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## Patients' Rights to Self-Determination at the End of Life

**Date:** Oct 28 2008 | **Policy Number:** 20086

**Key Words:** Patient Rights

The American Public Health Association (APHA) has long recognized patients' rights to self-determination at the end of life and that for some terminally ill people, death can sometimes be preferable to any alternative.<sup>1</sup> These rights include patients' ability to express their wishes in an advance directive, to appoint a surrogate to make care decisions when the patient is no longer able to do so, and to have these wishes honored by health care providers.

The quality of dying is a personal subjective assessment, and each dying person, family member, and loved one may have his or her own sense of what a "good death" would be. This may include dying quietly and with dignity, being pain free, and without distress.<sup>2-4</sup>

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.<sup>5</sup> Many Americans believe that the option of death with dignity should be open to those facing a terminal illness marked by extreme suffering [see, for example, OR. REV. STAT. §§127.800-127.995 (2003)].<sup>6</sup>

### The Oregon Model

The Oregon Death with Dignity Act (DDA) established procedures under which a competent, terminally ill adult in the care of an attending physician may obtain a prescription for medication to provide control over the time, place, and manner of his or her impending death.<sup>7</sup> The Dignity Act was recently considered, and upheld, by the US Supreme Court [Gonzales v. Oregon, 546 US 243 (2006)]. APHA filed an amicus brief in the case, supporting the Oregon law, stating, "Researchers have consistently found that experience in Oregon does not bear out concerns that physician assistance would be disproportionately chosen by or forced on terminally ill patients who were poor, uneducated, uninsured, or fearful of the financial consequences of their illness."<sup>8</sup>

The attending physician must determine that the person is mentally competent, an Oregon resident, and has "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within 6 months."<sup>9,10</sup> The attending physician also must inform people requesting such medication of their diagnosis and prognosis, the risks and probable results of taking the medication, and alternatives to hastening their deaths, including, but not limited to, hospice care and pain relief.<sup>11</sup> A consulting physician must confirm the attending physician's prognosis.<sup>12,13</sup> Finally, the attending physician may prescribe, but not administer, medication to enable the person to hasten death in a humane and dignified manner.<sup>14</sup>

DDA requires healthcare providers to file reports with the state documenting their actions.<sup>15</sup> Reports and articles on the experience in Oregon have been published in medical journals.<sup>16-20</sup> These articles demonstrate that patients are not put at risk when a carefully drafted law is in place<sup>21-24</sup> and that DDA has not been unwillingly forced on the poor, uneducated, uninsured, or otherwise disadvantaged. Although the Oregon law does not

require specific data collection concerning whether persons choosing to use DDA have disabilities that preexisted their terminal illness, there is no evidence that since its passage DDA has had a disproportionate impact on person in vulnerable populations, including persons with disabilities.<sup>25,26</sup> Perhaps this is because there is no requirement to collect this data. Some in the disability community remain concerned that DDA poses a threat to people with disabilities and argue that these many protections and safeguards are insufficient and that no safeguards would ever be sufficient. Concerns about whether enough data are collected and whether the collected data are preserved for a long enough period of time have been raised by opponents of DDA. Opponents also suggest that unreported instances of DDA may be occurring in Oregon; however, there are no data to support this contention.

A higher level of education is strongly associated with the use of DDA; those with a baccalaureate degree or higher were 7.9 times more likely than those without a high school diploma to choose to use DDA. All (100%) patients opting for DDA during the act's first 6 years had either private health insurance or Medicare/Medicaid and 92% were enrolled in hospice care.<sup>27</sup>

The use of DDA is rare. During the first 10 years it has been a legal option, only 341 Oregonians chose to use DDA.<sup>27</sup> Although there has been a gradual increase in the rate of those using DDA, the overall rate remains very low: the 38 terminally ill adults who chose this option in 2005 represented only 12 deaths for every 10,000 Oregonians who died that year.<sup>28</sup> A 2000 survey of Oregon physicians found that they granted 1 in 6 requests to use the DDA and that only 1 in 10 requests resulted in hastened death.<sup>29</sup> The annual reports reveal that each year a significant number of patients obtain the medications but do not go on to take them, reflecting that these patients are comforted to have this option but do not make use of it.

The Legislature of the State of Vermont commissioned a task force to review the Oregon experience and issued a report concluding that "it is [quite] 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."<sup>30</sup> Observers have found no evidence of abuse or coercion or misuse of the policy."<sup>31</sup>

DDA has galvanized significant improvements in the care of the dying in Oregon. Oregon doctors report that since passage, efforts have been made to improve their ability to provide adequate end-of-life care. These efforts include improving their knowledge of the use of pain medications for the terminally ill, improving their ability to recognize depression and other psychiatric disorders, and referring their patients to hospice programs more frequently. Representatives of a hospice-based palliative care provider in Oregon stated that the physicians they work with are more comfortable discussing end-of-life issues with their patients since the enactment of DDA, which focused attention on end-of-life care and the options available to individuals.<sup>22-24,32,33</sup> A survey of Oregon physicians found that 30% of respondents increased their number of referrals to hospice care and 76% made efforts to increase their knowledge of pain medication.<sup>34</sup> A survey of hospice nurses and social workers in Oregon revealed that they observed an increase in physician knowledge of palliative care and willingness to refer and care for hospice patients from 1998 to 2003.<sup>35</sup> However, at least one study suggested that high-quality of end-of-life palliative care has actually been reduced.<sup>36</sup>

Having the option of DDA provides important psychological benefits for the terminally ill because it gives the terminally ill autonomy, control, and choice, which physicians in Oregon have identified as the overwhelming motivational factor behind the decision to use DDA.<sup>37-39</sup>

The DDA prevents real and significant harms inherent in the ongoing, covert, back alley practice of aid in dying. Physicians throughout the country report that they regularly receive requests for aid in dying. The evidence shows that complications are more likely when this occurs in a covert, unsanctioned, and unregulated practice. For example, there is greater chance of an extended time until death after consuming lethal medications if the practice is unregulated or unsanctioned. 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.<sup>40</sup>

## Need for Accurate Language and Complete Information

The American Public Health Association notes the importance of using accurate language to describe care options. The Oregon Department of Human Services ([www.oregon.gov/DHS](http://www.oregon.gov/DHS)), which is vested with the responsibility to report on DDA, rejects using the term “assisted suicide” or “physician assisted suicide.”<sup>41</sup>

Profound psychological differences distinguish suicide from actions under DDA.<sup>42</sup> The American Psychological Association has recognized, “It is important to remember that the reasoning on which a terminally ill person (whose judgments are not impaired by mental disorders) bases a decision to end his or her life is fundamentally different from the reasoning a clinically depressed person uses to justify suicide.”<sup>43</sup> Medical and legal experts have recognized that the term “suicide” or “assisted suicide” is inappropriate when discussing the choice of a mentally competent terminally ill patient to seek medications that he or she could consume to bring about a peaceful and dignified death.<sup>21,42-50</sup>

## Need for Provision of a Full Range of Information

Empirical and anecdotal evidence reflect that health care providers do not inform terminally ill patients of all options legal in the state in which the patient is receiving care.<sup>51</sup> As a result, patients are not able to make fully informed decisions about care at the end of life. APHA rejects providing only partial information on which to base health decisions.<sup>52</sup>

## Recommendations

Accordingly, the American Public Health Association—

- Supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death, where safeguards equivalent to those in the Oregon DDA are in place. A “terminal condition” is defined in state statutes. Some states specify a life expectancy of 1 year or 6 months; other states refer to expectation of death within a “reasonable period of time.”<sup>i</sup>
- Rejects the use of inaccurate terms such as “suicide” and “assisted suicide” to refer to the choice of a mentally competent terminally ill patient to seek medications to bring about a peaceful and dignified death.
- Encourages that where such option is available to vulnerable populations, including persons who have a disability which existed before the terminal illness, data be collected on the incidence when vulnerable populations and persons with disabilities that are independent of their terminal illness decide to hasten their death.
- Supports measures to ensure that patients eligible to receive information about death with dignity and are able to choose alternatives such as aggressive pain and symptom management, palliative care, hospice care, and care to maximize quality of life and independence.
- Supports the provision of information about the full range of end-of-life care options to terminally ill patients permitted by law in the state in which the patient is receiving care, including, for example, voluntarily stopping eating and drinking and palliative sedation. Palliative sedation is the use of medication to induce sedation to relieve a dying patient’s severe distress that cannot be controlled despite other aggressive measures<sup>53,54</sup>
- Supports a moratorium on DDA should evidence emerge that vulnerable populations are disproportionately impacted by such policies.

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#### Note

i. Compare OR. REV. STAT. §127.800 (2003) defining terminal disease as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months." with WASH. REV. CODE §70.122.020 (2007) defining terminal condition as "an incurable and irreversible condition caused by injury, disease, or illness, that, within reasonable medical judgment, will cause death within a reasonable period of time in accordance with accepted medical standards, and where the application of life-sustaining treatment serves only to prolong the process of dying."

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