Oppose HB1328 End-of-Life Option Act
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In 2013 I had the opportunity to attend a full series of workshops on dementia and caregiving sponsored by the Anne Arundel County Department of Aging. While these sessions contained a wealth of extremely helpful information, there are two points that were discussed during the course of those classes that are particularly relevant for these hearings: 1) That people living with dementia can often appear to those not part of their inner circle to be very coherent, quite charming, and perfectly capable of making their own decisions regarding health care and their living situations; and 2) That when an elderly parent is no longer capable of living alone, in a large percentage of cases, even when there are multiple children, the caregiving often falls either by choice or default to one adult child.

My own experience confirms these assertions. My parents lived with my family for 4 ½ years, during which time I was their primary caregiver. Even though I have five siblings, I was the only one who actively participated in the caregiving of my parents. My mother, having had a series of mini-strokes, suffered from vascular dementia as well as a brain tumor. After the death of my dad, I managed all my mother's medical care, attending every doctor's appointment, every surgery, every emergency room visit. Time and time again, I watched my mom transform into a different person at her doctors' appointments. Indeed, the wit and sarcastic humor she displayed for her primary care physician convinced him that even though she had dementia, she could manage quite well. Somehow, in his ten-minute visits with her a few times a year, he was able to determine that she was certainly capable of making her own healthcare decisions. What he didn't see in those visits is what I routinely saw because I lived with my mom 24/7—that she had to ask me what a toothbrush was for, that she couldn't remember that she had three sons, and that she had just had a wonderful visit with her mother who, incidentally, had been dead for 25 years. It is no surprise, then, that I have no confidence when this bill assures us that a person requesting 'aid in dying' must possess the 'capacity to make medical decisions' and not be 'suffering from impaired judgment.' What if that person, like my mother, quite convincingly appears mentally fit to the very professional making that determination?

Additionally, although proponents of this bill insist that there is no risk of coercion regarding vulnerable populations, I would again offer my own personal experience. I can tell you that at every doctor's appointment whenever any decision had to be made regarding my mom's care, she always turned to me and said, "Whatever you think, Annie. You decide." In other words, *my* decisions *became* my mother's decisions. She was perfectly content, and insistent even, that all decision-making be left to me because she trusted me implicitly. And why wouldn't she? I was, after all, of all her children, the one who had faithfully cared for her for years. Never once was any decision I made ever questioned by my brothers and sisters because I had willingly assumed full responsibility for our mother's care. The potential danger here should be obvious. Let us not be so naïve to believe that undue influence over another's actions must be overt and forceful. It can be as subtle and unintended as the exhausted face of a caregiver. Anyone who has ever cared long-term for an ill family member knows that their loved one often feels acutely guilty for "being a burden." I can vividly recall my own mother routinely apologizing to me for needing my care and assistance. With a rapidly increasing aging population, my caregiving experience is bound to become more and more common. What a grave injustice to place any vulnerable person in the position of having to consider that it might just be better for all concerned if they simply chose to die. Legalizing physician-assisted suicide has the potential to do just that.

Furthermore, what if the coercion to make a drastic end-of-life decision comes from the physician himself? Eleven years ago, I sat in a doctor's office with my mother to complete the Maryland MOLST form. The MOLST (Medical Orders for Life Sustaining Treatment) form details one's preferences regarding life-sustaining treatment, and this form was required to be filled out before my mother was admitted to an assisted living facility. As my mother's physician went through the list of questions with us that day, I noticed he was filling in her preferences for treatment **before** we even responded to his questions. When he got to one question in particular regarding the time frame that my mother would want to be on an artificial ventilator, I stopped him and told him that I was not at all comfortable with the response he had written. I will never forget his reaction. He pointed his pen at my face and said to me, "I didn't ask you. You're not my patient; your mother is." However, this doctor knew my mother couldn't tell him her address or even what year it was, and he was aware that I had medical power of attorney. When I pressed him on the issue, telling him I thought the number of days he had picked was arbitrary, he sarcastically asked me, "Well, what number would make you happy?" He then proceeded to angrily scribble out his original response, initial it, and then select a different response. Though my mother died in November 2015, I still have a copy of that MOLST form in my possession because it serves as a very powerful lesson for us all. Had I not been there that day acting as my mother's advocate, it would have been her doctor's, not her preferences, that were represented on that form. I realize that this was just one instance with one doctor.

But if a doctor can so clearly violate the protocol and guidelines that establish our wishes for life-sustaining treatment, how can we have confidence that he will follow the requirements that allegedly establish our preferences regarding death?

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