The Art of Dying Bibliography

The Process of Dying:

http://www.cbc.ca/news/canada/british-columbia/it-was-cathartic-filmmaker-documents-cousin-s-terminal-illness-1.4092820. James Pollard asked his cousin to film his last three years with cancer – the film documents his story. He also set up a website to provoke conversations about death at www.fordearlife.ca.

https://deserthealthnews.com/stories/midwives-doulas-help-ease-way/. An article by a friend of mine about the role of death midwives or doulahs.

http://www.newyorker.com/magazine/2010/08/02/letting-go-2. An article by Atul Gawande about when to let a dying person go without further treatment.

Articles about dying from a variety of perspectives: http://www.theguardian.com/lifeandstyle/bereavement

http://www.kokuamau.org/resources/last-stages-life. This is a website page that describes the last stages of dying and how to be with the person who is dying. It's descriptive, helpful and realistic in my experience.

http://www.livinganddyingconsciouslyproject.org/#!about/c1se. Lots of practical help and wisdom from a group who focus especially on rites of passage, including dving.

http://www.cbc.ca/radio/popup/audio/player.html?autoPlay=true&clipIds=26586 34423. An interview with Anthony Bossis who is conducting research at New York University using psychedelics to relieve anxiety in dying.

http://www.gratefulness.org/resource/being-one-with-dying-showing-up-for-the-great-matter/. A beautiful reflection on dying for caregivers by Joan Halifax.

https://www.washingtonpost.com/news/inspiredlife/wp/2016/03/16/hospiceart/. A young woman draws portraits of dying hospice patients and records their stories.

End of Life Care:

https://www.nytimes.com/2017/05/25/world/canada/euthanasia-bill-john-shields-death.html?smprod=nytcore-ipad&smid=nytcore-ipad-share. A beautiful story about an ending of life.

http://www.cbc.ca/radio/thesundayedition/may-28-2017-the-sunday-edition-with-michael-enright-1.4132867/learning-how-to-die-with-grace-from-a-beloved-friend-1.4132914. A friend writes about learning how to die with grace.

http://healthydebate.ca/opinions/preparing dying home. A wife writes about her husband's death at home.

http://www.consciousdyinginstitute.com/events/. The Conscious Dying Institute in Boulder CO offers a two-part training program in Vancouver titled Sacred Passage: End of Life Doula Certificate.

https://www.nytimes.com/2017/02/18/opinion/sunday/first-sex-ed-then-death-ed.html. A critical and palliative care doctor talks about taking 'death ed' into high schools.

BJ Miller on TED,

http://www.ted.com/talks/bj miller what really matters at the end of life?utm s ource=newsletter weekly 2015-09-

12&utm campaign=newsletter weekly&utm medium=email&utm content=talk of t he week button

http://abcnews.go.com/Lifestyle/91-year-inspired-thousands-end-life-road-trip/story?id=42555115. An article about living fully and joyfully the last days of a life.

A three part series by Sharon Kirkey on end of life planning and decisionmaking: Part I - End of life care: doctors, machines and technology can keep us alive, but why? http://o.canada.com/health/end-of-life-care-a-doctors-machines-and-technology-can-keep-us-alive-but-why. Part 2 - End of Life Care: a shift to living well before dying. http://o.canada.com/health/end-of-life-care-dying. Part 3 - In the face of a debilitating disease like ALS, patients often seek control over what will happen. http://o.canada.com/health/end-of-life-care-creating-an-exit-strategy.

http://kindethics.com/2009/06/what-is-the-difference-between-palliative-care-comfort-care-and-hospice-care. A clear explanation of the distinctions between hospice, palliation and comfort care.

http://www.hpcintegration.ca/resources/the-national-framework.aspx. A Canadian report on integrated end of life care, summarized as: While the recent Supreme Court decision on the issue of physician-assisted suicide has captured most of the media attention over the past few months, a relatively small number of Canadians are likely to meet the criteria for those services. But everyone has the potential to benefit from the growing willingness to acknowledge that dying is part of living, and that people deserve and should receive an integrated palliative approach to care when they need – at all stages along their illness trajectory and in all settings of care.

https://www.ncbi.nlm.nih.gov/pubmed/7523740. Providing nutrition and hydration to those who are dying.

http://palliative.info/resource material/pneumonia eol.pdf. A clinical article focused on end of life pneumonia and how to treat it, as well as symptoms at the end of life and how to manage them.

http://willoweol.com. A blog on end of life planning with a 'heart will' questionnaire.

Comfort measures only: this means no other intervention or medications which are not related to making the patient more comfortable, that's no antibiotics, nor more lab work or diagnostic studies, therapies, or procedures; usually diet **as desired** (if the patient can take P.O), and oxygen treatments and medications to promote comfort are given. Note that in the dying patient, IV hydration causes more distress by preventing the natural decrease of secretions and urine, so IVs are usually stopped and discontinued period. Thirst is not an issue with the actively dying, but nausea and vomiting and wet lungs with a shortness of breath are. (oxygen and medications can provide relief).

DNR: so not resuscitate means no CPR, no intubation (although sometime this last has to be specified). No "code meds" sometimes notes specifics, like "no intubation," "no pressors," 'no external pacing," and the like, which may or may not include "comfort measures only," so be sure the doctor know what's wanted.

Physician Assisted Dying:

http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1 &DocId=8384014&Col=1. The Canadian Act passed in June 2016 on Physician Assisted Dying (PAD).

https://elplanning.ca/bill-c-14-medical-assistance-in-dying/. An explanation of the new assisted dying legislation.

Grief and Loss:

The 3 Kinds Of Grief Nobody Talks About - http://www.huffingtonpost.com/entry/different-kinds-of-grief us 572110f1e4b0f309baef8596

http://www.onbeing.org/blog/memoirs-of-a-griever/8000?utm source=On+Being+Newsletter&utm campaign=4d263dce37-20151017 mary oliver newsletter&utm_medium=email&utm_term=0_1c66543c2f-4d263dce37-69888813&mc_cid=4d263dce37&mc_eid=84da975901.

This article is entitled Memoirs of a Griever, a lovely description of the stages of grieving of a young woman who has lost her father.

http://thesunmagazine.org/issues/478/the geography of sorrow, Francis Weller on navigating our losses, The Sun Magazine.

A Daughter Pays Homage to Her Parents With an Intimate Look at Love and Loss, a photo journal, National Geographic,

http://proof.nationalgeographic.com/2015/10/19/a-daughter-pays-homage-to-her-parents-with-an-intimate-look-at-love-and-loss/.

https://onbeing.org/blog/mary-esselman-the-fish-a-story-of-love-and-letting-go/?utm source=On+Being+Newsletter&utm campaign=1012aa41d3-20170722 matthieu ricard newsletter&utm medium=email&utm term=0 1c66543 c2f-1012aa41d3-69888813&goal=0 1c66543c2f-1012aa41d3-69888813&mc cid=1012aa41d3&mc eid=84da975901. A beautiful 'fish story' about letting go of a close friend.

Green Burial and Other Alternatives:

http://amherstcremation.com/index.html. Taking care of the body, including green burial. Scott McFarlane comes highly recommended.

http://www.robp.ca/ and http://vancouver.ca/your-government/mountain-view-cemetery.aspx. Two cemeteries for green burial, the first, Royal Oaks, near Victoria on Vancouver Island has a natural 'woodlands' area. The second, Mountainview in Vancouver, offers cemetery plots for green burial.

http://www.naturalburialassoc.ca/how-it-works/. Another green burial site with lots of information.

<u>https://urnabios.com/.</u> A biodegradable urn including a tree seed to plant your ashes in after cremation.

Miscellaneous:

Five Choices You Will Regret Forever.

http://www.huffingtonpost.com/entry/five-choices-you-will-regret-forever us 591c7ce1e4b0e8f558bb22e7?section=us healthy-living&mc cid=f035c42a04&mc eid=18341693e6.

A Group Portrait of New York's 'Oldest Old' - <u>NYTimes.com</u> http://www.nytimes.com/2015/06/07/nyregion/a-group-portrait-of-new-yorks-oldest-old.html?emc=edit th 20150607&nl=todaysheadlines&nlid=46558113

Paul Kalinithi, *When Breath Becomes Air.* An article from the New Yorker on the book entitled <u>Meeting Death with Words</u> by Tom Rachman.

http://www.cbc.ca/news/health/organ-donation-family-veto-1.3874985. Care needs to be taken to have conversations about organ donation.

www.nidus.ca. Personal Planning Resource Centre and Registry for residents of BC.

https://itunes.apple.com/us/podcast/are-you-ready-for-glorious/id354668519?i=350702154&mt=2. A podcast on "The Glorious Sunset Plan", the idea of giving a cash bonus to those who choose NOT to have their life prolonged.

http://www.dailygood.org/story/482/the-body-s-grace-on-being/. Krista Tippett interviews Matthew Sanford about body-mind connection after his accident at 13 left him a paraplegic.

http://www.karmatube.org/videos.php?id=7604. A beautiful 5 minute animated film about The Life of Death, a reframing to decrease fear. Perfect for children.

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Bolan, Jean Shonola. (2007). *Close to the Bone: Life Threatening Illness as a Soul Journey.* San Francisco, CA: Red Wheel/Weizer.

Butler, Katy. (2013). *Knocking on Heaven's Door: The Path to a Better Way of Death.* New York: Simon & Schuster.

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Halifax, Joan. (2008). Being with Dying: Cultivating Compassion and Fearlessness in the Face of Dying. Boston, MA: Shambhala Publishers.

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Kubler Ross, Elizabeth. (1975). *Death: The Final Stage of Growth*. New York: Touchstone Books.

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Levine, Stephen. (1984). *Who Dies? An Investigation of Conscious Living and Conscious Dying.* New York: Anchor Books.

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Manahan, Nancy and Betty Bohan. (2007). *Living Consciously, Dying Gracefully: Journey with Cancer and Beyond.* Edina, MN: Beaver's Pond Press.

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Rinpoche, Sogyal, & Patrick Gaffney & Andrew Harvey. (1994). *The Tibetan Book of Living and Dying.* San Francisco, CA: Parker Publishers.

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Tatelbaum, Judy. (1984). *The Courage to Grieve: The Classic Guide to Creative Living, Recovery, and Growth through Grief.* New York: William Morrow Books.

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The differences between hospice and palliative care.

Hospice care and palliative care are very similar when it comes to the most important issue for dying people: care. Most people have heard of hospice care and have a general idea of what services hospice provides. What they don't know or what may become confusing is that hospice provides "palliative care," and that palliative care is both a method of administering "comfort" care and increasingly, an administered system of palliative care offered most prevalently by hospitals. As an adjunct or supplement to some of the more "traditional" care options, both hospice and palliative care protocols call for patients to receive a combined approach where medications, day-to-day care, equipment, bereavement counseling, and symptom treatment are administered through a single program. Where palliative care programs and hospice care programs differ greatly is in the care location, timing, payment, and eligibility for services.

Place

Hospice

Hospice programs far outnumber palliative care programs. Generally, once enrolled through a referral from the primary care physician, a patient's hospice care program, which is overseen by a team of hospice professionals, is administered in the home. Hospice often relies upon the family caregiver, as well as a visiting hospice nurse. While hospice can provide round-the-clock care in a nursing home, a specially equipped hospice facility, or, on occasion, in a hospital, this is not the norm.

Palliative Care

Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often at the facility where a patient will first receive treatment. These individuals will administer or oversee most of the ongoing comfort-care patients receive. While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility, or nursing home that is associated with a palliative care team.

Timing

Hospice

You must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from your insurance.

Palliative Care

There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not.