

**Testimony of Matt Whitaker, Director of Integrated Programs, Compassion & Choices
Regarding SB 579, Relating to the Oregon Death with Dignity Act
Senate Committee On Judiciary
Friday April 5, 2019 at 9:30 am**

Good morning Chair and Members of the Committee. My name is Matt Whitaker and I am the Director of Integrated Programs for Compassion & Choices, the nation's oldest and largest nonprofit organization working to improve care and expand choice at the end of life.^{1,2,3,4,5} Compassion & Choices advocates for legislation to improve the quality of end-of-life care for terminally ill adult patients and affirms their right to determine their own medical treatment options as they near the end of life.

The Oregon Death with Dignity Act has demonstrated for over 20 years that medical aid-in-dying laws work as intended by affirming patient autonomy while ensuring a high standard of care.

Compassion & Choices believes that it is the strict eligibility criteria and the core safeguards embedded in the act are the primary reason the Journal of Medical Ethics concluded in 2007 that: "Rates of assisted dying (in Oregon)...showed no evidence of heightened risk for the elderly, women, the uninsured...people with low educational status, the poor, the physically disabled or chronically ill...people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations."⁶

¹ Compassion & Choices brought landmark federal cases establishing that dying patients have the right to aggressive pain management, including palliative sedation. *Vacco v. Quill*, 521 U.S. 793 (1997); *Washington v. Glucksberg*, 521 U.S. 702 (1997).

² Compassion & Choices drafted and sponsored introduction of legislation requiring comprehensive counseling regarding end-of-life care options. See, California Right to Know End-of-Life Options Act, CAL. HEALTH & SAFETY CODE §442.5; New York Palliative Care Information Act, N.Y. PUB. HEALTH LAW § 2997-c.

³ For example, Compassion & Choices is pursuing accountability for failure to honor a patient's wishes as documented in a POLST, *DeArmond v Kaiser*, No. 30-2011-00520263 (Superior Court, Orange County, CA). In another case, Compassion & Choices represented a family in bringing into the public eye a situation where patient wishes to forego food and fluid were obstructed. See Span, "Deciding to Die, Then Shown the Door," *The New York Times*, Aug. 24, 2011, available at <http://newoldage.blogs.nytimes.com/2011/08/24/deciding-to-die-then-shown-the-door/?ref=health>; Uyttebrouck, "Couple Transported Out of Facility After Refusing Food," *Albuquerque Journal*, Jan. 08, 2011, available at <http://www.abqjournal.com/news/metro/08232859metro01-08-11.htm>.

⁴ Compassion & Choices brought two federal cases to the United States Supreme Court urging recognition of a federal constitutional right to choose aid in dying. *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793(1997). Compassion & Choices was in leadership in the campaigns to enact the Death with Dignity Acts in Oregon and Washington. OR. REV. STAT. § 127.800 (2007); WASH. REV. CODE ANN. § 70.245 (West 2011).

⁵ See supra n. 1, Bergman, Tomlinson, Tolliver, Hargett; See supra n. 3, DeArmond.

⁶ Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *Journal of Medical Ethics*, Volume 33, Issue 10, 2007. <http://jme.bmj.com/content/33/10/591>

However after two decades of rigorously examined experience, we now know that many of the well-intentioned regulatory requirements within the Act actually disincentivize provider participation and make it very difficult for terminally ill individuals to access this compassionate end-of-life care option. Based on this experience, Compassion & Choices supports increasing access to medical aid in dying by removing unnecessary regulatory requirements that create barriers while maintaining the established eligibility criteria, as well as updating antiquated or ambiguous language within the context of the law. With this goal in mind, we applaud the legislature's serious consideration of SB 579 and are pleased to offer our support.

Medical aid in dying should be viewed as one of the many choices under a medical standard of care that terminally ill adults may consider when determining what course of treatment they wish to pursue. Compassion & Choices supports informed healthcare decision-making that ensures thoughtful choices, however we have long believed that the waiting period mandated under the Death with Dignity Act is unnecessary. There is no evidence to support that a waiting period between requests for medical aid in dying enhances patient safety. On the contrary, there is substantial evidence which demonstrates waiting periods can actually prolong unbearable and unnecessary suffering by effectively depriving terminally ill individuals of autonomy, self-determination and what they consider to be the most peaceful and dignified death. Additionally, one of the greatest benefits of medical aid in dying is its palliative effect; the peace of mind that an individual achieves once they qualify for the law and obtain their prescription, regardless of whether they ultimately choose to self-administer it.

While allowing an exception to the current 15-day waiting period, as proposed under SD 0579, will reduce the burden on some terminally ill individuals, Compassion & Choices would suggest eliminating this regulatory roadblock in its entirety for the reasons described below.

For terminally ill individuals, there is no time to spare.

Studies show that doctors overestimate the amount of time a person is likely to live because they want to keep hope alive for terminally ill individuals and their families. In fact, one study showed that physicians tend to overestimate how long someone is going to live by five times. For a terminally ill patient with a prognosis of 6 months or less to live, 15 days is not an insignificant amount of time. And that time would be better spent enjoying family and friends or activities that make their end of days meaningful--not waiting for the peace of mind they so desire.

The qualification process required under the Act as it is written today, is too long and cumbersome.

The required consultations with the attending and consulting providers and when necessary, a mental health provider take time.

A study published in the Journal of Medical Ethics found that although one in 50 individuals formally make a request for medical aid in dying to their physician, only one in 25 complete the process.

Another study published by Kaiser Southern California demonstrated that, even in the most

supportive healthcare systems with an internal referral system and patient navigator to assist terminally ill individuals and doctors in navigating the process, the average length of time from the first oral request to obtaining the medical aid-in-dying medication and eventually death for those who chose to self-administer the medication was well over a month.

Additionally, more than 30% of terminally ill patients who began the qualification process through Kaiser's system become too ill to continue the process or die before they are able to complete the burdensome process and obtain a prescription for medical aid in dying.

Most terminally ill individuals are not in a system like Kaiser or have an immediately supportive doctor, so the length of time to go through the process can be much longer, if possible at all.

The mandated waiting period is discriminatory.

Because no other end-of-life care option (including removal from a ventilator, palliative sedation or VSED) requires multiple requests or a mandated waiting period, medical aid in dying is set apart. This unfairly stigmatizes and discriminates against terminally ill individuals who choose to request a medical aid-in-dying prescription over other end-of-life care options.

A terminally ill individual who chooses medical aid in dying as one of their end-of-life options actually makes two choices. First, they choose to make a request for a prescription that provides them comfort and peace of mind. Then, they must make a second choice of whether to self-administer the medication if their suffering becomes unbearable or leave it at the pharmacy or in a safe place and not use it. Therefore, the mandatory waiting period simply delays the tremendous palliative effect that a dying patient receives from having a prescription.

Again, we are pleased to see that now with more than 20 years of experience in the state without any abuses, the Oregon legislature is seeking to refine the law based on that experience and we appreciate the opportunity to share our thoughts with you regarding this proposed legislative language. We are hopeful that with the adoption of this amendment, we will meet our shared goal of improving care and expanding choice at life's end.

Thank you, Chair and members of the Committee for your timely leadership on this issue.

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