DKH DAY KIMBALL HEALTHCARE
Hospice & Palliative Care
of Northeastern Connecticut

TESTIMONY

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Before the Public Health Committee

Raised HB 5326 *AN ACT CONCERNING AID IN DYING FOR THE TERMINALLY ILL*

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Senator Gerratana, Representative Johnson and members of the Public Health Committee, my name is Janet Perry and I am an RN Supervisor at Hospice and Palliative Care of Northeastern CT, an affiliate of Day Kimball Hospital and Home Care. I have spent the last 21 years of my 40 year nursing career as a certified hospice and palliative care nurse providing end of life care to the patients and the families of northeastern Connecticut.

As an experienced hospice provider, I have seen firsthand how well symptoms can be managed and both patient and families supported so that the last weeks and months of life can be meaningful, comfort promoted and a legacy for those left behind. Yet, what my team and I continue to see far too often is the late referrals that continue to come to us so that those last days of a dying patient are motivated by fear and crisis. With these late referrals is the public misconception that hospice is only for the last few days if not hours of life so it is not utilized as it is intended.

I stronglyoppose HB 5326 An Act Concerning Aid in Dying for the Terminally Ill.

This bill concerns and frightens me because, once again, it cites the need for conversation between patient and health care provider when the patient is determined to be terminally ill. The reality in our area and throughout our state is that many of our late referrals to hospice have come through with health care providers who are not having those conversations until the very end when patient and family are nearing a crisis situation. Many of these conversations may center on unrealistic family expectations rather than what is wanted by the patient who is nearing end of life. These conversations need to be honest about prognosis and what the patient really wants when cure is no longer possible.

There is the continued perception by many of our health care providers that hospice is the last resort when there is 'nothing that can be done' when the reality is that hospice is

congruent with hope for quality of life and a peaceful natural death. Death is continued to be viewed as a failure or that it is "giving up without any hope." This is where the lack of end of life education in our medical and nursing schools is painfully apparent.

While cure is no longer possible, there is so much more that can be done and done with excellent assessment and use of best practices so that patients can have all their symptoms managed. Hospice care is a cost-effective option to continuing aggressive treatment that often occurs in Connecticut until the patient is within days to a few weeks of dying. Hospice care is not only looking at the physical but the emotional, psychological and spiritual aspects of the individual, and it fosters positive memories to be made while helping to address symptoms and prepare both the patient and family for those final weeks. Hospice care addresses the patient and the family together as a unit so that the hospice team is there to help and support them through the death of a loved one and through bereavement after the loved one dies.

HB 5386 does not address the real issue of how to live remaining days to their full potential and to die well. It perpetuates the idea that sickness is an inconvenience that must be addressed with a quick fix rather than seeing death as part of the normal cycle of life, a time of growth as is any other time of life. We can only imagine the feelings of guilt that families will experience if the decision to pass this bill endures. There is much work to be done but this bill does not address the real needs of the medical community nor the community at large. We have had so many patients and families come to us in crisis and given enough time on hospice, have seen very special transitioning and growth within the family structure. Often patients and families remark that they wished that they had been referred to hospice sooner as they transitioned from institutional treatment to a focus on comfort and quality of life. This can be a time where they can focus on what is important and to focus on their personal and family goals. The work that is done in those last weeks and months is special and can be therapeutic for both the patient and the family.

Let me tell you of a patient who was on our program and was able to elect hospice early in time. GG (name changed) was a patient whose cancer treatment was one in which she suffered so many of the possible side effects that treatment can cause that when it spread beyond the original site she made the decision to forego additional treatment although she was told doing so would shorten her life. She was given just months without treatment and possibly a year with treatment. She decided to focus on other things that were most important to who she was as a person. In essence she decided to focus on her family and to leave her final footprints. For more than a year that she was on our program she was able to be there for the birth of her second grandchild and to travel to where her son was stationed across country. She was able to tend to the business of living in that time and left a legacy for her family with the support of pastoral care and social work as well as our volunteers who provided integrative therapies that were an effective intervention that

allowed for her to need less in the way of pain medication until very close to the end of her life. When she did die, hospice was there to support her husband for many months as he worked through the pain of her loss. She was able to build relationships and trust of the hospice team members so that those last hours of her life she was surrounded by those who knew her best and could be there along with her family. Hers was a gentle passing and she was able to meet all the goals that she had in mind to complete before her death.

HB 5386 negates that people can contribute positively to society to that last breath and the memories built continue to positively impact indefinitely. I urge you not to pass HB 5386 but to focus efforts on having the conversation earlier in onset of serious illness and to promote positive hospice care.

Thank you.