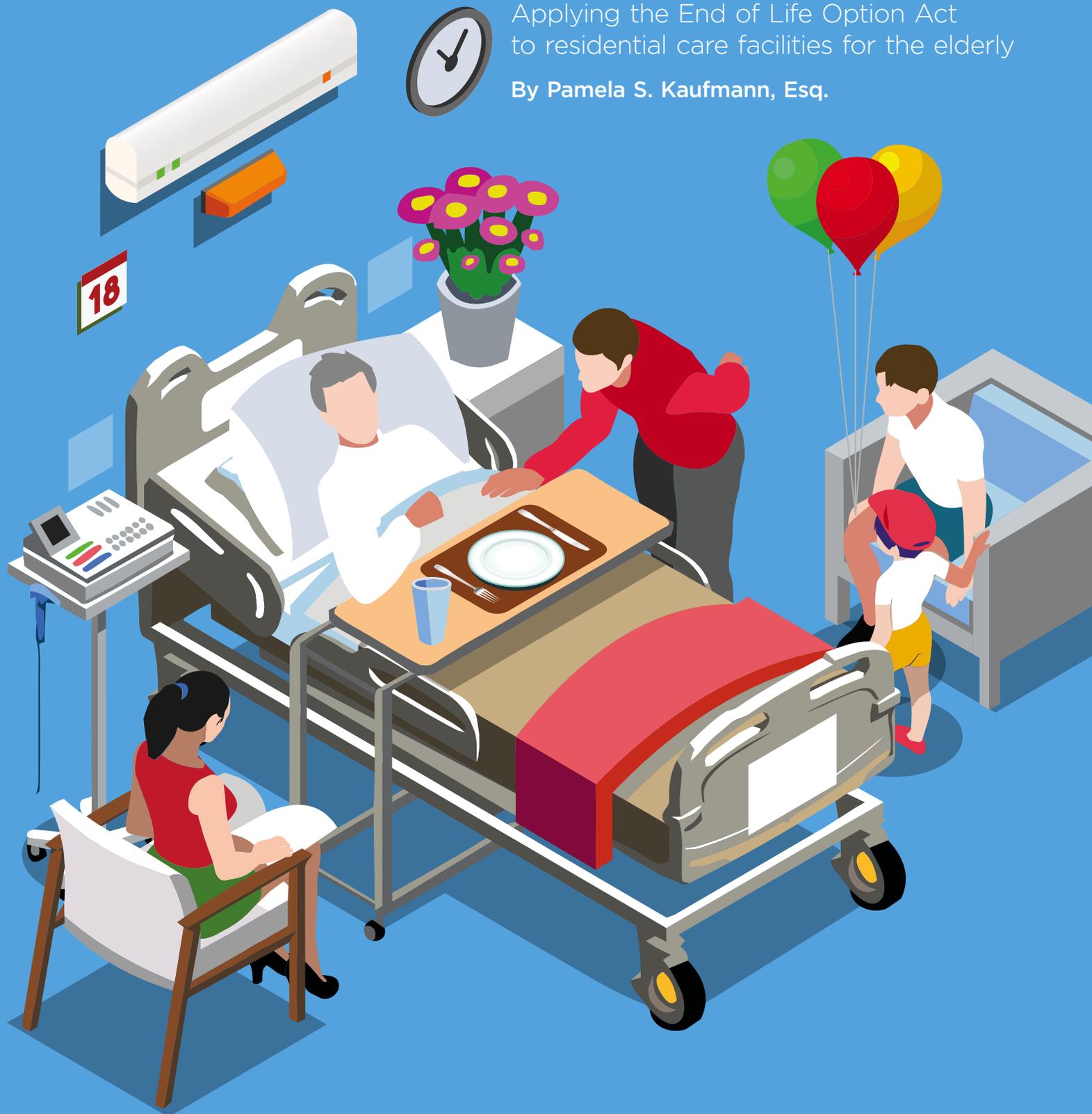


Death with Dignity

Applying the End of Life Option Act to residential care facilities for the elderly

By Pamela S. Kaufmann, Esq.





ON OCT. 6, 2016, Californians noted the one-year anniversary of Governor Jerry Brown's approval of the End of Life Option Act, which has been in effect since June 9, 2016. The past year has been filled with spirited debate, numerous what-if scenarios, and speculation about which healthcare providers would opt in and which would opt out. In a well-publicized news story, one California hospital opted in after rejecting the recommendation of its medical leadership to opt out. For residential care facilities for the elderly (RCFEs), which are by definition *not* healthcare providers, the speculation was accompanied by some hand-wringing as RCFEs across the state attempted to glean how the law applied to them.

The Act from 5000 Feet

Simply put, the Act allows terminally ill California residents who leap through various procedural hoops to take aid-in-dying (AID) drugs to expedite their death. These include two verbal requests and one written request for AID drugs, strict witnessing requirements, and visits to both an attending and a consulting physician to confirm the patient's terminal diagnosis (six months or less), residency, legal competency, and informed consent. No other person, not even a sibling or spouse, can help administer the drugs or make the request for the drugs. Where a patient shows signs of depression or mental illness, a referral to a mental health professional is also required. No medication may be prescribed until the mental health specialist determines that the patient no longer suffers from the condition impairing his or her judgment. Some commentators have observed that it takes a lot of stamina to die under this law! In my opinion, the Act's emphasis on process reflects the delicate balancing of the rights of all affected parties. It also designed to prevent impulsive action, duress, or abuse.

As with other ethical controversies, language matters. The Act clearly asserts that taking AID drugs under the Act is not suicide, homicide, or assisted suicide. (Its critics might take exception to this characterization.) Semantics aside, this statement is significant because it helps to assure that this action is not deemed criminal and will not affect the availability of insurance (life insurance, in particular). Furthermore, a death from consuming AID drugs is deemed a natural death from the underlying disease, and actions taken in accordance with the Act cannot form the basis for a neglect or elder abuse claim.

Another sign of the Act's balance is its even-handed treatment of providers, regardless of their position on the use of AID drugs. Whether a healthcare provider opts in or out of "participating" under the Act, the healthcare provider is

protected from adverse action, such as censure, disciplinary action, or loss of licensure—as long as the provider does not violate the Act.

"Participation" is actually a very narrow concept that includes only (1) performing the duties of an attending physician, consulting physician, or mental health specialist; (2) delivering the prescription for, dispensing, or delivering AID drugs; or (3) being present during ingestion of AID drugs. In fact, not all acts by a physician or mental health specialist constitute participation. The term expressly excludes (1) diagnosing a terminal disease, making a prognosis, or determining a patient has the capacity to make decisions under the Act; (2) providing a patient with information about the Act; and (3) referring a patient to a participating provider. Thus, the focus of "participation" appears to be on handling the drugs and being present during ingestion.

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Healthcare providers can prohibit their staff and contractors (and implicitly their volunteers) from participating under the Act, but they can only enforce this prohibition if they give these workers notice of their policy. Similarly, where a provider allows participation, employees and contractors can refuse to participate for reasons of "conscience, morality, or ethics" without penalty.

Here's the rub: the Act was not written with assisted living in mind. It was written for healthcare providers, and probably not all healthcare providers. Its language strongly suggests that it was designed primarily for doctors, hospitals, and pharmacies. This is significant because none of these healthcare settings is "home" for a patient. Contrast a hospital with a skilled nursing facility (SNF), which is defined as a healthcare provider and which is clearly home for its residents. It is neither easy nor convenient for SNF residents to ingest these drugs somewhere else. (At times, it may not be physically possible.) The same is true for RCFE residents, whose home is the RCFE.

DSS to the Rescue

Last fall, our firm began to identify several challenges for RCFE providers trying to discern how to apply the Act to their unique setting. For example:

- Can an RCFE provider require residents to disclose their end-of-life plans?
- Can it prohibit residents from self-administering AID drugs on its premises?
- Must it allow residents to store AID drugs on campus?

- Can it prohibit staff and contractors from participating under the Act?
- Must it call 911 if a resident is found dying after ingesting an AID drug?

We were very fortunate to receive clear guidance from the California Department of Social Services (DSS) last winter. In a four-page memorandum, DSS reasoned (correctly, we believe) that although they are not healthcare providers under the Act, RCFE licensees and their employees are entities or individuals under the Act who may, due to “conscience, morality, or ethics,” opt not to participate in activities authorized under the Act. DSS thus concluded that RCFEs could instruct their staff not to participate in activities permitted by the Act. Although the memo is silent about volunteers and contractors, we believe it is reasonable to apply the same logic to these two groups, at least on the RCFE campus.

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Other findings by DSS were potentially more troubling for our clients. For example:

- Regardless of the licensee’s choice, residents retain the right to obtain and self-administer AID drugs on the premises. Some clients find this policy offensive on religious or ethical grounds.
- Residents are solely responsible for obtaining, storing, and self-administering AID drugs (in a locked cabinet or off-site). Even if a cabinet is locked, it is obviously safer, for the RCFE and its residents, to store these drugs off-site. This step should be encouraged.
- Residents are not required to disclose their intent to consume AID drugs to the licensee. This is an obvious impediment to care planning and can trigger intense conflict if the family learns of a resident’s plans after the fact.

Our primary concern about the memo was that it offered no guidance regarding the need to call 911 after learning that a resident had ingested AID drugs. Calling 911 when the resident was clearly taking steps under the Act to end his or her life seemed contrary to the resident’s express wishes and the intent of the Act. Recently, DSS suggested (verbally) that RCFEs need not call 911 when a resident’s plans to take AID drugs in accordance with the Act are clear. In all other circumstances, DSS stated, providers should continue to call 911. We

have learned since then from the State that there will not be written guidance on this issue and that the decision to call 911 or not must be addressed on a case-by-case basis.

Risk Areas

As I advise clients about the Act, we quickly drill down to their key concern: will they participate, and to what degree? This is not an all-or-nothing proposition. Providers can choose to participate in certain acts but not others.

For many clients, the primary risk management concern is receiving or storing the medications. After all, the AID drug is a controlled substance that is designed (in the right dosage) to shut down one’s central nervous system and cause death. Other drugs that make up the “cocktail” include a sedative and anti-nausea medication.

Many clients also express concern about being present during ingestion of the AID drugs. They are not necessarily worried about the risk of harm; however, they have offered the following rationales for their position: (1) being present suggests that the provider condones dying in this manner; (2) an employee who is present when a resident ingests AID drugs may feel compelled to assist the resident (in violation of the law) if the resident is struggling with the medications; or (3) it may be traumatic to the employee to watch the resident die in this manner. The first rationale is the one I hear the most often from religiously affiliated clients.

Although it does not constitute “participation” under the Act, I routinely advise clients against allowing their staff, contractors, or volunteers to witness a resident’s written request to take AID drugs. I would catalogue this advice under the heading of “no good deed goes unpunished.” If there is any question about the resident’s competency, his or her prognosis, the absence of duress, or any other factor that could cast the validity of the form in doubt, you do not want your company or your workers implicated. If a resident declines to tell his family of his plans and a family member learns that your staff or agent witnessed the written request for the drugs, nothing good will come of this. Your best option is to bow out—and instruct your workers to do the same.

Trends

Having given about 20 presentations on the Act and spoken to numerous senior care and housing providers, I have observed some fascinating trends.

- Clients are largely opting out of participation. Some are carving out exceptions for contracting physicians or hospices, and one or two will allow their workers to be present during ingestion, but

no senior care client has yet advised me that it is fully opting in.

- Clients are uniformly advising their staff, volunteers, and contractors not to witness requests for AID drugs.
- I discern very little difference in the decisions made by clients based on faith affiliation. The tone of my clients' policies may vary, and their reasons for their position may vary, but the result is rather uniform.
- Caregiving staff at several of my clients' communities have expressed discomfort with having residents take AID drugs on campus. Many cite their faith as a large reason for this position.
- Be prepared for staff to decline to provide comfort care (think palliative care) after ingestion due to their faith or ethical concerns. Providing comfort care is not a form of participation, but it will follow ingestion by only a few minutes. Although RCFEs are not required to provide this service, it is not uncommon for clients to keep a dying resident company and to soothe the resident. I recommend that staff's wishes in this respect be honored.

Utilization

All four states with end-of-life statutes (California, Oregon, Washington, and Vermont) require that data be collected under their end-of-life laws. As a result, we know that in both Oregon and Washington (which have older statutes and more data than Vermont), roughly two-thirds of prescribed end-of-life drugs were ingested and one-third went untouched. Whether this is due to effective pain and symptom management by hospice agencies, the comfort of having the drugs nearby, sudden health declines, the influence of family or clergy, or other factors is unclear.

The data also reveal that the typical person taking AID drugs is a 70+ year old with cancer who dies at home, usually with hospice care. Only a small number (about 5%) of people ingesting these drugs in Oregon and Washington died in a long-term care or similar setting. Given these statistics, one might wonder what the fuss is about in senior

care. Residents feel otherwise. When I speak to groups of residents, they express keen interest in knowing their provider's position—and planning for it.

Next Steps

If a resident decides to invoke his rights under the Act tomorrow, do you know what your position will be? If not, I recommend that you make your end-of-life policy a high priority. There have already been a few reported instances of terminally ill California residents taking AID drugs, and your residents are very eager to know what your position is.

Once you finalize your policy, you will want to document it in a policy and procedure and start educating residents, staff, contractors, and volunteers about it. Disclosure is key. To support your efforts, I recommend describing your policy in your resident handbook or residence agreement, a letter or note to residents, and your personnel policy. If you opt out of any component of participation, you will also need written acknowledgment of your policy from your staff, volunteers, and contractors.

Parting Thoughts

California's relationship with this law is in its infancy. It will take time to learn how widespread the use of AID drugs is, what legal or practical challenges arise, and how various elements of the Act are interpreted. It seems likely that the incidence of death by taking AID drugs will spike now that our large, populous state offers this option. Be prepared for many interesting developments—and possibly for modifications to your end-of-life policy as we all become more experienced in the implementation of this law.

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More States Adopt Aid-in-Dying Laws

ON NOV. 8 voters of Colorado passed Proposition 106, the Colorado End-of-Life Options Act, by a nearly two to one margin. The new law went into effect Jan. 1. The Washington, DC, City Council approved an aid-in-dying bill on Nov. 15, by an 11 to 2 majority, and it was signed by the mayor on Dec. 20. The DC law could be overturned by the U.S. Congress, however. Several legislators have introduced a bill that would override the DC law.

Here in Illinois a bill modeled after aid-in-dying legislation in Oregon, Washington, California, Colorado, and Vermont, would establish this right for Illinois residents who are mentally competent adults with terminal illness. The Illinois End-of-Life Options Act includes the same protections implemented in Oregon over 20 years ago. The movement to establish the legal right to control the manner of one's dying is worldwide, with