LEGISLATIVE UPDATE

Alliance of Catholic Health Care

Week of February 24, 2020

State Issues	
Physician Assisted Suicide Informational Hearing	The Select Committee on End of Life Health Care held an informational hearing on the "Implementation of the End of Life Option Act Policy" on Tuesday, February 25 – *see attached agenda materials.* While only a few members attended, this 10-member, all Democrat, Select Committee is chaired by Assemblymember Susan Eggman, coauthor of the California End of Life Option Act (EOLOA). Assemblymember Eggman referenced that she is gathering information on a myriad of possible changes to the law, but that any amendments likely will happen closer to 2026, when the law is set to sunset. Among the many suggestions from panelists, several themes emerged from the panel of speakers that will likely inform any proposed revisions to the law: 1) Interest in changing the 15-day waiting period required in the law – similar to a change made in Oregon and currently proposed to be studied in Washington state. Similar to Oregon, California law requires a qualified individual wishing to receive the lethal prescription for assisted suicide to submit two oral requests, a minimum of 15 days apart, and then a written request to his or her attending physician. Oregon reduced the waiting period to 48 hours for those persons who are expected to live less than 15 days. 2) Examine eligibility requirements that would allow those with neuromuscular conditions (ALS) and cognitive impairment (Alzheimer's and dementia) to avail themselves of the lethal medication when they are no longer able to self-administer the drug. 3) Make permissible "telehealth" consults with physicians. Given the lack of sufficient physicians willing to participate in EOLOA, especially in more remote and rural areas, allow for the attending and/or consulting physician visits to be conducted through electronic means.
State Announces New Behavioral Health Task Force	This week the California Health and Human Services Agency announced the creation of the Behavioral Health Task Force, aimed at addressing "the urgent mental health and substance use disorder needs…" in California. Agency Secretary Ghaly expects the panel will provide recommendations to the Administration in their effort to provide timely access to high-quality behavioral health care. The Task Force membership was just announced and it includes nearly 40 participants, including Dr. Brad Gilbert, the new Director of the Department of Health Care Services, Charles Bacchi, the CEO of the California Health Plan Association, Toby Ewing with the Mental Health Services and Oversight and Accountability Commission, Kim Lewis with the National Health Law Program, Michelle Cabrera the Executive Director of the County Behavioral Health Directors Association, Shelly Rouillard with the Department of Managed Health Care, Mary June Diaz with SEIU, and Carmella Coyle representing the California Hospital Association. The Task Force is set to have its first meeting on March 4 from 10am – 12pm. They intend to have a total of 4 meetings this year, including this inaugural meeting. You can access the agenda and call in information via this link: https://www.chhs.ca.gov/wp-content/uploads/2020/02/BHTF-Agenda-March-4.pdf. Public Comment will be available the last 10 minutes of the meeting. ***(more)***

New Senate Committee Assignments	Senate Pro Tem Toni Atkins has announced some new committee assignments that have some impact on our health-related budget and policy committees. The changes are mostly related to the departure of Senator Jeff Stone (R-La Quinta), who left at the end of last year to take a position in the Trump Administration. Senator Jim Nielsen (R-Red Bluff) will be in the new Vice Chair of the Senate Health Committee. Senator Andreas Borgeas (R-Fresno) will fill Senator Stone's seat on the Budget Subcommittee No. 3 on Health and Human Services. Borgeas is relatively new, joining the Senate in 2018, and has garnered a reputation for his civility and professionalism. Borgeas and Senator Mike Morrell (R-Rancho Cucamonga) also fill seats on the full Senate Budget Committee, along with Senator Maria Elena Durazo (D-Los Angeles).
California Health and Human Services Agency I Public Charge	With the implementation of the Trump Administration's Public Charge Rule going into effect on February 24 after the ruling of the US Supreme Court, the California Health and Human Services Agency has just updated their materials used to inform the public, particularly those seeking health and human services supports, about the rule and what it means for their access to care and their immigration status. Links to the Administration's materials – in English and Spanish – are included blow. Also included is their list of recommended legal supports with expertise in the Public Charge and immigration law. English Version: https://www.chhs.ca.gov/wp-content/uploads/2020/02/CHHS-Public-Charge-Guide-Feb-24-2020.pdf Spanish Version: https://www.chhs.ca.gov/wp-content/uploads/2020/02/CHHS-Public-Charge-Guide-Feb-24-2020-Spanish.pdf List of Legal and Community Resources: https://www.cdss.ca.gov/benefits-services/more-services/immigration-services/immigration-services-contractors/public-charge-contact-list

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SACRAMENTO, CA 94249-0115

California Legislature

SELECT COMMITTEE ON END OF LIFE HEALTH CARE

INFORMATIONAL HEARING
Implementation of the End of Life Option Act

AGENDA
Tuesday, February 25, 2020
9:30 a.m. State Capitol, Room 444

1) **Data Panel**
   - Dr. Jim Greene, Deputy Director – Center for Health Statistics and Informatics, California Department of Public Health
   - Kim Callinan, CEO & President – Compassion & Choices

2) **Provider Panel**
   - Dr. Catherine Forest, Primary Care Physician – Stanford
   - Dr. Ryan Spielvogel, Family Physician – Sutter
   - Dr. Purvi Patel, Palliative Care Physician – Kaiser, Southern California

3) **Health Systems Panel**
   - Dr. David Conant, M.D. – Kaiser, Northern California
   - Dr. Chandana Banerjee, M.D. – City of Hope

4) **Hospice Panel**
   - Yelene Zatulovsky, Vice President of Patient Services – Seasons Hospice
   - Sue Kensel, R.N. – Mission Hospice
   - Ana Safarin, CEO – Olympia Hospice Care

5) **Patient Panel**
   - Bonnie McKeegan – Mother used medical aid in dying in February of 2018
   - Julie Stroud – Father went through the process. Did not end up ultimately using MAID
   - Amanda Villegas – Husband ultimately was unable to access MAID
   - Sharon Fells – Husband used MAID in January 2019

6) **Public Comment**

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End of Life Policy Issues

End of Life Option Act in California

On October 5, 2015, California became the fifth state in the nation to authorize medical aid-in-dying. AB X2-15, the End of Life Option Act (EOLOA), permits terminally ill adult patients with capacity to make medical decisions to be prescribed an aid-in-dying medication to peacefully end their suffering, if certain conditions are met. EOLOA became effective on June 9, 2016 and will sunset January 1, 2026. According to the Assembly Public Health and Developmental Services Committee's analysis, the author's legislative intent was to give "patients the legal right to ask for and receive an aid-in-dying prescription from his/her physician.... Californians that are faced with a terminal disease should not have to leave the state in order to have a peaceful death. In the end, how each of us spends the end of our lives is a deeply personal decision. That decision should remain with the individual, as a matter of personal freedom and liberty, without criminalizing those who help to honor our wishes and ease our suffering."

The measure was modeled after Oregon's first-in-the-nation statute and modified to meet the unique needs of California and its residents. To date, eight other jurisdictions have authorized medical aid-in-dying statutes:

- Washington – Washington Death with Dignity Act – 2008
- Vermont – Patient Choice and Control at the End of Life Act – 2013
- Colorado – End-of-Life Options Act – 2016
- District of Columbia – D.C. Death with Dignity Act – 2016/2017
- Hawaii – Our Care, Our Choice Act – 2018/2019
- New Jersey – Aid in Dying for the Terminally Ill Act – 2019
- Maine – Death with Dignity Act – 2019
- Montana – Supreme Court ruling 2009

The Aid-in-Dying Qualification Process

Patients

Health and Safety Code § 443 articulates a comprehensive qualification process that a patient must complete in order to receive a prescription for aid-in-dying medication. At any time in the

process, and for any reason, the patient has the right to withdraw their request or decide not to use the aid-in-dying drug.

Eligibility

In order to utilize the EOLOA, a patient must meet several criteria. First, the patient must be an adult resident of the state with the capacity to make medical decisions and have a terminal disease that will result in death within six months. These criteria must be confirmed by two physicians. Any request for aid-in-dying drugs must be fully informed and made voluntarily. Finally, the patient must have the physical and mental ability to self-administer the aid-in-dying medication.

Request, Witnesses and Documentation

A terminally ill patient must submit to their attending physician two oral requests, made at least 15 days apart, in addition to one written request on a statutory form. The written request must be signed and dated by the patient in the presence of two witnesses who must attest that the patient is of sound mind and not under duress, fraud, or undue influence. Of the two witnesses, only one may be a family member, be employed by the health care facility where the patient is receiving treatment or resides, or be entitled to a portion of the patient's estate upon death. The patient's attending physician, consulting physician, or mental health specialist may not act as witness.

The attending physician is required to counsel the patient on several topics, including: the benefits of participating in a hospice program and notifying their next of kin of their decision; the importance of maintaining the drug in a safe and secure location until they are ready to self-ingest it, the process of ingesting the aid-in-dying drug, the importance of having another person present when doing so, and not ingesting the drug in public.

Dispensing the Aid-in-Dying Drug, Final Attestation, and Self-Ingestion

A qualified patient may then obtain the aid-in-dying drug via one of two ways: direct dispensation from the attending physician if they are authorized to by the state to dispense, or the attending physician must inform a pharmacist about the prescription and deliver the prescription, personally, by mail or electronically to be dispensed.

Finally, 48 hours prior to self-ingesting the aid-in-dying drug, the patient is required to complete a final attestation form restating their intent and that they are of sound mind.

Medical Provider Obligations

Attending Physician

The attending physician is the physician who has primary responsibility for the health care of a requesting patient and treatment of the patient's terminal disease.

At the start of the process, the attending physician must make the initial determination of whether the patient meets the requirements to receive aid-in-dying medication under the EOLOA. This includes diagnosing the terminal nature of the disease and confirming that death will occur within 6 months, within a reasonable degree of medical certainty. The attending physician must also inform the patient that they may withdraw or rescind the request at any time and in any manner. The attending physician must then refer the patient to a consulting physician. At every step in the process, the attending physician is required to ensure that the patient has the mental capacity to make medical decisions, is making the request voluntarily, and confirm that the patient's request does not arise from coercion or undue influence.

Consulting Physician

Under the EOLOA, the consulting physician, qualified by specialty or experience, must also examine the patient and their medical records, confirm the diagnosis and prognosis, determine that the patient has the capacity to make medical decisions, and confirm that the patient is acting voluntarily to confirm eligibility. Additionally, the consulting physician must comply with the documentation requirements in the EOLOA to complete and submit the statutory forms to the attending physician.

End of Life Policy Hearing with stakeholders – January 2018

The first hearing of the Select Committee on End of life Health Care was held on Wednesday, January 24, 2018 at the State Capitol, room 447. The hearing included an overview of data from the California Department of Public Health (see below) and four panels of stakeholders from the medical community who provided a policy perspective from the medical provider experience, the health system experience, and the hospice experience, within their facilities. Also in attendance were several family members who shared their loved ones experience of the patient perspective of obtaining and ingesting the medical aid-in-dying drugs.

Panel 1: The Medical Provider Experience – Dr. Catherine Forest, Stanford University & Dr. Lynette Cederquist, UC San Diego

The key factors of concern from the medical provider experience included:

- Increasing access for terminal patients through more education of the policy for physicians
- Decreasing the time frame between oral requests from 15 days to 10 days
- Extending the prognosis to less than 12 months, instead of six months

Panel II: The Health System Experience - Dr. Nathan Fairman, UC Davis, Dr. Cindy Cain, UCLA, Dr. Neil Wenger, UCLA & Melissa Stern, Kaiser Northern California

The key factors of concern from the health system experience included:

- Lack of data on the range of approaches health care systems are using to implement the EOLOA, and the need for more information sharing within systems
- Patients need more information on the different options available to them, including the EOLOA
- The need for an efficient process to refer patients to participating physicians, a directory participating doctors would be helpful for referral; however, there is resistance from doctors to join because they are reluctant to be known as an EOLOA provider
- Interdisciplinary teams are crucial for information sharing and coordination
- Institutional structures that support participating physicians would encourage more physicians to participate
- The process can be cumbersome and many patients need to be their own coordinator/navigator

Panel III: The Hospice Experience – Yelena Zatulovsky, National Director- Seasons Healthcare Management, Inc. MK (Martha Kay) Nelson, Director of Spiritual Care – Mission Hospice and Home Care & Liz Sumner, Triage Manager, Elizabeth Hospice

The key factors of concern from the hospice experience included:

- Challenge presented for hospice patients to locate a second consulting physician if they decide to initiate the qualification process
- Challenge for hospice patients to utilize EOLOA if they have veteran's benefits, as the VA is federally funded

Panel IV: The Patient Experience – Kat West & Dan Diaz, Compassion and Choices, Dr. Barbara Koenig UCSF, Family members of EOLOA patients: Raheem Hosseini, Kelly Davis, Roberta Stone, Jackie Minor

The key factors of concern from the patient experience included:

- Feel a lack of sensitivity by pharmacists and insurance provider
- EOLOA process too burdensome for some patients
- Taste of medications was terrible
- Time frame between ingestion of aid-in-dying drug and death was longer than anticipated

California Department of Public Health 2016 - 2018 Data Report

As required under the EOLOA, the California Department of Public Health ("CDPH" or "Department") began collection of anonymous usage data on June 9, 2016. The data to be collected included the number of people who received a prescription, the number of individuals with prescriptions who died in each year and their causes of death, the number of known deaths in California from aid-in-dying drugs, and the number of physicians who wrote prescriptions. Demographic data on the patients, including age at death, education level, race, sex, and underlying illness, must also be collected.

Usage Statistics

The Department released its first report summarizing utilization of the EOLOA on July 1, 2017. The report, which spanned from June 9, 2016 to December 31, 2016, found that 173 unique physicians prescribed aid-in-dying medications to 191 patients. Of the 191 patients who received prescriptions, 111 (58.1%) died after ingesting the aid-in-dying drugs. 21 individuals (11%) died without ingesting the prescribed drugs, and the outcome of 59 patients (30.9%) was unknown at the time of publication.

Summary of EOLOA Prescription Written in 2016
191 individuals had prescriptions written in 2016
111 died after ingesting the drugs prescribed in 2016
21 did not ingest the drugs prescribed and subsequently died of the underlying illness or other causes
59 remaining individuals with undetermined outcomes

In June 2018, the Department released its second report that presented data from January 1, 2017 to December 31, 2017. The report found that 241 unique physicians prescribed 577 individuals aid-in-dying drugs. Of the 577 individuals who were prescribed such drugs, 363 (62.9%) were reported by their physician to have died after ingesting the aid-in-dying drugs prescribed under EOLOA and 86 individuals (14.9%) died without ingestion of the prescribed. The outcome of 128 individuals (22.2%) was unknown at the time of publication. 11 individuals prescribed medications in 2016, died after ingesting the drugs in 2017.

Summary of EOLOA Prescriptions Written in 2017
577 individuals had prescriptions written in 2017
363 died after ingesting the drugs prescribed in 2017
86 did not ingest drugs prescribed and subsequently died of the underlying illness or other causes
128 remaining individuals with undetermined outcomes
11 individuals with prescriptions written in 2016 died after ingesting the prescribed drugs in 2017
A total of 374 individuals ingested drugs and died in 2017

For the calendar year of 2018, 180 unique physicians prescribed 452 individuals aid-in-dying drugs. Of those, 314 (69.5%) were reported by their physician to have died following ingestion of the prescribed aid-in-dying drugs and 59 individuals (13.1%), died from the underlying illness or other causes. Of the remaining individuals, 42 (9.3%) have died but their ingestion status is unknown because follow up information is not yet available, and the outcome for 79 others is pending or unknown at the time of publication. Twenty-three individuals with prescriptions written in 2017 ingested and died from the drugs during 2018.

Summary of EOLOA Prescriptions Written in 2017 and 2018 and Drugs Ingested in 2018
452 individuals had prescriptions written in 2018
314 died after ingesting the drugs prescribed during 2018
59 did not ingest drugs and subsequently died of the underlying illness or other causes
79 individuals with undetermined or pending outcomes
23 individuals with prescriptions written in 2017 died after ingesting the drugs in 2018
A total of 337 individuals ingested drugs and died during 2018

Legal Update on the End of Life Option Act in California

After the EOLOA went into effect in June 2016, opponents of medical aid-in-dying began efforts to invalidate the law. They filed a complaint, *Ahn v. Hestrin*, with the Superior Court of California in Riverside County to overturn the law. At a hearing in May 2018, the court ruled that the EOLOA was unconstitutional because it was passed outside the scope of the special legislative session. This ruling prompted a slew of writ petitions and appeals between plaintiffs, the state (Defendants), terminally ill patients, and physicians who were represented by Compassion & Choices (Defendant-Intervenors). The law was reinstated after a short time when Compassion & Choices filed a notice of appeal on June 1st. Although the law was technically back in effect as of the filing of the appeal, there continued to be considerable uncertainty until additional stays were granted by the Court of Appeals shortly thereafter.

Ultimately, the Fourth District Court of Appeals of California ruled that the opponents in *Ahn v. Hestrin* did not have legal standing to file their lawsuit. Most recently, there was a hearing in January of 2020 in Riverside where the case was dismissed with leave to amend. The case will likely continue to be litigated for the foreseeable future until ultimate disposition by the California Supreme Court.