

Testimony to Aging and Long-Term Care Committee In Support of House Bill #286 October 3, 2017

Sarah Hook, MSN, RN, APRN, AGCNS, ACHPN
Palliative Care Advance Practice Nurse for Palliative Care of Central Ohio

Good afternoon Chairman Arndt, Vice Chair Pelanda, Ranking Member Howse and members of the committee. Thank you for the opportunity to testify today on House Bill 286 which establishes the Palliative Care and Quality of Life Interdisciplinary Council as well as the Palliative Care Consumer and Professional Information and Education Program under the direction of the Ohio Department of Health. My name is Sarah Hook, and I am a Palliative Care Advance Practice Nurse for Palliative Care of Central Ohio.

In 2006, the Hospice of Central Ohio developed and implemented Palliative Care of Central Ohio, a non-hospice palliative care program. Our palliative care program serves our nine-county community as well as Licking Memorial Hospital. I have had the privilege of working as an advance practice nurse with Palliative Care of Central Ohio for the past three years. As a palliative care clinician, I am the expert in complex symptom management, goals of care discussions and Advance Care Planning. Palliative Care of Central Ohio has grown over the years to a current census of 200 patients a day. We see our patients wherever they call home as well as providing inpatient support at our local hospital.

Over the past decade, a multitude of studies have shown the benefits of palliative care, including improved quality of life, reduced patient and caregiver burden, and an overall reduction in total health care costs. There has been a significant increase in the availability of palliative care, specifically in larger hospitals, but gaps in access remain, the consequence being that many people with serious illness are not able to receive this kind of person-centered care when it is most needed. We support House Bill 286 because it will help structure a palliative care framework for Ohioans and further integrate standards of practice throughout Ohio.

Let me walk you through a sample of a day in my shoes.

A typical day for me begins in the intensive care unit at our local hospital. Palliative care is specialized medical care for people with serious illness, and the intensive care unit houses the most seriously ill patients in the hospital. My day begins with interdisciplinary rounds including a hospital team of comprised of social workers, chaplains, nurses, hospitalists, and specialty physicians. With my specialized skills in identifying patients with serious illnesses at risk for less than optimal outcomes, I collaborate with the interdisciplinary team and consult with patients and families who I often meet at the worst time of their lives. On this particular day, I met a 56-year-old woman who became pulseless and unresponsive due to an unfortunate reaction to a chemotherapy drug being used to combat her breast cancer. She was on a ventilator, and her family was at the bedside, their faces were filled with worry and apprehension. When I introduced myself, and told them that I was with the Palliative Care team, they did not know what that meant. I went on to describe that I was there to walk with them through this scary time and to help them understand the medical care that was being provided and to review options for care moving forward. I explained that I would focus my time and energy on ensuring that the patient was comfortable and free from pain and distressing symptoms. I would be their cheerleader, their support person, and their advocate, not only in the hospital

but with our community-based palliative care program I would continue to walk with them after discharge as well. To a degree, their signs of stress and worry lessened from their faces.

I followed this patient throughout her hospital course, as she was successfully weaned from the ventilator and returned home with her family. Through community-based palliative care, I've remained in close contact with the patient and her family. I ensure her care and treatments remain in line with her overall goals and that she is living with the highest quality of life and optimal symptom management so she can continue to be successful with her ongoing cancer treatment. Currently, she remains in treatment for her cancer and has not been hospitalized again.

Following my morning of rounds and consults at the hospital, I visit my community-based palliative care patients in their homes. Next, I see a 60-year-old male with COPD who lives in a low-income apartment building with his spouse. Palliative care was originally consulted to see this patient in 2013 by his pulmonologist following a repeating cycle of hospitalizations for shortness of breath and anxiety caused by his COPD. Along with COPD, this patient suffers from bipolar disorder, making his chronic disease management even more of a challenge for all involved. Over the past four and a half years, palliative care has collaborated with the primary care physician and pulmonologist to develop an optimal medication regimen that has allowed this patient to have better relief from his symptoms while preventing further COPD related hospitalizations. I've collaborated with home care and durable medical equipment agencies to ensure this patient has the support and equipment he needs to remain successful in his home. During my visit in the home, I perform a physical assessment, review medications – being sure to look at each medication bottle for accuracy. I review any new symptoms or problems – always focusing my visit on what is most important to the patient at that time, and I say hello to the family cat. Through regular monthly visits over the past four and a half years, palliative care has been an integral part of this patient's healthcare team and has allowed him to live a better life with a serious illness.

The rest of my day is filled with similar visits, seeing patients dealing with serious illness in need of symptom management, advance directives discussions, and patient-centered well-coordinated care. Guided by the Clinical Practice Guidelines for Quality Palliative Care, which were developed by the National Consensus Project for Quality Palliative Care, we strive every day to provide palliative care that improves patient and caregiver quality of life. This approach assists the healthcare team to maintain a focus on the patient's goals of care, resulting in an efficient and effective plan of care that avoids unneeded or unwanted resources and helps reduce or control costs.

In summary, Palliative Care of Central Ohio supports House Bill 268. We believe The bill will help identify matters and standards of practice for palliative care initiatives in the state. We also support the language which would allow those hospice providers which operate independent inpatient units to use those resources to serve non-hospice palliative care patients, who at times move from their community to inpatient settings and back to the community. As other specialty care environments have developed, dialysis, cancer, pulmonary, even maternity, we see a benefit in caring for many of these patients in a dedicated unit of care. This legislation removes an unnecessary barrier to accessing the full potential of these inpatient facilities and allows for a focused level of palliative care to best meet the needs of the patient.

Finally, let me say how appreciative I am of Representative LaTourette for sponsoring this bill and for using her experience and understanding of the needs of seriously ill Ohioans. I am humbled to work in community-based palliative care and am looking forward to what the future holds in Ohio for this special field. Thank you for your time today. I am happy to answer any questions the committee has.

Sinclair, Stacie & Diane Meier. "How States Can Expand Access to Palliative Care." January 30, 2017. Health Affairs Blog. http://healthaffairs.org/blog/2017/01/30/how-states-can-expand-access-to-palliative-care/.