

California End-of- Life Option Act

HISTORY, HOW IT WORKS, WHO PARTICIPATES

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Disclaimer

- ▶ This presentation is not meant to either endorse nor oppose the End of Life Option Act, nor the concept of aid-in-dying medications in general.
- ▶ There are certainly a wide range of opinions to have on this subject, and reasonable, ethical, and empathetic medical providers and patients can have very different opinions on the subject.
- ▶ Other than touching on some ideas briefly, I am leaving out any major discussions of the ethics of aid-in-dying, as that could take a very long time to fully discuss.
- ▶ If you are fully in support of aid-in-dying laws, I hear you and I can understand where you are coming from. If you are fully opposed to such laws, I hear you and I can understand where you are coming from.
- ▶ Any opinions expressed are my own, and not those of UCLA, the Department of Family Medicine, the Department of Palliative Medicine, nor anybody else that I could conceivably be linked to.

Disclaimer

- ▶ I have no relevant disclosures to make.

Objectives

- ▶ 1) Understand the background and history of the EOLOA
- ▶ 2) Understand the difference between euthanasia and “aid-in-dying” or physician-assisted suicide.
- ▶ 3) Understand the process of how the EOLOA works for patients and providers in California.
- ▶ 4) Understand some problems with implementation of the law for certain groups of patients in the past few years.

Brittany Maynard

- ▶ Born November 1984 in Anaheim
- ▶ Graduated from Berkeley in 2006 with Bachelor's degree in psychology
- ▶ Graduated from UCI in 2010 with Master's degree in education
- ▶ Married in 2012
- ▶ In January 2014 was diagnosed with grade 2 astrocytoma
- ▶ Soon thereafter, had partial craniotomy and partial resection of temporal lobe
- ▶ April 2014 was found to have recurrence, now developed into glioblastoma
- ▶ Told that at this point, she had a roughly 6-month prognosis



Brittany Maynard

- ▶ Brittany decided to move to Portland, Oregon to establish residency so that she could enroll in Oregon's Death with Dignity Act, which allows a physician to prescribe a medication which a terminally ill patient can take in order to end their own life at a time of their choosing.
- ▶ In 2014, there was no such option in California.
- ▶ Her story became much publicized across the country, and she became an advocate for legalization of similar laws across the country.
- ▶ In October 2014, she visited the Grand Canyon with her family, and later in the month, celebrated her husband's birthday.
- ▶ On November 1, 2014, at the age of 29, Brittany ingested secobarbital at her home in Oregon, surrounded by family, and passed away.



Brittany Maynard – a few headlines

My right to death with dignity at 29

By Brittany Maynard



Vatican official condemns Brittany Maynard's assisted suicide

By | Associated Press

Dying cancer victim begs Brittany Maynard not to end her life



Friday, October 10, 2014

More States Considering Right-to-Die Laws

TIME After Brittany Maynard

Brittany Maynard

- ▶ Why did Brittany's story become so big? At this point, thousands of people had already taken medications via Oregon's law (or in a state with a similar one).
- ▶ She intentionally wanted her story to be well-known, to help advocate for change.
- ▶ She was much younger than the average patient who takes the medication.
- ▶ As in previous cases surrounding right-to-die questions, there was much controversy from some cancer patient groups and disability advocates.



History

- ▶ c. 500-100 B.C.: Ancient Greece and Roman cultures generally were open to the idea of suicide, euthanasia, and even "involuntary mercy killings."
- ▶ In the following centuries, many Christian thinkers and philosophers would have greater influence on ethics in the Western world.
- ▶ Sir Thomas Aquinas wrote in the 1200s that suicide was a sin against oneself, one's community, and God. Views such as his helped shape the Catholic Church's views on the subject, and for various reasons, any type of suicide was seen as a very serious sin.

History

- ▶ 1885 – American Medical Association describes the idea of euthanasia or assisted suicide as “the physician [donning] the robes of an executioner.”
- ▶ 1906 – Attempts to legalize physician-assisted death in Iowa and Ohio are defeated
- ▶ 1915 – Dr. Harry Haiselden (with permission of the parents) allows a newborn baby with severe deformities to die without intervention instead of attempting any surgeries. He stated that the hospital would “stand by passively” and “let nature complete its bungled job.” This was widely publicized and interestingly sparked support for some end-of-life issues nationwide. Well-known figures such as Helen Keller and Clarence Darrow voiced support.
- ▶ 1930s – A few attempts to gain support for euthanasia across the U.S.
- ▶ Late 1940s – General advocacy for legalizing euthanasia declines after revelations of the horrors of the Nazi regime

History

- ▶ 1957 – Pope Pius XII clarifies that it is morally permissible to withhold or withdraw "excessive treatments" at the end of life, though euthanasia or assisted suicide is not permissible.
- ▶ 1984 – AMA clarifies that it is ethically permissible to withhold or withdraw life-prolonging treatments at the end of life
- ▶ 1970s – 2000s – The cases of Karen Quinlan, Nancy Cruzan, and Terri Schiavo bring debates about end-of-life rights back to the national consciousness.
- ▶ 2020 – Approximately 72% of the U.S. population think that some form of aid-in-dying should be legal and allowed for patients with a terminal illness

Medical Aid in Dying in the U.S.

Dates of Implementation

- ▶ 1997 – Oregon
- ▶ 2008 – Washington
- ▶ 2009 – Montana
- ▶ 2013 – Vermont
- ▶ 2016 – California, Colorado
- ▶ 2017 – District of Columbia
- ▶ 2019 – Hawaii, New Jersey
- ▶ 2020 – Maine

- ▶ Some of the state legislatures, after 2014, named Brittany Maynard's case as influential on the introduction and passing of their respective laws.

Definition of Terms

- ▶ Euthanasia: Intentionally ending another person's life to relieve pain and suffering – example: a physician administers a lethal dose of morphine to a terminally ill patient with the intention of ending the patient's life
 - ▶ Generally illegal in most countries
 - ▶ Forms of voluntary euthanasia are legal in a few countries
 - ▶ Non-voluntary or involuntary euthanasia is illegal in all countries
- ▶ Medical aid in dying, or physician-assisted suicide, or physician-assisted death: a person ends their own life with the assistance of a medical professional – example: a physician prescribes a lethal dose of medication to a terminally patient, and the patient administers this dose to themselves to end their own life

Definition of Terms

- ▶ To clarify a difference between medical aid in dying and what we typically see in the hospital with patients on comfort care:
 - ▶ A patient on comfort measures only / “End of Life Order Set,” etc., may be given medications for the purposes of pain relief or comfort. In some instances, these medications may also shorten the patient’s lifespan. However, this is different from euthanasia, as the goal with this medication administration is pain or symptom relief, as opposed to the goal of ending a patient’s life.

End of Life Option Act

- ▶ Implemented in California in 2016 – Assembly Bill (AB) 15
- ▶ A patient can receive an aid-in-dying drug from a physician if:
 - ▶ They have been diagnosed with a terminal disease
 - ▶ They have voluntarily expressed the wish to receive this prescription
 - ▶ They are a resident of California
 - ▶ They have the physical and mental ability to self-administer the drug
- ▶ Having a terminal illness, in this case, refers to two physicians (including the prescribing physician) stating that the patient has a six-month prognosis or less (much like the requirement for being admitted to hospice)

End of Life Option Act – What the Patient Has to Do

- ▶ The patient must make two separate oral requests of the "attending physician" (which means the physician who will prescribe the medication), and these requests must be at least 15 days apart.
- ▶ The patient must make a written request (a specific form that is available from the state) which must be filled out, signed by the patient, signed by two witnesses.
- ▶ The witnesses cannot be any health care professionals involved in the patient's pursuit of the EOLOA.
- ▶ Only one witness can be related to the patient and/or be entitled to a portion of the patient's estate.

Quiz Question

A terminally ill patient tells you that they are interested in pursuing the End of Life Option Act. Which of the following are you NOT legally allowed to say in response?

- A) “That sounds like a very tough decision that you’ve made. I would be happy to support you in this journey and prescribe this medication for you once we’ve gone through the proper channels and discussed this some more.”
- B) “I respect your decision, but I do not personally prescribe the medication. Let me refer you to someone who can.”
- C) “I disagree with your decision, and I don’t feel comfortable referring you to anyone who can prescribe this medication.”
- D) “Don’t you know that killing yourself is unethical? I don’t agree with this at all!”
- E) [awkward silence]... “So, how have your blood sugars been this past month?”
- F) [plugs fingers in ears]... “LALALALALALA I CAN’T HEAR YOU I CAN’T HEAR YOU!!!”
- G) These are all legally acceptable

Quiz Question

- ▶ All of the answers are legally acceptable! Maybe not all very empathetic (or ethical), but they are all legal.
- ▶ From AB15 section 443.14 (e) (1): “Participation in activities... shall be voluntary. A person or entity that elects, for reasons of conscience, morality, or ethics, not to engage in [medical aid in dying] is not required to take any action in support of an individual’s decision.”
- ▶ This applies to prescribing the medication as well as even in basic discussion or counseling about the medication. If there is a provider who is ethically or morally opposed, they are not required to discuss this with the patient any further, nor are they required to refer the patient to someone who is willing to.
- ▶ In practice, it’s probably rare that someone will not even acknowledge what the patient has asked, but it is permissible.

End of Life Option Act – What the Attending Physician Has to Do

- 1) Determine if the patient has the capacity to make this decision
- 2) Determine if the patient has a terminal disease with a prognosis of six months or less
- 3) Talk to the patient INDIVIDUALLY to determine that they are voluntarily making this request without undue pressure from any friends or family.
- 4) If you determine that the patient has a “mental disorder,” refer to a mental health specialist. Medication will not be prescribed until a mental health specialist determines that the patient has capacity.
 - “Mental disorder” is not defined by the text of the law.
 - “Mental health specialist” is defined as a “psychiatrist or a licensed psychologist.”

End of Life Option Act – What the Attending Physician Has to Do

5) Refer the patient to a consulting physician

What does the "consulting physician do?"

They are meant to confirm the diagnosis and prognosis as well as also determine that the patient has capacity to make this decision

This is often a physician in the same specialty as the attending physician, or often practices in whatever specialty the patient is seeing for their terminal diagnosis.

However, there is no requirement as to what specialties can be an attending or consulting physician.

End of Life Option Act – What the Attending Physician Has to Do

- 6) Counsel the patient about the importance of all of the following:
 - a) Having another present when ingesting the drug
 - b) Not ingesting the drug in a public place
 - c) Notifying their next of kin about their request
 - d) Participating in a hospice program
 - e) Maintaining the drug in a safe and secure location until ingestion

Note that while you must counsel the patient about the importance, the patient is under no legal obligation to comply with any of the above

End of Life Option Act – What the Attending Physician Has to Do

7) Fill out paperwork

8) Give patient paperwork to fill out (including a form they are supposed to sign within 48 hours prior to ingesting the aid-in-dying drug)

A few other legal tidbits

- ▶ Contracts, wills, etc., cannot attempt to affect whether another person will take or not take an aid-in-dying drug
- ▶ Health insurance, life insurance policies, etc., cannot be conditioned upon status of taking an aid-in-dying drug
- ▶ Cause of death listed on death certificates for patients who utilize EOLOA medication will be whatever the person's terminal illness was
- ▶ Nobody can be legally liable for a death just by being present when someone else takes an aid-in-dying drug
- ▶ Someone else is allowed to help PREPARE the aid-in-dying drug, but cannot ADMINISTER it to the patient. The patient must self-administer.

A few other legal tidbits

- ▶ A healthcare worker cannot be subject to any punishment / loss of job, etc., for choosing to participate or not participate in the End of Life Option Act
- ▶ Healthcare providing companies can elect to not participate in the End of Life Option Act. If you work for such a company, you can be punished by your employer for participating in EOLOA if you do it on their premises. If you do it elsewhere (e.g., if you are moonlighting or run a concierge medical practice on the side), they cannot punish you for that.

What medications are used?

- ▶ The text of the law does not mention any specific medications. It is therefore up to individual providers and institutions to decide.
- ▶ In practice, pentobarbital was used heavily in Oregon until 2012, when its cost rose from about \$500 to \$25,000 (after Europe banned the drug in response to it being used heavily in capital punishment as well).
- ▶ Secobarbital was used as well, but its cost was about \$5,000.
- ▶ A cheaper option, phenobarbital/chloral hydrate/morphine was used for a time for only \$500. In a small number of patients, the chloral hydrate caused severe burning sensation in their throats, and this was discontinued.

What medications are used?

- ▶ UCLA's current aid-in-dying medication mixture: DDMP
- ▶ Diazepam / digoxin / morphine / propranolol
- ▶ Metoclopramide and ondansetron are usually given one hour prior
- ▶ Dosages:
 - ▶ 1,000 mg diazepam
 - ▶ 50 mg digoxin
 - ▶ 15,000 mg morphine
 - ▶ 2,000 mg propranolol
- ▶ Mix together in ½ cup of alcohol, water, or clear juice. Drink within 2-3 minutes.

What medications are used?

- ▶ This is a very effective regimen.
- ▶ Unconsciousness usually occurs within minutes.
- ▶ Patient generally dies within minutes or a few hours.
- ▶ There has been at least one documented case of a patient ingesting medication and surviving another 18 hours, though they were not conscious during that time period.

Who uses aid-in-dying medication in California, 2016-2018?

- ▶ From 2016-2018:
- ▶ 1220 individuals had prescriptions written
- ▶ 822 ingested and died from the aid-in-dying medication
- ▶ 166 died from their underlying illness or other causes
- ▶ 232 with unknown ingestion status

Who uses aid-in-dying medication in California, 2016-2018?

age	total	pct
under 60	88	0.107
60-69	186	0.226
70-79	239	0.291
80-89	203	0.247
90 and over	106	0.129

listed gender	total	pct
male	392	0.482
female	422	0.518

education	total	pct
no high school diploma	27	0.033
high school diploma or GED	161	0.196
some college no degree	143	0.174
associate, bachelor, or master degree	406	0.494
doctorate or professional degree	73	0.089
unknown	12	0.015

race/ethnicity	total		pct
white	746		0.889
asian/native american/pacific islander	46		0.055
african-american	6		0.007
hispanic	31		0.037
unknown	8		0.010
multi-race	2		0.002

insurance	total		pct
medicare or medicare with another type of insurance	561		0.682
medi-cal	24		0.029
private insurance	108		0.131
has insurance but unknown type	87		0.106
no insurance	7		0.009
other	1		0.001
unknown	34		0.041

illness	total		pct
malignant neoplasms	553		0.673
lung respiratory diseases (non-cancer)	42		0.051
heart disease	65		0.079
neurological disease	79		0.096
als	31		0.038
parkinson's disease	5		0.006
other neurological	8		0.010
cerebrovascular diseases	17		0.021
neuromuscular	20		0.024
other	46		0.056

Some Professional Opinions

- ▶ AMA, 2019: “Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”
- ▶ Other opposing organizations: National Spinal Cord Injury Association, American Association of People with Disabilities, American College of Physicians
- ▶ It should be noted that many (though certainly not all) disability rights advocacy groups have historically been against various so-called “right to die” laws or court cases. Their arguments generally state that allowing people to choose death only because of their current health state suggests that “healthy” people have no reason to end their lives, but people not considered “healthy” by society’s standards (including patients with disabilities) are living lives that are not desirable, and thus, less valuable.

Some Professional Opinions

- ▶ American Academy of Hospice and Palliative Medicine, 2016: “AAHPM takes a position of studied neutrality on the subject of whether PAD should be legally permitted or prohibited.”
- ▶ Previously, AAHPM had been officially in support of aid-in-dying laws.
- ▶ Concerns cited by AAHPM included a “normalization” of the process, to the exclusion of patients seeking out assistance from hospice or palliative providers. The argument would be that some patients simply need better symptom control, etc., and that it would not be beneficial to the patient if they saw aid-in-dying medications as their only recourse to discomfort.

Some Inequalities

- ▶ Clearly, the population taking the aid-in-dying medication is not representative of California's overall population
- ▶ Some of the more obvious examples include 89% of recipients being Caucasian, and greater than 50% having at least a college degree, and very little representation among those with Medi-Cal or no insurance.
- ▶ Insurance does not cover aid-in-dying medications.
- ▶ Depending on your insurance (and what physicians you are seeing), you may not even have a consultation office visit covered.
- ▶ Veterans Administration does not participate (since aid-in-dying is illegal on the federal level)

Money Matters

- ▶ Even the cheapest aid-in-dying medications currently will cost at least a few hundred dollars.
- ▶ Recently being advertised: concierge medicine practice that will (among other things) engage in the Aid-in-Dying process with you.
- ▶ Cost: \$2100 if you want their physician to be the prescribing physician
- ▶ \$600 if you just need a consulting physician
- ▶ \$600 listed price for the compounding pharmacy

What does it take to be a California resident?

- ▶ Keep in mind that only people considered residents of California are eligible for the EOLOA medication.
- ▶ Any of the following qualifies someone:
 - ▶ (A) Possession of a California driver license or other identification issued by the State of California.
 - ▶ (B) Registration to vote in California.
 - ▶ (C) Evidence that the person owns or leases property in California.
 - ▶ (D) Filing of a California tax return for the most recent tax year.
- ▶ This might make things more difficult for the unemployed, for those who don't own or rent a property, for the homeless, for undocumented immigrants, for those without internet access (to register to vote), etc.

Disease-based Inequality?


- ▶ One key component of the law is the requirement to “self-administer” the medication. On many levels, this certainly makes sense, as it will (theoretically) prevent family members or healthcare workers from administering the medication to a patient who is not yet ready for the medication, or who has perhaps changed their mind.
- ▶ But this requirement also may unwittingly cause some patients to take the medication prior to being fully ready for it.
- ▶ Imagine that you have cancer and you don't want to get to a point where you are unable to care for yourself, ambulate, etc., and wish to end your life prior to that moment. If you wait too long to ingest the medication, you may become too weak to self-administer.

Disease-based Inequality?

- ▶ Or more classically, imagine an ALS patient in that same situation. There will come a time where they literally will be unable to bring a cup to their mouth. But what if they want to continue living beyond that point, but not all the way to their natural death?
- ▶ The nature of the law also, by necessity, leaves out dementia as a practical diagnosis to have and use the medication.
- ▶ Is this fair to have this discrimination built into the law itself?
- ▶ Is there even any ethical and legal way around these problem?

References

- ▶ California End of Life Option Act 2019 Data Report. California Department of Public Health.
- ▶ The California End of Life Option Act (Patient's Request for Aid-in-Dying Drug). UCLA Health System Policy 1490.
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- ▶ Pence G. *Medical Ethics: Accounts of Ground-Breaking Cases*. 2015.



He did not know whether he was dying or falling asleep, but felt equally prepared for the one as for the other.

Leo Tolstoy, "Master and Man"

Sleep had come. Now I could reclaim all I'd lost. What's lost never perishes. I closed my eyes and gave myself over to sleep.

Haruki Murakami, *Hard-Boiled Wonderland and the End of the World*