

End-of-Life Options in California

A Work in Progress

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“You can always count on Americans to do the right thing—after they’ve tried everything else.” Winston Churchill’s aphorism served as an appropriate warning to California legislators as they decided to take no action this year on the controversial End of Life Option Act (SB 128), which would have allowed physicians to write prescriptions for a fatal dose of medication to be self-administered by a competent, terminally ill patient.

There is no question that the ability to receive aid in the dying process is a concept that has gained public support. The case of Brittany Maynard, the 29-year-old woman with brain cancer who chose to go to Oregon to die because the option of euthanasia did not exist in California, has framed the question as one of compassion. The California legislature seemed sympathetic to the issue but recognized that the proposed legislative solution was fatally flawed. However, requests for aid in dying will not go away just because the California State Assembly refused to consider a piece of legislation. It is important to recognize the problems inherent in SB 128 in order to avoid them in the future when crafting a more workable

solution for patients who request assistance in dying.

The goal of any aid-in-dying legislation should be to provide a method that is open to appropriate candidates, reliable, and free of perverse financial incentives. California’s End of Life Option Act failed in each of these categories.

The bill required patients to be able to self-administer and ingest the prescribed medication. Additionally, the request had to be put in writing. Terminally ill patients unable to swallow or physically unable to use their limbs—such as those with esophageal cancer, Lou Gehrig’s disease, or disabling strokes—suffer from conditions that might justify aid in dying, but SB 128 did not allow them to benefit from its provisions. Most disability groups were adamantly opposed to this piece of legislation, for obvious reasons, but its wording actually discriminated against those with disabilities.

Second, the California bill called on the wrong people to get the job done: medical practitioners. Physicians have a 2,000-year-old medical tradition that has specifically excluded willfully ending life from the ethical practice of the

Editor’s note: The above article was written shortly after California’s End of Life Option Act died in the Assembly Health Committee on July 7, 2015. Subsequently, the bill was reintroduced in a special session of the State Assembly and passed on September 9. Governor Brown signed the bill into law on October 7.

profession. They have spent many years training to preserve life, yet they have received no training in the practice of ending it. There were no provisions to teach all the doctors in California this new skill. There were no guidelines about what drugs and doses to prescribe as an end-of-life medication. Oral absorption of drugs is notoriously variable, and some attempts to end life have only resulted in persistent incapacity, not a quick end. Efforts by state correctional institutions to execute condemned prisoners are rife with reports of inhumane suffering during the dying process, even when intravenous agents are employed. How could we expect an untrained doctor to get it right every time with a pill? Surely an entrepreneurial pharmaceutical company would be able to develop some agent (they might brand it "Enditol"), but none exists right now. Countries like Holland, with far more experience than Oregon, are able to rely on intravenously administered medications with direct oversight to assure the desired end, but California's bill did not take advantage of this experience.

The End of Life Option Act also did not adequately ensure that the prescribed drugs would be reliably administered to the intended recipient. Data from Oregon show that in 2013 only 51.6 percent of patients who received life-ending medications actually took them. More than 48 percent of cases had medications left over. We know that one of the major ways that the narcotic Vicodin appears in our communities as a recreational drug is when unused pills are removed from the medicine cabinets of the patients to whom they were prescribed. How long would it have taken before "Enditol" began to appear on the street?

One concern that seems to have been overlooked was the financial one. This is the elephant in the room for some. California legislators' attempt to eliminate financial incentives by prohibiting direct reimbursement for writing the life-ending prescription was naïve. Most doctors, and the healthcare organizations they work with, now receive in advance the majority of their payment for the medical care they give to their patients. What is left over after the treatments are delivered is their profit. Advanced illness can be an expensive thing to treat, and, in the current reimbursement system, a quick end can save a lot of money. Physicians and hospital administrators howl whenever financial conflicts of interests are brought up, but how can they alone protest that they are impervious to them? Doctors and the healthcare organizations they represent have too much money riding on the outcome to be trusted with the process. If we are to have a system protected from financial concerns, the agents should not be within the healthcare system that stands to benefit.

California's effort to expand the end-of-life options for terminal patients did not succeed, because the proposed solution was impractical and flawed. A much more reasoned approach would have been to develop a distinct group of professionals, not necessarily physicians, who are specifically certified, monitored, and trained to oversee and administer the appropriate end-of-life procedures effectively, painlessly, and transparently. This professional class could be consulted by patients or physicians when the palliative care treatments offered in a terminal condition are not considered to be satisfactory.

America hears you Winston; we are just still working on it.