n 2008 four major national medical professional and health policy organizations adopted policy in support of aid in dying, the practice of a physician providing a prescription that brings about a peaceful death to a mentally competent, terminally ill patient.¹ This represents a

available would be harmful to patients and to the practice of medicine. By 2008, however, a decade of data on how aid in dying was working in the state of Oregon was available. The Oregon Death with Dignity Act (Dignity Act) was implemented in 1998.⁸ The law permits mentally competent individuals lieved to be able to make this choice. On a date chosen by the patient, loved ones may gather around for a final goodbye. The patient consumes the medication, becomes drowsy, falls deeply asleep, and after a short period of time ceases to breathe.¹² The long road from diagnosis to curative

At the Very End of Life:

The Emergence of Policy Supporting Aid in Dying Among Mainstream Medical & Health Policy Associations

Kathryn L. Tucker, JD, Director of Legal Affairs, Compassion & Choices

significant turning point in American society's evolution to empower terminally ill patients with information and choices about how they will die. This article reviews this development, sets it in context with other developments, and makes several predictions about the impact it will have on continued progress toward freedom of choice at the end of life.

The organizations adopting policy in support of aid in dying include the American Medical Women's Association (AMWA),² the American Medical Student Association (AMSA),³ the American College of Legal Medicine (ACLM),⁴ and the American Public Health Association (APHA).⁵ Previously, organizations of this sort, like the American Medical Association (AMA), held positions opposing aid in dying.⁶ Others, recognizing the split in views on the issue among members, had adopted a neutral position, such as that taken by the American Academy of Hospice and Palliative Medicine (AAHPM).⁷

What prompted so many medical and health policy associations to break with tradition on this issue in 2008? The answer, in short, is evidence.

The chief argument raised by medical professionals against aid in dying had been the idea that making this option who have less than six months to live to obtain a prescription for medication that can be self-administered to bring about a peaceful death.⁹ The Dignity Act survived a series of attacks brought by opponents in court, by federal legislators, and by a former United States Attorney General; it has been implemented without interruption since 1998.¹⁰

Under the Dignity Act, patients must follow a strict set of procedures to establish eligibility. A physician must determine that the patient has a life expectancy of less than six months; this diagnosis must be confirmed by a second opinion. The patient must make multiple requests, waiting at least fifteen days between the first and last request, must establish capacity to make medical decisions, and must be informed of palliative care options such as hospice, if not already receiving such services.11 If all of these procedures are followed, and the patient is deemed eligible by the physician to obtain the life-ending medication, an Oregon physician can provide the requested prescription.

During the decade that aid in dying has been legal in Oregon, close to 30 terminally ill individuals each year have gone through the process, obtained and taken the medication, and died peacefully. Those present at these deaths, usually close family members, report that the patient was enormously retreatment to palliative care to death has ended on terms acceptable to the patient. More patients obtain the medication than go on to use it: some fraction each year receive the medication, put it in the medicine cabinet, feel comforted to know it is there, and never take it.¹³

Demographic data about the patients who choose to use the Dignity Act show that most are dying of cancer.¹⁴ The next most common terminal illness is amyotrophic lateral sclerosis (ALS). Those using the law are insured, well educated, and receiving comprehensive pain and symptom management, typically through hospice services.¹⁵ Opponents of the Dignity Act legislation had argued that such a law would be forced upon the uninsured, the poor, minorities, persons without access to hospice, or disabled persons. The data have disproved this conjecture.¹⁶

In addition, a number of unexpected but significant developments occurred in Oregon following implementation of the Dignity Act. Referral of patients to hospice care increased dramatically, as did physician enrollment in continuing education courses on how to treat pain and symptoms associated with terminal illness.¹⁷ It is likely that physicians want to ensure that no patient makes use of the Dignity Act

SPOTLIGHT

due to inadequate pain and symptom management. This galvanized both the increase in hospice referrals and physician efforts to learn more about treating pain and symptoms.

Clearly this evidence persuaded medical professional and health policy experts at APHA, AMWA, AMSA and ACLM to

adopt policy supporting aid in dying. When the policies were under review by these groups, arguments against adoption were presented. For example, during the policy development and consideration process at APHA, the Dis-

ability Section of that organization argued vociferously 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, evidencebased consideration of those arguments, the health policy professionals at APHA ultimately rejected them as unconvincing and adopted its policy in support of aid in dving.

In another significant development in 2008, voters in the state of Washington considered the issue and, after an intense campaign with opponents making the same claims about harm to patients and the medical profession, voted to adopt the Washington Death with Dignity Act by the significant margin of 58% to 42%.¹⁸ The Washington measure is virtually identical to Oregon's and will be implemented in March 2009.

The experience in Washington with aid in dying will, no doubt, be closely watched and will contribute to the body of data on how the availability of this intervention impacts end-of-life care. Such data will then inform consideration of policy and legislation in other states.

As a result of a court case, Montana recently recognized that the freedom of its terminally ill citizens to choose aid in dying is a fundamental right protected by its state constitution's guarantees of privacy and dignity.¹⁹

this evidence persuad-

ed medical profession-

al and health policy ex-

perts at APHA, AMWA,

AMSA and ACLM to

adopt policy support-

ing aid in dying

Public support for empowering dying patients with the freedom to choose aid in dying is strong. The Pew Research group reported in 2006 that 60% of Americans "believe a person has a moral right to end their life if they are suffering great pain and have no hope of improvement," an increase

> of nearly 20 percentage points since 1975.²⁰ Certain religious groups and disability rights groups oppose adoption of policy and passage of laws permitting this choice.²¹ Yet, the opposition to aid in dying by religious organizations does not necessarily reflect

the views of those who profess to hold religious views.²² For many years the vocal, well funded opposition succeeded in limiting the legal practice to the state of Oregon; though, it is no secret that the practice goes on covertly in every state.²³ When a patient does not feel able to discuss the desire for aid in dying with his or her physician, or cannot find a physician willing to provide it, the patient may seek assistance in hastening death from a family member or loved one. Unfortunately, these incidents often involve a violent means to death, such as gunshot. Cases of this nature appear with disturbing frequency in the newspapers.24 That is now changing with the passage of Washington's law, recognition of a constitutional right in Montana, and the significant trend of support for the practice among medical and health policy associations. These changes should and likely will prompt other medical and health policy associations with policies opposing aid in dying, adopted before the evidence revealed that having this option presents no risk to patients or the medical profession, to revisit their outdated policies. Unfortunately, the AMA has a long, well known history of being slow to adopt policies reflecting changing societal norms. For example, for many years the AMA opposed most forms of medical insurance and group health plans, including Medicare, labeling them as "socialism."25

A fraction of terminally ill patients-including those who have excellent pain and symptom management-confront a dying process so prolonged and marked by such extreme suffering and deterioration that they decide aid in dying is preferable to the alternatives. Having this option harms no one, and greatly benefits both the relatively few patients in extremis who make use of it and many more who draw comfort from knowing it is available should their dying process become intolerable. The trend in policy among mainstream medical and health policy associations is clearly in favor of supporting this compassionate option.

References

- See Kathryn L. Tucker, In the Laboratory of the States: The Progress of Glucksberg's Invitation to States to Address End of Life Choice, 106 *MI. L. Rev.* 1593-1612(2008); Kathryn L. Tucker et. al., Patient Choice at the End of Life: Getting the Language Right, 28 *J. Legal Med.* 305-325(2007).
- Available at http://www.amwa-doc.org/index.cfm?objectId=242FFEF5-D567-0B25-585DC5662AB71DF9.
- Available at http://www.amsa.org/about/ppp/ pas.cfm
- Available at http://www.aclm.org/resources/ articles/ACLM%20Aid%20in%20Dying%20 Policy.pdf
- Available at http://www.apha.org/advocacy/ policy/policysearch/default.htm?id=1372
- 6. AMA Policy E-2.211 "Physician-Assisted Suicide". (The AMA policy, last updated in 1996, still refers to aid in dying as "assisted suicide," a term which has been denounced as inaccurate and value laden by most other medical professional associations, including the APHA, AMWA, AMSA, ACLM, and the AAHPM.)
- 7. Available at: www.aahpm.org/positions/suicide. html.
- 8. Or. Rev. Stat. §§ 127.800-.995 (2005). See also, http://www.oregon.gov/DHS/ph/pas/
- 9. Or. Rev. Stat. §§ 127.800-.995 (2005).
- See generally Kathryn Tucker, U.S. Supreme Court Ruling Preserves Oregon's Landmark Death with Dignity Law, 2 NAELA Journal 291-301(2006).
- 11. Or. Rev. Stat. §§ 127.800-.995 (2005).
- 12. See D. Colburn, "She Chose It All on the Day She Died," *Oregonian*, p. 1. September 30, 2007 (profiling the death of Lovelle Svart, who was terminally ill with inoperable, metastatic lung cancer and chose aid in dying pursuant to the Dignity Act.)
- Id. See also Death with Dignity Act Annual Reports, Oregon Department of Human Services, http://oregon.gov/dhs/ph/pas/ar-index.shtml.

- 16. See generally Margaret P. Battin et al., Legal
- Physician-Assisted Dying in Oregon and the

^{14.} Id. 15. Id.

SPOTLIGHT



Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups, 33 J. Med. Ethics 591 (2007) (no evidence of harm to persons in vulnerable groups).

- 17. See: 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 Jour. Am. Med. Ass'n 2363 (2001); Melinda A. Lee & Susan W. Tolle, Oregon's Assisted Suicide Vote: The Silver Lining, 124 Ann. Int. Med. 267 (1996).
- Available at http://wei.secstate.wa.gov/osos/en/ Documents/I1000-Text%20for%20web.pdf
- 19. Baxter v. Montana, No. ADV-2007-787 (Mont. 1st Jud. Dist. December 5, 2008).
- News Release, Pew Research Center, For The People & The Press, More Americans Discussing — and Planning — End-of-Life Treatment: Strong Public Support for Right to Die (Jan. 5, 2006), http://people-press.org/reports/pdf/266. pdf
- 21. These groups include the Alliance of Catholic Health Care, American Association of People with Disabilities, American Disabled for Attendant Programs Today, the National Right to Life Committee and its State affiliates, Disability Rights Education and Defense Fund, National Council on Disability, Not Dead Yet, the Christian Medical & Dental Associations, and the Traditional Values Coalition.
- 22. For example, "Roman Catholics (64%), Protestants (65%), people who subscribe to non-Christian faiths, or no single religion (80%), and even born-again Christians (54%) all support individual choice for the terminally ill at the end of life." California Progress Report, Opponents of AB 651 Include Extremists with Agenda to Dictate Patients' Dying Choices (citing Mark DiCamillo and Mervin Field, Press Release, Field Research Corp., Release #2188:

Continued Support for Doctor-Assisted Suicide, at 2 (Mar. 15, 2006)), http://www.californiaprogress-report.com/2006/04/opponents_of_ab.html

- 23. See: Helene Starks et al, Family Member Involvement in Hastened Death, 31 Death Studies 105-30 (2007). (Complications are more likely to occur in the underground. For example, there is greater chance of an extended time until death after consuming lethal medications. In addition, the stress and anxiety for the patient and family is much higher when no physician can legally be involved to counsel the patient and family and provide a prescription.)
- See: Carla Rubinski, Connecticut case puts spotlight on assisted suicide, Associated Press (March 5, 2005) (available at http://www.neilrogers.com/ news/articles/2005030818.html).
- 25. See: Jonathan Oberlander, "The Political Life of Medicare." Chicago: University of Chicago Press (2003), p. 109 ("AMA charge(d) that federal health insurance for the elderly was 'socialized medicine," and endorsed a "physician's strike or boycott" against Medicare using "bitter anti-Medicare rhetoric").