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House Bill 0643: End of Life Option Act (Richard E. Israel and Roger "Pip" Moyer Act)

Health and Government Operations Committee

Judiciary Committee

General Assembly Maryland

Chair Delegate Shane E. Pendergrass, Vice Chair Delegate Joseline Pena-Melnyk, and members of the House Health and Government Operation Committee and Chair Delegate Luke Clippinger, Vice Chair Delegate Vanessa Atterbeary, and members of the House Judiciary Committee:

My name is Ann Jackson. I live in Portland, Oregon. I am considered an authority about end-of-life issues and options, including Oregon's Death with Dignity Act (ODDA). I was the executive director and CEO of the Oregon Hospice Association (OHA) for 20 years between 1988 and 2008. I was OHA's voice during the public debates over the voter initiative, the legislative repeal effort, and the ODDA's implementation. In Oregon's "laboratory of the states", I was a co-investigator of published research about the experience and attitudes of hospice workers with aid-in-dying.

Since my retirement 12 years ago, I have made my expertise available as a consultant about end of life policymaking. I have testified before Maryland's legislature four or five times, most notably in 2016, when I was one of only three witnesses. I was able, then, to discuss at length about what really happens in Oregon.

For 32 years, now, I have offered fact without innuendo, and I have refuted deliberate lies meant to deny Americans, including Marylanders, access to medical aid in dying.

I am writing in support of Maryland's End of Life Options Act. I encourage you to pass the Act—and to refrain from adding unnecessary or punitive "safeguards". The bar is high enough. A safeguard in a guise of protection is intimidation.

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The Oregon Health Authority has indicated it will release the 2019 report of the Oregon Death with Dignity Act next week on March 6. I do not know how many people used the ODDA in 2019, but I knew one. I was with him at the end. On December 3, 2019, Bill, my partner of ten years, drank a lethal dose of prescribed medication and stopped his dying. In past years I have compared data from year to year and drawn various conclusions. The data is rich, and we have much to learn. This year, I will tell you what I saw: His final hours were very peaceful. And it was time.

Our story began in 2009, after I spent a week on Hupper Island in Maine, with an old friend and his partner. Ole and Carol had met online, something I thought I would never consider. However, I was very impressed with their match. I had been single since 1996, when my fiancé died just three months after I had moved to California to marry him.

So, 13 years after John's death, I joined eHarmony.com for just one month. I was matched with Bill. We had so much in common, it was eerie. In the early 1980s, we both bought Mazdas. He still had his. I only had photos. He took up vintage racing after he retired. I did my racing in my twenties. I practiced horse whispering on a ranch in Montana. I sent Bill a photo. His horse had the same blaze. When we arranged to meet in person, everything clicked. I was elated. I think he was, too.

However, when Bill was in China several months later, he experienced significant pain. When he returned, he stopped at the hospital for X-rays on his way to meet me. We had planned to celebrate our birthdays. The images revealed advanced pelvic bone metastases. The prognosis was not good. Bill advised me to get in touch with another person I had met on www.eHarmony.com. I was not interested in anyone else. But Bill did not rush off to get a prescription to end his life, just because he had been diagnosed with a terminal illness. He started treatment—and responded very well. In the meantime, the fellow Bill had advised me to contact died.

For ten years Bill (and I) lived. We traveled around the world. He raced his vintage Mazda RX7 in the Rose Cup. He skied in Canada and The Alps. We rode horses, ponies or bikes in Iceland, Central Oregon and Puerto Rico. He flew to the top of Mount Cook in New Zealand and went scuba diving in Australia, the Red Sea, the South Pacific, the Caribbean, and the Mediterranean. I did a bit of snorkeling. We played bridge. We had family reunions with our six granddaughters on three continents.

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And then it was over. In August 2019, gene therapy was working. In October, Bill visited his radiologist for radiation to eradicate some pelvic pain, had an MRI, and let me know that he had been “thrown under the bus!” His cancer had returned with a vengeance. He was no longer eligible for any curative treatment, experimental or established.

Bill’s oncologist recommended a consultation with the palliative care team. I suggested a hospice referral and explained that a hospice informational visit is covered by Medicare, when he was reluctant to make the necessary prognosis for hospice (or for a prescription under the ODDA) of 6 months or less. I thought it possible, but unlikely, that Bill would live long enough—and feel well enough—to get to Florida for a family reunion December 21, fewer than three months away. It is not unusual for hospice patients to get better when their symptoms are addressed.

Making a prognosis is not an exact science, as is stated frequently by opponents of medical aid in dying, trying to convince others that people may erroneously end their lives prematurely. However, physicians tend to be too optimistic. 63 percent of physicians overestimate life expectancies and miss the window of opportunity for advance care planning. <https://bmcmmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-019-0775-2>

As we were leaving his office, Bill’s oncologist said that he would make the referral to hospice, if that was what we wanted. The term “we” is appropriate because the patient and family are the unit of care in hospice. The caregiver, me in this instance, often needs hospice more than the patient. I was determined to try out everything hospice had to offer.

Bill’s oncologist thought that a palliative care consultation was a good first step. Perhaps he didn’t understand how sick Bill was. Hospice was the right call for him, for us. Getting up, getting bathed, getting dressed to go to an appointment are burdensome for the patient and for the person who is helping. Hospice provides its care at home and helps alleviate the burdens of illness. I know how difficult it is to accept “hospice”; I also know that “I wish we’d had it sooner” is a common lament.

The hospice medical director agreed that Bill’s life expectancy was six months or less. Bill was admitted to hospice. Bill also made an appointment with the doctor who had agreed to write his prescription under the ODDA.

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Bill was in considerable pain and had many distressing symptoms. The hospice addressed them. I have been making promises on behalf of Oregon's hospices for 32 years. Bill's hospice team delivered. Meds and DME were delivered to the house. One was a transportable wheelchair, smaller and easier to fit into a trunk. We took it across the Columbia River to Vancouver USA's new river walk and seafood restaurants on a beautiful sunny day, had lunch and walked. Bill's daughter and son, from Savannah and Tel Aviv, were with us. We all had a good day to remember.

Bill's last appointments—ones he had to go to—were to make his first and last oral requests and to deliver his written request for a prescription, under the provisions of Oregon's Death with Dignity Act. Because of the federal government's prohibition against using federal dollars for medical aid-in-dying, the line is cleanest when hospices and their staff do not directly participate. Some segregate funds, as does the Oregon Health Plan. Some physicians participate on their own time.

The job of hospice is to take care of people who are dying, regardless of their preferences or choices. Hospice workers are expected to set aside their own needs to meet the needs of their patients. The law allows them to choose.

Bill's primary oncologist has elected to not participate in the ODDA but will make referrals and support his patients. Bill's study oncologist, however, was willing to be his prescribing physician. His consulting physician, the second doctor, is a palliative care specialist and hospice medical director. He made house calls to complete his obligations. His employment agreement does not permit him to act as the prescribing physician.

Bill was very sick during this time. Nausea was chronic—and exacerbated by riding in a car. Anti-nausea medications were not very effective. His pain was managed by medications, for the most part. But his dosage was so high that his cognition was impaired. Opponents of the law point out that people are not using Oregon's law because they are in pain—as if experiencing pain should be a requirement for eligibility! They are not in pain, and most symptoms are being addressed, because 90 percent of people who use the ODDA are enrolled in hospice. Bill had stomach and bowel issues. Skin problems. Mouth sensitivity. He was miserable. He was dying.

The mandatory waiting period between a request for and delivery of a prescription under provisions of the DWDA is 15 days. It was 23 days between the time Bill made his first request and the time and his compounded prescription was delivered. It is recommended

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that people expect the process to take 45 days, unless they already have doctors willing to write the prescription. I strongly recommend that people who are considering a future prescription, if they should become terminally ill, ask their doctors if they will participate or include the question when interviewing new doctors. Physicians are likely employed by clinics, hospitals, or medical centers. Many employers prohibit participation. One could argue that a physician could participate off the clock. However, employers are often providing malpractice insurance.

I am sure I don't have to tell you that Bill and I talked about dying. We were in Seattle waiting for a flight to Dubai. I don't go anywhere without a copy of my advance directive; and I told him I wouldn't go unless he had one. When we boarded the plane, we had signed and witnessed documents in our possession. Our witnesses were waiting for the plane, too. Bill supported Oregon's Death with Dignity Law. He was a vascular surgeon. He intended, if his disease progressed, to check himself into Hopewell House, an inpatient hospice in Portland. He planned to hook himself up to an IV, fill it with morphine, and end his life. More red tape is required to comply with the law, but his way seems very reasonable.

Hopewell House closed in 2019, and Bill was disappointed. They had only recently adopted a policy that would have allowed patients to ingest medication under provisions of the ODDA in their facility. Only a few inpatient facilities in Oregon allow people to use the law on their premises. As of 2018, only 3 or 4 patients had taken medication in a hospital. People usually want to die at home.

Bill told me he wanted to take his medication as soon as it was delivered. I called End of Life Choices Oregon (EOLCO) to learn more about our options and their services. EOLCO is a 503(c)(3) public benefit organization that provides people who are dying with volunteers who can offer counseling and support and be with them if they use a prescription. I had never been present when a patient ingested medication. I knew what was supposed to happen, but I hadn't seen it. I made tentative arrangements to have a volunteer come to the house, but delivery was delayed. The second time, we were assured that the delivery would be made tomorrow—Saturday. I arranged to have someone we know join us. I went to the living room to tell Bill, feeling quite pleased with myself. His chin dropped and he looked at me as though it just hit him, what he was planning to do. Just then the phone rang. My daughter, on speaker phone, invited Bill to come over and watch the Patriots game on Sunday. Bill took a big breath and announced, "Well, that's an invitation I can't refuse!"

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For the next several weeks, his medication sat on his bureau and was ignored. Bill often lamented that he could think of not one redeeming reason for dying to be prolonged. He became too sick to get onto the bench in the bathtub. He insisted on going up and down the stairs, but it was getting harder and harder. The bathroom was too far, and commodes were used upstairs and down. The hospice arranged for a hospital bed in the dining room. Thanksgiving week was approaching, and he wanted to go to his much-loved cabin in Central Oregon. Bill and I had left it October 9, planning to return on the 11th. But he hadn't been able to make the 3-hour drive. His daughter was going to drive him over the pass on Monday—her car was the easiest to get into and out of. My daughter and I would follow. That was the day the west coast was hit by a “bomb cyclone”. We stayed home. My daughter and her partner prepared and delivered Thanksgiving dinner to our home in Portland. We decided to go to the cabin on Friday. The Portland hospice made arrangements with the Redmond hospice, to be on call in the event of an emergency. Or were snowed in. We drove to Camp Sherman.

Everything was covered in fresh, powdery snow, until we shoveled our way to the house. We lit fires and turned up the heat. The house had been sold. But the sale fell through. We left the house in October for an estate sale. My daughter, it is fortunate, had been spending weekends at the cabin. She and her partner had cleaned it up and rearranged furniture that hadn't sold. We had just enough beds, and I had washed new sheets in Portland before we came.

Snow continued through the weekend. Mountain passes were open, but a mess. Bill was not looking forward to the drive back to Portland. His daughter reminded him that he didn't have to, and he decided he wouldn't. I called EOLCO in Redmond. Their volunteers could come the next morning, Tuesday, December 3. Bill was given instructions to follow about eating and drinking. My daughter, who is on the mortuary and cemetery board, called the funeral home on Irving Street in Bend. My aunt lived on Irving Street, and, when I was 3 or 4 I was allowed to walk to the funeral home on the corner by myself. I found it a fascinating place.

Our EOLCO volunteer arrived at Noon. He is a retired general practitioner. No one could have been a better escort. He had a kind and calming influence. I introduced him to Bill, and they visited for a while, finding many common interests. Bill was asked if he understood what he was planning to do, whether he had been coerced in any way or otherwise influenced. He was told clearly the consequences of ingesting the medication

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and apprised of potential complications. Bill was very clear in his answers and understanding.

We watched as he drank his medications. I handed him a chaser—a sweet Old-Fashioned. It was one of his favorites. He was sleeping peacefully after a sip or two. He took his last breath in about an hour. There were no complications, nothing to even question. He looked comfortable and free of pain.

Dying was hard. The death was good. I am so bereaved.

Respectfully submitted,

A handwritten signature in cursive script, appearing to read "Ann Jackson".

Ann Jackson, MBA