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# Dying for the Cause

*Foundation funding for the “right-to-die” movement*

BY RITA MARKER

**F**EW PEOPLE REALIZE THE VITAL ROLE PRIVATE foundations play in promoting societal change. More often than not, major shifts in public attitudes and public policy come not from grassroots clamor but rather from the hard work of a committed few—activists with the ideas and the donors who fund them.

This is especially true for movements that begin with shallow popular appeal or in which much work is needed to change public attitudes. Without the money that is the mother’s milk of public advocacy, those inspired to agitate for change would not get very far.

*All of the major right-to-die organizations have their roots in attempts to legalize not only assisted suicide, but also euthanasia.*

The assisted suicide/euthanasia movement typifies this phenomenon. Often referred to euphemistically as the “right-to-die” or “death with dignity” movement, it seeks nothing less than legalization of mercy killing via a two-step process: the acceptance of assisted suicide and, later, a shift to active euthanasia.

Assisted suicide refers to a death in which the person who dies takes the final death-causing action after receiving assistance. For example, a doctor may intentionally prescribe a lethal dose of drugs and a family member may mix it into pudding, but the patient performs the death-inducing

act of swallowing. In euthanasia, someone other than the victim performs the final death-causing action, as when a doctor administers a lethal injection.

In 1995, the newsletter of a group called Choice in Dying listed seven organizations in a “Guide to Right-to-Die Organizations.” At least four of them (Compassion in Dying, Death with Dignity Education Center, the Oregon Death with Dignity Legal Defense and Education Center, and Choice in Dying itself) have attracted funding from large foundations.

One such foundation is George Soros’s Open Society Institute (OSI). The OSI, through its Project on Death in America, gives millions of dollars for enhancing end-of-life care and none of the Project’s money is used for assisted suicide purposes. But the OSI provides grants for assisted suicide advocacy through OSI’s President’s Fund in its U.S. Programs office.

OSI’s stance also illustrates another aspect of support for the “right to die,” namely, that funders generally see a great distinction between euthanasia and assisted suicide. As Gara LaMarche, director of U.S. programs for OSI, puts it, “We never use the word ‘euthanasia’ around here.”

## CREEPING RESPECTABILITY

WHAT UNDERMINES THIS ATTEMPT AT DELICACY IS the fact that all of the major right-to-die organizations have their roots in attempts to legalize not

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only assisted suicide, but also euthanasia. Like Eliza Doolittle, they have become respectable over time and no longer wear euthanasia advocacy on their sleeves.

Compassion in Dying was founded after the 1991 defeat of a Washington state initiative to legalize euthanasia and assisted suicide. The group's main purpose was to offer suicide assistance for "deserving cases." In a 1994 interview, the group's first executive director, Ralph Mero, described Compassion in Dying as an outgrowth of the Washington State Hemlock Society, which Mero had directed until taking over the helm of the new group.

As the first U.S. group publicly to admit offering assistance in committing suicide, the Hemlock spin-off was formed, in its own words, "to help terminal patients retain control over how their lives come to an end, including the option of hastening inevitable death." Compassion's actions, again according to the group's own materials, include "ask[ing] the patient's own primary care physician to prescribe lethal quantities of barbiturates for those patients who have decided on intentional death." As detailed by Mero himself in a 1996 journal article, Compassion was involved in 24 deaths, all involving overdoses of prescription drugs, during its first 13 months of operation. The organization then clammed up and refused to divulge its involvement in subsequent deaths.

In the summer of 1996, Barbara Coombs Lee (who had been the chief petitioner for Measure 16, the 1994 ballot initiative that legalized assisted suicide in Oregon) left her position as vice president of a large Oregon managed care company to take over the leadership of Compassion in Dying and moved the group's headquarters to Portland, Oregon.

Under Lee's leadership, Compassion in Dying unsuccessfully argued before the United States Supreme Court that assisted suicide is a constitutional right. The group is currently challenging Alaska's ban on assisted suicide before that state's highest court.

Foundation funding enabled Compassion in Dying to grow into a national organization, the Compassion in Dying Federation. The group received \$100,000 from the OSI in 1997, more than \$300,000 from the Gerbode Foundation during 1995-1999, a \$300,000, three-year grant in 1998 from the Columbia Foundation, and \$50,000 from the Donald A. Pels Charitable Trust in the same year.

The Death with Dignity Education Center grew out of a failed 1992 California attempt to legalize "physician-aid-in-dying" (defined to include both assisted suicide and euthanasia). The



Protestors with the Not Dead Yet group demonstrate outside the World Conference on Assisted Dying.

unsuccessful campaign was headed by attorney Michael White who, in 1994, became the Center's first president (the group is now headquartered in Washington D.C. under the name Death with Dignity National Center). With White in charge, the Center's purpose was to support change in the health care system to allow for "physician aid-in-dying."

Funding for the Center has included grants from OSI (\$100,000 in 1997), the Gerbode Foundation (\$544,900 since 1996), the Columbia Foundation (\$200,000 since 1998), and the Walter and Elise Haas Foundation (\$57,500 during 1996-97). Other past support for the center has come from Donald A. Pels Charitable Trust (\$50,000 in 2000), the Atkinson Foundation, the Women's Foundation, and Varian Associates (an electronics firm).

Oregon Right to Die (ORD) was formed in 1993 for the purpose of writing a right-to-die law for Oregon. Early drafts of the bill (which became Measure 16) included both euthanasia and assisted suicide, but proponents wanted to avoid the specter of a syringe-wielding physician that had successfully scuttled similar proposals in Washington and California. They settled on an

AP/WIDE WORLD PHOTOS

assisted-suicide-only version (the first proposal in the country to do so) and, in November of 1994, voters narrowly approved it. The law went into effect in late 1997.

As a result, Oregon doctors may deliberately prescribe drugs for the purpose of causing a patient's death. Remarkably, because it is now considered a medical treatment, Oregon Medicaid covers the cost of assisted suicide (at the same time that it rations some wanted, life-extending care).

Following Measure 16's passage, ORD leaders formed the Oregon Death with Dignity Legal Defense and Education Center to implement the new law and to defend it from legal challenges. Since its inception, combined foundation grants to the Center from the Pels, Gerbode, and Columbia

*Following passage of Oregon's assisted suicide statute, the Oregon Death with Dignity Legal Defense and Education Center was formed to implement and defend it.*

foundations and from the OSI have totaled more than \$550,000.

**LOOKING THE OTHER WAY**

SOME PRIVATE FOUNDATIONS THAT FUND ASSISTED suicide groups prefer to distance themselves from the actual controversy, no matter how implausibly. William Stubing, president of the Greenwall Foundation, explains, remarkably enough, that Greenwall "takes no stand on any issues which it funds." According to Stubing, Greenwall's mission is to bring out information about issues.

Still, following the passage of Oregon's Measure 16, Greenwall funded a project called "Support for the task force to improve care for the terminally ill" at Oregon Health Sciences University, which in turn published *The Oregon Death with Dignity Act: A Guidebook for Health Care Providers*, a step-by-step guide on implementing the assisted suicide law.

Greenwall's grantees include a group called *Choice in Dying* (in 2000, *Choice* began "evolving

into a new organization," called Partnership for Caring). Stubing takes issue with even referring to *Choice in Dying* as a right-to-die group, even though *Choice* is in fact the first and best-funded of all such groups. In recent years, *Choice* has received grants from a myriad of foundations, including the Nathan Cummings, Robert Wood Johnson, and the Fan Fox and Leslie R. Samuels foundations.

The grants have been overwhelmingly for the purpose of advancing *Choice's* programs addressing patient decision-making and advance directives (an advance directive can be either a living will or a durable power of attorney for health care). According to Karen Orloff Kaplan, *Choice's* president and CEO, the organization has viewed itself as "an information broker—a broker of unbiased information about both sides" of issues.

The group's Winter 1999 newsletter states that, for the past 62 years, *Choice in Dying* and its predecessor organizations had "worked to achieve a 'good death' for all." But that work has not been without controversial aspects.

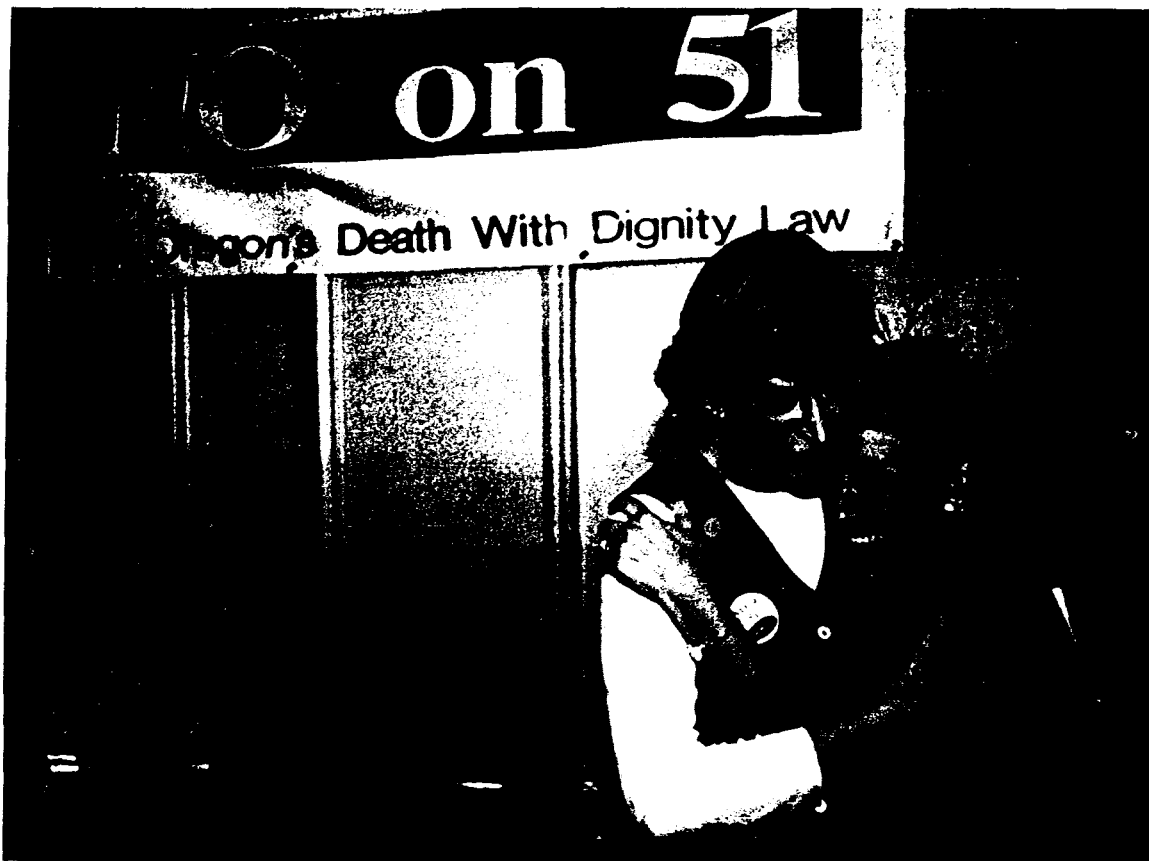
Since its 1938 incorporation in New York State, the organization has filed several amendments to its articles of incorporation, but they have only reflected name changes—from the Euthanasia Society of America to Society for the Right to Die (1975), to National Council on Death and Dying (1991), and finally, to *Choice in Dying* (1992). The group has never amended its stated corporate purpose:

To disseminate information to the public by all lawful means of the nature, purpose, and need of euthanasia, and to foster its general adoption. By the term "euthanasia" is to be understood the lawful termination of human life by painless means for the purpose of avoiding unnecessary suffering and under adequate safeguards.

In 1939, the organization proposed legislation which, its president told the *New York Times*, was intended eventually to legalize euthanasia for "born defectives who are doomed to remain defective, rather than for normal persons who have become miserable through incurable illness."

**PAINTING WITH SOFTER HUES**

ON ITS WEB SITE, IN A SECTION TITLED "A HISTORICAL PERSPECTIVE," *Choice in Dying* lists among its legal achievements the 1968 introduction of the first living will statute in Florida. That proposal—which was sponsored and reintroduced over a period of five years by Representative Walter Sackett—provided for removal of care from severely retarded persons in state hospitals.



AP/WIDE WORLD PHOTOS

Barbara Coombs Lee, left, hugs fund raiser Margaret Surguine after the defeat of a measure to repeal Oregon's assisted suicide law.

After the *San Francisco Examiner* reported Sackett's estimate that, with the bill's passage, "\$5 billion could be saved over the next half century if the state's mongoloids were permitted merely to succumb to pneumonia," the National Association for Retarded Children passed a resolution vowing to oppose it and any similar legislation. Subsequent living will legislation was less inflammatory, and by the 1980s, Choice in Dying had shed the radical image of its founders and was firmly ensconced in the mainstream.

In 1989, however, with funding from a grant in memory of Joseph S. Kornfeld, Choice convened a group of physicians to pen a report that PBS's *MacNeill/Lehrer News Hour* called the "strongest public endorsement of doctor-assisted suicide ever published." The report, which appeared in the *New England Journal of Medicine*, concluded that it is morally acceptable for doctors to give patients information about suicide and the necessary drugs to accomplish death. The article made front-page news across the country and catapulted advocacy of assisted suicide into the realm of respectable debate.

At the time, Dr. Ronald Cranford, one of the report's 12 physician authors stated, "We broke new ground and we were very aware we were doing it. We felt it was an opportunity to make a statement that's very controversial and stand by

it." He acknowledged that assisting suicide is "the same as killing the patient."

While Cranford was blunt in describing assisted suicide, five years later, Choice's Karen Kaplan was painting with softer hues. During a 1994 CNN interview following passage of Oregon's assisted suicide law, Kaplan described the law as simply a pain control measure. The law, she said, "really does limit physicians' intervention" and is only about "giving medication that will control pain at the end of life even though it may hasten death."

Misleading statements like the latter underscore the movement's fervent desire to appear mainstream, in part to avoid scaring off potential donors. The OSI's Gara LaMarche acknowledges that the donor base for right-to-die groups is small, and, to assist in expanding that base, OSI last year convened a group of individual philanthropists and foundation officials to hear presentations by the directors of Compassion in Dying and the Death with Dignity Center.

Yet, far from reflecting any grassroots desire for "death with dignity," the major right-to-die organizations are well-funded, "top down" creations. And if they are successful in transforming the "right to die" into just another "medical treatment," these little-known nonprofit organizations will be in a position profoundly to affect everyone. **P**