

# The End of Life Option Act: Important Considerations for Pharmacists as California Implements Physician Aid in Dying

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On June 9th, 2016, California joined Oregon, Washington, Vermont and Montana as the fifth state to permit physician aid in dying.<sup>1</sup> The California End of Life Option Act is modeled after the Oregon Death with Dignity Act, which was voted into law in 1994 and went into effect in 1997. Both laws make it legal for physicians to assist people in particular circumstances to end their lives (Figure 1). These circumstances include 1) the patient is an adult, California resident with a terminal illness, with a prognosis of six months or less 2) the patient has the ability to self-administer the aid-in-dying drug and 3) the request originates from the patient, not from the patient's surrogate or anyone other than the patient. The law has safeguards intended to ensure that patients are acting autonomously, including a 15-day waiting period between two requests, the requirement that patients meet privately with their physicians to confirm they are acting on their own, and the requirement that patients sign a form within 48 hours of taking the aid-in-dying drug to indicate that it is their choice. The law also requires that patients receive a second opinion from another physician to confirm their eligibility. In addition, the law makes it a felony to knowingly coerce a patient to request physician aid in dying, to falsify a request or to administer the aid-in-dying drugs to a patient without their knowledge or consent.<sup>1</sup>

## How Other States Have Experienced Physician Aid in Dying

Oregon's experience with nearly twenty years of the Death with Dignity Act provides one example of physician aid in dying in practice in the United States. In Oregon, individuals who have used physician aid in dying were most often white (96.6%), older adults (median age 71) with a cancer diagnosis (77%).<sup>2</sup> Patients most commonly cited concerns about "losing autonomy"

(91.6%) and "being less able to participate in activities that make life enjoyable" (89.7%) as motivation for their interest in physician aid in dying, according to data collected via physician report.<sup>2</sup>

One positive outcome of the Death with Dignity Act in Oregon is that 91% of people who received a physician aid in dying prescription between 1998 and 2015 were enrolled in hospice at the time of death,<sup>3</sup> which is double the national frequency of hospice enrollment.<sup>4</sup> This achievement is a testament to the efforts of the Oregon healthcare community to improve end-of-life care generally in response to the legalization of physician aid in dying.<sup>5</sup> One area of concern is the low frequency of psychiatric evaluations (5.3% over 1998-2015) for Oregon residents who received a lethal prescription through the Death with Dignity Act, despite the finding that depression is relatively common among requesters (26% of patients who made a request for physician aid in dying met criteria for clinical depression in one study).<sup>6</sup>

Data from the Seattle Cancer Care Alliance indicate that about five-fold more patients inquire about physician aid in dying than use it.<sup>7</sup> There are a variety of reasons for this difference: patients are unable to make it through the process due to illness progression, they do not qualify, they change their mind, or they find relief from their suffering from alternatives like pain control or hospice.<sup>7-9</sup> Comprehensive attention to patients' end of life needs by healthcare providers go a long way, not only to support patients and families<sup>10</sup> but also, in some cases, to change patients' minds about pursuing physician aid in dying.<sup>6</sup>

## What to Expect in California

Given the similarities between California's End of Life Option Act and the Oregon and Washington laws, California's experience

with implementation of physician aid in dying is likely to resemble the other states' in some ways. However, there are important differences between the states, including California's size, its ethnic, cultural and socioeconomic diversity, and the variability in healthcare access across the state (Table 1). These differences may have an effect on how acceptable physician aid in dying is to patients, or how accessible it is. An opinion poll done in August 2015 indicated that 76% of Californians support physician aid in dying, but support was higher among white, Asian-American and Latino adults (all  $\geq 75\%$ ) than among African-Americans (52.3%).<sup>11</sup>

It is reasonable to expect that as in Oregon and Washington, many more patients will inquire about physician aid in dying than will use it in California. The long, contentious debate about the law and the recent rise in public support for the issue may mean that even more patients will ask their physicians about physician aid in dying in California. It is essential that healthcare providers fully explore the reasons behind a patient's request and connect patients to resources like hospice, because many patients use the subject of physician aid in dying to bring up their fears about the future, rather than because they have a true interest in hastening death. In addition, for those who persist in their interest in physician aid in dying, hospice will help them in their remaining time before using the aid-in-dying drugs. An unfortunate, early case in San Diego underscored how important it is for healthcare providers to give dying patients support and anticipatory counseling in addition to a prescription; the patient's family reported that they were in a "race against her symptoms" to obtain the aid-in-dying drugs and that her death was "fraught and frightening."<sup>12</sup> They were surprised that the aid-in-dying drugs themselves did not take away the anxiety and discomfort of the dying process, a reflection of incomplete understanding about the limitations of physician aid in dying.

One important aspect of California's End of Life Option Act is that participation in the law is voluntary for healthcare providers, and the definition of "provider" includes clinics, health dispensaries and health facilities, in addition to individuals.<sup>1</sup> Therefore every facility where patients receive healthcare, including pharmacies, may choose whether or not to participate in the law. And within facilities that have opted to participate, individual providers may choose to opt out. Religious and federal healthcare systems will not permit providers to participate in the law, which may lead to difficulty for patients in finding a physician to prescribe the aid-in-dying drugs. Already, since the End of Life Option Act has gone into effect, reporters have raised concern of a shortage of willing physicians in rural counties like Humboldt.<sup>13</sup>

Several institutions have added requirements in addition to the law's safeguards in order to further protect patients from harm, such as mandatory palliative care or mental health evaluations, or credentialing for physicians who participate.<sup>14</sup>

These requirements are intended to reduce the risk of patients receiving a prescription as a result of coercion or insufficient evaluation for reversible causes of suffering, but may make it more difficult for patients to obtain a prescription.

## What Every Pharmacist Needs to Know

As described above, participation in the End of Life Option Act is voluntary. Any pharmacist may decline to participate for reasons of conscience, morality or ethics.<sup>1</sup>

The End of Life Option Act requires that the attending physician (the physician who ultimately writes the prescription) evaluate the patient's capacity and ability to self-administer the aid-in-dying drug. This is to prevent harm to patients whose ability to make decisions is compromised by cognitive impairment or mental illness, and to prevent patients who cannot self-administer from receiving aid in dying against their will. The attending physician is required to deliver the prescription by hand or mail it to the pharmacy, and the patient must pick the aid-in-dying drugs up herself or designate an agent to pick them up, or the attending physician can pick up the aid-in-dying drugs for the patient. If the patient designates an agent, the attending physician must inform the pharmacist of the agent's name. The pharmacy may also mail the aid-in-dying drug with a signature required upon delivery.<sup>1</sup> Unlike Oregon, California does not require that pharmacists submit a form to document that an aid-in-dying drug has been dispensed.

If a pharmacist has concern about any aspect of the process, he or she should call the attending physician. If the pharmacist and the physician together have concern about coercion or that someone other than the patient intends to administer or use the aid-in-dying drug, they should not release the aid-in-dying drug and should report the suspected party to the police. If a pharmacist or anyone else has concern about an inappropriate prescription, such as to an incompetent or ineligible patient, or by a physician who does not have an "attending physician" relationship to the patient (treating the patient's terminal illness), the pharmacist should report the physician to the California Medical Board.

As with any controlled substance, there is risk of harm to others in the patient's household who may have access to the lethal drug. Bereaved family members in particular are at increased risk of suicide in the period after the patient's death. Pharmacists can reduce the risk of harm by counseling patients' families and caregivers about safe disposal of unused aid-in-dying drugs after the patient's death. Pre-paid mailers would reduce the burden on families, but there are no state programs to cover the cost of safe disposal at this time.

## The Law in Action: Pharmacy Updates

The choice of aid-in-dying drug is at the discretion of the prescribing physician (the law does not specify this level of detail). In Oregon, the most commonly used drug for the Death with Dignity Act has been a large dose of secobarbital.<sup>2</sup> In anticipation of legalization of physician aid in dying in California, the pharmaceutical company that makes secobarbital, Valeant, increased its price, and as a result, the out of pocket cost is now about \$3,000.<sup>15</sup>

Because of the rising cost of secobarbital, proponents of physician aid in dying have been attempting to find new drug protocols. A cheaper combination of morphine, chloral hydrate and phenobarbital has been recently introduced in Oregon and used by 16 patients in 2015.<sup>2</sup> Patients have reported a burning sensation with ingestion.<sup>16</sup> The advocacy groups Compassion & Choices and Death with Dignity have suggested alternate protocols, such as large doses of opioids and tricyclic antidepressants,<sup>16,17</sup> though these are untested, and have limited to no data to support their use for this indication.

Whether insurance will cover physician aid in dying drugs is variable. Medicare will not cover physician aid in dying, nor will the Veterans Health Administration. Shortly after the End of Life Option Act passed, \$2.3 million in funding for services related to the End of Life Option Act was included in the Medi-Cal budget to cover the cost of the aid-in-dying drugs.

## Conclusion

The legalization of aid in dying through the End of Life Option Act represents a huge shift in the scope of end of life care for California. The law gives certain qualified patients more control over their death, and provides immunity for the healthcare providers who assist them. Healthcare providers are not obligated to participate in the law. Because of the potential for risk to patients and their families, the End of Life Option Act requires a tremendous amount of effort on the part of the healthcare system to ensure safe implementation. Healthcare providers who choose to participate, including pharmacists, should learn not only the law and its safeguards, but also the institutional policy and culture where they practice. Communication and collaboration among healthcare professionals is essential to keep patients safe.

## About the Author

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**Figure 1. End of Life Option Act Law Overview.<sup>1</sup>**

## End of Life Option Act Overview

- Adults (≥18) with a terminal illness may request a drug to end their lives from their physician
- Patients must: have the ability to make decisions, have the ability to take the drug and not have impaired judgment due to a mental disorder
- Prognosis and decision making capacity must be confirmed by two physicians
- Patients must make two oral requests, 15 days apart, and one written request
- Physicians must counsel patients about alternatives, including comfort care, hospice care, palliative care, and pain control

**Table 1. Comparison of California with Oregon and Washington, the two states that have had the longest experience with physician aid in dying, including: population differences,<sup>18</sup> demographic differences,<sup>18</sup> palliative care availability,<sup>19</sup> proportion of deaths at home,<sup>20</sup> and physician aid in dying death data<sup>2,21</sup>**

	California	Oregon	Washington
Population, millions	38.80	3.97	7.06
Race/ethnicity, %			
White, not Hispanic/Latino	38.5%	77.0%	70.4%
Black or African American	6.5%	2.0%	4.1%
Asian	14.4%	4.3%	8.2%
Hispanic or Latino	38.6%	12.5%	12.2%
Other	2.0%	4.2%	5.1%
Hospitals with palliative care, %			
≥50 Beds	74%(168/227)	88.9%(24/27)	92.7%(38/41)
<50 Beds	44.1%(15/34)	44.8%(13/29)	35.7%(10/28)
Sole community providers	33.3%(2/6)	100%(3/3)	80%(4/5)
Annual deaths	248,359	33,939	51,264
% death at home	35.0%	38.7%	33.2%
Physician aid in dying deaths, total	Not available	857	712
Physician aid in dying deaths, % of all deaths	Not available	0.22%	0.33%