

Links for Endnotes

Hard Choices for Loving People, by Hank Dunn, 6th Edition

Below are the endnotes that appear in the 2016 6th Edition of *Hard Choices for Loving People*.

All the links were active as of February 2018.

Some of the sources are available for free and others may require purchase.

Publication Abbreviations:

- BMJ = *British Medical Journal*
- J Am Geriatr Soc = *Journal of the American Geriatrics Society*
- Am J Hosp Palliat Med = *American Journal of Hospice and Palliative Medicine*
- Am J Med = *American Journal of Medicine*
- JAMA = *Journal of the American Medical Association*
- N Engl J Med = *New England Journal of Medicine*
- Arch Intern Med = *Archives of Internal Medicine*
- J Gen Intern Med = *Journal of General Internal Medicine*
- J Pain Symptom Manage = *Journal of Pain and Symptom Management*
- Clin J Am Soc Nephrol = *Clinical Journal of the American Society of Nephrology*

This full listing of the endnotes and additional references is available at:

www.hankdunn.com/references.

Introduction

1. Lynn J. Dying and dementia (editorial). *JAMA*. 1986;256:2244–5.
<https://jamanetwork.com/journals/jama/article-abstract/362793?redirect=true>
2. Kaldjian LC, Curtis AE, Shinkunas LSA, Cannon KT. Goals of care toward the end of life: A structured literature review. *Am J Hosp Palliat Med*. 2009;25(6):501–11.
<http://ajh.sagepub.com/content/25/6/501.short>

Chapter One: CPR—Cardiopulmonary Resuscitation

3. Rea TD, Fahrenbruch C, Culley L, et al. CPR with Chest Compression Alone or with Rescue Breathing. *N Engl J Med*. 2010;363:423–33.
<http://www.nejm.org/doi/full/10.1056/NEJMoa0908993>
4. Standards and Guidelines for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC). *JAMA*.1986;255(21):2905–2984. <https://jamanetwork.com/journals/jama/article-abstract/404537?redirect=true>
5. Girotra S, Nallamothu BK, Spertus JA, et al. Trends in survival after in-hospital cardiac arrest. *N Engl J Med*. 2012;367:1912–20. <http://www.nejm.org/doi/full/10.1056/NEJMoa1109148>
6. Sehatzadeh S. Cardiopulmonary resuscitation in patients with terminal illness: An evidence-based analysis. *Ont Health Technol Assess Ser*. 2014;14(15):1–38.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4552960/>

7. Applebaum GE, King JE, Finucane TE. The outcome of CPR initiated in nursing homes. *J Am Geriatr Soc.* 1990;38(3):197–200. <https://www.ncbi.nlm.nih.gov/pubmed/2312998>
8. Booth CM, Boone RH, Tomlinson G, Detsky AS. Is this patient dead, vegetative, or severely neurologically impaired? Assessing outcome for comatose survivors of cardiac arrest. *JAMA.* 2004;291(7):870–9. <http://jama.jamanetwork.com/article.aspx?articleid=198222>
9. Duthie E, Mark D, Tresch D, Kartes S, Neahring J, Aufderheide T. Utilization of CPR in nursing homes in one community: Rates and nursing home characteristics. *J Am Geriatr Soc.* 1993;41(4):384–8. <http://www.ncbi.nlm.nih.gov/pubmed/8463524>

Chapter Two: Feeding Tubes—Artificial Nutrition and Hydration

10. Cranford RE. The persistent vegetative state: The medical reality (getting the facts straight). *Hastings Center Report.* 1988;18(1):27–32. https://www.jstor.org/stable/3562014?seq=1#page_scan_tab_contents
11. Peck A, Cohen CE, Mulvihill MN. Long-term enteral feeding of aged demented nursing home patients. *J Am Geriatr Soc.* 1990;38(11):1195–8. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.1990.tb01498.x/abstract>
12. Zopf Y, Konturek P, Nuernberger A, et al. Local infection after placement of percutaneous endoscopic gastrostomy tubes: A prospective study evaluating risk factors. *Canadian Journal of Gastroenterology.* 2008;22(12):987–991. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2661185/>
13. Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding tubes and the prevention or healing of pressure ulcers. *Arch Intern Med.* 2012;172(9):697–701. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555136/>
14. Hoefler JM. Making decisions about tube feeding for severely demented patients at the end of life: clinical, legal, and ethical considerations. *Death Studies.* 2000;24(3):233–54. <http://www.tandfonline.com/doi/abs/10.1080/074811800200568>
15. Curtis E. Harris, who is both a physician and a lawyer, states “I do not consider the provision of food and water to be the medical treatment of a disease. Provision of food and water is normal or ordinary supportive care.” Harris CE, Orr RD. The PVS debate: Even evangelical doctors may differ on this crucial issue. *Today’s Christian Doctor.* 1999;30(1):8–13. <https://www.cmda.org/library/doclib/TCD-Spring-1999.pdf>

Also the U.S. Conference of Catholic Bishops, “The Ethical and Religious Directives for Catholic Health Care Services, 5th ed.” (2009), no. 58. <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>

16. Former Surgeon General C. Everett Koop, along with the Association of American Physicians and Surgeons, filed papers arguing against withdrawal of the feeding tube. “The clear object of the petition here is to end the life of Ms. Cruzan, an intent which is inimical to the very nature of medicine.” *Brief for the Association of American Physicians and Surgeons.* *Cruzan v. Director of Missouri Department of Health*, 497 U.S. 261(1990)(No. 88–1503). <https://www.law.cornell.edu/supct/html/88-1503.ZS.html>

17. "By definition, a patient in an irreversible coma cannot eat and swallow and thus will die of that pathology in a short time unless life-prolonging devices are utilized to circumvent the pathology. Withholding artificial hydration and nutrition from a patient in an irreversible coma does not introduce a new fatal pathology; rather it allows an already existing fatal pathology to take its natural course." Father Kevin O'Rourke, The AMA statement on tube feeding: An ethical analysis. *America: The National Catholic Weekly*. Nov 1986;22:321–4.
<http://opcentral.org/resources/wp-content/uploads/sites/11/2013/04/86040708.htm>
18. Gostin L, Weir RF. Life and death choices after Cruzan: Case law and standards of professional conduct. *Milbank Q*. 1991;69(1):143–73
https://www.researchgate.net/publication/21122193_Life_and_Death_Choices_After_Cruzan_Case_Law_and_Standards_of_Professional_Conduct
19. Sullivan Jr. RJ, Jr. Accepting death without artificial nutrition or hydration. *J Gen Intern Med*. 1993;8(4):220–3. <https://link.springer.com/article/10.1007/BF02599271>
20. Printz LA. Terminal dehydration, a compassionate treatment. *Arch Intern Med*. 1992;152(4):697–700. <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/616132?redirect=true>
21. Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydration—fundamental principles and recommendations. *N Eng J Med*. 2005;353(24):2607–12.
<http://www.nejm.org/doi/full/10.1056/NEJMs052907>
22. Palecek EJ, Teno JM, Casarett DJ, Hanson LC, Rhodes RL, Mitchell SL. Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc*. 2010;58(3):580–4.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2872797/>
23. Reisberg B, Ferris SH, de Leon MJ, Crook T. The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*. 1982;139(9):1136–9.
<https://www.fhca.org/members/qi/clinadmin/global.pdf>
24. Friedrich L. End-of-life nutrition: Is tube feeding the solution? *Annals of Longterm Care*. 2013;21(10). <https://www.managedhealthcareconnect.com/content/nutrition-end-life-tube-feeding-solution>
25. Finucane T, Christmas C, Travis K. Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*. 1999;282(14):1365–70.
<http://jama.jamanetwork.com/article.aspx?articleid=191992>
26. Lynn J, Harrold J, Schuster JL. *Handbook for Mortals: Guidance for People Facing Serious Illness*, 2nd Edition. New York: Oxford University Press; 2011:169–170.
<https://www.amazon.com/Handbook-Mortals-Guidance-Serious-Illness/dp/0199744564>

Chapter Three: Cure Sometimes, Comfort Always

27. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who died within a three-year window. *J Pain Symptom Manage*. 2007;33(3):238–246. <https://www.nhpco.org/sites/default/files/public/JPSM/march-2007-article.pdf>

28. Lynn J, Harrold J, Schuster JL. *Handbook for Mortals: Guidance for People Facing Serious Illness*, 2nd Edition. New York: Oxford University Press; 2011:1–14.
<https://www.amazon.com/Handbook-Mortals-Guidance-Serious-Illness/dp/0199744564>
29. Vick JB, Pertsch N, Hutchings M, et al. The utility of the surprise question in identifying patients most at risk of death. Presented at: 2015 Palliative Care in Oncology Symposium; October 2015; Boston, MA. http://ascopubs.org/doi/abs/10.1200/jco.2015.33.29_suppl.8
30. Wright AA, Keating NL, Ayanian JZ, et al. Family perspectives on aggressive cancer care near the end of life. *JAMA*. 2016;315(3):284–92.
<https://jamanetwork.com/journals/jama/fullarticle/2482326>
31. Callahan, D. *The Troubled Dream of Life: In Search of a Peaceful Death*. Washington, DC: Georgetown University Press; 1993:201–2. http://www.amazon.com/Troubled-Dream-Life-SearchPeaceful/dp/0878408150/ref=sr_1_4?s=books&ie=UTF8&qid=1338808526&sr=1-4
32. Aldridge MD, Canavan M, Cherlin E, Bradley EH. Has hospice use changed? 2000–2010 utilization patterns. *Med Care*. 2015;53(1):95–101.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4262565/>
33. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: Impact on treatment goals and integration of palliative care. *JAMA*. 2000;284(19):2469–75. <https://jamanetwork.com/journals/jama/fullarticle/193278>
34. McCabe MA, Rushton CH, Glover J, Murray MG, Leikin S. Implications of the patient self-determination act: Guidelines for involving adolescents in medical decision making. *J Adolescent Health*. 1996;19(5):319–24. <http://www.jahonline.org/article/S1054-139X%2896%2900160-7/abstract>
35. American Academy of Pediatrics Committee on Bioethics. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994;93(3):532–6.
<http://pediatrics.aappublications.org/content/93/3/532.abstract>

Chapter Four: Treatments to Consider—Practical Help for Decision Making

36. Lacey D. Tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia: Perceptions of key medical decision-makers. *American Journal of Alzheimer's Disease and Other Dementias*. 2005;20:211. <http://aja.sagepub.com/content/20/4/211.short>
37. Heunks LM, van der Hoeven JG. Clinical review: The ABCs of weaning failure—a structured approach. *Critical Care*. 2010;14(6):245.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3220047/>
38. Ankrom M, et al. Elective discontinuation of life-sustaining mechanical ventilation on a chronic ventilator unit. *J Am Geriatr Soc*. 2001;49(11): 1549–54.
<https://www.ncbi.nlm.nih.gov/pubmed/11890598>
39. Wong SP, Kreuter W, O'Hare AM. Treatment intensity at the end of life in older adults receiving long-term dialysis. *Arch Inter Med*. 2012;172(8): 661–3.
<https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/1135410>

40. Davison SN. End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010;5(2):195–204. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2827591/>
41. Kurella TM, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med*. 2009;361(16):1539–47. <http://www.nejm.org/doi/full/10.1056/NEJMoa0904655>
42. Span P. Learning to Say No to Dialysis. *The New York Times*. March 27, 2015. <https://www.nytimes.com/2015/03/31/health/learning-to-say-no-to-dialysis.html>
43. United States Renal Data System. 2015 USRDS annual data report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2015. https://www.usrds.org/2015/download/vol2_USRDS_ESRD_15.pdf
44. O'Connor NR, Dougherty M, Harris PS, Casarett DJ. Survival after dialysis discontinuation and hospice enrollment for ESRD. *Clin J Am Soc Nephrol*. 2013;8(12):2117–22. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3848402/>
45. United States Renal Data System. 2017 USRDS annual data report: Atlas of end-stage renal disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2017: https://www.usrds.org/2017/view/v2_12.aspx
46. Renal Physicians Association and American Society of Nephrology. Shared Decision Making in the Appropriate Initiation of Withdrawal from Dialysis: *Clinical Practice Guideline*, 2nd Ed. Rockville, MD: Renal Physicians Association; 2010. https://c.ymcdn.com/sites/www.renalmd.org/resource/resmgr/Store/Shared_Decision_Making_Toolk.pdf
47. Matlock DD, Stevenson LW. Life-saving devices reach the end of life with heart failure. *Prog Cardiovasc Dis*. 2012;55(3):274–81. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3523274/>
48. Bevins MB. The ethics of pacemaker deactivation in terminally ill patients. *J Pain Symptom Manage*. 2011;41(6):1106–10. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00202-8/pdf](http://www.jpmsjournal.com/article/S0885-3924(11)00202-8/pdf)
49. National Hospice and Palliative Care Organization. Pain at the End of Life—Common Questions. *Caring Info*. Published 2013. Accessed March 1, 2016. http://www.caringinfo.org/files/public/brochures/EOL_Questions.pdf
50. Fine RL. Ethical and practical issues with opioids in life-limiting illness. *Proc (Baylor University Medical Center)*. 2007;20(1):5–12. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1769525/>
51. Azoulay D, Hammerman-Rozenberg R, Cialic R, Ein Mor E, Jacobs JM, Stessman J. Increasing opioid therapy and survival in a hospice. *J Am Geriatr Soc*. 2008;56(2):360–1. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2007.01536.x/abstract>
52. Olsen ML, Swetz KM, Mueller PA. Ethical decision making with end-of-life care: Palliative sedation and withholding or withdrawing life-sustaining treatments. *Mayo Clinic Proceedings*. 2010;85(10):949–54. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947968/>

Chapter Five: The Journey to Letting Be—The Emotional and Spiritual Issues

53. Fusgen I, Summa JD. How much sense is there in an attempt to resuscitate an aged person? *Gerontology*. 1978;24(1):37–45. <https://www.karger.com/Article/Abstract/212235>
54. Tresch DD, Neahring JM, Duthie EH, Mark DH, Kartes SK, Aufderheide TP. Outcomes of cardiopulmonary resuscitation in nursing homes: Can we predict who will benefit? *Am J Med*. 1993;95(2):123–30. [http://www.amjmed.com/article/0002-9343\(93\)90252-K/pdf](http://www.amjmed.com/article/0002-9343(93)90252-K/pdf)
55. Justice C. The “natural” death while not eating: A type of palliative care in Banaras, India. *J Palliat Care*. 1995;11(1):38–42. <http://psycnet.apa.org/record/1995-37542-001>
56. Stoddard S. *The Hospice Movement: A Better Way of Caring for the Dying*. New York: Random House, Inc.; 1991:xii. https://www.amazon.com/Hospice-Movement-Better-Caring-Dying/dp/0679734678/ref=sr_1_1?s=books&ie=UTF8&qid=1338809784&sr=1-1
57. Mitchell SL. A 93-year-old man with advanced dementia and eating problems. *JAMA*. 2007;298(21):2527–36. <https://jamanetwork.com/journals/jama/article-abstract/209670?redirect=true>
58. Sonnenblick M, Friedlander Y, Steinberg A. Dissociation between the wishes of terminally ill parents and decisions of their offspring. *J Am Geriatr Soc*. 1993;41:599–604. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.1993.tb06729.x/abstract>
59. Thomasma DC. Reflections on the offspring’s ethical role in decisions for incompetent patients: A response to Sonnenblick, et al. (editorial), *J Am Geriatr Soc*. 1993;41:684–6. <http://onlinelibrary.wiley.com/wol1/doi/10.1111/j.1532-5415.1993.tb06746.x/full>
60. Rinpoche S. *The Tibetan Book of Living and Dying*. New York: Harper; 1992:34–5. https://www.amazon.com/Tibetan-Book-Living-Dying-International/dp/0062508342/ref=sr_1_1?s=books&ie=UTF8&qid=1338809838&sr=1-1
61. Koch KA, Rodeffer HD, Wears RL. Changing patterns of terminal care management in an intensive care unit. *Critical Care Medicine*. 1994;22:233–43. <http://europepmc.org/abstract/MED/8306681>
62. Callahan, D. *The Troubled Dream of Life: In Search of a Peaceful Death*. Washington, DC: Georgetown University Press; 1993:149–151. https://www.amazon.com/Troubled-Dream-Life-Search-Peaceful/dp/0878408150/ref=sr_1_4?s=books&ie=UTF8&qid=1338808526&sr=1-4
63. Finucane TE, et al. The incidence of attempted CPR in nursing homes. *J Am Geriatr Soc*. 1991;39:624–6. <https://www.ncbi.nlm.nih.gov/pubmed/2037756>
64. Becker, E. *The Denial of Death*. New York: The Free Press, 1973. https://www.amazon.com/Denial-Death-Ernest-Becker/dp/0684832402/ref=sr_1_1?s=books&ie=UTF8&qid=1338811567&sr=1-1
65. Singh, KD. *The Grace in Dying: How We are Transformed Spiritually as We Die*. New York: HarperCollins, 1998. https://www.amazon.com/Grace-Dying-How-Transformed-Spiritually/dp/0062515659/ref=sr_1_1?s=books&ie=UTF8&qid=1338811636&sr=1-1
66. Callahan D. “Death: ‘The distinguished thing.’” *Hastings Center Report* 2005;35(6):S5–S8. <https://muse.jhu.edu/article/189611/pdf>

67. Niebuhr, R. "The Serenity Prayer" (1934), quoted in *Familiar Quotations*, 16th Edition, edited by John Bartlett, Justin Kaplan, Boston: Little, Brown and Company, 1992:684. <https://www.amazon.com/Bartletts-Familiar-Quotations-16TH-Bartlett/dp/B000WD6ADQ>
<http://www.nytimes.com/2008/07/11/world/americas/11iht-prayer.1.14419826.html>
68. Rinpoche S. *The Tibetan Book of Living and Dying*. New York: Harper; 1992:33. https://www.amazon.com/Tibetan-Book-Living-Dying-International/dp/0062508342/ref=sr_1_1?s=books&ie=UTF8&qid=1338809838&sr=1-1
69. Psalms 103:14–16. <https://www.biblegateway.com/passage/?search=Psalm%20103:14-16>
70. Dunn H. *Light in the Shadows: Meditations While Living with a Life-Threatening Illness*, 2nd Edition. Naples, FL: Quality of Life Publishing Co.; 2005:67. <https://www.amazon.com/Light-Shadows-Meditations-Life-Threatening-Illness/dp/0997261234>
71. Frankl VE. *Man's Search for Meaning*. New York: *Washington Square Press*; 1984:90. https://www.amazon.com/Mans-Search-Meaning-Viktor-Frankl/dp/0807014273/ref=sr_1_1?s=books&ie=UTF8&qid=1338810003&sr=1-1
72. Flannery O'Connor letter to Betty Hester, June 28, 1956. *The Habit of Being: Letters of Flannery O'Connor*. New York: Farrar, Straus and Giroux; 1979:163. https://www.amazon.com/Habit-Being-Letters-Flannery-1979-01-03/dp/B01FKWA2X2/ref=sr_1_3?s=books&ie=UTF8&qid=1518729241&sr=1-3&keywords=the+habit+of+being+1979
73. Nuland, SB. *How We Die: Reflections on Life's Final Chapter*, New York: Alfred A. Knopf; 1993:138–139. https://www.amazon.com/How-We-Die-Reflections-Chapter/dp/0739344323/ref=sr_1_1?s=books&ie=UTF8&qid=1338810104&sr=1-1
74. Stoddard S. *The Hospice Movement: A Better Way of Caring for the Dying*. New York: Random House, Inc.; 1991:204–205. https://www.amazon.com/Hospice-Movement-Better-Caring-Dying/dp/0679734678/ref=sr_1_1?s=books&ie=UTF8&qid=1338809784&sr=1-1
75. Rinpoche S. *The Tibetan Book of Living and Dying*. New York: Harper; 1992:95. https://www.amazon.com/Tibetan-Book-Living-Dying-International/dp/0062508342/ref=sr_1_1?s=books&ie=UTF8&qid=1338809838&sr=1-1
76. Stoddard S. *The Hospice Movement: A Better Way of Caring for the Dying*. New York: Random House, Inc.; 1991:211, 225. https://www.amazon.com/Hospice-Movement-Better-Caring-Dying/dp/0679734678/ref=sr_1_1?s=books&ie=UTF8&qid=1338809784&sr=1-1
77. Hillesum E. *An Interrupted Life and Letters from Westerbork*. New York: Henry Holt & Co.; 1981:155. https://www.amazon.com/Etty-Hillesum-Interrupted-1941-1943-Westerbork/dp/0805050876/ref=sr_1_1?s=books&ie=UTF8&qid=1338810138&sr=1-1
78. Quoted in: Petersen D. "Where the Phantoms Brood and Mourn." *Backpacker*. 1993;21(7):40–8. <https://business.highbeam.com/435688/article-1G1-14218266/phantoms-brood-and-mourn>
79. Siegel B. "Laughing Matters" (interview). 1990;6(4):127–39. <https://www.humorproject.com/doses/interview.php?number=4>