

Written Testimony in OPPOSITION of SB443

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I write to you today as a disability rights activist with strong ties to the wider disability community throughout Maryland, as the daughter of someone who has lived over 24 years with a “terminal illness,” and as the dear friend of someone who died from lymphoma in 2022. These views do not represent those of any current or former employer. I write to you in opposition of the End-of-Life Option Act for several reasons which I will outline below.

1. On page 6 line 5 the bill states that “TERMINAL ILLNESS” MEANS A MEDICAL CONDITION THAT, WITHIN REASONABLE MEDICAL JUDGMENT, INVOLVES A PROGNOSIS FOR AN INDIVIDUAL THAT LIKELY WILL RESULT IN THE INDIVIDUAL’S DEATH WITHIN 6 MONTHS.

My mom was diagnosed with Chronic Myelogenous Leukemia (CML) in 2000 at the age of 42. At the time, the five year survival rate of someone with CML was 20%. Years later, my mom’s oncologist told her that he had never seen someone as sick as she was who survived. Today, my mom is still alive, and is currently in California celebrating her 66th birthday with her 10 year old grandson. This is something that 24 years ago, no one believed would be possible. But with advances in medical science, although most patients with CML will never go into remission, the 10 year survival rate is 85%¹, and most patients will die from something other than Leukemia. When the medication my mom went on first went on the market, no one had any idea how revolutionary it would be. Now, it is more and more common to see patients (including Elijah Cummings, for whom this bill is named) live decades with a cancer diagnosis.

I can also list several other people I’ve known who were believed to be terminal, but exceeded their life expectancy. These include 1) my grandma’s best friend who was diagnosed with pancreatic cancer and given 6 months to live, and who lived for 2 years, 2) my former mentor who was diagnosed with Juvenile Rheumatoid Arthritis in the 1950s, whose parents were told not to expect her to live past the age of 5, but who died at the age of 60 in 2014, and 3) my very dear friend Sheryl Grossman, who's 2017 testimony opposing this bill I have included at the end of my own. I’m writing this on behalf of Sheryl, who died in 2022, 5 years, and at least 4 cancer diagnoses after she gave that testimony. Sheryl deserved to have all the years she could, without having doctors try to coerce her into making decisions that she didn’t want.

Determining how long someone has to live is not something that any human or computer algorithm is capable of accurately predicting.

1 <https://www.lls.org/research/chronic-myeloid-leukemia-cml> retrieved February 6, 2024

2. On page 6 line 24 the bill states that AT LEAST ONE OF THE ORAL REQUESTS MADE UNDER SUBSECTION (A) 25 OF THIS SECTION SHALL BE MADE WHILE THE INDIVIDUAL IS ALONE WITH THE ATTENDING PHYSICIAN. As well, page 12 line 29 states that THE ATTENDING PHYSICIAN SHALL ... CONFIRM THAT THE QUALIFIED INDIVIDUAL'S REQUEST DOES NOT ARISE FROM COERCION OR UNDUE INFLUENCE BY ANOTHER INDIVIDUAL BY DISCUSSING WITH THE QUALIFIED INDIVIDUAL, OUTSIDE THE PRESENCE OF ANY OTHER INDIVIDUAL EXCEPT FOR AN INTERPRETER, WHETHER THE QUALIFIED INDIVIDUAL IS FEELING COERCED OR UNDULY INFLUENCED BY ANOTHER INDIVIDUAL

While I can understand that the intent of these sections are to ensure that the patient is not being coerced by anyone into making this decision, they do no such thing. There is no possible way to ensure that patients aren't being coerced by people in their life prior to coming to the appointment, or by the doctor during the appointment. An example of this can be seen in Sheryl Grossman's previous testimony, which I've attached.

3. Page 10 section C states that AN ATTENDING PHYSICIAN SHALL ENSURE THAT AN INDIVIDUAL MAKES AN INFORMED DECISION BY INFORMING THE INDIVIDUAL OF: ... (5) ANY FEASIBLE ALTERNATIVES AND HEALTH CARE TREATMENT OPTIONS, INCLUDING PALLIATIVE CARE AND HOSPICE.

As someone who has been disabled close to 40 years with a combination of disabilities that require me to have assistance with activities of daily living, such as laundry and cooking, which is similar to the type of assistance that someone with a terminal diagnosis might need, I can assure you that not a single practitioner I have seen throughout my life (from my PCP, to mental health practitioners, to ones highly specialized in my diagnoses) has had the faintest clue as to what was and is available to me. This resulted in a delay of 16 years from when I should have been receiving waiver services to when I actually started receiving them. Even now, when I go to appointments and talk about the services I'm receiving, my practitioners look at me either blankly or in shock. It's clear that their discussion with me is the first time they had anyone talk to them about the home and community based services (HCBS) that are available to anyone in Maryland who needs assistance with activities of daily living, regardless of type or age of onset of diagnosis.

If attending physicians aren't aware that HCBS exist, how can they counsel their patients on how to access them? The application process is onerous. It took me 3 years to get through the process, and that was after spending 8 years mistakenly trusting multiple professionals who wrongly told me that I wasn't disabled enough in the right way, wasn't the right age, to qualify. How is the state going to ensure that attending physicians are accurately educated on the eligibility criteria, application processes, and breadth of options for support available for sometimes little, or often no cost to patients? Are we going to institute mandatory training from MDH about the programs that they oversee?

4. Page 11 Line 22 states that IF, IN THE MEDICAL OPINION OF THE ATTENDING PHYSICIAN OR THE CONSULTING PHYSICIAN, AN INDIVIDUAL MAY BE

SUFFERING FROM A CONDITION THAT IS CAUSING IMPAIRED JUDGMENT OR OTHERWISE DOES NOT HAVE THE CAPACITY TO MAKE MEDICAL DECISIONS, THE ATTENDING PHYSICIAN OR THE CONSULTING PHYSICIAN SHALL REFER THE INDIVIDUAL TO A LICENSED MENTAL HEALTH PROFESSIONAL FOR A MENTAL HEALTH PROFESSIONAL ASSESSMENT.

As written, the bill does not require all individuals requesting aid in dying to undergo a mental health evaluation. This is left up to the subjective opinion of attending physicians, who have not been trained on how to recognize the symptoms of mental illness².

Additionally, it is well known within the chronic illness, physical, and developmental disability communities that there is a lot of prejudice against individuals living with disabilities throughout society. Often we're believed to be less deserving of respect, equal treatment, and equality before the law.³ This leads physicians to be less likely to refer someone with a presumed life limiting diagnosis for an assessment, since they're less likely to view their patient's depression as concerning.

Individuals with disabilities experience the effects of this prejudice (called ableism) daily, and one of the places that we experience often the most damaging ableism, is a physician's office.⁴ Even to this day, clinicians still aren't educated about the impact of long-term disabilities on individuals while in graduate school.^{2,5} When individuals are continuously on the receiving end of ableism, they begin to believe that these negative assumptions about our lives are true. This is called "internalized ableism,"³ and it can take years of difficult work to unlearn these assumptions and realize that they are NOT true. When doctors tell us and our families at diagnosis that we will be a burden⁴ it may lead individuals or their families to believe that they're better off dead than disabled.⁶

At the same time, the lack of training that mental health professionals receive on the effects of living with disabilities^{2,5}, combined with this stigma, leaves a lack of mental health parity throughout the state. It can often take months or years for individuals with co-occurring diagnoses to obtain appropriate inpatient or outpatient mental health care (in my personal experience, it just took me two years of sitting on a waitlist to be able to see the one adult neuropsychiatrist with experience with my diagnosis in the entire state), whereas individuals with a singular diagnosis of a serious mental illness can usually obtain services within a few weeks for outpatient services, or possibly hours through an ER or crisis walk in clinic.

I urge you to vote NO on SB 443.

² Werges, D. (2007). *The Other Dual Diagnosis: Intellectual Disability & Mental Illness*. Retrieved February 6, 2024, from <https://web.archive.org/web/20190930204727/http://thenadd.org/modal/bulletins/v10n5a2~.htm>

³ Johnson, M. (2006). *Disability awareness--do it right!* Louisville, KY: Advocado Press.

⁴ Seidman, E. (2016, July 12). How wrong were the doctors about your child? Retrieved February 6, 2024, from <https://www.lovethatmax.com/2016/07/how-wrong-were-doctors-about-your-child.html>

⁵ Quintero, M., PhD, & Flick, S., MD. (2010). Co-Occurring Mental Illness and Developmental Disabilities. *Social Work Today*, 10(5), 6. Retrieved February 6, 2024, from <https://www.socialworktoday.com/archive/092310p6.shtml>

⁶ Autistic Self Advocacy Network. (n.d.). 2024 Anti-Filicide Toolkit. Retrieved February 6, 2024, from <https://autisticadvocacy.org/projects/community/mourning/anti-filicide/>

**Oral Testimony from Sheryl Grossman
originally delivered February 2017**

retrieved from

<https://notdeadyet.org/2017/02/disability-advocate-sheryl-grossman-gives-moving-testimony-against-maryland-assisted-suicide-bill.html>

My name is Sheryl Grossman. I have a very rare genetic condition called Bloom's Syndrome, so rare in fact that I am the 72nd case ever recorded worldwide, historywide.

Back in the olden days when I was diagnosed doctors didn't know much and they advised my parents that I wouldn't live past 2, maybe 4 (it got longer every yr—I'm 41 now and they just throw up their hands and shake their heads). My parents were told I wouldn't walk, talk, or amount to much. They were told they should just put me away as they were young and could have other children. Clearly, doctors don't know everything.

This bill before you depends on doctors stating that someone has 6 months, or less to live, a prognosis that pretty much everyone agrees is impossibly hard to accurately predict. As a disabled person, this bill scares me even more because I know the societal barriers (stigma and discrimination) that we face. Our lives are often seen as being worse quality of life and less worthy than others. doctor's whole profession sees us as broken and something to be fixed, but often we can't be (and don't want to) be fixed.

Why does this bill scare me given this statement, let me give you a personal example. Bloom's Syndrome results in my being prone to multiple cancers. During my 7th cancer, a stage IV lymphoma that had metastasized to form a solid tumor in my liver, the head of Johns Hopkins Cancer Psychiatric Department entered my room during treatment, when I was barely conscious, barely able to speak. She said, "you know, you don't have to do this anymore. You have been through so much. You can stop at any time you know, it is ok. We can simply turn off the machines, or we can increase your pain meds—you're 37 lbs, it won't take long". I gave the last of my conscious energy to screaming NO and trying to get her out of my room. On her way out she said "I don't understand why you want to live like this, in and out of hospitals for years."

The answer is because I love my life. Sure, there have been plenty of times I have been bent over an emesis bowl when I didn't feel that way, but this is my life and I am worthy of it! It has been 3 ½ years and 2 cancers and 1 chemotherapy regimen since then and here I am before you, a happy 41 year old.

Ladies and gentlemen, I fear that if this law were on the books then, I wouldn't still be here today. It is far too easy to coerce someone into thinking themselves a burden to medical care staff, or family members. It is far too easy to make us think that our care is costing too much and draining those around us. This bill does not provide for a mental health evaluation before the prescription of lethal medications which takes away the only protection against this thinking.

When others in society say they want to harm themselves, crisis intervention services are provided. As a former certified crisis worker, I can tell you that many call back months and even years later to thank us for the intervention.

Why should people with disabilities and medical conditions with less than 6 months to live be treated any differently? I fear that even with a psychiatric evaluation, if one gets a psychiatrist like I did, who doesn't believe in the quality of our lives, people will still be encouraged to choose an early exit. We should be providing long term care services to help these individuals and their support networks, not methods to die.

Please, vote no.