

**TESTIMONY BILL #5499 3/16/2012**

**Dear Madame Chair and Distinguished Committee Members:**

As the Director of The Connecticut Hospice Arts Program for the last 15 years I am speaking to urge you not to replace the hospice regulations formerly under 19-13-D4b with the proposed bill, #5499.

Under the proposed bill arts services would not be required in an in-patient hospice setting. So that you may understand just what would be lost for many patients and families if this bill is implemented, I will describe the scope of our work. Our arts program is multi-faceted, offering music, music therapy, visual arts, art therapy, crafts, literary arts such as poetry and creative writing, life review, dance and movement therapy, and concerts and exhibits from community artists and performers. We are staffed by a full-time director, 7 paid staff, including board certified clinical therapists, and 40 volunteers. We offer services to patients and families 365 days a year, and we make approximately 6000 arts visits per year. We function as an integral member of the Interdisciplinary Team, consulting daily with other clinical professionals in all disciplines. Our mission is to provide a variety of arts experiences for hospice patients and their families, according to their individual wishes and interests. We strive to enable patients to live life fully and to add to the quality of life as long as life is lived. We facilitate expression and thereby afford dignity to the dying and their families, and we complement medical and other interventions by providing interventions which ease physical symptoms and nurture the spirit, using a variety of media.

Arts services have been mandated in any free-standing in-patient hospice setting in Connecticut since 1979. This has been so because of the wide range of physical, spiritual and emotional benefits that arts interventions have been proven to

provide. Experienced providers of *true* hospice care understand that quality of life, dignity, and patient/family control are more than just catch-phrases promised on a shiny new brochure.

These fundamental tenets of hospice care are all addressed in surprising and profound ways by the arts:

- By facilitating creativity and choice, the arts have the power to provide autonomy and control for patients and families at a time when very few aspects of their lives present are under their control. This often allows a dying person to transcend seeming chaos or despair.
- The arts can provide a conduit for emotion, and a language in which to express that emotion. When patients and families find it too painful to talk about the inevitable, the arts can become a catalyst for those discussions by providing a metaphorical framework, such as a painting, poem or song, and thereby ease understanding or acceptance of the complexity of the dying process. Unfinished business can be facilitated – for example, a memory album made by a 40 year old patient to leave for her estranged daughter.
- Every patient and family member is an individual with a unique life story, and the arts offer ideal opportunity for life review, an almost universal need at end of life. This holistic approach views every patient as no longer merely a person with a list of symptoms, on the receiving end of care, passive and not productive, but as a *whole* person, who can produce and create, express themselves actively. Through arts involvement a hospice patient can affirm him or her self and take pride in accomplishment. Some patients have asked to learn something they've never had the chance or the

time to pursue before, like playing the guitar or painting with watercolor. As the late Dr. Gene Cohen wrote: “There is no denying the problems that accompany aging. But what has been universally denied is the potential. The ultimate expression of potential is creativity.”

- The arts can regenerate the body, mind and spirit. Enjoying the arts, either actively or passively, can bring tranquility and peace, a connection to the beautiful in life and a connection to nature.
- Involvement in the arts fosters rapport and trust; stimulation, relief of boredom, fear or anger; diversion, recreation and play; emotional support, and assistance in coping.
- Significantly, there are many ways in which arts services can assist with relief of physical symptoms. When patients are focused and relaxing, for instance with music therapy, they often need fewer medications for pain, anxiety, agitation, shortness of breath, nausea and so on. Using fewer pharmacological interventions is not only cost-effective, but also, more importantly, allows patients to remain free of the associated side effects and more energetic and interactive, able to have quality time with their families.

More and more health care organizations across the country are introducing art and music therapies as their advantages become more widely known. In contrast, the new regulations make arts therapies an afterthought, barely mentioned as a remote *option* under complementary therapies. They would focus on a “deficit” approach that stresses losses and decline instead of focusing on an “asset” approach that recognizes the strengths, achievements and potential of later life.

The Department of Public Health's definition of palliative care is "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and the facilitation of patient autonomy, access to information, and choice".

And yet the proposed bill strips the integral services that make this possible, that make true hospice care what it is, leaving instead a bare-bones, diluted version. The proposed regulations mention "quality care that meets current professional standards" but leave nebulous definitions of just what that means. I propose it should mean the professional standards that have brought hospice care in Connecticut to the high level it enjoys, care which has evolved with fully enlightened experience of what patients and families truly need, not a return to the dark ages. I urge you to reject this proposal, as it would leave patients and families without the very standards of hospice care it purports to provide.

Katherine Blossom

Arts Director

The Connecticut Hospice