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## **TESTIMONY IN OPPOSITION TO HB403 - End-of-Life Option Act**

Good afternoon Committee Members, HGO Chair Joseline A. Pena-Melnyk and Vice-Chair Bonnie Cullison, and Judiciary Chairman Delegate Luke Clippinger and Vice-Chair Sandy Bartlett.

My name is Susan Marble Barranca - if I look familiar to you, it's because I worked for some years here at the Maryland General Assembly. I left to care for my husband, who died of Lewy Body Disease this past September 16th. Lewy Body Disease is very closely related to Parkinson's Disease, which of course was what Richard Israel and Pip Moyer (the original individuals for whom this bill was named) died of.

My background is in the law with a J.D., and philosophy - specifically ethics - with a PhD. I taught at University of Maryland, Global Campus, as well as teaching Medical Ethics at Notre Dame of Maryland.

Like many of you, I have sat through almost every hearing on the various iterations of this bill since it was introduced in 2015. I've heard all the arguments - for and against - as well as the various amendments offered.

Even though it feels negligent not to make the usual arguments, I promise to clench my teeth and *not* do so. You will hear enough of them, I'm sure, to remind you of how they go.

I have just 2 minutes - maybe just 1 depending on how many people signed up - so I can't speak at length on anything. This, then, is my full testimony in writing. The two new arguments I would like to bring up in opposition to this bill are:

1. The impact of Physician Assisted Suicide on people of color, and
2. The effect of redefined words on informed consent.

It is apparently well-known that people of color both oppose physician-assisted suicide more than do whites, as well as availing themselves of it less than do whites. What is *not* known, is why. This gap has remained steady over the years. The organization Compassion and Choices, which supports this bill, has an article on its website acknowledging this gap, which they address as a failure to access what they call “end of life services.” They acknowledge the “importance of understanding how end-of-life care decisions are informed by previous lived experiences with racism and how utilization, treatment preferences and outcomes can differ across racial and ethnic groups” but their stated “mission is to ensure that everyone is empowered to chart their own end-of-life journey. This will only be made possible by recognizing, confronting, and addressing the systemic barriers that create the inequalities in end-of-life care utilization that we see reflected in this data.” (Compassion and Choices, available online: <https://www.compassionandchoices.org/news/racial-inequalities-persist-in-end-of-life-care-for-dementia-patients>)

An earlier article by Georgetown University Professors Patricia King and Leslie Wolf also documented the racial disparity in both approval and utilization of physician assisted suicide, and in light of the racially charged history of the relationship of blacks and the medical profession (which I know has been a topic of concern already in this Legislative body) argues that some significant steps to better understand other ongoing racial disparities and disparate outcomes in medical treatment, prognosis, and results must take place before “PAS becomes an option in our health care system”:

“Central to our argument is the view that this society does not have a sufficient understanding of how and why competent individuals are rendered vulnerable near the end of life. We are especially concerned that inadequate attention has been given to the sociohistorical and cultural contexts in which competent individuals function.”

(King, Patricia A. and Wolf, Leslie E., "Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African- American Experience" (1998). Minnesota Law Review. 2053. Available online: <https://scholarship.law.umn.edu/mlr/2053>)

This is an area that needs further study. Unfortunately, with the passage of especially California's Physician Assisted Suicide bill in 2016, there will be an ever-greater opportunity to see how this plays out in communities of color, interacting with a medical profession that is still suspected of not treating patients of color fairly or equitably. Surely the better course, however, is to first shore up equal treatment before adding yet another variable - an end of life "option" that will likely further increase distrust of the medical profession in that community. Distrust, as we know, operates to undermine compliance with treatment options as well as to discourage seeking medical assistance until it is too late - which is exactly what was found in the study cited by Compassion and Choices. (See Pei-Jung Lin, PhD; Yingying Zhu, PhD; Natalia Olchanski, PhD; et al, "Racial and Ethnic Differences in Hospice Use and Hospitalizations at End-of-Life Among Medicare Beneficiaries With Dementia", Available online: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2793176>) We should not pass this bill before knowing how it will impact communities of color.

Second, I want to address the effect of redefining words on informed consent.

I take as my starting point the essay "Live Not By Lies", by Aleksander Solzhenitsyn, which was published on February 12, 1974, the day he was arrested in Russia. He was exiled to the West the next day, where he was hailed as a hero. In the essay, Solzhenitsyn criticizes the Soviet Union, but also his fellow citizens. They may feel impotent to act, he said, but they have recourse to the truth. At the very least, they must refuse to participate in the lie, he tells them:

“Never knowingly support lies! Having understood where the lies begin . . . step back from that gangrenous edge! Let us not glue back the flaking scales of the Ideology, not gather back its crumbling bones, nor patch together its decomposing garb, and we will be amazed how swiftly and helplessly the lies will fall away, and that which is destined to be naked will be exposed as such to the world.”

(Available online: <https://journals.sagepub.com/doi/pdf/10.1080/03064220408537357>)

I notice that the procedure in SB443 - The End of Life Option Act - is called “aid in dying” - rather than physician assisted suicide. In fact, the bill expressly notes that this is NOT suicide. Section 5-6A-11 (D)(2) I suspect the beginning of a lie.

Aid in dying is defined by the bill as the “medical practice of a physician prescribing medication to a qualified individual that the qualified individual may self-administer to bring about the qualified individual’s death.” Section 5-6A-01 (B)

That sounds an awful lot like suicide. Administering a drug to bring about your death would certainly qualify as “intentionally causing one’s own death”, which is the definition of suicide.

Likewise, the word “medication” is used to describe the drugs that will bring about this death. Medication is defined by the FDA as “a substance intended for use in the diagnosis, cure, mitigation, treatment, or prevention of disease.” (FDA Glossary of Terms, available online: <https://www.fda.gov/drugs/drug-approvals-and-databases/drugsfda-glossary-terms#:~:text=A substance intended for use,any function of the body.>) Medication, then, is intended to *help* the patient. This bill uses the word to describe a substance that does *not* “help” the patient in any traditionally understood manner. It kills.

The word “drug” - by contrast - can have either a positive or a negative effect. “All medicines are drugs; not all drugs are medicines.” (“The Difference Between a Drug and a Medicine?” available online: <https://pharmafactz.com/what-is-the-difference-between-a-drug-and-a-medicine/>)

Then there is the word “poison”, and we might note that both medicines and drugs can also be poisons. As the founder of toxicology in the 16th century said: “All things are poisons and nothing is without poison, only the dosage makes a thing not poison.” (Paracelsus, *Id.*) The Black’s Law Dictionary definition of poison is “A substance having an inherent deleterious property which renders it, when taken into the system, capable of destroying life.” Again, it sounds like what is being “prescribed” by the process contemplated in this bill is a poison - certainly by the dosage, as well as the intended effect.

While we’re at it, we should also take a look at “prescribe” - which, when associated with a doctor, also carries with it a positive connotation. Medical prescriptions, then, are “a written direction for a therapeutic or corrective agent, specifically: one for the preparation and use of a medicine.” (Merriam Webster Dictionary, available online: <https://www.merriam-webster.com/dictionary/prescriptions>). It would seem to be an oxymoron to speak of “prescribing” a poison, intended to end the life of the patient. Another oxymoron is “lethal medication.” A final oxymoron is to consider death as a “treatment option” by physicians.

The current form to be used as the “REQUEST FOR MEDICATION FOR AID IN DYING” reads as follows:

I AM SUFFERING FROM \_\_\_\_\_, WHICH MY ATTENDING PHYSICIAN HAS DETERMINED WILL, MORE LIKELY THAN NOT, RESULT IN DEATH WITHIN 6 MONTHS. I HAVE BEEN FULLY INFORMED OF MY DIAGNOSIS, MY PROGNOSIS, THE NATURE OF MEDICATION TO BE PRESCRIBED TO AID ME IN DYING, THE POTENTIAL ASSOCIATED RISKS, THE EXPECTED RESULT, THE

FEASIBLE ALTERNATIVES, AND THE ADDITIONAL HEALTH CARE TREATMENT OPTIONS INCLUDING PALLIATIVE CARE AND HOSPICE.

I HAVE ORALLY REQUESTED THAT MY ATTENDING PHYSICIAN PRESCRIBE MEDICATION THAT I MAY SELF-ADMINISTER FOR AID IN DYING, AND I NOW CONFIRM THIS REQUEST. I AUTHORIZE MY ATTENDING PHYSICIAN TO CONTACT A PHARMACIST TO FILL THE PRESCRIPTION FOR THE MEDICATION ON MY REQUEST.

I UNDERSTAND THE FULL IMPORT OF THIS REQUEST AND I EXPECT TO DIE IF AND WHEN I TAKE THE MEDICATION TO BE PRESCRIBED. I FURTHER UNDERSTAND THAT, ALTHOUGH MOST DEATHS OCCUR WITHIN 3 HOURS, MY DEATH MAY TAKE LONGER, AND MY ATTENDING PHYSICIAN HAS COUNSELED ME ABOUT THIS POSSIBILITY.

Imagine if the Request for Medication for Aid in Dying (which incorporates the informed consent provisions contained in Section 5-6A-04 (C) ) took out the euphemistic language and instead used the words commonly associated with the actual meaning intended, It would read something like this:

**“REQUEST FOR POISON TO END MY LIFE”**

I AM SUFFERING FROM \_\_\_\_\_, WHICH MY ATTENDING PHYSICIAN HAS DETERMINED WILL, MORE LIKELY THAN NOT, RESULT IN DEATH WITHIN 6 MONTHS. I HAVE BEEN FULLY INFORMED OF MY DIAGNOSIS, MY PROGNOSIS, THE NATURE OF **THE POISON TO BE DISPENSED TO ME TO ENABLE ME TO END MY LIFE [WHICH IS TO COMMIT SUICIDE]**, THE POTENTIAL ASSOCIATED RISKS, THE EXPECTED RESULT - **NAMELY IMMEDIATE DEATH**, THE FEASIBLE ALTERNATIVES, AND THE ADDITIONAL **OTHER [OR ALTERNATIVE]** HEALTH CARE TREATMENT OPTIONS INCLUDING PALLIATIVE CARE AND HOSPICE.

I HAVE ORALLY REQUESTED THAT MY ATTENDING PHYSICIAN **DISPENSE POISON** THAT I MAY SELF-ADMINISTER **TO END MY LIFE**, AND I NOW CONFIRM THIS REQUEST. I AUTHORIZE MY ATTENDING PHYSICIAN TO CONTACT A PHARMACIST TO FILL THE **ORDER** FOR THE **POISON** ON MY REQUEST.

I UNDERSTAND THE FULL IMPORT OF THIS REQUEST AND I EXPECT TO DIE IF AND WHEN I TAKE THE **POISON** TO BE **ORDERED FOR ME**. I FURTHER UNDERSTAND THAT, ALTHOUGH MOST DEATHS OCCUR WITHIN 3 HOURS, MY DEATH MAY TAKE LONGER, AND MY ATTENDING PHYSICIAN HAS COUNSELED ME ABOUT THIS POSSIBILITY.

Can we have true “informed consent” when we are playing word games that mask the true import of what is being consented to?

Finally - some practical questions relating to what this bill proposes, and how it characterizes those things. If this is truly nothing more than medical “aid in dying” - why do we require the person ‘dying’ to administer the ‘medication’ himself? Surely doctors and other medical professionals provide medical aid, they don’t expect the patient to administer their own medical treatment.

If it’s not a killing, why could we not have the doctor administer the drug directly, in a form that was much more comfortable and easy? In past years, we’ve heard at length about the difficulties ingesting the poison and the unpleasantness of attempting to swallow large quantities of the bitter drug, not to mention the allegation that some terminal medical conditions would prevent an otherwise “qualified individual” from self-administering the poison.

Why make the dying person go through multiple requests - oral and written - supposedly making him “understand” what he is actually doing (which is actually to kill

himself now, rather than to wait to die) all while using language designed to mask what is really going on?

One obvious problem is that Maryland Criminal Code Section 2-201 (a) (3) explicitly provides that a “A murder is in the first degree if it is: . . . committed by poison.” Redefining the words, however, doesn’t do away with the underlying facts of what this bill proposes. Moreover, the failure to provide adequate control over the dispensed poison sets us up for future nonconsensual poisonings.

Alexander Solzhenitsyn had it right: “Never knowingly support a lie. Having understood where the lies begin . . . step back from that gangrenous edge.” (“Live Not By Lies, available online: <https://journals.sagepub.com/doi/pdf/10.1080/03064220408537357>) Respectfully, the lies begin in these euphemistic re-definitions.

How would this bill fare if we used only words of truth in it? This would require us to confront the fact that by common law, we have traditionally condemned both suicide and physician-assisted suicide. Pretending that this is not a killing, but merely “aid in dying” or an “end of life option” does not adequately present what is actually being proposed. What is being proposed is to have a doctor authorize the dispensing of a lethal dose of poison to a “qualified person” (believed to be suffering from a terminal disease) so that he or she may kill themselves rather than die of the disease.

This is a new argument. And a challenge. If what is proposed is acceptable - use the words that truthfully express what is now sought to be made legal - something that has been illegal for all of human history. There is a burden of proof that requires the proponents of this bill to show why - now - our laws must suddenly change in spite of the long history outlawing it and the many objections that this honorable Committee has heard repeatedly each year - objections that are not answered. To those objections, I would add the issue raised by the racial disparities both in objection to



this physician-assisted suicide as well as utilization of it, and the efficacy of an “informed consent” that is couched in misleading and euphemistic terms.

In conclusion, if we want to be truly “compassionate” - I pray that our compassion will be directed towards caring for the patient, not mangling our language to enable him to kill himself - encouraging him - or her - to think he is doing no more than ‘aiding himself in dying’. Additionally, if we truly care about racial disparities and potential vulnerabilities from past abuses, we will be cautious moving forward without further inquiry before enabling a practice that has such potential to increase distrust of the medical profession by people of color and exacerbate disparities along racial lines.

On a personal note, as I mentioned, I lost my husband, Torre, just 5 months ago now. If Physician-assisted suicide had been available, I suspect he would have been tempted to take that route - not because he was in unmanageable pain or wanted to die sooner, but because he so very much didn’t want to be a burden to me. That would have broken my heart even more - if that’s possible.

I respectfully request an Unfavorable Report on HB403.