SENATE THIRD READING SB 380 (Eggman) As Amended August 30, 2021 Majority vote

SUMMARY

Extends the January 1, 2026, sunset date on the End of Life Option Act (EOLA) to January 1, 2031. Allows an individual to qualify for aid-in-dying medication by making two oral requests a minimum of 48 hours apart, rather than 15 days apart; requires that the date of all oral and written requests be documented in an individual's medical record and upon a transfer of care that record to be provided to the qualified individual; and, eliminates the final attestation form required to be filled out by the qualified individual within 48 hours prior to self-administering the aid-in-dying medication.

COMMENTS

On October 5, 2015, California became the fifth state in the nation to authorize medical aid-in-dying. AB 15 X2 (Eggman), Chapter 1, Statutes of 2015-16 Second Extraordinary Session, EOLA, 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. EOLA became effective on June 9, 2016, and will sunset January 1, 2026.

EOLA 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, Vermont, Colorado, the District of Columbia, Hawaii, New Jersey, Maine, and Montana.

1) DPH EOLA report. EOLA requires physicians to submit specified forms and information to the Department of Public Health (DPH), and DPH to compile an annual report. The most recent EOLA data report for 2019, was published in July of 2020. This report presents data as reported to DPH from the EOLA-mandated physician reporting forms received between January 1, 2019, and December 31, 2019, and reflects information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2019, as well as cumulative counts for the period commencing January 1, 2016. The information collected has been aggregated to protect the privacy of the individuals.

For the year ending December 31, 2019, 618 individuals received prescriptions under EOLA. In 2019, 405 individuals died following their ingestion of the prescribed aid-in-dying drug(s), which includes 27 individuals who received prescriptions prior to 2019. Of the 405 individuals, 88.6% were 60 years of age or older, 89.9% had health insurance and 85.4% were receiving hospice and/or palliative care, 11.4% were under 60 years of age, and 14.1% were 90 years of age and older. The median age was 76 years. The decedents were 87.2% white, and 55.3% were male. In addition, 84.0% informed their family of their decision to participate in EOLA.

Since the law came into effect June 9, 2016, through December 31, 2019, prescriptions have been written for a total of 1,985 people and 1,283 individuals, or 64.6%, have died from ingesting the medications. Of the 1,283 individuals who have died under EOLA, 1,112, or 86.7%, were receiving hospice and/or palliative care.

- 2) California Health Care Foundation Report (CHCF). According to a 2019 CHCF Report, "Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care," three in four Californians surveyed support the EOLA.
 - In February of 2012 CHCF published a survey, "Final Chapter: Californians' Attitudes and Experiences with Death and Dying." The survey found that most Californians would prefer a natural death if they became severely ill, rather than have all possible care provided; that they want to die at home rather than in a hospital or nursing home, and want to talk with their doctor about their wishes for end-of-life care. However, what individuals want isn't what happens in practice, as the survey numbers illustrate:
 - a) Seventy percent of Californians would prefer to die at home; however of deaths in 2009, 32% occurred at home, 42% in a hospital, and 18% in a nursing home;
 - b) Almost 80% say they definitely or probably would like to talk with a doctor about end of life wishes, but only 7% have had a doctor speak with them about it; and,
 - c) The survey also found that what matters most at the end of life varies by race and ethnicity, for example, Latinos rate living as long as possible more highly than do other groups. African Americans and Latinos are much more likely to place importance on being at peace spiritually. Asians and white/non-Latinos place the least importance on living as long as possible. Sixty percent of all respondents say it is extremely important that their family not be burdened by decisions regarding their care.
- 3) Barriers to accessing EOLA. As noted above, EOLA was modeled on the original Oregon statute. In 2019, Oregon updated their law because too many people were dying during the waiting period. Oregon authorized a waiver of the waiting period when the attending physician has medically determined that the qualified individual will, within reasonable medical judgement, die within 15 days after making the initial verbal request for aid-in-dying medication. Recent data shows that a significant number of patients (20%), who otherwise would have died during the waiting period, were able to access their medical aid in dying law after that change. Recently, New Mexico passed End of Life legislation that included a 48 hour period, which this bill codifies.

A study by Kaiser Permanente Southern California published in the *Journal of American Medicine (JAM)*, "Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation," shows that one-third of terminally ill adults who requested to use EOLA died before completing the process which includes a 15-day waiting period and often takes weeks or months to finish.

Additionally, another *JAM* report from 2019, "Hospital Responses to the End of Life Option Act: Implementation of Aid in Dying in California," as of approximately 18 months after implementation of the EOLA, most hospitals in California had an ELOA policy, the majority of which prohibited physicians, from participating while under the organization's purview. Of the 315 hospitals surveyed, the report's authors obtained responses for 270 (86%). Nonresponding hospitals were more likely to be rural and for-profit, and less likely to be part of a hospital system. The responding 270 hospitals were covered by 89 unique policies. Fifty-three EOLA policies (among 229 hospitals) applied to all health system inpatient and outpatient facilities. In contrast, 36 policies applied to 41 hospitals, but offered no guidance for outpatient locations.

Of the 270 hospitals, 235 (87%) had a formal policy for the EOLA. Overall, 106 (39%) hospitals permitted physicians to write ELOA prescriptions: 97 had a formal EOLA policy and nine did not. These hospitals accounted for 42% (1,289,236) of hospital discharges in 2016. Of the 164 (61%) hospitals forbidding physicians to write prescriptions under the EOLA, 138 hospitals had formal policies explicitly prohibiting EOLA prescribing, and an additional 26 hospitals had no written policy. Hospitals opting out of the EOLA accounted for 48% (1,501.452) of hospital discharges. The report also noted that hospitals and health systems that allowed the EOLA were more likely to offer palliative and bereavement services than those hospitals prohibiting aid in dying. This suggests that where the ELOA is permitted, it is not as a replacement for, but a complement to, existing end-of-life services.

According to information provided by the author and sponsors, another barrier to access is that certain healthcare facilities under the existing provisions of the EOLA, can forgo participation in medical aid in dying and have no obligation to tell their patients about their policy. This bill maintains that no health care provider who objects for reasons of conscience, morality or ethics is required to participate in EOLA. However, the bill clarifies that if a health care provider is unable or unwilling to carry out an individual's request for a prescription for medical aid-in-dying medication, at a minimum, a health care provider must inform the individuals that they do not participate in EOLA, document the patient's date of request and provider's notice to the patient of their objection in the medical record and transfer their medical record upon request.

According to the Author

The EOLA will sunset on January 1, 2026. After the sunset date, terminally ill, capable adults who want the option of medical aid in dying will be denied access. The author states that now is the time to remove the sunset and address impediments to access while preserving essential safeguards. Currently, the law requires individuals and their healthcare team to comply with a lengthy and administratively burdensome multi-step process. While on paper it appears that a person can get through the process relatively quickly, in reality it takes a dying person several weeks to several months to get through the process, if they are able to complete it and obtain the prescription at all. The empirical and anecdotal data collected shows that the current process is unnecessarily cumbersome, with too many roadblocks for many dying patients to access the law. These burdens are heaviest for underserved communities in rural areas and individuals from diverse communities, consistent with the inequities experienced during the COVID19 pandemic. The author states that the pandemic has placed a spotlight on the toll that lack of access to healthcare and administrative burdens exact in minority communities. While health care disparities are not new, the coronavirus pandemic has amplified persistent, systemic healthcare inequality. The author concludes that this bill will remove barriers, especially for underserved ethnic, racially diverse and rural communities, ensuring that all eligible terminally ill individuals are in charge of their end of life care while retaining the right to remain autonomous and die with dignity.

Arguments in Support

The Compassion and Choices Action Network (CCAN) is the sponsor of this bill and states that since EOLA went into effect in 2016, data collected by DPH shows that the law works as intended for those who can access it. Keeping in line with more than 60 combined years of data from all of the states that have similar medical aid in dying laws, there has not been a single incident of coercion or abuse. The law has directly benefited those who have used the law and indirectly benefited all terminally ill residents. Evidence clearly suggests that the passage of

medical aid in dying has resulted in: improved conversations between physicians and patients; better palliative care training; and improved enrollment in hospice care. CCAN notes that 75% of Californians and the majority of every demographic and county in California approve of EOLA, and for all of these reasons, it is essential that the sunset provision is removed and the California End of Life Option Act becomes permanent. CCAN also points to a study by Kaiser Southern California found that a third of eligible patients die unable to make it through the waiting period. Oregon amended their law to allow the prescribing physician the ability to waive the 15 day waiting period if, within the physician's best judgement, the terminally ill patient is unlikely to survive it. Oregon's data show that a significant number of patients (20%), who otherwise would have died during the waiting period, were able to access their medical aid in dying law thanks to that amendment. CCAN concludes that this bill similarly seeks to address the burden of the waiting period by shortening it to 48 hours, a provision that the New Mexico legislature just approved in March with their newly enacted medical aid in dying law.

Arguments in Opposition

Disability Rights California (DRC) is opposed to this bill and states that assisted suicide is not about choice when people with disabilities lack access to sufficient medical care. The COVID-19 Pandemic revealed long standing disparities in our health care delivery system as we witnessed disproportionate rates of infection and mortality in our aging and disability community as well as our Black and Latino communities. Now more than ever we should be focused on addressing inequities in our health care delivery system, not expanding access to assisted suicide. Finally, in California, patients' reasons for resorting to assisted suicide are not reported to the public. It is premature and dangerous to make EOLA permanent in the absence of data that would help us better understand the impact of assisted suicide on Californians. DRC concludes that a bad day should not result in a death sentence.

The California Catholic Conference (CCC) is opposed to this bill and states that the prime reason for individuals in a terminal state to choose to take their own lives is a fear of becoming a financial or emotional burden to their families. Due to our California COVID-19 experience we have all come to understand the stark reality of health care inequity in the Black and Latino communities. CCC states that the debate on this bill can be viewed as subtly encouraging terminally ill Medi-Cal patients to more easily choose the less expensive option of assisted suicide when faced with the reality that equitable quality care, especially hospice and palliative care, is not always available to them.

The Department of Finance is opposed to this bill because it results in General Fund impacts not included in the 2021 Budget Act.

FISCAL COMMENTS

According to the Assembly Appropriations Committee:

- 1) DPH projects total costs of \$139,216, including \$133,000 annually for increased staffing and \$6,216 in one-time costs to remove the final attestation and update an interpreter form. DPH currently uses the Health Statistics Special Fund (HSSF Fund 0099) to run the EOLA program. Due to Covid-19, DPH notes the main funding source's revenues have been severely diminished and there are no available funds to support this bill's staffing need.
- 2) The Department of Consumer Affairs (DCA) anticipates \$4,000 in absorbable costs to add new enforcement codes. DCA reports the Osteopathic Medical Board identified no impact

and the Medical Board of California identified the potential for complaints, anticipated to be minimal and unquantifiable, with absorbable costs.

3) The Department of Justice anticipates no significant impact.

VOTES

SENATE FLOOR: 26-8-6

YES: Allen, Archuleta, Becker, Bradford, Caballero, Dodd, Durazo, Eggman, Glazer, Gonzalez, Hertzberg, Hurtado, Kamlager, Laird, Leyva, McGuire, Min, Newman, Pan, Roth, Rubio, Skinner, Stern, Umberg, Wieckowski, Wiener

NO: Bates, Borgeas, Dahle, Grove, Jones, Melendez, Nielsen, Wilk

ABS, ABST OR NV: Atkins, Cortese, Hueso, Limón, Ochoa Bogh, Portantino

ASM HEALTH: 10-3-2

YES: Wood, Mayes, Aguiar-Curry, Eduardo Garcia, Burke, Carrillo, Maienschein, McCarty,

Nazarian, Luz Rivas

NO: Bigelow, Flora, Waldron

ABS, ABST OR NV: Rodriguez, Santiago

ASM JUDICIARY: 6-2-3

YES: Stone, Chau, Chiu, Holden, Kalra, Maienschein

NO: Gallagher, Davies

ABS, ABST OR NV: Lorena Gonzalez, Kiley, Reyes

ASM APPROPRIATIONS: 10-4-2

YES: Bryan, Carrillo, Chau, Gabriel, Eduardo Garcia, Levine, Quirk, Robert Rivas,

Akilah Weber, Kalra

NO: Bigelow, Megan Dahle, Davies, Fong

ABS, ABST OR NV: Lorena Gonzalez, Calderon

UPDATED

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