

SB 128 (Wolk): End of Life Option Act

1. Identification of the Problem:

News coverage of 29-year old Brittany Maynard, who moved from California to Oregon to receive the prescription for a lethal injection to end her life after being diagnosed with brain cancer and given less than six months to live, has prompted ethical and religious questions about what it means to have the option to take aid in dying medication.¹

Federal courts have protected an individual's right to decide to die through the Supreme Court ruling in *Gonzales v. Oregon*, finding that the freedom should be left to the states to decide.²

"Death with Dignity", or, aid in dying laws that allow mentally competent, terminally ill patients to request prescription medication to hasten their death, and are currently legal in five states.³ Three states legalized this option through the legislature: Oregon, Washington and Vermont.⁴ According to the aid in dying laws, two physicians must determine that a patient is not suffering from depression and has six months or less to live in order to prescribe a lethal dose of drugs.⁵ The patient may then choose to fill the prescription and take the drugs, but are not obligated to participate in the act once they request the medication.⁶ Maynard and her family moved to Oregon from California expressly to take advantage of Oregon law.⁷

Montana and New Mexico, affirmed the right through the courts.⁸ In a large majority of states, 41 plus Washington, D.C., aid in dying medication is illegal through legislation or common law.⁹ Depending on the state, the administration of aid in dying medication can lead to a charge of felony of the prescribing doctor.¹⁰

Only four states – Nevada, North Carolina, Utah and Wyoming – have no laws addressing aid in dying.¹¹ Euthanasia, in which a physician administers the lethal dose as opposed to the patients themselves, is illegal in all states.¹²

¹ Brittany Maynard, *My Right to Die with Dignity at Age 29*, CNN OPINION, (November 2, 2014), <http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/>.

² *Gonzales v. Oregon*, 546 U.S. 243 (2006).

³ *Death with Dignity*, DEATH WITH DIGNITY NATIONAL HEALTH CENTER, <http://www.deathwithdignity.org/acts>.

⁴ *Id.*

⁵ *Id.*

⁶ *Id.*

⁷ Brittany Maynard, *My Right to Die with Dignity at Age 29*, CNN OPINION, (November 2, 2014), <http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/>.

⁸ *Death with Dignity Around the U.S.*, DEATH WITH DIGNITY NATIONAL HEALTH CENTER, <http://www.deathwithdignity.org/advocates/national>.

⁹ *Id.*

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

2. Background Research:

a. Evidence of the Problem:

Each year, the state of Oregon files a report that illustrates the utilization of the Death with Dignity Act by analyzing the usage statistics reported by all participating physicians.¹³ Each year, this state report demonstrates that the safeguards in the Oregon law work and the option is used by a tiny percentage of dying Oregonians.¹⁴

Every day in California, suffering patients ask their doctors to hasten their death.¹⁵ These patients either stockpile and take medicines supplied by their doctor or resort to horrific and violent methods to end their suffering.¹⁶ Either choice traumatizes not only the dying patient, but also family and friends who are forced to cope with the desperate, secret and often violent means used by their loved ones to cope with their pain and suffering.¹⁷

According to a 2014 Harris Poll, 74% of Californians support the idea that a person has the right to make the decision to hasten their death on their own terms¹⁸. The majority of respondents also agreed that doctors should be allowed to comply with the wishes of dying patients in severe distress who ask to have their lives ended. These views are held by voters regardless of generation, educational group, gender, and political affiliation.

California can offer the comfort of legally protected discussions between physicians and their dying patients about the continuum of care options at the end of their life.¹⁹

Providing a legal option for terminally-ill, suffering patients would allow them to talk to their physicians and families about how they prefer to spend their final days. It should be reasonable that terminally-ill, suffering patients should have a right to control the circumstances of their death, and many patients seek the support and guidance of their physicians to help them during this complex and challenging time. Moreover, providing patients with this humane choice is preferable to the desperate and covert self-help practices some patients now employ.

A carefully crafted proposal does not have to force upon physicians any religious or ethical standards in that it specifically exempts physicians who do not wish to participate. A patient- not

¹³ *Id.*

¹⁴ *Id.*

¹⁵ San Jose Mercury News Editorial, *Brittany's Death Proved Need for California Death with Dignity Law*, SAN JOSE MERCURY NEWS, November 7, 2014, http://www.mercurynews.com/opinion/ci_26886266/mercury-news-editorial-california-needs-death-dignity-law?source=infinite.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸

<http://www.harrisinteractive.com/NewsRoom/HarrisPolls/tabid/447/ctl/ReadCustom%20Default/mid/1508/ArticleId/1531/Default.aspx>.

¹⁹ *Death with Dignity*, DEATH WITH DIGNITY NATIONAL HEALTH CENTER, <http://www.deathwithdignity.org/acts>.

a physician- must self-administer his or her medication, and can only do so after extensive procedural and medical safeguards have been performed.²⁰

b. Law on the Subject:

The Oregon legislature passed a law allowing aid in dying in 1997. Years of data show that the law is safe and utilized in a way that does not leave at-risk residents vulnerable. Since 1997, four other states have authorized aid in dying (Washington, Montana, New Mexico, and Vermont). At the time of this writing, 25 additional states have introduced some form of aid in dying legislation²¹. As of January 20th, 2015, California’s legislature is now looking to create a comprehensive and ethical spectrum of end of life care to include aid in dying medication.

Current California law authorizes an adult to give an individual health care instruction and to appoint an attorney to make health care decisions for that individual in the event of the patient’s incapacity pursuant to a power of attorney for health care.

c. Prior Attempts to Address the Problem in California:

Since the 1990s, lawmakers and activists have tried and failed several times to pass aid in dying legislation in California. Four bills and two initiatives have failed for various reasons related to the power the opposition had on the legislature.

In 1999, Assemblymember Aroner introduced AB 1592, the Death with Dignity Act. In 2006, Assemblymember Berg and Levine introduced AB 651, the CA Compassionate Choices Act. In 2005 they introduced AB 654 and again in 2007 AB 374. All four bills were substantially similar and modeled from the Oregon Death with Dignity Act.

Summary of AB 374 (last legislative attempt)

Safeguards and Comparison to Oregon Statute:

1. Patient must be terminally ill (6 months left to live)
2. Resident of California
3. Must make informed decision (doctor must provide alternatives in writing) (Oregon law does not require in writing)
4. If coercion is suspected, patient will be prohibited from participating in act by the physician
5. Patient must be evaluated by 2 physicians and diagnosed terminally ill
6. Mental capacity: if not enrolled in hospice, must be evaluated by psychiatrist or psychologist; patients enrolled in hospice are evaluated every day (Oregon law simply refers if mental capacity is questionable)
7. Patient must make 2 oral requests and 1 written request; written request must have 2 witnesses, none of which can be related to the patient (Oregon law requires only 1 to not be related)

²⁰ *Id.*

²¹ <http://www.deathwithdignity.org/advocates/national>.

8. 2 waiting periods: 15 days after first oral, 48 hours after second oral
9. Patient can rescind request at any time
10. Patient must self-administer (Oregon law does not specifically require self-administration)
11. Physicians can refuse to participate in Act
12. Violators of act will be prosecuted (felony)
13. Both participating physicians must submit reports to DHS (now DHCS).
14. Any unused medication must be disposed of according to current laws and regulations

d. Views of the Parties of Interest:

Medical Associations

Medical associations are concerned that managed care health plans would promote participation with the hopes to save on expensive end-of-life treatment. They also believe that the Act is fundamentally inconsistent with the physician's professional role in providing treatment. They strongly believe that physicians should only continue to improve and provide palliative and hospice care, not provide any assistance in ending a patient's life.

Disability Rights Groups

While this party of interest is divided into groups on both sides of the aisle, the most vocal disability rights groups are concerned that such an Act would place pressure on those who are deemed disabled but not terminally ill to end their life because they are seen as a burden to their families and their caregivers.

Compassion Groups

Compassion and Choices and similar groups who are advocates of patients' rights are supportive of this Act to pass because it allows a patient who is suffering intolerable symptoms to exercise control over their final days and choosing to die with dignity, rather than become incapacitated by the pain and suffering of cancer.

Senior Groups

Senior groups are also mainly in favor of this Act because of the control and freedom it provides them in deciding how to end their own suffering in light of terminal illnesses that may diminish their quality of life when given less than six months to live. Senior groups would rather have the right to decide for themselves than to be told by the government how to spend their final days. There are some who are worried they will be pressured to participate in the Act because they are seen as a burden to their families and caregivers.

Religious Groups

It is mainly the Catholic Church who is strongly and aggressively opposed to this Act because they find that ending one's life is not consistent with Catholic principles. They do not believe that a patient has the right to end their own life because it is at the hands of God to determine how long one should live. Pain and suffering does not justify the premature act of ending one's own life and they view suicide as a reprehensible sin.

3. Alternative Solutions:

The Initiative Process: If a proposed bill were to fail in the legislature, another possible solution would be to put the issue on the ballot through the initiative system. With record low turnouts to the 2014 election, the threshold is significantly lower to qualify an initiative to the ballot. However, it is unknown what the effect of the recently passed initiative reform bill would have on a DWDA initiative if the legislature were to hold hearings in an effort to block qualification.

Letting Present Trends Continue: Without the passage of SB 128, Californians only have the option of enrolling in palliative care or hospice. In fact, 89% of Oregon's Death With Dignity Act participants were enrolled in hospice or palliative care.²² This shows that sometimes, these options are simply not enough. Patients enrolled in alternative end-of-life-care options should also have the option to live their final days the way they best see fit.

4. Preferred Solution:

Draft a law mirroring legislation passed in Oregon.

The clinic group decided to use AB 374 as model language for several reasons. Firstly, the language did not have any weaknesses in terms of safeguards. In fact, the safeguards were at some points even more stringent than outlined in Oregon law (e.g. proposed California bill language requires that neither witness can be related to the patient, while Oregon law requires that at least one witness not be related). Secondly, the group believes enough concessions have already been placed throughout the bill to attempt to appease opposition without ultimately making the bill ineffective (i.e. ability for physicians to refuse to participate in the act, procedures to insure the patient is not coerced into participating). Lastly, the group has received overwhelming feedback from several previous supporters and an author of the bill that the problems with passing this legislation in 2007 were not related to the language of the bill, *per se*, but rather the emotions attached to opposition groups. When looking back at the bill files, it was apparent that many opposing groups were making illogical arguments to substantiate their opposition to any type of DWDA legislation. These arguments were fueled by emotion rather than an analysis of the actual bill (such as saving the immortal soul from the reaches of hell).

When we asked several past supporters what they would change about their fight plan in 2007, each advocate never suggested that the bill language was a reason for the death of the bill. In fact, many people we talked to said they still feel the bill is ironclad. The problem rested in the ability to evoke emotion from legislators. One of the challenges the 2007 coalition had was bringing would-be participants of DWDA legislation to testify. This would make sense since by the very nature of the bill, these star witnesses are often times in their deathbeds.

An additional reason why the bill may have failed was due to Fabian Nunez retracting his support after his mother's Catholic church threatened to refuse to give his family communion if he continued to strongly support the bill.

²² <http://static.deathwithdignity.org/i/OregonDWStats.pdf>.

a. Groups/Parties for and Against:

Support:

Compassion and Choices: Writes that expanded options at the end of life would provide California citizens with the ability to make crucial and extremely personal decisions. Although not listed as an official sponsor, C&C has provided the authors an immeasurable amount of support for the bill including providing several exclusive videos and testimonies of the late Brittany Maynard.

Congress of California Seniors: Historically in support. States that “providing terminally ill patients with this human choice is preferably to the desperate and covert self-help practices some patients are currently forced to employ.”²³

California Association of Physician Groups (CAPG): While historically in support in past iterations of DWDA legislation, CAPG will not be taking a position on the issue due its membership (Dignity and St. Joseph’s are both members of the association and oppose the issue)²⁴.

Opposition:

California Medical Association (CMA): Historically, CMA has come out in opposition to Aid in Dying legislation stating that assisting someone to die is unethical and unacceptable, and is fundamentally incompatible with the physician’s role as healer.²⁵

As of this writing, CMA has not yet formally claimed opposition to SB 128, but has submitted a “Letter of Concern” to the Senate Judiciary Committee²⁶. The organization has likely not officially opposed this legislation since it is speculated that much of its membership is split on the issue.

California Catholic Conference (and other various religious groups): Writes that safeguards in the bill are toothless and does not trust the metrics of other states public health reports.

Disability Rights Education & Defense Fund (DREDF and other various disability groups): View the bill as preying on the state’s “most vulnerable citizens” without sufficient safeguards to prevent abuse. Others also worry that while they are in favor of choice, choice can be eliminated among a lack of alternatives and services due to the location or affordability of medical treatment.²⁷

²³ Senate Judiciary Committee Analysis, 4/7/15. Pg. 8.

²⁴ Confidential meeting with Bill Barcellona.

²⁵ [https://dredf.org/assisted_suicide/Oncology%20Statement%20on%20AB%20374%20\(Berg\).pdf](https://dredf.org/assisted_suicide/Oncology%20Statement%20on%20AB%20374%20(Berg).pdf).

²⁶ Senate Judiciary Committee Analysis, 4/7/15. Pg. 19-20.

²⁷ Senate Judiciary Committee Analysis, 4/7/15. Pg. 21.

b. Strategy:

Coalition Building

It is important to assemble a solid coalition group before author shopping. The topic is extremely controversial, yet ripe considering recent events. Since this topic has been introduced in the legislature several times before, it is relatively easy to see which groups fall on either side. The best strategy would be to approach key “stakeholders” first to see if this issue would be appropriate for introducing in 2015. We reached out to several groups to get a handle on potential legislative support (Compassion and Choices, local democratic clubs and organizations, and internal members of California physician groups).

Public Affairs/Grassroots Campaigns

While many advocates cite polls that state that the public opinion of physician assisted suicide has changed in recent years, it would be beneficial for these groups to start to initiate public affairs/grassroots campaigns early on in the process. However, as with the nature of being a controversial subject, having groups begin to push campaigns will only, in turn, create a catalyst for opposition to respond to said campaigns. The benefit of early campaigns is that the media attention to the issue will promote discussion between several organizations that have not yet decided to take a stand on the issue.

Putting a face to the issue is also another impactful way of relaying the importance of the bill to voters and legislators. This can be done in a variety of ways including testimony from terminally ill patients, survivors and family members of terminally ill patients, celebrities, clergy, and medical professionals.

c. Realistic Outcome:

The preferred strategy above is the most realistic outcome because of the controversial nature of the bill. The scope of the bill is fairly black and white with little wiggle room to give in terms of making concessions to opposing groups. It is likely that no concessions can be made to religious groups. Safeguards to address the concerns of healthcare opposition would likely be expensive, and would likely slow down the bill in both houses if placed on the suspense file in each Appropriations Committee.

5. Excerpts of Legal Drafting:

Although the group decided to take up the Aid In Dying issue in Fall 2014 and created a draft bill for submission to Legislative Council, the group ultimately decided to not submit the draft and instead work with the primary authors and Compassion & Choices (the unofficial sponsor). The bill had been finalized in early January 2015 and introduced in the Senate on January 20, 2015. An excerpt of the bill is included below:

California Health and Safety Code Section 443.3. (a) A qualified individual wishing to receive a prescription for aid-in-dying medication pursuant to this part shall submit two oral requests, a minimum of 15 days apart, and a written request to his or her attending physician.

(b) A valid written request for aid-in-dying medication under subdivision (a) shall meet all of the

following conditions:

(1) The request shall be in substantially the form described in Section 443.9.

(2) The request shall be signed and dated by the qualified individual seeking the medication.

(3) The request shall be witnessed by at least two other adult persons who, in the presence of the qualified individual, shall attest that to the best of their knowledge and belief the qualified individual is all of the following:

(A) Competent.; (B) Acting voluntarily.; (C) Not being coerced to sign the request.

(c) Only one of the two witnesses at the time the written request is signed may:

(1) Be related to the qualified individual by blood, marriage, or adoption or be entitled to a portion of the person's estate upon death.

(2) Own, operate, or be employed at a health care facility where the qualified individual is receiving medical treatment or resides.

(d) The attending physician of the qualified individual shall not be one of the witnesses required pursuant to paragraph (3) of subdivision (b).

6. Explanation of Real World Efforts

a. Effects of the Passage of SB 128

This bill would provide a qualified individual diagnosed with a terminal illness (defined as having less than six months left to live) the legal right to request medication that would hasten his/her death by self-administration. This bill would also establish procedures that seek to establish several safeguards and reporting mechanisms to prevent potential abuse of the act.

b. Student Experiences/Lessons Learned

Support Outreach: Reaching out to clubs and organizations is an integral part to drawing up support for a bill. It is important to begin outreach as soon as possible because clubs and organizations often times have bureaucratic processes to formally support or oppose bills that can take up to two months. Sometimes clubs even require a guest speaker to give a presentation. However, it is great to see the names of clubs and organizations we reached out to listed as formal supporters on committee analyses.

Meeting times with Legislative Members: It is important to explicitly ask a member's scheduler how long the member is planning on meeting with a student. This gives the student a time framework for both giving a background on the clinic, an elevator speech on the bill, and leftover time for questions/opportunity to ask the member if the clinic can conduct any research for the office.

Organizing Volunteers: We were able to assist the authors and Compassion and Choices in a variety of roles throughout the year, from providing legal research and analysis of past bill attempts to helping organize supporters who have come to testify during committee hearings. Having been placed in leadership roles during these hearings allowed us to get a behind-the-scenes look at how a bill moves through the legislature and the enormous effect of in-person testimony has on members. Not only did we help heard people into the committee room, we also used this time to get face time with our most vocal supporters. We collected stories and took pictures for social media to help show legislative members and the public how much support the bill has attracted.

Sensitivity to Multi-Organization Involvement: One of the first lessons that we learned was that it is important to stay in tune with all involved players to a legislative effort. Although we spent all of the fall semester researching and drafting bill language to submit to Legislative Counsel, we were unaware that two senators were working together drafting their own. Had we submitted our own version of the bill we would have made more friends than enemies, especially if several members signed on to one bill over another. Rather than going the route of seeking a separate author, we decided to meet with as many co-authors as possible and offer research and organizing efforts.

Media Training: Having a third party be able to not only listen to an elevator speech and critique us on whether we play with our hair too much was invaluable. Media training allowed us to hone in on our public speaking skills and make us more aware of any strange quirks we do before we actually end up on camera. It also allows us to pitch our bill ideas to a new face for the first time in layman's terms, allowing us to reevaluate whether we have become too technical or cryptic throughout the semester.

c. **Outcome**

At the time of this writing, the authors of SB 128, and its vocal supporters, are confident that the bill will pass the Senate floor regardless of whether it is placed on the suspense file. It is uncertain whether the bill will become a two-year bill or whether the bill will be pushed through the Assembly in the fall.

7. Explanation of Work Remaining

At the time of this writing, SB 128 has just passed the Senate Judiciary Committee and is set to be heard next at the Senate Appropriations Committee, although a hearing date has not yet been scheduled. The bill has been keyed fiscal since it mandates the Department of Public Health (DPH) to generate usage reports each year (similarly to Oregon). The primary authors (Wolk and Monning) are scheduled to meet with DPH soon to determine the costs associated with the bill and any possible ways to minimize financial impact. Depending on the costs associated with SB 128, the bill may be placed on the suspense file, at which point the bill will not be heard until sometime in May.

Once the bill is picked up again, the authors' offices do not expect much opposition from the committee or Senate floor. If the bill were to be picked up by the clinic again, students should focus their efforts upon evaluating the California Assembly, helping the primary authors pick up additional Assembly co-authors and conduct lobby visits, and assisting Compassion & Choices with collecting additional letters of support and formal positions of support from Democratic clubs and organizations.

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Compassion & Choices sent out a survey to members of the Assembly in Winter 2014 to gauge the voting climate and found a small amount of members in support. So far, there are 15 confirmed members in support, including co-authors and one republican (Mathis). There are an additional 5 members undecided but open to supporting the bill including McGeorge alumnus Ken Cooley. Students in the next clinic should contact Compassion and Choices to coordinate

lobby visits with the members who are either on the fence or did not return a completed survey. We are unable to provide the Assembly Floor list at this time, as Compassion & Choices has specifically requested this working document to remain only between the contract lobbyists, the executive director, and the current clinic students.

8. Committee Hearings

- a. **Senate Health Committee: March 25, 2015**
http://calchannel.granicus.com/MediaPlayer.php?view_id=7&clip_id=2689 (11:33)
- b. **Senate Judiciary Committee: April 7, 2015**
http://calchannel.granicus.com/MediaPlayer.php?view_id=7&clip_id=2708 (12:28)
- c. **Senate Appropriations Committee: Not yet scheduled**