

## **Testimony on Senate Bill 74**

I'm Ellen Blackmer McKay Jewett. Thank you for inviting me to tell our family's story.

Many of you knew my husband Willem and served with him here in the State House. You knew how strong an advocate he was for Act 39 back in 2013.

I'm sure he never thought, back then, that he'd need to use it himself. But his diagnosis of very aggressive mucosal melanoma in December of 2020, and the failure of immunotherapy, chemotherapy, and radiation to control it, made medical aid-in-dying an option that gave him – and me and his girls – enormous peace of mind. We are extremely grateful he had that option.

You know Willem was a fighter. He had more energy, determination, grit and courage than anyone I've ever known. He wanted to live more than anything. We were making plans for adventures right up until the very end. This was a man who was 100% committed to living.

He loved his medical team at Dartmouth Hitchcock. His girls and I, and countless friends, supported him every step of the way throughout his sickness. He was all in with his treatment. But knowing that he had access to medical aid-in-dying gave him, me, and his daughters, great comfort during his last few months when it became clear that there would be no cure.

Willem hated using words like battling and fighting when talking about his condition. To him, it was more of a project. A project that he tried very hard to control. Karen Karen Oelschlaeger, another Vermonter who benefited from Act 39, put it well when she described her long illness. “There can be a lot of pressure in our society to keep fighting, keep fighting, keep fighting, especially as a young cancer patient. I think what folks don’t always realize is sometimes that ‘keep fighting’ is really just a lot of prolonged physical suffering that gets worse and worse.”

***Pointless suffering at the end of a terrible illness serves absolutely no purpose.***

Act 39 gave Willem control over the last chapter of his life. He had thought about it for months and very clearly knew this was the route he wanted to take. He gathered us together in June of last year and told us this would be his plan if treatment did not work. We all supported his decision.

He was a world-class athlete and he was good at listening to his body. It became very clear, very quickly when his prognosis worsened. He knew when it was time.

Willem got to the point where he could no longer get into the car and drive to Hanover for treatment. And for him, that was the signal that he’d reached the end of the road. And at that point, he was very, very grateful to have the medical aid-in-dying prescription on hand.

Five days before he died, he reached out to Patient Choices Vermont and offered to lend his voice and first-hand experience to their advocacy to revise some of the bill's original wording. Some of that language made it incredibly difficult for dying Vermonters to jump through all of the hoops necessary. Telemedicine visits, for example, rather than in-person visits, would make their last few weeks much easier. Doctors can decide, as they do with all other patient care, if telemedicine is appropriate in each case.

As Willem said "Let's not let the legislature get between patients and their doctors."

Act 39 gave Willem a peaceful and dignified death. It allowed all of us to be there with him in his last moments, while he was still the person we all knew and loved. He did not have to endure an increasingly medicated, painful, and drawn-out death. We are so very grateful for that gift.

Dr. Diana Barnard and Stephanie Stoddard, our spectacular hospice nurse from Addison County Home Health and Hospice, were with us at home that day. While it was a blur of emotions for all of us, what I remember most is the courage and humor that Willem was still able to share with all of us, and the gratitude we felt that he was still in control of the most important decision of his life.

It was a calm and peaceful and strangely happy death. None of us were happy that he was dying. But all of us were happy that he was still calling the shots.

I'd be happy to take any questions you have.