



TESTIMONY

Delivered by Tracy Wodatch, Vice President of Clinical and Regulatory
Services

The Connecticut Association for Healthcare at Home

Before the Public Health Committee

March 18, 2019

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

Senator Abrams, Representative Steinberg and members of the Public Health Committee, my name is Tracy Wodatch, Vice President of Clinical and Regulatory Services at the Connecticut Association for Healthcare at Home. I am also an RN with over 35 years' experience in home health, hospice, long term and acute care.

The CT Association for Healthcare at Home is the united voice for 25 of the 30 hospice providers in Connecticut. Our membership includes highly qualified, dedicated hospice provider experts who care for those facing terminal illness.

In a recent poll of our hospice provider agencies where 21 of the 25 responded, all are either opposed or neutral regarding their stance on this bill. None are in support of the bill. Regardless of stance, one message remains unanimous in that our Association and its hospice providers are committed to the hospice philosophy cherishing life until its natural end while reinforcing dignity, quality and comfort for both the patient and their loved ones.

According to the most current Medicare claims data from 2017, Connecticut ranks 2nd to last in the country (in front of rural Wyoming) in hospice median length of stay which still translates into "last minute hospice or end-of-life care." Our Association remains diligent in working with the provider continuum to promote hospice and palliative care



services and awareness with the goal of having informed consumers who know what options are available as they approach their end of life instead of waiting to have such conversations until the patient feels they have no choices. Perhaps this is why some feel a bill on Physician-Assisted Suicide is needed as the public may not be fully informed of the wide array of expert end-of-life services and supports available to them.

First and most importantly, the public and the providers frequently confuse hospice care and palliative care. I have included our flyer that defines both for your review. Essentially, Hospice is a holistic philosophy of care for the terminally ill in their last 6 months of life. Palliative care is also a holistic approach but should be offered early in a serious illness to help a patient and their family cope with side effects and the impact on their quality of life during treatment. In many situations, palliative care is offered once the patient becomes terminal, when in fact, the patient should be offered hospice care at this point.

Our society's emphasis on "cure" and the medical emphasis on intervention are often at the expense of good end-of-life care. Since practitioners and providers have been slow to embrace the practice and principles of palliative care (not offered early enough and often when it should be time for hospice) ultimately leaving hospice referrals for the final days, people think they have no other choice but to request physician-assisted suicide.

In response to this emphasis, Connecticut's healthcare provider collaborative efforts have focused on improving end-of-life care and advanced care planning initiatives. These efforts include:

- Educational programs on how to have conversations regarding end-of-life care options.
- The DPH MOLST (Medical Orders for Life Sustaining Treatment) is now statewide via Public Act 17-70 effective October 1, 2017 and encourages consumers with advanced serious illness to have the conversation with their physician helping to ensure informed decision-making and choice.
- The DPH appointed Palliative Care Advisory Council meets monthly and provides an annual report to DPH Commissioner with



recommendations to enhance awareness and standardization of Palliative Care services in CT.

- Also, in January 2018, the CT Association for Healthcare at Home launched standardized Hospice training for skilled nursing facilities in CT.

These are all efforts to help the public and the provider understand that there are many options for comfort and quality of life as one approaches the end of life. Instead of considering legalizing Physician-Assisted Suicide, let's instead focus our efforts on the essence of hospice care which is to allow patients to make the most of their remaining time. Hospice values people's lives until their natural end, making their death a true "death with dignity."

Here are some of the things Hospice and Palliative Care providers can do:

- Offer expert, compassionate relief of pain and suffering at end of life enhancing the quality of both living and dying.
- Strive to help patients and families deal with important physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears.
- Promote opportunities for meaningful experiences, and personal and spiritual growth so patients may live life to the fullest and die with dignity.
- Assist patients and families cope with loss and grief through best-practice bereavement support for up to 13 months following the death, and
- Support the patient's right to participate in all decisions regarding their care, treatment and services based on knowledge and access to all forms of treatment that have been shown to enhance quality of life and reduce suffering.

Should this bill move forward out of committee, we have grave concerns about some of the language within the bill itself which, in our minds, leaves much reasonable doubt. We recognize the attention that this bill has assumed in your committee and in the public. As you continue to debate this issue, we ask that you consider several specific concerns not addressed



currently or not defined/outlined in enough detail within the language of the bill.

- Under definitions:
 - Section 1.9, line 46 should read *“including, but not limited to, hospice care.”* Not palliative care...If someone is seeking this medication to end their life then they would/should have a prognosis of 6 months or less which means they would qualify for hospice care.
 - Section 1.11
 - *“Palliative Care” (A):* should read *...throughout the continuum of a patient’s serious (not terminal) illness.*
 - Under the same section, hospice care is mentioned briefly yet not defined and not encouraged. Please consider adding a definition for *“Hospice Care”* understanding that Palliative Care is holistic care throughout the serious illness; whereas hospice care is holistic palliative care once the serious illness becomes a terminal illness (with an anticipated prognosis of less than 6 months).
 - Section 1.18: *“Self-Administer”* is not just the act of ingesting medication. This definition needs to include the act of managing the medication as well. Families, friends, care providers should not be responsible for handling the medication at all. The person seeking Aid in Dying should be completely independent in preparing the medication and ingesting it. There should be no assistance from others.
 - Section 1.19: For a person to qualify for the hospice benefit, 2 physicians must determine that the patient has six months or less to live if the terminal illness runs its normal course. We highly recommend that at least 2 physicians determine prognosis is terminal in order for a patient to obtain this medication that will end their life.
- Determining terminal prognosis is not an exact science as many people 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.

- To avoid subjectivity in determining the competency (both cognitive and for s/sx's of depression) of the patient requesting a physician to assist in his/her suicide, we strongly recommend that the physicians determining competency use a standardized validated tool for both cognitive and depression assessment. And, physicians need to be trained in assessing and evaluating based on these tools. The bill doesn't adequately address this vital issue.
 - Research shows that depression is one of the most underdiagnosed illnesses among the elderly and seriously ill.
 - Left untreated, depression increases risk for morbidity, suicide, decreased cognitive and social functioning, self-neglect, and early death. Despite the devastating consequences, clinicians fail to diagnose up to 50% of depressed patients seen in primary care practices. If they are accurately diagnosed, only 22% receive adequate treatment, partly because practitioners fail to recognize depression's red flags - See more at:
<http://www.pharmacytimes.com/publications/issue/2011/January2011/Counseling-0111#sthash.Nhlnsk5H.dpuf>
- A glaring hole in this bill is the issue surrounding the physician being asked to provide a prescription for the lethal drugs.
 - Most importantly is the definition of "attending physician" described as the physician who has primary responsibility for the medical care of a patient and treatment of a patient's terminal illness.
 - Because many physicians don't (Oregon and Washington) or won't (reported in other states) prescribe lethal drugs to hasten someone's death, patients are forced to physician shop...they are desperate to find a physician willing to prescribe the lethal drugs. Hence, it would not be their "attending physician."
 - In Oregon, some physicians prescribe lethal drugs for patients whom they have only known as little as one week or less. Again, not their "attending physician."



- In Washington in 2010, half of the patients had a “relationship” with the physician prescribing the lethal drugs of only 3-24 weeks.
- This lack of a long-term relationship challenges the physician’s ability to truly understand the patient’s emotional and psychological state.
- With our nationwide opioid crisis, the disposal of unused medications has become problematic. This bill does not adequately address protections needed for powerful, death-inducing unused medication. It simply states unused medication needs to be returned to the attending physician or the Commissioner of Consumer Protection...
- There is no mention of the pharmacist’s role and responsibilities. I was recently informed that there is only one pharmacy in the southern area of rural Vermont that’s willing to fill such prescription.
- The cause of the death on the death certificate should not be the underlying disease. As “barbiturate overdose or toxicity” actually caused the death.
 - Putting the underlying disease as the cause is lying and also misinforms state and national statistics that are gathered annually.
 - Given the inexact science of determining a projected prognosis of a disease, a natural death may be for a number of reasons other than the underlying disease itself.
- There are no requirements in this bill to collect data regarding the incidence of requests, filled scripts and ingestion resulting in death. Some of the other states where this is legal, have processes in place and produce detailed annual reports outlining trends. This should also be mandated in Connecticut.
- Finally, any person requesting Physician-Assisted Suicide as outlined in this bill should first be required to have a Hospice and Palliative Care consult.

Despite all the reasons to promote good hospice and palliative care practices, early conversations to promote fully informed decision-making based on the individual’s goals of care, and early referrals to the appropriate level of care, this bill may pass this year or in some year to



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come in Connecticut. Should that day come when it is legal to allow physician-assisted suicide, the Association and its members strongly urge our state to develop a well-thought out plan for good policy and education along with standardized implementation plans and oversight to ensure the protections of both the consumer and the provider. The CT Association for Healthcare at Home and some of its Hospice and Palliative Care members would be interested in offering our expertise to assist in the development of such a plan.

Thank you for considering our association's testimony. If you have any further questions, please contact me directly at Wodatch@cthealthcareathome.org or 203-774- 4940.

Respectfully submitted,

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