

Statement on S16-025, The Colorado End of Life Options Act

Roland Halpern, Cultivation Manager, Compassion & Choices

February 3, 2016

Good morning Sen. Scott and Members of the State, Veterans and Military Affairs Committee.

My name is Roland Halpern, I am a resident of Denver and serve as the Cultivation Manager for Compassion & Choices, the nation's oldest and largest nonprofit organization working to improve care and expand options at the end of life. Based on my fourteen years of experience with this organization and the aid in dying movement, I am testifying today as an expert both how this law has worked in other states, and as someone who has experienced all too often the tragic and cruel deaths a law of this kind could have prevented, including the death of my own father.

Compassion & Choices President, Barbara Coombs Lee, coauthored the nation's first death-with-dignity law in Oregon, and Compassion & Choices has continued to serve as the custodian of that law in its 18 years of implementation. We provide public education about it and all available end-of-life options, we educate health care providers, and we work to ensure residents of every state where aid in dying is authorized have full access to this option. We do this work in Oregon, Washington, Montana, Vermont and are prepared for California where its law will go into effect later this year. Our extensive interaction with these laws and the people who use them is what gives us a unique, important perspective on medical aid in dying, a perspective I am pleased to share with you today.

Compassion & Choices supports SB16-025, the End of Life Options Act introduced in the Senate, and its goal of improving the quality of end-of-life care for terminally ill Coloradans and their families. We wish to thank Senator Michael Merrifield for introducing it.

We applaud the committee for considering the bill at this opportune time when it is clear public demand for this option is high. This bill is sound legislation, and the citizens of Colorado deserve its passage into law.

We are seeing a growing wave of people speaking out to demand an aid in dying option and end-of-life autonomy. Legislation similar to what you are considering today has been considered by more than 25 state legislatures both this year and last year and has been endorsed by The Denver Post, The Grand Junction Sentinel, The Durango Herald, The Aurora Sentinel, The Daily Camera, and The Longmont Times Call.

This end-of-life option is also endorsed or accepted by a growing number of organizations representing healthcare and medical professionals, including the American College of Legal Medicine, The American Public Health Association, The American Medical Women's Association and the American Medical Student Association, a group that represents the future of healthcare in this country. Both the Denver Medical Society and the Boulder County Medical Society have come out in support of the bill with the Denver Medical Society stating it: "provides an appropriate, responsible alternative for patients and their physicians who choose to exercise personal control under very difficult circumstances. As a community, we should support this show of courage and humanity."

The California Medical Association recently dropped its opposition to aid in dying after reviewing legislation introduced in California and the American Nurses Association/California actively supported California's death-with-dignity legislation. Additionally, the American Academy of Hospice and Palliative Care has taken a position of "studied neutrality" on aid in dying and does not oppose the practice when other options have been exhausted. Each of these organization's official statements on medical aid in dying are attached.

The bill you are considering allows a mentally capable adult who has a terminal prognosis of less than six months to live to bring about his or her own peaceful death with physician-prescribed medication. Aid in dying has overwhelming public support nationwide. A November 2014 Harris poll put popular support at 74 percent. In Colorado a 2016 Tamely-Drake poll comprised of 32% Republicans, 31% Democrats and 37% unaffiliated voters found 65% supported this option. Importantly, a majority of physicians (54%, according to a Medscape, December, 2014 poll of 17,000 physicians) also believe that providing a prescription that helps a dying patient achieve a peaceful death is appropriate care for them to deliver.

Many dying patients suffer, even with the best care and pain management. Others fear their symptoms will become unbearable and they will experience delirium or unconsciousness as a secondary effect of palliative medications. Supporters of medical aid in dying believe patients should have a full range of end-of-life options, whether for disease-specific treatment, palliative care, refusal of life-prolonging treatment or the right to request medication the patient can choose to self-administer to bring about a humane and dignified death.

Compassion & Choices is the nation's largest consumer organization working to improve care and protect patient rights at the end of life. We are leaders on this issue nationally and have helped to secure legal recognition of aid in dying in Oregon, Washington, Montana, Vermont and California.

Compassion & Choices has been at the forefront of efforts to:

- Ensure that terminally ill patients are able to receive adequate pain and symptom management;¹
- Provide comprehensive counseling regarding a wide range of end-of-life options;²
- Ensure that patient wishes are respected;³
- Bring accountability in instances where inadequate or inappropriate end-of-life care was provided;⁴

¹ Compassion & Choices brought landmark federal cases establishing that dying patients have the right to aggressive pain management, including palliative sedation. *Vacco v. Quill*, 521 U.S. 793(1997); *Washington v. Glucksberg*, 521 U.S. 702(1997).

² Compassion & Choices drafted and sponsored introduction of statutes requiring comprehensive counseling regarding end-of-life options. See, California Right to Know End-of-Life Options Act, CAL. HEALTH & SAFETY CODE §442.5; New York Palliative Care Information Act, N.Y. PUB. HEALTH LAW § 2997-c.

³ For example, Compassion & Choices is pursuing accountability for failure to honor a patient's wishes as documented in a POLST, *DeArmond v Kaiser*, No. 30-2011-00520263 (Superior Court, Orange County, CA). In another case, Compassion & Choices represented a family in bringing into the public eye a situation where patient wishes to forego food and fluid were obstructed. See Span, "Deciding to Die, Then Shown the Door," *The New York Times*, Aug. 24, 2011, available at <http://newoldage.blogs.nytimes.com/2011/08/24/deciding-to-die-then-shown-the-door/?ref=health>; Uyttebrouck, "Couple Transported Out of Facility After Refusing Food," *Albuquerque Journal*, Jan. 08, 2011, available at <http://www.abqjournal.com/news/metro/08232859metro01-08-11.htm>.

⁴ See supra n. 1, Bergman, Tomlinson, Tolliver, Hargett; See supra n. 3, DeArmond.

- Expand end-of-life options to include palliative sedation⁵ and aid in dying.⁶

There are four additional points that should be considered in your decision:

1. Aid in Dying is an emerging practice in the laboratory of the States

The right to ask one's physician for aid in dying is based on the simple premise that people should be free. When a person is terminally ill and death is near, he or she should be free to decide whether to try therapies to prolong life as long as possible, cease burdensome therapies that degrade the quality of life, or act to end unbearable suffering. This freedom rests on twin understandings that:

- (1) Aid in dying is a voluntary, self-determined option, that remains solely in control of the dying person from beginning to end, and
- (2) A dying person's rational decision to ingest a life-ending medication is fundamentally different from "suicide," which arises from mental illness and impulsive action. The House of Delegates of the American Public Health Association and the American Psychological Association's Working Group both assert the importance of this fundamental distinction, as did the New Mexico Psychological Association in its amicus brief in *Morris v. New Mexico*.

Compassion & Choices' two landmark federal cases before the United States Supreme Court in 1997, *Washington v. Glucksberg* and *Vacco v. Quill*, asserted that mentally competent, terminally ill patients have a constitutional right to choose aid in dying.⁵

Although at the time the Supreme Court declined to recognize a federal constitutional right to aid in dying, it reserved the possibility to do so in the future.⁷ The Court acknowledged "the earnest and profound debate" taking place on the morality, legality and practicality of aid in dying. It encouraged the states to grapple with the issue. Several states have done so, although the path chosen has varied widely. Oregon and Washington have used citizens' initiatives to protect dying patients and physicians.⁸ In nearby Montana, the right is protected under a state Supreme Court decision.⁹ In May of 2013, the Vermont legislature became the first in the nation to enact death with dignity through the legislative

⁵ *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793(1997); *Hargett v Vitas*, No. RG10547255 (Cal. Super. Ct. July 6, 2011).

⁶ Compassion & Choices brought two federal cases to the United States Supreme Court urging recognition of a federal constitutional right to choose aid in dying. *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793(1997). Compassion & Choices was in leadership in the campaigns to enact the Death with Dignity Acts in Oregon and Washington. OR. REV. STAT. § 127.800 (2007); WASH. REV. CODE ANN. § 70.245 (West 2011).

⁷ The *Glucksberg* and *Quill* cases are widely acknowledged to have prompted much-needed attention to improving care of the dying, and to have established a federal constitutional right to aggressive pain management, including palliative sedation.

⁸ Compassion & Choices has been the steward of implementation of the Death with Dignity Acts in both Oregon and Washington. And our legal team was involved in the successful defense of the Oregon Death with Dignity Act from attack by the United States Department of Justice in *Oregon v. Gonzales. Gonzales v. Oregon*, 546 U.S. 243, 275 (2006). See also Kathryn L. Tucker, *U.S. Supreme Court Ruling Preserves Oregon's Landmark Death with Dignity Law*, 2 NAT'L ACAD. ELDER L. ATT'YS. J. 291(2006).

⁹ *Baxter v. Montana*, 224 P.3d 1211, 1214, 1222 (Mont. 2009). The Court decided aid in dying is consistent with current and historic public policy affirming Montanans' right to self-determination in healthcare matters.

process. Gov. Shumlin, after campaigning on end-of-life choice, signed the bill. And more recently, in October of 2015, Gov. Jerry Brown signed the California End of Life Options Act. In a letter to the California Assembly, Gov. Brown concluded: "I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."

In a growing number of jurisdictions, lawmakers like yourselves are examining the Oregon and Washington experience and developing new legislative approaches that are appropriate for them. We thank you for your leadership in making Colorado one place where this important work is now underway.

2. The public and health care communities support Aid in Dying

A December 2014 article from **Harris Interactive** reported on its November polling on end-of-life issues stating: "An overwhelming 74 percent of American adults now believe that terminally ill patients who are in great pain should have the right to end their lives, the poll found. Only 14 percent were opposed." "Support for the right-to-die movement cut across all generations and educational groups, both genders, and even political affiliation, the poll found." In a related interview with *Physician News*, Humphrey Taylor, chairman of The Harris Poll, added: "Public opinion on these issues seems to be far ahead of political leadership and legislative actions."

According to a May 2014 **Gallup poll**, nearly 7 out of 10 Americans (69%) think that doctors should be allowed by law to end the life of a patient who has a disease that cannot be cured "by some painless means if the patient and his or her family request it." "Strong majorities have supported this."

In state-specific polls from coast to coast, majorities of Americans in every demographic category (religious, political, ethnic, ability) express support for giving a terminally ill individual the option to shorten a dying process they find unbearable.

More than two-thirds of California voters (68%) -including 71 percent of Republicans - strongly agreed that the government has no right to make decisions for them if they are terminally ill. A similar proportion (67%) strongly agree that if they are terminally ill, the decision about whether or not they end their life should be up to them and their family, under a doctor's care. (Source: Goodwin Simon Strategic Research, July 7 to July 10, 2014. Margin of error +/- 4.4%.) One year later, a bipartisan poll confirmed this strong support, with 69% of California voters supporting the California End of Life Option Act. (Source: Goodwin Simon Strategic Research & Probolsky Research, June 22, 2015, margin of error +/- 4.0%.)

In Montana, 69% of voters support allowing a terminally ill adult to end his or her life in a humane and dignified way, including 48% who strongly support such a choice and 71% of Montana voters say that if they were terminally ill and in distress, they would want the legal option to end their lives in a humane and dignified way. (Source: Global Strategy Group, April 2013, Margin of error +/- 4.0%.)

Here in Colorado, voters expressed strong support for an End of Life Options proposal with 65% supporting and just 24% opposing. (Source: Tamley-Drake Omnipoll Survey, January, 2016, margin of error +/- 4.4%.)

Support is also growing among health care professionals and the organizations representing them. These national organizations have endorsed medical aid in dying: The GLMA (Health Professionals Advancing LGBT Equality); The American Public Health Association; The American Medical Students' Association; The American Medical Women's Association; The American College of Legal Medicine.

Importantly, most U.S. physicians now believe, by a 23 percent margin (54% vs. 31%), that patients with an "incurable and terminal" disease should have the option to choose death with dignity, also known as the medical practice of aid in dying. (Source: Medscape's annual Ethics Report 2014, based on a survey of 17,000 U.S. doctors. Margin of error +/- .72%.)

3. Seventeen years of experience and scientific data answer legitimate concerns

Oregon today stands in a landscape rich with data about how the availability of aid in dying impacts end-of-life care, the patients who choose it and the practice of medicine. This is a very different landscape than existed when the U.S. Supreme Court considered *Quill* and *Glucksberg*, when there was no data, and the opponent's arguments about risk could not be assessed in light of solid evidence.

The results in Oregon have demonstrated that aid in dying does not put dying persons at risk,¹⁰ as evidenced by a comprehensive report that examined the Oregon experience to assess whether vulnerable populations were at risk and concluded that there was no evidence of this.¹¹ The Oregon data show that the dire predictions of those initially opposed to the Death with Dignity Act were unfounded, and that the option of aid in dying has not been unwillingly forced upon those who are poor, uneducated, uninsured or otherwise disadvantaged.¹² In fact, the data show just the opposite: for

¹⁰See Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in 'Vulnerable' Groups*, 33 J. MED. ETHICS 591, 593-95 (2007); Linda Ganzini et al., *Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death With Dignity Act*, 285 J. AM. MED. ASS'N 2363, 2368 (2001); Melinda A. Lee & Susan W. Tolle, *Oregon's Assisted Suicide Vote: The Silver Lining*, 124 ANNALS INTERNAL MED. 267, 267-69 (1996); Quill & Cassel, Timothy E. Quill & Christine K. Cassel, *Professional Organizations' Position Statements on Physician-Assisted Suicide: A Case for Studied Neutrality*, 138 ANNALS INTERNAL MED. 208, 209 (2003); Kathryn A. Smith et al., *Quality of Death and Dying in Patients who Request Physician-Assisted Death*, 14 J. PALLIATIVE MED. 445, 446-47 (2011); Joseph B. Straton, *Physician Assistance with Dying: Reframing the Debate; Restricting Access*, 15 TEMP. POL. & CIV. RTS. L. REV. 475, 479, 482 (2006); American Public Health Association, *APHA Policy on Patient Self-Determination at the End of Life* (2008) (During the policy development and consideration process at APHA, the Disability Section of that organization argued against adoption of the policy, claiming that it would put persons with disabilities at risk. This argument was thoroughly considered; indeed, it prompted APHA to consider the policy over a two-year policy cycle rather than a single-year cycle. After careful, evidence-based consideration of those arguments, the health policy professionals at APHA ultimately rejected them as unconvincing and adopted its policy in support of aid in dying.) Observers outside the U.S. examining the experience in the U.S. with an open practice of aid in dying have also found no evidence of harm. See, the Royal Society of Canada Expert Panel on End-of-Life Decision Making (RSC EOL Panel) (Nov. 2011) ("Despite the fears of opponents, it is also clear that the much-feared slippery slope has not emerged following decriminalization, at least not in those jurisdictions for which evidence is available. Nor is there evidence to support the claim that permitting doctors to participate in bringing about the death of a patient has harmed the doctor/patient relationship. What has emerged is evidence that the law is capable of managing the decriminalization of assisted dying and that state policies on this issue can reassure citizens of their safety and well-being." @ p. 90).

¹¹Margaret P. Battin et al., *supra*.

¹²Arthur Eugene Chin et al., *Oregon's Death with Dignity Act: The First Year's Experience*, OR. HEALTH AUTH. 1999, at 7, available at

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year1.pdf>.

"Patients who chose physician-assisted suicide were *not* disproportionately poor (as measured by Medicaid status), less educated,

example, the reports reflect that patients choosing aid in dying have a high level of education,¹³ are overwhelmingly insured (98.5% of patients opting for aid in dying had either private health insurance, Medicare or Medicaid), and almost all (90.3%) were enrolled in hospice care.¹⁴ Furthermore, the data demonstrate that aid in dying is rare: During the first 17 years this option was openly available in Oregon, only 859 patients ultimately chose it.¹⁵ In 2014, 105 people used the law compared with 33,931 deaths that same year from all causes.¹⁶ Aid in dying deaths account for a stable .24% of Oregon deaths each year.

A survey of Oregon physicians found that they granted one in six requests for aid in dying, and that only one in ten requests resulted in patients ingesting the medication.¹⁷ Further, more than one-third of patients who complete the process of seeking medication for aid in dying never take it,¹⁸ but derive comfort from having an option to control their time of death if their suffering becomes unbearable. These patients ultimately died of their disease without exercising that control.¹⁹ Physicians and caregivers often observe a positive impact on the quality of life when patients obtain a prescription or medication, persuading many to assign a palliative therapeutic purpose to the writing of an aid-in-dying prescription.

Overall, objective, third-party observers studying aid in dying in Oregon have concluded that the law poses no risk to patients, to the medical profession, to utilization of hospice and palliative care, or to society as a whole. For example, a Task Force in the state of Vermont, after thoroughly reviewing the Oregon experience, concluded that “it is quiet [sic] apparent from credible sources in and out of Oregon that the Death with Dignity Act has not had an adverse impact on end-of-life care and in all probability has enhanced the other options.”²⁰ Leading scholars have concluded: “I [was] worried about people being pressured to do this ... But this data confirms ... that the policy in Oregon is working. There is no evidence of abuse or coercion, or misuse of the policy.”²¹

lacking in insurance coverage, or lacking in access to hospice care.” *Id.*; Battin et al., *supra* at 591; Kant Patel, *Euthanasia and Physician-Assisted Suicide Policy in The Netherlands and Oregon: A Comparative Analysis*, 19 J. HEALTH SOC. POL’Y 37, 51-52 (2004) (finding no empirical evidence of slippery slope in Oregon, but more potential for a slide in the Netherlands). See APHA policy, *Supra*

¹³See e.g., Or. Dept. of Human Servs., *Annual Report on Annual Oregon’s Death With Dignity Act*, OR. HEALTH AUTH., at 2, available at

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> [hereinafter *Annual Reports*].

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷Linda Ganzini, et al., *Physicians’ Experiences with the Oregon Death with Dignity Act*, 342 NEW ENG. J. MED. 557, 557, 561 (2000) (finding that the availability of palliative care led some, but not all, patients to change their mind about hastening death).

¹⁸See *Annual Reports*.

¹⁹ *Id.*

²⁰ROBIN LUNGE ET AL., LEGIS. COUNCIL, OREGON’S DEATH WITH DIGNITY LAW AND EUTHANASIA IN THE NETHERLANDS: FACTUAL DISPUTES, at § 3.E. (Vt. 2005), available at http://www.leg.state.vt.us/reports/04Death/Death_With_Dignity_Report.htm.

²¹William McCall, *Assisted-suicide Cases Down in '04; 37 Terminally Ill Oregonians Took Lethal Drug Doses*, THE COLUMBIAN,

Indeed, rather than posing a risk to patients or the medical profession, the Death with Dignity Act has galvanized significant improvements in the care of the terminally ill and dying in Oregon. Oregon physicians report that since aid in dying has been openly available, they have worked hard to improve end-of-life care, taking educational courses in how to treat pain in the terminally ill, how to recognize depression and other psychiatric disorders, and more frequently referring patients to hospice.²² Surveyed on their efforts to improve end-of-life care since aid in dying became available, 30% of responding physicians had increased referrals to hospice care, and 76% made efforts to improve their knowledge of pain management.²³ Hospice nurses and social workers surveyed in Oregon observed an increase in physician knowledge of palliative care and willingness to refer to hospice.²⁴

In addition to the improvement of end-of-life care, the option of aid in dying has psychological benefits for both the terminally ill and the healthy.²⁵ The availability of the option of aid in dying gives the terminally ill autonomy, control and *choice*, the overwhelming motivational factor behind the decision to request assistance in dying.²⁶ Healthy Oregonians know that if they ever face a terminal illness, they will have this additional end-of-life option. Being able to openly and candidly discuss end of life concerns has allowed for better communication with the person's family and healthcare providers. Survivors of patients who choose aid in dying suffer none of the adverse mental health impacts suffered by the survivors of those who commit suicide.²⁷

4. Healthcare professionals support aid in dying

The California Medical Association (CMA) withdrew its opposition to aid in dying, clearing the way for the California End of Life Option Act to move through the legislature. The CMA, the largest medical association in the country, concluded that: "it's up to the patient and their physician to choose the

Mar. 11, 2005, at C. (quoting Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania School of Medicine). *See also* Straton, *supra* at 482.

²²See Ganzini *et al.*, *supra*, at 2363, 2367-68; Lee & Tolle, *supra*, at 267-69; Quill & Cassel, *supra*; Lawrence J. Schneiderman, *Physician-Assisted Dying*, 293 J. AM. MED. ASS'N 501 (2005) (reviewing *PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE* (Timothy E. Quill, & Margaret P. Battin eds., 2004.)) ("Indeed, one of the unexpected yet undeniable consequences of Oregon's Death with Dignity Act permitting physician aid in dying is that 'many important and measurable improvements in end-of-life care' occurred following the Act's implementation. Rather than becoming the brutal abattoir for hapless patients that some critics predicted, the state is a leader in providing excellent and compassionate palliative care.")

²³Ganzini *et al.*, *supra*, at 2363.

²⁴Elizabeth R. Goy *et al.*, *Oregon Hospice Nurses and Social Workers' Assessment of Physician Progress in Palliative Care Over the Past 5 Years*, 1 PALLIATIVE & SUPPORTIVE CARE 215, 218 (2003).

²⁵Kathy L. Cerminara & Alina Perez, *Empirical Research Relevant to the Law: Existing Findings and Future Directions, Therapeutic Death: A Look at Oregon's Law*, 6 PSYCHOL. PUB. POL'Y & L. 503, 512-13 (2000).

²⁶*Id.* (acknowledging concerns about negative effects of aid in dying, but the data from Oregon in one year justifies optimistic view); Smith *et al.*, *supra*, at 445, 449. *See also* Linda Ganzini *et al.*, *Oregon Physicians' Perceptions of Patients who Request Assisted Suicide and Their Families*, 6 J. PALLIATIVE MED. 381, 381 (2003) (finding physicians receiving requests for lethal medication perceive patients as wanting to control their deaths); Linda Ganzini *et al.*, *Experiences of Oregon Nurses and Social Workers with Hospice Patients who Requested Assistance with Suicide*, 347 NEW ENG. J. MED. 582, 582 (2002) (showing nurses and social workers rated desire to control circumstances of death as most important reason for requesting aid in dying).

²⁷Linda Ganzini *et al.* *Mental Health Outcomes of Family Members of Oregonians Who Request Physician Aid in Dying*, 38 Journal of Pain and Symptom Management 807 (2009).

course of treatment best suited for the situation - and CMA's new position on physician aid in dying allows for that." The American Medical Association (AMA) remains opposed, and has not altered its position in over 20 years. The AMA position reflects neither the substantial body of published scientific research nor the beliefs of a majority of our nation's doctors. A Medscape poll from December 2014 shows a majority of U.S. physicians believe in the medical option of aid in dying for terminally ill individuals. Indeed, a growing number of national medical and health policy organizations, including the American College of Legal Medicine (ACLM), the American Medical Women's Association, the American Medical Students Association and the American Public Health Association (APHA), the nation's oldest and largest organization dedicated to protecting the public health of the nation, have evaluated the evidence and concluded that aid in dying is an important end-of-life option, and as such have adopted policy supportive of the practice.²⁸ The Oregon experience has caused even staunch opponents to acknowledge that continued opposition to such a law can only be based on personal, moral or religious grounds.²⁹

Conclusion

The bill before you is a responsible piece of legislation that responds to your many constituents who believe that aid in dying should be available as a medical treatment option and that this deeply personal decision should be left to the patient, their family, their faith and their doctor.

Some people fear the bill will promote "suicide" and somehow cause the deaths of healthy people. But aid in dying is an option only for people whose deaths are already imminent. A person diagnosed as terminal is facing an inevitable death, his or her choice is not "whether or not to die" ...but rather "how and when to die...how much pain and suffering to endure before death." This is one reason that the public strongly supports aid in dying, under parameters such as those laid out in the Colorado End of Life Options Act.

²⁸See AM. C. LEGAL MED. POLICY ON AID IN DYING (2008) ("[T]he ACLM recognizes patient autonomy and the right of a mentally competent, though terminally ill, person to hasten what might otherwise be objectively considered a protracted, undignified, or painful death . . ."); AM. MED. STUDENT ASS'N 71, *available at* <http://www.amsa.org/AMSA/Homepage/About/AMSAConstitution.aspx> (follow "2011 AMSA Constitution, Bylaws and Internal Affairs" hyperlink) (last visited Jan. 13, 2012); Am. Pub. Health Ass'n, *Patients' Rights to Self-Determination at the End of Life*, POL'Y STATEMENT DATABASE (Dec. 28, 2008) <http://www.apha.org/advocacy/policy/policysearch/default.htm?id=1372> ("A small fraction of dying people confront a dying process so prolonged and marked by such extreme suffering that they determine hastening impending death to be the best alternative. Many Americans believe that the option of death with dignity should be open to those facing a terminal illness marked by extreme suffering."); AM. MED. WOMEN'S ASS'N, AMERICAN MEDICAL WOMEN'S ASSOCIATION POSITION PAPER ON AID IN DYING ¶¶ 1-2 (2007), *available at* <http://www.amwa-doc.org/page3-8/PositionStatements> (follow "Aid in Dying" hyperlink under "Ethical Issues" heading) (supporting the passage of aid-in-dying laws which empower mentally competent, terminally ill patients and protect participating physicians, such as that passed in Oregon, the Oregon Death with Dignity Act). See also, Kathryn L. Tucker, *At the Very End of Life: The Emergence of Policy Supporting Aid in Dying Among Mainstream Medical & Health Policy Associations*, 10 HARV. HEALTH POL'Y REV. 45 (2009).

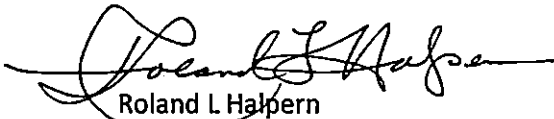
²⁹Daniel E. Lee, *Physician-Assisted Suicide: A Conservative Critique of Intervention*, HASTINGS CTR. REP. 1, 1, 4 (2003). A recent statement opposing aid in dying adopted by the Conference of Catholic Bishops reflects this as well. UNITED STATES CONFERENCE OF CATHOLIC BISHOPS, *To Live Each Day with Dignity: A Statement on Physician-Assisted Suicide 2* (2011), *available at* <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/bishops-statement-physician-assisted-suicide-to-live-each-day.pdf>.

Some people fear such legislation would allow doctors to “kill” people. But the bill specifically rejects illegal practices such as euthanasia, mercy killing and assisted suicide. It only permits those already dying to ask their personal physician for a prescription for medication which they can, if they choose, self-administer for a peaceful and dignified death.

Some fear that the elderly and disabled will be singled out, but the bill specifically prohibits that. It provides strong patient protections and clear guidance for physicians honoring a patient’s request for aid in dying.

The Oregon experience has shown us that the decision to use the law is not something made by the person alone, but in concert with the person’s family, physician, faith leader if appropriate, and only after all options have been explored and considered. Coloradans want the same opportunity.

Thank you again for your timely leadership on this important issue. If you have further questions I urge you to contact me.



Roland L. Halpern
Cultivation Manager

303-217-2162 (wk)

303-720-9293 (cell)

rhalpern@compassionandchoices.org



OFFICE OF THE GOVERNOR

OCT 5 2015

To the Members of the California State Assembly:

ABx2 15 is not an ordinary bill because it deals with life and death. The crux of the matter is whether the State of California should continue to make it a crime for a dying person to end his life, no matter how great his pain or suffering. .

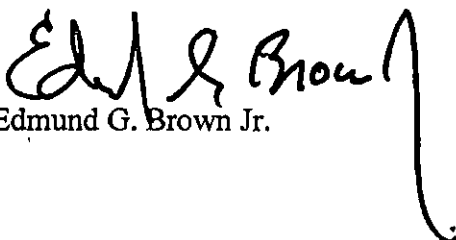
I have carefully read the thoughtful opposition materials presented by a number of doctors, religious leaders and those who champion disability rights. I have considered the theological and religious perspectives that any deliberate shortening of one's life is sinful.

I have also read the letters of those who support the bill, including heartfelt pleas from Brittany Maynard's family and Archbishop Desmond Tutu. In addition, I have discussed this matter with a Catholic Bishop, two of my own doctors and former classmates and friends who take varied, contradictory and nuanced positions.

In the end, I was left to reflect on what I would want in the face of my own death.

I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others.

Sincerely,


Edmund G. Brown Jr.

THE DENVER POST

OPINION

GUEST COMMENTARY

Please, I want to die

By Charles Selsberg

Guest Commentary

POSTED: 02/27/2014 04:34:37 PM MST | 13 COMMENTS | UPDATED: 3 MIN. AGO

Dear representatives and senators of the Colorado General Assembly:

There is no bill on this issue in this legislative session, but I'm hoping my statements will encourage you to consider one, if not this year, then soon. I have to give my testimony to you now, because by next week I hope to be dead.

You see, I made a terrible mistake. I chose to live when I should have chosen to die, at my own hands, many months ago. Because now I can't swallow the foods that made my mouth water or the sweets that added a few pounds to my middle. I can't talk to my friends and family who surround me; my voice is barely audible, and every whispered word takes monumental effort. I can't walk; my muscles have atrophied. I can't breathe; I'm on a machine that inhales and exhales for me.

In October 2013, at the age of 77, I was officially diagnosed with amyotrophic lateral sclerosis (ALS), but I had been suffering for probably a year and half before that. The disease has progressed at an alarming rate. No time to check anything off a bucket list; no time to even *make* a bucket list. I was a healthy man my whole life — didn't smoke, rarely drank, and I exercised and ate well. I loved going out to dinner, movies, street fairs and to the theater. I loved to travel. I was strong. I never thought I would be this person, really just this mind now, trapped in a dead body.

I know that some people would carry on, choosing to be alive through artificial support, happy just to be in the silent presence of others, propped up in a wheelchair or visited



Charles Selsberg of Denver is a retired residential Realtor. (Photo courtesy Selsberg family)

bedside. But that's not me. This is not living. I am not in pain, but I am suffering. Living with this disease is a cruelty we wouldn't tolerate for a pet.

I contemplated suicide a long time ago, but thinking about it is much easier than actually doing it. And the ways in which I could think to kill myself are gruesome and would put my loved ones in the position of being investigated for my death. That's not how I want to be remembered.

I want to ask a doctor for help in dying, but Colorado does not allow assisted dying. Five other states do: Oregon, Washington, Montana, Vermont and New Mexico. I contemplated driving to Oregon, but it has a residency requirement. It has other restrictions, too, carefully worded and easy to enforce: You have to be an adult suffering from a terminal illness with six months or less to live as evaluated by two physicians. You have to make two verbal requests at least 15 days apart and one written request with two witnesses. In addition, you have to be able to administer the lethal drug by yourself.

These are good safeguards, and they have been proven to work. Washington and Vermont followed suit in crafting their laws. In Montana, assisted dying was made legal by court decision and, as of January of this year, the same happened in New Mexico.

It is time for Colorado to show its compassion. I ask you to look at the studies available on the Oregon law, survey Colorado doctors to see if they would volunteer, call for the testimony of the terminally ill.

I asked my pulmonologist at National Jewish whether his ALS patients waited to die a natural death. He said nearly none of them did. I asked my kind caregivers from hospice what their experiences have been, and their responses were the same. You have tackled complex and difficult issues before; I'm asking you to consider this one again.

I stopped taking any nutrition a week ago. It was the only choice I saw to end my life, the only thing I can control. The literature I read said it wouldn't be hard, and it isn't — it's brutal. My loved ones support me, but this is as difficult on them to watch as it is for me to execute.

Legislators, you have shown mercy on patients in pain before. Take the next step: Show mercy on the terminally ill.

Please.

Charles Selsberg of Denver was a residential real estate agent in Wisconsin for 45 years and retired in 2007. He wrote this with assistance from his daughter, Julie.



An Affiliate of ANA

The Honorable Edmund G. Brown, Jr.
Governor, State of California
State Capitol Suite 1173
Sacramento, CA 95814

Sept 2nd, 2015

RE: ABX2 15 (Eggman) – Support as Amended on September 1st, 2015

Dear Governor Brown,

The American Nurses Association\California (ANA\C) supports ABX2 15 (Eggman) amended on September 1st, 2015. ANA\C is a bi-partisan professional organization representing the interests of nearly 400,000 registered nurses in California. Our mission is to advance the quality of health care and ethical practice of nursing in contemporary society through legislation, regulations and policy advocacy. ANA\C has been extensively involved in legislative efforts, supporting many bills that have become California law and that are assisting in making California a place of nursing excellence.

ABX2 15 would enable the *End of Life Option Act* authorizing adults that meet certain criteria and qualification and who have been seen, examined and their health status determined by their treating physician as suffering from a terminal disease to request prescribed medications for the purpose of ending their life. Moreover, this bill would establish approved procedures, including appropriate documentations, for making these requests. Additionally, ABX2 15 would require specific medical records documenting and clearly stating all oral and written requests for aid-in-dying medication.

ABX2 15 removes barriers in accessing care that prohibits individuals from exercising their own individual healthcare choice and/or life decision. For these reasons, ANA\C is in full support of ABX2 15!

Sincerely,

Roxanne Gould
ANA\C Lobbyist



Press

California Medical Association removes opposition to physician aid in dying bill

Now neutral on SB 128, CMA is nation's first state medical org to change decades-long position on issue

May 20, 2015

Sacramento – Today, the California Medical Association (CMA) announced that it has become the first state medical association in the nation to change its position on the long-debated issue of physician aid in dying. By removing decades-old organizational policy, CMA has eliminated its historic opposition and is now officially neutral on Senate Bill 128 (Monning/Wolk), the End of Life Option Act.

"As physicians, we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we've made and the world-class hospice or palliative care we can provide, it isn't always enough," said Luther F. Cobb, M.D., CMA president. "The decision to participate in the End of Life Option Act is a very personal one between a doctor and their patient, which is why CMA has removed policy that outright objects to physicians aiding terminally ill patients in end of life options. We believe it is up to the individual physician and their patient to decide voluntarily whether the End of Life Option Act is something in which they want to engage. Protecting that physician-patient relationship is essential."

In 1987, the CMA House of Delegates (HOD) directed that CMA oppose enactment of any law that would require a physician to provide medicine, technique, advice or referrals necessary for a patient to pursue end of life. Then, in the 1990s, CMA determined that while physicians may diagnose a patient as having a terminal condition or illness and may find a patient competent to make informed decisions, CMA condemned voluntary active euthanasia by physicians as unethical and unacceptable and opposed physician-assisted suicide clinics. During that time, another resolution passed that required CMA to remain receptive to the multiple views and perspectives expressed by various participants in the social dialogue on physician-assisted suicide. "CMA's focus has

historically been on improving end of life options and enhancing palliative care and hospice for patients who are terminally ill,” said Dr. Cobb. “Ultimately, however, it’s up to the patient and their physician to choose the course of treatment best suited for the situation – and CMA’s new position on physician aid in dying allows for that.”

Throughout the bill’s process through the legislature, CMA has engaged in open and active conversations with the authors of SB 128. “We all agreed that the greatest importance must be on the primacy of the doctor-patient relationship, consistent with the principle of patient centered health care,” said Senator Bill Monning, co-author of the legislation.

“As the authors of SB 128, we are pleased to learn that the medical community is making a historic shift from a previous position on this issue,” added Senator Lois Wolk.

“Collaborative conversations that enhance safeguards for both physicians and patients were possible because of CMA’s shift in policy,” added Dr. Cobb. “Ensuring that participation in the End of Life Option Act is completely voluntary and that patients have the necessary protections has resulted in sound policy that we’re now able to remove opposition from.”



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

Statement on Physician-Assisted Death

Approved by the AAHPM Board of Directors on February 14, 2007

Background

Suffering near the end of life arises from many sources, including relentless pain, depression, loss of sense of self, loss of control and dignity, fear of the future, and/or fear of being a burden upon others. A primary goal of the American Academy of Hospice and Palliative Medicine (AAHPM) is to promote the development, use, and availability of palliative care to relieve patient suffering and to enhance quality of life while upholding respect for patients' and families' values and goals.

Excellent medical care, including state-of-the-art palliative care, can control most symptoms and augment patients' psychosocial and spiritual resources to relieve most suffering near the end of life. On occasion, however, severe suffering persists; in such a circumstance a patient may ask his physician for assistance in ending his life by providing physician-assisted death (PAD). *PAD* is defined as a physician providing, at the patient's request, a lethal medication that the patient can take by his own hand to end otherwise intolerable suffering. The term PAD is utilized in this document with the belief that it captures the essence of the process in a more accurately descriptive fashion than the more emotionally charged designation physician-assisted suicide.

Situations in which PAD is requested are particularly challenging for physicians and other healthcare practitioners because they raise significant clinical, ethical, and legal issues.

Statement

When a request for assistance in hastening death is made by a patient, AAHPM strongly recommends that medical practitioners carefully scrutinize the sources of fear and suffering leading to the request with the goal of addressing these sources without hastening death. A systematic approach is essential.

AAHPM recognizes that deep disagreement persists regarding the morality of PAD. Sincere, compassionate, morally conscientious individuals stand on either side of this debate. AAHPM takes a position of "studied neutrality" on the subject of whether PAD should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care. Whether or not legalization occurs, AAHPM supports intense efforts to alleviate suffering and to reduce any perceived need for PAD.

Whenever PAD is being considered by a patient with his or her physician, patients should continue to receive the best possible palliative care. Although many hospice and palliative care practitioners find it morally unacceptable to participate in PAD even where legal, neither a person requesting PAD nor his family should be deprived of any other measure of ongoing palliative care during the dying process and period of bereavement. The most essential response to the request for PAD in the practice of palliative care is to attempt to clearly understand the request, to intensify palliative care treatments with the intent to relieve suffering, and to search with the patient for mutually acceptable approaches without violating any party's fundamental values.

Evaluating Requests for PAD

Access AAHPM's Advisory Brief "[Guidance on Responding to Requests for Physician-Assisted Dying](#)"

Bibliography

Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. (4th ed.) New York: Oxford University Press, 1994.

Block SD, Billings JA. Patient requests to hasten death: Evaluation and management in terminal care. *Arch Intern Med*. 1994;154:2039-2047.

Foley K, Hendin H, eds. *The Case Against Assisted Suicide: For the Right to End-of-Life Care*. Baltimore: Johns Hopkins University Press, 2002.

Meier DE, Emmons C, Wallenstein S, Quill TE, Morrison RS, Cassel, CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med*. 1998;338:1193-1201.

Okie S. Physician-assisted suicide—Oregon and beyond. *N Engl J Med*. 2005;352(16):1627-1630.

Oregon Health Authority Public Health. *Death with Dignity Act*. Available at:<http://egov.oregon.gov/DHS/ph/pas/index.shtml>. Accessed February 27, 2014.

Quill TE, Battin MP, eds. *Physician-Assisted Dying, The Case for Palliative Care and Patient Choice*. Baltimore: Johns Hopkins University Press, 2004.

Quill TE, Byock I. Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM End-of-Life Care Consensus Panel. *Ann Intern Med*. 2000; 132:408-414.

Quill TE, Cassel CK. Professional organizations' position statements on physician-assisted suicide: A case for studied neutrality. *Ann Intern Med*. 2003;138(3):208-211.

I, Robert Joondeph, declare as follows:

1. My name is Robert Joondeph and I make this declaration based on personal knowledge.

2. I am the Executive Director of the Oregon Advocacy Center (OAC)*I have held this position since 1991. OAC is the *Protection and Advocacy* program for Oregon, providing legal based advocacy for individuals with mental and physical disabilities throughout the state. I have been a licensed attorney in Oregon since 1976. Our staff includes ten other attorneys, paralegal/investigators, intake specialists, benefits planners and support staff. OAC is mandated under federal law to investigate complaints of abuse or neglect of individuals with disabilities including inappropriate actions taken to hasten the death of an individual.

3. In the decade since passage of the Oregon Death with Dignity Act (the Dignity Act), OAC has received very few complaints from disabled Oregonians about the Dignity Act. All of the complaints that have been received have focused on the concern that the Dignity Act might discriminate against persons with disabilities who would seek to make use of the Act but have disabilities which would prevent self administration, thereby denying these persons the ability to use the Dignity Act. OAC has never received a complaint that a person with disabilities was coerced to make use of the Dignity Act. I am not aware of any data that suggests that Oregonians with disabilities that are not related to a terminal illness have made use of the Dignity Act.

4. I have reviewed the recent report on the Oregon experience, co-authored by an epidemiologist who I know and respect, Dr. Linda Ganzini. LEGAL PHYSICIAN-ASSISTED DYING IN OREGON AND THE NETHERLANDS: EVIDENCE CONCERNING THE IMPACT ON PATIENTS IN 'VULNERABLE' GROUPS, Margaret P. Battin, Ph.D., Agnes van der Heide, M.D., Ph.D, Linda Ganzini, M.D., M.P.H., Gerrit van der Wal, M.D. Ph.D., and Bregje D. Onwuteaka-Philipsen, Ph.D., J. Med. Ethics, 2007, 33:591-597 ("The Report").

5. The Report sets out to review all annual and cumulative data collected by the Oregon Department of Human Services on utilization of the Dignity Act, as well as three independent studies of the data. The Report concludes that rates of assisted dying in Oregon show no evidence of heightened risk for the physically disabled or chronically ill, the elderly, women, the uninsured, people with low educational status, the poor, minors, persons with psychiatric illnesses including depression, or racial minorities, compared to background populations.

6. The Report concludes that there is no evidence that where assisted dying is legal there is any slide down a "slippery slope", causing disproportionate impact on vulnerable groups. The Report finds that there is no evidence that people in vulnerable groups are at heightened risk for physician-assisted dying compared to others not in these groups.

7. I have no personal knowledge of cases in Oregon that contradict the findings in The Report.

I hereby declare that the above statement is true to the best of my knowledge and belief, and that I understand it is made for use as testimony before the American Public Health Association.

DATED this ____ day of October, 2007 at Portland, Oregon.

Robert Joondeph

*The Oregon Advocacy Center is now Disability Rights Oregon

LAW, ETHICS AND MEDICINE

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups

Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen

J Med Ethics 2007;33:591–597. doi: 10.1136/jme.2007.022335

Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a "slippery slope", predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

See end of article for authors' affiliations

Correspondence to: Margaret P Battin, Department of Philosophy, 260 South Central Campus Drive, Rm 341, University of Utah, Salt Lake City, UT 84112, USA; battin@utah.edu

Received 10 July 2007
Accepted 10 July 2007

If physician-assisted suicide (PAS) and/or voluntary active euthanasia were legalised, would this disproportionately affect people in "vulnerable" groups? Although principles of patient autonomy and the right to avoid suffering and pain may offer support for these practices, concerns about their impact on vulnerable populations speak against them. Warnings about potential abuse have been voiced by many task forces, courts and medical organisations in several countries where the issue is under debate. Box 1 presents some of these concerns.

We must take these concerns seriously, not only because they are repeated so often but because they are of such gravity. Would accepting or legalising physician-assisted dying at a patient's explicit request weigh more heavily on patients in vulnerable groups—the elderly, women, the uninsured, the poor, racial or ethnic minorities, people with disabilities, people with sometimes stigmatised illnesses like AIDS, and others? Would vulnerable patients be especially heavily targeted? Would these patients be pressured, manipulated, or forced to request or accept physician-assisted dying by overburdened family members, callous physicians, or institutions or insurers concerned about their own profits? This slippery-slope argument assumes that abusive pressures would operate on all seriously or terminally ill patients but would selectively disfavour patients whose capacities for decision making are impaired, who are subject to social prejudice or who may have been socially conditioned to think of themselves as less deserving of care. These pressures would result, it is assumed,

in heightened risk for physician-assisted dying among vulnerable persons compared with background populations.

These are concerns both for those who oppose physician-assisted dying on moral grounds and for those who support it but are uneasy about the possible social consequences of legalisation. They are also concerns for proponents of legalisation who assume that the risks for vulnerable patients are heightened if these practices remain underground, as well as for those who favour legalisation but fear that vulnerable patients will be denied a privilege reserved for better-situated patients and that healthcare inequities already affecting vulnerable persons will be exacerbated. In short, slippery-slope concerns about vulnerable patients confront both those who do and those who do not find physician-assisted dying objectionable on moral grounds.

Of course, to observe that patients are members of potentially vulnerable groups is to assert neither that each such person or the group as a whole is actually vulnerable nor that people who are seriously or terminally ill but not considering physician-assisted dying are not vulnerable. But it is to recognize a special and appropriate concern about persons and groups seen as vulnerable because of impairment, disadvantage or stigmatisation.

Warnings of potential abuse rest on predictive claims, claims typically assuming that higher rates of death in this way suggest abuse. We do not attempt to evaluate putative criteria

Abbreviations: ALS, amyotrophic lateral sclerosis; ODDA, Oregon Death with Dignity Act; PAS, physician-assisted suicide

Box 1 "Slippery-slope" concerns about vulnerable patients in health policy statements on physician-assisted dying

"... no matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care. The practices will pose the greatest risks to those who are poor, elderly, members of a minority group, or without access to good medical care."

New York State Task Force on Life and the Law, 1994¹

"... the State has an interest in protecting vulnerable groups—including the poor, the elderly, and disabled persons—from abuse, neglect, and mistakes. The Court of Appeals [Ninth Circuit] dismissed the State's concern that disadvantaged persons might be pressured into physician assisted suicide as ludicrous on its face.... We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations ..."

US Supreme Court, joint opinion in *Washington v Glucksberg* (1997) and *Vacco v Quill* (1997)²

"Euthanasia and assisted suicide are opposed by almost every national medical association and prohibited by the law codes of almost all countries. ... If euthanasia or assisted suicide or both are permitted for competent, suffering, terminally ill patients, there may be legal challenges ... to extend these practices to others who are not competent, suffering or terminally ill. Such extension is the "slippery slope" that many fear."

Canadian Medical Association, 1998³

"Both society in general and the medical profession in particular have important duties to safeguard the value of human life. This duty applies especially to the most vulnerable members of society—the sick, the elderly, the poor, ethnic minorities, and other vulnerable persons. In the long run, such persons might come to be further discounted by society, or even to view themselves as unproductive and burdensome, and on that basis, "appropriate" candidates for assistance with suicide."

"... the ramifications [of legalization] are too disturbing for the ... value our society places on life, especially on the lives of disabled, incompetent, and vulnerable persons."

American College of Physicians–American Society of Internal Medicine (ACP–ASIM), 2001⁴

"... the College concluded that making physician-assisted suicide legal raised serious ethical, clinical, and social concerns and that the practice might undermine patient trust and distract from reform in end of life care. The College was also concerned with the risks that legalization posed to vulnerable populations, including poor persons, patients with dementia, disabled persons, those from minority groups that have experienced discrimination, those confronting costly chronic illnesses, or very young children."

American College of Physicians, 2005⁵

"... allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks ..."

"Euthanasia could also readily be extended to incompetent patients and other vulnerable populations ..."

American Medical Association, 1996, 2005^{6, 7}

"In the BMA's view, legalizing euthanasia or physician-assisted suicide would have a profound and detrimental effect on the doctor-patient relationship. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives... The BMA acknowledges that there are some patients for whom palliative care will not meet their needs and wishes, but considers that the risks of significant harm to a large number of people are too great to accommodate the needs of very few."

British Medical Association, 2003⁸

for whether assisted dying might seem "appropriate" for some vulnerable groups. Rather, we ask the prior question of whether there is evidence that where assisted dying is already legal, the lives of people in groups identified as vulnerable are more frequently ended with assistance from a physician than those of the background population. We can now begin to evaluate this factual issue by examining directly what is happening in the two principal jurisdictions—Oregon and the Netherlands—where physician-assisted dying is legal and data have been collected over a substantial period.

DATA AVAILABLE IN OREGON AND THE NETHERLANDS

In Oregon, nine annual reports issued by the Department of Human Services cover the period since the Oregon Death with Dignity Act (ODDA) took effect in 1997.⁹ Three surveys of Oregon physicians and hospice professionals add information beyond that drawn from official reports.¹⁰⁻¹² In the Netherlands, four nationwide studies (the first of which is known as the

Remmelink report) commissioned by the Dutch government used cross-sectional analyses of data from interviews, death certificates and questionnaires to cover all end-of-life decision making in the years 1990,¹³ 1995,¹⁴ 2001¹⁵ and 2005.¹⁷ Several smaller, focused Dutch studies provide additional data, as noted below. The Oregon data are from the 2006 report and cumulative study⁹ and the Dutch data are from the 2005 nationwide study¹⁷ unless otherwise mentioned. The Oregon Department of Human Services data include all legal cases reported under the ODDA; additional surveys have not uncovered extralegal or unreported cases.^{10, 12} The nationwide Dutch data cover cases reported to the authorities as required under Dutch guidelines as well as extralegal, unreported cases.

Box 2 provides the legal background, incidence and regulation of assisted dying in the two jurisdictions. The term "physician-assisted suicide" was used by Oregon in reporting its data for the first several years of legalisation, but it does not appear in the statute; Oregon now refers to "death under the Oregon Death with Dignity Act". The term "physician-assisted suicide" is used here to distinguish the form of physician-assisted

Box 2 Legal background, incidence and regulation of assisted dying in Oregon and the Netherlands**Oregon**

- The Oregon Death with Dignity Act was passed as a ballot initiative in 1994; implementation was delayed by a legal injunction and the measure was returned to the ballot by the legislature and passed again in 1997; the Act became law on October 27 of that year. A federal challenge to the ODDA was rejected by the US Supreme Court in 2006. Oregon is the only US state to legalize PAS (now referred to as utilisation of the ODDA). Euthanasia remains illegal.
- A total of 292 people have died under the ODDA in the 9 years since its enactment; this is approximately 0.15% of people who have died during this period.
- The Act allows terminally ill Oregon residents to obtain from their physicians a prescription for lethal medication for the purpose of ending their lives if the following conditions are met:
 - The patient must be adult (18 years of age or older) and a resident of Oregon.
 - The patient must be capable (defined as able to make and communicate healthcare decisions).
 - The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
 - The patient must be diagnosed by two physicians as having a terminal illness (defined as 6 months or less to live).
 - The patient must make two oral requests to his or her physician, separated by at least 15 days, and one witnessed written request.
 - If either physician believes the patient's decision may be influenced by a mental disorder, the patient must be referred for a mental health evaluation.
 - The patient must be informed by the prescribing physician of feasible alternatives, including comfort care, hospice care and pain control.
 - The prescribing physician must request, but may not require, the patient to notify his or her next of kin of the request.
 - The physician must report the prescription for lethal medication to the Oregon Department of Human Services (formerly the Oregon Health Division); and the Department must make available an annual statistical report of information collected under the Act.¹⁸
 - Pharmacies are required to report filling such prescriptions.
- Oregon's statute requires terminal illness but makes no reference to the patient's pain, symptoms or suffering. It does not indicate whether the prescribing physician must, may or may not be present at the patient's death. It stipulates that ending one's life under the Death with Dignity Act does not constitute suicide.

The Netherlands

- Voluntary active euthanasia and PAS have been openly practised and, in effect, legal since the 1980s under guidelines developed in the courts and by the Royal Dutch Medical Association. According to an exception in the criminal code enacted in 2002, physicians who perform euthanasia or provide assistance in suicide commit no offense if they follow the guidelines for "due care".
- Of the total annual mortality of 136 000 (2005), approximately 1.7% of deaths are by voluntary active euthanasia and 0.1% by physician-assisted suicide; another 0.4% involve life-ending acts without explicit current request (known as LAWER).
- The guidelines require that:
 - The patient must make a voluntary, informed and well-considered request.
 - The patient must be facing unbearable and hopeless suffering, either currently or in the immediate future and with no outlook for improvement.
 - The physician must agree with the patient that no reasonable alternative treatment that might reduce the suffering is available.
 - The physician must consult with another, independent physician.
 - The action must be performed with due care.
 - The action must be reported to the appropriate authorities.
- Since 1998, five regional committees appointed by the Ministry of Justice review all reported cases. If they decide that the physician's behavior met the requirements of due care, their decision is final.
- Dutch law does not require that the patient be terminally ill but does require that the patient be facing "unbearable and hopeless suffering". Advance directives requesting euthanasia in the event that the patient becomes comatose or demented are also legal. Both before and after statutory legalization in the 2002 law, a physician has been protected from prosecution if the guidelines are met.

dying legally permitted in Oregon from the wider range of physician-assisted dying in the Netherlands, namely, both physician-assisted suicide and voluntary active euthanasia.

This paper examines available data concerning the use of physician-assisted dying (PAS in Oregon; PAS or voluntary

active euthanasia in the Netherlands) to determine whether there is evidence of disproportionate impact on vulnerable populations. Are the lives of people in vulnerable groups more frequently ended with a physician's assistance than those of other, less vulnerable people? The results presented (table 1)

move from the most robust data to that which is partial, inferential or in other ways less secure. Detailed accounts of the statistical and other methods used in each source study are available in those studies, variously including information on response rates, survey questions asked, sample sizes, actual numbers, statistical power and confidence intervals, methods of calculation of rate ratios, detectable differences, changes over time, and methodology, design and analysis techniques. We recognize that substantial differences in the methodologies of the source studies make it impossible to determine with certainty the actual incidence of assisted dying in several of the vulnerable groups studied. Our question is whether the available data show evidence of heightened risk to persons in vulnerable groups.

IS THERE EVIDENCE OF HEIGHTENED RISK TO PEOPLE IN VULNERABLE GROUPS?

Findings based on robust data

The elderly: *no evidence of heightened risk*

In Oregon, 10% of patients who died by PAS were 85 or older, whereas 21% of all Oregon deaths were among persons in this age category. Persons aged 18–64 years were over three times more likely than those over age 85 years to receive assisted dying. In the Netherlands, rates of assisted dying were lowest in the people over 80 (0.8% in 2005), next lowest in the age range 65–74 years (2.1%) and higher below age 65 (3.5%). People over 80 formed 30% of the group of patients whose requests were refused and 13% of those whose requests were granted and carried out.¹⁹

Women: *no evidence of heightened risk*

In Oregon, 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide. In the Netherlands, despite some fluctuation in different years of the nationwide studies, the rates tend to be slightly higher in men.

Uninsured people: *no evidence of heightened risk*

Three Oregon patients (1%) did not have documented health insurance, and in four cases, insurance status was unknown. In contrast, 16.9% of non-elderly adults in Oregon were uninsured²⁰ (persons 65 and older are insured by Medicare). In the Netherlands, virtually all patients are covered by mandated nationwide health insurance.

People with AIDS: *heightened risk found*

In 9 years in Oregon, a total of six persons with AIDS died under the ODDA; although the numbers are small (2% of the total of 292 ODDA deaths), persons with AIDS were 30 times more likely to use assisted dying than those who died of chronic respiratory disorders in the interview portions of the nationwide studies in the Netherlands, very few patients with AIDS had received a physician's assistance in dying. However, in an Amsterdam cohort of 131 homosexual men with AIDS diagnosed between 1985 and 1992 who had died before 1 January 1995, 22% died by euthanasia or PAS.²¹

Findings based on partly direct, partly inferential data

People with low educational status: *no evidence of heightened risk*

In Oregon, the likelihood of dying by PAS was correlated with higher educational attainment. Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high school diploma. While no direct quantified data are available in the Netherlands about the educational status of patients receiving assisted dying, information in the 1990 study about professional status,

associated with educational status, showed no special relationships to patterns of euthanasia or PAS.

The poor: *no evidence of heightened risk*

The Oregon data do not include direct measures of income, employment or assets, but death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence. In the Netherlands, data inferred from the postal codes of the location in which the person was living before death showed that the overall rates of assisted dying were somewhat higher for people of higher socioeconomic status.²²

Racial and ethnic minorities: *no evidence of heightened risk*

In Oregon, 97% of the 292 patients who had a physician's assistance in suicide were white; six of the non-white patients were persons of Asian descent, one was Hispanic and one was Native American. Although 2.6% of Oregonians are African-American, no African-American has received physician-assisted dying under the Act. Dutch mortality statistics do not include information about race or ethnicity; however, even the most vocal opponents of assisted dying in the Netherlands do not claim that it is imposed more frequently on stigmatised racial or ethnic minorities.

People with non-terminal physical disabilities or chronic non-terminal illnesses: *no evidence of heightened risk*

In one sense, virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill. Patients who are dying lose functional capacities and may be bedridden toward the end; in this sense, most patients who received assistance in dying in either Oregon or the Netherlands were chronically ill and (recently) disabled. Cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and the Netherlands, is often identified as a chronic illness; so is amyotrophic lateral sclerosis (ALS), also a frequent diagnosis. Concerns about persons in vulnerable categories have focused, however, on pre-existing physical disabilities and chronic non-terminal illnesses.

Although the data from Oregon do not indicate whether a person had a disability before becoming terminally ill (defined as having 6 months or less to live), no one received physician-assistance in dying who was not determined by two physicians to be terminally ill—that is, no one received such assistance for disability alone. That some patients received lethal prescriptions that they did not ingest and lived longer than 6 months may represent limitations in prognostication, although clinicians caring for terminally ill cancer patients are likely to overestimate rather than underestimate survival.^{23, 24} In the Netherlands, assisted dying for disability alone would not be illegal in principle; a terminal diagnosis is not required by the Dutch guidelines, and a person who faces unbearable suffering, in his or her own view, and who has been offered all forms of treatment but has no hope of improvement may request assistance in dying. Estimates made by physicians of the amount of life forgone can be used to make an approximation of disability or chronic illness status: about 0.2% of patients receiving euthanasia or assistance in suicide were estimated to have forgone more than 6 months of life, or less than 10 of the approximately 2400 cases in 2005. Dutch general practitioners infrequently grant and frequently refuse assistance in dying to patients whose diagnosis is “old age/general deterioration” or “other” (this includes the category of patients with no terminal illness and no ALS or multiple sclerosis).¹⁹ There is thus no evidence that physician-assisted dying poses

heightened risk to people with disabilities who are not also seriously ill.

Minors and mature minors: no evidence of heightened risk

The Oregon ODDA requires that a patient be an adult (18 years of age or older) before assisted dying is granted; no cases of physician-assisted death were reported among minors. In the Netherlands, mature and relatively mature minors are understood to have some decision-making capacity and are not excluded under the Dutch guidelines, but because they are below the age of majority must be regarded as "vulnerable". Since death rates among minors in the Netherlands (0.4% of all

deaths) were the lowest in any age group, it is difficult to reach statistically firm conclusions. In 2001, less than 1% of all deaths of persons aged 1–17 years were the result of euthanasia: no cases of PAS were found in this age group.

The Netherlands has recently developed a protocol for euthanasia in newborns with very serious deficits who have a hopeless prognosis and experience what parents and medical experts deem to be unbearable suffering; the decision is to be made in collaboration with the parents and requires their full approval. This is known as the Groningen protocol.²³ Such cases are infrequent—22 cases have been reported to district attorneys in the Netherlands during the past 7 years, and there are an estimated 10 to 20 cases annually among the somewhat

Table 1 Physician-assisted dying in potentially vulnerable groups in Oregon and the Netherlands: overview of data from Oregon reports and studies, and Dutch nationwide and focused studies

Potentially vulnerable group	Oregon—PAS patients 1998–2006			Netherlands*—PAS/euthanasia patients 2005 (n = 2400)		
	Characteristic	No. (%)	Rate ratio	Characteristic	No. (%)	Rate ratio
Findings based on direct data						
The elderly (age in years)	18–44	11 (4)	3.4	0–64	900 (38)	1.7
	45–64	83 (28)	3.2	65–79	950 (39)	1.7
	65–84	170 (58)	2.3	80+	550 (23)	1.0
	85 +	28 (10)	1.0			
	Median 70 (range 25–96)					
Women	Male	157 (54)	1.1	Male	1350 (56)	1.3
	Female	135 (46)	1.0	Female	1050 (44)	1.0
Uninsured people	Private insurance	180 (62)		Not applicable (all are insured)		
	Medicare or Medicaid	105 (36)				
	No insurance	3 (1)				
	Status unknown	4 (1)				
People with AIDS	HIV/AIDS†	6 (2)	30.3	HIV/AIDS‡	29 (22)	7.9
Findings based on partly direct and partly inferential data						
People with low educational status	<High school	25 (9)	1.0	Indirect data (via SES); no direct relationship		
	HS graduate	82 (28)	1.8			
	Some college	64 (22)	3.2			
	Baccalaureate or higher	121 (41)	7.6			
The poor (people with low SES)	Rate low‡			Low SES§	1400 (38)	1.0
				Moderate SES	1200 (33)	1.0
				High SES	800 (22)	1.2
				Institutions§	300 (8)	0.3
Racial and ethnic minorities	White	284 (97)	1.0	No data (Dutch mortality statistics are not kept by race)		
	African-American	0 (0%)				
	Hispanic	1 (<1%)	0.4			
	Native American	1 (<1%)	0.5			
	Asian	6 (2)	1.8			
	Other	0	0			
People with chronic physical or mental disabilities or chronic non-terminal illnesses	Not legal; no cases reported or identified			No data to calculate denominator; probably 10 cases or fewer per year		
Minors	Not legal; no cases reported or identified			1.6% of all deaths of minors aged 1–16 years		
Findings based on inferential or partly contested data						
People with psychiatric illness, including depression and Alzheimer disease	Not legal; no clear cases; three disputed cases among those given prescription (n = 456)			No data to calculate denominator; increased requests among cancer patients with depression; probably rare for psychiatric illness as main diagnosis; legal in Alzheimer disease with advance euthanasia directive but compliance rare		

*All estimates are based upon data about a sample of 9000 deaths from August to November 2005, unless indicated otherwise; 2005 data are used for simplicity. Data are roughly comparable for entire period studied. Also see van der Meide *et al.*, 2007.¹⁷

†Referent is chronic lower respiratory disorder.

‡Estimate based upon prevalence study from early 1990s.

§Indirect data (via educational level and insuredness).

¶Estimates based upon 2001 nationwide study; also see Onwuteaka-Philipsen *et al.*, 2003.¹⁴

LAWER, life-ending acts without explicit current request; PAS, physician-assisted suicide; SES, socioeconomic status.

over 1000 children born in the Netherlands who die during the first year of life, about 1% of newborn deaths.

Findings based on inferential or partly contested data
Patients with psychiatric illness, including depression and Alzheimer disease: no evidence of heightened risk

Approximately 20% of requests for physician assistance in dying came from depressed patients, but none progressed to PAS.¹⁰ None of the 292 patients who died under the ODDA were determined to have a mental illness influencing their decision, though there have been three disputed cases among the 9-year total of 456 who received prescriptions.^{26, 27} Because not all patients who requested assistance were specifically evaluated by mental health professionals and because many cases of depression are missed in primary care, it is possible that some depressed patients received lethal prescriptions; it is also possible that a patient without a mental disorder at the time of receiving the prescription became depressed by the time they ingested it. There is, however, no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA.

In the Netherlands, about two-thirds of explicit requests for assistance in dying are not granted. In 31% of all requests not granted in the 1995 study, the physician gave the presence of psychiatric illness as at least one reason for not complying. Physicians in the interview portion of the 1995 Dutch nationwide study mentioned depression as the predominant symptom in patients who died by PAS or euthanasia in 3% of all cases, compared with "loss of dignity" in 60%, pain as an associated complaint in 45% and debility in 43%. In one study, cancer patients with depressed mood were four times more likely to request euthanasia, but how often the request was granted is unknown.²⁸

In 1994, the Dutch supreme court ruled in the *Chabot* case, in which a psychiatrist assisted with suicide for a woman with intractable depression but without concomitant physical illness, that "intolerable suffering" might consist in mental suffering alone without somatic origins and not involving the terminal phase of a disease, though the court commented that such cases would be rare and that they require heightened scrutiny.²⁹ The 2001 Dutch interview study estimated that about 3% of all requests for euthanasia or PAS that physicians had received the previous year were from patients with predominantly psychiatric or psychological illnesses, but none were granted. In the Dutch 1995 nationwide substudy on end-of-life decision making in psychiatric practice, there appeared to be about

two to five physician-assisted deaths on request per year, mostly but not always in patients with a concurrent serious physical illness, often in the terminal phase. Explicit requests for a physician's assistance in dying are not uncommon in psychiatric practice in the Netherlands, and a majority of Dutch psychiatrists consider assisted suicide for psychiatric patients acceptable in certain circumstances. However, this rather liberal attitude appears to be associated with quite reluctant practice: despite the fact that Dutch law would permit it, it occurs only very rarely.

Since 2002, the Netherlands has also recognised as legal advance euthanasia directives of patients with dementia, including Alzheimer disease. Although approximately 2200 demented patients with advance directives requesting euthanasia after the onset of dementia die annually having been treated by a physician who knows about this directive—indeed, in 76% of such cases, compliance with the directive was discussed—euthanasia is seldom performed.³⁰

Table 2 summarises the comprehensive data provided in table 1.

THE COMPREHENSIVE PICTURE IN OREGON AND THE NETHERLANDS

The data from Oregon and the Netherlands are the most informative sources concerning legal physician-assisted dying, though they are not comparable in a number of respects: they cover different time periods, were obtained by different methods, and are of different strengths. Neither the Oregon nor the Dutch studies were corrected throughout for considerations of whether diagnoses that may make physician-assisted dying attractive are equally distributed in vulnerable and non-vulnerable groups. Clearly, more work needs to be done.

Where they do overlap, however, the studies are largely consistent. Where the data are robust, the picture in Oregon and the Netherlands is similar: in both jurisdictions, a smaller percentage of older people received assistance in dying than of younger patients; gender ratios were slightly higher for males over time; and assistance was not more common among the uninsured. Socioeconomic data of intermediate strength, usually inferred from other, more robust data, also suggest similar pictures in the two jurisdictions: recipients of assistance in dying were likely to be of equal or higher educational status and were less likely than the background population to be poor. Data that are robust in one jurisdiction but partly inferential and hence less secure in the other did not reveal cases in either

Table 2 Summary of evidence of heightened risk in physician-assisted dying in Oregon and the Netherlands

Potentially vulnerable group	Evidence of heightened risk	No evidence of heightened risk
Direct data		
The elderly		x
Women		x
Uninsured people		x
People with AIDS	x	
Partly direct, partly inferential data		
People with low educational status		x
The poor: people with low socioeconomic status		x
Racial and ethnic minorities		x
People with chronic physical or mental disabilities or chronic non-terminal illnesses		x
Minors		x
Inferential or partly contested data		
People with psychiatric illness, including depression and Alzheimer disease		x

data set of assisted dying associated with physical disability alone without concomitant serious or terminal illness. The rates of physician-assisted dying among mature minors, which is legal in the Netherlands, were too low to be statistically valid. Although the rates of request for physician-assisted dying may have been higher among patients with depression, it appears that most such requests did not culminate in euthanasia, even though such cases may be legal in the Netherlands if given heightened scrutiny; studies of patients in the process of making requests are needed to clarify the risk conferred by depression. Even where the data involve very few cases or are absent in one or the other jurisdiction, the picture appears to match: neither in Oregon nor in the Netherlands was there any report of assisted dying disproportionately practised among racial minorities. Thus, there is no evidence of heightened risk of physician-assisted dying to vulnerable patients in either legal or extralegal practice groups, with the sole exception of people with AIDS.

Thus, we found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups. The evidence available cannot provide conclusive proof about the impact on vulnerable patients, and full examination of practice in Oregon would require studies of the complexity, duration and comprehensiveness of the four Dutch nationwide studies. Nevertheless, the joint picture yielded by the available data in the two jurisdictions shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges. This conclusion does not directly speak to the moral issues in physician-assisted dying; it does not argue whether physician-assisted dying would be more or less appropriate for people in some groups; and it does not show that people in vulnerable groups could not be disproportionately affected in the future or in other jurisdictions. It also does not show whether low rates of physician-assisted dying among vulnerable persons reflect a protective effect of safeguards or, rather, are evidence of unequal access to assistance. But it does show that there is no current factual support for so-called slippery-slope concerns about the risks of legalisation of assisted dying—concerns that death in this way would be practised more frequently on persons in vulnerable groups.

ACKNOWLEDGEMENTS

We are grateful to Katrina Hedberg, Mette Rurup, Hermann van der Kloot Meijberg and John Griffiths.

Authors' affiliations

Margaret P Battin, Department of Philosophy and Division of Medical Ethics and Humanities, University of Utah, Salt Lake City, UT, USA
 Agnes van der Heide, Department of Public Health, Erasmus Medical Center, Rotterdam, The Netherlands
 Linda Ganzini, Oregon Health & Science University, Portland, OR, USA
 Gerrit van der Wal, Bregje Onwuteaka-Philipsen, Department of Social Medicine, EMGO Institute, VU University Medical Centre, Amsterdam, The Netherlands

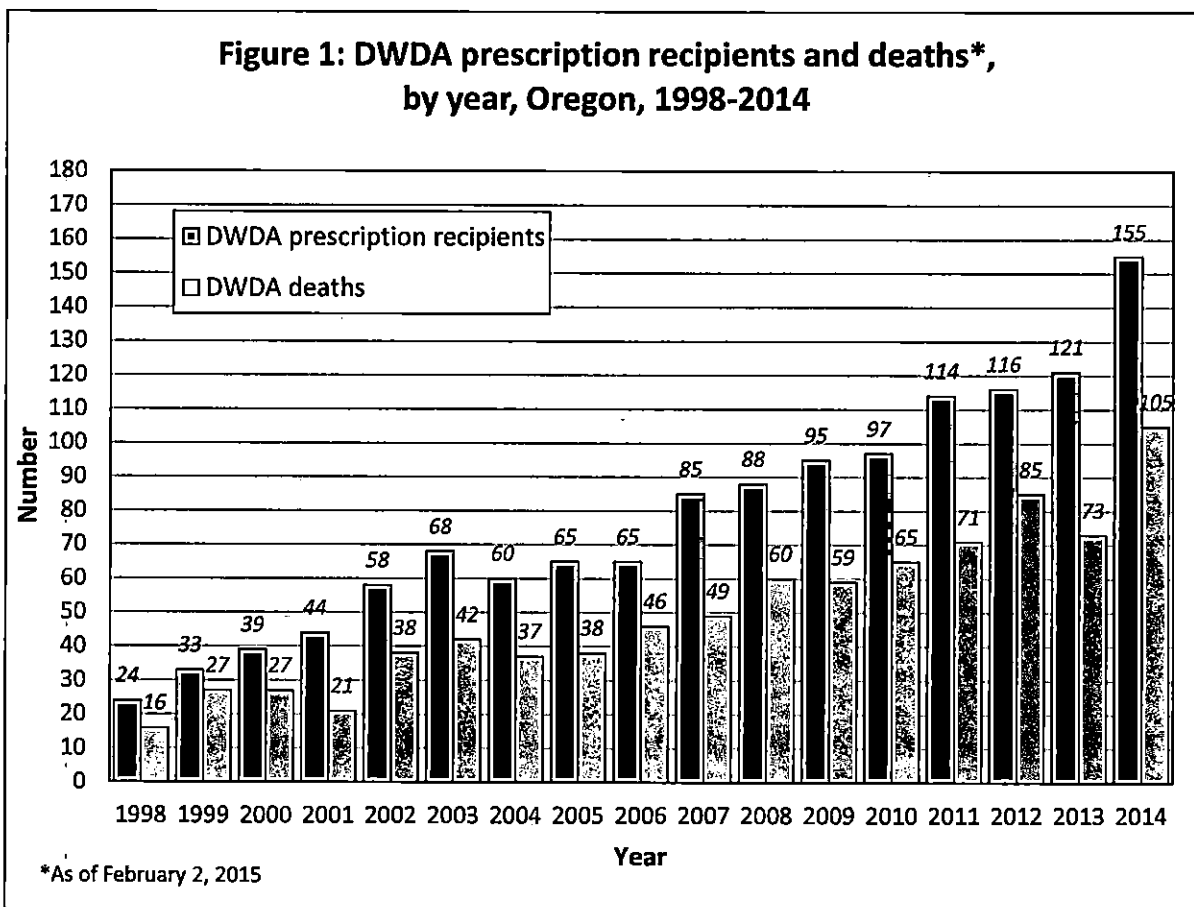
Competing interests: None declared.

REFERENCES

- 1 New York State Task Force on Life and the Law. *When death is sought. Assisted suicide and euthanasia in the medical context*. New York: New York State Task Force on Life and the Law, May 1994 (executive summary, p. xiii).
- 2 *Washington v Glucksberg*, 521 US 702 (1997) and *Vacco v Quill*, 521 US 793 (1997).
- 3 Canadian Medical Association. *Euthanasia and assisted suicide (update 1998)*. Ottawa: CMA, 1998.
- 4 Snyder L, Sulmasy DP, for the Ethics and Human Rights Committee, American College of Physicians-American Society of Internal Medicine. Physician-assisted suicide. *Ann Intern Med* 2001;135:209–16.
- 5 Snyder L, Leffler C, for the Ethics and Human Rights Committee, American College of Physicians. Ethics manual: fifth edition [position paper]. *Ann Intern Med* 2005;142:560–82.
- 6 American Medical Association. Ethical statement, E-2.211 Physician-assisted suicide (adopted 1993) revised 1996, reaffirmed August 22, 2005. <http://www.ama-assn.org/ama/pub/category/8459.html> (accessed 8 Aug 2007).
- 7 American Medical Association. Ethical statement, E-2.21 Euthanasia (adopted 1991), revised 1996, reaffirmed August 22, 2005.
- 8 British Medical Association. End of life issues – Patient (Assisted Dying) Bill, June 2003.
- 9 Oregon Department of Human Services, Office of Disease Prevention and Epidemiology. 2006 Annual Report on the Death with Dignity Act, March 2007 <http://egov.oregon.gov/DHS/ph/pos/> (accessed 9 Sep 2007) (Includes references to all previous annual and cumulative reports).
- 10 Ganzini L, Nelson HD, Schmidt TA, et al. Physicians' experiences with the Oregon Death with Dignity Act. *New Engl J Med* 2000;342:557–63.
- 11 Ganzini L, Harvath TA, Jackson A, et al. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *New Engl J Med* 2002;347:582–8.
- 12 Tolle SW, Tilden VP, Droch LL, Fromme EK, Ferrin NA, Hedberg K. Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *J Clin Ethics* 2004;15:111–18.
- 13 van der Maas PJ, van Delden JJ, Pijnenborg L. Euthanasia and other medical decisions concerning the end of life: an investigation performed upon request of the Commission of Inquiry into the Medical Practice Concerning Euthanasia. *Health Policy* 1992;21:1–262.
- 14 van der Maas PJ, van Delden JJ, Pijnenborg L, et al. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669–74.
- 15 van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995. *New Engl J Med* 1996;335:1699–705.
- 16 Onwuteaka-Philipsen BD, van der Heide A, Koper D, et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. *Lancet* 2003;262:395–9.
- 17 van der Heide A, Onwuteaka-Philipsen BD, Rurup M, et al. End-of-life practices in the Netherlands under the euthanasia act. *N Engl J Med* 2007;356:1957–65.
- 18 Oregon Death With Dignity Act, Oregon Revised Statutes, 1996 (127.800–127.897, sections 3.09, 3.11).
- 19 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005;165:1698–704.
- 20 Kaiser Family Foundation. *State Health Facts* online.
- 21 Bindels PJE, et al. Euthanasia and physician-assisted suicide in homosexual men with AIDS. *Lancet* 1996;347:499–504.
- 22 van der Wal G, van der Heide A, Onwuteaka-Philipsen BD, et al. Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie. *Utrecht: De Tijdstroom*, 2003:69–70.
- 23 Glare P, Virik K, Jones M, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003;327:195–8.
- 24 Christakis N. *Death foretold*. Chicago: University of Chicago Press, 1999.
- 25 Verhagen E, Sauer PJJ. The Groningen protocol—euthanasia in severely ill newborns. *N Engl J Med*, 2005;352:959–62. (Despite its appearance in the title of this article, the practice is more frequently called "termination of life" rather than "euthanasia" when referring to newborns.)
- 26 Hamilton NG, Hamilton CA. Competing paradigms of response to assisted suicide requests in Oregon. *Am J Psychiatry* 2005;162:1060–5.
- 27 Ganzini L. Physician-assisted suicide [letter to the editor]. *Am J Psychiatry* 2006;163:1109–10.
- 28 van der Lee ML, van der Bom JG, Swarte NB, et al. Euthanasia and depression: a prospective cohort study among terminally ill cancer patients. *J Clin Oncol* 2005;23:6607–12.
- 29 Griffiths J, Bood A, Weyers H. *Euthanasia and law in the Netherlands*. Amsterdam: Amsterdam University Press, 1998:329–40.
- 30 Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, et al. Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands. *J Am Geriatr Soc* 2005;53:1138–44.

Oregon's Death with Dignity Act--2014

Oregon's Death with Dignity Act (DWDA), enacted in late 1997, allows terminally-ill adult Oregonians to obtain and use prescriptions from their physicians for self-administered, lethal doses of medications. The Oregon Public Health Division is required by the DWDA to collect compliance information and to issue an annual report. The key findings from 2014 are presented below. The number of people for whom DWDA prescriptions were written (DWDA prescription recipients) and the resulting deaths from the ingestion of prescribed DWDA medications (DWDA deaths) reported in this summary are based on paperwork and death certificates received by the Oregon Public Health Division as of February 2, 2015. For more detail, please view the figures and tables on our web site: <http://www.healthoregon.org/dwd>.



- As of February 2, 2015, prescriptions for lethal medications were written for 155 people during 2014 under the provisions of the DWDA, compared to 121 during 2013 (Figure 1). At the time of this report, 105 people had died from ingesting the medications prescribed during 2014 under DWDA. This corresponds to 31.0 DWDA deaths per 10,000 total deaths.¹

¹ Rate per 10,000 deaths calculated using the total number of Oregon resident deaths in 2013 (33,931), the most recent year for which final death data are available.

Oregon Public Health Division

- Since the law was passed in 1997, a total of 1,327 people have had DWDA prescriptions written and 859 patients have died from ingesting medications prescribed under the DWDA.
- Of the 155 patients for whom DWDA prescriptions were written during 2014, 94 (60.6%) ingested the medication; all 94 patients died from ingesting the medication. No patients that ingested the medication regained consciousness.
- Eleven patients with prescriptions written during the previous years (2012 and 2013) died after ingesting the medication during 2014.
- Thirty-seven of the 155 patients who received DWDA prescriptions during 2014 did not take the medications and subsequently died of other causes.
- Ingestion status is unknown for 24 patients who were prescribed DWDA medications in 2014. For all of the 24 patients, both death and ingestion status are pending (Figure 2).
- Of the 105 DWDA deaths during 2014, most (67.6%) were aged 65 years or older. The median age at death was 72 years. As in previous years, decedents were commonly white (95.2%) and well-educated (47.6% had a least a baccalaureate degree).
- While most patients had cancer, the percent of patients with cancer in 2014 (68.6%) was lower than in previous years (79.4%), and the percent with amyotrophic lateral sclerosis (ALS) was higher (16.2% in 2014, compared to 7.2% in previous years).
- While similar to previous years that most patients had cancer (68.6%), this percent was lower than the average for previous years (79.4%); in contrast, the percent of patients with ALS was higher in 2014 (16.2%) than in previous years (7.2%).
- Most (89.5%) patients died at home, and most (93.0%) were enrolled in hospice care either at the time the DWDA prescription was written or at the time of death. Excluding unknown cases, all (100.0%) had some form of health care insurance, although the number of patients who had private insurance (39.8%) was lower in 2014 than in previous years (62.9%). The number of patients who had only Medicare or Medicaid insurance was higher than in previous years (60.2% compared to 35.5%).
- As in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%).
- Three of the 105 DWDA patients who died during 2014 were referred for formal psychiatric or psychological evaluation. Prescribing physicians were present at the time of death for 14 patients (13.9%) during 2014 compared to 15.9% in previous years.

- A procedure revision was made in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about the time of death and circumstances surrounding death only when the physician or another health care provider was present at the time of death. Due to this change, data on time from ingestion to death is available for 20 of the 105 DWDA deaths during 2014. Among those 20 patients, time from ingestion until death ranged from eleven minutes to one hour.
- Eighty-three physicians wrote 155 prescriptions during 2014 (1-12 prescriptions per physician).
- During 2014, no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements.

Figure 2: Summary of DWDA prescriptions written and medications ingested in 2014, as of February 2, 2015

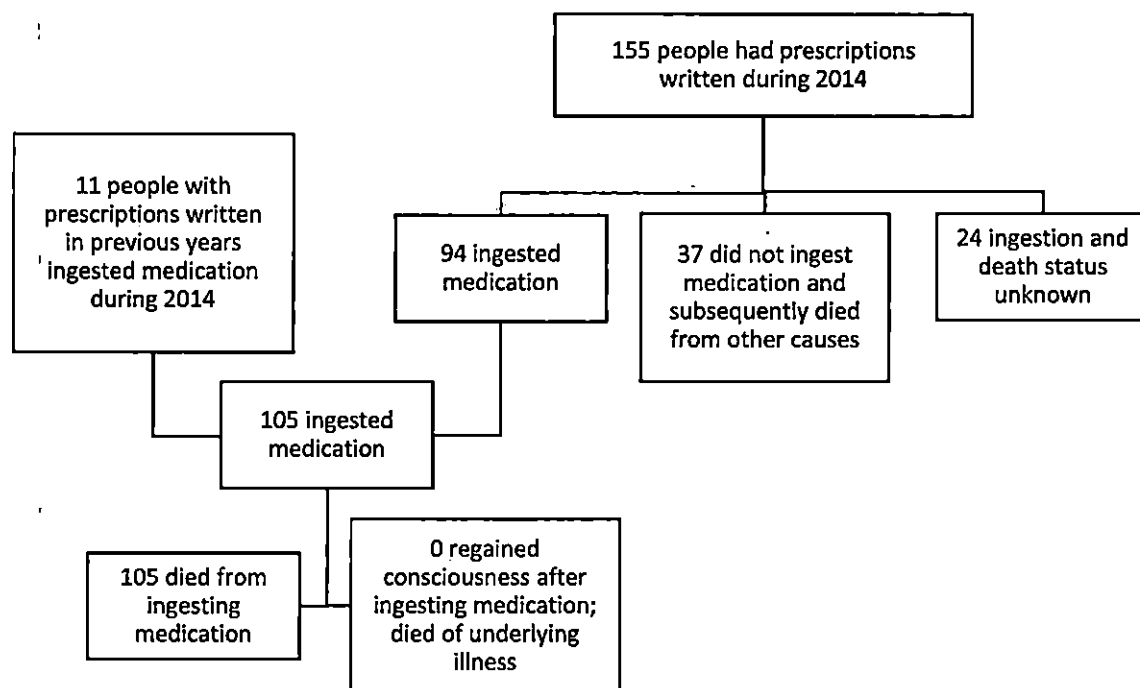


Table 1. Characteristics and end-of-life care of 857 DWDA patients who have died from ingesting a lethal dose of medication as of February 2, 2015, by year, Oregon, 1998-2014

Characteristics	2014 (N=105)	1998-2013 (N=754)	Total (N=859)
Sex	N. (%) ¹	N (%) ¹	N (%) ¹
Male (%)	56 (53.3)	397 (52.7)	453 (52.7)
Female (%)	49 (46.7)	357 (47.3)	406 (47.3)
Age at death (years)			
18-34 (%)	1 (1.0)	6 (0.8)	7 (0.8)
35-44 (%)	2 (1.9)	16 (2.1)	18 (2.1)
45-54 (%)	3 (2.9)	58 (7.7)	61 (7.1)
55-64 (%)	28 (26.7)	156 (20.7)	184 (21.4)
65-74 (%)	29 (27.6)	218 (28.9)	247 (28.8)
75-84 (%)	23 (21.9)	206 (27.3)	229 (26.7)
85+ (%)	19 (18.1)	94 (12.5)	113 (13.2)
Median years (range)	72 (29-96)	71 (25-96)	71 (25-96)
Race			
White (%)	100 (95.2)	731 (97.3)	831 (97.1)
African American (%)	0 (0.0)	1 (0.1)	1 (0.1)
American Indian (%)	0 (0.0)	2 (0.3)	2 (0.2)
Asian (%)	1 (1.0)	8 (1.1)	9 (1.1)
Pacific Islander (%)	0 (0.0)	1 (0.1)	1 (0.1)
Other (%)	2 (1.9)	1 (0.1)	3 (0.4)
Two or more races (%)	1 (1.0)	2 (0.3)	3 (0.4)
Hispanic (%)	1 (1.0)	5 (0.7)	6 (0.7)
Unknown	0	3	3
Marital Status			
Married (%) ²	48 (45.7)	347 (46.2)	395 (46.1)
Widowed (%)	26 (24.8)	172 (22.9)	198 (23.1)
Never married (%)	6 (5.7)	63 (8.4)	69 (8.1)
Divorced (%)	25 (23.8)	169 (22.5)	194 (22.7)
Unknown	0	3	3
Education			
Less than high school (%)	6 (5.7)	45 (6.0)	51 (6.0)
High school graduate (%)	23 (21.9)	164 (21.9)	187 (21.9)
Some college (%)	26 (24.8)	198 (26.4)	224 (26.2)
Baccalaureate or higher (%)	50 (47.6)	342 (45.7)	392 (45.9)
Unknown	0	5	5
Residence			
Metro counties (%) ³	46 (44.7)	315 (41.9)	361 (42.3)
Coastal counties (%)	6 (5.8)	57 (7.6)	63 (7.4)
Other western counties (%)	40 (38.8)	325 (43.3)	365 (42.7)
East of the Cascades (%)	11 (10.7)	54 (7.2)	65 (7.6)
Unknown	2	3	5
End of life care			
Hospice			
Enrolled (%) ⁴	93 (93.0)	654 (90.0)	747 (90.3)
Not enrolled (%)	7 (7.0)	73 (10.0)	80 (9.7)
Unknown	5	27	32
Insurance			
Private (%) ⁵	37 (39.8)	452 (62.9)	489 (60.2)
Medicare, Medicaid or Other Governmental (%)	56 (60.2)	255 (35.5)	311 (38.3)
None (%)	0 (0.0)	12 (1.7)	12 (1.5)
Unknown	12	35	47

Characteristics	2014 (N=105)	1998-2013 (N=754)	Total (N=859)
Underlying illness			
Malignant neoplasms (%)	72 (68.6)	596 (79.4)	668 (78.0)
Lung and bronchus (%)	16 (15.2)	139 (18.5)	155 (18.1)
Breast (%)	7 (6.7)	57 (7.6)	64 (7.5)
Colon (%)	5 (4.8)	49 (6.5)	54 (6.3)
Pancreas (%)	9 (8.6)	47 (6.3)	56 (6.5)
Prostate (%)	2 (1.9)	33 (4.4)	35 (4.1)
Ovary (%)	5 (4.8)	28 (3.7)	33 (3.9)
Other (%)	28 (26.7)	243 (32.4)	271 (31.7)
Amyotrophic lateral sclerosis (%)	17 (16.2)	54 (7.2)	71 (8.3)
Chronic lower respiratory disease (%)	4 (3.8)	34 (4.5)	38 (4.4)
Heart Disease (%)	3 (2.9)	14 (1.9)	17 (2.0)
HIV/AIDS (%)	0 (0.0)	9 (1.2)	9 (1.1)
Other illnesses (%) ⁶	9 (8.6)	44 (5.9)	53 (6.2)
Unknown	0	3	3
DWDA process			
Referred for psychiatric evaluation (%)	3 (2.9)	44 (5.9)	47 (5.5)
Patient informed family of decision (%) ⁷	95 (90.5)	634 (93.6)	729 (93.2)
Patient died at			
Home (patient, family or friend) (%)	94 (89.5)	716 (95.3)	810 (94.6)
Long term care, assisted living or foster care facility (%)	8 (7.6)	29 (3.9)	37 (4.3)
Hospital (%)	0 (0.0)	1 (0.1)	1 (0.1)
Other (%)	3 (2.9)	5 (0.7)	8 (0.9)
Unknown	0	3	3
Lethal medication			
Secobarbital (%)	63 (60.0)	403 (53.4)	466 (54.2)
Pentobarbital (%)	41 (39.0)	344 (45.6)	385 (44.8)
Other (%) ⁸	1 (1.0)	7 (0.9)	8 (0.9)
End of life concerns⁹			
Losing autonomy (%)	96 (91.4)	686 (91.5)	782 (91.5)
Less able to engage in activities making life enjoyable (%)	91 (86.7)	667 (88.9)	758 (88.7)
Loss of dignity (%) ¹⁰	75 (71.4)	504 (80.6)	579 (79.3)
Losing control of bodily functions (%)	52 (49.5)	376 (50.1)	428 (50.1)
Burden on family, friends/caregivers (%)	42 (40.0)	300 (40.0)	342 (40.0)
Inadequate pain control or concern about it (%)	33 (31.4)	178 (23.7)	211 (24.7)
Financial implications of treatment (%)	5 (4.8)	22 (2.9)	27 (3.2)
Health-care provider present¹¹			
When medication was ingested ¹²			
Prescribing physician	14	119	133
Other provider, prescribing physician not present	6	238	244
No provider	4	76	80
Unknown	81	251	332
At time of death			
Prescribing physician (%)	14 (13.9)	107 (15.9)	121 (15.7)
Other provider, prescribing physician not present (%)	6 (5.9)	263 (39.2)	269 (34.8)
No provider (%)	81 (80.2)	301 (44.9)	382 (49.5)
Unknown	4	13	17
Complications¹²			
Regurgitated	0	22	22
Seizures	0	0	0
Other	0	1	1
None	20	487	507
Unknown	85	244	329
Other outcomes			
Regained consciousness after ingesting DWDA medications ¹³	0	6	6

Characteristics	2014 (N=105)	1998-2013 (N=754)	Total (N=859)
Timing of DWDA event			
Duration (weeks) of patient-physician relationship ¹⁴			
Median	19	12	13
Range	1-1312	0-1905	0-1905
<i>Number of patients with information available</i>	105	752	857
<i>Number of patients with information unknown</i>	0	2	2
Duration (days) between 1st request and death			
Median	43	48	47
Range	15-439	15-1009	15-1009
<i>Number of patients with information available</i>	105	754	859
<i>Number of patients with information unknown</i>	0	0	0
Minutes between ingestion and unconsciousness ^{11, 12}			
Median	5	5	5
Range	2-15	1-38	1-38
<i>Number of patients with information available</i>	20	487	507
<i>Number of patients with information unknown</i>	85	267	352
Minutes between ingestion and death ^{11, 12}			
Median	27	25	25
Range (minutes - hours)	11mins-1hr	1min-104hrs	1min-104hrs
<i>Number of patients with information available</i>	20	492	512
<i>Number of patients with information unknown</i>	85	262	347

1 Unknowns are excluded when calculating percentages.

2 Includes Oregon Registered Domestic Partnerships.

3 Clackamas, Multnomah, and Washington counties.

4 Includes patients that were enrolled in hospice at the time the prescription was written or at time of death.

5 Private insurance category includes those with private insurance alone or in combination with other insurance.

6 Includes deaths due to benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson's disease and Huntington's disease), musculoskeletal and connective tissue diseases, cerebrovascular disease, other vascular diseases, diabetes mellitus, gastrointestinal diseases, and liver disease.

7 First recorded beginning in 2001. Since then, 37 patients (4.7%) have chosen not to inform their families, and 16 patients (2.0%) have had no family to inform. There was one unknown case in 2002, two in 2005, one in 2009, and 3 in 2013.

8 Other includes combinations of secobarbital, pentobarbital, phenobarbital, and/or morphine.

9 Affirmative answers only ("Don't know" included in negative answers). Categories are not mutually exclusive. Data unavailable for four patients in 2001.

10 First asked in 2003. Data available for all 105 patients in 2014, 625 patients between 1998-2013, and 730 patients for all years.

11 The data shown are for 2001-2014 since information about the presence of a health care provider/volunteer, in the absence of the prescribing physician, was first collected in 2001.

12 A procedure revision was made mid-year in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about time of death and circumstances surrounding death only when the physician or another health care provider is present at the time of death. This resulted in a larger number of unknowns beginning in 2010.

13 There have been a total of six patients who regained consciousness after ingesting prescribed lethal medications. These patients are not included in the total number of DWDA deaths. These deaths occurred in 2005 (1 death), 2010 (2 deaths), 2011 (2 deaths) and 2012 (1 death). Please refer to the appropriate years' annual reports on our website (<http://www.healthoregon.org/dwd>) for more detail on these deaths.

14 Previous reports listed 20 records missing the date care began with the attending physician. Further research with these cases has reduced the number of unknowns.

Opinion: Why people living with disabilities support death with dignity legislation

By Times of Trenton Guest Columnist

January 08, 2015

By Sara Myers and Dustin Hankinson

“If you have a terminal illness, and are in great pain, I think you should have the right to end your life It is discrimination against the disabled to deny them the right ... that able-bodied people have.”

Those are words famed physicist, best-selling author and U.S Presidential Medal of Freedom winner Stephen Hawking expressed last July in an interview with BBC-TV. Hawking has a motor neuron disease related to amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease. He is almost entirely paralyzed and communicates through a speech-generating device. As two individuals who also live with significant physical disabilities, ALS and Duchenne muscular dystrophy, we could not agree with him more.

Hawking spoke in support of an assisted-dying bill in the United Kingdom modeled after Oregon’s time-tested 17-year-old Death With Dignity Act that Brittany Maynard, who suffered from terminal brain cancer, recently used to end her suffering. Like Oregon’s law, the U.K. bill would authorize terminally ill, mentally competent adults to request aid-in-dying medication they can take to end their suffering if it becomes unbearable.

A report published in the Journal of Medical Ethics about the Oregon Death With Dignity Act concluded: “Rates of assisted dying in Oregon showed no evidence of heightened risk for ... the physically disabled or chronically ill.” Historically, one-third to one-half of Oregonians who obtain the medication never take it.

Since Oregon’s law went into effect in 1997, four other U.S. states have allowed the medical practice of aid in dying: Washington, Montana, Vermont and New Mexico.

We are volunteers for the nation's leading end-of-life choice organization, Compassion & Choices, a nonprofit group working to expand the list of death-with-dignity states to include California, Colorado, Connecticut, Massachusetts, New Jersey and many others, thanks to Maynard.

Last July, we commemorated the anniversary of the 1990 Americans with Disabilities Act with a video explaining why we support increased autonomy and expanded options for all people at the end of life, including aid in dying. We invite people who watch the video to sign a petition on the Compassion & Choices website to show their support.

As people with disabilities who support death with dignity, we are by no means alone. Recent state polls show a strong majority of voters living with disabilities support death with dignity in Connecticut (65 percent), Massachusetts (74 percent) and New Jersey (63 percent), and support for the bill is nearly identical for all voters in these three states.

Like others, we want the freedom to enjoy life. This freedom should include the full range of options at the end of life, including hospice, palliative care and aid in dying.

Stephen Hawking summarized it well: "We should not take away the freedom of the individual to choose to die," he concluded in his BBC-TV interview. "I believe one should have control of one's life, including its ending."

As California and other states consider whether to adopt death-with-dignity laws to honor Brittany Maynard, we hope they recognize that most people living with disabilities share Stephen Hawking's viewpoint: They strongly support aid in dying.

Sara Myers, who resides in New York City and Kent, Conn., and Dustin Hankinson, who lives in Missoula, Mt., are volunteers for Compassion & Choices.

http://www.nj.com/opinion/index.ssf/2015/01/opinion_why_people_living_with_disabilities_support_death_with_dignity_legislation.html



I-1000: Base the debate on facts

By JOHN A. KITZHABER, GUEST COLUMNIST

Published 10:00 pm, Tuesday, October 28, 2008

Washington voters have been misled about Initiative 1000, the Death with Dignity initiative. A debate on such a serious topic should be based on facts but the commercials opposing the initiative have twisted reality.

You may have seen the story of a woman on the Oregon Health Plan that makes the insinuation that services covered under Oregon's Death with Dignity Act are prioritized over chemotherapy because it costs less for patients to die than to live. Nothing could be further from the truth.

Unfortunately, a poorly worded letter to this individual contributed to that mistaken impression. Since then, the political campaign against I-1000 has made it difficult for the public to get the facts. I would like to set the record straight.

Like most insurers, the OHP covers nearly all chemotherapy prescribed for cancer patients, including the multiple rounds of chemotherapy this patient received. The request for second-line treatment was denied because of the drug's limited benefit and very high cost.

When the Oregon Health Plan went into effect in 1994, it was backed by principles that remain relevant today, including a process for setting health care priorities that reflects a consensus of social values and considers the good of society as a whole.

The Health Services Commission is the volunteer group responsible for creating health care priorities used by the Legislature to define covered benefits for the OHP. In 2003, the commission invited all Oregon oncologists to comment on its end-of-life treatment policy, which was supported by a 4-1 margin.

It was updated last year, receiving unanimous approval from the 11-member commission, which includes a practicing oncologist and four consumer representatives.

Weighing the cost of end-of-life treatment against the voter-approved Death with Dignity Act was never a part of those discussions. No treatment has ever been denied because death would be more "cost effective." The very idea is both abhorrent and a blatant distortion of the facts. It didn't happen in Oregon, and it would not happen in Washington.

The Oregon Health Plan is charged with prioritizing services that reflect the values of Oregonians. Oregonians have told us twice, through their ballots, that death with dignity is an option they want at the end of life. But the fact that it is covered by OHP has no bearing on the decision in this or any other case.

I deeply regret the distress caused by insensitive wording in the letter this patient received. But I also feel strongly that this case has been twisted and distorted for political gains. Whether voters approve, and whether patients choose death with dignity, remains a very personal decision.

Washington voters deserve better. The debate over I-1000 and death with dignity should be based on facts. The fact is that the Oregon Health Plan follows good health care principles even though they don't make sensational headlines.