October 1, 2021

The Commonwealth of Massachusetts Joint Committee on Public Health State House Boston, MA 02133-1054

## Re: An act relative to end-of-life options - H.2381/S.1384

When I first heard about this type of legislation, I was all for it. It seemed like an option that I would want for myself or loved ones. But as I studied this issue, the more I learned, the more I realized that there were just too many inequities and risks to vulnerable people. I developed second thoughts. I urge all of you to keep an open mind and really look, look hard at the facts of assisted suicide.

I am sure that you want MA policies to work in the best interest of everyone. Before I became disabled, I was a member of the group that advocates for this — the white, well-educated, and well-off. Now that I am a member of the marginalized, I see things very differently. I recognize the need for the common good. When two-thirds of communities of color are opposed, as well as those of the working class and low-income, and major disability rights organizations, then attention must be paid to this opposition. I am here to say that the interests of a small number of people who want this option should not outweigh the many people whose lives will be impacted, people like me, people with disabilities. I am part of a community that often doesn't get considered. We get left out, not included, not even thought of. Except to be used as an example of what it is to live without dignity — to be in a wheelchair, incontinent, dependent on others for care. The presumption that one could not possibly have quality of life. That is a fate worse even than death. And that is false.

These are judgments made by people that result in existential fears about what will happen when they age, become sick, and disabled. This devaluation of life, based on an ageist and ableist view of some perfect checklist of functional abilities, is what lies at the heart of this type of legislation. This is what makes people feel like a burden, that we ought to check out, rather than live out our lives.

I co-led a series on End-of-Life issues at my church and was struck by how many of these good-hearted people, who care about social justice, were filled with worry that they would be a "burden" on their loved ones if they couldn't completely take care of themselves, as they aged or became sick. Or in other words, became disabled. They didn't want to "take away" money from their family, or ask for help in taking care of themselves. They didn't want to be "humiliated" and couldn't imagine how life would be "worth living". I hope that my presence, as a wheelchair user who does require care, and has a good quality of life, helped remind them that we are all interdependent at different times and in different ways. And this does not lessen the inherent worth and dignity of our lives.

Instead of assisting people in dying, let's provide medical assistance in living. Let's meet the real needs of people who are dying, aging, and are disabled. Let's offer real choices in treatment and palliative care. Let's provide home and community based care, not an unsafe, miserable life in a nursing home that people fear (and rightly so, as 40% of the Covid deaths occured before the vaccine). Let's correct health inequities and level the playing field in healthcare, not discriminate against people, deny treatment, and then offer assisted suicide. I recall a time when I was severely ill with septic shock and I was questioned whether I would want life support. Why wouldn't I want to live? Did the wheelchair alongside me in the Emergency Room influence how people viewed me and my quality of life?

And let's stop pretending that elders and the disabled are not at risk of abuse. Or that there are adequate safeguards. Or that this is always a peaceful death. Let's stop the euphemisms. This is suicide. This is not dignity.

Dignity means that people are worthy of respect. Everyone that needs care, at the end of life or throughout their life, deserves that care. Not demoralized for needing care. Or a social pressure to die. Imagine how wearing it is to constantly have to justify one's existence, to prove that your life *is* worth living. Legalizing assisted suicide sends the wrong message to people with disabilities —that we are better off dead. People with disabilities, like those confronting terminal illnesses, deserve real compassion, not a hastened death.

Codifying this into law is sanctioning assisted suicide, and a way of promoting it. This is a socially dangerous policy, no matter how well-intentioned. Safeguards are simply not practical. How will they be implemented? Paid for? There will be no realistic way that this will be monitored, just as this does not happen in other states.

The Covid-19 pandemic has caused tremendous loss and tragedy. The majority of those killed were people with disabilities, not just by the virus but by biased responses to people with disabilities, such as forced DNR's and denial of treatment. The initial Crisis Standards of Care for our state would have placed people with disabilities at the back of the line for treatment. Ableism can and has led to death for people with disabilities. And this bill will threaten their lives, no matter how well intentioned.

Please, this committee must not now focus on making death more accessible. This is not the time to move this socially dangerous policy forward. Massachusetts will be less safe for individuals with disabilities if assisted suicide is legalized, and that is not the compassionate and inclusive state we aspire to be. I urge this committee to vote no on assisted suicide.

Thank you,

Ellen Leigh Arlington, MA Second Thoughts Massachusetts