Testimony of Sam DeWitt, Regional Campaign & Outreach Manager, Compassion & Choices

Regarding Support of SB 579, Relating to the Oregon Death with Dignity Act House Rules Committee June 5, 2019

Good afternoon Chair and Members of the Committee. My name is Sam DeWitt and I am the Regional Campaign & Outreach Manager 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 I am writing today, in support of Senate Bill 579. 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."

However after two decades of rigorously examined experience, we now know that many of the

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.

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

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

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 legislative efforts to remove unnecessary regulatory requirements that create barriers as well as updating antiquated or ambiguous language within the context of the law, while maintaining the established eligibility criteria and the proven core safeguards. With this goal in mind, we applaud the legislature's serious consideration of SB 579 and are pleased to offer our support for the bill.

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.

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

The process to qualify for and obtain aid-in-dying medication is long and cumbersome, requiring multiple appointments with various providers. In fact, one 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.⁷

According to the most recent Oregon report, the process averages more than seven weeks time from first request until death.⁸ 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. For those who wait to start this process until they are much closer to their inevitable death, studies from other authorized states demonstrate that many of them quite literally die waiting for the peace of mind they so desire.⁹

Particularly because studies show that doctors generally overestimate the amount of time a

⁷ Tolle, Tilden, Drach, Fromme, Perrin, and Hedberg, Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide, Journal of Clinical Ethics, Vol. 15, Issue 2, 2004. Available from: http://www.eutanasia.ws/hemeroteca/t336.pdf

⁸ Oregon Health Authority, Public Health Division Center for Health Statistics, Oregon Death with Dignity Act 2018 Data Summary, Released February 15, 2019. Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

⁹Nguyen HQ, Gelman EJ, Bush TA, Lee JS, Kanter MH. Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation. JAMA Intern Med. 2018;178(3):417–421. doi:10.1001/jamainternmed.2017.7728. Available from: https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2665731

person is likely to live¹⁰ by as much as five times,¹¹ allowing an exception to the current 15-day waiting period as proposed under SD 0579, will greatly reduce the burden on those terminally ill Oregonians, who in their final few days of life, decide they want the option of medical aid in dying to avoid unbearable and unnecessary suffering.

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.

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

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¹⁰ Tough Question to Answer, Tough Answer to Heat, Brody, J. March, 6, 2007, New York Times, available via: http://www.nytimes.com/2007/03/06/health/06mbrody.html? r=0

¹¹ Nicholas A Christakis, Elizabeth B Lamont, Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study, The British Medical Journal, 2000;320:469–73, Available from: http://www.bmj.com/content/bmj/320/7233/469.full.pdf