhaps it could be subtitled *carpe diem*.

- Tolstoy, L. (2009). The death of Ivan Ilyich. In [Collected works in twenty-two volumes (Moscow Khudozhestvennaya Literature, 1982-83). Volumes X, XII, and XIV.] (R. Pevear, L. Volokhonsky Trans.). (, pp. 39-91). New York: Alfred A. Knopf.  
 Considered "one of the most precious gems of Tolstoy's work", the story begins and ends with Ivan Ilyich's death at age 44. Life for Ivan had been consumed with the external world-his work as judge and what other highly placed people considered right. A self-reliant man he had no real friends - including his wife. A stomach discomfort changes it all. As the discomfort increases, terrible physical pain and moral suffering overwhelm him. He knows he is dying. Screams envelope the despair and aloneness. As the end comes, an inner world, an almost mystical transformation takes place through the compassion of his servant Gerasim and Ivan's schoolboy son who bring caring into his life. Tolstoy's search for an answer to "Is there meaning in my life that will not be annihilated by the death that inevitably awaits me?" pervades the story. Pevear and Volokhonsky's recent translation captures all the richness of Tolstoy's writing to create a memorable literary experience.
- Twain, M., & Locke, C. I. (1909). *Report from paradise*. (1953rd ed.). New York: Harper and Brothers Publishers.  
 Twain, known for his impatience with hypocrisy, narrow dogma, race prejudice and cruel secularism, worked on this book for forty-three years and was finally finished and published six months before his death. This volume includes the two satires, *Captain Stormfield's Visit to Heaven* and *Letter from the Recording Angel*. They offer a full statement of Mark Twain's view on the religious doctrine and practices of his time. The main charm of what heaven, as Sandy McWilliams explains to Stormfield, is that "there's all kinds here - which wouldn't be the case if you let the preachers tell it." This is no Zion of a chosen few but a democratic heaven in which the captain, when he finally reaches the right gate, is welcomed in by a Piute Indian whom he once knew in Tulare County. But though there are no distinctions of race or religion, "there are limits to the privileges of the elect, even in heaven."
- Updike, J. (2009). *Endpoint and other poems*. New York: Alfred A. Knopf.  
 These magnificent poems were written during the last seven years of John Updike's life. The dedication reads "Martha, who asked for one more book: here it is, with all my love." For Updike writing poetry was a joy. He loved "turning the oddities of life into words." For the reader the poems are gifts that an extraordinary writer gave us. This book was published a few weeks after he died.
- Updike, J. (2009, Endpoint. *The New Yorker*, (March 16, 2009) Retrieved from <http://archives.newyorker.com>  
 Acclaimed poet, critic, novelist and short story writer John Updike confronts his final illness in these 2008 poems. The poem entitled *Fine Point* was written in Boston's Massachusetts General Hospital on December 22, 2008. The poems follow Updike's thoughts as he lay dying. Updike died on January 27, 2009. After his death his book Endpoint was published.
- Wilder, T. (2003). In Margulies D., forward (Ed.), *Our town. A play in three acts*. New York: HarperPerennial-ModernClassics.  
 Timeless, simple, profound, life itself, gem of the American theater debuted on Broadway in 1938. Thornton Wilder introduces us of life and death in Grover's Corners, NH. "It captures the universal experience of being alive." (Margulies). Emily now in Heaven says it all " Do any human beings ever realize life while they live it? - every, every minute.?" Life is precious. Life is ordinary. The play is extraordinary. Available in DVD.
- Young, K. (Ed.). (2010). *The art of losing. Poems of grief and healing*. New York: Bloomsbury Press.  
 Award-winning poet Kevin Young brings together 150 beautiful, contemporary poems (elegies) that take readers to the realm of pain, heartbreak and healing. Poetry expresses the inexpressible and the rich variety of these poems offer companionship through their words. The chapters are divided into: Reckoning; Regret; Remembrance; Ritual; Recovery; Redemption and each segment includes the most important names in modern poetry.

## CHILDREN'S BOOKS FOR KIDS OF ALL AGES

Asher, J. (2007). *Thirteen reasons why*. New York: Razorbill.

When Clay Jensen plays the cassette tapes he received. He is surprised to hear the voice of dead classmate Hannah Baker who died two weeks earlier. Clay is one of 13 people who receive Hannah's story. This young adult/teen novel by Jay Asher details the circumstances that led to her suicide. A controversial topic, the book has helped teens, parents and teachers start a conversation about how the reader's personally relate to Hannah's feelings and did they become aware of how we treat others.

Brown, W. M., & Hurd, C., illustrator. (2005). *The runaway bunny*. New York: HarperCollinsPublishers. doi:1942 A classic since 1942, adults and children alike celebrate a mother's steadfast love for her bunny. You may even shed a tear or two as you read and remember all the people you love and who love you. [The Runaway Bunny](#) is available in Spanish, Chinese, Japanese and Italian.

Krementz, J. (1981). *How it feels when a parent dies*. New York: Alfred A. Knopf.

They come from different backgrounds, situations and circumstances but have one thing in common - death of a parent. Eighteen boys and girls, seven to sixteen, individually talk about what it was like for them. Author and photographer Jill Krementz gives us a book of beauty, heartbreak, and bravery as each author express inner feelings, pain and courage. Alletta, age 9, writes "When Mom told me that Daddy was dead, my knees started shaking." Later she writes "I still have dreams about my father - happy dreams...Nobody knows about it because the light only shines in my window. It makes me happy." These youngsters have much to teach all of us about death and life.

Rappaport, D., & Lewis, B. E., illustrator. (1995). *The new king*. New York: Dial Books for Young Readers.

Where's Father?" the young Prince Rakoto asks his mother. "He was killed during a hunt." Unable to accept or understand, the sobbing Rakoto rushes to the doctor, the Imperial Wizard, the High Councilor and the wise woman demanding that they bring his father back to life. All give him the same answer - they could not. Only the old woman passes on wisdom that ultimately will make Rakoto a king who rules with love and justice. Wonderful illustrations complement the accessible text to create a moving, memorable book.

Rockliff, M., & McMenemy, S., illustrator. (2009). *The busiest street in town*. New York: Alfred A. Knopf.

Rushmore Boulevard was the busiest street in the entire town. Two older women, Agatha May Walker lived on one side of the street and her best friend Eulalie Scruggs on the other. They want to visit but the traffic is unrelenting. Initially the two women place themselves in the center of the street to sell cookies. Cars stop by to nosh on gingerbread cookies. Bit by bit children join them to play, Mrs. Mooney plants flowers, teenagers play music. The street works now not just for cars but for people too. The story and illustrations present an example of how people of all ages come together to make a liveable community.

Schwiebert, P., DeKlyen, C., & Taylor, B., illustrator. *Tear soup: A recipe for healing after loss*. Portland, OR: Death Watch.

Because of her great loss "Grandy" knew this was the right time for her to make a big pot of tear soup. With wonderful illustrations and text this book speaks to young and old, to anyone who has lost someone or something special and needs to sort through feelings and memories. That means it probably speaks to all of us.

Seuss, D. (1990). *Oh, the places you'll go!* (2010th ed.) doi:1990

The book is more than just the quintessential graduation gift. Its power is that it recognizes the ups and downs that life presents. With the usual Dr. Seuss (a.k.a. Theodor Seuss Geisel) verbal panache, the rhyming advice serves young and old, grieving, well and sick of all ages. How to get going again when discouraged or sad? Remember "And will you succeed? Yes! You will indeed! (98 and 3/4 percent guaranteed.)"

Silverman, J. (1999). *Help me say goodbye*. Minneapolis, MN: Fairview Press.

An art therapy workbook for families with young children, a book that can be used by teachers and grief counselors help children say goodbye to someone they love who is sick or loved and he/she died. It may be it a relative, a special friend (a pet?) Children express the pain of love and then loss through words and pictures that respond to questions Silverman asks. Example: "When your special someone is dying, what can you do to show how much he or she means to you? Draw or write your ideas."

Valery, S. (1984). *Badger's parting gifts*. New York: Lothrop, Lee & Shepard Books.

"Badger was so old that he know he must soon die." "All the animals loved Badger, and everyone was very sad." So the story begins. Glorious illustrations complement the narrative simply and honestly said as each friend tells of a special memory they have of Badger. A tale told about accepting death even as you grieve. Accessible to children and meaningful to adults, it is used in courses on death and dying.

Williams, V. (1984). *Music, music for everyone*. New York: Greenwillow Books.

Grandma is sick. Rosa wants to raise extra money to take care of her so that is how the Oak Street Band got started. Rosa (accordion) and her friends Leora (drums), Mae (flute) and Jenny (violin) practice to play at a fund raising party. Lots of people from their block come. The table in the back yard was covered with dishes of food and then "there was music and dancing for everyone." The girls played, everyone clapped and shouted. With her usual aplomb Vera Williams writes and illustrates a glorious book which you and a child will want to read and reread. Caring for others can start early.

## **DATABASES, GUIDELINES, PUBLIC POLICY**

Cochrane Collaboration. (Regularly updated). The cochrane collaboration. [www.cochrane.org](http://www.cochrane.org)

An international, not-for-profit organization making up-to-date, accurate information about the effects of health-care readily available worldwide. It produces and disseminates systematic reviews of health-care interventions and promotes the search for evidence in the form of clinical trials and other intervention studies.

Gottfried, e. a., & Duane, e. a. (September 25, 2010). New your state bar association family heath care decisions act information center. Retrieved December 23, 2010, 2010, from

<http://www.nysba.org/Content/NavigationMenu/PublicResources/FamilyHealthCareDecisionsActInformationCenter/FHCDARC.htm>

New York's Family Health Care Decisions Act (FHCDCA) establishes the authority of a patient's family member or close friend to make health care decisions for the patient in cases where the patient lacks decisional capacity and did not leave prior instructions or appoint a health care agent. This "surrogate" decision maker would also be empowered to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.

Medical orders for life sustaining treatment (MOLST). (2010). Retrieved November 5, 2010, from

[www.health.state.ny.us/professionals/patients/patient.../molst/](http://www.health.state.ny.us/professionals/patients/patient.../molst/)

Honoring patient preferences is a critical element in providing quality end-of-life care. To enable physicians and other health care providers to discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment, the Department of Health has approved a physician order form (DOH-5003), the Medical Orders for Life Sustaining Treatment (MOLST), that can be used statewide by health care providers and facilities. The form can be used to issue any orders for life-sustaining treatment for general hospital inpatients and nursing home residents. In the community, the form can be used to issue a non-hospital Do Not Resuscitate (DNR) or Do Not Intubate (DNI) order, and in certain circumstances, orders concerning other life-sustaining treatment. For information and forms there is a link [www.compassionandsupport.org](http://www.compassionandsupport.org)

National consensus project (NCP) for quality palliative care guidelines. (2009). Retrieved January 10, 2011, from

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

NCP establishes clinical practice guidelines that promote consistent and high-quality care and guide the development and structure of new and existing palliative care services in a range of delivery system. the guidelines include physical, psychological, social, spiritual, religious, existential, cultural, imminently dying patient, ethical and legal aspects of care. The Guidelines can be downloaded from the website. The next updated Guidelines will be ready by 2013.

New York State Bar Association Family Health Care Decisions Act Information Center. (2010). New york state family health care decisions act., 2010, from [www.nysba.org/Content/NavigationMenu/.../FHCDARC.htm](http://www.nysba.org/Content/NavigationMenu/.../FHCDARC.htm)

The New York State Health Care Decisions Act was enacted June 1, 2010. This website includes: key provisions, complete text, questions and links to the New York State Department of Health materials.

Multiple Chronic Conditions-A Strategic Framework: Optimum Health and Quality of Life for Individuals with Multiple Chronic Conditions. (2010). Retrieved from [http://www.hhs.gov/ash/initiatives/mcc/mcc\\_framework.pdf](http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf)  
This new report was created to provide "a road map for the nation to foster changes in the health care system that can reduce poor health outcomes, improve patients' quality of life and reduce costs."

Who will speak for you? (July 2010). Retrieved November 5, 2010, from [http://www.health.state.ny.us/professionals/patients/health\\_care\\_proxy/](http://www.health.state.ny.us/professionals/patients/health_care_proxy/) The New York Health Care Proxy Law allows you to appoint someone you trust - for example, a family member or close friend - to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Forms available in English, Spanish, Chinese, Russian. Links to [Compassion and Support](#) and [Aging With Dignity](#) websites.

World health organization (WHO) definition of palliative care. (2011). Retrieved 02/2011, 2011, from <http://www.who.int/cancer/palliative/definition/en/> WHO defines palliative care for adults and children. Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

## **BLOGS AND OTHER WEB WISDOM**

Aull, F., PhD. *Literature, art and medicine blog*. <http://medhum.med.nyu.edu/blog>  
This blog is linked to and is an extension of the NYU School of Medicine medical humanities web site and its Literature, Arts and Medicine Database. It is intended to be a forum for scholarly discussion of ongoing projects in medical, nursing, premedical, graduate and postgraduate education and research that use the humanities, social sciences and the arts to address current issues in medicine and bioscience from a variety of perspectives.

Bach, P. (2011). *Essays about my wife's breast cancer*. Retrieved 03/2011, from [www.nytimes.com/well](http://www.nytimes.com/well)  
Peter Bach, MD, an attending physician at Memorial Sloan-Kettering Cancer Center in New York City, writes about his wife's breast cancer. His first article appeared in print in the NY Times Science Section on Tuesday, February 22, 2011, page D5. Through all his training he never learned how to be a patient. When his colleague and close friend Hiram (Chip) Cody MD said "Ruth, I think this is cancer," Bach's familiar exam rooms and hospital floors were transformed into places of terror. To think only half an hour earlier, his biggest concern had been finding a parking place. Stay tuned with his new Tuesday blog.

*Bioethics forum*. [www.thehastingscenter.org/bioethicsforum](http://www.thehastingscenter.org/bioethicsforum)  
As defined on the website: "Bioethics Forum, hosted by the Hastings Center Report, publishes thoughtful commentary from a range of perspectives on timely issues in bioethics. The opinions expressed in it are those of the authors and not The Hastings Center."

Bomba, P. (2010). *Compassion and support*. Retrieved December 30, 2010, from [www.compassionandsupport.org](http://www.compassionandsupport.org)  
Listen up. It's all about the all important conversations. This website is the information center for MOLST - Medical Orders for Life Sustaining Treatment in NYS. The site includes videos, information and an e-mail newsletter that stresses the importance of planning ahead, knowing your choices, making sound decisions and sharing your wishes your doctor and with the person who will be your agent (health care proxy). Pat Bomba, MD is an authority on MOLST.

Department of Veteran Affairs. (2011). [http://www.ethosconsult.com/files/va\\_transforms.pdf](http://www.ethosconsult.com/files/va_transforms.pdf)  
This report portrays advances in end-of-life care for veterans by the Department of Veterans Affairs (VA). A joint project of VA and the National Hospice and Palliative Care Organization (NHPCO), this report describes VA hospice and palliative care benefits, the needs of terminally ill veterans, and the role of partnering community hospice programs. It features stories of individual veterans and their families who have benefited from that care.

Facebook. [www.facebook.com](http://www.facebook.com)

With more than 500 million users world wide, Facebook, the social network that began it all, has individual (friends) and business (fans). If you haven't heard of it yet see *The Social Network*.

Fitbie. (2011). Retrieved February 1, 2011, 2011, from [www.fitbie.msn.com/](http://www.fitbie.msn.com/)

A new health section on MSN called *Fitbie* delivers fitness, nutrition and weight-loss content as part of the Lifestyle options. It includes a wealth of ways to stay in good shape and in good health for any age, illness or disability. There is an important program called *Diabetes DTour Diet*. *Fitbie* is found at [www.fitbie.msn.com/](http://www.fitbie.msn.com/)

Goodman, D. (11/30/2010). *Dartmouth atlas of health care*. Retrieved 12/1/2010, 2010, from [www.dartmouthatlas.org/](http://www.dartmouthatlas.org/)

For more than 20 years, the Dartmouth Atlas Project has documented striking discrepancies in how medical resources are distributed and used in the United States. The project uses Medicare data to provide comprehensive information and analysis about national, regional and local markets, as well as individual hospitals and their affiliated physicians. Searches are available by region, hospital, topic. Interesting data on hospice care being underused by those who need it most.

Growth house blogging portal. <http://growthhouse.typepad.com>

The Growth House is a website with free access to 4,000 pages of educational materials. It focuses on education about life-threatening illness and end-of-life care. The Blogging Portal features guest bloggers who have something to say about hospice care, palliative medicine and how to get things done in healthcare systems and making a difference in the quality of compassionate care for people approaching the end of their lives.

Healthcare cost monitor. (2011). Retrieved 02/2011, 2011, from <http://healthcarecostmonitor.thehastingscenter.org>  
Commentaries and opinions on cost control in the implementation of health reform.

Hiller, J. R., & Hiller, B. *Obit - life, death, transition*. [www.obit-mag-com](http://www.obit-mag-com)

Defined on the website: "Death gives life its immediacy. Because we know it will end, we savor and value life all the more. *Obit* examines life through the lens of death. Whether it's the loss of a person, a place, an object or an idea, life's constant change presents an opportunity for examination, discussion and even celebration. By examining the transformations we face, we can understand how the past influences our time and our future. *Obit* aims to offer a forum for ideas and opinions about life, death, and transition that you will find nowhere else." This links to a blog called "About Judy."

Jennings, D. <http://well.blogs.nytimes.com/tag/jennings>

Dana Jennings, an editor at *The NY Times*, writes that he asserts ownership of his cancer every day and refuses to give in to it. His blog is about life after prostate cancer diagnosis and continuing treatment. You can upload photos of your life after cancer and it will be added to a collage of the photos and insights submitted by the blog readers.

Leven, D. (2010). *Compassion and choices of new york*. Retrieved December 21, 2010, <http://www.compassionandchoicesofny.org/>.

This website provides free information, counseling, support, and advocacy services to terminally ill patients and their families and those planning for the end of their lives. Its primary goal is to facilitate end-of-life choices that reflect the values and wishes of the dying person. Compassion & Choices presses for improved state-of-the-art pain and palliative care. It works to improve care and expand choice at life's end by initiating legislation, educating the public, health care professionals and seniors and by using the media. Contact [davidcleven@aol.com](mailto:davidcleven@aol.com)

Levine, J. (2010). *Easing the pain. Successes and challenges in international palliative care*. New York: Open Society Foundation. Retrieved from [www.soros.org/initiative/health](http://www.soros.org/initiative/health)

The Open Society Foundation report by Judith Levine hopes to inspire others to support innovative efforts in the area of palliative care. At least 60 percent of people worldwide "will have a prolonged advanced illness before dying and would benefit from palliative care." The complete ninety-two page report is available as PDF on the website.

Michael J. Fox Parkinson Foundation. (2010). *Understanding a complex disease*. Retrieved December 23, 2010, from <http://www.michaeljfox.org/living.cfm> Parkinson's disease is a neurodegenerative disorder of unknown cause that affects nearly 5 million individuals worldwide. While advancing age remains the greatest risk factor, PD can strike people even under 30. The full spectrum of Parkinson's disease is not well addressed by current treatments. The website has clear, easy-to-understand information about PD symptoms, treatments and care options, how to cope with diagnosis, a guide for caregivers, individual stories, clinical trials, current news and position papers and an e-newsletter.

*Morbid ink: Memorial tattoos*. Retrieved July 21, 2010

<http://culture.wnyc.org/articles/features/2010/jul/21/morbid-ink-tattoo-memorial/>

WNYP public radio interviews Dr. John Troyer, deputy director of the University of Bath's Centre for Death and Society who studies tattoos as a living memorial to someone loved. The website has an audio connection to the interview and a link to a YouTube video. Once on YouTube you might want to peruse other memorial tattoo videos.

National Institute of Health, NIH. (2010). *What is chronic obstructive pulmonary disease (COPD)?* Retrieved January 19, 2011, from [http://www.nlm.nih.gov/health/dci/Diseases/Copd/Copd\\_WhatIs.html](http://www.nlm.nih.gov/health/dci/Diseases/Copd/Copd_WhatIs.html)

The National Institute of Health website for COPD is a comprehensive information source for the disease. Areas covered include: What is; Other names; Causes; Who is at Risk; Signs and Symptoms; Diagnosis; Treatment; Clinical Trials; Prevention; Living With; Key Points; Links. There are images of healthy and COPD lungs.

National Institute of Health, NIH. (2011). *The United States national library of medicine*, 2011, from [www.nlm.nih.gov/](http://www.nlm.nih.gov/)

This largest medical library in the world has a vast amount of information on palliative care and end-of-life in both English and Spanish.

*New York University Langone medical center medical humanities*. (2011). Retrieved 02/2011, 2011, from

<http://medhum.med.nyu.edu/blog/>

The blog is a forum for scholarly discussions of ongoing projects in medical, nursing, premedical, graduate, and postgraduate education and research that use the humanities, social sciences, and the arts to address current issues in medicine and bioscience from a variety of perspectives.

Parker-Pope, T. (2011). *New York Times Well*, 2011, <http://well.blogs.nytimes.com>

Join columnist Tara Parker-Pope as she sifts through medical research and expert opinions for practical advice to help readers take control of their health and live well every day. The consumer health columnist for the *New York Times* since 2007, she writes on medical research and societal trends in health. There are links to current articles, websites and other blogs and archived articles. Pick your disease, enter and follow the link.

*Poetry Foundation*. (2011). Retrieved January 31, 2011, 2011, from <http://www.poetryfoundation.org>

The Poetry Foundation is an independent literary organization committed to a vigorous presence for poetry in American culture. Its easy to navigate website is an entry to the world of poetry. Resources include The Poetry Tool, Glossary, and Learning Lab. The Poetry Tool brings up poems by poet, category, occasion, title and first lines. Featured areas include Time, Season, Funerals, Friends, and Economics, School. There is a collection of audio and podcasts, an e-newsletter and a magazine. Put in a term and see what you get.

*RefWorks*. [www.refworks.com](http://www.refworks.com)

RefWorks is an online research management, writing and collaboration tool to designed and help researchers easily gather, manage, store and share all types of information, as well as generate citations and bibliographies.

*Remember that you will die: Death across cultures*. <http://rma2.org/nav/exhibitions/view/543>

The Rubin Museum of art in NYC presented this exhibition in Spring/Summer 2010. It explored and contrasted concepts of death and the afterlife in Christian European and Tibetan Buddhist traditions (a footnote: in both traditions sooner or later the Grim Reaper comes for everyone). The website preserves the exhibit with a download audio tour at iTunes U, Remembrance Poetry, and the exhibit brochure which has choice images and explanatory text.

Rose, C. (2011). *The charlie rose brain series*. Retrieved January 27, 2011, 2011, from [www.charlierose.com](http://www.charlierose.com)  
The Charlie Rose Brain Series explores the scientific frontiers of the human brain. Each of the 13 episodes examine a different subject such as perception, social interaction, aging and creativity, advances in technology, and the mentally ill brain. Individual episodes are available on DVD at [www.amazon.com](http://www.amazon.com)

Rosielle, D., MD. *Pallimed*. [www.palimed.org](http://www.palimed.org)  
Drew Rosielle, MD reviews current palliative medicine, hospice and end-of-life research.

Tippett, K. *Being*. <http://blog.onbeing.org>  
This is the blog for the Being radio program (formerly called Speaking of Faith) about the big questions at the center of human life, from the boldest new science of the human brain to the most ancient traditions of the human spirit. It is hosted by Krista Tippett . Being is broadcast on NPR stations and its website is [www.being@nationalpublicradio.org](http://www.being@nationalpublicradio.org)

*Twitter*. [www.twitter.com](http://www.twitter.com)  
A micro-blogging service with 160 million users who "tweet" with 140 character messages. You are actually sending them to a few, or perhaps thousands, of people who have signed up to receive them from you. .

*YouTube*. <http://www.youtube.com>  
YouTube is a video-sharing website on which users can view, share and upload videos. Corner that embodies and promotes democracy." Periodically, various countries deny access to the site.

## A WEBSITE LIST

- AARP. [www.aarp.org/health](http://www.aarp.org/health) Founded in 1958, the AARP is a nonprofit, nonpartisan membership organization that helps people 50 and over improve the quality of their lives. Also available as [www.aarp.org/espanol](http://www.aarp.org/espanol)
- AIDS Community Research Initiative of America (ACRIA). [www.acria.org](http://www.acria.org). Founded in 1991, ACRIA brings an activist approach to the study for new treatment for HIV and AIDS. A treatment education component was added in 1997.
- Alzheimer's Association. [www.alz.org](http://www.alz.org). Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. For information in Spanish go to [www.alz.org/espanol](http://www.alz.org/espanol)
- American Bar Association Commission on Law and Aging. [www.abanet.org/aging](http://www.abanet.org/aging) The mission of the ABA Commission on Law and Aging is to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of elders. It carries out this mission through research, policy development, technical assistance, advocacy, education, and training.
- American Cancer Society. [www.cancer.org](http://www.cancer.org). ACS provides information and a Cancer Survivors Network. There is information in *Español* and Asian and Pacific Islanders materials.
- Alzheimer's Disease Education and Referral (ADEAR) Center. [www.nia.nih.gov/Alzheimers/](http://www.nia.nih.gov/Alzheimers/) This web site provides current, comprehensive Alzheimer's Disease information and resources from the National Institute on Aging (NIA). Most of the ADEAR publications are free. The NIA, which is part of NIH leads the Federal Government's Alzheimer's research.
- American Diabetes Association. <http://www.diabetes.org>. For all people with, or at risk for, diabetes. The website provides *Información en Español*.
- American Parkinson Disease Association. [www.apdaparkinson.org](http://www.apdaparkinson.org) Headquartered in New York the organization focuses on research, patient support, education and raising awareness about the disease.
- American Society of Transplantation [AST]. [www.a-s-t.org](http://www.a-s-t.org) Improving human life through the field of transplantation.
- Atul Gawanda. [www.gawande.com/about](http://www.gawande.com/about) Boston surgeon and author website that includes his books, *The Checklist Manifesto*, *Better*, *Complications*, articles, links
- Being. <http://being.publicradio.org/> *Being* is a spacious conversation, an evolving media space about the big questions at the center of human life, from the boldest new science of the human brain to the most ancient traditions of the human spirit. Hosted by Krista Tippett and formerly called Speaking of Faith.
- Cancer Support Team. [www.cancersupportteam.org](http://www.cancersupportteam.org). A unique, non-profit home care organization that provides professional nursing, social work, and other supportive services, free of charge, to cancer patients and their families living in lower Westchester County, New York. Materials available *en Español*
- Center to Advance Palliative Care (CAPC). [www.capc.org](http://www.capc.org). Diane E. Meier, MD is Director of the Center to Advance Palliative Care, a national organization devoted to increasing the number and quality of palliative care programs in the U.S. The Mount Sinai School of Medicine, NY, provides direction and technical assistance.
- Center for Practical Bioethics. [www.practicalbioethics.org](http://www.practicalbioethics.org) The Center helps patients and their families, healthcare professionals, policymakers and corporate leaders grapple with ethically complex issues in medicine and research.
- Center for Spirituality, Theology and Health. [www.spiritualityandhealth.duke.edu](http://www.spiritualityandhealth.duke.edu) Based in the Center for Aging at Duke University Medical Center it focuses on conducting research, training others to do so, and supporting dialogue and discussion on spirituality, religion, and health as related to public health and clinical practice.

The Cochrane Collaboration. [www.cochrane.org](http://www.cochrane.org) The Cochrane Collaboration is an international, independent, not-for-profit organization of over 28,000 contributors from more than 100 countries, dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide. Their online database is regularly updated.

Collaborative for Palliative Care/Westchester & NYS Southern Region. [www.cpcwestchester.org](http://www.cpcwestchester.org) The CPC is a broad-based collaborative of community organizations and volunteers dedicated to improving care of the seriously ill through creating, supporting and mobilizing education, research and advocacy for compassionate palliative and end-of-life care and enriching the quality of life for people facing chronic and life-limiting illnesses.

Compassion and Choices. [www.compassionandchoices.org](http://www.compassionandchoices.org). An organization that supports, educates and advocates for choice and care at the end-of-life.

Columbia University Graduate Program in Narrative Medicine. <http://www.narrativemedicine.org> A Columbia University Master of Science degree program in Narrative Medicine seeks to fortify clinical practice and training with narrative skills in order to strengthen the overarching goals of medicine, public health and social justice.

Compassion and Support. [www.compassionandsupport.org](http://www.compassionandsupport.org). This is the information site for MOLST—Medical Orders for Life Sustaining Treatment. It includes videos and contact information. The web site stresses the importance of planning ahead, knowing your choices, making sound decisions and sharing your wishes with your loved ones and health care professionals.

Dartmouth Atlas of Health care. <http://www.dartmouthatlas.org/> This research has helped policymakers, the media, health care analysts and others improve their understanding of our health care system and forms the foundation for many of the ongoing efforts to improve health and health systems across America.

Dying Well. [www.dyingwell.com](http://www.dyingwell.com) Ira Byock, MD's provides resources for people facing life-limiting illness, their families and their professional caregivers.

Encyclopedia for Death and Dying. [www.deathreference.com](http://www.deathreference.com) Covers all aspects of death and dying. For information on dying and death in Islam use <http://www.deathreference.com/Ho-Ka/Islam.html>

EPERC. [www.eperc.mcw.edu](http://www.eperc.mcw.edu) The purpose the End of Life/Palliative Resource Center is to share educational resource material among the community of health professional educators involved in palliative care education.

Gilda's Club Westchester. [www.Gildasclubwestchester.org](http://www.Gildasclubwestchester.org) Creates welcoming communities of free support for everyone living with cancer, men, women, teens and children, along with their families and friends.

Growth House, Inc. [www.growthhouse.org](http://www.growthhouse.org) Growth House, Inc., provides free access to over 4,000 pages of high-quality education materials about end-of-life care, palliative medicine, and hospice care, including the full text of several books.

Hastings Center. [www.thehastingscenter.org](http://www.thehastingscenter.org). The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute founded in 1969. The Center's mission is "to address fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities, and societies."

HealthCare Chaplaincy. [www.healthcarechaplaincy.org](http://www.healthcarechaplaincy.org). HealthCare Chaplaincy's expertise in professional multi-faith spiritual care is transforming how health care is understood and delivered through research, education, monthly and quarterly newsletters, clinical practice, advocacy, and innovation. They do most of the Hospital Chaplaincy work in the New York City area.

Hearthstone Alzheimer Care. [www.thehearth.org](http://www.thehearth.org) Creates environments where people with Alzheimer's Disease can live and flourish. Located in Westchester, Rockland and Boston. The Hearthstone Institute offers courses and training.

Hospice Foundation of America. [www.hospicefoundation.org](http://www.hospicefoundation.org). Helps those who cope personally or professionally with terminal illness, death, and the process of grief and bereavement. It is a Source for the *Living With Grief* series, which is available in a variety of formats.

Hospice and Palliative Care Association of New York State. [www.hpcanys.org](http://www.hpcanys.org) The Association promotes the availability and accessibility of quality hospice and palliative care for all persons in New York State confronted with life-limiting illness.

Huntington's Disease Society of America. [www.hdsa.org](http://www.hdsa.org) A national, non-profit voluntary health agency dedicated to finding a cure for Huntington's Disease that provides vital support, information and educational services to improve the lives of those affected by HD.

Michael J. Fox Foundation for Parkinson Research. [www.MichaelJFox.org](http://www.MichaelJFox.org) Funds research that can lead to the creation of better Parkinson's treatments.

Montefiore-Einstein Center for Bioethics . [www.montefiore.org/pro/bioethics/](http://www.montefiore.org/pro/bioethics/) Bioethics is the field that addresses value-laden issues at the interface of medicine, law and public policy. Though Bioethics can encompass a broad range of topics, the Montefiore-Einstein Center for Bioethics focuses on those issues most likely to improve patient care, human subjects research, and health policy. A Certificate Program in Bioethics & Medical Humanities is available.

National Alliance for Caregiving. [www.caregiving.org](http://www.caregiving.org). Founded in 1996, NAC is a non-profit coalition of national organizations focusing on issues of family caregiving.

National Center of Complementary and Alternative Medicine. [www.nccam.nih.gov](http://www.nccam.nih.gov) Federal Government's lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. Información de Salud en Español.

National Center for Ethics in Health Care. [www.ethics.va.gov](http://www.ethics.va.gov) Integrated Ethics provides proven solutions to the many challenges facing ethics programs in health care organizations today. The Ethics Center makes tools and materials available to ethics program health care professionals via this web site at no cost.

National Hospice and Palliative Care Organization. [www.nhpco.org](http://www.nhpco.org). Advancing care at the end-of-life. *Información En Español*.

National Multiple Sclerosis Society. [www.nationalMSSociety.org](http://www.nationalMSSociety.org). The Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by Multiple Sclerosis.

National Palliative Care Research Center. [www.npcrc.org](http://www.npcrc.org). The mission of NPCRC is to improve care for patients with serious illness and the needs of their families by promoting palliative care research. Partners with Center to Advance Palliative Care [www.capc.org](http://www.capc.org) to translate their findings into clinical practice.

National Parkinson's Foundation. [www.parkinson.org](http://www.parkinson.org). The Foundation's mission is to improve the quality of care for people with Parkinson's disease through research, education and outreach.

National Resource Center on LGBT Aging. [www.lgbtagingcenter.org](http://www.lgbtagingcenter.org) The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and transgender (LGBT) older adults. Established in 2010 through a federal grant from the U.S. Department of Health and Human Services, the National Resource Center on LGBT Aging provides training, technical assistance and educational resources to aging providers, LGBT organizations and LGBT older adults. The center is led by Services & Advocacy for GLBT Elders (SAGE) in partnership with 10 leading organizations from around the country.

National Institute of Neurological Disorders and Strokes. [www.ninds.nih.gov](http://www.ninds.nih.gov) The National Institute of Neurological Disorders and Strokes website is a gold mine of information on disease symptoms, research, funding, brochures (English and Spanish). It covers illnesses from A to Z e.g. ALS, Autism, Cerebral Palsy, Spina Bifida, Zellwegan Syndrome.

New York Academy of Medicine. [www.nyam.org](http://www.nyam.org) The New York Academy of Medicine advances the health of people in cities. An independent organization NYAM addresses the health challenges facing the world's urban populations through interdisciplinary approaches to policy leadership, education, community engagement and innovative research.

New York State Bar Association. [www.nysba.org](http://www.nysba.org) Serving the legal profession and the community since 1876.

New York State Government. [www.state.ny.us](http://www.state.ny.us) Portal to all government information, departments, NYS Assembly and NYS Senate etc. etc. Many materials available *en Español*.

New York Times Dana Jennings. <http://well.blogs.nytimes.com/tag/jennings/> Dana Jennings, journal and editor at The Times writes about his journey with Prostate Cancer.

New York Times Well. <http://well.blogs.nytimes.com/> Tara Parker-Pope, *NY Times Well* columnist and blogger on the latest medical research and societal trends on health. Links to current articles, websites, and blogs, and archived articles. Pick your disease, enter and follow the links

New York University Langone Medical Center Medical Humanities. <http://medhum.med.nyu.edu/blog/> The blog is a forum for scholarly discussion of ongoing projects in medical, nursing, premedical, graduate, and postgraduate education and research that use the humanities, social sciences, and the arts to address current issues in medicine and bioscience from a variety of perspectives

Next Step in Care. [www.nextstepincare.org](http://www.nextstepincare.org) New York Hospital Fund created Next Step in Care in cooperation with health care providers, including hospitals, nursing homes, home care agencies and family caregivers.

National Kidney Foundation. [www.kidney.org](http://www.kidney.org) The National Kidney Foundation, Inc (NKF), is the major voluntary health organization dedicated to preventing kidney disease, improving the health and well-being of individuals and families affected by kidney disease and increasing the availability of all organs for transplantation.

*Obit Magazine*. [www.obit-mag.com](http://www.obit-mag.com). *Obit* magazine is an eclectic mix of ideas, essays, cartoons, profiles and opinions about life, death, and transitions. Links to obits, books, blogs, science, forums etc.

On Our Own Terms: Moyers on Dying. [Http://www.pbs.org/wnet/onourown/terms](http://www.pbs.org/wnet/onourown/terms). The web site includes resources and an Inter-Institutional Collaborating Network (IICN) that joins major end-of-life care organizations from the United States.

Pace Women's Justice Center. [www.law.pace.edu/wjc](http://www.law.pace.edu/wjc) Source for *the Westchester Elder Law Q & A: Answers to Questions About Estate and Financial Planning, Health Care Planning and Elder Abuse*, third edition, written by Steven A. Schurkman, Esq., of Keane & Beane, P.C. The Q & A is available *en Español*.

Pallimed. [www.pallimed.org](http://www.pallimed.org) Drew Rosielle, MD reviews current palliative medicine, hospice and end-of-life research.

Pancreatic Cancer Action Network. [www.pancan.org](http://www.pancan.org) The organization is about active research, patient support, creating hope. It offers free educational materials (such as [An Overview of Pancreatic Cancer](#)), a video story, ways to get involved and materials *En Español*.

Partners Against Pain. [www.partnersagainstpain.org](http://www.partnersagainstpain.org). Partners Against Pain® is a resource that serves patients, caregivers, and healthcare professionals to help alleviate unnecessary suffering by advancing standards of pain care through education and advocacy.

Père Lachaise Cemetery. [http://en.wikipedia.org/wiki/P%C3%A8re\\_Lachaise\\_Cemetery](http://en.wikipedia.org/wiki/P%C3%A8re_Lachaise_Cemetery) Père Lachaise is one of the most famous cemeteries in the world at which those who have enhanced French life over the past 200 years now reside. It is located in Paris's 20<sup>th</sup> arrondissement.

Pioneer Network. [www.pioneernetwork.net](http://www.pioneernetwork.net). Since 1997, the Pioneer Network has been dedicated to creating culture change in all settings where aging and supportive services are delivered. It is committed to establishing the kind of care that each of us wants for our loved ones and ourselves.

Pitney Bowes Caregiving Program. <http://news.pb.com> The Pitney Bowes Caregiving Program stresses the importance of providing transparency and support to caregivers within an organization. *The Caregiving Quandary* White Paper available for download.

Reclaiming the End-of-Life. [www.ReclaimtheEnd.org](http://www.ReclaimtheEnd.org). A nonprofit, nonpartisan, New Hampshire-based project designed to make bold changes in the way we care for frail elderly, seriously ill persons of any age, and family caregivers. Ira Byock, MD is the cofounder of the website.

Robert Wood Johnson. [www.rwjf.org](http://www.rwjf.org) RWJ efforts focus on improving both the *health* of everyone in America, and their *health care*, how it's delivered, how it's paid for, and how well it does for patients and their families.

StopPain.org. Beth Israel Medical Center Department of Pain and Palliative Medicine. [www.stoppain.org](http://www.stoppain.org) The Center offers a broad array of therapies for chronic pain of all types.

United Hospital Fund. [www.uhfnyc.org](http://www.uhfnyc.org) The Fund advances policies and support programs that promote high-quality, patient-centered health care services in New York that are accessible to all.

UNOS. United Network for Organ Sharing. [www.unos.org](http://www.unos.org) United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system under contract with the federal government.

United States Department of Health and Human Services. Health Resources and Services Administration. [www.hrsa.gov/culturalcompetence/measures](http://www.hrsa.gov/culturalcompetence/measures) A project to develop a cultural competence measurement profile comprising a conceptual measurement framework and set of measures for gauging cultural competence in health care settings.

United States National Library of Medicine. National Institutes of Health. [www.nlm.nih.gov/](http://www.nlm.nih.gov/) This largest medical library in the world has a vast amount of information on palliative care and end-of-life in English and Spanish.

Westchester Alliance. [www.westchesterpartnership.org](http://www.westchesterpartnership.org) The focal point for the Alliance is to encourage and foster greater infusion and integration of aging related content into curricula and to play a major role in helping young people plan their life's work fully aware of the vast opportunities in aging

Westchester County Department of Senior Programs and Services (DSPS). [www.westchestergov.com/seniors](http://www.westchestergov.com/seniors). The Department of Senior Programs and Services (Area Agency on Aging) offers a variety of services, seminars and activities for seniors and caregivers throughout the year. Links to information about the Livable Communities Approach, the Caregiving Coaching Program and a myriad of other services. Information available *en Español*.

Westchester County Government. [www.westchestergov.com](http://www.westchestergov.com) For all things Westchester use this website.

Westchester County Office for Women. [www.westchestergov.com/women](http://www.westchestergov.com/women). The office provides online support and information for Sandwich Generation Caregivers-women caught between kids, careers, and elderly in Westchester County.

Westchester End-of-Life Coalition. [www.westchesterendoflife.org](http://www.westchesterendoflife.org). This community-based coalition draws on local resources to expand awareness of the importance of end-of-life issues and inform professionals and the public about services available to them.

Westchester Public/Private Partnership for Aging Services. [www.westchesterpartnership.org](http://www.westchesterpartnership.org). The WPPP develops resources to provide myriad services that help seniors age with independence and dignity in their home community. It also helps caregivers assist their family members and successfully meet their work and other family responsibilities.

World Health Organization (WHO). <http://www.who.int/cancer/palliative/definition/en/> WHO defines palliative care of adults and children.

YouTube. [www.youtube.com](http://www.youtube.com) A video-sharing website where users can upload, share and view videos. It was awarded a 2008 George Foster Peabody Award and cited for being "a 'Speakers' Corner' that both embodies and promotes democracy. Among the huge variety of videos many relate to healthcare and life-limiting illnesses.

*This is a poem of gratitude about the simple pleasures of life.  
Jane Kenyon died several years ago of cancer.*

## **Otherwise**

*Jane Kenyon*

**I got out of bed  
on two strong legs.  
It might have been  
otherwise. I ate  
cereal, sweet  
milk, ripe, flawless  
peach. It might  
have been otherwise.  
I took the dog uphill  
to the birch wood.  
All morning I did  
the work I love.**

**At noon I lay down  
with my mate. It might  
have been otherwise.  
We ate dinner together  
at a table with silver  
candlesticks. It might  
have been otherwise.  
I slept in a bed  
in a room with paintings  
on the walls, and  
planned another day  
just like this day.  
But one day, I know,  
it will be otherwise.**

*From *Otherwise*, 1996  
Graywolf Press, St. Paul, Minn.*

Copyright 1996 by the Estate of Jane Kenyon.  
All rights reserved.  
Reproduced with permission