March 12th, 2025

Senator Cabral-Guevara, Chair Members of the Senate Committee on Health

Testimony on 2025 Senate Bill 39

Relating to: establishment of a Palliative Care Council

Thank you, Madam Chair and other members of the committee, for hearing my testimony on Senate Bill 39 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 utilizes it, but unfortunately, lack of access and education on palliative care prevents people from utilizing it.

That is what is 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 and 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,

Senator Jesse James 23rd Senate District

Sen.James@legis.wisconsin.gov



Patrick Snyder

STATE REPRESENTATIVE • 85th ASSEMBLY DISTRICT

Testimony in Support of Senate Bill 39

Senate Committee on Health

March 12, 2025

Chairwoman Cabral-Guevara and members of the Committee:

For those unfamiliar, palliative care is a specialized type of medical care delivered by a team of caregivers such as physicians, nurses, social workers, and 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, physicians' assistants, 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.

TO:

Members of the Senate Health Committee

FROM:

Kimberly Casper, MSN, FNP-C

Palliative and Hospice Nurse Practitioner

DATE:

March 12th, 2025

RE:

Senate Bill 39- a bill establishing a state palliative care council

Good morning – Chair Cabral-Guevara, Vice Chair Testin, Ranking Democratic Member Smith – and committee members.

I would like to take a minute to thank the committee chair for holding this hearing today. My name is Kim Casper, and I am a Palliative and Hospice Nurse Practitioner. I have been in health care for a total of 15 years with my most recent experience as a Palliative Care provider for the last 1.5 years. I currently work for Tomah Health which is a small, rural hospital in Tomah, WI. The care that our Palliative care team provides is unique from other Palliative services as we are the only in-home palliative care program in the Southwestern region. Our patients receive individualized care within the comfort of their own homes or in facility settings to support any symptoms that may accompany a chronic disease. Most of our patients are in a rural area which makes it difficult for them to get out of their homes to receive the proper care that they need. The need for Palliative care in Wisconsin has been growing considerably. In 2017, our Palliative care census was 34 patients. We have now over tripled this number in 2024 and are continuing to grow at a steady pace.

When referencing the Center to Advance Palliative Care map which demonstrates the ratings for access to Palliative care services in the US, Oregon and Massachusetts have the highest ratings. Oregon has a mandate for palliative care education. While Massachusetts has several initiatives to educate both providers and the community about Palliative care. Both of these states have Palliative care councils.

I would like to take this time to provide some insight on the importance of the passing of Senate Bill 39. I am willing to bet that everyone here has either dealt with a chronic health problem themselves or has a family member or friend that has a chronic health condition (i.e. chronic obstructive pulmonary disease, heart failure, kidney disease, cancer, etc.). All of those people that you know, are people that Palliative care providers serve. We aren't just treating the patient's chronic disease, but we are incorporating spiritual care services, emotional care support, and providing support to the patient's family members. Patients may be struggling with aspects of the chronic health condition that their primary care provider does not have enough time for. Palliative care providers can provide more than a primary provider as we usually have more time to spend with our patients and/or visit them more frequently. This allows us to listen and address their concerns which builds a trusting relationship. Our patients then develop a deeper understanding of their condition to make informed decisions about their care.

Many of our patients are not aware of Palliative care services due to a lack of community education. Even many providers are not aware of the difference between Palliative and hospice care. This results in a disadvantage to the patients as many times their health has deteriorated to the point that they are hospice appropriate when we are trying to have our first conversations with them. When patients are referred too late, they lose out on the benefits of Palliative care. I would like to take this time to read a

section of a testimonial letter from a patient's family member and their perspective on how Palliative care has made an impact on their lives.

"If it wasn't for Palliative care, we would have to try to take him to the doctor or hospital. He has COPD and isn't able to do much. We live in a rural community and Palliative Care is very much needed in our rural community. Palliative care is such a blessing. Our hope is that Palliative care is never discontinued-We speak for ourselves and everyone that gets this great care."

You may be asking yourself how approving this bill would be of benefit to both patients and at a financial level. For the patient, this bill would increase their knowledge of Palliative care services, so they are more willing to utilize these services at the beginning of their diagnosis rather than waiting until they are to the point where they are more hospice appropriate. This would prevent them from missing out on the benefits of Palliative care. From a financial standpoint, Palliative care can help decrease ER visits and hospitalizations by treating symptoms sooner. I want to express my appreciation for this gathering today to discuss the importance of this bill to improve Palliative care education and provide more access to this service for others in need.

Thank you,

Kimberly Casper, MSN, FNP-C

asper, APNP

TO: Members of the Senate Health Committee

FROM: Michelle Theige APNP, ACHPN

DATE: March 12, 2025

RE: Senate Bill 39 – a bill establishing a state palliative care council

Good morning – Chair Cabral-Guevara, Vice Chair Testin, Ranking Democratic Member Smith – and committee members.

I would like to thank everyone for being here for this hearing in support of Senate Bill 39 to establish a Palliative Care Council and to hear of the importance of Palliative care services. My name is Michelle Theige and I work for Tomah Health Palliative Care and Hospice. I have worked as a Board certified Palliative Care and Hospice Nurse Practitioner for the past 4 years.

One of the biggest challenges we face in Palliative care is combatting misconceptions about Palliative Care. One of the most common misconceptions is that Palliative care is only for patients who are near end of life or that it is hospice care. Palliative care is specialized care. Our focus is on alleviating symptoms and improving quality of life for patients with serious illnesses such as heart and lung disease, cancer, kidney failure, and Alzheimer's disease. We strive to be expert in the management of distressing symptoms including pain, depression, anxiety, shortness of breath, nausea, and difficulty sleeping. Palliative care can be started at any point of a serious illness regardless of prognosis, and there is no limit to how long a patient can remain on our services.

Evidence has shown that, in the outpatient setting, Palliative care has reduced hospitalization admission rates by up to 50% and reduced Emergency room visits by up to 35%. I can think of a number of our high needs patients whose Emergency room and hospitalization rates were significantly reduced after initiating Palliative care services. With our thorough physical and psychosocial assessments and medication reconciliations, we are often able to identify issues in the home setting that may be missed in the inpatient and clinic setting. Another one of our primary goals is having discussions about goals of care. These are very in depth, and often very difficult, conversations to have with patients and their families. We discuss advanced directives, living wills, and also help patients to identify those who are closest to them, who they would want involved in making health care decisions on their behalf. These conversations cannot be made in a 15-20 minute clinic visit and is often why we receive a large number of our referrals. We are able to set aside a significant more amount of time for each of our patients to have these conversations.

I would like to share the story of a patient of mine that I feel exemplifies the best of Palliative care services. He was a 63 year old male patient who was referred to us because of chronic pancreatic insufficiency. Shortly after his initial consult, he was, unfortunately, diagnosed with pancreatic cancer. During our visits together, we identified 3 very important goals he wished to accomplish. First, was to extend his life for as long as possible for his family. Second, was to attend his first Green Bay Packer game at Lambeau field. Third, was to stay in his home for as long as possible. Over the next 2 years, I met with him at his home on average of once a month, but sometimes every 2 weeks depending on his needs and symptoms. My focus was on prescribing medications to treat pain and nausea due to advancing pancreatic cancer and side effects from chemotherapy as well as monitoring his mood and adjusting medications for his depression. Over these 2 years, he was able to achieve his goals of attending his first, and only, Packer game at

Lambeau field. He was able to spend quality time with his children and grandchildren which included meeting his goal of more hunting trips with grandpa, where he watched his 10 year old grandson shoot his biggest Whitetail buck. Finally, he was able to stay in his own home until we agreed that it was no longer safe for him to do so due to increasing weakness and falls. Throughout our time together, we were able to have open conversations about the signs of his cancer progression. We were able to discuss his anxiety and concerns related to completing his living will and advanced directives, and ensuring that his children and grandchildren would be taken care of financially after he was gone. As time went on it was evident that his cancer was progressing despite chemotherapy. When he was ready, the transition to our hospice services was made smoothly, and he passed away comfortably while under the care of our hospice staff at our inpatient serenity house in Tomah. Our goal is to meet our patients where they're at, whether their goal is curative and aggressive treatment focused, or more comfort focused.

The passing of this bill would have a significant positive impact for Palliative care services throughout Wisconsin. According to the Center to Advance Palliative Care (CAPC), Wisconsin scores only 2.5 out of 5 on the American Serious Illness scorecard. Data also shows that there are only 2.8 prescribers with whom hold certification in Palliative care per 100,000 patients throughout the U.S. This is a significant disparity as compared to other medical specialties. As the aging population continues to increase, the need for more Palliative care services will also continue to increase. Please consider supporting the passing of this Bill that would improve Palliative care education and access to patients and their families throughout Wisconsin. Thank you so much for your time today and I am happy to answer any questions that committee members may have.

References

NHPCO: https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf

CAPC: https://www.capc.org/making-the-value-case/

CAPC: https://scorecard.capc.org/

TO:

Members of the Senate Health Committee

FROM:

Siera Williams, BSN, RN

Director of Hospice Touch & Palliative Care

DATE:

March 12, 2025

RE:

Senate Bill 39 – a bill establishing a state palliative care council

Good morning – Chair Cabral-Guevara, Vice Chair Testin, Ranking Democratic Member Smith – and committee members.

Thank you for hearing our testimony in support of Senate Bill 39, the state palliative care council bill. My name is Siera Williams, BSN, RN, and I am the Director of Hospice Touch and Palliative Care at Tomah Health. I have been a registered nurse for 10 years, with the last five years dedicated to hospice and palliative care. Serving patients and families in my rural community is my passion, which is why I strongly advocate for this bill. While our team has worked hard to expand palliative care access and education in our area, there is still much more we can do in our state.

Palliative care at its core is designed for patients at any stage of illness, particularly those with multiple chronic conditions who need help managing symptoms and coordinating care. Our providers focus on the whole person—their health, treatments, and personal goals. Many patients have dreams beyond their illness, and we strive to help them achieve those as well.

I'd like to share a case that highlights the profound impact of palliative care. This patient we serve is navigating multiple chronic illnesses, they require care from oncology, wound care, physical therapy, pain management, otolaryngology, infectious disease, vascular surgery, hematology, primary care, podiatry, and a nutritionist. With so many specialists focusing on their respective areas, who is looking at this patient as a whole? Who is discussing their goals of care—what treatments they want to pursue and what they may no longer wish to continue? While primary care physicians play a crucial role, most patients see them only once or twice a year. This is where palliative care steps in. While adding another specialty service to this person's care may seem unnecessary, our nurse practitioners and Registered nurses work closely with all existing providers. We provide clarity, coordination, and regular in-home visits—typically every 2–4 weeks in complex cases—to ensure thorough assessment and expert guidance. This is just one example, but there are many like it. Palliative care helps patients navigate their care with dignity and understanding.

A Palliative Care Council in Wisconsin, made up of experts in the field, could improve access to community-based palliative care programs like ours, ensuring that all Wisconsinites who need this essential service can receive it.

The council would work with DHS to evaluate existing programs, assess the impact of palliative care on quality of life and healthcare costs, review reimbursement policies, and address other important issues. By doing so, it would help strengthen the quality of care provided and improve outcomes for patients and communities across the state

I urge the committee to support this bill and make palliative care a vital component of Wisconsin's healthcare system. Thank you again for your time and for holding this important hearing. I appreciate the opportunity to speak with you today and would be happy to answer any questions.

Siera Williams, BSN RN

Director of Hospice Touch & Palliative Care



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

March 12, 2025

To: Senate Committee on Health

From: The American Cancer Society Cancer Action Network

Re: Testimony in Favor of Senate Bill 39 - Establishment of a Palliative Care Council

Good morning, Chairwoman Cabral-Guevara 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 39 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 would like to recognize and thank Senator James as the lead sponsor.

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 Senate Bill 39 is key to doing this.

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 39.

95. B

3/12/25

To: Chair Cabral-Guevara

Dear members of the Senate Health Committee,

My name is Melissa Kultgen, and I live in Belgium, WI. I am a volunteer with the American Cancer Society Cancer Action Network, and I am a seven-year Melanoma survivor and was a caregiver for my mom, a three-time cancer warrior. I am writing to express my support for Assembly Bill 23 to establish a Palliative Care Advisory Council in Wisconsin.

During my mom's cancer journey, palliative care was never offered as an option until it was too late. Without access to palliative care, there was a lack of a cohesive care plan which had a devastating effect on my family. During my mom's third fight with cancer, the tumor was inoperable, but we tried several treatments, hoping for a miracle. The tumor created an open wound in my mom's abdomen, requiring her to have daily wound care. She had appointments at the local wound clinic every few weeks, but her oncologist and the wound clinic had minimal communication and no coordination in care plans. It was up to me and my dad to perform her daily wound care and help her manage her pain. Instead of being a husband and a daughter, we tried our best to perform medical care.

There were days the bleeding was uncontrollable, and I had to be brave for my mom as to not scare her even though my heart was breaking. We took her to the ER several times because the bleeding wouldn't stop. The ER doctors were inexperienced with my mom's cancer journey and each ER visit led to new complications in her care. My dad and I became physically, mentally, and spiritually exhausted as caregivers.

The doctors stopped my mom's treatment in January of 2023, and we went into management mode, trying to help my mom live as comfortably as possible during her remaining time. We were given zero resources or support. Palliative care wasn't mentioned until the final month, and by that point my mom required hospice. My mom passed away July 12, 2023.

If my family would have known about palliative care, my mom would have had better quality of life in her last year. My family would have been able to act as a family and would not have felt so alone and unsupported.

Assembly Bill 23 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 support Assembly Bill 23.

Sincerely, Melissa Kultgen 183 S Lar Ann Street Belgium, WI 53004

3/12/25

To: Chair Cabral-Guevara

Dear members of the Senate Health Committee,

My name is Tammy Brown, and I live in Janesville, WI. As a volunteer with the American Cancer Society Cancer Action Network, I urge you to support Assembly Bill 23 to establish a Palliative Care Advisory Council.

In 2005, my stepson Drew was diagnosed with leukemia. He passed away 17 months later. During that time, my husband and I had to be his nurses to change his IV medicine, social calendar monitors, home-school teachers, mental health advisors, activity coordinators, respite workers (for each other), and many other responsibilities to support his quality of life. Meanwhile, we both had full-time jobs and another son who was a freshman at UW-Milwaukee. Our hands were full.

The intensity of Drew's cancer care caused us a lot of stress. We slept an average of two hours per night because his IV bags had to be changed around the clock. We were exhausted. My husband and I took it out on each other constantly. One day, during one of Drew's inpatient stays at the American Family Children's Hospital, a social worker walked past the room when my husband and I were arguing. She asked to see us in the hallway and told us that we had to stop fighting. We weren't doing Drew - or his treatment - any good by fighting all the time. My first reaction to what she said was to start crying. I said, "I don't want to fight with Tim, but I am just so **expletive** tired!" The absence of palliative care meant that we had to do all these things ourselves, and it spread us so thin that we couldn't spend our time being PARENTS to this terminally ill child. Palliative care would have provided us with the resources we so desperately needed to be better caregivers.

In August 2023, I was diagnosed with Invasive Ductal Carcinoma and Ductal Carcinoma in Situ. These are very fancy words that mean "breast cancer". It was caught early, treated with surgery and radiation, and my prognosis is good. However, I will live the rest of my life fearing a recurrence of my cancer. If that happens, and the treatment is more disruptive than my last one, I will be able to focus on getting well if I have access to palliative care.

Assembly Bill 23 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 support Assembly Bill 23.

Sincerely, Tammy Brown 1512 Dayton Dr Janesville, WI 53546

3/12/25

To: Chair Cabral-Guevara

Dear members of the Senate Health Committee,

My name is Kelly Leibold. I live in La Crosse and serve as an elected official on the La Crosse County Board of Supervisors. I am also an eight-year cancer survivor and a volunteer with the American Cancer Society Cancer Action Network. I'm writing to share my story and voice my support for Assembly Bill 23 to establish a Palliative Care Advisory Council in Wisconsin. While palliative care is a rapidly growing specialty, it is still not found in all areas of the state. Outside of Wisconsin, 22 other states have already taken similar steps to establish similar advisory groups.

I lived in one of those states, Minnesota, when I was diagnosed with medulloblastoma, a central nervous system tumor, at just 20 years old. After emergency brain surgery, I underwent 30 days of proton beam radiation therapy and four months of chemotherapy to treat my cancer. While receiving my treatment, my care team always took the extra steps needed to make sure my treatments were comfortable, my symptoms were managed, and that my quality of life was as good as it could be. Because of the palliative care I received, after years of dealing with fatigue I am now able to return to the full-time working world. I give back to my community as the La Crosse Habitat for Humanity's Volunteer Coordinator. I am also the president of the La Crosse Toastmasters Club.

When I look back at the care that I received, I realize it allowed me to get where I am today. 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.

Improving the quality of life for cancer patients during and after treatment is one of 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.

Establishing a committee that can evaluate the palliative care system in Wisconsin and make policy recommendations will help all patients and their families get the care and support they need. I urge you to support Assembly Bill 23.

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



To: Chairperson Rachael Cabral-Guevara

Members, Committee on Health

From: Amanda Johnson MSM, PA-C, CAQ-PMH

Date: March 12, 2025

Re: Support for Senate Bill 39 – Palliative Care Council

Good afternoon, my name is Amanda Johnson. I've been a PA for almost twenty years after having graduated with a Master of Science in Medicine from Western Michigan University. I have practiced in primary care, oncology, and for the last six years, as an inpatient Palliative Care PA. I became board certified in Palliative Medicine and Hospice in April 2023. I served as the sole healthcare provider for the Palliative Care program at Mercyhealth's 240-bed hospital in Janesville from July 2021 until September 2024; I continue to practice there as part of a team of caregivers.

I'm appearing on behalf of the Wisconsin Academy of Physician Assistants and in support of Senate Bill 39.

WAPA represents physician assistants practicing in Wisconsin. Over 4,600 PAs practice in Wisconsin, working with physicians to provide quality, cost-effective team-based care to patients across the state. While PAs work in all areas of medicine, every PA is initially educated as a primary care provider. No matter where a PA practices, every six to ten years he or she must recertify by taking a primary-care based board examination. PAs' practice can include performing physical exams, diagnosing and treating illnesses, assisting in surgery, and prescribing medication.

WAPA supports Senate Bill 39, which requires the Department of Health Services to create a Palliative Care Council of health care professionals, patients of family members familiar with palliative care services, members of the legislature, and other stakeholders. The work of this council would be to help promote patient awareness of and access to this specialized form of medicine.

I've seen firsthand how palliative care benefits not only those suffering from a serious illness, but their families and other loved ones, too, by providing relief from the symptoms, pain, and stress of a serious illness, regardless of the patient's age or stage of the illness. Palliative care is not about curing the disease, but rather improving the quality of life for both the patient and their family. Palliative care ensures that individuals receive compassionate care that addresses their physical, emotional, and spiritual needs, offering support during challenging times. It also helps families navigate difficult decisions, ensuring that patients are treated with dignity and respect.

On behalf of WAPA, I respectfully ask you to support SB 39. I'm happy to try to answer any questions.



Testimony in Opposition to Senate Bill 39: establishing a Palliative Care Council Senate Committee on Health By Matt Sande, Director of Legislation / March 12, 2025

Good afternoon, Chairwoman Cabral-Guevara 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) 39, legislation that would establish a Palliative Care Council within the Department of Health Services (DHS).

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.

(over)

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Accountability measures for patient safety are of the utmost importance. As you will read in the physician testimony submitted 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 for doing so. This is deeply troubling, and I urge Committee members to press them for an answer.

We do appreciate the proposed protections included in SB 39 on page 5, lines 1-6, that prohibit the council from consulting with or advising DHS on physician-assisted suicide and euthanasia. But for Pro-Life Wisconsin to remove our opposition to SB 39 and even support it, the statutory definition of palliative care must be amended to exclude hastened death.

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 39 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 39. Thank you for your consideration, and I am happy to answer any questions from Committee members.

March 2025

Senator Rachael Cabral-Guevara, Chair and Members of the Senate Committee on Health

RE: Opposition to SB 39 creating a Palliative Care Council within DHS

Dear Senator Cabral-Guevara and Committee Members:

Thank you for the opportunity to explain why I oppose SB 39.

I am a retired attorney and CPA who has worked on health care issues for over 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 advocated for the elderly and disabled and wrote health care decision making articles for a State Bar publication. I recently served on the board of the Euthanasia Prevention Coalition USA as 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. Many palliative care programs are owned by hospices¹ and used as "loss leaders" ² to enroll people sooner and sometimes inappropriately in hospice. 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. Palliative care programs are financially unstable, leading to cost saving³ justifications and the resulting pressure for inappropriate clinical decisions. If they are not owned by hospices, they are likely owned by health insurers.⁴

Needed protective language would chill dangerous palliative care. 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. Ask

¹ Hospices are the largest provider of palliative care in the U.S.; 95% of hospital palliative care programs are linked to hospices, https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2016.0113; 69% of hospices offer palliative care programs, https://www.nhpco.org/2020-pc-needs-survey/.

² 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/

³ 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.

⁴ Elevance, formerly Anthem Blue Cross Blue Shield, bought Aspire Health, the nation's largest provider of non-hospice, community-based palliative care, in 2018.

https://www.elevancehealth.com/newsroom/anthem-inc-completes-acquisition-of-aspire-health

yourselves why anyone would oppose this language? Do they support intentionally causing patient deaths?

I will be happy to answer any questions or provide additional information. If SB 39 were amended to exclude medical killing from the statutory definition of palliative care, I would reconsider my opposition to the legislation.

Sincerely,

/s/

Attorney Sara Buscher



WISCONSIN CATHOLIC MEDICAL GUILDS

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

March 12, 2025

To: Members, Senate Committee on Health

FROM: Robin Goldsmith, MD, State Director, Wisconsin Catholic Medical Guilds

Elizabeth Anderson, MD, Assistant State Director; President - Madison Catholic

Medical Guild

RE: Senate Bill 39 – to establish a Palliative Care Council under Department of

Health Services

Good afternoon, Chairwoman Cabral-Guevara and members of the Senate Health 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 Guilds to speak in opposition to Senate Bill (SB) 39.

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 39 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 39, 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 39 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 these changes, we would be able to consider supporting SB 39 as a means to identify and promote ethical and excellent palliative care.

Thank you for your consideration.

To: Members, Senate Committee on Health

Re: Opposition to SB 39, establishing a state Palliative Care Council

Date: Wednesday, March 12, 2025

Good afternoon, Chairwoman Cabral-Guevara, and members of the Senate Health Committee. Thank you for allowing me to speak in opposition to Senate Bill 39.

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 39, 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 39. 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 39. Thank you for listening to my concerns.



WISCONSIN CATHOLIC CONFERENCE

TO: Senator Rachael Cabral-Guevara, Chair Members, Senate Committee on Health

FROM: Tia Izzia, Associate Director for Human Life & Social Concerns

DATE: March 12, 2025

RE: Opposition to Senate Bill 39, Palliative Care Council

On behalf of the Wisconsin Catholic Conference (WCC), the public policy voice of the bishops of Wisconsin, thank you for the opportunity to testify in opposition to Senate Bill 39, which would establish a palliative care council.

The Catholic Church supports the use of quality palliative care for those who are gravely ill and/or 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. It never hastens 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 a person's death. Until this change is made, 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.

TO:

Members of the Senate Health Committee

FROM:

Carrie Schepp, RN BSN MSM, VITAS Healthcare General Manager

DATE:

March 12, 2025

RE:

Senate Bill 39 – a bill establishing a state palliative care council

Good morning – Chair Cabral-Guevara, Vice Chair Testin, Ranking Democratic Member Smith – and committee members.

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 have 25 years of experience caring for Wisconsinites in their homes, including home health, hospice, and palliative care. I am here to speak in support of Senate Bill 39, as it will greatly benefit Wisconsinites with serious illnesses.

Palliative Care is care that focuses on what the patient wants for his/her treatment of a serious illness in conjunction with a medical team on how treatment may or may not benefit the patient. We often refer to this as goals of care conversations. When we understand the goal of the care to be provided, we often learn that patients seek appropriate treatment with quality of life above all else. Perhaps that means more time with family, time to take that last trip to see the ocean, time to get their affairs in order, etc. When we don't have these conversations and we don't approach patients and families with a treatment plan that meets their needs, we fail them. Our health care system as we know it focuses mostly on the treatment....more chemotherapy, more radiation, more dialysis, more hospitalizations, more tests but to what end? Palliative care bridges the gap between patient goals and a health care system that primarily focuses on treatment and tests. It's also important to note that palliative care is not end-of-life care. Palliative care is often confused with hospice care. Hospice care is end-of-life care and is generally provided to patients who have a prognosis of six months or less to live.

- In fact, a medical study showing improved quality of life and longer life for palliative care patients with lung cancer a 2010 study led by Jennifer Temel, MD, (Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, New England Journal of Medicine, August 19, 2010) a Harvard Medical School Professor of Medicine, concluded that: "Among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival."
- Palliative Care not only provides a better quality and quantity of life, it also provides necessary cost savings to Medicare, Medicaid, and private insurance companies. See attached savings outlined by the American Cancer Society. Palliative care savings extend beyond those diagnosed with cancer by reducing unnecessary hospitalizations and treatments for chronic illnesses such as COPD, congestive heart failure, end stage kidney disease, etc.
- The reality is Wisconsin is facing the "Silver Tsunami" This refers to the increase of the number of senior citizens in Wisconsin in the coming years. With more seniors, more palliative care providers will be needed and more education provided on the benefits of palliative care. Our seniors deserve

to be heard on what their goals are and what treatment can and cannot provide. Of course, this also affects the health care workforce, as well – more palliative care providers will be retiring in the coming years and more of them will be needed to replace them. There's a June 3, 2024, Milwaukee Journal-Sentinel article that goes into this topic. There is also a 2024 Wisconsin Hospital Association Workforce report that addresses this issue (see pages 2 and 9). The Palliative Care Council will not only bring more awareness and education to residents but also to new health care providers who may upon learning more about palliative care choose to focus their career on the treatment of patients with palliative care.

There are some organizations that are opposing this bill due to a misunderstanding of what palliative care is. They are operating under the assumption that palliative care is end-of-life care. Palliative care is not end-of-life care. Actually, their misguided opposition to this bill shows the need for the creation of a palliative care council in our state. The creation of a palliative care council — and the accompanying palliative care consumer and professional information and education program created in this bill — would make great strides in educating and clarifying Wisconsinites on the nature and value of palliative care.

More specifically, opponents to legislation creating a palliative care council have suggested that the purpose of palliative care is to hasten death. This is simply wrong, and in fact, many studies have shown that palliative care extends a patient's life through appropriate treatments, involvement of an interdisciplinary team, appropriate symptom management, and an undeniable focus on quality of life. The National Institute of Health (NIH) published a study in 2010, "Palliative Care: Earlier is better," which demonstrated that patients with cancer who received palliative care early had a median survival rate of 11.6 months as opposed to the control group of 8.9 months.

In addition, hastening another individual's death is already illegal under state statute. Section 940.12 of Wisconsin statutes states: "Whoever with intent that another take his or her own life assists such person to commit suicide is guilty of a class H felony." The suggestion that palliative care hastens death is 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.

In closing, the palliative care council's main objectives will include, but are not limited to, increasing awareness of palliative care with education throughout Wisconsin for residents, health care providers, and educational institutions, increasing access to palliative care, and serve as a quality council. Ultimately, creating such a council would help more Wisconsinites who could benefit from palliative care, access such care.

Thank you. Committee members, I am open to any questions you may have.

TO: Members of the Senate Committee on Health

FROM: Agron Ismaili, MD

VITAS Healthcare Milwaukee, Palliative Care-Hospice Medical Director

DATE: March 12, 2025

RE: Senate Bill 39 – a bill establishing a state palliative care council

Dear Committee Members:

My name is Agron Ismaili MD.

Vitas Healthcare, Milwaukee (Palliative Care-Hospice)-Medical Director

Board Certified in Palliative Care Hospice,

Board Certified in Internal Medicine,

Board Certified in Addiction Medicine

Certified Medical Director in Post-Acute Care (Nursing Home, Outpatient Rehabilitation Facilities)

and I hold a degree in Master of Business Administration

With 20 years of clinical experience direct/indirect in the field of Palliative Care.

I am here today to ask for your support of Senate Bill 39, which establishes a state palliative care council, and to discuss the value that palliative care provides to patients.

Patient story/coordination of care PALLIATIVE CARE DEFINITION/ASSISTANCE/COORDINATION WITH PRIMARY CARE -SPECIALTIES:

"Palliative care focuses on improving quality of life for patients with serious illness and their families. This approach may include providing relief from pain and/or other distressing symptoms, integrating psychological and spiritual aspects of care, assisting with difficult decision-making, and supporting patients and families. Palliative care can be provided alongside therapies intended to treat the underlying disease or prolong life (for example, chemotherapy), and it is appropriate at any age or stage of serious illness."

Here is an example of patient in Palliative Care: Patient (P.F.) was a 77-year-old female who enrolled in VITAS palliative care services. Her past medical history included: combined systolic and diastolic CHF (Congestive Heart Failure), severe pulmonary hypertension, COPD (Chronic Obstructive Pulmonary Disease) emphysema and chronic back pain. Goals of care were to continue life prolonging treatments by continuing outpatient appointments with cardiology/pulmonology/primary care physician and pain MDs (palliative care coordinated the care with above specialties, assisted her in controlling acute symptoms of exacerbation (example: leg edema, shortness of breath, respiratory failure), kept her comfortable at home by reducing unnecessary hospitalization and/or outpatient clinic visits). Valuable services of palliative care provided education/self-management of her chronic diseases (example: monitor blood pressure, manage diet by monitoring sodium and fat intake, follow physical activity as per guidelines), recognize the above symptoms and determine whom and when to call for assistance. To respect patient's wishes and values, multiple goals of care conversations occurred. Over time, patient/other providers relationship and trust grew within the Palliative Care Team. Patients and families are appreciative of the extra time given in the community setting, whereas it is not always experienced in outpatient doctor visits. Above patient care portrays Palliative Care Integration (with Primary Care/Specialty Clinics/Cardiology-Congestive Heart failure)

Palliative care may be delivered by palliative care specialists who work alongside the patient's primary clinicians. For example, a patient with advanced cancer may see a palliative care specialist in addition to their oncologist. This type of palliative care is called "subspecialty palliative care." Hospice and Palliative Medicine is now recognized as a medical subspecialty by the American Board of Medical Specialties...-PALLIATIVE CARE SPECIALIST.

Palliative care may also be provided by clinicians who are not palliative care specialists. For example, internists, family medicine doctors, cardiologists, oncologists, and many other clinicians who care for seriously ill patients may provide basic palliative care. Palliative care provided by clinicians who are not palliative care specialists is sometimes called "primary" or "basic" palliative care - PRIMARY PALLIATIVE CARE

Palliative Care added benefits-value, supports patient care needs, with ever increasing complexities-chronic medical problems-aging population. Patient/family/caregivers/community-education-symptom treatment-reduction of avoidable hospitalizations- community resources, are some of the benefits that improve quality of care.

Specifics of benefits of Palliative Care:

- Access-increase: Rural residents may have difficulty accessing healthcare providers, especially if they live far away or don't have transportation.+ Telehealth/Palliative Care can help patients in remote areas access palliative care.
- 2. Better symptom management: can help care providers monitor symptoms and intervene early.
- 3. More efficient care: can help care teams manage time and resources.
- 4. Better patient experience: can help patients feel more secure and comfortable.
- 5. Remote education and support: Providing remote education and support to community providers can help them provide palliative care.

Primary palliative care: This model delivers some palliative care services in primary care settings, which can help address workforce shortages.

Community-based palliative care: This model allows patients to receive care in their communities.

Based on my clinical experience, I suggest a few solutions:

- Support for strengthening institutional priorities-budgets-funding-reimbursements to assist with decreasing workforce shortages-hiring adequately trained palliative care physicians and nurses.
- Increasing healthcare resources allocated to palliative care.
- Recognition Program for centers/institutions that have attained a high level of palliative care integration. This can help patients become more educated in choosing appropriate treatment centers.

Thank you to all the committee members for holding this hearing and for giving me the opportunity to share these valuable services that are offered in the community, and it is our hope that Senate Bill 39 will help increase the awareness of palliative care across the state and help more patients access this type of care. I am open to any questions you might have.

Sources:

- o BMJ Support Palliative Care, 2023 June; (13(2) 199-208
- o https://www.uptodate.com/contents/primary-palliative-care

- National Institute of Health National Cancer Institute -Delivering Palliative Care by Telehealth meets the needs of people with cancer.
 - Top ten tips palliative care clinicians should know about Rural Palliative Care in the USA (CAPC.ORG)- (J Palliat Med 2024 Sep;27(9):1220-1228. doi: 10.1089/jpm.2024.0032. Epub 2024 Mar 15).
- o Improving Palliative Care Access Through Telehealth
 - Kristen Allen Watts ¹, Emily Malone ², James Dionne-Odom ³, Susan McCammon ⁴, Erin Currie ⁵, Jennifer Hicks ⁶, Rodney Tucker ⁷, Eric Wallace ⁸, Ronit Elk ⁹, Marie Bakitas ¹⁰
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Heather Weininger, Executive Director, Wisconsin Right to Life

Senate Committee on Health

SB 39, relating to: establishing a palliative care council.

Wednesday, March 12, 2025

Thank you to the Senate Committee on Health for the hearing today on SB 39, relating to establishing a palliative care council.

Wisconsin Right to Life is taking an other position on this bill. This is an informational item only for the members of the committee.

While we appreciate some of our concerns being addressed in the current draft of this bill, we continue to believe that this is the appropriate time to address the definition of palliative care in our current state statutes.

We ask before this bill moves any further, this issue is addressed.

Without a clear definition of palliative care within our state statutes, it continues to leave an avenue for those who support assisted suicide to use this as a vehicle for their cause.



TO:

Senate Committee on Health

FROM:

Charles "Barry" Rothschild, MD, Attending Physician, Pediatric Critical Care & Palliative Care Medicine, and Associate Medical Director, Provider Well-Being,

Children's Wisconsin

DATE:

Wednesday, March 12, 2025

RE:

Support for SB 39, SA 1 - Establishment of a Palliative Care Council, Senate

Amendment 1

On behalf of Children's Wisconsin, I appreciate the opportunity to offer written comments in support of SB 39 and Senate Amendment 1. I am Dr. Barry Rothschild, Attending Physician, Pediatric Critical Care & Palliative Care Medicine, and Associate Medical Director, Provider Well-Being, at Children's Wisconsin. Children's Wisconsin's (Children's) appreciates Senator James and Representative Snyder for their leadership in authoring this proposal, and especially appreciate their willingness to introduce Senate Amendment 1 to include a pediatric specialist as part of the membership of the palliative care council.

At Children's Wisconsin, we are dedicated to the health and well-being of kids and their families. In my practice, this includes caring for children with serious, life-limiting or life-threatening illnesses with a focus on improving their quality of life and supporting their physical, mental and emotional well-being. My team and I provide family-centered, compassionate care alongside other specialists involved in the child's care to develop a care plan that is specific to each child's needs and treatment goals. We promote comfort, love, hope and dignity and empower children and families to make their health care decisions. At Children's, many of our patients have serious or life-threatening illnesses. We help them manage their pain or physical symptoms, understand and cope with their circumstance, and offer compassionate support and connection to resources.

SB 39 outlines members of the proposed palliative care council, including approximately a dozen health care professionals. Senate Amendment 1 proposes including a pediatric palliative care physician as one of the 5 physician members of the council. As is true across pediatric specialty care, kids are not just little adults. Kids with life-limiting or life-threatening conditions and those nearing end-of-life are often best served by those with pediatric palliative expertise. In fact, our patients and families, especially those living in rural areas, often struggle to find community-based palliative care and hospice services as many adult providers aren't comfortable or familiar with serving children and their families.

Understandably, many of the health care professionals on the proposed palliative care council focus on serving adult populations, however I believe including a pediatric palliative care physician on the council would provide insight and value in their work to advise the Department of Health Services about palliative care issues. I especially appreciated the legislation's aim to consider concurrent care — the economic and quality of life effectiveness of palliative care that is provided along with curative treatment. In pediatrics, we have deep experience with concurrent care, specifically hospice care at the same time as curative treatment. A pediatric palliative care physician will bring important expertise and perspectives to this and many topics, to help represent children facing unimaginable circumstances and the providers who care for them. The proposed council could be impactful in working to improve palliative care and hospice access for all Wisconsinites, including our kids and their families.

Thank you for the opportunity to share Children's Wisconsin's perspectives on the importance of Senate Amendment 1. We are happy to answer any questions through our contact information listed below.

Barry Rothschild, MD
Attending Physician, Pediatric Critical Care & Palliative Care Medicine
Associate Medical Director, Provider Well-Being
Children's Wisconsin
crothschild@mcw.edu

Jodi Bloch
Director, State & Local Government Relations
Children's Wisconsin
jbloch@childrenswi.org

Children's Wisconsin (Children's) serves children and families in every county across the state. We have inpatient hospitals in Milwaukee and the Fox Valley. We care for every part of a child's health, from critical care at one of our hospitals, to routine checkups in our primary care clinics. Children's also provides specialty care, urgent care, emergency care, dental care, school health nurses, foster care and adoption services, family resource centers, child health advocacy, health education, family preservation and support, mental health services, pediatric medical research and the statewide poison hotline.

March 10, 2025

Dear Members of the Senate Committee on Health:

As a practicing Business Manager I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

This legislation will create a palliative care council to improve awareness of and expand access to this specialized type of care that provides patients with relief from the symptoms, pain and stress of serious, life-altering illnesses, such as cancer, congestive heart failure, Alzheimer's disease, as well as other serious medical conditions. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Expanding awareness of and access to this specialized type of care would not only help patients, but it would also help reduce health care costs for patients and payers, including the state's Medicaid program. According to a summary of palliative care studies prepared by the American Cancer Society, palliative care reduces health care costs:

- According to a 2020 studyⁱ, hospital patients who received a quick palliative care referral had median hospital charges that were \$56,700 less than other patients.
- A 2022 study found that palliative care provided to adult patients at home decreased their medical costs by 16.7%.
- Hospital patients with cancer who received a palliative care consultation within two days of admission experienced up to 32% lower health care costs, according to a 2016 study...

Many other states have already taken the step of creating a similar advisory group to increase awareness of access to this specialized type of care. In fact, according to the National Academy for State Health Policy, 22 other states from coast to coast – both red and blue states – have formed such entities. There are many good people delivering health care across Wisconsin who have still not worked directly with a specialist in palliative care. This is where a Palliative Care Council would play a valuable role in assessing its availability, identifying barriers, and pooling wisdom to recommend ways to expand access to and awareness of this specialized type of medical care.

I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Malisa Baecker
Business Manager
VITAS Healthcare

Macmillan PJ, Chalfin B, Fard AS, and Hughes S. Earlier Palliative Care Referrals Associated with Reduced Length of Stay and Hospital Charges. Journal of Palliative Medicine. Jan 2020. 107 111.

(http://doi.org/10.1089/jpm.2019.0029)

Marvin J. Gordon, Tao Le, Emmet W. Lee, and Aijing Gao. Home Palliative Care Savings. Journal of Palliative Medicine. Apr 2022.591-595. (http://doi.org/10.1089/jpm.2021.0142)

May P, Garrido MM, Cassel JB, et al., Palliative Care Teams' Cost-Saving Effect Is Larger For Cancer Patients With Higher Numbers Of Comorbidities, Health Affairs, 2016, 35, pp. 44-53.

Dear Members of the Senate Committee on Health:

As a hospice representative, I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Megan Federighe VITAS Healthcare

¹ Macmillan PJ, Chalfin B, Fard AS, and Hughes S. Earlier Palliative Care Referrals Associated with Reduced Length of Stay and Hospital Charges. Journal of Palliative Medicine. Jan 2020. 107 111. (http://doi.org/10.1089/jpm.2019.0029)

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Dear Members of the Senate Committee on Health:

As a practicing hospice chaplain, I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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- According to a 2020 study¹, hospital patients who received a quick palliative care referral had median hospital **charges that were \$56,700 less than other patients.**
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Many other states have already taken the step of creating a similar advisory group to increase awareness of access to this specialized type of care. In fact, according to the National Academy for State Health Policy, 22 other states from coast to coast – both red and blue states – have formed such entities. There are many good people delivering health care across Wisconsin who have still not worked directly with a specialist in palliative care. This is where a Palliative Care Council would play a valuable role in assessing its availability, identifying barriers, and pooling wisdom to recommend ways to expand access to and awareness of this specialized type of medical care.

I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Russell Hurst Chaplain

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VITAS Healthcare

Dear Members of the Senate Committee on Health:

As a practicing RN, I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Julie Hiemer RN Team Manager IPU Vitas Healthcare

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March 10, 2025

Dear Members of the Senate Committee on Health:

As a practicing Registered Nurse, I am contacting you to respectfully request that you support **Senate Bill 39,** authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

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Kristin Gegare RN Team Manager VITAS Healthcare

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3/10/2025

Dear Members of the Senate Committee on Health:

As a practicing Manager of Volunteer/Bereavement services, I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Chris Mulloy
Manager of Volunteer/Bereavement Services
VITAS Healthcare

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Dear Members of the Senate Committee on Health:

As a practicing hospice and palliative care physician, I am contacting you to respectfully request that you support **Senate Bill 39**, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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I strongly support the creation of a palliative care council in Wisconsin. Thank you for your consideration.

Sincerely,

Dr. David Munoz

Board certified hospice and palliative care physician

Vitas Healthcare

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March 11, 2025

Dear Members of the Senate Committee on Health:

As a practicing Licensed Practical Nurse, I am contacting you to respectfully request that you support Senate Bill 39, authored by Senator Jesse James and Representative Pat Snyder, to create a palliative care council. Wisconsin would benefit from a Palliative Care Council because palliative care adds so much to patient care and not everyone in the world of health care in Wisconsin is aware of this.

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lilly Shoulden LPN

Vitas Healthcare

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