

Testimony of James D. McGaughey
Regarding Raised House Bill 7015, An Act Concerning Aid in Dying for Terminally Ill Patients
Judiciary Committee
March 18, 2015

For a variety of sound public policy reasons, assisting someone to commit suicide has traditionally been held to be illegal. This Bill would change that for physicians who write lethal prescriptions for certain “qualified” individuals - people who could then take the prescribed drugs to end their lives. Proponents of this change believe that this is a question of compassion and individual rights. Opponents, and I am certainly one, see this change as leading in a dangerous direction – one that not only fundamentally re-defines the role of medicine in our society, but also creates a new dynamic wherein affirmatively ending one’s life will be understood as a legitimate, perhaps even a preferred or expected alternative to living with significant physical care needs.

Much of the debate about this proposal focuses on the adequacy of the “safeguards” written into the legislation – provisions that proponents assert will prevent abuses and limit its application only to people who are terminally ill and within the last six months of their lives. They point to the experience in Oregon, where similar legislation has been on the books for 17 years, claiming that, “there hasn’t been a single confirmed case” of misuse. However, close examination of the record in Oregon reveals that the absence of “confirmed” cases is more a function of that state not having mechanisms to effectively monitor and investigate concerns than it is evidence of a perfect record. Although Oregon’s Health Authority is charged with monitoring compliance with its Death with Dignity Act requirements, it largely confines its activities to gathering self-reported data from physicians and pharmacists and producing annual statistical reports based on that data. After the first year of its operation, the Epidemiology Section of Oregon’s Health Authority issued an unusually candid newsletter describing this essentially passive surveillance system, and admitting that:

... [T]he possibility of physician recall bias must be considered. Because of the unique nature and requirements of the Death with Dignity Act, prescribing physicians may have recalled their conversations with requesting patients in greater detail than physicians for patients in the comparison group. **For that matter, the entire account could have been a cock-and-bull story. We assume, however, that physicians were their usual careful and accurate selves. Finally, the Health Division has no formal enforcement role;** however, we are required to report any noncompliance with the law to the Oregon Board of Medical Examiners for further investigation. Because of this obligation, we cannot detect or accurately comment on issues that may be under reported.

From “A Year of Dignified Death”, published in *CD Summary*; March 16, 1999 by the Center for Disease Prevention and Epidemiology of the Oregon Health Division. Emphasis Added

Interestingly, a similar newsletter issued in 2011 stated that “there have been a total of 22 reports [of non-compliance by physicians] filed with the Oregon Medical Board since 1998.” (*CD Summary*, March 15, 2011). So even the passive monitoring conducted by the Oregon Health Authority has detected the presence of at least some problems.

More troubling, however, are the questions about certain cases that have surfaced independently of the official monitoring system. For a listing of these I would refer you to testimony submitted by others. In some of the cases referred to, very troubling questions are raised about the competency and psychological status of individuals who obtained and consumed lethal prescriptions, about the circumstances under which the drugs were “ingested”, and about the potential for undue influence on the part of others.

The Oregon Health Authority has not investigated, and seems to have no authority to investigate these matters. Many of the unanswered questions center on the circumstances under which the patient actually consumed the drugs and died. Because Oregon does not require that any healthcare provider be present when a patient ingests a lethal prescription, and, further, does not record any information regarding the circumstances surrounding the patient’s death unless it is provided by a healthcare provider, officials in that State simply cannot know whether there are problems surrounding this process or not. Nor can we. In fact, the Oregon Health Authority’s annual reports indicate a steadily decreasing number of patients being attended by doctors or other health care providers at the time of death. In 2014, approximately 80% of those deaths occurred without any kind of health care personnel being present. In contrast, in 2009 (five years earlier), a physician or other healthcare provider was present over 60% of the time. So, when questions have arisen about possible coercion or abuse or whether a patient actually self-administered the drugs, as they have from time to time through probate proceedings or collateral investigations, there have been no answers and no mechanisms for finding answers. This highlights one of the major safeguarding weaknesses of both the Oregon law, and the proposal here in Connecticut: no impartial observer must be present when the person swallows the lethal prescription. The fact that a person has requested the prescription creates an almost insurmountable presumption that he or she knowingly and voluntarily consumed it. If that is not the case, however, it is highly unlikely that anyone would ever know.

Notwithstanding the limitations in Oregon’s monitoring system, there is information contained in the Health Authority’s annual reports that should give us pause. For example:

- The average (median) length of time an “attending physician” has treated a patient before the patient took the lethal prescription is between three and four months. (Oregon’s definition of “attending physician” is almost identical to that found in this Bill.) Given the built-in statutory delays between initial requests and the point in time when an attending physician can write a lethal prescription, this data suggests that a fair number of those “attending physicians” became the patients’ doctors solely for the purpose of writing those prescriptions. Indeed, according to the Oregon report, 83 doctors wrote 155 lethal prescriptions in 2014, with some writing as many as twelve. In Oregon, as would be the case in Connecticut under this Bill, there is no requirement that the attending physician be trained in recognizing signs of depression, or specialize in (or even be more than passingly familiar with) state-of-the-art palliative care options before advising patients about those options. Palliative medicine is increasingly being recognized as a specialty area. Unfortunately, many practicing physicians are unfamiliar with the possibilities and benefits of state-of-the-art palliative care, a situation that is aggravated by the increasingly compartmentalized nature of medical practice and highly fragmented nature of health care delivery in this country.

- Most people seeking lethal prescriptions do not do so out of concerns about pain or discomfort. According to the Oregon Health Authority's reports, the primary reasons people sought those prescriptions were: "loss of autonomy" (91.4%); "less able to engage in activities making life enjoyable" (86.7%); and, "loss of dignity" (71.4%). Historically, "inadequate pain control or concerns about it" has been listed as a factor in fewer than 25% of requests. These figures offer cold comfort for people who live with significant disabilities, many of whom live with the daily reality of needing assistance with personal care. Most adapt to that reality, and, in fact, come to think of personal care as simply a way of getting simple things done so that they can then do other, more important things. However, for people who live with significant disabilities, it is deeply troubling to see a state accepting and publishing rationales that essentially validate the view that death is a legitimate and possibly even preferable alternative to needing care from others - that "losing autonomy" and needing personal assistance somehow translates into the kind of "loss of dignity" that can justify taking one's own life.
- The trends in Oregon clearly show steadily increasing numbers of people requesting and dying from lethal prescriptions. In 2014, 105 people there took lethal prescriptions. (In contrast, in 2000, three years after passage of the Death with Dignity Act, 25 Oregonians reportedly died from lethal prescriptions.) The Health Authority's annual report for 2014 indicates that a majority of those who died by ingesting lethal prescriptions did not have private medical insurance – the first year where that was the case. Over the past several years, the numbers of people taking lethal prescriptions who do not have private health insurance has been creeping upward. While it is too early to know whether the latter trend will continue, it should be noted that Oregon has, for several decades, explicitly rationed healthcare for recipients of Medicaid. As pressures to contain healthcare costs increase, and concern increasingly focuses on the costs of end-of-life care, "rationing" – whether it be openly embraced, as in Oregon, or pursued indirectly through various drug formularies and prior-approval mechanisms – tends to reduce options for care and treatment for those who cannot independently finance and arrange their own supports. Subtle as these pressures may be, they may alter the calculus for people who feel that things are closing in on them.

Perhaps the biggest "safeguarding" problem associated with this type of proposal lies with the assumption that doctors can determine, with reasonable medical certainty, when someone is terminally ill and within six months of death. The business of predicting the timeframe for an individual's death is just not that precise. Hospice programs commonly report that they have seen patients who were admitted to care because they were thought to be within six months of death, but who subsequently were discharged because their disease process was not progressing as expected and they no longer met the criteria for hospice care. In fact, research on the question has demonstrated that medical prognostications regarding the prospective timeframe for an individual's death are often unreliable, sometimes missing the mark by years. Add the complications inherent in long term progressive conditions such as the various types of Muscular Dystrophy or Multiple Sclerosis, or any number of other chronic conditions, and things get even murkier. What about people who are born with disabilities that involve complex medical problems or genetic syndromes that can, but do not always, result in shortened life expectancy? Or people with physical disabilities who may experience repeated episodes of life-threatening infections or inflammatory processes that can periodically make them sick to the

point where their lives are threatened? What about people who depend on life-support technologies to breathe or to eat? At what point could these people be considered “terminally ill” or “within six months of death”? Given the considerable confusion that often exists in the medical world about the degree to which people with disabilities are “suffering”, there is a very real risk that people with these types of significant disabilities who become despondent about their futures and the lack of support options available to them, but who could otherwise have many years of life in front of them, will ask for and be given lethal prescriptions.

Medical practitioners often do not know about the ways that people with these types of disabling conditions can live productive, contributing, satisfying lives, and doctors are not immune from common prejudices about disability. They can be just as subject to the, “I wouldn’t want to live like that” syndrome as anyone else. The requirement for two physicians’ opinions hardly helps. In my thirty plus years working at the Office of Protection and Advocacy for Persons with Disabilities, I encountered doctors who were very willing to declare that an individual living with a disability was in the end stages of a “terminal” disease process in order to justify medical orders withholding nutrition, hydration and beneficial medical treatment. Usually this was done at the behest of a relative or guardian, but invariably the doctor’s view of the patient’s quality of life factored into the medical decision making. And, not infrequently, that doctor could come up with a second opinion confirming his or her own. Those individuals did have guardians, so I am not suggesting that they would be considered as competent, “eligible patients” under this Bill. But, the ease with which I saw some medical practitioners justify a “terminal” prognosis of six months or less certainly raises questions about the effectiveness of this requirement as a safeguard.

It is also deeply troubling that physicians – medical professionals to whom we have historically turned for comfort, advice and treatment – may be writing prescriptions that are used to end life. Not only would this represent a significant departure from thousands of years of professional tradition, but it cloaks the act of ending one’s life with the trappings of medical legitimacy. This is a slippery slope – one which can be seen in some of the trends that have emerged in the Netherlands over the past several decades. Physician assisted suicide has been tolerated there for nearly 40 years, and “euthanasia laws” have been formally adopted. Surveys reveal that many Dutch doctors now consider having a long-term disability with a “poor prognosis” for improvement as justification for writing a lethal prescription. In addition to practicing active euthanasia - administering lethal injections to newborns with significant disabilities and to older people with dementia - some physicians there now see no problem with administering deadly doses of drugs at the request of people who have no physical signs of disease, but who are experiencing chronic emotional distress from conditions such as anorexia nervosa. There are even reports indicating that some elders whose relatives can no longer care for them opt for physician-administered death rather than enter nursing homes. (One of the most distressing consequences of all this physician-assisted death has been a notable lack of investment in palliative care and hospice programs in the Netherlands.)

These things have a way of spreading. In neighboring Belgium, which has allowed physician administered euthanasia for the past thirteen years, the slippery slope is also operative: Several years ago two brothers who were deaf and who relied on manual language to communicate, requested and received euthanasia because they were losing their vision, and feared they would no longer be able to communicate with each other. Just last month the Belgian Parliament adopted a measure permitting

even young children to request and be given lethal doses of drugs, provided they meet certain conditions and have parental consent.

The lesson from the places that have been doing this the longest is clear: Once it becomes culturally and professionally acceptable to involve medical doctors in the business of ending life, rationalizations can emerge for carrying the practice far beyond what was originally intended. I recognize that the proponents of this measure may sincerely believe that will not happen in Connecticut; that attempts to expand the scope of an “aid in dying” statute beyond the contours laid out in this Bill would surely and swiftly be defeated. But, the change that would be signaled by adopting this legislation cannot be corralled by mere statutory language. Practices that are legitimized in law have a way of reframing how we see things and of getting us to see each other differently. Sometimes that is a very good thing – legislated reforms have often helped us recognize aspects of our common humanity that were previously obscure. Much of the civil rights legislation enacted over the past sixty years has had that effect. But, legitimizing a practice that has been shown to increase the risk of premature death for vulnerable people in the name of expanding individual rights is a wholly different matter.

For people who are truly at the end of life’s journey, palliative medicine and hospice programs can offer relief from both the physical and emotional suffering they may experience. Unfortunately, these options are not always sufficiently available or accessed in time. We would do better to address that problem rather than take the route outlined in this bill.

Thank you for your attention. If there are any questions, I will try to answer them.