

Testimony in Support of Raised H.B. No. 5898:
An Act Concerning Aid In Dying For Terminally Ill Patients
Public Health Committee Hearing
March 18, 2019

Good Morning: Representative Steinberg, Senator Abrams, Ranking Member Petit, Ranking Member Somers and honorable members of the Public Health Committee. Thank you for the opportunity to provide testimony in support of Raised H.B. No. 5898: An Act Concerning Aid In Dying For Terminally Ill Patients.

I am Shannon E. Sanford, MSN, RN, I currently teach nursing, including clinical practicum with hospice patients. I am working on my doctoral degree in nursing education. I studied the Oregon Death With Dignity Act in detail when I earned my Master's as an Oncology Clinical Nurse Specialist at the Yale School of Nursing. It is within this context that I offer my testimony in support of Raised H.B. No. 5898: An Act Concerning Aid In Dying For Terminally Ill Patients.

An important factor to consider in passing this bill is the effect that it will have on nurses. As a member of the American Nurses Association (ANA) I am pleased to share with you that the organization has recently issued a draft document entitled "The Nurse's Role When a Patient Requests Aid in Dying" in order to solicit public comment on how the nurse ought to handle these requests when the law allows for them. While I am unable to cite from this document, given it is only a draft, I share this information as an example of the ANA's willingness to consider the need to have a position statement for the membership as Aid in Dying is now legal in eight states (California, Colorado, District of Columbia, Hawaii, Montana, Oregon, Vermont, and Washington) with legislative initiatives taking place in several others.

Consistent with previous organizational statements from the ANA including, "*Euthanasia, Assisted Suicide, and Aid in Dying*," and "*The ANA Code of Ethics for Nurses*," the proposed document is clear to state that direct administration of medications to hasten death by the nurse is prohibited; however, the overall tone of "The Nurse's Role When a Patient Requests Aid in Dying" is one of engaged neutrality towards having these discussions with patients provided the patient initiates the conversation. This demonstrates a shift in thinking towards patient-centered care, as it allows nurses the ability to communicate freely with patients on aid in dying issues. The ability of the nurse to engage the patient in a non-judgmental discussion of the reason behind his or her request for aid in dying is essential in order to ensure the patient understands the complete range of medical options that are available and chooses the one that is consistent with his or her own values and priorities.

On a more personal level, I have advocated on behalf of the legislative effort to legalize medical aid in dying since becoming a Registered Nurse in 1999. I witnessed the death of my father from multifocal liver cancer while I was in nursing school. My father was a high school teacher and supporter of the death with dignity movement. He was not the type of person who wanted to linger in protracted dying. Unfortunately that is exactly

what happened to him. He was what you would call a late referral to Hospice care, having died less than 2 weeks after being on their service. My dad suffered from several co-morbid health conditions including emphysema, which required him to sleep in a recliner chair and to be dependent on steroids and oxygen, in order to feel comfortable breathing. In retrospect he would have benefited from a palliative care referral long before he received the liver cancer diagnosis.

If my dad could have had complete autonomy he would have died in his recliner chair at home, on a day of his choice, surrounded by his family, having utilized medical aid in dying legislation. Instead, he died in his home, in a rented hospital bed, after days of slowly dying from no longer eating or drinking, responding only in pain, as our family watched and I injected him with morphine every 2 hours in an attempt to keep that pain at bay. My dad never met his primary hospice nurse (she was on vacation). Different float nurses visited our family; and each time it seemed as if we fought battles in order to get proper care for my dad. I am willing to share more details if you ask me. There was zero continuity of care, in an area where continuity is so vital.

I do want to be clear that I believe my dad died surrounded by loved ones and his pain was managed. However his entire hospice experience could have been much improved. I like to think that my dad still teaches in his death. My experience caring for him guides me to teach about comprehensive patient-centered palliative and Hospice care to my students. It also influenced my dissertation topic on improving communication in palliative care.

The thing that breaks my heart about my dad's death is that I wish I could have given him the autonomy he would have wanted at the end of his life. That is why I continue to testify on behalf of aid in dying legislation and make myself available to educate and answer questions. It is too late to advocate for my dad, but I will continue to advocate on behalf of my patients. Thank you for your consideration and support of Raised H.B. No. 5898: An Act Concerning Aid In Dying For Terminally Ill Patients.

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