

Testimony to the House Health and Government Operations Committee

In Support of HB 933 End-of-Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)

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Submitted by Nancy Soreng

Some of you know me as an advocate who spends a fair amount of time in Annapolis testifying on behalf of a non-profit organization. I want to make clear that this testimony is submitted as an individual as it is about my personal experience with the Death with Dignity option in Oregon that was used by my closest friend in 2014, and by my mother in October of 2018. These experiences were very different. However, in both cases, having this end-of-life option didn't make the loss any easier for me. But, for my friend and for my mother, it was a true blessing. I considered testifying in person, but the experiences were so personal that they are still difficult to talk about so once again I am submitting this in writing.

I met my friend Betty in 1974 in Corvallis, Oregon. Like me, she loved politics, public policy and working for non-profit organizations. Her husband, like my husband, was a research biologist. And the four of us shared an enthusiasm for outdoor adventures. Even though my husband and I moved away from Oregon in 1978, over the 40 years we knew each other, the four of us took dozens of trips together in the US and abroad. We went white water rafting, canoeing, biking, cross-country skiing, hiking and camping. When she was diagnosed in December of 2013 with pancreatic cancer, I couldn't believe that this energetic, full-of-passion-for-life friend was struck by such a deadly disease.

She threw herself into beating the cancer. She endured multiple surgeries, chemo and radiation therapy and tried both traditional and non-traditional treatments. By the time I was able to visit, I was shocked by how the disease had ravaged her body. By late October, she was in extreme pain and the heaviest opioids were not providing relief. She called me in November to tell me that she had applied for the Death with Dignity Program. I talked to her a few more times after that, and she told me she didn't think she could wait much longer to take the medication. Just before Thanksgiving, with her husband, her son and her daughter-in-law by her side she ended her life the way she had lived it – on her own terms. I was saddened, but thankful she was no longer suffering. She had just turned 70.

The experience with my mother was more difficult. But then, what is easy about losing a parent? In mid-May, just before her 89th birthday, my mom was diagnosed with an aggressive form of cancer that was in her breast and lymph nodes. They also found a mass in her colon, that they had not confirmed, but suspected, was another form of cancer. She did not want to undergo a colonoscopy. They had said that without treatment, she would have 6 months to a year to live. She was firm in her decision that she did not want to spend the rest of her time on earth going through painful, and likely unfruitful, treatments. I understood and respected that decision. I flew to Portland where she lived in a retirement community with Henry, whom she had met there and married 6 years prior at the age of 83, for a week or more every month after the diagnosis. I was surprised, when I visited her in July, that she was already receiving hospice care.

Each time I saw her, her stamina was waning and her body seemed to be melting away. Most frustrating to her, she couldn't do much to take care of herself or their apartment and she sometimes had difficulty tracking conversations and the events around her. Yet, she could answer Jeopardy

questions better than the rest of us and could still win at Scrabble. In August, she told me that she had applied for the Death with Dignity program, but about 40% of the people who qualify, don't end up taking the medication. I was there in September when her primary care physician came to do the first interview. I was impressed by how thoughtful his questions were. He asked her if any one had suggested that she apply for the program. He asked if she understood what she was asking for and asked her to explain it to him. He asked if she felt pressure from her family or anyone else to apply. He also asked questions about her health, how she was sleeping and eating and generally how she felt. She was clear that this was her decision and firm in expressing that she did not want to wait until she could no longer have the capacity to express herself with clarity or function physically. The next step in the process was to wait 3 weeks and be interviewed again by a different physician. She called me and told me that the second physician had indicated he would recommend her for the program.

It was quite a shock when she called me about a week later, on a Saturday and said that she had qualified, and a pharmacy had delivered the medications, and could I come on Monday as I had said I wanted to be with her at the end. I told her that if she could hang on, I needed some time to process this and that I would be there as soon as I could. She understood and said that, actually, she needed some time to make arrangements.

I arrived in Portland on October 21st. On October 24th, my brother, my husband and I, along with her minister and two volunteers from Death with Dignity, were with her as that was the day she had arranged to take to the medication. The volunteers were wonderful. They asked her to explain what was going to happen that day, including what would happen when she took the medication. Then they left the room and let the family have time together. They came back and gave her an anti-nausea medication so she would be able to keep the lethal medication down. They gave us time alone again as they waited for the first medication to get into her bloodstream. Then they came back and asked her again what they were there for and if she still wanted to do this. When she answered that they were there because she was ready to die, they left the room to mix the powdered medication with liquid. They came back with the medication in a cup and a straw. Before they handed it to her, they asked her a third time if she knew what she was doing and if she still wanted to do it. When she answered affirmatively, she took the cup, and drank the contents in less than a minute. They had told her she could have a glass of wine, something she hadn't had since she became ill and really missed. So, she reached for her wine, had a few sips, and was gone.

It was incredibly hard having her leave us when much of who she was, at least in spirit, was still there. But she hated to be dependent on others and had begun taking pain medications that dulled her sharp mind which bothered her tremendously. I'm glad we had those last few days together and could be with her at the end. She spent a lot of time telling us what a wonderful life she had had, and how lucky she felt she was to have a loving family and to have had two caring husbands. Selfishly, I wish she would have waited a bit longer, but once she made up her mind about something, it wasn't like her to waiver.

Because both of these strong women found great relief in having the option not to continue to suffer in the face of terminal illness, I urge you to pass HB 933.