

## Death with Dignity Laws

*The desire to control how and when one's life ends*

The area of elder law and special needs planning is constantly evolving. On November 8, 2016, Colorado joined a handful of states—Washington, Oregon, California and Vermont—that have Death with Dignity laws, or physician-aid-in-dying laws. (Montana also allows it under a 2009 State Supreme Court ruling.)

This issue of *ElderCounselor* will explore how these laws work, why some people are attracted to them, who actually uses them, and concerns of others who are opposed to them.

### What are Death with Dignity Laws?

According to the website [DeathwithDignity.org](http://DeathwithDignity.org), death with dignity is an end-of-life option that allows certain terminally ill people to voluntarily and legally request and receive a prescription medication from their physician to hasten their death in a peaceful, humane and dignified manner. They reject the terms “assisted suicide,” “doctor-assisted suicide” and “euthanasia.”

To qualify under Death with Dignity statutes, you must be an adult resident of a state where such a law is in effect; be mentally competent (capable of making and communicating your healthcare decisions); and diagnosed with a terminal illness that will lead to death within six months, as confirmed by two physicians. The process includes two oral requests, one written request, waiting periods and other requirements. You must be able to administer and ingest the medications yourself. Physician participation in the law is strictly voluntary.

### Why Patients Want These Laws

A recent article in [The Washington Post](http://The Washington Post) explored the motivation of patients who want and use these laws. According to the Post article, supporters have convinced voters, lawmakers and courts that terminally ill patients have the right to die without suffering pain that is difficult to manage in their final

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days or weeks. Yet the latest research shows that terminally ill patients who seek aid in dying aren't primarily concerned with pain. Those who have used these laws have been more concerned about keeping control over how they end their lives than about controlling pain.

Oregon and Washington, the first two states to legalize physician-assisted dying, provide the most complete details about people's motivations. They found that pain ranks near the bottom of patients' concerns. Only 25% of the 991 Oregon patients who died after taking lethal prescriptions from 1998 to 2015 were concerned about pain or had inadequate pain control. In Washington, 36% of 917 who died were concerned about pain.

By contrast, at least 90% of patients in both states were motivated by a loss of autonomy. 41% of patients in Oregon and 53% in Washington said they feared burdening the people they loved.

A 2009 [study](#) reported in the Archives of Internal Medicine (now known as JAMA Internal Medicine) reached similar conclusions. 56 Oregon patients were asked to rank their most important reasons for requesting physician-assisted dying using a scale of one to five, with one being least important and five being most important. At the top of the list (ranking of five) were: wanting to control the circumstances of death and to die at home; loss of independence; and concerns about future pain, poor quality of life, and inability to care for themselves. All physical symptoms (pain, dyspnea, and fatigue) at the time of the interview were rated as unimportant (median rating of 1), but concerns about physical symptoms in the future rated higher (median rating of 3).

### **Who Uses The Laws**

Most of those who use aid-in-dying laws are well-educated and have excellent health care, good insurance, access to hospice, and financial, emotional and physical support. Two out of three are aged 65 or older; the median age at death is 71 years. Most patients have cancer or ALS, most die at home, and most are enrolled in hospice care. The three most frequently mentioned end-of life concerns are loss of autonomy, decreasing ability to participate in activities that made life enjoyable and loss of dignity.

By and large, they are people who are used to controlling every aspect of their lives, and they want to control this final one.

But not all who request and receive the medications take them. Since 1998, when the first person in Oregon took medication prescribed under the Death with Dignity Act, a total of 1,545 patients have received the prescription, of whom 991 (64.1%) ingested it and died. Washington reported similar numbers. So, roughly about one-third who obtain the prescription never take it.

The Post reporter spoke with several experts, including Barbara Coombs Lee, president of Compassion & Choices. She notes that "it's difficult for people to predict how they will feel as they face a deadly illness. While a healthy person might not imagine being able to tolerate physical disability, people facing the prospect of an early death are often willing to accept harsh treatments or a reduced quality of life in exchange for more time."

Thomas Smith, director of palliative medicine at Johns Hopkins Medicine in Baltimore, added "some may have found meaning and purpose, and adequate symptom control" and that "hospice and pain relief may also alleviate some concerns."

“Hospice staff are on call 24 hours a day to help patients in pain. Palliative-care and hospice teams can also train family caregivers how to administer emergency pain medications that take effect before nurses can arrive,” the article quotes Dr. Ira Byock, a specialist in palliative care, as saying. He is executive director and chief medical officer for the Institute for Human Caring of Providence Health and Services, based in Torrance, CA.

The article also quotes Ms. Lee: “A change in perspective may explain why some of those who advocate for the right to die, including those who obtain lethal prescriptions, never actually choose to hasten their deaths. But having the prescription on hand can ease patients’ anxiety and give them some peace of mind, knowing they have the option to control the timing, place and method of death.”

### **Arguments Against Physician-Assisted Dying**

Not surprisingly, there are opponents to the Death with Dignity movement. The following concerns are from the text of Colorado’s [Proposition 106](#), which voters recently approved and which creates the “Colorado End-of-Life Options Act.”

- 1) Encouraging the use of lethal medication by terminally ill people may send the message that some lives are not worth living to their natural conclusion. People who are in the final stages of life are often fearful of the dying process. The availability of medical aid-in-dying may encourage people to make drastic decisions based on concerns about the potential loss of autonomy and dignity, not realizing that modern palliative and hospice care may effectively address these concerns. Services such as pain and symptom management, in-home services, and counseling can help individuals navigate the end of their lives while minimizing suffering.
- 2) There are opportunities for abuse and fraud. The protections in Proposition 106 do not go far enough to shield vulnerable people from family members and others who may benefit from their premature death. Proposition 106 allows a family member or heir to be one of the witnesses to a request for the medication, potentially subjecting the individual to coercion. A physician is not required to have any specific training in order to make an assessment of the individual or require independent verification that the medication was taken voluntarily or under medical supervision. It also fails to ensure that the lethal medication will be stored in a safe location, potentially placing others at risk or leading to its misuse.
- 3) Physicians may be forced to choose between medical ethics and a request to die from a person for whom they feel compassion. It compromises a physician’s judgment by asking him or her to verify that an individual has a prognosis of six months to live, yet fails to recognize that diagnoses can be wrong and prognoses are estimates, not guarantees. The physician or hospice director must list the terminal illness or condition on the death certificate, which requires these professionals to misrepresent the cause of death.

### **What’s in the Future?**

The Death with Dignity movement has been joined by like-minded national groups, such as Compassion and Choices, the ACLU and the Secular Coalition, and on-the-ground efforts of local grassroots groups. Washington, DC just passed the first of two required votes, with the second coming in 2017.

Efforts are currently underway with grassroots groups and nonprofit organizations in Hawaii, Illinois, Maine, New York, Ohio, Texas, Virginia and advocates in several other states.

The movement has started, not surprisingly, with the more progressive, liberal states and works through the legislative process. It has not yet been tested in more traditional, conservative states.

As mentioned in the beginning, elder law and special needs planning are continually changing areas of law. If you have any questions or would like to speak to us about elder law or special needs planning, please don't hesitate to reach out.

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