

Testimony of Seth A. Morgan, MD, FAAN
Support for SB701
The End-of-Life Option Act (The Richard E. Israel and Roger "Pip" Moyer Act)
February 28, 2020

My name is Seth Morgan. I am a Maryland resident, Board Certified Fellow of the American Academy of Neurology, Commissioner of the Maryland State Commission on Disabilities, Vice-Chair of the Maryland Alliance of Disability Commissions and Committees, Chairman of the Montgomery County Commission on People with Disabilities, advocate for people with disabilities and a person living with a disability. The opinions expressed in this testimony are my own and not those of any of the aforementioned groups.

I am in strong support of the End-of-Life Options Act (Richard E. Israel and Roger "Pip" Moyer Act); SB701/HB0643.

Contrary to the alarmist claims of the legislation's opponents, this bill provides strong protections to the residents of the State, including people with disabilities. The bill is, in large part, designed in a fashion similar to state laws enacted in multiple other states

Disability Rights Oregon (DRO) is the Oregon state agency in charge of the legally based protection and advocacy for individuals with disabilities and has a mandate under Federal law to investigate complaints of abuse or neglect of individuals with disabilities, including inappropriate actions taken to hasten the death of an individual. It's Executive Director, Bob Joondeph, reports that since passage of the Oregon Death with Dignity Act in 1997, DRO has never received a complaint that a person with disabilities was coerced to make use of the Act (1).

Thus, concerns that medical aid in dying would lead to abuse and coercion of people with disabilities is unfounded. The safeguards in the legislation are rigorous and preclude any individual with a cognitive disability from being eligible to use it. The bill specifically states that, "An individual is not a qualified individual solely due to age, disability, or a specific illness".

It has been suggested that potential heirs of a person with a disability could be witnesses to a request for medical aid in dying and thereby misuse this end-of-life care option for their benefit. However, the required written request for medical aid in dying must be witnessed by an adult who is **not** "a relative of the individual by blood, marriage or adoption", nor any individual who "would be entitled to any benefit on the individual's death". Further the individual's attending physician may not serve as a witness.

The current practice of palliative sedation does not provide any of the safeguards that are required for medical aid in dying. Palliative sedation is the practice of giving a terminal, hospitalized patient increasing sedation for pain control. Frequently, palliative sedation becomes terminal sedation and results in death. It is the family members, not the patient, who are asked for permission to use terminal sedation.

The suggestion put forward (most frequently by self-appointed advocacy groups that claim to speak for all individuals with disabilities) that the individuals they represent are against medical aid in dying is particularly offensive.

The premise that all people with disabilities are a monolithic group incapable of independent ability to make self-care choices and in need of a condescending umbrella advocacy group to speak for them is infuriating.

Yes, there are individuals with disabilities for whom the proposed legislation is not an option they would want to avail themselves of. But, there are many others who might.

Advocacy group representatives should be clear that they speak for the position of their Boards of Directors and acknowledge that individual people with disabilities may take a different personal position. They cannot speak for all the people they advocate for.

A polling company, Purple Insights, published surveys in 2014 documenting the level of support for medical aid in dying in New Jersey (2), Massachusetts (3) and Connecticut (4) amongst self-identified individual with disabilities.

These polls showed that 63 to 75 per cent of people with disabilities in those states supported medical aid in dying, nearly identical to the general population support ranging from 65 to 70 percent.

Nowhere is the private and personal nature of medical aid in dying clearer than as reflected in the official position and subsequent alternative position statements issued by the American Medical Association (AMA).

The American Medical Association reaffirmed its longtime opposition to medical aid in dying at its annual meeting while the AMA's Council on Ethics and Judicial Affairs stated that physicians who provide medical aid in dying are not violating their professional obligations. In the words of AMA President Dr. Barbara McAneny, "There are irreducible differences in moral perspective between thoughtful, morally admirable individuals who oppose physician-assisted suicide and equally thoughtful and morally admirable individuals who support it. Nonetheless, individuals from all perspectives are committed to the core values of care, compassion, respect, and dignity for their patients- an underlying principle of medical ethics. How each individual understands and acts on physician's common goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by their individual deeply held beliefs." (5)

While this dichotomy of positions has been the subject of criticism, it underscores that differing positions can coexist. In fact, 58 percent of physicians across 29 specialties say that medical aid in dying, "should be made legal for terminally ill patients," according to a December 2018 Medscape survey. (6)

Those of us in favor of passage of this bill are asking to be allowed a decision if the situation arose in which medical aid in dying were a legal option we could consider. For anyone for whom this is not an option they would want, no one will be forced to use it. Paradoxically, the availability of medical aid in dying in those states where it has been legalized has, in fact, served to help many terminally ill individuals fight on in the setting of impending death. About one third of prescriptions for medical aid in dying in Oregon are never utilized. (7) The comfort of knowing that it is available if the person's suffering were to become too severe is enough to let them feel safe to fight on longer.

Respectfully Submitted,

Seth A. Morgan, MD, FAAN

Disability Rights Advocate and Person with a Disability

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CITATIONS

- (1) Letter from Bob Joondeph, Executive Director, Disability Rights Oregon, February 14th 2019; Copy attached. Available from: <https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/>
- (2) Recent Polling in NJ. Purple Insights. February 2014. Available from: <http://compassionandchoices.org/wp-content/uploads/Purple-CC-NJ-voter-disabled-topline-02.11.14.pdf>
- (3) Purple Insights. February 2014. Available from: <http://compassionandchoices.org/wp-content/uploads/FINAL-UMT-Purple-CC-Press-Memo-06-11-14.pdf>
- (4) Voters + Disabled Community. Connecticut Survey. Purple Insights. February 2014. Available from: <http://compassionandchoices.org/wp-content/uploads/CT-PurpleStrategies-CT-Voters-Feb-2014.pdf>
- (5) Medscape Medical News, "AMA Reaffirms Stance Against Physician-Aided Death," Marcia Frellick, June 11, 2019. Available from: <https://www.medscape.com/viewarticle/914231>
- (6) 2018 Ethics Report on Life and Death, December 2018. Available from: <http://compassionandchoices.org/wp-content/uploads/Medscape-Ethics-Report-Dec-23-2016.pdf>
- (7) Oregon Death with Dignity Act, Data Summary 2018; Oregon Health Authority Public Health Division Center for Statistics; February 15, 2019. Available from: www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf