HB0443

Dr. Frank Arlinghaus

Opposed

I ask the committee to oppose House Bill 443, The End of Life Option Act. I join both the National Council on Disability and the American Medical Association in opposition to this bill (as well as numerous other disability rights and medical groups). I believe there are many good reasons for such opposition. Additionally, I find a number of reasons for those who support the ideas in the bill to oppose this particular bill on the basis of its flaws, particularly the insufficient protections for many vulnerable groups. I outline a few of these reasons below.

The National Council on Disability opposed Physician Assisted Suicide in a comprehensive 2019 report.

Please note that if you were to refer to one resource for information, I would ask that you look at the National Council on Disability report from October 2019 (at https://beta.ncd.gov or by searching on "The Danger of Assisted Suicide Laws: Part of the Bioethics and Disability Series", which documents a number of issues which contradict the narrative from Compassion and Choices. Importantly, this 70 page paper analyzes the law and examines whether the previous predictions by the NCD about these laws was correct (for example, their prediction on the ineffectiveness of claimed safeguards). For a shorter read, I recommend the 4 page executive summary on pages 11-14 of the report. However, I mention a few quotes from that summary:

"Many national disability organizations have taken positions opposing these laws due to concerns regarding their impact on people with disabilities" (p.11)

"Insurers have denied expensive, life-sustaining treatment but offered to subsidize lethal drugs" (p.11)

"People with the disability of depression are subject to harm where assisted suicide is legal" (p.11)

"Assisted Suicide laws apply the lowest culpability standard possible to doctors...which creates the potential for abuse" (p.12)

"Evidence of suicide contagion in states where assisted suicide is legal has been found in several studies" (p.13)

"States should not legalize any form of assisted suicide" (p.14)

The NCD is not the only organization to oppose PAS. However, in their bioethics report on PAS, they document evidence for these and other claims made in that executive summary. Other groups opposed range from the Disability Rights Education and Defense Fund or the Patients Rights Council to Not Dead Yet. All of these groups are concerned that patients with disabilities are put at even greater risk by these laws. Proponents of the law cite the number of safeguards and assert the strength of those safeguards; however, the NCD report addresses the problems with those safeguards by providing specific examples, many from the state of Oregon.

1. Vulnerable populations are at risk from this bill

-There will be an economic incentive that leaves the poor more vulnerable. The "right to die" will become a "duty to die".

Medical care options vary by socioeconomic status, and insurance companies and the healthcare industry are driven by profit. Over time, options offered to people may be limited, particularly for expensive end-of-life care. There are no protections from insurance companies who will offer to pay for ending one's life, but not for the treatment to prolong that life. Two such examples are the 2008 case of Barbara Wagner in Oregon (whose lack of treatment by the Oregon Health Plan can be compared to the Randy Stroup case, and which is described on page 20 of the NCD report referenced above with further details in the article "Oregon Rationing" Cancer Treatment But Offering Assisted Suicide to Cancer Patients-Paying to Die but not to Live") and the 2016 case of Stephanie Packer in California (referenced on page 16 of the NCD report and both the Center for Bioethics and Culture Network and Patient Rights Action Fund). Such arguments are already being made in Canada, utilitarian arguments that recognize the expense of end-of-life health care (note that savings is provided by hospice options which promote positive experiences for patients and families). One envisions a not-to-distant future where some will experience a pressure not to hang on to life; long before that, it is not difficult to predict that insurance will have at least a bias toward end-of-life solutions over those which prolong life, and that the limiting of options will fall more heavily on the poor. In fact, these arguments are being made already in Canada, which legalized assisted suicide less than a decade ago, and is moving toward euthanasia, and each year gets progressively worse for those in vulnerable groups.

-Those with some form of medical limitation (physical or mental challenges, for example) will be at greater risk.

I make this claim based on our history of mistreatment and misunderstanding of those who are born less than perfect and those who have some progressive medical condition that puts them in a higher risk category. I defer to the examples that the disability rights community provide, and only wish to reinforce that they constitute a group at much higher risk than many others. Similarly, many of us are familiar with the increased vulnerability of our parents and other elderly persons as they become more susceptible to such risk. You have heard many of these stories over the past eight years, and you see that society lacks respect for those vulnerable groups—the physically or mentally challenged, the elderly, the poor, the depressed.

2. Mental Health protections are inadequate.

The bill fails to adequately protect patients who may be depressed--note that only 5 of over 200 patients in Oregon (cf. Oregon 2017 report) were referred for counseling, and these numbers declined in 2020-2022 despite the number of deaths and prescriptions rising dramatically (cf Oregon 2022 report); that doctors are only required to refer if they believe the depression rises to the level of impairing the patient's judgment; and that doctors may have no training in detecting or fully understanding depression. Significantly, almost three times the number of patients cite being a burden than cite pain as a reason for terminating their life. A proper mental health evaluation should be done for each patient before a prescription can be issued. The case of Michael Freeland presented on pages 23-24 of the 2019 NCD report involves a man with a 43 year history of depression whose history was ignored by a C&C-associated doctor, and who was rescued by Physicians for Compassionate Care, who treated his depression instead. In fact, a British Medical Journal study of 58 patients in Oregon receiving lethal prescriptions showed that 26% presented for depressive disorder and 22% for anxiety disorder. We're seeing suicide rates increasing dramatically as well as significant amount of depression, but we rarely see the doctors involved referring for depression (perhaps this is because the median length of time of the doctor-patient relationship in the Orgon cases is only 5 weeks).

3. The bill sends an ambiguous message on suicide to our youth and to the rest of society at a time when suicide is increasing across the United States.

As **the parent of a teenager who considered suicide**, I have had to deal with responding to her concerns that society allows people to kill themselves, so why shouldn't she be permitted to do so. I have another child who dealt for multiple years with depression, and who was at similar risk. Both of them have heard the message we're sending, and it makes it more challenging for me (and for them).

Whether we call aid in dying "suicide" or not, we are allowing a segment of society to self-terminate life with the cooperation of medical professionals. The United States is seeing a continued increase in suicide, mental health issues are increasing, and our teenagers are considering suicide at an alarming rate. Suicide increases have been even higher in states that have legalized assisted suicide. The message this bill sends is that suicide under certain circumstances is acceptable, and it's not surprising for people to extend those parameters under which suicide is acceptable. If such laws become more prevalent across the United States, one of the next debates we will be having will cover the various circumstances under which we'll permit this, as we've seen other jurisdictions expand suicide laws to wider populations. If we just look at Oregon, between 1999 and 2010, the suicide rate among the age group 35-64 rose 49% compared to a 28% increase nationally, and the overall suicide rate in Oregon went from near average levels to 41% above the national average. Between 2011 and 2019, the number of suicides (excluding those which were physician assisted by lethal prescription) rose from 685 to 906 (an increase of 32%). During that same time period, the number covered by Oregon's version of this bill rose by more than 100 additional deaths, and in 2020 would result in over 250 additional deaths.

Additionally, we are in a state of emergency concerning the mental health of minors, and a mental health crisis across all ages. Just **one adult category that is at even greater risk is that of our veteran population**. At the same time, the study of reasons in Oregon that people seek this treatment includes the top two warning signs for suicide listed by the US National Institute of Mental Health. Talking about wanting to die, feeling guilt or shame, or believing that one is a burden to others, and planning or researching ways to die are warning signs for other patients, and things which we seek to treat with counseling, not counseling those people to die.

4. Safeguards still leave patients vulnerable.

In previous hearings, caregivers, family, and medical professionals presented specific scenarios of vulnerable patients that should raise serious concern. Each of these cases is an existential threat under the law proposed in this bill. Beyond that, the law leaves patients vulnerable due to potential financial interest of heirs (as an heir of my father, I need only have a friend serve as the other witness, so we could conspire to influence my father toward PAS; he has a number of underlying conditions that without treatment, would qualify under current

Oregon law). Other scenarios mentioned above include the vulnerability of the economically disadvantaged, especially the poor, the immigrant, the disabled, experiencing a form of health care rationing where insurance companies or providers steer them toward PAS and away from life-extending treatment (two examples cited above are the Wagner and Packer cases).

Within the Senate, during a previous year's committee hearing, the legal and medical standards were questioned by one of the senators, and the main sponsor did not have an answer for the weaker standards. One specific case of this is the unwarrantedly weak standard for physicians that replaces the standard negligence model (used for virtually all other physician duties) to the weaker "good faith" model. This is indicative of how flawed the bill is when examined carefully, and the extensive analysis presented in that hearing provides guidance as to the areas of greatest concern, including multiple areas where the professional standards protect doctors more than the proposed patients, whether standards of care or level of scrutiny by those who watch over and protect those patients. The good faith model is the **weakest standard** we would use, and is **lower than what we use for almost all other physician duties.** It is designed to protect the doctor and not the patient.

Furthermore, **the investigatory powers of the state are limited**, so protections from abuse are perfunctory at best. To quote the Oregon Department of Health and Human Services, "We are not given the resources to investigate and, not only do we not have the resources, but **we don't have the legal authority** to insert ourselves".

5. Bill fails to provide "Death with Dignity" and moves physicians from healer to agent of death.

With no doctor or other medical personnel present to attend to any difficulties while taking a megadose of pills, likely in a slurry of some sort, the likely scenario for consuming the lethal medication is anything but dignified. This bill has further complications from moving doctors from their traditional role as healers, and instead having them prescribe death.

Much time will be spent discussing the Hippocratic oath and how it might fit into the modern context. Instead I look to the Marbella statement made in 1992 at the 44th World Medical Assembly well after the international right to die movement had pushed for assisted suicide and aid in dying. It said "Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession." In the years since, most medical groups continued their opposition to such legislation, while the right to die lobbying efforts have tried to get them to stay neutral. Doctors remain uncomfortable at prescribing lethal medications, and are even more

uncomfortable at being present (thus we have a law in which the "attending physician" rarely attends the patient during the lethal act). These acts are in fundamental conflict with the view of doctor as healer.

6. The term "Medical Aid In Dying" gets confused with hospice care.

Supporters of the bill object to the term "Assisted Suicide" because the language weakens their support. To be accurate, we have a patient who seeks to end their life, who administers the means of ending that life by their own hand, and who is enabled in self-termination by a physician prescribing a lethal dose of medication. If the same patient were to commit this same act by collecting the same dose on their own, administering it the same way the law prescribes, but without a physician's involvement, we would call it suicide. However, "Assisted Suicide" conjures up images of Dr. Jack Kevorkian who set back the Aid in Dying movement at least a decade. In the meantime, the term "medical aid in dying" makes one think of hospice care, which has an entirely different approach, providing palliative care and comfort, and which the state should instead make an increased investment in. Additionally, polls which use the term "Medical Aid in Dying" gain broad support due to this confusion.

7. Holes in safeguards for lethal medications leave dangerous medication unaccounted for.

I will refer repeatedly to the 2017 Oregon report listed elsewhere in the report. Once a prescription is obtained and filled, there is no effective tracking of the medication. A significant portion of the lethal medication is prescribed and never used. Proponents claim that the prescription is rarely filled in that case, but there's no evidence of that. Given the types of medication used, the state should have an obligation to track it more carefully. In the case where the prescription is filled and is not used, there is a real potential for abuse of several types, including use on an unwilling victim as well as abuse of the drug in other ways. Once the prescription is filled, a patient who changes their mind is at risk for coercion or unwittingly consuming the medication.

Record-keeping rules inhibit investigations of such scenarios, making it difficult to expose and investigate problems. One need only look to the opioid death epidemic and a recent case in Ohio to some potential abuses in other contexts. Proponents of the bill fail to consider the risk of those drugs being used on a patient who has changed their mind, or used on someone else.

In the most recent version of the Oregon report available (2022), 431 people were reported to have received lethal prescriptions, and of them, 246 had died by ingesting the medications (278 patients had died, but 32 had

received the lethal drugs in 2021 or earlier). The past four years have seen an increasing number of prescriptions unused.

8. Canadian and European examples show that further risks to patients are likely to rise in the future

There is a steady progression over time where such laws "evolve". Sometimes we refer to the potential for a "slippery slope" while others may refer to it as the method for "boiling a frog". Proponents point to court cases that fundamentally changed what is permitted, and yet dismiss the possibility of it happening again. The Candians have had PAS legal for less than a decade, and yet many of the concerns expressed are becoming a reality there. Some of the examples we're concerned about may not be happening in this country yet, but are some of the next logical steps in such a progression, and in fact, supporters of this bill in other states have proposed amendments relaxing protections, extending the scope of the bill, or even using the courts to argue for doing the same. Thirty years ago, I argued against denying patients nutrition and hydration when the law changed to allow them to decline medical treatment. Refusing medical treatment didn't guarantee death as long as patients were given food and water. In order to guarantee they would die, rules had to "evolve" to treat nutrition and hydration as a medical treatment that could be refused. This would allow one to guarantee death. Now denying nutrition and hydration is cited as an inhumane way to die, justifying more humane methods. Perhaps the proper response is not to permit the inhumane way rather than to find other ways one may choose to die. We have seen a similar progression in European countries regarding assisted suicide and even euthanasia. The medical establishment and the courts may decide that medical treatments aren't worth the cost, that patients should die against their wishes (in Belgium, where a patient was physically restrained by their own family) or the wishes of their parents (in England even to the point of not allowing a child to be treated out of country at someone else's expense). In such cases, we are not all treated as equally valuable with an equal right to life-extending treatment, and unfortunately, the first to be devalued are the disabled and the elderly. Furthermore, those in poorer communities have less opportunity for life-affirming treatments, less access to mental health care, and are at greater risk. The cases cited above from the NCD report include evidence that denial of treatment of medical conditions in favor of PAS was based on estimated 5 year survival rate (which is a far different standard than the 6 month standard).

9. Conscience protections should be extended further—to nurses, pharmacists, other health care workers, and facilities.

Given the definitions within the bill, it's not clear that a healthcare facility could prohibit assisted suicide deaths on its site. Additionally, if a facility permits assisted suicide deaths on its site, additional protections are needed to prevent that facility from requiring participation (or other forms of facilitation) by pharmacists, nurses, and other health care workers. Additional protections should be put into the bill to protect them more fully.

10. Statistics that deceive: what's missing leads to serious questions on use of medication among other points.

Proponents of the bill will cite over 80 years of legality to dismiss problems. We have not had 80 years of legality, we have had over 80 state-years (one state-year is one year of legality in one state). Only in Oregon do we have as many as 20 years of legality, and we will note some of the gaps and some of the trends, drawing directly from the 2017 Oregon report (the 2021 and 2022 reports show a big increase in death, consistent with https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year20.pdf). Note that the number of deaths has increased in all but two of the years, and that there is a steady trend upward with greater increases over the last nine years of the data. Elsewhere the report lacks a number of items of interest. The data not collected often would answer opponents' objections which are at this hearing dismissed by proponents, including the tracking of medication and ingestion of said medication (prescription versus fulfillment of said prescription versus death of the patient by ingestion). Many of the times between ingestion and death are mostly unknown, but even given that, the time to unconsciousness and death can be much longer than expected. Further buried in the report is the detail that in 2017, morphine sulfate became one of the two prominent medications used, of further concern because of the better known abuse potential of morphine, and now a variety of drug mixtures is used.

11. The bill is based on a false compassion: doctors who specialize in care for the elderly are less likely to support the bill, and pain is not one of the core underlying reasons PAS is pursued..

People on both sides have genuine concerns, but the premise of compassion (in ending suffering) is contraindicated in two ways. First is that pain is cited less than 25% of the time in the most recent Oregon report. Also previous medical surveys have shown that the doctors more involved with patients favor bills like this at a much lower rate, and the lowest rate of approval comes from specialists in palliative care and care of the elderly. Those who attend the elderly and those in hospice see the greatest suffering in their patients. Seeing patients near the end of their lives, they should approve of this in the name of compassion. A survey by the Glasgow University Institute of Law and Ethics in Medicine showed pharmacists supported physician-assisted

suicide at rates twice as high as medical general practitioners. A survey of over 3700 physicians by the National Council for Palliative Care showed that over 90% of doctors who specialized in palliative care or in the care of the elderly did not support making changes in the law to allow physician-assisted suicide.

In the 2017 Oregon report, 92 doctors wrote 218 prescriptions, but at least one doctor wrote 29 of those. In

12. "Doctor Shopping" will and does exist.

2021, a single doctor wrote 47 prescriptions, while in 2022, a single doctor wrote 51 prescriptions. In a 2015 article in the Oregonian ("Physician-assisted suicide: A family struggles with the question of whether mom is capable of choosing to die," Oregonian, February 4, 2015. Available at: http://www.oregonlive.com/health/index.ssf/2015/02/physician-assisted suicide a f.html), a case of doctor shopping was described, one which raises additional questions on the testimony of the proponents of this legislation. A woman died of assisted suicide under Oregon's "Death with Dignity Act," even though she was suffering from early dementia (a condition which appears to disqualify her from being able to make the decision). Her own physician declined to provide a lethal prescription for her. When counseling to determine her capacity was sought, a psychiatrist determined that she was not eligible for assisted suicide since she was not explicitly pushing for it and her daughter seemed to be coaching her to do so (another disqualifying condition). She was then taken to a psychologist who determined that she was competent but possibly under the influence of her daughter who was "somewhat coercive." Finally, she was assessed by a managed care ethicist who determined that she qualified for assisted suicide, and the lethal dose was prescribed. Beyond this, one could imagine a doctor who would be receptive to helping patients he felt were in need--we had one where I grew up in Michigan whose name became infamous--and this case from 2015 shows the potential for redefining who qualifies for help.

14. The state has an obligation to err on the side of protecting life

From a purely secular governmental view, this state has an obligation first to protect its citizens. Ask yourself what level of "collateral damage" you are willing to accept given that such damage involves ending someone's life. Those susceptible to abuse are among the most vulnerable and in greatest need of protection.

These are only some of the reasons for opposing this flawed bill. You may also stand with the religious opponents of the bill, ministers and leaders of many faiths who find the bill objectionable on moral grounds. You may stand with the many doctors, nurses, and other health professionals who find the bill objectionable on professional and ethical grounds. You may find yourself favoring personal autonomy in principle, but see that in

practice this bill is too flawed to provide sufficient protection to people at risk. In any of these cases, I ask that you stand against this bill.

15. This is a continued public relations campaign of the international right-to-die movement, the positions of the Hemlock Society dressed up in the guise of compassion and of choices.

The ideas in the bill are very similar to those debated in the 1980's and 1990's when Derek Humphry's Hemlock Society was pushing for medically assisted and medically enabled death, and were strongly opposed by the medical establishment. In the past 20 years, there has been a calculated public relations campaign to dress up the same ideas to be more palatable to the public and to legislators. At this hearing, you will hear objections to language that might weaken public opinion, and statistics presented using language designed to elicit your support. Anything that I claim you are welcome to question, and I will be happy to provide appropriate references (contact me at farlinghaus@yahoo.com). I also ask that you test this by offering amendments to the bill to provide reasonable protections mentioned.

I respectfully ask that you oppose this bill. Even if you are a supporter of this conceptually, the bill is fundamentally flawed and must be amended to provide additional protections for so many of the things mentioned here.