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Regarding Proposed Hospice Regulations

Hospice: it is a solemn word associated with the final weeks or days of life. Here in Stamford, through the sincerely dedicated care provided at the Richard L. Rosenthal Hospice Residence, it was a word that had come to mean hope, and a kind of nurturing that allows sorrowful endings to become profound, new beginnings. Hospice is about the quality of final experiences during those precious final days.

Connecticut proudly created the first American hospice in 1979, based upon, what was then, pioneering State regulations. However, the State has neglected to modernize these regulations to meet the naturally evolving needs of Connecticut's population. We have fallen from being innovators of conscientious care to a State that fails to provide accessible end-of-life care to all.

While Connecticut's current largest growing population is 85 years of age and older, our regulations allow for only one hospice residence in the entire State, denying the majority of patients and, their families, access to hospice care. The entire ideology that defines hospice requires that it be easily accessed within the very community that supported the life of the person who now faces death. If only one hospice was allowed to exist statewide, then Connecticut's entire mission to create a more humane, family based, community centered end-of-life support is completely eradicated.

Some have argued that end-of-life care can be met by hospitals or nursing homes. However, even with their adjunct hospice departments, hospitals remain focused on acute care and are not inherently equipped to provide the full range of patient and family support that is the singular mission of a hospice facility. Similarly, nursing homes also lack this singularity of focus. Their concentration is on long-term care or rehabilitation.

Nonetheless, however one wishes to view the ability of hospitals or nursing homes to act as fully functioning hospice facilities, patients facing death should have the right to choose the care of a *local* hospice if they so desire. This is a fact that drove Connecticut to initiate hospice care to begin with.

I have heard it said, "People don't get cancer, families do." This is so true because the lives of every single person in a patient's family will change forever as they share the anguish brought on by cancer or other serious illnesses. In Stamford, The Rosenthal Hospice had aided over 1,100 patients along with their families, enabling them to walk this uniquely arduous path in a home-like setting, in an atmosphere of comfort and privacy, with exceptional emotional and spiritual support. I have experienced firsthand this very special place, where families grew to include the staff whose compassion extended beyond typical healthcare, as if we, and our suffering, belong to them as well.

Here, most appropriately hospice meant family, one bigger than we could have imagined or hoped for. And most importantly, it was accessible. There was no added stress or strain of driving across the state, and the location meant that everyone within each patient's community could be present to the needs at hand and the anticipated passing as it unfolded.

At the Rosenthal Residence, hospice meant when someone is too ill to face the inevitable in their own beds, there was a home away from home easily accessible to them and their loved ones. It meant medical professionals who go beyond the textbook definition of their jobs to treat all patients and their families with added dignity and comfort.

Over 20 years ago a group of people had the dream of a local hospice facility and saw it realized in the best way possible through the Rosenthal Residence, only to have the harsh and sudden news of its closing forced upon us, with little to no time to find a solution to the previously undisclosed financial strain that took this essential gift from our community.

The Rosenthal Hospice is gone, not because it suffered financial losses due to a lack of need, a lack of community support, or because of a trend towards shorter patient stays. It's gone because of outdated, 30 year old State regulations that are not viable for a service of this kind in this day and age.

The residents of our State desperately need and deserve a broad network of community based hospice facilities. This is not simply a renewed dream of a small group, but rather an essential personal right that must be made available, conveniently to all, and can only be realized by the passing of new State regulations that allow such a facility to remain competitive and financially solvent. It is such a shame that the standing regulations were not reviewed and updated in time to save the Rosenthal Hospice. However, if the State acts quickly and wisely to pass more current and broader regulations, new community based hospice facilities can begin forming here in Stamford and across all of Connecticut.

When I was on the committee to create it, I thought I knew why the Rosenthal Hospice Residence was important to our community. I honestly didn't discover the depth of its importance until I was there, experiencing firsthand what felt like bottomless despair soothed by an environment and staff that blanketed my mother, and all who cared for her, with such mindful and tender attention.

Each day that passes without new regulations is a day where patients, with precious little time left here on this earth, are denied the comforts I witnessed and experienced first hand at the Rosenthal Residence; comforts that are not only their right, but are their very last wish.

I implore our State Legislature to pass these more viable and broader hospice regulations immediately.

Thank you -
with respects
Christel