

**TESTIMONY of
HOSPICE SOUTHEASTERN CONNECTICUT**

**Before the Legislature's Public Health Committee
10 am, Friday March 16, 2012
Room 1D, Legislative Office Building Hartford, Connecticut**

My name is Joanne Davis. I am a Patient Care Volunteer for Hospice Southeastern Connecticut in Norwich. I am submitting testimony in support of **House Bill 5499 (Raised): An Act Concerning Regulations Relating to Hospice Care.**

At last year's public hearing, I listened with keen attention to the testimony of hospice professionals and representatives about these proposed regulation changes. One message that saddened me was that patient care would be intentionally decreased and negatively impacted if they were enacted. Today, I come before your committee to share a patient's personal story that, had a hospice residence been available, his care would have been more compassionate because he would have been encircled by caregivers who "gentle the journey."

My testimony is about a **PERSON**: He was 61 years old and spent the last 4 months of his life in a nursing home when he was no longer able to be cared for in his own home. His lower legs were purple and hard and his skin was dry and cracked. He fell a couple of times, broke his nose, and had bruises and skin tears on his back from scraping the door hinge as he slid down against the closet door to the floor. As the days shortened, I wheeled him to the end of the corridor to get a glimpse of the trees and the setting sun. There wasn't much of the day left and it may have been the first . . . and last . . . time he saw nature while he was in the nursing home. All he wanted was to be at home with his wife; he even considered leaving the nursing home just to be with her at their home. He was so very disappointed to hear that he would never be able to leave. He deserved a better ending of his life's journey than this.

My testimony is about a **FAMILY**: They had only been married 8 years. Her caregiver stress increased significantly after he was admitted to a nursing home. She was concerned about the staff's lack of skin care, burdened by the need to do his laundry, and troubled about his decreasing ability to eat independently. She physically cared for him when she could be there and worried about him when she couldn't. The visible strain on her face and the deterioration of her own health told the story of how difficult this experience was. She deserved to be with him in a place where her hand . . . and nature . . . were just a touch . . . and a glance . . . away. He wanted this and she wanted this.

My testimony is about **2 ENVIRONMENTS**: The one that was and the one it should have been: He was in a nursing home where the sights and sounds were not pleasant and were best dealt with behind a

closed door, heightening his sense of isolation. His life, as turbulent as it had been, should be honored by the same dignified death that each of us wants, but even this became elusive in an environment in which he was often physically and emotionally separated from the most important person in his life – his wife.

This is the family for whom every aspect of a hospice residence is designed. He deserved a place that felt like home and where his dignity was respected. She deserved a place where she had peace of mind, comfort, and rest. They deserved a place where they were cared for and supported as individuals and as a couple. When I think of this couple, the hospice residence “comes to life” as the optimal environment to promote a meaningful and peaceful death and to reduce the emotional agony of the family members facing the loss of their loved one.

We all deserve options and choices that “gentle the journey” at the end of life. Everyone in this room knows families like this couple who deserve no less. Isn't your family 1 of them?

I strongly urge you to support the proposed changes and become a champion for quality of end-of-life care to clients and their families throughout our state. Having access to all levels of hospice services across the continuum of care (home, nursing home, hospital, hospice residence) is a critical and strategic component of the provision of care that hospice patients, and their families, deserve. The adoption and subsequent implementation of these proposed regulations assure that access to this level of care is available to all patients throughout our state - care that is based on patient and family need, is consistent with clinical practice standards, strives for continuous quality improvement, and is without regard to geographical location.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at (860) 848-5699 or Joanne_Davis@comcast.net.