Testimony in Opposition to SB 891 Sharon Quick, MD, MA (Bioethics) President, Physicians for Compassionate Care Education Foundation Submitted to: Oregon Senate Committee on Judiciary March 6, 2023, 1:00 pm

Dear Chair Prozanski and members of the Committee,

I am President of the Physicians for Compassionate Care Education Foundation (PCCEF), an organization without religious or political affiliation that promotes safeguarding vulnerable human lives, *especially those at the end of life. There are about 800 physicians and health care professionals who are members in Oregon. I have expertise in pediatrics, anesthesiology, pediatric critical care, and medical ethics. I ask you to oppose SB 891.

The waiting period is cut from 15 days to 48 hours between oral requests and can be eliminated if the patient is thought to be within 48 hours of death. A prediction that a patient is close to death only occurs when patients' organ systems are already beginning to shut down—that is, death is not some future event, but is already in process. Lethal drugs are not only unnecessary during the dying process, but likely contraindicated near death. The first organ systems to decline are usually the brain and the ability to ingest liquids. Within 3 days of death 90% of patients have compromised brain function and an inability to ingest liquids. 1 It is difficult to predict when a patient will die, and specialists are frequently wrong in their prognosis.² This bill does not prevent providers from relying on reports of a tired caregiver or staff with no defined expertise, through virtual or phone visits, to determine that the patient is declining and "near death." Allowing one provider, even a non-physician without specialization and without a second opinion, to assess this near-death prognosis and decision-making capacity and provide immediate lethal drugs (Sec. 9) demonstrates reckless disregard for the complexity and dangers of this situation. Misjudgment could result in serious complications. It is virtually impossible to get valid consent or ingest lethal drugs this close to death, and this stipulation in the bill is irresponsible and medically contraindicated. Hastening death with lethal drugs is never urgent and never necessary, and they are no guarantee of a "peaceful death." Lethal cocktails consist of a large volume of bitter-tasting and mouthburning liquids, and patients have to ice their mouths with popsicles and take anti-emetics just to get them down. Risks include nausea, vomiting, aspiration, seizures, and not dying. Palliative care can do far better.

The word change from "examine" to "evaluate" seems to allow virtual visits with both attending and consulting providers (Section 1 (8) and Section 5). Virtual visits are inadequate to independently establish a prognosis for a terminal state of illness, that a patient does not have an impaired capacity to choose, or that death is near. Nonverbal clues are essential to diagnosing depression, picking up coercion, and completing a full psychosocial evaluation; virtual visits are inferior for such a serious decision. There is no way to ensure that an exhausted caregiver or a greedy heir is not subtly coercing or even threatening the patient to request lethal drugs. There is no requirement that one of the two "providers" must be a physician. Medicare requires two physicians to determine whether a patient is terminally ill with a prognosis of six months—professionals with less expertise are banned from doing this³—but this bill allows lethal drugs to be prescribed without any physician involvement. There is no stipulation that a PA and his/her supervising physician cannot be the two providers, which essentially removes a second opinion. This bill allows two PAs (who are not independent clinicians) to determine eligibility and prescribe lethal drugs, but they do not have the training or experience to do this; only 0.1% of PAs practice hospice and palliative medicine, and only six PAs in the US report completing postgraduate training in this field. This bill may economically compel PAs to rubber-stamp decisions outside their professional standards and practice agreements, and for which they have not been trained. 4 When the diagnosis and prognosis can result in causing a patient's immediate death, ensuring the highest level of expertise and the most care in creating safeguards to prevent abuse is essential; convenience of patients or providers cannot override safety.

This bill demolishes safeguards and eliminates the one right promised in the original law—to allow patients to change their minds. New rights and powers are given to health care "providers," not patients, by expanding <u>subjective</u>, error-prone criteria by which they place people into two classes: a protected group (where the standard of care for those who wish to hasten their death is mental health services) or a marginalized group (who can be harmed, as they are deemed unworthy of this protection).

Autonomy has two parts: a right to choose and the capacity to choose. The terminally ill are vulnerable with a high likelihood of a compromised capacity to choose due to a myriad of complex circumstances. They commonly have good and bad days, fluctuating and progressively declining decision-making capacity, grief, pain, depression, external pressures, changing relationships, etc. In one study of cancer patients, 90% had deficits in some subscale measurement of decision-making capacity, and physicians did not readily recognize these impairments. Depression is common and treatable in the terminally ill, and it may manifest as a desire for a hastened death; it often goes unrecognized and untreated by physicians. In one study, only 6% of psychiatrists were "very confident" that they could "adequately assess whether a psychiatric disorder was impairing the judgment of a patient requesting" lethal drugs. Many psychiatrists feel that specialized forensic psychiatrists may be needed to determine a terminally ill patient's decision-making capacity. If a patient's wishes are acted upon at face value, without recognizing underlying deficiencies in a person's capacity to choose, that person's autonomy has been violated. By lowering the expertise of providers so that even more patients with depression and deficits in their capacity to choose will be missed and allowing less time for patients to change their minds, this bill preys on vulnerable patients, ensuring that more will be put in the marginalized group. This is not compassion, it is abuse.

Pain or inadequate symptom management should <u>never</u> be a reason for terminally ill patients to seek lethal drugs. Even a physician who advocates for lethal drug prescriptions admits this. Testimonies about patients with excessive pain or other symptoms at the end of life indicate that these patients had inappropriate palliative care. Most patients do not have intolerable pain as they approach death, and in the rare situation where various analgesics, nerve blocks, and other treatments are not sufficient, temporary sedation can be used to relieve pain. Studies show that doctors may lack knowledge about palliative care possibilities. Pather than removing safeguards to obtain lethal drugs, we should ensure that patients have access to good palliative care and physicians are not deficient in their use if it.

Most dying patients are comfortable and do not seek lethal drugs because of pain. A wish to die might really mean "I'm afraid I'm a useless burden." Often this is a plea for help and assurance of their value, not a desire to kill themselves. Despite developing disabilities, the terminally ill, if given sufficient time and support to adjust, often overcome despair to have meaningful experiences in the last months or even hours of their lives. A physician's role is to value a patient's inherent, unchanging dignity, no matter what that person's condition, abilities, autonomy, or social situation. This benevolent responsibility turns malevolent when physicians supply lethal drugs to patients—who may be in a vulnerable period of temporary despair—within this short time frame of 48 hours that fails to allow time for interventions or mind changes. Offering lethal drugs to despondent patients implies agreement that their loss of function makes their lives expendable and not worth living and not worth even attempting a trial of palliative care and mental health interventions. This condemns the despondent and those with disabilities, violating their right to change their mind, and leaves them dying hopeless with their dignity disregarded. These patients need love and care from family and health care professionals, not cold abandonment to a lethal prescription. The National Council on Disability and many disability organizations oppose lethal drug prescription and all expansions of such laws.¹³

One terminally ill man requested lethal drugs because he didn't want his mom to care for his personal hygiene. However, his doctor worked with him to find a solution and he no longer wanted lethal drugs. Vulnerable patients often make rash decisions out of fear, depression, embarrassment, subtle pressure by a tired caregiver who makes them feel like a burden, or other reversible concerns. Sorting through the reasons behind a patient's

request for lethal drugs—is it pain (unusual, but it can be controlled), depression (medicines take two weeks to begin to work, longer for full effect¹⁴), reversible or transient emotional issues (coming to terms with losses, new disabilities, or overcoming embarrassment), feeling alienated from or devalued by family, etc.—takes time. Fifteen days may be inadequate to do this but chopping it to 48 hours or eliminating it entirely represents patient abandonment under a guise of "autonomy."

Terminal illness is highly associated with depression, and suicidal thinking is highest at initial diagnosis and becomes less frequent with time and supportive measures. In spite of this, and the fact that depression is missed by as many as 40% of physicians, ¹⁵ in Oregon less than 4% of patients are referred for psychiatric evaluation. ¹⁶ It has been shown that depressed patients in Oregon have received lethal drugs and died from them. ¹⁷ As mentioned previously, even psychiatric specialists find it difficult to assess a terminally ill person's level of judgment. State-run veterans' homes in Washington provide access to assisted suicide organizations. Shortening the waiting period and reducing the expertise of providers may increase the already alarmingly high rate of suicides among veterans¹⁸ without first allowing them a chance for interventions that might change their minds about hastening death.

Families and friends need education, as they may be uninformed about normal aspects of the dying process and transfer their feelings of revulsion about patient disabilities or inadequacies as complaints that their loved one is "suffering." Some aspects of "suffering" seem to bother family members more than they could have bothered the patient. For example, patients are not usually aware or bothered by coma, but family sometimes labels a patient in a coma as "suffering." Family members do not like to see loved ones declining and losing function. Sometimes they transfer their own idea that they would not want to be like that to the patient and assume he/she would feel the same way—that the patient would rather be dead than disabled. Patients may sense when those around them are bothered by their appearance or disabilities, and this can contribute to making them feel like a burden and push them toward asking for lethal drugs. If patients are supported wholeheartedly through the onset and progression of disability, they often come to terms with their dysfunction and find renewed meaning in living (even when terminal). Lethal drugs are not a substitution for family education and support—which takes much longer than 48 hours.

The current law and this bill allow the following:

- The lethal drugs can be given to a person designated by the patient, and there is no safeguard to ensure that the patient was not coerced into stipulating a particular designee. No neutral party needs to be present when the patient actually ingests the lethal concoction, and no capacity evaluation is required prior to ingestion. Some patients do not take the drugs for months (or never take them) and capacity declines as patients near death. There are no safeguards to ensure that patients actually have capacity when ingesting the lethal drugs, that the drugs cannot be forced on patients by a greedy heir, or that the drugs could not be stolen for nefarious use from patients who have lost capacity. There is no mechanism required for disposal of lethal drugs if not used.
- The written request form does not have to be signed in front of a neutral third party, nor does it require a notary to verify the identity of the witnesses or that the patient signature was voluntary (OR 127.897s.6.01).

Therefore, this bill does not prohibit heirs or others from taking advantage of a vulnerable sick person by falsifying signatures and coercing two virtual oral requests. Combining these problems and the lack of oversight with the removal of the residency requirement creates a scenario where people not only in Oregon, but in other states, can be given terminal diagnoses and prognoses and prescribed lethal drugs without physical examination and without seeing even one physician. Undetected abuse of the vulnerable terminally ill is possible. Lethal drugs can be given to the Oregon provider who could mail them out of state to patients. Providers must be licensed in other states and abide by that state's laws. However, in states where prescribing lethal drugs is

illegal, how would this be policed when no one has to be present nor family notified when a patient takes lethal drugs?

Oregon's 2021 Report¹⁶ states that 81 patients (21% of the lethal drug recipients) were exempted from one of the waiting periods (15 days or 48 hours) because they were close to death. Since a prognosis of near death cannot be given until there are signs of organ dysfunction (usually declining brain function and inability to swallow liquids), the likely possibilities for these patients are (1) that the physician was wrong in prognosis and the patient was farther from death so that decision-making capacity was intact, or (2) the vulnerability and compromised condition of a patient close to death was taken advantage of to get an invalid consent for lethal drugs. In both situations the law was violated and patients mistreated.

The same Report¹⁶ lists deaths due to anorexia, arthritis, hernia, and medical care complications as some of the terminal diagnoses—but none of these are terminal diseases by themselves. Yet there is no oversight of this whole process and no mechanism to challenge physicians. Why is this bill being introduced to drastically reduce safeguards and legalize medically contraindicated practices when evidence suggests that more oversight and further safeguards are needed to protect patients, especially those with terminal illness-related disabilities, mental health problems, and those nearing death, from being inappropriately prescribed lethal drugs?

Instead of insisting on a high level of evidence that decision-making capacity is not compromised, and reversible conditions are not the source of the patient's desire to hasten death, this bill lowers the bar and violates the autonomy of vulnerable terminally ill patients. It is a mistake that will drive Oregon over an ethical cliff, and patients, especial those with disabilities and depression, will pay for with their lives. This bill gives health providers more power but preys on patients in their most vulnerable moments, abandoning them to their fears under a guise of autonomy and allows a bad day to become their last day.

Answers to Questions at the hearing:

In contrast to what was stated, there have been documented cases in Oregon where vulnerable patients inappropriately received lethal drugs. These cases never become visible through reporting to the Oregon Health Authority because oversight and enforcement are insufficient. Only when patients or their families allow their stories to be made public do abuses come to light.

- Kate Cheney was denied a lethal prescription twice because of dementia and concern that Kate's daughter was coercive. Kate's daughter took her doctor shopping until lethal drugs were prescribed. Kate died by lethal ingestion.¹⁹
- Michael Freeland was given a prescription for lethal drugs without a mental health evaluation despite a history of depression. He was later hospitalized for suicidal behavior; before discharge, his guns were removed from his home, but not his lethal drugs. Doctors with Compassion in Dying (later named Compassion & Choices) renewed his 6-month prognosis to make his lethal drugs "legal." He lived two years beyond his original prognosis, and never took the lethal drugs. He reconciled with his estranged daughter prior to death, an opportunity he would have missed had he taken lethal drugs.²⁰
- Ganzini et al. documented patients with active depression in OR who got lethal drugs and died from them. 17

Doctors view the quality of life of patients with disabilities as lower than the how patients themselves view their quality of life. There is an attitude that patients with terminal illness and disabilities, fatigue, hopelessness, etc. are "normal" to be depressed about their situation and doctors can agree that lethal drugs seem like a reasonable option that they might want themselves—so they do not think that such a patient's depression needs treatment. This means the doctor is transferring his/her own biases about quality of life onto patients, with a negative view, when most people with disabilities, losses, or other problems overcome their hopelessness and come to terms with their losses over time and with support; depression can and should be treated in the terminally ill too.

The idea that patient choice should be elevated to the top concern is not consistent with medical ethics norms. The right to choose is limited when decisions harm patients themselves, others, or society. For example, doctors generally refuse patients' requests for antibiotics for a viral illness because the patient does not benefit and only risks harm and society risks harm from resistant organisms. Both sides agree that patient autonomy is vital but disagree on where limits on autonomy should fall because there is disagreement on what constitutes harm to patients and society. This bill gives new rights and powers to providers, not patients, by creating subjective, error-prone criteria²² by which they place people into two classes: a protected group (where the standard of care for those who wish to hasten their death is mental health services) or a marginalized group (who can be harmed, as they are not deemed worthy of such protection). More providers can expand their role to judge, jury, and assistant executioner. The prime witness is dead, and the provider accomplice is given immunity from civil and criminal charges. Financial forces favor death, and the balance of power is shifted away from the patient. With practices where providers are given incentives to reduce costs or with government-sponsored health plans, physicians and/or government have conflicting goals—the primary responsibility to protect the weak and vulnerable is challenged by the enticement of killing them to save money. Barbara Wagner, for example, received a letter from the Oregon Health Plan refusing to pay for a chemotherapy agent to extend her life but offering a lethal prescription as one of her options.²³

Statements were made that providers act as a team, relying on other labs and doctors' findings to validate virtual visits for determining eligibility for and prescribing lethal drugs. However, the whole point of having 2 physicians independently evaluate the patient is to get independent decisions that do not rely on someone else who might have erred. For example, I remember examining a patient who had been admitted to the hospital and examined by other doctors, but I found a breast lump that had been previously missed, and this was unrelated to the reason for her admission.

References

- 1. This study of cancer patients found that wiithin 3 days of death, 90% of patients had dysphagia of liquids and 93% had a Palliative Performance Score (PPS) of \leq 20%.1 A PPS score measures the level of ambulation, activity, self-care, oral intake, and level of consciousness, with 100% being normal. A score of 20% indicates the patient would be bed bound, cannot do any work, requires total care, has reduced to no oral intake, and is likely drowsy, confused, or in a coma. (Hui D, Dos Santos R, Chisholm G, et al. Clinical signs of impending death in cancer patients. The Oncologist 2014; 19(6): 681.)
- 2. I have been wrong, and studies confirm this is not uncommon for specialists. One study found that "even when patients are in the terminal phase and close to death, clinicians are not very good at predicting how much longer they will survive." The study found palliative care specialists were wrong about 1/3 of the time. (White N, Reid F, Vickerstaff V, Harries P, Stone P. Specialist palliative medicine physicians and nurses accuracy at predicting imminent death (within 72 hours): a short report. BMJ Supportive & Palliative Care 2020; 10(2): 209-12.)
- 3. 42 USC 1395f (a)(7)(A)(i). https://uscode.house.gov/view.xhtml?req=(title:42%20section:1395f%20edition:prelim)
- 4. PA educational standards do not require instruction on patient decision making capacity, intractable suffering, or how long a patient will live. These topics are not addressed in students' clinical training or covered in board exams. The Accreditation Review Commission on Education for the Physician Assistant current standards https://www.arc-pa.org/accreditation/standards-of-accreditation/; The National Commission on Certification of Physician Assistants develops and administers these tests. https://www.nccpa.net/become-certified/pance-blueprint/; Statistical Profile of Certified PAs, 2021 Annual Report, p. 17, 35. https://www.nccpa.net/wp-content/uploads/2022/08/2021StatProfileofCertifiedPAs-A-3.2.pdf (From the testimony of Jonathan Clemens, PA in WA, in opposition to SB 5179, Feb. 2023)
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- 8. "[No] patient should take medications to die because they're receiving inadequate symptom management at the end of their life. Hospice care is a way of assuring that patients aren't forced to consider aid in dying because of inadequate end-of-life-treatment." Shavelson, Lonny. Medical Aid in Dying: A Guide for Patients and Their Supporters. American Clinicians Academy on Medical Aid in Dying, 2022. (p. 36)
- 9. Enguidanos S, Rahman A, Hoe D, Meyers K. Provider-Identified Barriers To Palliative Care For Medicaid Patients. *Innovation in Aging* 2019; **3**(Supplement_1): S689-S.
- 10. Kavalieratos D, Mitchell EM, Carey TS, et al. "Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc* 2014; **3**(1): e000544-e.

- 11. Platt M. Pain Challenges at the End of Life Pain and Palliative Care Collaboration. Rev Pain 2010; 4(2): 18-23.
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- 13. National Council on Disability. The Danger of Assisted Suicide Laws. Washington D.C., 2019. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf. The executive summary is here: https://ncd.gov/newsroom/2019/federal-study-assisted-suicide-laws.
- 14. Antidepressants begin to have substantial effect by 2 weeks, but full effectiveness may take 6-8 weeks. https://www.verywellmind.com/how-long-does-it-take-for-antidepressants-to-work-2584277; Mitchell, Alex J. "Two-week delay in onset of action of antidepressants: new evidence." Brit J Psych188, no. 2 (2006): 105-06; APA. "Treating Major Depressive Disorder: A Quick Reference Guide." 2010, p. 8, 18.
- 15. Testimony of Mark Komrad, MD, in opposition to SB 5179. 2023.
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