

LeadingAge California
engageTM

Perspectives on the
End of Life Option Act



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inspire...serve...advocate

Founded in 1961, LeadingAge California is the state's leading advocate for quality, not-for-profit senior living and care. The association's advocacy, educational programs and public relations help its members best serve the needs of more than 100,000 of the state's older adults. LeadingAge California represents more than 600 nonprofit providers of senior living and care – including affordable housing, continuing care retirement communities, assisted living, skilled-nursing, and home and community- based care.

Mission

It is the mission of LeadingAge California to advance housing and services for older adults and to support and inspire its members through advocacy, education, research and services enabling them to meet changing needs of their clients and communities.

Vision

LeadingAge California is a catalyst for members to advocate, enrich and advance aging services.

Shared Values

The values shared by LeadingAge California members include:

- Long term commitment to the security of older adults
- Mission driven
- Mutual support and assistance among members
- Respect of all peoples
- Commitment to socioeconomic and multicultural diversity
- Advocate for not-for-profit status
- Consumer focused
- Dignity and quality of life for older adults
- Community-based



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A Note From The Editor

Confronting the End

This special issue of *Engage Magazine* focuses on the way we confront end-of-life issues as a society; namely – our end-of-life options and the new law signed October 5, 2015 by Governor Brown. While the debate leading up to enacting the law was somewhat polarizing in the California Legislature, some in the senior housing provider community are wrestling with how to implement the new law with conflicting regulations and moral dilemma.

Our guest authors focus on various aspects of the end-of-life discussion, ranging from practitioners, lawmakers, advocates, and others. This issue's feature is penned by Dr. Karl Steinberg, a geriatrician who provides a behind the scenes look with in-depth observations of the end of life in his practice. Sen. Lois Wolk (D-Davis) offers the policymaker's perspective in our interview that covers a retrospective on political debate and what motivated her to author the bill. We also include a column from Barbara Coombs Lee, with Compassion & Choices, the main advocacy group for the End of Life Option Act. Henry Fersko-Weiss, founder of the International End of Life Doula Association discusses how a new class of guides are forming to help individuals seeking options.

Our expert, Brenda Klütz will provide guidance on what licensed providers should do to comply with the law and not run afoul with regulators. Gabriel Garcia,

of Kronick, Moskovitz, Tiedemann & Girard, provides a full analysis of the End of Life Option Act and provides tips and recommendations for responding to the law for senior living providers.

We hope you enjoy this issue. Our Fall 2016 issue will examine the issues around mental health and housing. Enjoy your summer and look for our next issue in early November!

Eric Dowdy
Editor-in-Chief
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Feature



Perspectives on the End of Life Option Act in California

With the passage of the End of Life Option Act in June of 2016, California became the fifth state in the nation to allow terminally ill patients to end their lives with prescriptions from their physicians. In this issue we hear from Dr. Karl Steinberg MD, CMD, HMDC and board chair of the Coalition for Compassionate Care of California; one of the co-authors of the bill, Senator Lois Wolk; and Barbara Coombs Lee, president of Compassion & Choices, for their perspectives on the impact of this landmark legislation.



From the CEO Quarterly topic from Jeannee Parker Martin: Welcomed Aboard!



Have you Heard? Members in their Community; Members in the News; Anniversaries & Milestones



Member Spotlight Article from Lewis & Associates on how California's End of Life Option Act could impact professional liability policies.

Sections



Dear Brenda Advice column with questions on compliance or care issues from the expert.



People in Focus The Heart to Heart cafes provide a space for residents to discuss end-of-life issues and share their own wishes.



Legal Corner Kronick, Moskovitz, Tiedemann & Girard examine how the End of Life Option Act will impact senior living communities in California, best practice considerations and more.



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Wyndham Anaheim Garden Grove

The two-day conference will prepare housing providers for those inevitable and time consuming visits from regulatory agencies performing audits and reviews.

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- Management Occupancy Reviews: Are You Ready?
- Meeting the Needs of Residents with Mental and Behavioral Health Challenges

Full Conference agenda and registration available online at www.aging.org/seniorhousingconference16



Covering Your
ASSETS

From The CEO

Welcomed Aboard!

I was recently asked what some of the biggest surprises were in my first weeks on the job as LeadingAge California's new CEO. I responded that there haven't been any major surprises, but rather constant affirmations of what I had heard about our members, our staff, our community partners, our vendor partners, and our relationship to LeadingAge national. Without exception, every person, every interaction and every communication has supported our vision *to be a catalyst for members to advocate, enrich and advance aging services.*

These first weeks have provided powerful insights into your organizations – affordable housing, life plan communities, skilled nursing, and home and community based services – the successes you've had, the challenges you face, and the advocacy and support you are looking for going forward. It's been inspirational talking with you, confirming what I know and need to learn, and setting the stage and tone for the road ahead. It's a road that will continue to support our mission *to advance housing and services for older adults and inspire members through advocacy, education, research and services.*

And, these first weeks have been framed by excellent onboarding by Joanne Handy – who gracefully made introductions and helped assure a smooth leadership transition – and to the staff and members who have welcomed me and given their all to help smooth my transition onboard.

Two members deserve special congratulations – **Jerry Brown, Bethany Center Housing**, has been selected by LeadingAge to receive its highest honor, the Award of Honor, at its annual conference in Indianapolis. **Retirement Housing Foundation**, led by Laverne Joseph, is celebrating its 55th Anniversary this month in Los Angeles. Congratulations for your leadership in advancing services to older adults!

The road ahead will be informed by my past work – in running a company, in collaborating

with others, in positioning home care and hospice services, and in leading efforts to think strategically and differently about issues that matter. In fact, the theme of this issue – The End of Life Option Act – is a perfect segue to stimulate discussion, establish organizational policies, and think strategically about your residents. In *Being Mortal*, author Atul Gawande said, "You may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them." What better way to advance thinking in aging services than by starting this conversation?

Over the weeks and months ahead, I will talk with you, learn from you, and partner with you in our advocacy and education, so that together we achieve our vision and mission.

Please contact me at any time to introduce yourself, discuss an issue, seek advice, or invite me for a visit.

Thank you for the opportunity to serve you, and for your strong "welcome aboard!"





Have you Heard?

CCH celebrated with First Community Housing in May at the grand opening of [Japantown Senior Apartments](#), a CCH-managed community in San Jose.

The Redwoods, a Community of Seniors was voted “[Best of Marin](#)” for senior retirement communities by the Pacific Sun in May.

Openhouse announced Tim Daniels their new [Interim Executive Director](#) in June.

Eskaton Greenhaven's executive director is quoted in a recent [Sacramento Bee article](#) titled “Music reaches memories for Sacramento seniors with Alzheimer’s.”

PEP Housing's Gary Hermes was featured in a recent [Santa Rosa Press Democrat article](#), titled, “LGBT Seniors Face Unique Challenges in Santa Rosa.”

The Samarkand welcomed Bob Howell, former Executive Director of Covenant Village of Turlock, as their new [Interim Executive Director](#) in June.

Beacon Communities

celebrated the [grand opening](#) of the Tower Park affordable housing complex in Modesto, along with their partners in the project, Satellite Affordable Housing Associates and the city of Modesto.

O'Connor Woods was featured in a [Stockton Record article](#) titled, “Firefighters Cut a Rug at O'Connor Woods.”

Angelus Plaza resident Luther Fortinberry was recognized by the L.A. County Commission for Older Adults for his many years of volunteer service to Angelus Plaza and the greater community.

Bethany Center Senior Housing's

Executive Director Jerry Brown is receiving LeadingAge's highest award at its annual meeting, the Award of Honor, this fall.



LeadingAge California is excited to begin the 2016 Wage Survey starting August 9, 2016

As a free member-added benefit through National Research Corp./My InnerView LeadingAge California, members who participate by submitting data for the survey will get a free compensation report.

SCENE

1

Accompanied by LeadingAge California's Policy and Grassroots Manager Susan Holt, residents from affordable senior housing communities walk over to the Capitol for the Annual Affordable Senior Housing Resident Advocacy Day in June.

2

ACC Greenhaven Terrace resident Dorothy Masui celebrated her 100th birthday in July.

3

PEP Housing board member and centenarian Leota Fisher, having her face painted at PEP's 2nd Annual "Home on the Range" Gala in May.

4

Scott Peifer from Aging2.0 at the 2nd Annual Global Startup Search, hosted by Eskaton at Eskaton Village Carmichael on June 30.

5

A group of participants at the Annual Affordable Senior Housing Resident Advocacy Day meeting with Assemblymember Cheryl Brown at the Capitol.

6

House Representative Tom McClintock's office presented both RHF and Gold Country Retirement with congressional recognition at one of their anniversary celebrations in July. Pictured (L-R): Dr. Laverne R. Joseph, president and CEO, RHF; Bryant Milesi, district representative of House Representative Tom McClintock, and Sandy Haskins, Executive Director of Gold Country Retirement Community.

7

The Institute on Aging held a special LGBT Senior Prom in June. Pictured: Lawrence Levere (center) enjoying the festivities.

8

Attendees at our Annual Conference in Palm Springs were treated to some special entertainment in the exhibit hall.

9

The formal affiliation of ABHOW and be.group was approved by state regulators in May. Pictured (L-R): John Cochrane, CEO; be.group chair Albert Kelley; ABHOW board chair Randall Stamper, and executive advisor and former ABHOW CEO David Ferguson following the organizations' July 7, 2015, announcement of their plans to affiliate.

10

Past LeadingAge California board chairs honored Joanne Handy at the Annual Conference in Palm Springs. (L-R): David Ferguson, Kay Kallander, Joanne Handy, Jim Graunke, and Todd Murch.





Perspectives on the End of Life Option Act

In June of 2016 California passed the End of Life Option Act (SB 128). We reached out to Dr. Karl Steinberg, chair of the Coalition for Compassionate Care of California; Senator Lois Wolk, co-author of the bill along with Senator Bill Monning (D-Carmel) and Assemblymember Susan Talamantes Eggman (D-Stockton); and Barbara Coombs Lee, president of Compassion & Choices, for their perspectives - how it will affect the way healthcare and senior care providers approach the issue with their patients and residents, how states that have already passed similar legislation have been impacted, and how passage of the bill could help change the conversation about how we deal with death and dying in California.



California's End of Life Option Act *Musings from a Geriatrician*

By Dr. Karl Steinberg, MD, CMD, HMDC

As a nursing home and hospice medical director for over 20 years, and as a geriatrician, I've been asked innumerable times questions like, "Can't you just give me something to end it all? You'd do it for your dog, wouldn't you?" I must say, as much as those requests — whether truly serious or just said to make a point — made me feel a bit uncomfortable, it was always a relief to be able to say, "Now, you know I can't do that. That is not part of my job description, and it's illegal." And then to use it as a springboard for a discussion as to what in my patient's life has gotten them to the point of making such a request — then working together to help relieve symptoms, alleviate fears of progressive disability and death, and discuss treatment options and advance care planning.

As of June 9, 2016, we have entered a brave new world in California. I can no longer just dismiss such requests from my patients out of hand. Of course, it still presents a great opportunity to get to some deep, meaningful conversation about life, death, beliefs, goals, and priorities. But it is now legal for me to prescribe a lethal prescription of barbiturates (along with anti-nausea medicine, and maybe some opioids) to a patient who has decision-making capacity, has a life expectancy of less than six months, and can self-administer the drug.

Granted, there are a number of hoops that have to be jumped — and many people in Oregon and Washington (where physician-assisted dying is legal) opt not to take the medication once they have

received it. But the bottom line is that if patients really want to do this, and assuming they can find a doctor (and usually a hospice) to assist, they can end their lives with an overdose. Of course, people have always been able to take their own lives in any number of ways. However, if they do those things, their manner of death on the death certificate is generally ruled a suicide. With physician-assisted dying, the manner of death is considered "natural" — as the result of the patient's underlying terminal condition, not the overdose.

One option that many people overlook, and may not be aware of, is voluntarily stopping of eating and drinking (VSED, also sometimes referred to as VRFF or voluntary refusal of food and fluids). I have had a number of patients in nursing homes over the years make the decision to stop eating and drinking in the face of a terminal illness. These patients, if they are strict about taking in essentially zero food and fluids, usually die within 10 to 14 days, and appear to die very comfortably. This usually occurs in the context of hospice care. These patients may have some dry mouth and thirst, and to a lesser degree hunger, for a few days, but ultimately they drift off to sleep and usually after five-to-seven days they don't wake back up. If needed, medication can be given to help promote comfort, but it's often not necessary. This is such a more benign death than many of the alternatives! Yet the public has a horrible impression of "dying of dehydration," prompting family members to clamor for intravenous (IV) hydration that does far more harm than good in

patients who are in the last days of life. One other bonus of VSED is that patients can change their minds — unlike the situation with physician-assisted dying, where they usually have died within an hour or two of ingestion. But if you take anything away from this article, I urge you to remember that dying of dehydration, for the great majority of patients, is a very peaceful way to die.

There is a wide public misperception that CPR is almost universally effective in "saving lives." On television, the great majority of CPR recipients not only survive, but are completely back to normal in short order after their cardiac arrest. The reality is, only a tiny fraction of patients in this population survive a full cardiac and respiratory arrest with CPR. Of those who do survive, most don't make it out of the ICU. And for those who make it out of the ICU, only a fraction will get back to their baseline functional and cognitive status.

When I give talks to audiences of long-term care professionals, I often ask how many of them have had a resident suffer a full arrest, get CPR, get sent to the hospital, and actually return to the facility. There are usually zero positive responses, or occasionally one or two out of a hundred or more people. It's really a rarity in the frail elderly population to survive CPR to hospital discharge. Of course, this doesn't mean people who want CPR shouldn't get it. But I am afraid most people don't understand how unlikely it is that they will make a meaningful recovery.

Because of the risks of CPR, if you don't want to be "kept alive

on tubes and machines,” then you probably don’t want it — because if you are in the small minority who survive it, you will be on tubes and machines. The Coalition for Compassionate Care of California has some excellent [patient information guides](#), written at a low health literacy level, to help people make informed decisions about interventions like CPR. If CPR were an elective surgical procedure, imagine being asked to consent to it! For a nursing home resident, there is probably

a 1 percent survival rate, and an extremely high risk of serious complications or death. Who would say yes to that if asked in advance? Yet we assume everyone wants the most aggressive treatment unless we know for sure that they don’t.

Which brings up my last point: It is very important to discuss these things in advance before a crisis occurs — because decision-making in a crisis is never optimal. So please, readers. Do your own advance care planning, fill out an

Advance Health Care Directive, and talk to your families about your wishes and their wishes. And at work, be sure your residents are making informed decisions. When they don’t want the most aggressive, often ineffective and burdensome treatment, have them document that.

POLST forms have been a tremendous gift to the people we look after. And please keep in mind that when a person checks “Do Not Resuscitate” in Section A of the POLST, that only applies



Interview with Senator Lois Wolk, co-author of the End of Life Option Act

How did you become involved in co-authoring this bill?

I was involved in end-of-life issues prior to this. I had authored a bill that authorized the use of the POLST form in California. And I was involved in senior issues in terms of elder financial abuse. That was on a policy level. On a personal level, my mother died from cancer when I was a teenager, and it was a brutal death. I just always felt that there should’ve been a better way. So I made common cause with [Senator] Bill Monning and we introduced SB 128.

What has contributed to the shift in public perception about this issue?

First of all, the population is aging and our demographics are changing rapidly. So more and more people have experience with elderly relatives or friends and death and dying. Also, medicine has changed. Two decades ago the doctor was viewed as a god, and whatever he or she — usually he — would say, was the way things were. There was very little conversation that went on about choice. That’s not true nowadays.

Medicine is patient-centered, and that means you’re involved in your own treatment *and* diagnoses. So that’s a very different situation than existed years ago. The other thing that’s changed is technology. Medical technology has enabled people to live longer, but it’s not necessarily the best quality of life. So all of those things have really changed dying, and people want to talk about it. They know they have choices and they want to have a say in how they exit this world.

Surveys have shown that people want to die at home. But the reality

to a person who has no pulse and is not breathing. Where I come from, that means “you are dead.” Short of a full-on cardiac and respiratory arrest, though, the POLST Section B will direct what to do in the event of less extreme change in condition. So, checking “DNR” does not mean, “Just let me die.” People who choose “Full Treatment” in Section B will be intubated, ventilated, and receive shocks if they have a shockable rhythm. So please be sure residents in your facilities understand that.

“DNR” has a sort of hospice-y flavor in public awareness that is not accurate. A substantial majority of my patients, when they receive a good explanation of the POLST, opt for DNR in Section A, and Selective Treatment in Section B. This translates to “no heroics” for most people. In other words, okay to send to the hospital, do IVs, antibiotics, etc., but nothing invasive or overly aggressive.

One of the most important aspects of the work we do is to help those we serve in making informed decisions

about their future healthcare needs, and about their end-of-life care. Whatever our personal feelings about physician-assisted dying, and whatever our personal desires for our own treatment options, our duty is to ensure that we give our residents the kind of care they want to receive — and not force them to get treatments that they would prefer to avoid. We should all try to keep that in mind in our day-to-day work.

Dr. Steinberg is a multi-facility and hospice medical director in Oceanside, California.

is most people die in the hospital. So they're beginning to talk about what the end of their lives should be like with their families. We also know from Oregon, Washington, Vermont, Montana and New Mexico, Canada and other countries in the world that people are beginning to approach death in a different way. For doctors and nurses, this notion of having to talk to patients, not only about death but about life, is much more prevalent now – accepting the fact that death is a part of life. And even though their job is to make you as healthy as you can be, they recognize that death is a part of what they've been called to do.

What would you say to those who are concerned about coercion by family members or others?

There are lots of safeguards in the bill — a lot of people think there are too many — but we felt that it was important. We have language restrictions in the California bill that don't exist elsewhere. If English is not your primary language, for example, those conversations have to be in your primary language. And the medical association and the psychiatric association of California were very helpful to us in not opposing the bills.

Therefore, that enabled their doctors and their boards, their lawyers and others to work with us on the language and the safeguards, so we're very pleased about that. The cornerstone of this bill is that the individual has the right to make that choice, that they are of sound mind and have the ability to make this medical decision. That's the key.

People were really ready. And part of it was Brittany Maynard. You can't underscore enough that her bravery and willingness to open her life at the most extraordinarily personal time really reached people nationally. Her family was there and every time we would go through a hearing — and there were many hearings that were very, very long — they would bare their souls and relive what must've been a horrible time. This young, beautiful woman — newly married with everything to live for was struck down by one of the worst possible brain tumors. And everyone knew that the end would be horrible. Her family enabled her to move to Oregon so she could die in peace. There are very few people who can afford to do that or have the emotional wherewithal to do that. And then expose everything. It's an incredible gift that she left us.

It's not for everyone and it isn't meant to be. That's why we call it the End of Life Option Act. I thought the Governor's statement was wonderful. At the end he said, 'I don't know what I would do if I was confronted with this kind of choice, but I'd like to know that I *have* that choice.' And that's the bottom line.

How do you foresee the aging population and senior care providers being affected?

This is a big deal – it's going to change the way people and institutions approach the end of life. What we discovered with Oregon and Washington in our research is that very few people choose this option. But now, more people are having these discussions with their families. More doctors and more nurses are trained now to confront this issue and have these conversations. And that alone is an important consequence of this bill.

Following the State Legislature's passage of AB X2-15, the End of Life Option Act, Sept. 2015. (L-R): Sen. Mark Leno (D-San Francisco), Sen. Lois Wolk (D-Davis), Sen. Bill Monning (D-Carmel), California Senate President Pro Tempore Kevin de León (D-Los Angeles), and Asm. Susan Talamantes Eggman, (D-Stockton). Photo: Lori Shelley, Senate Rules Photography

Perspectives on the End of Life Option Act

Reforming our End-of-Life Healthcare System

By Barbara Coombs Lee

On June 9, California began implementing the End of Life Option Act, effectively tripling the number of Americans with the option of medical aid in dying to nearly one in six adults nationwide.

This historic law is a tribute to the power of storytellers like [Brittany Maynard](#), a 29-year-old Californian who moved to Oregon to utilize its Death with Dignity law to end her unbearable suffering from terminal brain cancer. But that's not all. Brittany's story led to a [five-fold increase in bills to authorize medical aid in dying](#) nationwide as an option for terminally ill adults.

In fact, our society is in the midst of a profound shift in attitudes toward end-of-life healthcare. We are increasingly aware that too many suffer needlessly in their dying. Too many endure tests and treatments that increase suffering but do nothing to extend life. Too many carry memories of the pain, confusion and agony of a dying loved one.

Every day, [10,000 people turn 65](#). The proportion of the population reaching age 85 is [48 times larger](#) than a century ago. Increased life expectancy brings challenges of advanced illnesses among the aged.

Our medical system focuses almost exclusively on extending life by any means, often at the expense of its quality. The Centers for Medicare and Medicaid Services reinforces this focus by reimbursing doctors generously for complicated tests, ICU stays and medical device implantations.

Lacking clear guidance on how an individual weighs the quality of life against its absolute duration, physicians default to the latter, and propose agonizing tests and treatments that steal life's joys as they prolong the dying process.

Most Americans want to die at home, peacefully and with loved ones close by. But nearly 40 percent

die in a hospital, and almost 60 percent of these hospitalizations include an ICU admission.

As noted in the Jan. 19 issue of the *Journal of the American Medical Association*, devoted entirely to end-of-life care:

"ICU care in the United States at the end of life appears unwanted, expensive, and futile."

"The literature has established that when care is provided with a narrow focus on disease control, without palliative care expertise directed at eliciting these broader goals and tailoring care to include them, patients experience more pain, more anxiety, and more family exhaustion; they receive more non-beneficial care and more hospitalization; and they do not live longer."

In other words, our healthcare system is failing to deliver what people need as they approach an inevitable and imminent death.

Polls shows people across the country increasingly expect candid information, more and clearer options, and more personalized care at the end of life.

Authorized medical aid in dying fosters frank conversations about the crucial balance between the quality of life and its absolute quantity. It empowers patients to die on their own terms, and that is a potent beginning for many types of reform. Empowered patients ask more and better questions. They weigh treatment decisions carefully, and they understand how an ICU admission, with its cascade of tests and treatments, impacts the end-of-life experience.

People need greater access to information and options as the end of life approaches. And they want our national and state policymakers to address this need.

No one should suffer needlessly at the end of life.

[Barbara Coombs Lee](#) was an ER and ICU nurse and physician assistant for 25 years. Currently, she is an attorney and president of [Compassion & Choices](#), the nation's largest end-of-life choice advocacy organization.

California's End of Life Option Act and Its Possible Impact on Professional Liability Policies

The language inherent in California's End of Life Option Act (SB 128), provides immunity for healthcare providers and those offering skilled nursing services (including those organizations licensed pursuant to Division 2, Section 1200 of the Health and Safety Code) who either participate or choose not to participate.

However, the statutory provisions for immunity that are built into SB 128 will not prevent a lawsuit against a senior care organization. Not only could this type of lawsuit have a devastating financial impact, but a senior care organization could also suffer lasting harm to its reputation. While it is impossible to predict every detail, a lawsuit citing SB 128 would likely allege harm or financial loss during the rendering or failure to render professional medical services. As such, a Professional Liability policy would typically respond to a claim of this nature.

Then again, this bill does not absolve a provider of all responsibility. Each community should consult an attorney to draft protocols regarding this issue. An

attorney will provide guidance concerning how the community would fulfill each of the bill's requirements; advise the community on how best to work with physicians; and discuss what role hospice will play in these end of life care decisions. The End of Life Option Act only applies to adult individuals who have the capacity to make medical decisions. Since many residents have cognitive issues, a community must be vigilant and exercise caution in determining a resident's "capacity to make medical decisions." This is another area where consultation with an attorney is vital.

It is also suggested that each community complete a review of its Professional Liability policy. Consult your insurance broker to assist in this review in order to ensure your current policy contemplates the possible exposures related to SB 128.

*by Kelly Ventura, Senior Living Account Executive
Lewis & Associates Insurance Brokers*

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Brenda Klütz has 30 years of experience in California state service; with over eight years of working in the Legislature as a consultant on Aging and Long-Term Care issues and 15 years with the Department of Health Services serving as the Assistant Deputy Director and Deputy Director. Currently, she provides LeadingAge California members technical support on issues related to reimbursement, licensing, and regulation interpretation.

Dear BRENDA

Dear Brenda: Have state regulators issued guidance on how the End of Life Option Act affects our communities from a regulatory compliance perspective? How about Medi-Cal reimbursements?

Answer: Yes, some state departments have issued guidance related to the End of Life Option Act. You should also be aware that LeadingAge California released a Member Resource Guide to provide information on the subject. Here is a summary of guidance or information issued by state departments.

California Department of Public Health, Licensing and Certification Program (L&C): At the last quarterly providers meeting on June 14, L&C shared that the program would not be issuing an All-Facilities Letter on the End of Life Option Act. L&C did invite provider members to submit questions from membership through their associations, but did not yet commit to issuing guidance based on those questions.

Recommendation: Communities licensed by L&C should consider establishing policies and procedures, notify current residents, and provide information upon admission that outlines the extent to which the community will participate/support a resident who chooses to exercise the end of life option.

Department of Social Services, Community Care Licensing (CCL): The Community Care Licensing Division issued guidance in 2015 through the issuance of [15APX-15](#). LeadingAge California also [released an alert](#) to RCFE member communities.

Department of Health Care Services (DHCS) - Medi-Cal Reimbursement: End-of-life services, including office visits and prescription drugs will be covered by the Medi-Cal program. Providers will be able to submit claims for reimbursement for end-of-life services for eligible Medi-Cal beneficiaries.

Medical and pharmacy billing requirements, as well as counseling, documentation, and reporting requirements for the attending physician, consulting physician, and, if deemed necessary, psychiatrist or licensed psychologist, will be released in a future *Medi-Cal Update*. Providers should not submit claims for services until billing instructions have been published in the Medi-Cal provider manual on the [Medi-Cal website](#).

Medi-Cal Managed Care All-Plan Letter: DHCS has issued [All-Plan Letter](#) (APL 16-006) providing direction to MMCPs.

All Other Member Communities (PACE, housing, home and community-based services): There is no specific guidance from state agencies regarding the impact of the End of Life Option Act in other settings. Unless the member operates a licensed health facility or is a licensed health care provider, then the requirements, choice and obligations available to “entities and individuals” would apply. (See *LeadingAge California’s Member Resource Guide on the End of Life Option Act*).



If you have any questions about this, or any other regulatory issue, please contact Brenda Klütz at: bklutz@aging.org or (916) 469-3377.

Perspectives on the End of Life Option Act

Interview with Henry Fersko-Weiss, founder of the International End of Life Doula Association

What is an end of life doula and how did the concept originate?

An end of life doula is someone who guides and companions a dying person and family through the dying process. I came up with this approach back in 2003 when I was working as a hospice social worker in New York City. I witnessed deaths that didn't turn out the way patients of mine had wanted. I saw people die in the hospital instead of dying at home where they wanted to be. Loved ones missed their last breaths because they were too tired to stay awake or didn't realize the end was that close. As I thought about ways to avoid this, a friend of mine was learning to be a birth doula. As I learned about that I realized that the birth doula approach was a good model for what could be done at the end of life to fill in the gap in services that led to some of the bad deaths I'd seen. So I translated the work of birth doulas into the end of life and created the first such program in the country.

How does it work once an end of life doula program is integrated into a hospital or hospice setting?

Patients and families are made aware of the program by the professional staff. Ideally people are informed about the program as early as possible. Another way people learn about the doula work is through websites, articles in newspapers and magazines, as well as word of mouth. The longer the doulas have to work with a patient and family, the greater the benefit. Deep work around the meaning of the dying person's life, the legacy they will leave behind, and planning for how the last days will look and

feel requires time. Of course, good work on these issues and helping to work with guided imagery and ritual can still occur even in a short timeframe — but more time and greater bonds between the doulas and the people they are serving makes for a richer experience.

What inspires you about the work?

I felt that it was a calling for me to do this work exclusively with the remainder of my work life. I am inspired by the incredible need for guidance and support that people have at the end of life. And I'm inspired through every case I have been involved in by the incredible tenderness and love the dying and their families show each other at the most intimate moments. I know that our doula program can make an incredible difference and transform the dying experience of people.

Can you share some successes and challenges?

The successes come in many individual moments during a dying process: a mother caring for her adult son without the great fear and anxiety that she experienced at first — even washing his body after he died and feeling she did everything right to honor his life and his body; an adult daughter snuggling up against her dying mother and telling her stories that she would hold onto forever; a son bringing his mother home to die in the surroundings she loved, rather than the sterile hospital room because the doulas were there to support him. One of our challenges is to get people to face their dying openly and honestly so they can do the work of exploring their lives, healing damaged relationships, and thinking through all the choices around dying at home.

What are some misconceptions people have about what you do?

That this work must be depressing and terribly sad. The truth is quite the opposite. This work is amazingly rewarding. It feels so good to touch people's lives in a way that makes dying so much more meaningful and peaceful. All the doulas feel they get much more out of this work than what they bring to the people they serve. This work changes the way you look at life and how you live, so that each moment becomes so very precious.

Do you see the conversation changing about how we face end-of-life issues?

More people are beginning to understand that they have control over the environment in which they die and how people care for them and their family in the dying process. They also realize they can live the last days of their life with purpose and meaning as they create a memory book, a video, audio, or life scroll that they can leave behind to express important things they have learned or discovered in their life. But we are still at the beginning of this transformation and so much more work needs to be done before a greater percentage of people can face their death without tremendous fear. Our society is still quite death phobic and we need to change that.

To learn more about the International End of Life Doula Association (INELDA) and how to become an end of life doula, visit www.inelda.org.

People In Focus



The Heart to Heart Café

Developed by the Chinese-American Coalition for Compassionate Care (CACCC), the Heart to Heart Café provides a space for older adults to talk about end-of-life issues and share their own wishes using a special deck of cards as a tool for conversation. We met with Sandy Chen Stokes, founder and board chair of CACCC, and service coordinators Mia Almonte with Beacon Communities' Valley Vista in San Ramon, and Leyan Li with Beacon Communities' Hillcrest Gardens in Livermore to learn more about the cafés. [Watch the video interview here.](#)

How do the Heart to Heart cafés work?

Sandy: We go out to the communities, the hospital and clinic settings. Between six to 10 people get together and have tea, pastries, and talk about end-of-life issues. A trained facilitator leads the group and gives the rules for how to play the game. The cards are like regular poker cards, but there is end-of-life content on each one, so people can pick the cards that are important to them. The spade represents physical concerns. Diamond is your financial situation. Club means relationships. The heart is spiritual needs. At first, we didn't know if the cafés would be accepted by the Chinese seniors. In the beginning they might hesitate, but once they start playing, everyone

says, "Hey it's my turn, I want to say something!"

We did some evaluations and at least 80 percent of the seniors said, "You know, I have never had anyone talk to me about end-of-life issues. I have lots of questions."

Leyan: It has a two-fold emphasis – the first is to encourage people to talk about their end-of-life wishes. The other part is to fill out an advanced healthcare directive.

Sandy: It helps us raise the question, "What is POLST?" After the cafés we normally follow up with a workshop or presentation so people can come back, ask questions and complete the advanced healthcare directive.

What kind of feedback have you received?

Sandy: Many people say, "What a surprise! I didn't know that talking about end of life can be so much fun!" It's wonderful to see them start to relax and talk about their wishes.

What would people be surprised to know about these discussions?

Mia: You find cards that you can relate to and really show how you feel. There is one that says "I want my family and friends to know they can laugh and they can cry with me."

What have you learned from the cafés that has changed your own perspective?

Leyan: In Chinese culture, we think that talking about something bad will make it happen. I feel like these cafés help change peoples' view about discussing death. Talking about something bad won't make it happen, but it will make you better prepared for it.

What are your future plans for the cafés?

Sandy: Although the cafés aren't limited to seniors, I think they have a greater need to start to share their wishes in end-of-life care. We go to the senior homes, senior centers, we work with assisted living, hopefully to bring the Heart to Heart Café conversation into their facilities. We are also already planning to do out-of-state training as well. Hopefully more people will benefit from that.

Member Resource

End of Life Option Act in California

LeadingAge California has developed a resource document for members to reference regarding the End Of Life Option Act in California. This document clearly outlines what the law requires of providers, and offers guidance and ideas for implementation. Included is a snapshot of Oregon's data – the first state in the nation to implement an aid-in dying law in 1997 – detailing the number of prescriptions requested, actual deaths that occurred as a result of ingesting prescribed medications, and age, gender and racial demographics for those individuals.

For questions, contact Jedd Hampton, director of policy – health services for LeadingAge California at (916) 469-3366.

Visit the Open Forum Library at communities.aging.org to download.



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Navigating California's New End of Life Option Act

by Gabriel S. Garcia, senior counsel, Kronick, Moskowitz, Tiedemann & Girard

On June 9, 2016, California's End of Life Option Act (EOLOA) became law. The California legislature passed the law after being persuaded by the case of 29-year-old Brittany Maynard, who in 2014 moved from California to Oregon to die under Oregon's Death with Dignity law. EOLOA permits terminally ill adult patients who have the capacity to make medical decisions to be prescribed an aid-in-dying (AID) medication by a participating physician if certain conditions are met. Because it is likely that a high percentage of patients who may invoke their right under the new law will be elderly, it is worth examining how senior living facilities in California will need to determine if they will provide permit their residents to exercise the rights created under EOLOA and adapt to the myriad requirements encompassed in the statute.

End of Life Option Act – Basic Framework

It is important to remember that the underlying premise of EOLOA is that it is *voluntary*. Everyone from patients, physicians, healthcare providers, and pharmacists may choose whether or not to participate. Under the law, an adult in California that has been diagnosed with a terminal disease and has the mental

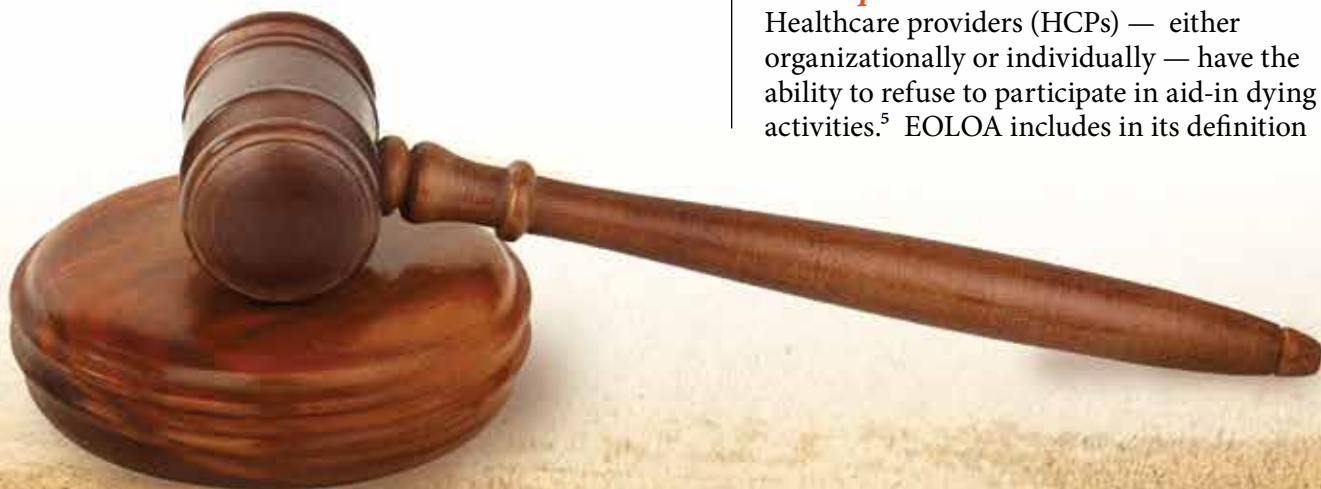
capacity to make and understand the medical decision to die on their own may request a prescription for an AID drug if a number of preconditions are satisfied.

EOLOA requires that: (1) the individual's attending physician has diagnosed the individual with a terminal disease (i.e., *less than six months left to live*); and (2) the individual has voluntarily expressed the wish to receive a prescription for an AID drug¹. The individual must make, at a minimum, two oral requests and a written request, with the timing and format of the requests complying with specific statutory requirements². The attending physician then must comply with a number of requirements before prescribing an AID drug³.

If all the statutory conditions are met, two physicians — an Attending Physician and a Consulting Physician — are required to be present when the patient ingests the AID drug. Of note is the fact that the law explicitly provides that aid-in-dying activities that are undertaken, pursuant to and in compliance with the law's terms, are *not* suicide.⁴ Rather, the legal cause of death is attributable to the underlying disease.

Opting In/Out and Consequential Immunities

Healthcare providers (HCPs) — either organizationally or individually — have the ability to refuse to participate in aid-in dying activities.⁵ EOLOA includes in its definition



of HCPs skilled nursing facilities, nursing facilities, and hospice care facilities. It does not make mention of Residential Care Facilities for the Elderly (RCFEs), independent living facilities (ILFs), or unlicensed housing.

HCPs may prohibit their employees, independent contractors, or other persons from participating in such activities while on premises owned, managed, or under the direct control of the prohibiting HCP or while acting within the course and scope of any employment or contract with the prohibiting HCP.⁶ Any healthcare provider that intends to enforce such a prohibition must first give notice of its policy prohibiting participation in EOLOA to the affected parties.

An HCP is not subject to discipline, suspension, loss of license, loss of privileges or any other penalty for participating in good faith with the law. However, staff of the HCP may object to participating in the end-of-life activities even if their employer does not. Furthermore, staff may not be disciplined for participating or refusing to participate.

Impact on RCFEs and ILFs

EOLOA does not list RCFEs and ILFs as healthcare providers under the law. This creates certain ambiguities in the regulatory environment: *Can senior living facilities require residents to disclose end-of-life plans? Can it prohibit residents from self-administering AID drugs on its premises? Must the facility store the AID drug for the resident? May it prohibit staff from participating as HCPs are entitled to under the law?*

A memo from the California Department of Social Services (DSS), which is responsible for community care facility licensing, identified RCFE licensees and its employees as entities or individuals under the statute that may, due to “conscience, ethics or morality” opt not to participate in activities authorized by EOLOA. Practically speaking, this allows RCFEs to elect not have its employees participate in end-of-life activities and it may inform residents of the facility’s choice not to participate in EOLOA activities.

The DSS memo further clarifies that RCFE residents retain the right to obtain and self-administer AID drugs on the premises; provided, however, that the resident is solely responsible for obtaining, storing, and self-administering the AID drugs. Furthermore, an affirmative exercise by a resident of their rights under the law cannot be a basis for having a resident transferred out of the facility.

Federal Funding Restrictions

Under the federal Assisted Suicide Funding Restriction Act of 1997⁷, federal funds cannot be used either “directly or *indirectly*” for the provision of healthcare services “to provide any healthcare item or service furnished for the purpose of causing, or for the purpose of assisting in causing, the death of any individual, such as by assisted suicide, euthanasia, or mercy killing.”⁸ Medicare will pay for end-of-life *planning* only, which includes learning about options such as the aid-in-dying provisions covered by EOLOA.

The healthcare programs specifically covered by the federal funding restriction include:

- the Medicare program
- the Medicaid program
- the Indian Health Care Improvement Act
- the Federal employees health benefits program
- the military healthcare system, and
- Veterans medical care.⁹

Due to the federal funding restriction discussed, it is highly recommended that continuing care retirement communities which participate in federal healthcare programs (e.g., *skilled nursing beds with Medicare patients*) seek legal advice on their ability to effectively participate in aid-in-dying activities under state law. If prohibited from participation, the most prudent course of action is for the facility to implement policies and procedures prohibiting aid-in-dying activities permitted by EOLOA.

Best Practice Considerations

Senior living facilities should budget the time and resources to make an organizational decision as to whether or not it will permit EOLOA activities on its premises. Once a decision is made, a written policy should be distributed to employees and residents and a rigorous training program should be developed for all staff.

Facilities should also encourage residents to share their end-of-life plans so as to properly accommodate residents while remaining in compliance with the facility’s newly-drafted policy. Issues such as medication storage, who will be present during the AID drug ingestion, engaging family and/or hospice involvement, and whether to call 911 during the process are all key considerations for facilities that care for elderly residents that may wish to proceed with aid-in-dying activities.

¹ Section 443.2(a). ⁴ Section 443.13(a)(2); 443.18.

² Section 443.3. ⁵ Section 443.14 and 443.15.

³ Section 443.5. ⁶ *Id.* at (a).

⁷ 42 USC § 14401 *et seq.*

⁸ 42 USC § 14402 (a)(1)(*emphasis added*).

⁹ 42 U.S.C. § 11402(d)(1).

AGING 2.0

Aging2.0's 2016 Innovation & Technology Use Survey

Aging2.0 recently conducted its “Senior Care Innovation and Technology Use Survey” with the goal of understanding how senior care providers from across the care continuum are approaching innovation and implementing technology to support care. More than 100 organizations completed the survey, representing a near equal split between for profit and not-for-profit providers with balanced representation of organization size and services provided.

Preliminary results showed that the majority of organizations ranked innovation high or very high in importance for business strategy, and prioritized areas for innovation across the four domains of Independence, Care, Mind and Mobility:

When asked for their #1 innovation priority, respondents frequently cited care coordination/management, staff management/education

and technology integration. They also indicated that government and regulations are most likely to disrupt their business, not tech companies and startups.

The majority of companies currently use technology in the areas of electronic health records (64 percent), wander detection/management (56 percent) and care planning/documentation (53 percent), with significant utilization of entertainment/communications (44 percent) and fall prevention technologies (45 percent). Care coordination technologies ranked highest in “planning to use” at 22 percent. Areas of greatest interest in learning more about include dementia engagement/therapy and cognitive fitness. Although technology has made many leaps, survey respondents identified several areas for improvement, including functional capabilities, user interface (easier to use) and decreased cost.

Subscribe to Aging2.0's [CoverAGE newsletter](#) and watch for the complete survey analysis.

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