

Honorable Members of the Public Health Committee:

Thank you for the opportunity to submit this written testimony in strong support of HB 5326, An Act Concerning Aid in Dying for the Terminally Ill.

I strongly support HB 5326 because of what happened to my 90-year-old husband during the last eight days of his life.

(I am Virginia F. Sendor, residing at 66 Glenbrook Road, Apt. 2122, Stamford, CT 06902-8404)

My husband was still working full time, as a graphic arts consultant in bookbinding and finishing. *On Friday evening, May 29, 2009*, Bernie was a guest speaker at the City College of New York (CUNY), College of Technology's Annual Dinner of Gamma Epsilon Tau (Gamma Chapter of the International Graphic Arts Honor Society). He spoke fervently about the technology and changes developing in the graphic arts field and in bookbinding - and the importance of adjusting our thinking and adapting to the 21st Century. He also stressed the importance of maintaining one's individuality and integrity. How we use our computers and other new technologies depended on continuing education, communication, understanding, and individual choice. He stressed individual choices, communication, and education, education, education!

Bernie had served three years in the United States Army Air Force in World War II. He was aware of difficult and sometimes horrific survivor situations, but did not speak about them, even though we were married almost 56 years. As we grew older and some dear friends and relatives had passed on, we had conversations about end-of-life situations and our own quality of life. I am a former hospice director with a graduate degree in rehabilitation counseling. We agreed on the importance of having a written Health Care Proxy and a Living Will (Advanced Directive). If we were to become terminal, we wanted to die in peace, at home. We did not want any heroic life-saving measures. We did not want artificial resuscitation, no respirator, no feeding tubes. We did want that DNR. We hired an attorney to draw up these papers, also stating we did not want to be in pain. We requested we be given pain medication, even if it should shorten our life. We included the statement: *"I trust that my family and physicians will honor my wishes."*

We were selling our home of 55 years, to move to New Jersey to be near Bernie's office in Little Ferry. *That Saturday morning, May 31st*, the day after his talk, we were shopping in a local supermarket and were at the deli counter. He was salivating over the cooked salmon filets and the chicken cutlets and wondered which we should buy. "It's a no brainer," I said. "We'll get both." And that was our last conversation. I had turned to speak to the clerk - and Bernie fell. He landed on his back, like a children's "snow angel," arms outstretched, blood seeping from his mouth. The ambulance rushed him to the emergency room at Nassau County Medical Center and then transferred him to the Surgical ICU. He was comatose, non-responsive. There was blood in the fluid draining from a shunt in his brain. He was on a respirator, had a feeding tube and other high tech medical equipment all around the bed. He was in a private room because of an infection. Medical staff were rushing in and out and gowns and masks were worn.

I told the Admissions Clerk that Bernie has a Living Will (Advanced Directive), a DNR, that I am his Health Care Proxy - and gave them the documents. That same afternoon, my daughter rushed down from Stamford; my son flew in from Denver. We had a family pow-wow.

On Tuesday, June 2nd (three days after his fall), the Surgical ICU physicians called a family meeting. They said it was a 30% to 70% chance Bernie would regain consciousness. About his "survival" - they didn't know. The same for his quality of life, going forward. They said he needed more surgery. Then they would subject him to more neurological testing and evaluation, and perhaps be able to provide a more optimistic prognosis. I demurred. The doctors said this surgery was necessary for Bernie's treatment, that they could not define the procedure as an "heroic life-saving measure." And it was necessary that he remain in the private room because they were not happy about his infection. I demurred again, referred to his DNR, to the Living Will. I asked the doctor: "If he has this surgery, should we re-arrange our ground floor den and bathroom, and make arrangements for him to come home afterward?" We were told he would not be coming home for a while. He would need extensive rehabilitation, even though he might remain comatose. I had more discussions with my two adult children. We were distraught and stressed out. My children thought we should listen to the doctors and "give Dad every chance" to survive. But what about the quality of his life? I phoned a hospice friend to schedule a hospital visit, to evaluate Bernie for their

program.

I was still conflicted about the surgery, as Bernie's wife (and proxy), as a mother and a grandmother, experienced in hospice end-of-life situations, with rehabilitation and quality of life. So what did I do? I acted as a mother and gave permission for the surgery. It was performed that *Thursday, June 4th*. Bernie survived the extensive surgery, still comatose and non-responsive. He died three days later, the *evening of Sunday, June 7th, 2009*.

The medical expenses for Bernie's last eight days: Medicare paid 80%, a bit over \$200,000. Our AARP Medicare Supplement paid the other 20%. That is almost a quarter of a million dollars!!

Aftermath: Still conflicted about not honoring my husband's wishes, I sold our home of 55 years, rented an apartment in Stamford to be near my daughter, and made arrangements to move there in August. Instead, I went into heart failure and was in the hospital when my children and daughter-in-law moved me up to Stamford. I was transferred to a nursing home on Long Island, and arrived in Stamford the end of September in a wheel chair. Then I went in and out of heart failure, needing a full-time home health aide. There were two visits to Stamford Hospital's emergency room, subsequent inpatient stays and two transfers to a nursing home. Open heart surgery was performed in January, 2010.

We tend to be a death-denying society, even though it is inevitable that our "time" will come. It is the shape, timing, and form that can be "problematical." Is it an unexpected accident or a long-drawn-out illness? Is it a six-month prognosis or a shorter one? As difficult and discomfoting as it is for families and significant others - well before such heartbreaking and distressful situations arise - it is so important to have meaningful discussions that can be loving and caring, to know that we can make our own choices about our own end-of-life situations - in advance - before we are confronted with that inevitable situation.

Different cultures and mores, different religious beliefs, and different educational backgrounds and awareness will lead to different decisions and outcomes. All should be recognized and honored. Above all, more timely education and awareness - perhaps in public seminars or adult education programs and in religious institutions - could stress that the individual patient's needs and wishes must come first - and be recognized and honored. We do not need to suffer in pain - and legalized aid in dying is a comforting thought. What a better World it would be, when we have "Compassion for Ourselves and Each Other."

Thank you.

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