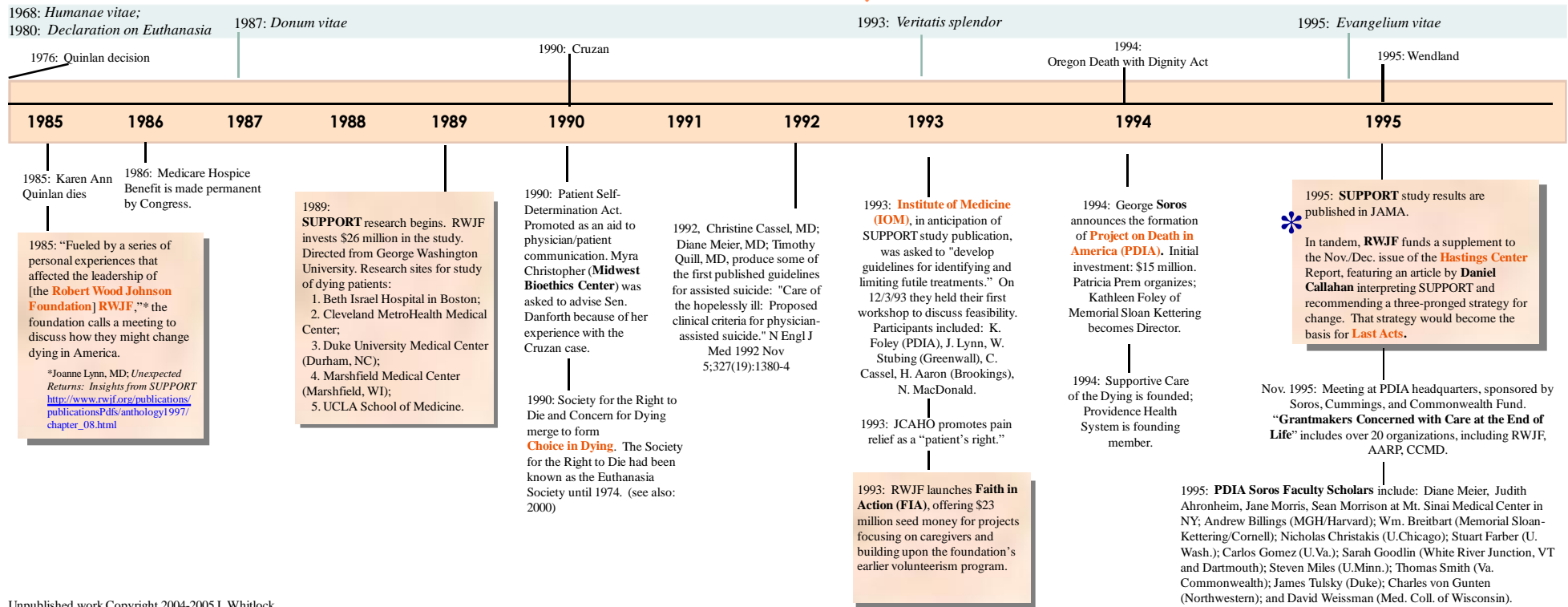


Foundation collaboration: *two decades to an American Culture of Death*



Unpublished work Copyright 2004-2005 I. Whitlock
The information on this timeline is an overview of the chronology at <http://www.lifetree.org/timeline.html>.

* Last Acts:

Ira Byock supplies levers to move a "culture of denial."

Last Acts held its first leadership conference in March, 1996, in Arlington, Virginia. Daniel Callahan set the overall strategy.

Strategy for Change

- 1) Create opportunities for talking about death
- 2) Change the language (Including: "Establish working relationships with educators in secondary school systems, particularly those who teach family life or health, aimed at making the vocabulary of death and dying more natural.")
- 3) Promote advance care planning
- 4) Improve communications skills of health care professionals
- 5) Strengthen health care professional education related to death and dying.
- 6) Palliative care -- move it upstream
- 7) Develop measurement methods. (Outcomes-based death)
- 8) Broaden insurance coverage of palliative care and counseling.

- 9) Hospice: Incorporate successes of the hospice movement into other health care settings.
- 10) Identify other institutional models demonstrating humane, effective, and realistic approaches to caring for patients near the end of their lives.
- 11) Reduce the misunderstandings about legal issues surrounding care at the end of life.

The second Last Acts conference was held in 1997. Ira Byock gave the keynote address, setting out tactics for the movement:

Levers of Change

- 1) Standards
- 2) Measurement based on standards.
- 3) Accreditation and Certification
- 4) Policy and Public

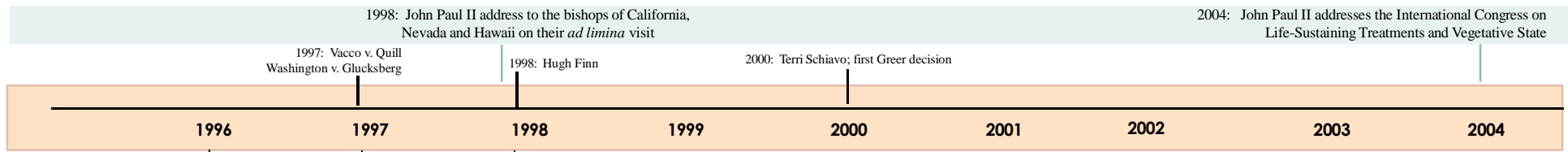
Agents of Change:

- 1) Medical Establishment
- 2) Boomer Consumers
- 3) Payors
- 4) Funders of Research and Demonstrations
- 5) Media

"In my own practice, while I steadfastly refuse to write a prescription with lethal intent or otherwise help the patient commit suicide, I can share with the patient information that he or she already has the ability to exert control over the timing [of] death. Virtually any patient with far-advanced illness can be assured of dying -- comfortably, without any additional physical distress -- within one or two weeks simply by refusing to eat or drink."

Ira Byock, *American Journal of Hospice and Palliative Care*; pp. 8-13, March/April 1995.
<http://www.dyingwell.com/pmnh.htm>

- References:**
- 1996 Last Acts leadership conference (see "Challenges and Opportunities" and "Next Steps"): http://web.archive.org/web/20030716044704re_/www.lastacts.org/la_ala/la_abt_conf-a.htm
 - 1997 Last Acts leadership conference: http://web.archive.org/web/20040124181710re_/www.lastacts.org/la_ala/levtoc.htm



1996: March 12: **Last Acts** convenes its first national leadership conference, which was built around **Callahan's three themes**:

- 1) improve communication & decision-making
- 2) change health care institutions
- 3) change American culture & attitudes toward death.

Oct. 1997: Last Acts, Second Leadership Conference: "Leverage Points." Ira Byock, in his keynote address, lists "Levers to Move a Culture of Denial."

1998: Christine Cassel, Diane Meier, Sean Morrison, Timothy Quill produce a "Survey of Physician Assisted Suicide and Euthanasia in the United States" (*NEJM*, 4/23/98). The next day, the New York Times publishes Diane Meier's "Change of Heart" on assisted suicide.

1999: "Roman Catholic EPEC" <http://epeconline.net/EPEC/webpages/partnerrc.cfm>
In 1999, Myles Sheehan, S.J., MD, was awarded PDIA grant to create EPEC for Catholics. http://www.2.soros.org/death/1999_fs.htm
Working with Supportive Care of the Dying and Partnership for Caring, the result was unveiled in 2002 as "Recovering Our Traditions."

2000: Byock & Quill: "Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids," *Annals of Internal Medicine*, March 7, 2000; Volume 132 Issue 5, Pages 408-414. <http://www.annals.org/cgi/content/full/132/5/408>

2001: **Faith in Action** moves from NY to Wake Forest Medical School. The project is directed by Burton Reifler, M.D., M.P.H.

2002: **Rallying Points** names three regional resource centers:
• Hospice of the Florida Suncoast
• Midwest Bioethics
• Missoula Demonstration Project.

2003: "Palliative Sedation," written by Edward Yellig, MD, (medical director of Hospice of Wake County, North Carolina) is published in the *Wake County Physician*, the newsletter of the Wake County Medical Society Summer (3rd Quarter), 2003
2003: C. Cassel, MD, & T. Quill, MD, re PAS: "We argue in favor of medical organizations' taking a position of studied neutrality on this contentious issue." -*Annals of Internal Medicine*. Vol. 138, Issue 3, pp. 208-211.

2004: **Partnership for Caring** merges with **Last Acts**, and as of Jan. 2004, they become **Last Acts Partnership**; new focus is lobbying. Karen Kaplan leaves LAF to join Wye River Group on Healthcare, and Mount Sinai medical faculty.
2004: Richard Payne, MD, moves to the Duke Institute.

April, 1996: IOM hosts first of two public hearings. Christine Cassel hosts the program; participants include Ira Byock, Colleen Scanlon, Joseph Fins, Linda Blank, Thomas Reardon, Gretchen Brown, Melanie Merriman, Charles Sabatino.

Sep 24, 1996: Assisted-Suicide Funding Restriction Act introduced in House by Ralph Hall (D-TX) and Senate by Byron Dorgan (D-ND). The bill excepted: "(1) the withholding or withdrawing of medical treatment or medical care; (2) the withholding or withdrawing of nutrition or hydration; (3) abortion; or (4) the use of an item, good, benefit, or service furnished for the purpose of alleviating pain or discomfort, even if such use may increase the risk of death, so long as such item, good, benefit, or service is not also furnished for the purpose of causing, or the purpose of assisting in causing, death, for any reason."

1998: **Choice in Dying** coordinating center for health care agent project launches with \$115,000 from Samuels Foundation.

1999: Midwest Bioethics Center announces \$11.5 million "**Community-State Partnerships**" project, to work with state end-of-life coalitions. Developed on a model inspired by James Towey.

2000: **Choice in Dying** reorganizes to become **Partnership for Caring (PFC)**. By August of that year, RWJF awards PFC \$1 million, names PFC as Last Acts national program office, and taps Karen Orloff Kaplan to direct **Last Acts**.

2002: National Hospice and Palliative Care Organization (NHPCO) awards Partnership for Caring (right-to-die advocates) the "Award for Excellence in Public Education," and names Karen Orloff Kaplan "2002 Person of the Year."

2003: *Boston Globe* reports the **end of the RWJF and Soros end-of-life projects**. "... the Project on Death in America, financed by billionaire George Soros and the [RWJF] poured more than \$200 million over the last decade into end-of-life programs and research." (Carey Goldberg, *Globe Staff*, 11/9/2003) **Projects will seek other funding sources. (Continuing via: NHPCO, AAHPM, NIH, and others)**

Daniel Callahan's

3 bullet points, modified slightly by an Institute of Medicine (IOM) recommendation, became the strategy for Last Acts

Objectives included:
--change American death-denying culture to death-accepting culture;
--normalize withholding/withdrawing nutrition & hydration;
--provide avenue for hastening death by use of opioids.

Soros PDIA scholars were principal investigators for many of the RWJF-funded projects.

Professional Education

Physicians (EPEC)
1996: **EPEC** -- Education for Physicians on End of Life Care. Linda Emanuel [RWJF; Oxford/Cambridge/Harvard] develops the EPEC curriculum with Charles F. von Gunten, MD, PhD [Soros], Frank D. Ferris, MD [Soros 1998; Canadian] and Russell Portenoy, MD [Soros 1998]. RWJF: \$5 million; Soros approx \$140,000.

Nurses (ELNEC)
1997: RWJF grants approx. \$800,000 to City of Hope, and approx. \$27,000 to AACN to begin review of nurses' education. This sets groundwork for the **End-of-Life Nursing Education Consortium (ELNEC)**, which will launch in 2000. By 2001, RWJF will invest approx. \$3.5 million more in this project.

Rewrite Textbooks
1999: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.

Journals & Associations
1998: *Journal of Palliative Medicine* (in 2001 became official journal of AAHPM)
2000: *Innovations* -- by the Education Development Center (EDC); \$467,000 from RWJF.
2004: American Academy of Hospice & Palliative Medicine (AAHPM) receives \$1.2 million from PDIA to create a College of Palliative Care.

EPEC2
2000: EPEC2: End-of-life care education for **African-American** health care professionals (RWJF grant #37552 to Secundy, then #43073 to Payne for \$447,000; PDIA grant for \$166,000). Leads to "Last Miles of the Way Home" conference in 2004.

Institutional Change

Missoula: Promoting Excellence
1996: Ira Byock's Promoting Excellence in End-of-Life Care national program was approved in 1996, with \$1.1 million from RWJF. Uses toolkit to assess quality of life.

State Legislatures
1997: RWJF grant for \$149,486 (#32334) to National Conference of State Legislators to produce the "Policy Guide for State Legislators" (<http://www.ncsl.org/programs/pubs/contents.htm>) covering advance directives, physician-assisted suicide, pain legislation. Joanne Lynn collaborated (RWJF grant #31243).

State Pain Initiatives
1997: Pain & Policy Studies Group at the University of Wisconsin-Madison. David Joranson; RWJF \$650,000; PDIA \$225,000.

JCAHO standards
2000: RWJF grants Univ. of Wisconsin-Madison \$1.6 million to help JCAHO develop new pain control standards.

CAPC at Mt. Sinai
2000: RWJF awards nearly \$5 million (#37515) to Diane Meier & Christine Cassel to establish Center to Advance Palliative Care (CAPC)

Public Engagement

Public TV, Public Radio
1997: "Before I Die" on PBS with Tim Russert -- RWJF begins media campaign to build grass roots reaction to SUPPORT study. RWJF invests approx. \$800,000 in the program and its marketing.
1997-98: National Public Radio. "The End of Life: Exploring Death in America," began airing November 3, 1997, and will run through 1998

Hollywood
1998: **Writers' Project** RWJF provides technical experts and story ideas to TV and movies. Their accomplishments include episodes of *ER*, *NYPD Blue*, *Wit*, *Scrubs*.

Television News
1998: **RTNDA Guide for Journalists** \$39,900 from RWJF to RTNDF to create a 100-page "primer for journalists covering end of life." Encourages reporters to contact Choice in Dying. Spins the Cruzan case; Helga Wanglie's story.

Moyers; Rallying Points
2000: RWJF and Cummings Foundation invested approximately \$3 million for the \$6 million **television** series by Bill Moyers, *On Our Own Terms*. The broadcast organized local activists, who formed "Rallying Points" three months later. Partnership for Caring directed Rallying points, and received \$12 million from RWJF for the project.

Newspaper
2001: **RWJF, Samuels Foundation, and Life Institute (headed by PFC member Daniel Tobin)** launches a 15-part newspaper series on death, carried by Knight-Ridder. \$300,000 from RWJF to Life Institute; \$150,000 from Samuels to PFC. "**Finding Our Way**," is online at <http://www.findingourway.net/>

Faith in Action (FIA)
2001: RWJF announces it will invest \$112 million to develop 2000 faith-based coalitions by 2007. At the same time, the Faith in Action headquarters is moved to Wake Forest Univ. in North Carolina. FIA primarily serves caregivers. Many FIA coalitions are headquartered in hospices. RWJF forbids proselytizing by Faith in Action volunteers.