

## HB 7015 – An Act Concerning Compassionate Aid in Dying for the Terminally Ill.

My mother – Jewel was the picture of health at age 74 in 2002 when she started to stumble now and then while walking. The problem worsened and she started using a cane. She went to see several specialists who were perplexed by her condition. She soon began to slur her words and within six months her speech was unintelligible. Shortly thereafter she became unable to walk and was confined to a wheel chair. My mother was finally diagnosed with a rare disorder called Primary Lateral Sclerosis (PLS) in 2003. PLS is akin to ALS. The disease took its toll over the next seven years and my mother fought hard to retain her independence and her spirit. The disease kept up its insidious course, depriving my mom of her bodily functions. Her brain was completely intact and sharp, 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 became a requirement. She amazingly continued to enjoy life and would hand write all of her thoughts and needs. The disease continued to take its toll and Jewel was slowly losing her ability to communicate through writing. Her arms and fingers were stiffening much like her legs and trying to write became an exhausting experience. I marveled at my mom's positive attitude with the nightmarish 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 help with most everything that we take for granted.

My mom had an incredible inner strength, that reminded me of stories that I read about Rose Kennedy. Jewel could handle any adversity that life threw her way. How she remained so strong and upbeat through the course of her illness amazed me. I learned a good many life lessons from my mom. Here was a woman who most certainly would die if she caught a common cold because she couldn't even cough to clear her throat. We worried as did she that she might die by choking.

My mother was 82 years old in the summer of 2010, and had lived a full and wonderful life. On July 1<sup>st</sup>, 2010, my mom sent a request that her three children come to her house that evening for a family meeting. My stepfather had left my mom earlier that day for a one week visit with one of his daughters in Illinois. We sat down with our mother that evening and she carefully wrote out short notes, amidst tears (she had problems controlling emotions from her illness) telling us that she had made a decision to end her life. She was simply too tired and she wanted to leave on her own terms. She informed us that night, that she would not take any more nutrition through her feeding tube. She was very proud of her family and wanted our understanding. Jewel was Irish, and very stubborn when she made up her mind to do something. We knew that it was useless to try and change her mind. Her decision was a long time in the making. There was no depression going on with Jewel. She had simply come to terms with her situation. Her decision was hard on everyone, especially my stepfather who loved my mother dearly.

Jewel requested that we inform her friends and family of her decision and to offer them an opportunity to say goodbye. We sat down as a family one day later watching a video that a doctor had made chronicling his decision to end his life after enduring a similar

terminal disease. We learned that starvation is a slow death and that she would probably live for four weeks or more. The next two weeks, we literally had a parade of visitors who came to say their final goodbyes. Many great memories were shared and there were a lot of emotions laid bare. I recalled how my father had died at the age of 58 after suffering a heart attack. There was a code blue in the hospital and then he was simply gone. That was heartbreaking.

My mother's departure was both beautiful and painful. My brother and sister and I got the chance to spend three weeks of wonderful heart warming time with my mother and all of her close friends and family members. No false pretenses, no tiptoeing around the subject of death, just sharing in a wonderful life.

Jewel slowly slipped away into unconsciousness during her final days. The last week of week of her life was very traumatizing, as her breathing became very labored. Each breath became farther and farther apart as her internal organs were beginning to fail. The death watch was on. 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. Death was not pretty. It was prolonged and painful to those who loved her, however I don't believe that my mother suffered at the end. A small minority of us will have the fairy book ending where we die peacefully in our sleep, while the majority of us will die a slow death as our bodies fight longer than we might desire to live.

I hope that there will be an option for me to end my life if I suffer a fate such as my mother's. When it is my time, and I hope it's due to old age, I want to exit this life with dignity and not cause any suffering or added burden to my loved ones. I'd be very disappointed if I had to move out of Connecticut (a state that I have lived in all my life), just so that I could die with dignity. I believe that a civilized, secular society should recognize personal freedom of choice.

I am in total support of HB 7015 – An Act Concerning Compassionate Aid in Dying for the Terminally Ill.

Respectfully,

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