



TESTIMONY BEFORE PUBLIC HEALTH COMMITTEE H.B. 5499
AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

MARCH 16, 2012

Members of the Public Health Committee my name is Carol Mahier and I am the Director of Hospice Southeastern CT for the past 24 years, former board member of CT Association for Home Care & Hospice (CAHCH), former chair of the CAHCH Hospice & Palliative Care Committee.

I am submitting testimony in support of H.B.5499 with revisions as proposed below.

I also strongly support the passing and implementation of revisions to hospice facility regulations (Section 19a-122b-1 to 19a-122b-14) as developed by DPH in collaboration with 28 of the 29 licensed and certified hospice programs in Connecticut.

These hospice facility revisions must be passed as soon as possible since access to hospice residence care for terminally ill patients is compromised due to distance necessary to travel to the one hospice residence in CT. Patients who entrust the end of life time to a hospice program deserve the choice to have care across all settings available to them in their own community. If hospice care can no longer be provide in their own home, care in a hospital under a contacted agreement with the hospice program is not necessary and care in a skilled nursing facility (again under a contract with the hospice program) is not acceptable, then the choice of care in a hospice residence must be available. A hospice residence is a place where the dying person is in a private room, family may visit and stay overnight with their loved one, highly skilled professional hospice care givers provide direct care, solace can be found in the chapel, private time in the library or a cup of tea in the dining area. A hospice residence must be close to where loved ones live; traveling to Branford from anywhere in the state to access that residence care takes valuable time away from being with a loved one. Families in Connecticut deserve access in their own community to this type of care

I suggest Revisions for H.B.5499section (a) after "pursuant to 42 USC 1395x" (line 6) :
Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence, must be able to provide the following levels of hospice care: routine, general inpatient, continuous or respite.

Resuming in the H.B. 5499 with the sentence (line 11)“The residence shall provide a homelike environment...”

There can be only one focus here and that is to provide access to the continuum of quality end of life hospice care for every person in our state. The proposed regulations have been written mirroring the federal Medicare standards and provide for quality end of life care. The proposed regulations are supported by all but one of the Medicare certified hospice programs in CT; all of whom are licensed, certified with many, many years of providing quality care to thousands of our neighbors. All of whom have NO desire WHATSOEVER to in any way diminish or alter the quality care we have been and are committed to providing. We seek access and advocate for the neighbors in our communities to have access to care in a hospice residence.

The concerns brought forth by opponents to the revised regulations are not valid. None of us would tolerate such poor quality guidelines because the care is about what is the BEST for the patient.

Concerns regarding no pharmacy on site in the proposed hospices regulations are not valid. With current medication delivery and access even in people’s homes to “comfort packs “that include the medications necessary to treat untoward symptoms and guidelines for administration, medications are not an issue. Of the over 200 skilled nursing homes in CT there are only 2 who have their own pharmacy. Patient’s medications are delivered and stored in the residence along with emergency medications to treat multiple situations.

The concern of not having a medical director on site 24/7 is not a quality issue. Skilled hospice nurses who are providing direct patient care have expertise in accurately assessing and treating a myriad of symptoms and are in constant communication with the physician. These clinicians are highly trained and used to anticipating the issues faced by those at the end of life. Palliative care and excellent symptom management are cornerstones of their practice.

Thank you to this Committee for advocating for access and to the Department of Public Health for doing the same. The citizens of our state are counting on us.

Should you have any questions please contact me,

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