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

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1968</td>
<td>Humanae vitae; 1980: <em>Declaration on Euthanasia</em></td>
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<td>1976</td>
<td>Quinlan decision</td>
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<td>1980</td>
<td>Foundation collaboration</td>
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<tr>
<td>1985</td>
<td>Karen Ann Quinlan dies</td>
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<td>1985</td>
<td>Medicare Hospice Benefit is made permanent by Congress.</td>
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<td>1989</td>
<td>SUPPORT research begins. RWJF invests $25 million in the study. Directed from George Washington University. Research sites for study of dying patients: 1. Beth Israel Hospital in Boston; 2. Cleveland MetroHealth Medical Center; 3. Duke University Medical Center (Durham, NC); 4. Marshfield Medical Center (Marshfield, WI); 5. UCLA School of Medicine.</td>
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<td>1990</td>
<td>Patient Self-Determination Act. Promoted as an aid to physician/patient communication. Myra Christopher (Midwest Bioethics Center) was asked to advise Sen. Danforth because of her experience with the Cruzan case.</td>
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<td>1990</td>
<td>Society for the Right to Die and Concern for Dying merge to form Choices in Dying. The Society for the Right to Die had been known as the Euthanasia Society until 1974. (see also: 2000)</td>
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<td>1992</td>
<td>Christine Cassel, MD; Diane Meier, MD; Timothy Quill, MD; produce some of the first published guidelines for assisted suicide. “Care of the hopelessly ill. Proposed clinical criteria for physician-assisted suicide.” N Engl J Med 1992 Nov 5;327(19):1380-4</td>
</tr>
<tr>
<td>1993</td>
<td>Institute of Medicine (IOM), in anticipation of SUPPORT study publication, was asked to “develop guidelines for identifying and limiting futile treatments.” On 12/9/93 they held their first workshop to discuss feasibility. Participants included: R. Foley (PDIA), J. Lynn, W. Studding (Greenwall), C. Cassel, H. Aaron (Brookings), J. Lyle (RWJF Foundation).</td>
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<td>1993</td>
<td>JCAHO promotes pain relief as a “patient’s right.”</td>
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<td>1993</td>
<td>RWJF launches Faith in Action (FIA), offering $23 million seed money for projects focusing on caregivers and building upon the foundation’s earlier volunteerism program.</td>
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The information on this timeline is an overview of the chronology at http://www.lifetree.org/timeline.html.

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### 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 health coverage of palliative care and counseling.
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
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

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#### References:

1996 Last Acts leadership conference (see "Challenges and Opportunities” and “Next Steps”):

1997 Last Acts leadership conference:

“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/prnh.htm
Daniel Callahan’s

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

Objectives included:

—change American death-denying culture to death-accepting culture; —nurture withholding/withdrawing nutrition and hydration; —provide avenue for hastening death by use of episodic treatments.

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

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.


1998: Choosing Dying coordinating center for health care agency project launches with $115,000 from Sams e Foundation.


In 1999, Myles Shereran, S.J. MD was awarded PDA grant to create EPEC for Catholics. [http://www2.soros.org/death/99ftp.shtml]

“Working with Supportive Care of Dying and Partnership for Caring, the result was invented in 2002 as ‘Recovering Our Traditions.”


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

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

2002: Rall ying Points names three regional resource centers:

— Hospice of the Florida Suncoast
— Midwest Bioethics
— Missoula Demonstration Project.

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: “Palliative Sedation,” written by Edward Yellin, 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.


2004: John Paul II addresses the International Congress on Life-Sustaining Treatments and Vegetative State