

Faithfully Facing Dying: A Lenten Study Guide on Critical Issues and Decisions for the Members of the United Church of Christ

Resources

UCC Resources:

Bruce Epperly, & John Mills (2009). *A word to the Church on end of life care: Theological, spiritual, and ethical reflections*. <http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethical-spiritual-resources.pdf>

Julie R. Harley, Ed., *Making End-of-Life Decisions: United Church of Christ Perspectives*, 1993.1997 updated: <http://www.deathisnottheenemy.com/media/media-115462.pdf>

GS Resolutions:

GS 26 (2007) Resolution on “Legalization of Physician Aid in Dying” Background and Theological Statement: <http://www.ucc.org/synod/resolutions/physician-aid-in-dying-final.pdf>

GS 27 (2009) Proposed resolution from the Central Atlantic Conference, “In Support of Physician Assistance in Dying,” referred by Executive Council for study: <http://www.ucc.org/synod/resolutions/g27/g27-18.pdf>

GS 27 (2009) Follow up on Legalization of Physician Aid in Dying – Working Group Report <http://www.ucc.org/synod/pdfs/g27report-pas.pdf>

Websites:

On Our Own Terms: Moyers on Dying Companion for the PBS Special <http://www.pbs.org/wnet/onourown/terms/>

Growth House’s primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Their search engine gives you access to the Internet's most comprehensive collection of reviewed resources for end-of-life care. <http://www.growthhouse.org/>

Respecting Choices – an advance care planning system <http://www.respectingchoices.org/>

National Hospice and Palliative Care Organization website www.nhpco.org

Hospice Foundation www.hospicefoundation.org

American Academy of Hospice and Palliative Medicine www.aahpm.org

Dying Well www.dyingwell.com

Death is not the Enemy www.deathisnottheenemy.com

Websites for State Health Care Proxy and Living Will Forms

This website will enable you to download a form that is acceptable for your specific state. <http://www.caringinfo.org/stateaddownload>

Websites for Other Advance Care Planning Documents:

Caring Conversations Center for Practical Bioethics

<http://www.practicalbioethics.org/cpb.aspx?pgID=986>

Finding your Way Sacramento Health Care Decisions

<http://www.sachealthdecisions.org/finding.html>

Five Wishes <http://www.agingwithdignity.org/5wishes.html>

Respecting Choices An advance care planning system from Gundersen Lutheran Medical Foundation <http://www.respectingchoices.org/>

Ethical Wills:

Offers a way to leave your legacy by writing down your values and beliefs.

www.ethicalwill.com

Information about Organ Donation:

U.S. Government information about organ and tissue donation and transplantation

<http://www.organdonor.gov/>

Donate Life America <http://www.donatelife.net/>

The Gift of a Lifetime: Organ & Tissue Transplantation in America

<http://www.organtransplants.org/>

Other Web Resources:

The Hastings Center Bioethics Briefing Book, which you will find on line at

<http://www.thehastingscenter.org/Publications/BriefingBook/Default.aspx>. The Hastings

Center is a non-partisan research institution dedicated to bioethics and the public

interest since 1969. We have cited this briefing book in several areas of our study guide

and we believe you will find them of help as you prepare to lead these sessions.

Download-able PDF's

The report from Congressional Research Service/Congressional Research Reports for the People, End-of-Life Care: Services, Costs, Ethics and Quality of Care, published in February 2009. The report can be downloaded from http://assets.opencrs.com/rpts/R40235_20090223.pdf.

Improving End of Life Care: Why Has It Been So Difficult? A Special Report from The Hastings Center. <http://www.webmedleystb.com/media/media-189617.pdf>

Recognizing Death while Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life? by Adrienne Asch
<http://www.webmedleystb.com/media/media-189616.pdf>

Selected Additional Print Resources

Books

David John Doukas and William Reichel, *Planning for Uncertainty: Living Wills and Other Advance Directives for You and Your Family*, 2nd ed. (Baltimore: Johns Hopkins University Press, 2007). As the title suggests, this book is an in-depth guide to advance care planning.

Arthur J. Dyck, *When Killing Is Wrong: Physician-Assisted Suicide and the Courts* (Cleveland: Pilgrim Press, 2001). An moral analysis of court decisions that culminated in the Supreme Court's 1997 denial of a Constitutional right to physician aid in dying. The author clearly favors the Court's action (note that the UCC's Pilgrim Press is the publisher).

Kathleen Foley and Herbert Hendin, eds., *The Case Against Physician-Assisted Suicide: For the Right to End-of-Life Care* (Baltimore: Johns Hopkins University Press, 2002). This collection of essays makes a case against PAS; a companion collection (below) argues for the availability of PAS.

J. Giordano and M. D. Boswell, eds., *Pain Medicine: Philosophy, Ethics, and Policy* (Chicago: Linton Atlantic Books, 2009). Wide-ranging consideration of pain management issues. Some essays may seem rather heavy on the philosophy, but there are instructive chapters on legal and regulatory factors constraining pain control, inadequate training of clinicians in understanding and managing pain, and more.

Ronald P. Hamel and Edwin R. DuBose, eds., *Must We Suffer Our Way to Death? Cultural and Theological Perspectives on Death by Choice* (Dallas: Southern Methodist University Press, 1996). An older collection that often pairs “euthanasia” with “physician-assisted suicide” in its focus. The discussions of multiple Christian perspectives and a Jewish perspective on “death by choice” are still enlightening. Beware one error: The sole reference to UCC views (p. 46) mistakes a 1991 Conference resolution supporting “assisted suicide” for a denomination-wide action.

Martha R. Jacobs, *A Clergy Guide to End-of-life Issues*, (Cleveland: The Pilgrim Press, 2010). A new book that provides clergy with specific tools to help families navigate end-of-life issues and a graceful death. It offers a foundational understanding about end-of-life issues for clergy so that they can put their own issues around dying aside to assist others in charting their own course through life’s end.

Phillip M. Kleespies, *Life and Death Decisions: Psychological and Ethical Considerations in End-Of-Life Care*, (Washington, DC, American Psychological Association, 2004). An excellent resource, although highly clinical, to assist in understanding the various end-of-life issues that arise for people.

Charles Meyer, *A Good Death: Challenges Choices and Care Options* (New London: Twenty-Third Publications, May 1998). This little book is an excellent resource for clergy to use in their considerations about end of life issues and how they discuss them with their congregants.

Margaret E. Mohrmann, *Medicine as Ministry: Reflection on Suffering, Ethics and Hope*, (Cleveland: The Pilgrim Press, 1995). This book emphasized the importance of interpreting the lives of the suffering as meaningful and ongoing stories – stories that require us to respond in healing ways. Both pastoral and prophetic, Mohrmann challenges us to rethink the purposes of health care- and to better discern the human condition.

Timothy E. Quill and Margaret P. Battin, eds. *Physician-Assisted Suicide: The Case for Palliative Care and Patient Choice* (Baltimore: Johns Hopkins University Press, 2004). This collection of essays makes a case for PAS, and is the counterpart to Foley and Hendin’s edited collection (above) arguing against PAS.

Lawrence J. Schneiderman, *Embracing Our Mortality: Hard Choices in an Age of Medical Miracles*. A compact, quite readable volume aimed at helping people prepare for and face difficult medical situations and decisions. The author’s passing references to PAD are not altogether clear or consistent, but the book is useful in many respects.

David H. Smith, *Partnership with the Dying: Where Medicine and Ministry Should Meet*, (New York: Rowman & Littlefield, 2005). Based on interviews with a cross sample of health care professionals, Smith details how the churches could not only be supportive

of these primary caregivers but also enlist their help in informing their own congregations about the realities of death and dying.

Articles

Harriet Goetz, "Euthanasia: A Bedside View," *Christian Century* 106, no. 20 (June 21-28, 1989), 619-622. A classic article written by a nurse. May be harder to find than some, but worth the search. While the title's focus on "euthanasia" is not the subject of the UCC study guide, the arguments Goetz takes up (and makes) are often germane to what is today called physician aid in dying. Particularly noteworthy are the author's theological arguments favoring the availability of "euthanasia."

Katrina Hedberg et al., "The 10-Year Experience of Oregon's Death with Dignity Act: 1998-2007," *Journal of Clinical Ethics* 20, no. 2 (Summer 2009): 124-132. Attends to some features of Oregon's data that are not often cited, such as a small but real incidence of complications arising in the use of medications prescribed for PAD, a significant recent decrease in requests for psychiatric assessments of patients requesting PAD, an increase in reports of inadequately managed pain, and the reality that a handful of physicians write a significant percentage of the prescriptions for PAD.

Multiple articles on Oregon's experience with PAD, in *American Journal of Bioethics* 20, no. 9 (March 2009): 1-2, 19-34. A "target article" and three responses address Oregon's "experience" with legalized PAD. The target article finds no indication that fears about higher incidences of PAD in identified vulnerable populations have been realized. The respondents do not refute this claim but do raise other issues. In addition, an editorial reflects on the concentration of legalized PAD in the Pacific Northwest (first Oregon, and recently Washington).

Judith K. Schwartz, "Voluntarily Stopping Eating and Drinking," *American Journal of Nursing* 109, no. 9 (September 2009): 53-61. An excellent overview of VSED by a nurse on staff at Compassion and Choices (an advocacy organization). The author presents an account of a patient's decision for VSED as the best option available to her and follows the process to the patient's death. Also a first-rate set of references pointing to relevant literature on this subject.

Resources from the Support for Physician Aid in Dying/Physician-Assisted Suicide

www.compassionandchoices.org: A leading proponent of a wide range of choices at the end of life, including physician aid in dying in carefully safeguarded circumstances; many links to specific topics

California Mediated Public Policy Dialogue on Physician-Assisted Suicide and End-of-Life Issues: "Improving Care at Life's End" – California State Assembly's Select Committee on Palliative Care, RESOLVE and The Adams Group, 2002. (Out of print; essays in support and in opposition to Physician Aid in Dying/Physician Assisted Suicide available from johnrbrooke@earthlink.net)

www.physicianaidindying.com This website presents a timeline on how a local church proposal became a Conference Position Statement, then a proposed Resolution to General Synod, then an amended Resolution which Synod approved, leading to a Task Force which studied and expanded the subject matter to include a wide range of end-of-life issues, and finally to a Lenten Study Guide engaging congregations, associations and conferences in a denomination-wide study. It is an example of UCC polity at work. Links include earlier General Synod resolutions (1973 and 1991); a full copy of the landmark Oregon law as enacted in 1997; a list of the safeguards contained in the Oregon law; full text of the proposed resolution as originally submitted to General Synod by the Northern California Nevada Conference; and other links, including an article entitled "Don't Call It Suicide."

www.apha.org: American Public Health Association (APHA) Policy No. 20086 (2008): "Patients' Rights to Self-Determination at the End of Life"

"Privacy and Dignity at the End of Life: Protecting the Right of Montanans to Choose Aid in Dying," Kathryn L. Tucker, *Montana Law Review*, Summer 2007, pp. 317-332.

"Death Do Us Part" by Barry Corbet in *New Mobility* magazine – "a magazine for active wheel chair users", April, 1997: a conversation from two disability rights activists (Andrew Batavia and Paul Longmore) on opposite sides of whether physician aid in dying should be legal in limited circumstances

Resources on Disability Experience, Culture, Rights, and Physician Aid in Dying/Physician-Assisted Suicide

Disability Rights Education and Defense Fund (DREDF) is a wonderful source on the legal rights of individuals with disabling conditions, including those with terminal illness. http://www.dredf.org/assisted_suicide/index.shtml

The National Council on Independent Living provides information on Independent Living and links to 369 Centers across the U.S. which offer a wide range of programs and services to help people with any disabling condition, including terminal illness. www.ncil.org

Powers, Hélène. *Friends Indeed: How to Help During a Serious Illness*. Part memoir, part how-to-guide and resource manual, this booklet tells the story of a group of friends

who organized themselves to care for Adam de la Barr and his wife H el ene Powers during the last year of Adam’s life. <http://www.fiftyshift.com/content/buy-our-booklet-friends-indeed-how-help-during-a-serious-illness>.

Brightman, Alan J., *Ordinary Moments: The Disabled Experience*. Syracuse: Human Policy Press, 1985, also Baltimore: University Park Press, 1984. A glimpse into the living with disability written by eight adults with a wide range of disabilities from muscular dystrophy and deafness to amputation. The opening chapter is written by Denise Karuth, one of the authors of this Lenten study series.

Longmore, Paul K. *Why I Burned My Book and Other Essays on Disability* Philadelphia: Temple University, 2003. This book details the disability community’s efforts to address social prejudice and oppression.

Pelka, Fred. *The ABC-CLIO Companion to the Disability Rights Movement*, Santa Barbara: ABC-CLIO, Inc, 1997. An encyclopedic dictionary featuring significant individuals, historical events, concepts, organizations, and every Supreme Court case related to disability. Clearly written, extremely informative and engaging, it’s a page-turner!

Shapiro, Joseph. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Times Books, 1993, 1994. This book describes the disability community’s efforts to shift the perception of people with disabilities from objects of pity to fellow citizens who deserve their full civil rights. A great book with powerful stories, it also shows parents of children with disabilities the potential and possibilities of their children.

Shaw, Barrett. *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*. Louisville: Avocado Press, 1994. This book is wonderful way to immerse yourself in disability culture, experience, politics and recent history.

Physician Aid in Dying/Physician-Assisted Suicide Resources

Disability Rights Education and Defense Fund (DREDF) assisted suicide links. http://www.dredf.org/assisted_suicide/index.shtml

Not Dead Yet offers press reports about physician-assisted suicide and euthanasia <http://www.notdeadyet.org>

Physician Aid in Dying/Physician-Assisted Suicide Bibliography (Please also see the notes to “A Plea on Behalf of Disability Rights Activists.”)

- Anspach, Renee. *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*. Berkeley: Univ. of California Press, 1993.
- Dyck, Arthur et al. *Life's Worth: The Case Against Assisted Suicide*. Grand Rapids, MI: William B. Eerdmans Publishing Co., 2002.
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- Ganzini, Linda. Psychiatry and Assisted Suicide in the United States. *N Engl J Med* 1997; 336:1824-26.
- Jeffrey, David. *Against Physician Assisted Suicide: A Palliative Care Perspective* Radcliffe: Medical PR. October 2008.
- Marker, Rita Marker. *Deadly Compassion: The Death of Ann Humphry and the Truth About Euthanasia*. New York: William Morrow, 1993.
- Smith, Wesley J. *Culture of Death: The Assault on Medical Ethics in America*. San Francisco: Encounter Books. 2000.
- Smith, Wesley J. *Forced Exit: the Slippery Slope from Assisted Suicide to Legalized Murder*. Dallas: Spence Publishing, 2003.
- Somerville, Margaret. *Death Talk: the Case Against Euthanasia and Physician-assisted Suicide*. Margaret Somerville. Montreal: McGill-Queen's University Press, 2001.
- Stevens, Kenneth R. Jr., M.D., "The Consequences of Physician-Assisted Suicide Legalization." <http://www.pccef.org/articles/art42UofO.htm>, 2005.