

**Written Testimony Regarding HB 5898
Better Care at the End of Life,
Not Physician-Assisted Suicide**

Matthew R. Kenney, PhD

Distinguished members of this committee, I am Dr. Matthew Kenney, Senior Director of Ethics for Ascension, the largest Catholic healthcare system in the world, and the largest not-for profit organization in the United States. I write on behalf of all of Ascension, including St. Vincent's Medical Center in Bridgeport, as well as the other Catholic hospitals in the state.

I am a clinical ethicist, an educator and someone who works extensively with dying patients, their families and health care providers. I also and perhaps most primarily, testify as a widower who accompanied his wife through chronic and terminal illness. I stand in opposition to this bill and in favor of true and authentic end of life care. . . . yet again. In fact, this is the fifth time I, like many of you, have considered this bill, with many of the same faces on both sides of the aisle. This same process has taken place in 17 other states this year.

Raised Bill 5898 has a number of terminal flaws, from both a procedural and substantive perspective: it hides the truth behind deceptive nomenclature and allows practitioners and agencies to escape accountability. It violates Catholic teaching on the sacredness and dignity of human life and the *Ethical and Religious Directives for Catholic Health Care Services* as well as fundamental tenets of bioethics. Most importantly, it does not accomplish the goals it purports to attain: promotion of patient autonomy, lessening of a sense of burden, loss of self and alleviation of pain and suffering.

The bill goes to great lengths to distance itself from the moniker "physician-assisted suicide", yet this is exactly what it is. If this legislature, and transitively, the people of the state of Connecticut, agrees that assisting in suicide is ethical and should be legal, why are you afraid to call it what it is?

You cannot have it both ways. The bill states that "A person is guilty of murder when such person, without authorization of the patient, willfully alters or forges a request for aid in dying . . . or conceals or destroys a rescission of such a request for aid in dying with the intent or effect of causing the patient's death" (Sec. 14). Yet, it also states that "Nothing in sections 1 to 14, inclusive, of this act or sections 16 to 19 inclusive of this act . . . authorizes a physician or any other person to end another person's life by lethal injection, mercy killing, *assisted suicide*, or any other active euthanasia" (Sec. 15). Directly and intentionally ending another person's life is murder (*homicide*). Directly and intentionally ending one's own life is *suicide*. The euphemism which the Bill uses to refer to

assisted suicide is “participate in the provision of medication” (Sec. 13). This represents an even further attempt to obscure the reality it represents.

This distinction is more than just semantics. It draws attention to one of the fundamental flaws of the Bill. It hides from the truth and lets doctors and reporting agencies do the same. There is no accountability in this Bill. Section 9 states that “The attending physician may sign the qualified patient's death certificate that shall list the underlying terminal illness as the cause of death” (Sec. 9, 6b). This is a lie. The cause of death is the ingesting of up to 80 pills that are designed to kill the patient in less than three hours. Why are proponents of this bill afraid to call it what it is? In addition, how are we to track deaths that fall under this Act? If we cannot track them and differentiate them from all other deaths, how can we measure either sanctioned use or potential abuses? How can we be held accountable?

This draws attention to another critical flaw in the Bill. It does not differentiate between the foregoing of extraordinary medical treatment, which is recognized as a fundamental legal and ethical right, and assisting in suicide. These are very different things. US Jurisprudence has unequivocally stated that physician-assisted suicide is not a fundamental constitutional right (see USSC rulings in *Washington v Glucksburg* and *Vacco v Quill*). In these rulings, it recognized legitimate state's interest in prohibiting physician-assisted suicide, among which were preservation of the integrity of the medical profession and avoidance of the “slippery slope”. What the Supreme Court did call for was a better use of existing resources: appropriate and aggressive palliative care, preservation of patient autonomy through Advance Directives, and the right of patients to refuse treatments that pose little or no medical benefit or undue burden, as well as the recognition of the need to provide better emotional, psychological and spiritual support for the terminally ill. The Medical Orders for Life-Sustaining Treatment (MOLST) program can, if framed within the context of ethical principles and guidelines, help promote these goals. This physician-assisted suicide bill does not. It makes end-of-life a misguided medical treatment. It should be much more than this.

Proponents of this bill will cite the experience of the Death with Dignity Act (DWDA) in Oregon and will note that the bill has improved overall care for the dying in that state. They will cite a greater willingness on the part of physicians to discuss end of life issues with patients and to effectively pursue pain management. However, discussions regarding goals of care and end of life issues as well as a willingness to provide appropriate palliative care do not de facto flow from a physician-assisted suicide bill, but from the desire on the part of health care providers to enter into the experience of the dying patient and accompany them on this journey. In addition, safeguards that are in place to prevent potential abuse are sometimes unmet. For example, in 2018 the state of Oregon reported that only three (1.8%) of the 168 DWDA patients who died

during 2018 were referred for formal psychiatric or psychological evaluation (2018 Death with Dignity Act Annual Report, p.11), and since its inception only 4.5% of all patients who received life-ending medication were referred for psychiatric evaluation. This percentage is steadily declining even though “Despite its prevalence among patients with serious illness, clinical depression is often unrecognized” (National Cancer Institute), and even though assessment of decision-making capacity, possible depression, and emotional stability is a key component of the Act. The current Bill under consideration has similar provisions regarding optional referral to psychiatric support and evaluation; however, they, like the provisions in the Oregon Bill, will likely go unmet.

It is worth noting that while only three *patients* were referred for psychiatric evaluation and support under the DWDA in 2018, two *physicians* were referred to the Oregon Medical Board for failure to comply with DWDA requirements. In addition, the percentage of patients killed through the ingestion of lethal drugs who first are referred for hospice support is also steadily declining. It seems that the safeguards included in these bills are fundamentally flawed. Yet, we see legislative bills modeled after the Oregon Bill come before legislatures in state after state, year after year.

Therefore, I want to challenge this legislature, and the people of Connecticut, to *do something new*. Be the state where instead of asking (again) “Should we be legalizing physician-hastened death,” let us be the state where we ask the harder questions: “Why are so many people still dying badly?” and “Who is accountable?” and “What will it take to fix the problem.”

We who oppose this bill and others like it are also much to blame. We coalesce when a bill comes before this body, but then all but disappear once it is defeated. We argue against assisted suicide, but often don’t posit any alternatives. Here are my alternatives:

1. *Consistently provide the best possible end of life care, rather than a bill which has nothing to do with care.* At its heart, physician-assisted suicide is neither a legal issue nor a political issue. It is a human issue. As such, it transcends political, legal and religious boundaries. Factors that lead to requests for aid in dying such as loss of a sense of control, loss of a sense of meaning and purpose, fear of being a burden on others, and even physical pain or other uncontrolled bodily symptoms are at the heart of human dignity. Healthcare which addresses these fundamental concerns is an obligation we owe to all. Exceptional programs, like those recognized in the American Hospital Association’s Circle of Life Award, already exist, and have proven that much better care and outcomes are both feasible and affordable. If we use these programs as a model, high performing programs could be the norm rather than the exception.

2. *Make use of our legacy and existing resources:* Connecticut is the birthplace of the hospice movement in the United States, yet, according to a recent Yale study, “Connecticut ranks *last in the nation* in terms of people accessing hospice care and the average length of stay in the state is *six days*.” This does not allow for adequate time to address the physical, emotional, spiritual and psychological needs of patient and family. Referrals to hospice are supposed to occur when a patient has six months or less to live as judged by a physician (ironically, the same span of time in which patients may request assisted suicide, according to this bill).

In addition, Connecticut has passed recent MOLST legislation, but the forms and more importantly, the conversations of which these and other advanced care planning are the fruit *are not happening*. We need to train healthcare providers to have these serious illness and goals of care conversations much earlier on the continuum of care, with patients and their family members. Patients who have such conversations report feeling more in control, cared for, and less of a burden on others (3 of the five factors listed above which contribute to requests for assisted-suicide). Our resources *and our votes* should be dedicated towards supporting these initiatives. On the Federal level, the Palliative Care and Hospice Education and Training Act (PCHETA), with appropriate safeguards, could go a long way towards promoting the provision of true and authentic care at the end of life. The World Health Organization’s definition of palliative care is as follows: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” This approach addresses the real causes of requests for assisted suicide, while at the same time respecting human life and human dignity. Connecticut should take advantage of the federal funds being allocated to palliative care education and training so that we can become a leader in this area, not last amongst all states in the union. We can and must do better.

3. *Make palliative care the norm rather than the exception.* Contrary to what many think, palliative care and curative care are not mutually exclusive, and palliative care consultation should be part of the plan of care for all those with life-limiting illness. In order to do this, we need to ensure that our physicians are being trained in this area. Legislative proposals could hold medical schools accountable for turning out physicians unskilled at treating pain and uncomfortable talking with – or listening to- their patients, particularly those who are scared, sick, and dying. State (and/or federal) funding could be tied to major improvements in curriculum and testing within a short, two or three-year timeline. In addition, each palliative care

team would consist of a full component of professionals to attend to the whole person, physically, emotionally, psychologically, and spiritually. This includes physicians, nurses, social workers and chaplains. Staffing levels would meet this need and ensure both access and care along the entire continuum. [And, as a quality and safety standard, every person cared for in a palliative care program, hospice, PACE, geriatric long-term care and dementia care program or facility would have individualized contingency plans for any foreseeable symptom emergency.]

4. *Pursue a proactive rather than reactive legislative and public policy agenda:* Proposals that effectively address the entrenched causes of suffering among dying “Nutmeggers” would challenge and encourage reconsideration for those who currently assume that the enlightened path is for doctors to end life. In addition to policies that encourage medical schools to place a priority on the end-of-life care trainings they provide, lawmakers can also encourage nursing homes to maintain sufficient staff to help frail residents eat, or to answer a call bell rung by a frail elderly patient who needs help getting to the bathroom before becoming incontinent. Those that fail to meet those standards should be held accountable. These are the hallmarks of human dignity, not subject to staffing ratios. Repeated failures to meet quality goals could result in the loss of licensure. Meaningful transparency, with due process for providers, for consumers and quality watchdog groups will also help to fuel the cycle of needed improvements.

A word about cost. Research has shown that better care at the end of life actually reduces healthcare costs since nationally close to 70 percent of healthcare costs are expended in the last few months of life in the provision of interventions that, if asked, many patients would say they don't want. In addition, the changes in healthcare financing – from volume to value- and the emphasis on the Quadruple Aim of improving quality of care and the health of populations as well as the experience of caregivers, while controlling runaway costs, present opportunities to accelerate adoption of highly personalized goal-aligned care that includes reliably excellent end-of-life care.

There is also a moral cost of inaction as well. Even if some choose not to believe it, western society is sliding into acceptance of voluntary death as a response to an ever-wider range of maladies and life situations. Indeed, in finding that the right to physician-assisted suicide or euthanasia was not restricted to terminally ill people, but instead to those who are “ . . . enduring suffering that is intolerable to the individual in his or her condition” the Supreme Court of Canada confirmed that the slippery slope is real. We need to pursue other avenues of care.

Dr. Ira Byock writes:

If somebody feels they are trapped within a burning room and there is no alternative but to either die in horrible suffering or end their life prematurely, the notion of assisting them in suicide seems reasonable, even progressive. But if we know that there is a fire extinguisher behind a panel in that room and that a fire escape is behind the door if you just know where to push, the idea of giving them a lethal dose of medication or a way to end their life prematurely would seem absurd. I know that those ways of alleviating suffering are readily available. We're simply not making people aware of them and not building them into the health care environment (Byock, 2015).

Proper care at the end of life involves addressing those factors cited above, which can lead to requests for aid in dying: loss of a sense of control, loss of a sense of meaning and purpose, a sense of being a burden on others, and in some cases, physical pain. Conversations around end-of-life are our fire extinguishers; appropriate and fully-integrated palliative care is our fire escape.

Fundamentally, providing better "end-of life-care" as this bill is called, means helping the terminally ill to see that they are not disposable. The dying have a lot to teach the living about life, if we choose to listen. We promote compassionate care for the most vulnerable among us when we affirm their existence, listen to and acknowledge their fears, aggressively treat their pain and help them alleviate their spiritual and existential suffering, not by assisting them with suicide. Instead of sliding down this slope we can earn people's confidence in being well cared for, their comfort assured, their loved ones supported and their dignity and worth affirmed at the end of life.

We can and we must do better. We must choose to do something new.