

Professor Camosy Testimony Against in Opposition to H.F. 1930
END OF LIFE OPTION ACT
Health Finance and Policy Committee– Public Hearing January 25, 2024

Dear Chairwoman Liebling and Members of the Committee:

My name is Charlie Camosy, a bioethics professor at the Creighton University School of Medicine in Omaha, Nebraska. Over my 16 years as a bioethicist, I've made a career building bridges of dialogue across polarized differences: religious and secular, life and choice, science and religion—and, significantly, red and blue. I've tried to show that once you study issues of bioethics in depth, these kinds of distinctions—so prominent in our toxic public discourse today—don't really hold at all. Indeed, I am the founding editor of a new book series we are calling "The Magenta Project" (magenta being the color between red and blue on the color wheel) which will demonstrate a brilliant, beautiful moral and legal vision which goes so far beyond red and blue.

The issue of physician-assisted suicide (PAS) is one of the most "magenta" issues in all of bioethics. Notice how it doesn't fit at all into traditional red and blue categories. You have progressives testifying before this committee sounding like libertarians, arguing on the basis of individual freedom, autonomy, and government staying away from the choices of the individual. Meanwhile, you have conservatives sounding like left-wing activists: talking about nonviolence, showing true care and concern for the most vulnerable, and doing analysis of the unintended structural evils that are created when physician-assisted suicide is legalized.

Most bizarrely of all, you have the party of business and wealth doing an implicit critique of capitalism—by insisting that one's value does not come from autonomy, productivity, or how much you "contribute to society." But rather simply because of the fundamental equality of all.

But these are only bizarre places to be if we have a red/blue mindset rather than a magenta mindset.

It no longer becomes bizarre to see right wing pro-life activists taking the same view as left-wing disability rights activists. The magenta commitment to human dignity is the same.

Both are deeply concerned about pain and suffering, of course, but both also know that PAS is not about that. In Oregon, which has had PAS since the 1990s, physical pain and suffering don't even make the top five reasons people request it. Many are sympathetic to end-of-life cases where someone is wracked with terrible pain, but data on the reasons why people ask for PAS from Oregon's public health department shows that physical pain doesn't even make the top five:

1. loss of autonomy (91.4%)
2. decreased ability to engage in enjoyable activities (86.7%)
3. loss of dignity (71.4%)
4. loss of control of bodily functions (49.5%)
5. becoming a burden on others (40%)

Physical pain and suffering doesn't make the top-5 because in the overwhelming majority of cases we can control pain through palliative care. And with all due respect to those pushing this bill, that's where I believe your focus should be—improving access to and trust in palliative care.

Indeed, based on reasons related to the terrible history of explicit and structural racial injustice in medicine, African American communities and other communities of color disproportionately distrust hospice and end of life practices in general. Considered a throwaway population for so long, they are also deeply skeptical of physician assisted suicide and euthanasia. Indeed, when Pew asked whether “there are circumstances in which a patient should be allowed to die” or “medical staff should do everything possible to save a patient’s life in all circumstances,” a striking racial gap revealed itself.ⁱⁱ For whites, only twenty percent say everything possible should be done but for Blacks, that number is fifty-two percent. For Hispanics it is fifty-nine percent. Distrust of the medical system which serves them at the end of life is so profound among Blacks that it even leads to skepticism of hospice—something that, for most white families, is close to an unquestioned good.ⁱⁱⁱ

An authentic focus on racial justice would instead direct us to the structural inequities in health care and especially palliative care. Those who have been told throughout history that they had lives that were not worth living are understandably loath to accept laws which open the door to that disastrous state affairs once again. In true magenta fashion, you will find that many of the groups and individuals opposing you on this bill will be partners in restructuring our health care system with these concerns in mind.

The recent COVID-19 pandemic has given us terrible insight into the ageist and ableist country we are—one which treats the old and disabled like throwaway populations, discarded into warehouses of death. We've also seen how terribly we treat those with dementia in particular, and the thousands and thousands of “excess deaths” of this population during the pandemic is too awful to contemplate. For example, I read about the story of a family who had their loved one with dementia die outside, frozen to death, when she slipped outside and somehow her absence went unnoticed over three different shifts.

In my recent book—titled *Losing Our Dignity*—I argue that we could very well be headed toward opening the door to PAS for people with dementia. This population will triple over the next generation and we already don't put enough cultural resources into their care. What will happen as the population grows older and fewer people have fewer and fewer children? The writing, in some sense, is on the wall.

Indeed, a study of Canadian practices found that people who requested PAS “tended to be white and relatively affluent and indicated that loss of autonomy was the primary reason for their request. Other common reasons included the wish to avoid burdening others or losing dignity and the intolerability of not being able to enjoy one’s life. Few patients cited inadequate control of pain or other symptoms.”^{iv}

In my book, I argue that if we don't fundamentally change our eldercare and dementia-care structures and systems, we will slouch toward robot-care and, yes, physician-assisted suicide and euthanasia.

Think that's too dramatic? Think it couldn't happen?

It is already happening. Consider that the Netherlands—a country which has a longstanding practice of euthanasia and assisted suicide—recently found not guilty of murder a doctor who euthanized a patient with dementia against her will.^v The patient had previously requested physician-assisted suicide, but later (after she developed dementia) said at three different times that she had changed her mind and no longer wanted to die. The doctor and the woman's husband dismissed the views of this patient, conspired to have a sedative drug put in her coffee, and stealthily killed her via lethal injection. After acquitting the doctor, the Netherlands formally moved to legalize sedating patients with dementia before killing them—in part because, the new code claims, “it is not necessary for the doctor to agree with the patient the time and manner in which euthanasia will be given.”^{vi}

If you think similar things cannot happen here, think again. The State of California is already feeling serious pressure to euthanize patients with Alzheimer's disease.^{vii} Once on the slope of legalized medical killing, it is very difficult to stop the slide. And though we aren't quite there with the Dutch when it comes to direct killing, nursing homes are already overmedicating people with dementia (often with antipsychotic drugs) simply to keep them “docile” and generally in need of less care.^{viii}

In addition, take a look at how legalizing PAS has played out in Canada, your “neighbor to the north.” In 2016, Canada enacted a bill legalizing PAS for the terminally ill. Then, in 2021, Canada expanded the availability of PAS to those living with physical disabilities as well as those with “chronic, incurable conditions.” Now, in March of 2024, Canada is poised to again expand the availability of PAS to include those suffering from mental illness.

Furthermore, there has been pressure on Oregon and other states to move to six months to twelve months. If, after all, the right is one of autonomy and not coming between a patient and his doctor, then, well, it isn't clear what the principled limitation might be.

And the smartest people defending the law in Oregon know this. Including when they faced pressure to extend their law from six months to twelve months.^{ix}

“We think it's a very bad idea,” said Steve Telfer, president of the board of the Portland-based Death with Dignity National Center. Telfer said the six-month limit was “a very appropriate time frame” for the law and that extending it to a year would send the wrong message to lawmakers considering similar laws in other states. “You just run the risk of the slippery-slope argument big time,” Telfer said.

Indeed.

Again, there is no principled reason why it should stay at six months. Or even be withheld from people who are dying at all. The fastest growing group in the Netherlands to request PAS are people over 80 in nursing homes who are simply “tired of life.” And who could blame them, given what they are told about what their lives are worth—or, more precisely, what their lives are not worth. Who is to tell them what they can and can’t do with their bodies? Who is going to get between them and their doctor?

Let me finish with perhaps the most important point of all. If you pass this bill, you totally change the very nature of what medicine is in the State of Minnesota, home of the Mayo Clinic, widely recognized as one of the finest hospitals in the world. A medical system that kills is no longer recognizable as healing and caring. It becomes what I and others have called “The Burger King” model of medicine. Burger King is, of course, where you “have it your way.” The consumer is in charge. If you want a Whopper without meat, great. Without bread? Great too. There’s nothing that is “a Whopper” that is independent of what the consumer says it is. This is capitalism at work.

We must not allow medicine to be deformed like this. Medicine is something objective. Healing and caring are objective concepts that mean something apart from whatever the market says it is. This is what it means to have a profession.

We should be focused on how best to leverage the healing and caring of medicine to make these populations feel valued. And we should absolutely not be telling them, “Hey, your life is so bad—and such a burden on others—that we can kind of understand why you’d want to kill yourself.”

i “Oregon’s Death with Dignity Act—2014,” Oregon Public Health Division, February 2015, <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>.

ii Pew Research Center, “Views on End-of-Life Medical Treatments: Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive,” Pew Forum, last updated November 21, 2013, <https://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.

iii Sarah Varney, “Toward Hospice Care,” New York Times, August 21, 2015, <https://www.nytimes.com/2015/08/25/health/a-racial-gap-in-attitudes-toward-hospice-care.html>.

iv Madeline Li et al., “Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada,” New England Journal of Medicine Vol. 376, No. 21 (May 25, 2017), <https://www.nejm.org/doi/full/10.1056/NEJMms1700606>.

v “Doctor Cleared of Murder in Euthanasia Case Says She Would Do it Again,” Dutch News. June 15, 2020. <https://www.dutchnews.nl/news/2020/06/doctor-cleared-of-murder-in-euthanasia-case-says-she-would-do-it-again/>

vi Daniel Boffey, “Dutch Euthanasia Rules Changed After Acquittal in Sedative Case,” The Guardian, November 20, 2020. <https://www.theguardian.com/world/2020/nov/20/dutch-euthanasia-rules-changed-after-acquittal-in-sedative-case>

vii Nicholas Goldberg, "Column: California's Aid-in-Dying Law is Working. Let's Expand it to Alzheimer's Patients." Los Angeles Times. July, 15, 2020.

viii Human Rights Watch, "Using Medicine In a Wrong Way," February 5, 2018.

https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia?fbclid=IwAR3UVMBBDBKT81uCbGyp8CbF9Ed4iD8DXFV2uYX8x52_KeRUtmqDEyG-05Q#

ix Vijosa Isai, "Death by Doctor May Soon Be Available for the Mentally Ill in Canada," New York Times, December 27, 2023

<https://www.nytimes.com/2023/12/27/world/canada/medical-assisted-death-mental-illness.html>

x https://www.oregonlive.com/mapes/2015/03/bill_to_expand_oregons_death_w.html