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Testimony to be submitted to the Public Health Committee regarding HB 5499, An Act Concerning Regulations Related to Hospice Care

March 16, 2012

Senator Gerratana, Representative Ritter, and members of the Public Health Committee, I regret that I cannot attend today's hearing, but I sincerely appreciate the Public Health Committee's effort to address the need for licensure and regulations for Hospice Facilities/Residences.

I would be in support of HB 5499 if the language were amended to include the ability to provide inpatient hospice care at the Hospice Facility. The following change is suggested:

(a) Notwithstanding the provisions of chapters 368v and 368z, an organization licensed as a hospice [pursuant to the Public Health Code] by the Department of Public Health or certified as a hospice pursuant to 42 USC 1395x, shall be authorized to operate a ~~residence for terminally ill persons, for the purpose of providing hospice home care arrangements including, but not limited to, hospice home care services and supplemental services.~~ **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.** ~~Such arrangements shall be provided to those patients who would otherwise receive such care from family members. The residence shall provide a homelike atmosphere for such patients and their family members, for a time period deemed appropriate for home health care services under like circumstances.~~ Any hospice that operates a **hospice facility or** residence pursuant to the provisions of this section shall cooperate with the Commissioner of Public Health to develop standards for the licensure and operation of such **facilities and residences** homes.

No doubt you are aware that over the last two years, 28 of the 29 hospices in CT worked cooperatively with the CT Association for Home Care & Hospice (CAHCH) and the CT Dept. of Health (DPH) to develop regulations for "hospice facilities". Those regulations include Hospice Residences as a type of hospice facility. Approval of those regulations would be a great step forward for the State of CT and its residents.

I served as President & CEO of the Stamford Hospice for 21 years. It was under my leadership that the Rosenthal Hospice Residence came into existence. Former Representative Christel Truglia provided critical assistance to the Residence by introducing legislation that allowed the Residence to serve as a pilot for the State of CT and by securing bonding money which was used to retrofit an existing building for use as the Hospice Residence. Christel is very knowledgeable about the Stamford Residence not only from a legislative perspective but a personal one as well. Her mother was admitted to the Residence for end-of-life care only a few months after it opened in 2000.

The pilot legislation included a sunset clause. The sunset date was extended several times but in 2007-2008, when there still were not any regulations for Hospice Residences, those in charge of the Residence at that time decided to apply for licensure as a SNF. While it allowed the Hospice to provide and bill for inpatient hospice care, it imposed many new regulations which did not enhance the hospice care that was being provided and it added significant operating costs. The Rosenthal Hospice Residence was closed in the fall of 2011 to the great dismay of the greater Stamford community.

I apologize if my testimony and suggestions for revised wording in this bill comes on too strong. It is due to frustration that after more than 30 years, the State of CT still lacks legislation and regulations that would not only ensure, but “promote”, access to all the components of hospice care for all the residents of the State. The closure of the Rosenthal Hospice Residence, which truly served the patients and families as it was intended to, has been permanently closed. Families are suffering as a result ... and that is shameful.

I thank you for your efforts to finally resolve this problem in 2012.

Sincerely,

Janice Casey, RN, MS

former President & CEO, Visiting Nurse & Hospice Care of SW CT  
former VP, Hospice & Home Care Services, Stamford Health Systems  
former director, National Organization for Hospice & Palliative Care, CAHCH, etc.