



February 1st, 2024

Senator Stroebel, Chair

Members of the Senate Committee on Government Operations

Testimony on 2023 Senate Bill 703
Relating to: establishing a Palliative Care Council.

Thank you, Chairman Stroebel and other members of the committee, for hearing my testimony on Senate Bill 703 today. Health care is a complex world; different people have different conditions that require different levels of care. Palliative care is not limited to any age or prognosis, but instead focuses on helping anyone with a serious or chronic illness with tailored support to improve the quality of life.

Palliative care treatments range from person to person, but in general, palliative care often includes: medication, nutritional help, emotional and spiritual support, relaxation techniques, and support for the patient's family. The treatment timeline also varies depending on if a patient is able to make a full recovery, it's a lifelong chronic condition, or it eventually evolves into a terminal illness. This differs from hospice care, which is end-of-life care for those with life-threatening illnesses with an expectancy of six months left to live. Palliative care teams also work with social workers and chaplains to provide a comprehensive treatment approach. This type of treatment should be available to any patient or family that wishes to utilize it, but unfortunately, lack of access and education on palliative care prevents people from utilizing it.

That is what legislation aims to address. This bill would establish a Palliative Care Council through the Department of Health Services, with a goal of trying to promote the education and awareness of palliative care. This 22 person council would be comprised of medical and clinical professionals, as well as actual patients and families from all over the state to work with DHS on the following palliative care issues: evaluating established palliative care programs, the effectiveness of palliative care that is provided along with treatment, the reimbursement for palliative care services, and any other issues relating to palliative care the council finds appropriate. This bill also requires DHS and the council to establish educational and informational programs for patients and professionals about palliative care services.

Living with a chronic or serious illness takes a toll on the patient, family, friends, and other caregivers. Palliative care aims to help everyone involved with the healing and treatment process. This tailored care helps improve the quality of life for these patients and is worth investing in. Thank you, and I will take any questions at this time.

Respectfully,

A handwritten signature in black ink, appearing to read 'Jesse James'.

Senator Jesse James

23rd Senate District

Sen.James@legis.wisconsin.gov



PATRICK SNYDER

STATE REPRESENTATIVE • 85th ASSEMBLY DISTRICT

Testimony in Support of Senate Bill 703

Senate Committee on Government Operations

February 1, 2024

Chairman Stroebel and Members of the Committee:

For those unfamiliar, palliative care is a specialized type of medical care delivered by a team of caregivers – physicians, nurses, social workers, spiritual care professionals – that provides patients with relief from the symptoms and pain of life-limiting illnesses, including Alzheimer's Disease, Amyotrophic Lateral Sclerosis (ALS), cancer, congestive heart failure, and other conditions. Palliative care is designed to support not just the patient, but also their families as the patient undergoes treatment intended to cure their condition.

While there are numerous successful palliative care programs throughout Wisconsin, there are barriers in place to access this type of specialized medical care. One barrier is the limited number of palliative care health care providers in Wisconsin. Additionally, there simply isn't enough information about palliative care available to educate providers and those individuals who could potentially benefit from this amazing resource.

This bill addresses these issues by creating a Palliative Care Council through the Department of Health Services to promote high quality palliative care, as well as work towards improving awareness and access to this specialized type of medical care. This council would have 22 members, including physicians, nurses, a spiritual care professional, palliative care patients or their family members, and a bipartisan group of legislators. Under the bill, the council would be required to meet at least twice per year in different parts of the state. Specifically, the council would:

- Consult with and advise DHS on various aspects of palliative care, including outcome evaluation of existing palliative care programs, the economic and quality of life effectiveness of palliative care, as well as palliative care reimbursement from insurance providers.
- Submit a recurring report to the Legislature addressing access to palliative care, as well as the impact of such care.
- Work with DHS to create a palliative care information and education program focused on the general public and health care providers.
- Not be permitted to consult with and advise DHS on euthanasia or related matters.

Thank you for allowing me to testify on this bill today. This bill is incredibly important to me because I know the benefits of palliative care first hand, after seeing how it benefited my father and promoted the quality of his life in his final years. I am happy to answer any questions you may have.



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Kirsten L. Johnson, Secretary

TO: Members of the Senate Committee on Government Operations
FROM: HJ Waukau, Legislative Director
DATE: February 1, 2024
RE: SB 703 relating to: Establishing a Palliative Care Council

The Wisconsin Department of Health Services (DHS) would like to submit written testimony for information only for Senate Bill 703 (SB 703), relating to the creation of a Palliative Care Council (Council) within DHS. SB 703 specifies the size, member requirements, and responsibilities for the Council. It also requires the Council to consult and advise DHS on the evaluation of established palliative care programs, the economic and quality of life efficacy of palliative care, mechanisms for reimbursement of palliative care, best practices, and any other palliative care issues the Council would determine as appropriate; and submit reports to the legislature. DHS would also be required to establish and make publicly available a statewide palliative care consumer and professional information and education program. Additionally, SB 703 prohibits the Council from consulting with or advising DHS on physician-assisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any act to end life other than the withholding or withdrawing of health care under an advance directive or power of attorney for health care.

It is well documented Wisconsin has an increasingly aging population with those who are age 60-plus growing 38 percent since 2010.¹ As Wisconsin's population continues to age palliative care is likely to play an increasing role in how people receive care and treatment. Palliative care as a treatment modality has been shown to improve quality-of-life outcomes for patients,² lower costs and hospital visits,³ and improve both patient and family experiences.⁴ It has been shown to be an effective method of treatment for a wide range of illnesses⁵ including but not limited to cancer,⁶ pediatric care,⁷ and dementia.⁸

¹ "Vintage 2022 Estimates of National, State, and County Population by Age, Sex, Race, and Hispanic Origin; and Estimates of Puerto Rico Commonwealth and Municipios Population by Age and Sex," United State Census Bureau, last accessed January 8, 2024, <https://www.census.gov/newsroom/press-kits/2023/population-estimates-characteristics.html>.

² S Milazzo et al. "How Effective is Palliative Care in Improving Patient Outcomes," *Current Treatment Options in Oncology* 21, no. 12 (2020) doi: [10.1007/s11864-020-0702-x](https://doi.org/10.1007/s11864-020-0702-x).

³ KL Quinn et al. "Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study," *BMJ* 370 (2020) doi: [10.1136/bmj.m2257](https://doi.org/10.1136/bmj.m2257).

⁴ M Glajchen et al. "Family Meetings in Palliative Care: Benefits and Barriers," *Current Treatment Options in Oncology* 23, no 5 (2022) doi: [10.1007/s11864-022-00957-1](https://doi.org/10.1007/s11864-022-00957-1).

⁵ AE Singer et al. "Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review," *Journal of Palliative Medicine* 19, no. 9 (2016) doi: [10.1089/jpm.2015.0367](https://doi.org/10.1089/jpm.2015.0367).

⁶ J Mathews et al. "Models of Integration of Specialized Palliative Care with Oncology," *Current Treatment Options in Oncology* 22, no. 5 (2021) doi: [10.1007/s11864-021-00836-1](https://doi.org/10.1007/s11864-021-00836-1).

⁷ MS Weaver et al. "Palliative Care as a Standard of Care in Pediatric Oncology," *Pediatric Blood & Cancer Suppl* 5, (2015) doi: [10.1002/pbc.25695](https://doi.org/10.1002/pbc.25695).

⁸ N Weisbrod, "Primary Palliative Care in Dementia," *Neurotherapeutics* 19, no. 1 (2022) doi: [10.1007/s13311-021-01171-x](https://doi.org/10.1007/s13311-021-01171-x).

The Council created under SB 703 could help in promoting awareness and best practices for palliative care in Wisconsin. Neighboring states Minnesota and Illinois have also created palliative care councils with similar requirements and structures as SB 703. Under SB 703, DHS would be responsible for developing consumer and professional education materials, external communications such as a website, coordinating between council members and the legislature, and assisting with meeting logistics. 1.0 FTE would be needed for the communication and education activities and a 0.5 FTE would be needed for coordination between council members, the legislature, and meeting logistics. The Council will also incur operational costs for materials, equipment, lodging, meeting space, and other related costs. DHS estimates the staffing needs will cost \$117,200 GPR annually and the operational costs will be \$23,766 GPR, for a total estimated cost of 1.5 FTEs and \$158,216 annually. SB 703 as currently drafted does not provide funding for DHS to administer and oversee the functions of the Council. By comparison Minnesota provides for administrative services for its council, and Illinois provides for reimbursement of council member expenses.

Additionally, DHS does not oversee the scope of practice for the professions that would be on the Council, nor does it have expertise in the area of palliative care. As such this would be a new program area for DHS to develop. While evaluating and promoting best practices for palliative care may be worthwhile endeavor, DHS does not currently have the capacity or expertise to sufficiently run a Council. Without sufficient funding for operations DHS would not be able absorb the costs of a Palliative Care Council as defined by SB 703 at this time.

DHS thanks the Committee for the opportunity to provide written testimony for information only and offers itself as a resource for the Committee.



Moving Wisconsin Hospice & Palliative Care Forward

TO: Members of the Senate Committee on Government Operations

FROM: Danielle DiGennaro, MSN, APNP-BC, ACHPN
*Director of Supportive Care, Agrace
on behalf of the Wisconsin Hospice & Palliative Care Association (WiHPCA)*

DATE: February 1, 2024

RE: Senate Bill 703, related to creation of a Palliative Care Council to advise the Wisconsin Department of Health Services and provide reports to Legislature.

Good morning, Chair Stroebel, Vice Chair Bradley, Ranking Member Roys, and members of the Senate Committee on Government Operations.

My name is Danielle DiGennaro, and I am the Director of Palliative Care at Agrace, which is a nonprofit, community-based health care agency; I have been a palliative care nurse practitioner for nine years. Agrace provides hospice and supportive/palliative care services in private homes, and in skilled nursing, assisted living and other community based residential facilities across southern Wisconsin. Agrace is a member of WiHPCA – the Wisconsin Hospice and Palliative Care Association.

I have worked in four states and at multiple institutions including private, non-profit, and academic health centers. While each state's scope of practice, licensing and regional practice patterns vary, one consistent element has been the lack of understanding of palliative care. According to the Center to Advance Palliative Care (CAPC), "**Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness.** The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by a specially trained team...to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis...and it can be provided along with curative treatment."

Throughout my practice, I have expected to educate patients and families on the nuances of palliative care services, however, I am routinely surprised by the lack of understanding among the public and medical professionals. I was fortunate to start an inpatient palliative care service at a 550-bed hospital and during my seven years there, I interviewed physicians on how they utilize palliative care and where they see added benefit to their practice and patients. The most frequent, and honest, answer was "I don't know exactly what palliative care is, but I know when I need help on a case". While it is fortunate that those providers recognized when extra support provided superior care, it is disappointing to hear the continued lack of understanding around palliative care - even within the field of medicine.

Palliative care continues to be considered a relatively new medical field and was born out of hospice care. It wasn't until 2006 that the American Board of Medical Specialties recognized hospice and palliative care as separate specialties. There are multiple studies that show disease directed therapy, concurrent with

palliative care, reveals patient-centered benefits such as increased quality of life and, in some cases, increased survival.

The proposed legislation will help combat misunderstandings regarding this important medical specialty, which focuses on improving quality of life. The multidisciplinary council proposed will have a breadth of experience, including medical professionals, a health insurance representative, members of the Legislature and importantly, patients and families. I'll end with a story, and while the details have been slightly changed to protect patient privacy, it exemplifies common themes throughout palliative care.

Sarah is a palliative care patient suffering from chronic obstructive pulmonary disease (COPD). She lives with her adult son and is on home oxygen. She is hard of hearing. She gets overwhelmed easily by clinic appointments, including the quick questions and the walk through the facilities. She finds herself anxious and increasingly short of breath as the visit unfolds. As a result of her increasing anxiety and resulting shortness of breath, she has frequent emergency room visits, rarely resulting in hospitalization and instead providing reassurance and discharge. Palliative care was involved at the request of her pulmonologist, who struggled to be as responsive and available as Sarah and her family needed to keep her out of the emergency room. A palliative care team worked closely with Sarah's primary care provider, pulmonologist, and family, coordinating care, and providing visits at her home. Her palliative care team included providers who helped prescribe medications to ease her symptoms, but also provided education about her prognosis and what to expect in the future. The palliative care social worker was available to provide options such as in-home care and placement should her care become overwhelming for her family. Ultimately, she was able to significantly reduce her emergency room utilization and spend more time at home, with an improved quality of life.

For Sarah, palliative care could have been integrated into her care sooner to help avoid emergency room visits related to uncontrolled symptoms. By eliciting goals of care from individual patients and families, palliative care can help align stated goals with what medical care is reasonable. It would have been expected for a palliative care team to partner with Sarah earlier in her illness trajectory and describe what to expect, such as worsening symptoms with exertion, like walking into a clinic. Earlier intervention may have also collaborated with physical therapy to build strength or request an assist device such as walker or wheelchair or help obtain a handicapped parking permit.

The creation of a Wisconsin Palliative Care Council could help elevate awareness of palliative care among providers – thereby helping more patients like Sarah, and their families.

Thank you for your time and consideration of my testimony in support of Senate Bill 703. Please contact WiHPCA's government relations representatives, Tim Hoven (at 414.305.2011 or tim@hovenconsulting.com) or Nathan Butzlaff (at 608.310.8833 or nathan@hovenconsulting.com) if you have any questions or need additional information.

TO: Members of the Senate Committee on Government Operations

FROM: Najmus Sehar Liang, MD
Medical Director, Wisconsin, VITAS Healthcare

DATE: February 1, 2024

RE: Senate Bill 703 – a bill establishing a state palliative care council

Good morning – Chair Stroebel, Vice Chair Bradley, Ranking Democratic Member Roys – and committee members.

I thank the committee chair for scheduling a hearing on Senate Bill 703, a bill that I support. I am a board-certified family medicine and palliative and hospice care physician. I have been practicing palliative and hospice medicine for the last 6 years and have been graced by the utmost heartwarming and bittersweet encounters.

My training in palliative and hospice care was at a well-established hospital network in Bethlehem, Pennsylvania. As a full-fledged palliative physician, I moved to Wisconsin to lead an established palliative care practice consisting of a social worker, licensed nurse, chaplain, and two advanced practitioners. We as a team had the opportunity of establishing a palliative consulting service for patients suffering from life-limiting diseases in the hospital and offer these individuals individualized care plans including understanding values, goals, and addressing symptoms including pain, anxiety, and depression.

It took over a year to have others, including cardiologists, pulmonologists, interventional radiologists, intensive care unit clinicians, emergency department clinicians, and physical/speech/occupation/respiratory therapists to understand the true value of palliative care services when it is offered and practiced by compassionate, highly trained, and dedicated staff.

Within two years during my first role as a palliative care physician, we were able to reduce re-hospitalization rates, have the quickest palliative care referrals out of all the other hospitals in the network, and have our emergency department geriatric-palliative care certified. Not only was our work recognized at the local level, but we also received grants and donations from patients, families, and community members as they understood the value of patient-oriented care with an entire team dedicated to their advocacy.

Palliative care is a service like any other medical specialty, except the individual is not looked at as a single failing organ system. This type of care can be provided at any age and any stage in someone's disease trajectory, with a focus on excellent symptom management and support for any individual and their loved ones.

The most regretful aspect of my career as a palliative care physician is the question that I have been asked over a thousand times by patients and families – a question that I am still not able to answer – “Why didn't we meet you sooner?” Indeed, there are studies that prove that when palliative care is involved at the time of a cancer diagnosis, those patients live longer and have a better quality of life. We know from experience that navigating the healthcare system is exquisitely challenging and to have access to a team dedicated to your loved one's dignity, quality of life, and values whilst they are battling with a life-threatening illness can only ameliorate their situation and give their loved one peace of mind.

In writing this testimony, so many individuals and their loved ones came to mind, but I wanted to share a story of a 48-year-old husband and father. Unfortunately, the father has a rare genetic disease that only a few people have in the entire world. This disease is so debilitating and rare that it usually is not diagnosed.

This patient spent the majority of his adulthood with debilitating bone pain, kidney stones, fractures, and strains/sprains of his muscles without any known cause. When this individual finally did get diagnosed and was under the care of an endocrinologist, he was able to self-advocate for a referral to palliative care services.

Various members of his palliative care team contributed to his care, including a palliative social worker, who worked on insurance approval for his multimillion-dollar treatment; a chaplain, who provided psychosocial support not only for him but his family; and a registered nurse, who had discussions about medication education with the patient.

In addition, his palliative clinician collaborated with an endocrinologist, an orthopedic surgeon, the hospital team, and a pharmacist to put in place a concise plan of care to address his significant pain. This plan required medications that were previously only allowed to be administered in a hospital setting – either in the emergency department or requiring hospitalization with heart monitoring. After his palliative care team advocated for him by educating the hospital's medical committee, the hospital approved a protocol in which the pain medicine could be administered orally, instead of via injection. Additionally, when this young father had to have elective surgery, his palliative provider consulted with his anesthesiologist and surgeon regarding his intra-operative and post operative pain regimen.

It's quite a process for someone to be admitted to the hospital and get pain medications. I am proud to share this successful story of how palliative care services can benefit not only the person dealing with life-limiting disease, but also their loved ones.

Senate Bill 703 would help improve awareness of palliative care in Wisconsin among the general public and health care providers. There is a dire need for more trained professionals that choose palliative care as their calling. Ultimately, the creation of a palliative care council would help more patients access this type of valuable care.

Again, thank you for holding a hearing on Senate Bill 703. I am happy to answer any questions you may have.



American Cancer Society Cancer Action Network
Sara Sahli, WI Government Relations Director
608.215.7535
sara.sahli@cancer.org
fightcancer.org/wisconsin

February 1, 2024

Chairman Duey Stroebel
Senate Committee on Government Operations
Public Hearing, Senate Bill 703

Good morning, Chairman Stroebel and members of the committee, my name is Sara Sahli, I'm the Government Relations Director for the American Cancer Society Cancer Action Network (ACS CAN) in Wisconsin. ACS CAN, our board members, our volunteers, and our staff advocate for public policies that reduce death and suffering from cancer.

I am here today to testify in favor of Senate Bill 703 which seeks to improve health care quality and outcomes, through the delivery of patient-centered and family-focused care by establishing a state advisory council on palliative care. I also bring messages of support from our volunteer leadership team with me today. I'd like to recognize and thank Senator James as the lead sponsor as well as Representative Snyder in the Assembly. This bill has bi-partisan support and recently passed unanimously out of the Assembly Committee on Health, Aging and Long-Term Care.

Palliative care is a type of coordinated care that is designed to work alongside curative care by treating the whole patient, not just the disease. It is appropriate at any age and any stage – whether the diagnosis is chronic or terminal - and is designed to improve the quality of life for a cancer patient, and by extension, their family, and caregivers by providing an extra layer of support. A patient's palliative care team focuses on things such as relieving pain and managing treatment-related physical, emotional, social, financial, and spiritual needs. The team itself might include a social worker, an occupational therapist, a physical therapist, a mental health professional, a dietician, and if appropriate, a chaplain. Each team is designed to treat a specific patient, but whatever the case, the goal is to improve quality of life and help reduce health care costs.

Improving the quality of life for cancer patients during and after treatment is one of the American Cancer Society, and the American Cancer Society Cancer Action Network's main goals. Studies have shown that when palliative care teams work together with oncologists, patients are able to remain at home – they don't end up in the ER and hospital with pain and symptom crises. As a result, they go through fewer unnecessary tests and procedures, which in turn leads to lower costs. In short, palliative care programs provide higher-quality care for patients and a better bottom line.

While palliative care is a rapidly growing specialty, it is still not found in all areas of the state, which is why it's important to identify existing barriers to this care and ensure that accurate, comprehensive information and education about it is made available to the public, health care providers and health care facilities. ACS CAN contends that SB 703 is key to doing this, and in fact 35 other states have passed similar legislation.

Establishing a committee that can evaluate the palliative care system in Wisconsin and make policy recommendations to the legislature on how to improve it will help all patients with serious or chronic conditions and their families get the care and support that they need. Palliative care, especially the parts of palliative care that do NOT address end-of-life care, have received little attention at the state level, and with Wisconsin's coming age wave, now is the time to talk about how patients can have the highest quality of life for as long as possible.

Thank you for the opportunity to testify, and I urge you to vote yes on Senate Bill 703.

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard

Dear members of Senate Committee on Government Operations,

My name is Carolyn Rodgers, and I live in Menomonee Falls, WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

Palliative care is important because it improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness. This type of care provides some relief and solace for the family. In addition to improving quality of life, palliative care can help people understand their choices of medical treatment options. Pain by itself can be debilitating, and without relief can affect the patient's strength and ability to carry on with regular activities.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer.

Please vote yes on Senate Bill 703.

Sincerely,

Carolyn Rodgers

N77W17700 Lake Park Drive, Apt 232

Menomonee Falls, WI 53051

Debra Nevels
12023 W. Lynx Avenue
Milwaukee, Wisconsin 53225
414-544-6227
Debra.nevels12@gmail.com

January 26, 2024

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard

Dear members of Senate Committee on Government Operations,

My name is Mrs. Debra Nevels, and I live in Milwaukee, WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

Senate Bill 703, the establishment of a Palliative Care Advisory Council is critical for cancer survivorship and quality of life. It is anticipated that this council will be able to play an important role in examining pathways to quality of life for those diagnosed with cancer. Understanding palliative care is critical in offering support and specialized care to individuals who have completed cancer treatment. Cancer survivors may experience long-term side effects from treatment including pain, fatigue, neuropathy, and emotional distress. Palliative care focuses on managing these symptoms, improving the individual's quality of life, and helping them adapt to the physical and emotional challenges they may face. I am very familiar with this as a support for many who have been diagnosed and whose quality of life was enhanced with the support of holistic services that considered the entire person and did not focus on the disease or diagnosis.

In addition, the emotional toll of a cancer diagnosis can be challenging. Survivors deal with anxiety, depression, fear of recurrence and other psychological issues. Palliative care professionals provide emotional support, counseling, and resources to help survivors cope with these challenges and enhance their mental well-being. This continues the holistic approach to overall well-being. Recognizing that survivorship involves not only physical health, but also social, spiritual, and cultural aspects should be part of the treatment plan. By addressing these dimensions of well-being, palliative care contributes to a more comprehensive and individualized survivorship experience.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer.

Please vote yes on Senate Bill 703.

Sincerely,



Debra Nevels
12023 W. Lynx Avenue
Milwaukee, WI 53225

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard

Dear members of the Senate Committee on Government Operations,

My name is Jon Florin, and I live in Waunakee, WI. As a volunteer with the American Cancer Society Cancer Action Network, I urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

My brother-in-law fought his battle with stomach cancer and passed away just two years ago at the age of 40. Because stomach cancer is typically found in late stages, there are limited options for treatment, and patients often begin palliative care after diagnosis.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it to help all patients with complex diseases like cancer.

Please vote yes on Senate Bill 703.

Sincerely,

Jon Florin
1305 Manchester W, Waunakee, WI 53597

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard

Dear members of Senate Committee on Government Operations,

My name is Kathi Hansen, and I live in Wrightstown, WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

I am a breast cancer survivor myself, and through my cancer volunteer work, I have connected with many others who have experienced cancer in the past, are currently going through treatment, or are living with metastatic cancer. In every case, the availability of palliative care services either has made a huge difference in their quality of life or could have made that difference if palliative care were more readily available. I have also seen the positive impact palliative care services have made in the lives of family members and friends living with other serious conditions like Parkinson's disease, Alzheimer's disease, and Multiple Sclerosis.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer.

Please vote yes on Senate Bill 703.

Sincerely,
Kathi Hansen
1240 Washington St.

Wrightstown, WI 54180

February 1, 2024

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard

Dear members of Senate Committee on Government Operations,

My name is Kay Mittelstadt-Lock, and I live in Fond du Lac, WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

My son, Ian Lock, is a childhood cancer survivor. He was diagnosed with osteosarcoma when he was 16 years old. That was in 2010. Ian's treatment consisted of multiple surgeries, multiple chemotherapy treatments and many long stays in the hospital and home care. Ian had many teams of professionals coordinating his care. He had a pain team, a social worker, an oncologist, a tutor, home care, physical therapist, psychologist and many others. Ian is doing well today physically and mentally because of the amazing care he received. The amazing Palliative Care!

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer.

Please vote yes on Senate Bill 703.

Sincerely,

Kay Mittelstadt-Lock

ACS CAN CD6 ACT Lead

W6858 Riverbend Road

Fond du Lac, WI 54937

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard
Dear members of Senate Committee on Government Operations,

My name is Kelly Leibold and I live in La Crosse WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

In late 2016 at just 20 years old, I was diagnosed with brain cancer. Because the tumor was in my cerebellum, to this day I still struggle with fatigue and balance issues—but thankfully I'm celebrating my one-year anniversary having returned to full-time work! After an emergency brain surgery, in 2017 I underwent a month of proton-beam radiation treatments followed by four months of chemotherapy. While receiving care at the Mayo Clinic in Rochester Minnesota, I benefited from palliative care (Minnesota has one of those advisory councils). Because my care teams coordinated and collaborated with one another, I felt like I was being treated like a person and not just another patient. At the beginning of treatment, these weekly check-ins were incredibly helpful as well since I was really struggling with being under the radiation mask.

Now that I've finally found balance—metaphorically and literally—I've thrown myself into community activism. Along with serving as the President of the La Crosse Toastmasters Club, this spring I'll be running for a seat on the La Crosse County Board. I'm so thankful to be where I am today, thanks in huge part to the phenomenal, coordinated care I received and the strong support system I had.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer. Please vote yes on Senate Bill 703.

Sincerely,
Kelly Leibold
1824 Liberty St
La Crosse, WI 54603

To: Chair Stroebel, Vice-Chair Bradley, Senator Feyen, Senator Roys & Senator Agard
Dear members of Senate Committee on Government Operations,

My name is Kelly Leibold and I live in La Crosse WI. As a volunteer with the American Cancer Society Cancer Action Network, I am writing to urge you to vote yes on Senate Bill 703 to establish a Palliative Care Advisory Council. Cancer advocates like me have been advocating for this bill for nearly a decade, and this is a crucial step forward in improving the quality of life for cancer patients in Wisconsin.

In late 2016 at just 20 years old, I was diagnosed with brain cancer. Because the tumor was in my cerebellum, to this day I still struggle with fatigue and balance issues—but thankfully I'm celebrating my one-year anniversary having returned to full-time work! After an emergency brain surgery, in 2017 I underwent a month of proton-beam radiation treatments followed by four months of chemotherapy. While receiving care at the Mayo Clinic in Rochester Minnesota, I benefited from palliative care (Minnesota has one of those advisory councils). Because my care teams coordinated and collaborated with one another, I felt like I was being treated like a person and not just another patient. At the beginning of treatment, these weekly check-ins were incredibly helpful as well since I was really struggling with being under the radiation mask.

Now that I've finally found balance—metaphorically and literally—I've thrown myself into community activism. Along with serving as the President of the La Crosse Toastmasters Club, this spring I'll be running for a seat on the La Crosse County Board. I'm so thankful to be where I am today, thanks in huge part to the phenomenal, coordinated care I received and the strong support system I had.

Senate Bill 703 will make a big difference in the lives of patients with cancer and other serious illnesses. Establishing a council to evaluate the palliative care system in Wisconsin and make policy recommendations on how to improve it helps all patients with complex diseases like cancer. Please vote yes on Senate Bill 703.

Sincerely,
Kelly Leibold
1824 Liberty St
La Crosse, WI 54603



ProLife
LOVE. FOR LIFE. WI.

**Testimony in Opposition to Senate Bill 703: establishing a Palliative Care Council
Senate Committee on Government Operations
By Matt Sande, Director of Legislation / February 1, 2024**

Good afternoon, Chairman Stroebel and Committee members. My name is Matt Sande and I serve as director of legislation for Pro-Life Wisconsin. Thank you for this opportunity to express our opposition to Senate Bill (SB) 703, legislation that would establish a Palliative Care Council within the Department of Health Services.

Pro-Life Wisconsin has had serious concerns with legislation establishing a state Palliative Care Council since it was first introduced in 2017. The past several sessions we remained confident that, working with the bill authors, our concerns could be alleviated. Some changes have been made to the legislation that have been beneficial, such as adding primary care physicians along with patients and family members who have received palliative care services to the council membership. Other changes have been detrimental, such as removing anesthesiologists, pharmacists, and patient advocates from the council membership. **Our most critical concern, amending the statutory definition of “palliative care” to specifically exclude intentionally ending life, has gone unheeded.** To be sure, we do not question the intentions of the authors in forwarding this legislation - we know they are good and noble.

Pro-Life Wisconsin continues to believe that it is not the place of government to create such a council. We prefer to let the medical community create their own, private palliative care council and educate the public and legislature on best practices. Beyond that, we would prefer to have the legislature first create a balanced study committee to assess the need for appropriate palliative care and its safety.

It is critical that palliative medicine be understood and defined as managing pain, not hastening death – or rather, helping dying patients live well, not helping patients die. According to hospice physician and Duke University professor Farr Curlin, many families have said that when “hospice and palliative medicine (HPM) professionals became involved in their care, their loved ones were put on powerful drugs, became unconscious and unresponsive, and were soon dead. These stories are clearly shared within communities and powerfully shape people's perceptions of HPM, which many see as a sophisticated and seductive way of getting people to die.” (*Excerpts from Farr A. Curlin, MD Hospice and Palliative Medicine’s Attempt at an Art of Dying, ch 4 in Dying in the Twenty-First Century, edited by Lydia Dugdale, MD, MIT Press 2015*)

Dr. Curlin further explains that “(w)hen the goal of HPM shifts from helping patients who are dying to helping patients die, practices that render patients unconscious or hasten their death no longer seem to be last-resort options.” The heavy opioids/sedatives that are a part of current palliative care drug protocols can easily cause overdoses that result in respiratory failure. Accountability measures for patient safety are of the utmost importance. As you will hear from

physicians testifying today, the practice of palliative medicine in the field is quite controversial. How medicine is practiced and with what intention can make it salutary or deadly.

Pro-Life Wisconsin opposes sedating people to death in the name of palliative medicine. We support reducing pain, fatigue and other symptoms thus allowing patients to actively participate in dying well. That is true palliative medicine. Accordingly, we support amending the current law definition of “palliative care” found in Wis. Stat. 50.90(3) to specifically exclude intentionally hastening, assisting in, or causing death. Regrettably, the palliative care community has continually and steadfastly resisted amending the statutory definition of palliative care to exclude hastened death, and without any satisfactory explanation. This is deeply troubling, and I urge Committee members to press them for an answer.

Another critical reason it is imperative to place safeguards directly in the definition of palliative care is that the proposed protections included in SB 703 on page 4, lines 15-20, creating s.146.695(2)(b), violate First Amendment free speech protections. **Wisconsin elder law attorney Sara Buscher, the immediate past chairperson of the Euthanasia Prevention Coalition USA, provides written testimony today stating,**

“Consultation and advice to the Department of Health Services by a government entity such as the Palliative Care Council is protected speech under the First Amendment which SB 703 cannot restrict. Even speech directed at people encouraging or advising them to commit suicide is protected as long as it does not explain how to commit suicide. There are two cases on point from Minnesota, one decided by the state’s Supreme Court and another by the state’s Court of Appeals.”

Attorney Buscher then summarizes the two Minnesota cases which clearly demonstrate that the protective language in SB 703 would not withstand a challenge on free speech grounds. I encourage Committee members to read it closely. To resolve this dilemma, the definition of palliative care in s.50.90(3) needs to be amended to exclude hastened death. This would not violate free speech because s.50.90(3) does not concern speech. Rather, it lays out conditions of being licensed and of qualifying for reimbursements for providing palliative care services. This is the proper statute to add any protective language around the practice of palliative medicine.

It is imperative that palliative care be collaborative and integrated. Palliative care physicians and practitioners must work with primary care doctors to ensure full knowledge of patient medical history and patient end-of-life wishes so as to provide the most appropriate type and level of care. We believe the current makeup of the council as proposed in SB 703 is too heavily weighted toward palliative care doctors and specialists. We support amending the bill to include anesthesiologists, pharmacists, patient advocates (especially those for disabled people), health care professionals that have pain relief and symptom management work experience, more primary care doctors, and more patients.

In sum, if our shared goal is to promote safe and responsible palliative care, we must understand and employ it as pain management promoting activity and interaction, not sedation inducing premature death. We believe this goal can be achieved by properly amending SB 703, and if that can happen, Pro-Life Wisconsin would strongly consider removing our opposition to the legislation and even supporting it. Thank you for your consideration, and I am happy to answer any questions from Committee members.



WISCONSIN CATHOLIC MEDICAL GUILDS

Upholding the Principles of the Catholic Faith in the Science and Practice of Medicine

February 1, 2024

To: Members, Senate Committee on Government Operations

FROM: Robin Goldsmith, MD, State Director, Wisconsin Catholic Medical Guilds
Elizabeth Anderson, MD, Assistant State Director; President - Madison Catholic Medical Guild

RE: Senate Bill 703 – to establish a Palliative Care Council under Department of Health Services

Good morning Chairman Stroebel and members of the Assembly Government Operations Committee.

My name is Elizabeth Anderson. I am an emergency medicine physician here in Madison. I graduated from the Medical College of Wisconsin in 2005 and completed my residency at Froedtert Hospital in Milwaukee in 2008. I have been an ER physician here in Madison since then. I am also the current president of the Catholic Medical Guild of the Diocese of Madison and the Assistant Director of the Wisconsin Catholic Medical Guilds. I am here today on behalf of the Wisconsin Catholic Medical Guilds which represents the six guilds of the Catholic Medical Association throughout Wisconsin, with more than 100 physician and healthcare provider members.

I am here today on behalf of the Wisconsin Catholic Medical Guild to speak in opposition to Senate Bill 703.

The World Health Organization states that palliative care: “provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families.”

I include this definition because it is important to distinguish palliative care from hospice care. Unfortunately, these are often used interchangeably and even practitioners generally consider these a continuum. In fact, at least 50% of home-based palliative care programs are administered by hospice agencies, which helps grow hospice.

(<https://hospicenews.com/2020/09/25/amedisys-expanding-palliative-care-operations/>)

Senate Bill 703 seeks to establish a state Palliative Care Council. Evaluating the availability and need for Palliative care resources in Wisconsin is important. Palliative care can be a very positive and beneficial addition to a patient’s care and to their families. However, the bill as currently written has some very concerning components. The make-up of the committee is heavily weighted to palliative care practitioners. Current protocols in palliative care in Wisconsin

contain concerning doses of medications including sedatives (such as Propofol) and opiates (such as fentanyl) that could in fact hasten death in patients. As such, a broader spectrum of specialties, such as anesthesiologists who are specifically trained in these medications, is needed. We also believe that for the safety of patients, any definition of palliative care needs to include that it does not intentionally hasten, assist in, or cause death. Palliative care and hospice utilize very powerful sedating medicines and high dose opioids that can be helpful to terminal patients who are in severe pain but can also be dangerous, especially when given to people who are not in pain.

Although we appreciate the authors' addition of two primary care physicians to the council membership in SB 703, we would like to see more. These are the physicians who know their patients' medical, emotional, and psychological condition, as well as their end-of-life wishes, the best. Primary physicians have expressed concerns re: palliative and hospice care, including rapid demise of hospice patients, loss of contact with patients after hospital admission, and transfer to hospice without notifying the primary physician.

As physicians, we have taken the Hippocratic oath. Hippocratic principles of medicine may seem old fashioned. However, the point is we treat persons in a most vulnerable state of illness who can be taken advantage of by various parties, some even with good intentions, including insurance companies or health care institutions that have their bottom financial line to worry about; as well as organizations interested in promoting "death with dignity" for those whose lives they deem "not worth living."

Hippocratic medicine means our patients are our solemn charge, and we must not allow their most important decisions to be delegated to others. We have vowed to put our patients first, superseding all other considerations, despite being told this is not "best practice" or "evidence based." Situations, which may include palliative care and hospice, where non-physicians with no previous medical experience are trained to explain to patients the disadvantages of life sustaining treatments are inexcusable. Ideally, palliative care should be managed by, and the community/legislature educated by, the medical community and not a government entity.

As representatives of the Wisconsin Catholic Medical Guilds, we urge you to amend SB 703 to include in the definition of palliative care, as mentioned above, that it does not intentionally hasten death. We also urge you to assess the make-up of the proposed council, so it is more inclusive of multiple specialties that are involved in palliative care and the medications used, including more primary care physicians, anesthesiologists, and pharmacists, as well as more patient care advocates including a disability rights member.

With the changes, we would be able to consider supporting this bill as a means to identify and promote ethical and excellent palliative care.



Moving Wisconsin Hospice & Palliative Care Forward

TO: Members of the Senate Committee on Government Operations

FROM: Carrie Schepp
General Manager, VITAS Healthcare – Wisconsin
on behalf of the Wisconsin Hospice & Palliative Care Association (WiHPCA)

DATE: February 1, 2024

RE: Senate Bill 703, related to creation of a Palliative Care Council to advise the Wisconsin Department of Health Services and provide reports to the Legislature.

Chair Stroebel and members of the Senate Committee on Government Operations. My name is Carrie Schepp, and I am the General Manager of VITAS Healthcare - Wisconsin, a palliative care provider with a service area in southeastern Wisconsin. In addition, I am also a board member of the Wisconsin Hospice and Palliative Care Association (WiHPCA). I am here to speak in support of Senate Bill 703, as it will greatly benefit Wisconsinites with serious illnesses.

As all of you are familiar with what palliative care is and that it is a patient centered right of choice, I am not going to address the specifics of palliative care. Instead, I would like to address some of the questions raised about this bill in previous testimony by other organizations regarding the make-up of the proposed palliative care committee and the current definition of palliative care.

First, these organizations testified that they would like to add additional members to the council. It is important to note that Senate Bill 703 already expands the membership of the council beyond what was included in the version of this bill that was introduced during the 2019-2020 legislative session. In particular, it adds: (1) two patients or family members of patients who have experience receiving palliative care services, (2) two non-clinical health care leaders with experience operating community-based palliative care programs, and (3) a representative from a health care insurance company who has experience making decisions about reimbursement for palliative care services.

In particular, these organizations would like to add various positions to the council, including an anesthesiologist and additional primary care physicians. Working with the bill authors, two primary care physicians were added before the final version of the bill was drafted. As it relates to adding an anesthesiologist, this medical specialty rarely, if ever, works in palliative care or hospice. Instead, board-certified palliative care physicians already receive extensive training and education in the appropriate utilization and dosing of medications – including opioids and sedatives – through their fellowship and are subsequently tested on this knowledge when they take board exams. It is also important to note that the dosing of medications for patients in palliative care is vastly different in alleviating symptoms versus sedation. With all of this in mind, the inclusion of an anesthesiologist on the palliative care council is unnecessary and duplicative.

We feel that the number of council members – 22 – is more than adequate. Even with 22 members, it will be a challenge to secure the time and talent of Wisconsinites, as well as ensure that there is a quorum at each council meeting.

Second, during prior testimony on this legislation, organizations also testified that the definition of palliative care in state statute needs to be amended *“to specifically exclude intentionally hastening, assisting in, or causing death.”* This is completely unnecessary, as existing state law explicitly prohibits such actions and classifies them as a felony. In addition, the bill already includes a provision prohibiting the council from consulting or advising the Department of Health Services regarding euthanasia and related matters. In fact, when our association consulted with one of these organizations several months ago on a draft version of this bill, that organization actually requested that we expand this prohibition to ensure that it also covered the statewide palliative care consumer and professional information and education program in the bill. That change is reflected in this legislation.

I'd like to make one last comment regarding prior testimony provided by some of these organizations. Several of them shared unsubstantiated innuendoes implying that there have been situations in which medical professionals have engaged in acts of assisted suicide. In particular, these individuals stated that medical professionals have purposely provided excessive levels of medication to patients in order to hasten death. This was the rationale they provided when requesting a modification to the definition of palliative care in state statute. Such unsubstantiated allegations are outrageous, offensive, and disrespectful to all of the honorable, hard-working physicians, nurses and other palliative care professionals who take care of seriously ill Wisconsinites.

As I've already addressed, assisted suicide is already a felony under state statute. If someone is aware of a specific case of this occurring in our state, I would certainly hope that they would report it to law enforcement and appropriate medical boards.

Thank you for the opportunity to share the views of the Wisconsin Hospice and Palliative Care Association. I would like to reiterate that palliative care remains a patient centered right of choice. I would be happy to answer any questions you may have.



TO: Members of the Senate Government Operations Committee

FROM: Wisconsin Hospice and Palliative Care Association (WiHPCA)

DATE: January 31, 2024

RE: Senate Bill 703 – Relating to: establishing a Palliative Care Council

The Wisconsin Hospice and Palliative Care Association is an organization committed to ensuring optimal outcomes and expanding access to high-quality, compassionate care for Wisconsinites facing life-altering illness, we are respectfully requesting your support for legislation – Senate Bill 703 – authored by Representative Pat Snyder and Senator Jesse James to create a palliative care council to advise the Wisconsin Department of Health Services (DHS) and provide recurring reports to the Legislature.

Definition of Palliative Care

Palliative care is specialized, integrated medical care for people with serious illness, focused on providing patients and families with relief from the symptoms, pain, and stress of a serious illness. Examples of such illness include cancer, congestive heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer’s disease, and Parkinson’s disease.

- Palliative care is meant for the sickest, most vulnerable, costliest patients and their families. It provides an additional level of support for patients and their caregivers. It is appropriate for children and adults.
- Working with a palliative care provider helps simplify patient transitions across care settings.
- Patients in palliative care receive medical care for their symptoms, along with treatment intended to cure their serious illness.
- Palliative care specialists may include a physician, nurse, social worker, chaplain, and other care specialists who work alongside a patient’s doctor to provide an extra layer of support.

Why do we want to create a Palliative Care Council?

- Access to palliative care varies widely across our state. Palliative care in Wisconsin is mostly provided during a patient's hospitalization, and this is typically only in the larger hospitals. 52% of rural hospitals do not provide any type of palliative care specialists.
- Home and clinic based palliative care is extremely limited in Wisconsin. There are less than a dozen health care organizations who provide palliative care in patients' homes.
- The purpose of the council will be to study ways to increase awareness and usage of this highly valuable type of care. In addition, there is a shortage of health care providers in Wisconsin who specialize in palliative care, with only 4.0 providers per 100,000 residents.

The following are examples when palliative care has been extremely valuable to patients:

Example One

- A 32-year-old female with metastatic cancer was suffering severe pain, which resulted in her inability to function and to be frequently admitted to a hospital. Also, she is a single parent of a 13-year-old daughter. The patient was reluctant to have a palliative care assessment, as she did not understand palliative care and wanted to continue active cancer treatment to prolong her life for the sake of her only child.
- Her oncologist struggled to manage her pain and needed the expertise of palliative care specialists to assist in pain management. This patient was in crisis and needed help now. Fortunately, the oncologist was able to find a community-based palliative care program – a type of care that she would be able to receive in her home. Upon receiving the referral, a palliative board-certified physician and a nurse practitioner (NP) were able to work with the patient and her oncologist to develop a regime that would manage her pain and provide her with an improved quality of life. Without palliative care, this patient would have continued to suffer severe pain – and would likely have made multiple expensive visits to a hospital’s emergency department.

Example Two

- Kathy had been struggling to manage her heart disease for some time. It had become clear to her cardiologist that she was not taking her medications. On the palliative care team’s initial visit to her home, Kathy was proud to show her a fishbowl full of a colorful array of pills. Kathy explained she was pretty sure she knew which pills to take based on their color. Over a series of visits, the palliative care nurse reconciled Kathy’s medications and got them organized in a pill box. Furthermore, the team’s social worker was able to steer Kathy’s children towards community services to assess her for dementia. If Kathy had not received palliative care, her heart disease would have likely worsened and her mental state may also have gotten worse, as she would have likely not received a dementia assessment. This could also have resulted in multiple expensive visits to a hospital and her loss of independence.

Palliative Care Saves Costs

Evidence-based research has demonstrated that patients in hospital systems with palliative care programs experienced reduced emergency department visits, fewer days in intensive care, and fewer hospital readmissions after discharge.

Palliative Care Provides Access to Needed Support for Patients

The provision of palliative care is flexible – it may be provided to patients in various settings. In addition to being provided in some hospital settings, palliative care may be provided in facilities, such as skilled nursing (e.g., “nursing homes”), assisted living, and other community-based facilities. In addition, palliative care teams are also able to travel to patients’ homes and provide care in that setting.

The creation of a Palliative Care Council – via Senate Bill 703 – will help increase awareness of palliative care throughout the state and help Wisconsinites receive needed medical care for their symptoms that will improve the quality of life for them and their families.

If you have any questions, please contact the WiHPCA government affairs team, Tim Hoven and Nathan Butzlaff, at tim@hovenconsulting.com or nathan@hovenconsulting.com.



WISCONSIN CATHOLIC CONFERENCE

TO: Senator Duey Stroebel, Chair
Members, Senate Committee on Government Operations

FROM: Barbara Sella, Executive Director

DATE: February 1, 2024

RE: Opposition to Senate Bill 703, Palliative Care Council

On behalf of the Wisconsin Catholic Conference, the public policy voice of the bishops of Wisconsin, thank you for the opportunity to testify in opposition to Senate Bill 703, which would establish a palliative care council.

The Catholic Church supports the use of quality palliative care for those who are gravely ill and at the end of life. As Pope Francis has stated:

Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. Indeed, the person, under any circumstances, is an asset to him/herself and to others and is loved by God. This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.¹

True palliative care, which improves a suffering person's life and that of their loved ones, is the appropriate response to human suffering and disease. Studies show that when patients receive proper physical, psychological, emotional, and spiritual care, they live longer and score substantially higher on quality-of-life measures. In short, true palliative care is meant to help manage pain and care for individuals who are dying, not to hasten their death. We support and encourage efforts to provide more true palliative care options for patients in Wisconsin.

However, any public policy designed to aid those who are vulnerable and facing serious illness cannot include any means of treatment that values expediency over life. Nor can we encourage a system of care that places undue cultural, financial, or other pressures on an individual to hasten the end of his or her life. And while there are many testimonies of true palliative care, unfortunately there are also growing testimonies of palliative care that has hastened death.

In past sessions, the WCC, along with other groups here today, has requested that the authors include clear protection for those at the end of life. The current bill prohibits discussion with the department on "physician-assisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any affirmative or deliberate act to end life."

Regrettably, however, the bill does nothing to prohibit the actual practice of hastening someone's death, especially via the overuse of sedatives and opiates.

The best way to protect patients is to amend the current definition of palliative care in Wisconsin statute. The definition in Wis. Stat. 50.90(3) should explicitly state that palliative care excludes intentionally hastening, assisting in, or causing someone's death. Until this change is made, either by amending this bill or introducing another one, the WCC cannot support the creation of a state palliative care council.

We are deeply indebted to physicians and other professionals who continually strive to provide compassionate and appropriate care for their patients. As individuals and as a society, we can and must comfort those facing serious illness and reassure them that we cherish their continued presence. We can and must tell them that their need does not diminish their value. We respectfully urge the authors of this bill to make this explicit by amending the bill.

Thank you again for the opportunity to testify today.

¹ Address of His Holiness Pope Francis to Participants in the Plenary of the Pontifical Academy for Life (March 5, 2015), http://w2.vatican.va/content/francesco/en/speeches/2015/march/documents/papa-francesco_20150305_pontificia-accademia-vita.html

February 1, 2024

Senator Duey Stroebel, Chair and Members of the
Senate Committee on Government Operations

RE: Opposition to SB 703 creating a Palliative Care Council within DHS

Dear Senator Stroebel and Committee Members:

Thank you for the opportunity to explain why I oppose SB 703.

I am a retired attorney and CPA who has worked on health care issues for 40+ years. I ran employee benefit programs at the Department of Employee Trust Funds and at the University of Wisconsin. I served on Governor Thompson's task force on health care costs. As an elder law attorney, I advocate for the elderly and disabled and wrote health care decision making articles for a State Bar publication. I currently serve on the board of the Euthanasia Prevention Coalition USA as immediate past chair and their resource person for palliative care. Palliative care is an extension of hospice and a pathway to hospice.

I am not against good palliative care for those who choose it. I appreciate your desire to help folks. Sadly, dangerous palliative care is often identified too late; distinguishing it from safe palliative care is difficult. I have seen many cases where people who were not terminal were tricked into hospice (comfort care) which then went on autopilot with strong drugs followed shortly by death. Many palliative care programs are owned by hospices and used as "loss leaders"¹ to enroll people sooner and sometimes inappropriately in hospice. Palliative care programs are financially unstable, leading to cost saving² justifications and the resulting pressure for inappropriate clinical decisions. This is why protective language in the Bill is important. The Bill's sponsors recognize this need and have included protective language at s.146.695 (2)(b).

The proposed protective language in SB 703 at s.146.695 (2)(b) is unenforceable because it violates the Free Speech protections of the U.S. Constitution. It also allows euthanasia by omission as it is limited to acts. Section 146.695 (2)(b) says:

¹ Palliative Care Needs a Defined Scope to Expand Access, Reimbursement, Hospice News Oct. 2022 at <https://hospicenews.com/2022/10/20/palliative-care-needs-a-defined-scope-to-expand-access-reimbursement/>

² Savings typically accrue to providers not the State because Medicaid pays flat fixed rates for hospitalizations and many other services. So, if Medicaid pays \$20,000 per case and the provider spends \$13,000, thereby saving \$7,000, the State pays the provider \$20,000 and the provider keeps the \$7,000.

The council may not consult with or advise the department on physician-assisted suicide, euthanasia, medical aid in dying, or any other act that would condone, authorize, approve, or permit any affirmative or deliberate act to end life other than the withholding or withdrawing of health care under an advance directive or power of attorney for health care so as to permit the natural process of dying.

Consultation and advice to the Department of Health Services by a government entity such as the Palliative Care Council is protected speech under the First Amendment which SB 703 cannot restrict. Even speech directed at people encouraging or advising them to commit suicide is protected as long as it does not explain how to commit suicide. There are two cases on point from Minnesota, one decided by the state's Supreme Court and another by the state's Court of Appeals.

Melchert-Dinkel posed as a depressed and suicidal nurse online who encouraged others to commit suicide by hanging themselves while he watched online. In State v. Melchert-Dinkel, 844 NW2d 15 (MN 2014) the Supreme Court of Minnesota held the State, consistent with the First Amendment, can prosecute a person for assisting another in committing suicide but not for encouraging or advising another to commit suicide. Assisting means "...speech or conduct that provides another person with what is needed for the person to commit suicide... [such as] instructing another on suicide methods..."

A subsequent case, State v. Final Exit, Inc., 889 NW2d 296 (MN App 2016), applied the Supreme Court's holding to an organization, Final Exit, Inc. which advocates for assisted suicide and also provides "exit services" to individuals. The advocacy is protected speech, but the "exit services" which instruct the individuals about how to commit suicide using a helium filled hood and provide addresses of companies that supply the materials are not protected speech. Exit guides attend the death and then remove the hood and helium tank.

The language I have recommended in the past would chill dangerous palliative care practices. It would amend s.50.90(3) by excluding "the intentional hastening, assisting or causing of deaths" from the definition of palliative care for the licensing of medical and care organizations.

I will be happy to answer any questions or provide additional information. If SB 703 were amended to exclude hastened death from the statutory definition of palliative care, I would reconsider my opposition to the legislation.

Sincerely,

/s/

Attorney Sara Buscher

To: Members, Senate Committee on Government Operations

Re: Opposition to SB 703, establishing a state Palliative Care Council

Date: Thursday, February 1, 2024

Good morning, Chairman Stroebel, and members of the Senate Government Operations Committee. Thank you for allowing me to speak in opposition to Senate Bill 703.

My name is Dr. Stephen Pavela. I am a retired Internal Medicine physician from La Crosse, Wisconsin. I am Board Certified in Internal Medicine and practiced in La Crosse for 39 years. I was a Department Chair and a Chief of Staff for my hospital system. I also taught Internal Medicine to Family Practice Residents for 34 years.

My practice included the hospital care of patients, including intensive and acute cardiac care; outpatient clinics, as well attending at local nursing homes. I did the end-of-life care for all my patients throughout my career. I was involved in the beginning of the hospice movement in the 1990s. In the last 5 to 10 years of my practice, the Palliative Care specialty was introduced to my healthcare system. Since I was the long-time physician for my adult patients I took care of them right up to the end of their lives, whether they were in hospital, at home or in a long-term care facility. I took care of my own patients who were on hospice care. I tell you all of this so that you understand that I am thoroughly familiar with palliative and hospice care, both its good points and its failings.

In my opinion, done well and done ethically, palliative care and hospice care can be beneficial to patients. Despite this ideal, I am here to tell you that on the local, practical level this is frequently not the case. Why do I say this? Because I have observed it and have heard it from the families of my patients. For example, the families would be surprised that despite an oncologist's estimate of lifetime in weeks or months, when palliative care transitioned the patient to hospice, their loved ones died so quickly. The main culprit in most of these cases was the inappropriate sedation of their loved ones by excessive dosing of medication to treat pain and perceived shortness of breath. Because of this excessive use, the families felt deprived of their loved one's alertness and their companionship in their last days. Another culprit, I often found, was the aggressive discontinuance of even routine medications for on-going chronic conditions

that had nothing to do with the primary terminal illness. Medications for diabetes or cardiac conditions were often prematurely withdrawn.

I don't mean to say what I am describing happens in all cases, but it happens enough that family members would call on the phone or come into my office a bit bewildered at the rapid unexpected death of their loved one. A Catholic priest friend of mine observed that he used to go to a deathbed to administer the last rights to a dying person and be able to talk to them. But he notes that in recent years in most cases that person is unarousable due to sedation.

What I am telling you is common knowledge among primary care physicians. And, in recent years, there is another problem. Today, except for rural areas, hospital care is done not by the primary physician but by hospitalists. When a patient with a serious medical condition, possibly terminal, is admitted to the hospital, a palliative care consult is routinely placed by the hospitalist, and upon discharge the patient is either sent home or to a nursing home without any communication to the primary physician. All the counseling is done by physicians unknown to the family. The patient is quickly transitioned to hospice care. The quality of that care highly depends on the physician and nurses directing that care and may not match the values of the family as they only are assigned a team, not the ones they choose.

I have found that the best protection for a patient is an inquisitive family member, or a primary care physician known and trusted by the family who can appropriately assess recommendations being made by Palliative Care or the Hospice team.

Again, I am not testifying that this is a universal occurrence, but it happens often enough to be known by longtime physicians who have observed the evolution in end-of-life care in recent years.

When I look over SB 703, I note the make-up of the council is very heavy on those practicing Palliative Care. Only two primary care physicians are included. In my opinion, this is exactly opposite of what it should be. Most of the council should be made up of those skilled in the ongoing long term primary care of patients. Not just those who enter the person's life for only a short time. Also, the council should include pharmacists and anesthesiologists who are medication and pain care specialists who can help supervise proper protocols and the use of medications.

I have second more fundamental objection to SB 703. Why is the state getting involved with this specialty at all? Shouldn't it be done by private healthcare systems who are

responsive to the local needs of their patients? Shouldn't the need be started at the grass roots level, rather than directed "top-down" from the governmental level?

We have just been through several years of the Covid pandemic. During that time, a government agency, namely, the Center for Disease Control (CDC), made numerous "recommendations" regarding lock downs, school closures, travel restrictions, and masking. It actively interfered with the medical profession's prescribing of medication. And how did that turn out? The CDC's so-called "recommendations" were taken as necessary mandates by most institutions. But we now have scientific evidence that almost all those recommendations had no effect on Covid disease spread, were unnecessarily mandated, and in some cases caused great harm. This is an example of government attempt to control medicine "top down."

What I am saying is that if something is worth doing and of great value, the private sector will see that it is done; it doesn't need government involvement. So, I am curious as to the origin of this bill? Where is the evidence that a government sponsored palliative care council is needed? There is no similar government sponsored council for any other specialty in medicine such as pediatrics, surgery, or cardiology. Why this one? From my own experience, it is not necessary.

For these reasons I oppose the passage of SB 703. Thank you for listening to my concerns.