

[Home](#) > [Publications](#) > [GP Solo](#) > [2013](#) > [July/August 2013: Retirement Planning and Elder Law](#)

Twenty Years of Living with the Oregon Death with Dignity Act

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By Eli Stutsman

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Twenty years this summer ago I was involved in a small group that had been working quietly and un-noticed for several years. We first met in a public library, then in a church, and later we leased our own small office space. We would soon go public with a new idea. We believed that a competent, terminally ill adult, with a prognosis of six months or less to live, should be allowed to hasten a difficult death within narrow and well-defined circumstances, if he or she so desired.



In June 1993 we filed with the Oregon Secretary of State's office a statement of organization, which was necessary to create our political committee. We named the committee Oregon Right to Die. Later that same year we filed a citizen's initiative. Our initiative was first known as Measure 16, but today it is known as the Oregon Death with Dignity Act (codified at Or. Rev. Stat. 127.800 et seq.).

A Time for Action

The early 1990s was a pivotal time for the right to die movement. Dr. Jack Kevorkian was at the height of his fame. One of his early patients, Janet Adkins, was an Oregonian who in 1990 traveled to Michigan (Kevorkian's home state) to hasten her death. She did so in a Volkswagen bus owned by Kevorkian. Yet as unusual as these circumstances appeared, the Adkins family was grateful

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someone was willing to listen to and help a beloved member of their family. The next year, Derek Humphry's book, *Final Exit*, reached the top of *The New York Times* best-seller list. *Final Exit* was, and remains, a definitive guide to dying patients on how to hasten one's own death. Humphry was also an Oregonian and still lives in the bucolic foothills of the coastal mountain range, just west of Eugene, Oregon.

Against this backdrop, Oregon Right to Die sought to change the law. Others had tried before us but were unsuccessful. In 1991 Washington voters defeated Initiative 119, and in 1992 California voters defeated Proposition 162. In the summer of 1993 we felt ready, even anxious, to take the next step: to file our proposed ballot measure, obtain a ballot title, collect signatures, and do all that was necessary to secure a spot on the November ballot for the 1994 general election. Only a few sought to dissuade us. They had been closest to the losses in Washington and California, and they counseled it was too soon—the "movement" could not afford another loss.

We thought differently. We had studied the losses in Washington and California. We learned from those who had gone before us. We were willing to meet the many burdens imposed when campaigning for social reforms against a well-funded opposition, but more importantly, we were taking a fresh approach. Unlike the recently failed efforts, our proposed measure would not seek to "legalize euthanasia," in loosely defined circumstances. We sought to outlaw Kevorkian's conduct and render Humphry's book unnecessary in Oregon by allowing only a competent, terminally ill adult patient, with a prognosis of six months or less to live, to obtain prescription medications to hasten his or her death, within narrow, tightly defined circumstances. All other conduct—conduct outside the contours of the Oregon Death with Dignity Act—would remain illegal and punishable. We would, in effect, campaign for the right to die and *against* Dr. Jack Kevorkian in the same breath.

Our research, dependent in great part on the heated public debate that swirled around the 1991 Washington and 1992 Californian campaigns, led to three key revelations. First, dying patients were already hastening the dying process in a covert practice, most often by accumulating and ingesting prescription medications, occasionally with wink-and-nod assistance from their physicians. Second, there were in fact genuine competing public policy interests held by valued and trusted community stakeholders, and we needed their support or, in the alternative, to minimize or neutralize their opposition. Third, our political opponents were ready with numerous fear-based arguments—arguments that played well in the media—and our clip file and polling data proved

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Armed with this much information we asked three related questions. First, if we were going to make the current, covert practice legal, what would that practice look like? Normally, a medical standard of care evolves over time, but our task was to establish a new standard of care now, on a clean sheet of paper. Second, how were we to balance the competing policy interests, so important to those we may disagree with, but nonetheless respect? Third, how were we to inoculate against the fear-based arguments advanced by our opponents? By answering these three questions, we drafted the Oregon Death with Dignity Act, one clause at a time.

We balanced competing policy interests, we countered against political attack, and we crafted a new medical standard of care that works—and we won.

On November 8, 1994, Oregon voters passed Measure 16 by a margin of 51 percent to 49 percent, making the Oregon Death with Dignity Act the first law of its type. Three years later, on November 4, 1997, Oregon voters defeated Measure 51, a legislatively inspired repeal effort, by a margin of 60 percent to 40 percent. Although our opponents had oft criticized our 1994 victory as too little support for too controversial a subject, their 1997 repeal effort had badly backfired, resulting in a clear voter mandate: Oregon voters intended to keep their unique new law. We won, again.

Remarkably, as if two statewide campaigns and one run through the state legislature were not enough to manage, we had all the while been litigating in federal court. Only eight days before the November 4, 1997, election, the Ninth Circuit Court of Appeals released its decision reversing the District Court and vacating the injunction that had prevented Measure 16, as many still called it, from taking effect 30 days after its passage in 1994. In the span of eight days, we won our first round of federal court litigation and our second statewide election. Three years after its passage, the Oregon Death with Dignity Act would finally take effect, the beneficiary of much public discussion and support.

The Act in Operation

Fast forward to today—it has been 20 years since we formed our political committee, 19 years since Oregon voters first approved the Death with Dignity Act, and 16 years since the federal injunction was lifted, allowing the Act to go into effect. One important provision of the Act is that attending physicians are required to report their participation to the state, and the state is required to publish an annual statistical report. We now have 15 years of data.

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Although Oregon's groundbreaking law remains widely popular, the occurrence of a hastened death is relatively rare, averaging just more than 44 hastened deaths per year over a 15-year span.

In 2012, the most recent year for which we have an annual statistical report, terminally ill patients who died after ingesting medication under the Act accounted for 0.2 percent of all deaths in Oregon. The top three concerns patients expressed to their attending physicians when requesting medication under the Act reflect the patients' desire to maintain control over their final days. Of the end-of-life concerns expressed, the *least* common was "financial implications of treatment."

Reviewing 15 years of data in the aggregate, 1,050 terminally ill patients have received prescriptions, and 673 of these patients have ingested the prescribed medications to hasten their deaths, while 377 chose not to. Over 15 years, only 2 percent of the people who used the law did not have insurance coverage. In 2012, excluding those few for which insurance status was unknown, all of the participants were covered by some form of insurance.

One notable trend is the percentage of in-home deaths. The 1997 annual report revealed that 80 percent of patients dying after ingesting medication under the Act died in the comfort of their own home. The 2012 annual report places the proportion of in-home deaths at 94 percent. In comparison, a 2012 report from the Centers for Disease Control and Prevention indicates that 45 percent of deaths throughout the United States occur in a hospital setting.

Another notable trend is the dramatic increase in hospice enrollment. The 1997 annual report revealed that 71 percent of the patients dying after ingesting medication under the Act were enrolled in hospice. The 2012 annual report places this number at 97 percent hospice enrollment. By way of comparison, the National Hospice and Palliative Care Organization estimates that 45 percent of deaths in the United States are under the care of hospice.

The data is consistent over 15 years, so much so that there has been little media attention once the pattern of use was understood. Annual reports published after particular milestones—five years, then ten years—were met with media attention and some national notice, but the most recent milestone—15 years—was met with little notice.

Opposition to the Act

It has not always been easy, and there have been significant challenges along the way. Consider, for example, two acts of Congress—the 1998 Lethal Drug Abuse Prevention Act and the

1999 Pain Relief Promotion Act—either of which would have nullified Oregon’s new law. It is worth noting these two congressional acts predated the accumulation of significant data that has since verified proponents’ early claims and informs today’s understanding of how the law works.

Soon after the failed congressional acts, in fall 2001 newly appointed U.S. Attorney General John Ashcroft, presiding over the Drug Enforcement Administration, determined that prescribing or dispensing federally controlled substances under the Oregon Death with Dignity Act would be in contravention of the federal Controlled Substances Act. Ashcroft directed that his determination be enforced, placing Oregon physicians and pharmacists at risk of investigation, prosecution, fines, and imprisonment, and prompting four more years of federal court litigation, culminating in an opinion by the U.S. Supreme Court. Justice Anthony Kennedy, writing for the majority of the Court, concluded in his 28-page opinion:

The Government, in the end, maintains that the prescription requirement delegates to a single Executive officer the power to effect a radical shift of authority from the States to the Federal Government to define general standards of medical practice in every locality. The text and structure of the CSA show that Congress did not have this far-reaching intent to alter the federal-state balance and the congressional role in maintaining it. (*Gonzales v. Oregon*, 126 S.Ct. 904 (2006))

The Movement Continues

The political and legal landscape appears to have settled, with the Supreme Court having had the last word in 2006. In November 2008, voters in the State of Washington turned out in an overwhelming show of political support, 59 percent to 41 percent, in favor of the Washington Death with Dignity Act (codified at Rev. C. Wash. 70.245.010 *et seq.*), making that state the second to pass such legislation.

More recently, on May 13, 2013, the Vermont House of Representatives voted 75 to 65 to concur with the Senate’s version of an Oregon-style death with dignity law. With the addition of the governor’s signature on May 20, 2013, Vermont became the third state in the nation to enact a death with dignity law and the first state to pass such law out of its legislative assembly to the desk of an awaiting governor.

All in all, the Oregon Death with Dignity Act has survived the scrutiny of two statewide campaigns, two acts of Congress, and

two rounds—seven years—of federal court litigation, with many smaller skirmishes along the way. What was once a novel idea has become model legislation, codified in other states. Twenty years after we founded our political committee, we are in the midst of another Oregon summer, and the Oregon Death with Dignity Act is working as expected, with nothing new to report.