

TESTIMONY

Delivered by Karen Mulvihill, Chair Palliative Care Advisory Council

Before the Public Health Committee

March 18, 2018

HB 5898: An Act Concerning Aid in Dying for Terminally Ill Patients

Senator Abrams, Representative Steinberg and members of the Public Health Committee, thank you for the opportunity to provide comments on HB 5898 on behalf of the Connecticut Palliative Care Advisory Council.

My name is Karen Mulvihill and I am currently the Chair Person of the CT DPH Palliative Care Advisory Council. The Council was created as per section 19a-60 (Appendix 1) of the General Statutes and requires the Department of Public Health to establish, within available appropriations, a Palliative Care Advisory Council to analyze the current state of palliative care in Connecticut; and advise the department on matters relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses. The Council consists of 13 appointed members.

Per the National Consensus Project for Quality Palliative Care Clinical Practice Guidelines – Fourth Edition

Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs and coordination of care. Palliative care attends to the physical, function, psychological, practical and spiritual consequences of serious illness. It is a person- and family- centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and family.

Palliative care is:

- Appropriate at any stage of a serious illness, and is beneficial when provided along with treatments of curative or life-prolonging intent.
- Provided over time to patients based on their needs and not their prognosis
- Offered in all care settings and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices and long-term care providers.
- Focused on what is important to the patient, family and caregivers, assessing their goals and preferences and determining how best to achieve them

Connecticut Palliative Care Advisory Council

- Interdisciplinary to attend to holistic needs of the patient and their identified family and caregivers

Palliative care principles and practices can be delivered by any clinician caring for the seriously ill in any setting. Palliative care focuses on providing patients with relief from the symptoms and stress of a serious illness and at the end-of-life. All clinicians should be encouraged to acquire core skills and knowledge regarding palliative care and to refer to palliative care specialists as needed. The goal of the council is to expand access to palliative care across the continuum of care in Connecticut.

The Council has identified gaps in access to quality palliative care in the State of Connecticut. The gaps are centered on a knowledge deficit of what palliative care and hospice provide. There are areas in the State where quality palliative care is lacking. It is the Council's opinion that there may be fewer requests for Physician Assisted Death with improved statewide access to high quality palliative care. The focus should be on access and promoting palliative care education, not only medical professionals but also the community at large.

Quality palliative and hospice care have been shown to improve quality of life from diagnosis through to death. Experts in palliative and hospice care can provide patients and families with a peaceful and comfortable death without crossing the ethical and moral line of suicide.

Having a qualified palliative care and hospice provider will:

- Ensure expert pain and symptom management to eliminate physical and refractory symptoms
- Determine and understand the bases of the patient's request for PAD
- Determine the decisional capacity of the patient
- Consult specialist as appropriate to manage pain and symptoms
- Establish short and long term goals
- Develop a plan for crisis symptom control
- Communicate effectively and compassionately

It is the recommendation of the Council to include language that:

- Requires Palliative care and Hospice consult for all patients requesting PAD
- Standardize a mechanism, as in psychiatric referral, to determine capacity of the patient when discussing PAD
- Palliative Care and Hospice education should be a key discussion point when discussing PAD with patients and their families.
- It is important to include the correct definitions of hospice understanding that Palliative Care is holistic care throughout the serious illness; whereas hospice care

Connecticut Palliative Care Advisory Council

is holistic palliative care once the serious illness becomes a terminal illness (with an anticipated prognosis of less than 6 months).

- Determining terminal prognosis is not an exact science and is a “best guess”. Many patients outlive a 6 month prognosis and go on to live several months or years beyond their initial prognosis. However, there are accepted standardized tools/scales used to predict prognosis. We strongly recommend that these tools (e.g, Karnofsky or FAST) be mandated as part of determining prognosis just as they are in determining hospice eligibility.

Please feel free to contact me for any addition questions. 203-676-3984.

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References

Guidelines for the Role of the APRN and RN When Hastened Death is Requested. Access at: https://advancingexpertcare.org/HPNA/Leadership/Position_Statements/HPNA/Leadership_Advocacy/Position_Statements.aspx?hkey=a794c17f-c88f-42d9-a09f-caf413e42aa3

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care: 4th Ed. (2018). Accessed at: <https://www.nationalcoalitionhpc.org/ncp/>