

# What Data From California's New Assisted Dying Law Tells Us

By Lael Duncan • Sep 25, 2017

Many people who are hoping to take advantage of the End of Life Option Act are unable to locate a physician who will walk them through the process and assist them with end-of-life care planning.

In the first six months of California's new End of Life Option Act, which allows some terminally ill patients to end their lives with medication, there have been no initial surprises. California statistics are so far quite similar to those reported by Oregon and Washington, which also have aid-in-dying laws.

As a quick overview, 258 people started the end-of-life option process by speaking with two different physicians at least 15 days apart, according to the data released by the California Department of Public Health this July. Of these patients, 191 had prescriptions written for aid-in-dying drugs between June 9, 2016 and December 31, 2016. Physicians reported that 111 of the patients died following the ingestion of the drugs.

The median age of those who died using aid-in-dying drugs was 73; 46 percent of the patients were male and 55 percent female. The majority of those who died were white (nearly 90 percent) and most were diagnosed with cancer (nearly 60 percent).

What remains unknown at this point is how California statistics and demographics may change over time as a result of our size and diversity.

One factor, not definitively related to age, gender, culture, ethnicity or spiritual preference that might be expected to strongly influence how California data looks in the near future is the issue of access. Based not only on the information provided in the CDPH report, but anecdotally in my work as a physician at the Coalition for Compassionate Care of California, I know that many people seeking to use the End of Life Act are having trouble doing so.

At the coalition, we regularly receive phone calls from patients or caregivers seeking information and hoping for a referral to a participating physician. This seems to be the largest barrier for patients who are knowledgeable about the law and seeking information on participation—many are unable to locate a physician who will walk them through the process and assist them with end-of-life care planning.

Data from Washington and Oregon, and our own California data, demonstrates that not all those who seek participation are eligible and not all those who are eligible will go on to take the aid-in-dying medication. But many of our interested California residents are not able to engage with a provider in the thoughtful conversations necessary for an initial determination of eligibility for aid-in-dying or an associated in-depth discussion of alternative end-of-life care plans.

There are several reasons for the challenges patients face in locating a participating physician in their area. First, not all health systems are participating and allowing their physicians to prescribe aid-in-dying medication. Second, we have found that most physicians across the state aren't currently participating—regardless of the policy under which they are practicing.

In the wake of the passage of the law, providers, health systems and others need to clarify their role, deciding whether or not to participate, as well as preparing for how they will handle individual requests for information about the law and how they will meet the needs diverse of these patients.

Among reasons for physician non-participation there are those who are fundamentally opposed to deliberately hastening a patient's death. But these do not seem to comprise the majority of non-participating physicians. Anecdotal evidence and conversations among experts and those involved in policy development suggest that many physicians who are open to the concept of aid-in-dying for patients in general, are not ready to be personally involved. Some physicians feel that the professional risks are too great. A number have adopted a "wait and see" approach to give the law time to mature and to see how implementation unfolds.

Across the state, most physicians have not had the opportunity to understand fully the process and practices necessary to provide excellent care for those participating in aid-in-dying. Some have said they might consider participation but are waiting for one of their own patients to ask for this option. This is not new information, prior studies looking at physician attitudes and practices regarding physician assisted death suggest that 1 to 5 percent of practicing physicians may be open to assisting patients in this way.

This evolving process of has underscored a larger more important issue, one that we at CCCC are very interested in: How do we as a society ensure that each person can access the care they want and also avoid treatments they don't want, especially at the end of life?

The reality is that the end of life is complicated. From pain management to spiritual and mental wellbeing, to family and caregiver support, bereavement and beyond, the needs of patients vary widely and extend well beyond aid-in-dying.

The End of Life Option Act data report highlights issues of access to a specialized type of care that will be important for a small percentage of our population. But, it brings into the spotlight across-the-board deficits in end-of-life care. It underscores the limited availability of time-pressured physicians to openly and skillfully talk with patients about end of life and to engage in timely planning for that stage of life—something that all patients facing end of life should be able to access.

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