

Testimony on behalf of The Connecticut Hospice, Inc.  
State of Connecticut Department of Public Health Hearing  
March 16, 2012

Good morning,

My name is Rebecca Paul and I would like to share my position with you today on the topic of this hearing.

There is a time in life when we have experienced many deaths – those of our parents, relatives, close friends and business colleagues. And, we have come to witness various models for end-of-life care provided to our loved ones as recommended by those who supposedly knew best.

I'm afraid I have experienced courses of care for the dying that were truly unacceptable.

Most tragic was my mother's end-of-life. She was diagnosed one April with stomach cancer, and the recommendation was made to remove her stomach. After surgery the surgeon advised that cancer was in her stomach, liver and pancreas. She was terminal. She returned home to recuperate. She was not told she had cancer by her general practitioner, gastroenterologist, or her surgeon. She was referred to "another specialist" (oncologist) who told her she "had a tumor". The word cancer was never spoken.

After a few weeks of radiation the patient became dehydrated and weak. One morning she was picked up off her bedroom floor by EMT's and returned to the hospital. After being rehydrated she was delivered to a care facility where she lay curled up in bed by herself in dirty diapers being cared for by CNA's. Once a day a nurse came by. She could not see a doctor unless he happened to be in the facility. She could not eat by herself, she did not receive comfort, she did not have anyone ask her who she was, what her hobbies were, or if she'd like to pray. She was not told she was dying. And, neither were we.

I had her removed and sent back to the hospital because she could not breathe and her abdomen was distended as if she was nine months pregnant. She was admitted, brought into a private room on the oncology floor and left alone in a dark room. She told me she was scared. I did not know what to say because I was too.

After a week, though she was alert and communicative, she was given morphine and moved but, this time to The Connecticut Hospice.

Something changed for our family then. We were welcomed by staff – a social worker, nurse and doctor who explained what was happening, and asked questions about our family. We were taught the signs and symptoms of dying. We were told my mother could hear us even though she was at the affect of morphine, and we were directed to speak to her and touch her – she knows you are here. The spiritual contact called our priest. When he arrived our family

stood together around her bedside holding hands and praying the prayers that she so loved – comforting all of us. We were invited to share her end-of-life journey by staying with her through the night. Volunteers offered us anything we needed.

Less than 48 hours later she died. The family was invited to visit her before she was moved to a funeral home. We did. She was clean, her hair was brushed, she was holding a favorite doll, and covered with a beautiful hand-made afghan. She was finally at peace and she was beautiful. And, our family was at peace.

Exactly one year later I was able to enter the volunteer training program at The Connecticut Hospice. It was my personal mission to volunteer in a role to educate others that there is a “better” way to die – a “Gold Standard” of care that addresses the needs of the patient and their family – one that is proven and in pure form.

That was ten years ago. I was trained in a 9-week training program to learn about the Interdisciplinary Team who deliver multi-dimensional care to patients and families – on-site doctors, nurses, social workers, chaplains, art therapists, and volunteers. I’ve taken numerous other sessions of specialized training, as well as an extensive training course on providing spiritual care – all provided through Connecticut Hospice. I’ve attended many sessions by The John D. Thompson Institute to receive further hospice education.

Over the last ten years I am confident that I have impacted the lives of numerous patients and families who were under The Connecticut Hospice’s Gold Standard of Care. Today I continue to be a member of the Interdisciplinary Team as a Spiritual Care Volunteer

After 38 years of setting the standard in the United States as THE quality provider of hospice care, should there be ANY question whatsoever of why The Connecticut Hospice’s mission, methods, and business model should be affected by the insatiability of for-profit institutions?

I’m afraid that once changed, too many people will suffer the effects of an “end-of-life” business commodity so similar to that our family witnessed before being enlightened.

Thank you.