

Douglas H. Wade Jr

To whom it may concern,

My mother was diagnosed with Primary Lateral Sclerosis (PLS) in 2003. She had started stumbling several months earlier and then began to slur her words. She lost the ability to speak within six months and couldn't walk less than a year later. The disease took its toll over the next seven years and my mother fought gallantly to preserve her freedom and spend her days living at home with her husband. The disease kept up its insidious course, depriving my mother of her dignity. Her brain was completely intact, but her body was failing terribly. She drooled, she couldn't speak and over the next several years, she lost the ability to swallow. All nourishment had to come through a peg. 24 hour care was now a requirement. She amazingly still enjoyed life and would hand write all of her thoughts and needs. The disease continued to take its toll and Jewel was losing the ability to write. The arms were stiffening much like the legs and trying to write brought on exhaustion as her body was shutting down on her. Myself, and everyone around her marveled at her positive attitude with the nightmare existence that she had to endure. She couldn't roll herself over in bed, get up to use the bathroom or even hold up a book to read. 24/7 there was care needed to do life's most basic functions.

July 1<sup>st</sup>, 2010, I along with my sister and brother received a call from my mother's caregiver that she wanted to see us all that evening. My mother was now 82 years old and had lived a wonderful life. She was a very good woman and reminded me of what I had read about the life of Rose Kennedy. My mom could handle any crisis. There was no load too much for her to manage. This meeting that my mother called was a shock to her children.

My mom was done with her struggle to survive with her disease. Catching the common cold was a potential death sentence as she could no longer even cough to clear mucus from her throat. She informed us that night that she was not going to take any more food through her feeding tube. She was quite simply too tired to continue fighting her disease. She wanted to die on her own terms and not by choking to death. She had raised her children well and had enjoyed a wonderful life. We talked as a family and accepted our mother's wishes. She was Irish and you weren't going to change her mind. There was no depression going on with Jewel. She had simply come to terms with the situation at hand.

It was extremely difficult and yet beautiful, how she chose to die. My mother was once again in control of her destiny. There was literally a parade of visitors as my mother requested that we tell anyone who was close to her that it was time to say their goodbyes. My mother remained cognizant of everyone coming to visit for the next three weeks and then her body started the final shutdown. Jewel slowly slipped away into a comatose state waking for moments and then fading back into unconsciousness. The final week of her life was traumatizing to everyone that stayed by her side. Her breathing became very labored and each breath became farther and farther apart as her organs began to fail. We were all with her during her final hours. Numerous times we thought that she had passed away. Minutes would tick by and then her body would again convulse and she would suck in air with her mouth suddenly gaping open. I was angry that our society was so inhumane as to force my mother to suffer through this prolonged type of a death. The human body is genetically programmed to survive and it will fight long and hard before it shuts down completely. A small minority of us will have the fairy book ending where we die peacefully in our sleep, while the vast majority of us will die a painfully slow death as the body struggles to keep the heart pumping blood.

I hope that there will be options for me to end my life if I suffer a fate such as my mother's. I would hate to think that I would have to leave my home state of CT where I have lived my entire life, just to die with dignity.

I am in total support of HB 5326 – An Act Concerning Compassionate Aid in Dying for the Terminally Ill.

Respectfully,  
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