A Calling, and a Call to Physicians

End-of-Life Option Act Offers Patients Dignity in Death

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SINCE CALIFORNIA ASSEMBLY BILL 15, the End of Life Option Act (EoLOA), was passed in 2015 and enacted in 2016, hundreds of patients with terminal illnesses have received lethal medications by physicians to end their suffering.

Notice that I didn’t say “by their physicians.” Very few physicians are participating in the end-of-life services enabled by the bill, especially in senior-dense areas like Roseville and some outlying rural communities. In fact, the chance of one’s own physician participating is quite low.

After involvement in about a dozen EoLOA cases over the last two and a half years, I am by no means an expert. But I have a wonderfully compassionate and resourceful colleague, Ryan Spielvogel MD, who has trailblazed this service for our family medicine clinic. Through him and others, I have seen many successes and bear traps along the way. Participating physicians in our Sutter Health clinic often get requests to travel to Roseville and other outlying areas because so few providers offer this service.

I hope that my story might persuade you to consider adding this service to your practice. I have found it to be among the most rewarding experiences in my 14 years of practice.

Any licensed physician may participate in the EoLOA process. Of course, in this era of Big Box Medicine, some physicians are limited by the policies of their institution, including any religious affiliation. But I suspect that most physicians just aren’t comfortable with prescribing lethal medication (“First Do No Harm”), that it might be perceived as too much paperwork or logistics, or that this is all just too new to jump into. It also doesn’t reimburse any more than an office visit, and there’s no sexy cutting-edge technology like robotic surgical arms, helipads, or catheters under fluoroscopy. It involves talking with patients and family. Yet it can be the final and most important touch we have in a patient’s life.

Surprisingly, the EoLOA is a well-written bill with a process that is not hard to follow. A patient must be evaluated by the attending physician twice, at least 15 days apart. The patient must be a resident of California, have a terminal illness, be of sound mind, and be physically able to administer the lethal medication themselves whether by mouth, feeding tube, or rectal tube in a witnessed fashion. It cannot be administered by IV.

A second physician needs to consult with the patient somewhere within this 15-day period and concur with the plan. For any significant mental health issues, a mental health provider must be consulted as well. The patient must consent in writing and verbally, and two witnesses must sign on; not more than one may be family, and not more than one may be from a health worker involved in the patient’s care. The various forms and templates to use for the process are available online through the California Department of Public Health (CDPH).

According to CDPH, 632 patients in 2017 started the EoLOA process. Fifty-five died during the waiting period. Of 577 patients receiving lethal prescriptions, 86 did not ingest the drugs and died of the underlying illness, 363 ingested
and died from the drugs, and 128 had “undetermined outcomes.” The gold standard lethal cocktail is high dose secobarbital. Unfortunately, this costs several thousands of dollars and is cost-prohibitive to most patients.

Although it often leads to unconsciousness in minutes and death in an hour or two, there have been cases of prolonged deaths. High-dose morphine alone is rarely used as many patients with a terminal illness are already opioid-tolerant. The current most popular and economical regimens contain various combinations of high-dose amitriptyline, diazepam, digoxin, morphine and propranolol. Patients are often pre-medicated with antiemetics and anxiolytics.

I never really imagined myself doing this. I grew up in a religious home and went to religious schools. I consider myself Christian tempered by a little agnosticism. I volunteered in hospice during college. My parents were not thrilled to hear that I was participating in helping terminal patients end their lives when I first mentioned it over a holiday dinner (think awkward silence and silverware clinking). I would never want to harm a patient or break my Hippocratic Oath, but I see patients harmed every day by well-meaning medical intervention that just leads to more suffering. Most patients are able to die peacefully with hospice, but some do not. Some reach a state of disability that they had hoped never to experience.

I was first asked to be a consultant on an EoLOA case through a connection within SSVMS. A retired surgeon’s friend’s wife was dying of breast cancer and did not want to suffer anymore. Although she lived locally, her care was through a renowned medical center in the Bay Area

Her oncologist and I discussed the case. He stated incorrectly that his institution must do an ethics review and that their palliative care service must sign off on the process. Despite the institution’s many helipads, no doctor could make the 80-mile trip out to do the home visit. My credentials were questioned (“You mean you’re not a palliative care specialist?”). Through persistence and frequent reference to the legislative source document—I’m a family doc and this is not my first rodeo—I was able to participate in helping the patient fulfill her wishes and the family was very grateful.

My colleagues and I have had many interesting experiences since. Most have gone smoothly, but not all. One patient of mine, after getting the lethal prescription, waited a couple days for a family member to be present and became delirious the day he was to take it, and suffered several days longer until he expired from the illness. Another patient of mine became unconscious quickly but

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took almost a full day to expire.

Having your cell phone available to the family and hospice services involved is tremendously helpful in reassuring the families during this waiting period. The patient is almost always in a sleep-like and peaceful state. One of our clinic patients was a young lady with cancer, reminiscent of Brittany Maynard. We found prescribing for her emotionally hard for us, but she was sure of her decision.

One patient had a horrible fungating oral cancer and simply couldn’t swallow medicine, but could use his G-tube. Another was on TPN with short gut syndrome and couldn’t take it by G-tube but could use a rectal tube. One patient with a hypercoagulable disorder had frequent strokes/TIAs and unfortunately became too debilitated to finish the EoLOA process because she couldn’t physically administer it. She did mercifully pass not too long after, however.

The patient I saw who seemed to be suffering the most had ALS. He was in pure misery, and he and his family wasted not one second to get the prescription so he could pass. We’ve had patients from rural communities seek us out because they heard of a friend having the EoLOA service through us with good results for the patient and family. Many of the patients, interestingly, are from well-to-do backgrounds.

Let me be clear: We do not rubber stamp. One patient was severely depressed and just didn’t qualify. Another man refused dialysis and we tried to talk him into peritoneal dialysis, where he would have more control over the treatment, but he ended up refusing this too and went on to take the lethal medication. Interesting family discussions and dynamics have come up, as one could imagine. One patient’s daughter gave me some wonderful advice to take an oral history from your parents, something that proved invaluable to me when my own father passed away a few months ago. One can learn a lot about life through death.

We often consider death a failure in our profession. But through many of my home visits and experiences over the years, I am amazed by the amount of suffering that goes on behind the closed doors we drive past every day. Indeed, my last EoLOA patient marveled that we sometimes treat pets better than humans when it comes to ending their suffering.

EoLOA is not the right path for most patients, but it’s an important option for some. And don’t we all like options? It’s always good to First Do No Harm, but sometimes patients want the Harm undone, and now we have a merciful way to complement hospice services to do just that.