

Dear Members of the Public Health Committee,

My name is Jennifer Barahona and I live in Fairfield, Connecticut. I am writing in strong support of *HB 5417: An Act Concerning End of Life Care*. This is a highly emotional and personal issue for me and my family and I thank you in advance for taking the time to read my testimony and take my experience into consideration as you vote on this important matter.

When my father passed away in 2006 from an aggressive form of cancer the end came relatively quickly and peacefully. He was comfortable and he drew his last breath while I held his hand and with his wife of 49 years and 3 out of his 6 children by his side. It was one of the most important moments of my life and I will be forever grateful that I was with him at the end.

My mother was the pillar of strength and courage after he died, as she had always been. Giving the toast at my wedding 12 weeks later that he was supposed to give, continuing to chair the National Pastoral Musician conference held in Stamford that summer, working full time as a director of music at a local Catholic Church, living alone, and continuing to be an amazing mother to six and grandmother to ten. She was going strong until the fall of 2008 when her speech started to slur and her gait became unsteady. Her devastating diagnosis of ALS came in February 2009 and she deteriorated at a rate that was astonishing.

I wanted the same kind of peaceful end for her that we had experienced with my dad. My incredible mother had cared, protected, and loved me every moment of my life and as her youngest child and her health care proxy I wanted to do the same for her in her final months, weeks, and days. And I did up until the last 2 ½ weeks of her life. Together we made the decision the first days of September to stop nourishment and hydration through her feeding tube to hasten the inevitable. It was the last act she could consent to. In a span of just 7 months ALS had robbed her of control of every voluntary movement, including the ability to blink yes or no responses. I am haunted by her pleading eyes, her groans, her black limbs from lack of oxygen, and the inability for any person, medical or otherwise, to ever know what was causing her pain/distress. The only thing she had asked was that she remain lucid until then end. What choice did we have? To respect her wishes to remain alert and aware while having no idea what she was thinking or feeling? Or to keep her as comfortable as we thought we could by authorizing around the clock morphine? The only humane thing to do was the latter. None of us, especially my mother when she made the decision, imagined that we had more than a few days and we gathered family near and far (including my brother in England) to be with her. To our horror she lived for 2 ½ unbearable weeks this way. We stayed with her 24 hours a day, expecting each moment to be her last. Having been with my father at the end it was incredibly important for me to be there with her as well. But all of us could not stay over each night in her hospice room and I had an infant at home who needed me as well. The night of September 17, 2009 was my brother's turn on the cot by her bed and when he woke the morning of the 18<sup>th</sup> she was gone. No one held her hand as she had done to the six of us children through every difficult moment of our lives. No one was there to whisper loving words into her ear. She died alone in a strange bed after unimaginable suffering.

The fact that we allow this kind of inhumane suffering, the kind that we don't even allow our pets to endure, is shameful. I would like to point out that my family has strong Roman Catholic roots. My

mother was the director of music in the Catholic Church for over 30 years and put more heart, soul, and time into the weekly liturgy than most priests that I have ever known. I know there is a strong lobby against this bill by the Catholic Church and want you to understand that they do not speak for all of us. While in the end my mother may not have exercised the option that this bill would have provided to her, I can say with certainty that she would want others to have this right. I implore you not to legislate based on the position of a segment of the religious community. We do not all share the same views and to force the general population, who overwhelmingly support this measure, to fit their dogma is simply not right. If this bill becomes law, those who are opposed still win. They simply do not need to choose this for themselves. Additionally, there are safeguards in place that prevent this from being used carelessly or liberally. We know that many people take matters into their own hands and end their suffering in horrible ways instead of planful and supportive ones.

Finally, I ask that you consider your own sons, daughters, husbands, wives, partners, or others who love you and ask yourself what you would do to protect them from the emotional trauma of watching you suffer a terminal, painful, debilitating illness that will leave them with lifelong feelings of helpless and guilt over their inability to assist or respect final wishes. The only thing harder than losing someone you love is watching them suffer. And I pray that I never have to put my children and family through what we went through with my mother. We each deserve to have a humane, dignified, and well planned departure from this life with final moments surrounded not by pain and fear but by love and comfort.

Thank you.

Respectfully,

Jennifer Donalds Barahona, LCSW

74 Cardinal Street

Fairfield, CT 06825

Jennifer.d.barahona@gmail.com