Modern Healthcare

What California providers will do when asked to help patients die

By **Harris Meyer** | March 11, 2016

"I understand that bumping off your patients isn't why you went to medical school. But I believe it falls squarely within the Hippocratic oath because making me drown in bodily fluids is doing more harm than giving me the prescription," said Elizabeth Wallner. Compassion & Choices

Elizabeth Wallner, an educational consultant who lives in Sacramento, Calif., has Stage 4 colon cancer that has metastasized to her liver and lungs. She campaigned for her state's new physician aid-in-dying law, which will take effect in June.

Wallner has talked with her three physicians about obtaining a prescription to end her life if and when she chooses not to continue her cancer treatment. None is willing to help her. "I understand that bumping off your patients isn't why you went to medical school," she said. "But I believe it falls squarely within the Hippocratic oath because making me drown in bodily fluids is doing more harm than giving me the prescription."

California patients like her who are 18 or older and want to take advantage of the End of Life Option Act are likely to face challenges in finding cooperative physicians, hospice workers, pharmacists and other healthcare providers, at least initially. Terminally ill patients who live in communities where the sole or dominant provider organizations are **Catholic-owned or -affiliated**[1] will face even tougher problems because those systems will not allow their physicians and staff to help patients exercise their rights under the law. Patients in more conservative, rural parts of the state also may face hurdles. Unlike in other states, Compassion & Choices, the group that led the effort to pass the law, says it will not steer patients to participating doctors, though it will list participating health systems on its website.

But two giant California systems, **Kaiser Permanente**[2] and **Sutter Health**[3], told Modern Healthcare that they and their physicians and staff will participate in the law, though their individual providers have the right to opt out.

There also are questions about health insurance coverage for aid-in-dying services and drugs. Congress barred Medicare, the Veterans Health Administration and other federal programs from paying for these services, while California's Medicaid program and most private insurers have not yet clarified their payment policies. The drugs alone can cost several hundred to several thousand dollars.

A statewide Field Poll last October found that 65% of Californians surveyed support the law, with 27% opposed and 8% undecided. While California providers disagree about the morality of the law, everyone hopes its existence will spur more and better end-of-life care discussions, and increase the use of **palliative**[4] and **hospice**[5] care.

“It shines a light on end-of-life care generally, and it requires physicians to explore all these options with patients who make requests for pain control, comfort care and palliative care,” said Leah Newkirk, vice president of health policy at the California Academy of Family Physicians, which adopted a neutral position on the law.

Four other states allow physician aid in dying, but California's experience will receive heightened scrutiny because of the state's enormous size and diversity, and its history as a national trendsetter. In those other states, a small percentage of terminally ill patients have asked doctors for a lethal prescription, and an even smaller percentage followed through to end their lives.

MH TAKEAWAYS

Two of the largest California health systems say they'll support physicians who participate in the state's new aid-in-dying law, but many patients may still struggle to find providers who are willing to cooperate.

In Oregon, the first state to pass a “death with dignity” law almost 20 years ago, nearly 0.4% of all deaths in the state in 2015—132—were patients who availed themselves of aid in dying; 218 patients that year had received a

lethal prescription. If California patients use the law at that same rate, the annual death total would be around 850.

Those other states have seen few if any abuses of the process, but some fear that California's free-wheeling culture creates greater potential for problems. “We're a different, more diverse, much bigger state, and we're definitely thinking a lot about protecting vulnerable people and making sure no one is acting in a way that devalues lives,” said Newkirk, whose group is actively educating its 9,000 physician members about the new law.

The End of Life Options Act allows healthcare organizations and providers to opt against participating in aid in dying. It also lets organizations sanction doctors and staffers who violate their policy. But doctors and employees cannot be disciplined for simply telling patients about their options under the law or referring them to participating providers. That could become a contentious issue inside nonparticipating provider systems.

Under the law, two physicians must independently determine that requesting patients have six months or less to live, are making an informed, voluntary decision, and are mentally competent. The California Medical Association, which took a neutral position on the law, recently published a 15-page set of guidelines for physicians.

Compassion & Choices said it's working with health systems throughout California to educate and encourage them to have their doctors and staff offer aid in dying for qualifying patients who request it. It has launched doctor-to-doctor and pharmacist-to-pharmacist phone consultation hotlines, and it will have educational videos available for doctors and patients. Unlike in Oregon and Washington, however, the group is not planning to assemble a confidential referral list of participating doctors, though it will initially keep a confidential list of participating pharmacists.

Since C&C started focusing on providing technical assistance to health systems in Oregon, the number of participating physicians there has grown by nearly 60%, said Sean Crowley, a group spokesman. “Our goal is to normalize medical aid in dying into the standard of care,” he said.

Staff physicians at Kaiser Permanente who are willing to do so will write lethal prescriptions for qualifying patients who request aid in dying, and Kaiser pharmacies will dispense the drugs. “We encourage our patients to have thoughtful conversations with their doctors, families and other loved ones about their end-of-life wishes,” said John Nelson, Kaiser's vice president of government relations.

Dr. Stephen Lockhart, Sutter Health's chief medical officer, said his system “will support patients who explore making this difficult decision. We're also planning comprehensive education with our doctors and employees that will equip them to respond to questions from our patients and their families.” He added that his organization is still drafting its policies and procedures.

Participation is also expected at non-Catholic hospices, which will be more directly involved in aid-in-dying requests than hospitals are. Susan Negreen, executive director of the California Hospice and Palliative Care Association, said most of her member hospices will support their patients through the process without providing the lethal prescriptions.

“It doesn't matter what our personal opinion is,” said Linda Gibson, CEO of Collabria Care, a not-for-profit hospice serving Napa County. “It has to do with the promise we make to patients to be with them through this difficult time and to help them understand what they want and make that a reality for them.”

The U.S. Conference of Catholic Bishops' Ethical and Religious Directives rule out physician-assisted suicide, so Catholic hospitals and other healthcare facilities will prohibit physicians and staff from helping patients exercise their rights under the law, said Lori Dangberg, vice president of the Alliance of Catholic Health Care in Sacramento. Thirteen percent of California's hospitals are Catholic-owned or affiliated or generally follow Catholic doctrine, including facilities operated by Dignity Health, St. Joseph Health and Providence Health & Services, she said. And 20% of home health visits are provided by Catholic agencies.

“When a patient requests aid in dying from our doctors or staff, we won't forbid a conversation,” Dangberg said. “But we will talk about the underlying reasons for that concern. Experience has shown it often has to do with fears about pain management or that the patient and family won't be supported through the dying process. Those issues must be addressed first.”

Dangberg said doctors and staff at Catholic facilities will be allowed to refer patients to their attending physicians for counseling about the law.

But Newkirk said that simply referring patients back to their attending physicians won't help if those physicians are part of Catholic systems and are discouraged from discussing the aid-in-dying option. “In some locations where a Catholic system may be the dominant system,” she said, “that could

create challenges for patients who want to exercise this option." When patients bring up the aid-in-dying issue, she added, any physician has the right "to just stop the conversation, but we are hopeful no one will."

Despite the looming effective date of the law, many California providers are early in the process of deciding whether and at what level to participate in the law and establishing policies and procedures. Organizations choosing to opt out must formally notify their physicians and employees. Dr. Terrell Van Aken, medical director for hospice and palliative care at NorthBay Health Care in Fairfield, said he will soon go before his system's board members to try to convince them to approve full participation, including allowing doctors to write prescriptions. But he's not sure he'll succeed. "I've thought about the first prescription I'll write; it's anxiety-provoking for sure," he said. "But I've seen the other side, people suffering at the end of life on palliative sedation, and that's why I believe in it and am prepared to do it."

In the past, Compassion & Choices always tried to have a volunteer present when a patient took the lethal medication to make sure proper procedures were followed. But now the organization hopes hospice and other providers will take on that role in California.

With the group's support to hospices and health systems in Oregon, "they are now becoming comfortable with providing the necessary support to their own patients," said Kat West, the group's national director of policy and programs. "Medical professionals are stepping up, and demand for our volunteers is much less now. We're hoping that will continue into California."

But Collabria Care's Gibson expressed doubt about whether California patients will be able to find participating doctors and other providers without more direct assistance from Compassion & Choices. She had expected to be able to refer patients to the group for help. She's also not sure how many hospice staffers or other providers will agree to be present when patients self-administer the lethal prescription. She predicts some will and some won't, though willingness may grow as providers gain experience with the aid-in-dying process.

"Some people may initially say, 'I feel strongly I don't want to be there during the process,' " she said. "You have to respect their feelings about that. But it's so important at the end of life to respect what our patients want and create an environment where they leave the world with great dignity and love."

Wallner, the patient with Stage 4 cancer, said she's going to keep trying to

persuade her doctors to help her if she chooses aid in dying. “I'm working on them,” she said. “I won't walk into a total stranger and say, 'Hey, bump me off.' But if things head south, I'll have to switch doctors.”

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