

PATRICK SNYDER -STATE REPRESENTATIVE • 85th Assembly District

Testimony in Support of Assembly Bill 23

Assembly Committee on Health, Aging & Long-Term Care

February 12, 2025

Chairman Moses 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.

STATE SENATOR

February 12th, 2025

148 3. d. l. int grant de Minde Country investments and a second Representative Moses, Chair Members of the Assembly Committee on Health, Aging and Long-Term Care

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Testimony on 2025 Assembly Bill 23

Relating to: establishment of a Palliative Care Council

And THE TERRET CONTRACTOR COMMENDATION FOR SERVICE AND alle an air leannach Thank you, Chairman Moses and other members of the committee, for hearing my testimony on Assembly Bill 23 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.

af et tal set i set este set a set spacing substantion i set set a set set a 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.

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Respectfully,

Senator Jesse James 23rd Senate District Sen.James@legis.wisconsin.gov

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- PO Box 7882 • Madison, WI 53707-7882 (608) 266-7511 • (888) 437-9436 • Sen.James@legis.wisconsin.gov • www.SenJesseJames.com

AMES 23RD DISTRICT

TO:	Members of the Assembly Health Committee	
FROM:	Siera Williams, BSN, RN Director of Hospice Touch & Palliative Care	
DATE:	February 12, 2025	
RE:	Assembly Bill 23 – a bill establishing a state palliative care council	

Good morning – Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck – and committee members.

Thank you for hearing our testimony in support of Assembly Bill 23, 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 dedicated to hospice and palliative care. Serving patients and families in my rural community is my passion, which is why I advocate for this cause. While our team has worked hard to expand palliative care access and education, there is still much more to do.

Palliative care is often misunderstood, but it is designed to support patients at any stage of a serious illness. It focuses on managing symptoms, improving quality of life, and helping individuals navigate complex medical care, especially those with multiple chronic conditions. Our providers focus on the whole person; their health, treatments, and personal goals. Many patients have dreams beyond their illness, that we can also help them achieve.

Integrating palliative care into our healthcare system has major benefits. Research shows it improves patient outcomes, reduces hospitalizations, and lowers costs by providing care in the right setting, tailored to each patient's needs. I have seen its profound impact, especially in rural and underserved areas like ours, where patients face transportation barriers, financial struggles, and limited local resources. Without palliative care, many patients go without the support they need. By bringing care into the home, we help manage symptoms, prevent hospital visits, and ensure patients receive the compassionate, personalized care they deserve.

Creating a Palliative Care Council would help raise awareness and improve access to palliative care in Wisconsin. The council would identify gaps, promote best practices, and recommend ways to ensure all patients receive quality, personalized care; no matter their location or financial situation. In communities with limited healthcare resources, this could be life-changing for many patients and families.

I urge the committee to support this bill and ensure that palliative care is recognized as an essential part of Wisconsin's healthcare system. By improving education, collaboration, and access, we can better support patients with serious illnesses while easing the strain on our healthcare system.

Thank you for your time and for holding this important hearing. I appreciate the opportunity to speak today and am happy to answer any questions.

Ilien, BSN, RN

Siera Williams, BSN, RN Director of Hospice Touch & Palliative Care

TO:	Members of the Assembly Health Committee
FROM:	Kimberly Casper, MSN, FNP-C
DATE:	February 12, 2025
RE:	Assembly Bill 23– a bill establishing a state palliative care council

Good morning – Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck – 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 Care and Hospice Nurse Practitioner. I have been in health care for a total of 15 years. I have been a Palliative Care provider for 1.5 years and 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. The majority 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 the assembly bill 23. 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. Have you ever had an experience where you go in to see your doctor and they are only in the room for 5-10 minutes and your visit is done? Did you feel that your problems were heard or that you understood the medical advice given? 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 for us to listen and address their concerns which builds a trusting relationship. This allows for patients to have 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 is not taught in the medical education systems. 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 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 and missing out on the extra support they likely needed. From a financial stand point, Palliative care can help decrease ER visits 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

то:	Members of the Assembly Health Committee
FROM:	Michelle Theige, APNP, ACHPN, CHPN
DATE:	February 12, 2025
RE:	Assembly Bill 23 – A bill establishing a state palliative care council

Good morning – Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck – and committee members.

My name is Michelle Theige and I am a Nurse Practitioner for Tomah Health Palliative Care and Hospice. I have been in this role for 4 years and have been Board certified in Palliative care and hospice for the past 2 years. I have also been working as a board certified Hospice nurse for Mayo Clinic for the past 9 years. I would like to thank everyone for being here for this hearing in support of Assembly Bill 23 to establish a Palliative Care Council and to hear of the value of Palliative care services.

First, I would like to discuss Palliative Care and how it differs from hospice. When I initially meet a patient and their family for a consultation, I find that I typically spend the first portion of our visit explaining what Palliative care is. It is not only patients and families who tell me that they don't know what Palliative care is, I find that many Primary Care Providers and other specialty providers may also have a misunderstanding about who we are and what we have to offer.

Palliative care is specialized care that is focused on alleviating symptoms related to many chronic and terminal illnesses including, but not limited to, heart and lung diseases, cancer, kidney failure, and Alzheimer's disease. Common distressing symptoms that we treat include complex pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite, and difficulty sleeping. Palliative care can be started at any point of a chronic or terminal illness diagnosis, though unfortunately, I find that referrals are placed to us very late into a diagnosis. There is no time limit for how long a patient can be on Palliative care services, in fact, many of our patients have been with us for over 1-2 years or more. Hospice is for patients who have a predicted life expectancy of 6 months or less, if their illness runs its normal course. With hospice, there is also the possibility of patients being on services for over 6 months as long as they remain eligible based on Medicare guidelines. The primary difference between Palliative care and hospice is that Palliative Care patients are often still seeking curative treatment for their illness, and also still desire to be hospitalized for treatment and diagnostics. Hospice typically does not provide diagnostic measures, or have patients seen in the hospital, unless it is for symptom management or is requested for a respite stay.

I would like to share the story of a patient of mine that I feel exemplifies the benefits 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 (which was then mounted and given to his grandson as a Christmas present). 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 ensuring that his children and grandchildren were 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.

I think that it is important to understand why Palliative care and hospice are so closely related, but not the same. Many patients believe that palliative care means hospice or end of life care, but that is not the case. They are different by means of what the patient's goals and prognosis are. Following patients under Palliative care allows for more regular conversation about hospice, its philosophy and how it can improve a patient's quality of life. Earlier Palliative care enrollment for our patients has been directly related to an increased median length of stay under our hospice care and better outcomes for patients and their families.

Another benefit to Palliative care services is its value as far as cost savings. 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 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. I think it is directly related to our regular home visits, physical assessments, and education we provide to patients and their families. We are identifying things in the home settings that may be missed in the inpatient and clinic setting. We provide medication reconciliation to ensure our patients are taking their medications as prescribed, and that they understand why they take them. We are also there to support caregivers of our patients as well. We provide regular psychosocial assessment of both patients and their caregivers, because if the caregiver is not caring for themselves adequately, the patient is also likely to be affected negatively. We work to connect our patients and caregivers with local caregiving agencies, which unfortunately, in the rural setting, is a challenge in and of itself.

Over the past few years, we have successfully increased our Palliative Care patient census from an average of 35 patients to an average of 110-115 or more patients with ongoing steady growth. With this growth, we have initiated a care coordination program with our services. Many of our patients have many complex health care needs and are often established with a number of different specialty providers. Our Palliative care social worker and Registered Nurse provide significant care coordination services on behalf of our patients to ensure that communication is being shared between specialty providers, managed care organizations such as My Choice, and Inclusa, and primary care providers. Many of our patients verbalize how much they appreciate the assistance with navigating communication between these different services.

I would also like to specifically identify that home based palliative care is especially valuable. In fact, a large portion of our referrals are often placed from nearby larger health care organizations with only inpatient or clinic based Palliative care. When a palliative care referral is placed, many patients state

that they cannot make it in for another clinic visit and many are pleasantly surprised to learn we come to their home. In fact, with the growth of our Palliative care department, we have been able to extend our service area to serve more patients in our outlying areas. As I mentioned, these patients are often declining physically and functionally. For many of these patients, getting out of their home and into the clinic for a visit is extremely difficult. Not only related to their physical limitations, but also transportation can be another significant barrier. We hear continually that our home visits are especially appreciated and beneficial in many aspects.

I think that 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. This shows that Wisconsin has some room for improvement in providing access for patients with serious illness to high quality specialty care. 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. This is a significant disparity compared to other states, and in other specialties. This bill would establish a council of experts in the field of palliative care to identify how we can best meet the needs of our patients in Wisconsin. As the aging population continues to increase, the need for more Palliative care services will also continue to increase. Please join me in support of this bill that will work to improve access to Palliative care for patients and their families during a time of significant physical, psychological, and emotional distress. 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: <u>https://www.capc.org/making-the-value-case/</u> CAPC: https://scorecard.capc.org/



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

February 12, 2025

To: Assembly Committee on Health, Aging and Long-Term Care From: The American Cancer Society Cancer Action Network Re: Testimony in Favor of Assembly Bill 23 - Establishment of a Palliative Care Council

Good morning, Chairman Moses 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 Assembly Bill 23 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 Representative Snyder as the lead sponsor as well as members on this committee who are among the bi-partisan cosponsors.

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 AB 23 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 Assembly Bill 23.

February 12, 2025

To: Chairman Moses, Vice-Chair Brooks, and members of the committee

Dear members of the Assembly Committee on Health, Aging and Long-Term Care,

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

February 12, 2025

To: Chairman Moses, Vice-Chair Brooks, and members of the committee

Dear members of the Assembly Committee on Health, Aging and Long-Term Care,

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

February 12, 2025

To: Chairman Moses, Vice-Chair Brooks, and members of the committee

Dear members of the Assembly Committee on Health, Aging and Long-Term Care,

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

TO:	Members of the Assembly Health Committee
FROM:	Agron Ismaili, MD, MBA, FACP, FAAHPM, FASAM, DABPM, CMD VITAS Healthcare Milwaukee, Medical Director
DATE:	February 12, 2025
RE:	Assembly Bill 23 – a bill establishing a state palliative care council

Dear Committee Members: Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck and other committee members.

I am Agron Ismaili, MD, of Vitas Healthcare, Milwaukee (Palliative Care-Hospice)-Medical Director. I am board-certified in palliative care-hospice care, internal medicine, and addiction medicine. I am also a certified medical director in post-acute care (nursing home, outpatient rehabilitation facilities) and I also have a Master of Business Administration degree. I have 20 years of clinical experience in the field of palliative care.

"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 ..."

Please allow me to provide an example of a palliative care patient. Palliative care patient (P.F.) was a 77year-old female who enrolled in VITAS palliative care services. Her past medical history includes: 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, continue outpatient appointments with cardiology/pulmonology/primary care physician and pain MDs (palliative care coordinated the care with above specialties, assisted her in preventing exacerbation of acute symptoms, kept her comfortable at home by reducing unnecessary hospitalization and/or outpatient clinic visits). Valuable services of palliative care provided education/selfmanagement on her chronic diseases, in addition multiple goals of care Conversations occurred. Over time, patient/other providers rapport and trust grew within the Palliative Care Team. Patient noted a positive outcome with decreased shortness of breath and leg edema by providing palliative care services at home. Patients and families are appreciative of the extra time given in the community setting, whereas this is not always experienced in outpatient doctor visits.

Palliative care may be delivered by palliative care specialists who work alongside a 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 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.

Benefits of Palliative Care:

- Tele-Palliative Care
- Rural Medicine
- Access: 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.
- Beter symptom management can help care providers monitor symptoms and intervene early.
- More efficient care: can help care teams manage time and resources.
- Better patient experience: can help patients feel more secure and comfortable.
- 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.
- Remote education and support: Providing remote education and support to community providers can help them provide palliative care.

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 this bill 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: https://www.uptodate.com/contents/primary-palliative-care
- National Institute of Health National Cancer Institute -Delivering Palliative Care by Telehealth meet 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).
- 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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WISCONSIN CATHOLIC CONFERENCE

- TO: Representative Clint Moses, Chair Members, Assembly Committee on Health, Aging, and Long-Term Care
- FROM: David Earleywine, Associate Director

DATE: February 12, 2025

RE: Opposition to Assembly Bill 23, 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 Assembly Bill 23, 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), <u>http://w2.vatican.va/content/francesco/en/speeches/2015/march/documents/papa-francesco 20150305 pontificia-accademia-vita.html</u>



Contact: Connie Schulze Director, Government Affairs

Assembly Committee on Health, Aging and Long-Term Care Support for Assembly Bill 23: Palliative Care Council Testimony of Kaylee Litchfield, RN February 13, 2025

Chairman Moses and Members of the Committee,

I am here today representing UW Health to express our support for Assembly Bill 23, which seeks to improve health care quality through the establishment of a state advisory council on palliative care. Special thanks to the authors, Representative Snyder and Senator James, for introducing this legislation and to Chairman Moses for this opportunity to share our perspective regarding care for those with serious illness.

My name is Kaylee Litchfield. I have been a Registered Nurse for six years and since graduating nursing school, I have held a variety of positions either in hospice or palliative care. I currently work as a clinic nurse in Ambulatory Palliative Care which is embedded in the UW Health | Carbone Cancer Center (Carbone).

It's important to note there is a difference between hospice and palliative care, although the terms are often used interchangeably. The most distinct difference is palliative care can be implemented at any age or stage of a serious illness. Whereas hospice is care when curative treatment is no longer a feasible option and/or when life expectancy is predicted to be six months or less.

Palliative care is considered a standard of high-quality care for certain populations, such as patients with advanced cancer, and is codified by NCCN (National Comprehensive Cancer Network) and ASCO (American Society of Clinical Oncology); however, access to palliative care is not always readily available. The latest scorecard from the Center to Advance Palliative Care (CAPC) states Wisconsin has a rating of 2.5 out of 5 possible stars, indicating there's considerable room for improvement. To that end, the legislation before you would create a palliative care council – an important step to assessing the quality of and access to palliative care services available across Wisconsin.

In my work at Carbone, we focus on patient-centered outcomes like symptom burden, caregiver burden, quality of life, and bereavement. We have open and honest discussions with people facing serious illness about the relative value of different treatment options. I would like to share a few patient stories from our team at Carbone to give you a better sense of palliative care's role in health care.

Patient A is middle-aged with advanced cancer. She first started seeing our palliative care team last year. She came to our team with hopes of decreasing her use of opioids and taking better care of herself. Over time, our team has successfully assisted with tapering her opioid dosage, connected her with health psychology for psychosocial support, and introduced her to yoga for improved physical and social wellbeing. This patient is very pleased and often refers others to palliative care. She frequently states, "I wish I would have known about palliative care sooner."

Patient B is a young adult with advanced cancer. Upon initial contact, the patient was on a high daily dose of Oxycontin. Over the years, we have been able to adjust the patient's pain medications and address their pain from a multimodal focus. We have been able to provide support throughout many life changes. The patient is currently on stable doses of pain medications that have allowed them to continue to do activities they enjoy. One such activity is making hand-crafted cookies for different events. Thankfully, the patient shares their delicious baked goods with our team every month.

Patient C is a middle-aged adult with advanced metastatic cancer. This patient has experienced all of the symptoms you could imagine accompanying cancer, especially pain. Over the past few months, we have built a strong rapport with one another. Not only have I been able to support the patient's physical symptoms, but I have served as an emotional support as they expressed anxiety and concern relative to their treatment. We have been able to have candid and sincere conversations about treatment options and symptom management. This has aided their care and quality of life.

Evidence-based research has demonstrated that palliative care improves quality of life, improves symptom burden, prolongs life, and improves caregiver burden all while saving the health care system money. Palliative care does not alter the outcome of a serious illness, but it does significantly impact patients and families living with that illness. For this reason and those outlined in my testimony, we hope you see fit to support AB23 and advance it out of committee.

Thank you for your consideration. I'd be happy to take questions at this time.

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TO:	Members of the Assembly Health Committee
FROM:	Carrie Schepp General Manager, VITAS Healthcare - Wisconsin
DATE:	February 12, 2025
RE:	Assembly Bill 23- a bill establishing a state palliative care council

Good morning – Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck – 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 Assembly Bill 23, 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, Representative Moses, for holding this hearing. Committee members, I am open to any questions you may have.

23



Palliative Care: Key Studies on Cost Savings

The table below lists key studies and review articles that examine the effect that the addition of palliative care has on overall patient costs. While results vary, the addition of palliative care typically either reduces overall costs or is cost neutral, while improving patient quality of life.

Study	Setting	How Palliative Care Effected Costs
May 2016 ¹ Health Affairs	Inpatient hospital patients with advanced cancer in 6 sites in NY, OH, VA, WI	Receipt of a palliative care consultation within 2 days of admission was associated with 22% lower costs for patients with a comorbidity score of 2–3 and with 32% lower costs for those with a score of 4 or higher.
Macmillan 2020 ² Journal of Palliative Medicine	Patients with a palliative care referral at a university-affiliated community-based urban hospital	Significant association between reduced length of stay and hospital charges when consults for palliative care were initiated within 24 hours of hospital admission regardless of underlying disease. Patients who received an early referral had median total hospital charges of \$38,600 – compared to \$95,300 for the control group.
Hua 2020 ³ JAMA	Patients who died during hospitalization in New York	Implementation of palliative care at a hospital was associated with a 10% reduction in intensive care unit use for patients who died during their hospitalization.
Sheridan 2021⁴ American Journal of Hospice and Palliative Care	Medicare patients with metastatic lung, colorectal, breast and prostate cancers	Palliative care consultation within 7 days of death decreased healthcare costs by \$451, while palliative care consultation more than 4 weeks from death decreased costs by \$4,643.
Ernecoff 2021⁵ Journal of Palliative Medicine	Patients receiving palliative care services in an integrated delivery finance system	Palliative care was associated with significant cost saving and decreased length of stay when occurring early in a hospitalization and used for goals-of-care and hospice evaluation.
Gordon 2022 ⁶ Journal of Palliative Medicine	Adult home palliative care program	Adult home-based palliative care is effective in decreasing total medical costs by 16.7% during a calendar year compared with a control group. Savings were greater for patients enrolled for 6- 12 months as compared to 1-5 months, and were most prominent for patients enrolled in commercial insurance products.

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Palliative Care: Key Studies on Cost Savings - November 2022

Conclusions of Meta-Analyses

Hughes 2014 ⁷	"The benefits of palliative care have now been shown in multiple clinical trials, with increased patient and provider satisfaction, equal or better symptom control, more
Annual Review Public	discernment of and honoring choices about place of death, fewer and less intensive
Health	hospital admissions in the last month of life, less anxiety and depression, less caregiver distress, and cost savings."
May 2018 ⁸	Hospital costs were lower for patients seen by a palliative care consultation team than for patients who did not receive this care. The estimated association was greater for those
JAMA	with a primary diagnosis of cancer and those with more comorbidities compared with those with a noncancer diagnosis and those with fewer comorbidities.

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Testimony in Opposition to Assembly Bill 23: establishing a Palliative Care Council Assembly Committee on Health, Aging and Long-Term Care By Matt Sande, Director of Legislation / February 12, 2025

Good morning, Chairman Moses 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 Assembly Bill (AB) 23, 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 <u>Hospice and Palliative Medicine's Attempt at an Art of Dying</u>, 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.

PRO-LIFE WISCONSIN, INC PO BOX 221 BROOKFIELD, WI 53008 262.796.1111 PROLIFEWI.ORG INFO@PROLIFEWI.ORG @**PROLIFEWI** (over)

Page 2 (PLW Testimony / AB 23)

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.

Another critical reason it is imperative to place safeguards directly in the definition of palliative care is that the proposed protections included in AB 23 on page 5, lines 1-6, 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 AB 23 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 AB 23 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 AB 23 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 AB 23, 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.

February 2025

Representative Clint P. Moses, Chair and Members of the Assembly Committee on Health, Aging and Long-Term Care

RE: Opposition to AB 23 creating a Palliative Care Council within DHS

Dear Representative Moses and Committee Members:

Thank you for the opportunity to explain why I oppose AB 23.

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 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 hospices and used as "loss leaders" ¹ 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 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 AB 23 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. Section146.695 (2)(b) says:

The council may not consult with or advise the department on physicianassisted suicide, euthanasia, medical aid in dying, or any other act that

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

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.

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 AB 23 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 <u>State v.</u> <u>Melchert-Dinkel</u>, 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, <u>State v. Final Exit, Inc.</u>, 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 AB 23 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



WISCONSIN CATHOLIC MEDICAL GUILDS

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

February 12, 2025

То:	Members, Assembly Committee on Health, Aging and Long-Term Care
FROM:	Robin Goldsmith, MD, State Director, Wisconsin Catholic Medical Guilds Elizabeth Anderson, MD, Assistant State Director; President - Madison Catholic Medical Guild
RE:	Assembly Bill 23 – to establish a Palliative Care Council under Department of Health Services

Good morning, Chairman Moses and members of the Assembly Health, Aging and Long-Term Care 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 Assembly Bill 23.

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/)

Assembly Bill 23 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 Assembly Bill 23, 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 AB 23 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 AB 23 as a means to identify and promote ethical and excellent palliative care.

Thank you for your consideration.

To: Members, Assembly Committee on Health, Aging and Long-Term Care

Re: Opposition to AB 23, establishing a state Palliative Care Council

Date: Wednesday, February 12, 2025

Good morning, Chairman Moses, and members of the Assembly Health, Aging and Long-Term Care Committee. Thank you for allowing me to speak in opposition to Assembly Bill 23.

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 endof-life care in recent years.

When I look over AB 23, 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 AB 23. Why is the state getting involved with this specialty at all? Shouldn't it be done by private healthcare systems who are

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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 AB 23. Thank you for listening to my concerns.

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TO:	Members of the Assembly Health Committee
FROM:	Carrie Schepp General Manager, VITAS Healthcare - Wisconsin
DATE:	February 12, 2025
RE:	Assembly Bill 23- a bill establishing a state palliative care council

Good morning – Chair Moses, Vice Chair Brooks, Ranking Democratic Member Subeck – 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 Assembly Bill 23, 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, Representative Moses, for holding this hearing. Committee members, I am open to any questions you may have.



Palliative Care: Key Studies on Cost Savings

The table below lists key studies and review articles that examine the effect that the addition of palliative care has on overall patient costs. While results vary, the addition of palliative care typically either reduces overall costs or is cost neutral, while improving patient quality of life.

Study	Setting	How Palliative Care Effected Costs
May 2016 ¹ Health Affairs	Inpatient hospital patients with advanced cancer in 6 sites in NY, OH, VA, WI	Receipt of a palliative care consultation within 2 days of admission was associated with 22% lower costs for patients with a comorbidity score of 2–3 and with 32% lower costs for those with a score of 4 or higher.
Macmillan 2020 ² Journal of Palliative Medicine	Patients with a palliative care referral at a university-affiliated community-based urban hospital	Significant association between reduced length of stay and hospital charges when consults for palliative care were initiated within 24 hours of hospital admission regardless of underlying disease. Patients who received an early referral had median total hospital charges of \$38,600 – compared to \$95,300 for the control group.
Hua 2020 ³ JAMA	Patients who died during hospitalization in New York	Implementation of palliative care at a hospital was associated with a 10% reduction in intensive care unit use for patients who died during their hospitalization.
Sheridan 2021 ⁴ American Journal of Hospice and Palliative Care	Medicare patients with metastatic lung, colorectal, breast and prostate cancers	Palliative care consultation within 7 days of death decreased healthcare costs by \$451, while palliative care consultation more than 4 weeks from death decreased costs by \$4,643.
Ernecoff 2021⁵ Journal of Palliative Medicine	Patients receiving palliative care services in an integrated delivery finance system	Palliative care was associated with significant cost saving and decreased length of stay when occurring early in a hospitalization and used for goals-of-care and hospice evaluation.
Gordon 2022 ⁶ Journal of Palliative Medicine	Adult home palliative care program	Adult home-based palliative care is effective in decreasing total medical costs by 16.7% during a calendar year compared with a control group. Savings were greater for patients enrolled for 6- 12 months as compared to 1-5 months, and were most prominent for patients enrolled in commercial insurance products.

American Cancer Society Cancer Action Network | 655 15th Street, NW, Suite 503 | Washington, DC 20005

Palliative Care: Key Studies on Cost Savings - November 2022

Conclusions of Meta-Analyses

Hughes 2014 ⁷	"The benefits of palliative care have now been shown in multiple clinical trials, with
	increased patient and provider satisfaction, equal or better symptom control, more
Annual Review Public	discernment of and honoring choices about place of death, fewer and less intensive
Health	hospital admissions in the last month of life, less anxiety and depression, less caregiver
	distress, and cost savings."
May 2018 ⁸	Hospital costs were lower for patients seen by a palliative care consultation team than for
and many second and	patients who did not receive this care. The estimated association was greater for those
JAMA	with a primary diagnosis of cancer and those with more comorbidities compared with
	those with a noncancer diagnosis and those with fewer comorbidities.

References

¹ 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.

² 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

³ Hua M, Lu Y, Ma X, Morrison RS, Li G, Wunsch H. Association Between the Implementation of Hospital-Based Palliative Care and Use of Intensive Care During Terminal Hospitalizations. JAMA Netw Open. 2020;3(1):e1918675. doi:10.1001/jamanetworkopen.2019.18675

⁴ Sheridan PE, LeBrett WG, Triplett DP, Roeland EJ, Bruggeman AR, Yeung HN, Murphy JD. Cost Savings Associated With Palliative Care Among Older Adults With Advanced Cancer. Am J Hosp Palliat Care. 2021 Oct;38(10):1250-1257. doi: 10.1177/1049909120986800. Epub 2021 Jan 11. PMID: 33423523; PMCID: PMC9019862.

⁵ Natalie C. Ernecoff, Andrew Bilderback, Johanna Bellon, Robert M. Arnold, Michael Boninger, and Dio Kavalieratos. Associations between Reason for Inpatient Palliative Care Consultation, Timing, and Cost Savings. Journal of Palliative Medicine.Sep 2021.1525-1538.http://doi.org/10.1089/jpm.2020.0636

⁶ 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

⁷ Hughes MT, Smith TJ, The growth of palliative care in the United States, Annu Rev Public Health 2014;35:459-75.

⁸ May P, Normand C, Cassel JB, et al. Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Metaanalysis. JAMA Intern Med. 2018;178(6):820–829.

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WISCONSIN CATHOLIC CONFERENCE

TO: Representative Clint Moses, Chair Members, Assembly Committee on Health, Aging, and Long-Term Care

FROM: David Earleywine, Associate Director

DATE: February 12, 2025

RE: Opposition to Assembly Bill 23, 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 Assembly Bill 23, 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.

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¹ Address of His Holiness Pope Francis to Participants in the Plenary of the Pontifical Academy for Life (March 5, 2015), <u>http://w2.vatican.va/content/francesco/en/speeches/2015/march/documents/papa-francesco 20150305 pontificia-accademia-vita.html</u>

620 S. 76th St., Ste. 160 Milwaukee, WI 53214

4600 American Parkway, Ste. 103 Madison, WI 53718

2700 Vernon Dr., Ste. 340 Green Bay, WI 54304 505 S. 24th Ave., Ste. 304 Wausau, WI 54401 404 1/2 N. Bridge St. Chippewa Falls, WI 54729 PO Box 1472 Rhinelander, WI 54501

ALZHEIMER'S RASSOCIATION

Date: Wednesday, January 12, 2025

To: Chairman Moses and Members of the Assembly Committee on Health, Aging, and Long-Term Care **Subject:** 2025 Assembly Bill 23, relating to: establishing a Palliative Care Council

Dear Chairman Moses and Members of the Assembly Committee on Health, Aging, and Long-Term Care,

I am writing on behalf of the Alzheimer's Association Wisconsin Chapter to express our support for Assembly Bill 23, which seeks to establish a Palliative Care Council within the Department of Health Services. Alzheimer's disease is a prevalent neurodegenerative disorder characterized by progressive cognitive decline, memory loss, and impaired daily functioning, making it the most common form of dementia—an umbrella term for conditions marked by memory loss and cognitive impairment. There are several causes of dementia, including¹:

1.) Alzheimer's Disease	The most common cause. Caused by plaque build-up in the brain.
2.) Vascular Dementia	Caused by damage to the vessels that supply blood to the brain.
3.) Lewy Body Dementia	Caused by balloon-like clumps of protein deposits in the brain.
4.) Frontotemporal Dementia	Caused by breakdown of nerves and cells in the frontal and temporal part of the brain.
5.) Mixed Dementia	Caused by combination of several causes listed above
6.) Disorders Linked to Dementia	Huntington Disease: genetic mutation causes nerve cell breakdown Traumatic Brain Injury: results from repeated head trauma Creutzfeldt- Jacob Disease: depositions of infectious prion proteins Parkinson's Disease: people with advanced disease develop dementia

This bill signifies a step forward in recognizing the importance of palliative care for individuals affected by Alzheimer's disease and related dementias, a growing concern in Wisconsin as reflected in the following statistics²:

- 110,900 people aged 65 and older are living with Alzheimer's disease in Wisconsin.
- 10.6% of people aged 45 and older have subjective cognitive decline.
- 205,000 family caregivers bear the burden of the disease in Wisconsin providing 297 million hours of unpaid care.

Palliative care, with its focus on relieving symptoms, managing pain, and addressing the emotional and psychological needs of patients and their families, is particularly relevant in the context of Alzheimer's disease and related dementias. Palliative care provides a framework for addressing these challenges and improving the overall well-being of those affected by Alzheimer's disease and related dementias.

The proposed Palliative Care Council, comprising medical and clinical professionals with expertise in palliative care services, along with individuals who have direct experience as patients or family members, ensures a holistic and nuanced understanding of the unique needs and complexities faced by those with Alzheimer's disease and related

¹ Malhi R, McElveen J; DNP;2; O'Donnell L. Palliative Care of the Patient with Dementia. Dela J Public Health. 2021 Sep 27;7(4):92-98. doi: 10.32481/djph.2021.09.012. PMID: 34604771; PMCID: PMC8482977. ² Wisconsin 2024 Alzheimer's Statistics

dementias. This targeted focus enables the council to address the multifaceted nature of the disease, offering guidance on outcome evaluation, economic and quality of life effectiveness, reimbursement mechanisms, and other pertinent issues related to palliative care. The Council's formation is a crucial step toward enhancing the quality of care and support for the 110,900 individuals aged 65 and older living with Alzheimer's disease and others diagnosed with related dementias in Wisconsin, addressing not only their medical needs but also providing compassionate assistance to families navigating the challenges of this devastating condition.

Thank you, Chairman and Committee members, for the opportunity to submit comments and for your consideration of Assembly Bill 23.

Sincerely,

Allison Cramer Director of Public Policy Alzheimer's Association Wisconsin Chapter amcramer@alz.org | (608) 571-3939

02/11/2025

Dear Members of the Assembly Committee on Health, Aging & Long-Term Care:

As a practicing Nurse Practitioner, I am contacting you to respectfully request that you support **Assembly Bill 23,** authored by Representative Pat Snyder and Senator Jesse James, 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 studyⁱⁱ 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 studyⁱⁱⁱ.

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,

Christine Glen, MSN, RN, APNP, AGPCNP-BC Nurse Practitioner, Palliative Care Hospice Alliance

ⁱ 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)

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

^{III} 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.

February 11, 2025

Dear Members of the Assembly Committee on Health, Aging & Long-Term Care:

As a practicing RN, I am contacting you to respectfully request that you support **Assembly Bill 23**, authored by Representative Pat Snyder and Senator Jesse James, 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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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:

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

Sincerely,

Jennifer K. Bingham, BSN, RN Director of Clinical Services Hospice Alliance, Inc.

ⁱ 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)

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

^{III} 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.

February 11th 2025

Dear Members of the Assembly Committee on Health, Aging & Long-Term Care:

As a practicing registered nurse, I am contacting you to respectfully request that you support **Assembly Bill 23,** authored by Representative Pat Snyder and Senator Jesse James, 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 studyⁱⁱ 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 studyⁱⁱⁱ.

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,

Lindsey Mayer Registered nurse Hospice Alliance

ⁱ 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. (<u>http://doi.org/10.1089/jpm.2019.0029</u>)

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February 11, 2025

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As a practicing Family Nurse Practitioner, I am contacting you to respectfully request that you support **Assembly Bill 23,** authored by Representative Pat Snyder and Senator Jesse James, 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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Sincerely,

Toni C. Kesler, RN, MSN, FNP Vitas Healthcare

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^{III} 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. Hello Members of Assembly Committee on Health, Aging and Long-Term Care

Please accept this written testimony regarding <u>AB-023</u> to establish a palliative care council.

My name is Susan Wurzer and I am asking committee members to please consider amending the Bill to:

• **Expand the mission** to create a comprehensive council by including representation from other equally important programs and services. As depicted in the below graphic, palliative care is but just one service in an array of care and services aiming at helping those afflicted with a serious illness, their families and caregivers.

Other care and services include: Chronic, Advanced & Serious Illness Programs, Home Health, Hospice Care, Advance Care Planning, Caregiving & Long-Term Care Programs, Quality Care Initiatives and Transitional/Community-Based Post Acute Care Services.



• **Rename the council to <u>Wisconsin Serious Illness & Caregiving Advisory Council</u> to reflect representation of the full array of care and services and with language that is health literacy friendly. This is vital if we want all people to have an understanding of the words we use and readily ACCESS the services they need.**

I have served Wisconsin's public as the former State Educator for the Wisconsin Hospice and Palliative Care Association, current Founder & Director of the Wisconsin Coalition for Serious Illness & Caregiving, and as an educator/medical social work in serious illness & end-of-life care for over 35 years. I know first-hand the needs of individuals, families and caregivers and the programs and services offered to those impacted by chronic, serious and life-threatening illness

Through my mission to educate and increase access, I also know it is imperative to provide consumers information about **all** options for care and services. With wider representation, a <u>Wisconsin Serious Illness & Caregiving Advisory Council</u> assures the development of comprehensive public education, gives voice to all equally important care and services in policy setting and offers recognition to the crucial and vital role of caregiving.

Wisconsin has an opportunity to create a council that builds on its legacy of leading efforts to transform care for those living with serious illness. It is home to some of the earliest established hospice programs, and the Wisconsin Cancer Pain Initiative (WCPI), Respecting Choice

Advance Care Planning Program and the Governor's Taskforce on Caregiving have garnered national attention.

We have an opportunity to build a council that will serve as a national model for other states.

Let's **take** the opportunity to build on our legacy and do the best we can for Wisconsin residents. Please amend this bill to expand the mission to include broader representation on the council and appropriately name the council, <u>The Wisconsin Serious Illness & Caregiving Advisory Council.</u>

I would appreciate the opportunity to provide further information and am available to assist in making the necessary amendments.

My best, Susan Wurzer MBA BSW 715.630.6779 <u>gslfarm@wi-net.com</u>

FACT SHEET

Concerning AB-023 to Establish Palliative Care Council

WHAT? Amend the bill to expand to all Serious Illness & Caregiving

WHY? Broaden the Council Mission to include <u>Comprehensive</u> Representation & Correctly Name:

Wisconsin Serious Illness & Caregiving Council

- Wisconsin's health and service providers that assist seriously ill individuals, their families and caregivers with accessing a multitude of equally sensitive and important care and services need to be included on the council.
- Serious Illness is the industry-accepted overarching term. Palliative care is just one service/program in an array of care and services

Serious illness takes a significant physical, emotional, social, and financial toll on patients, families, caregivers, and communities.

Some communities are burdened more than others.

~120,000 people in WI are living with <u>Alzheimer's Disease</u>. By 2040 the number is projected to increase to 213,000

Currently **~205,000** family caregivers of those afflicted with Alzheimer's Disease in Wisconsin



Accepted Serious Illness Definition

Serious illness is a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers

Most Common Serious Illnesses

- Congestive Heart Failure (CHF)
- Chronic Obstructive Pulmonary Disease (COPD)
- End Stage Renal Disease (ESRD)
- Diabetes
- Cancer
- Dementia

How?

• Renaming to <u>Wisconsin Serious Illness & Caregiving Council</u> to accurately reflect a broader mission and comprehensive representation on the council.

Improve the Bill by: **Expanding council seats to include providers and subject experts working in serious illness care to include**, *but not limited to:* palliative care, hospice care, chronic/advanced illness programs, home health, advanced care planning, caregiving, community-based care, transitional/post-acute services, quality care initiatives and other programs.



Representative Clint Moses, Chair Assembly Health Aging and Long-Term Care Committee Room 12 West State Capitol Madison, WI 53708

RE: Support of Assembly Bill 23 – Establishment of a Palliative Care Council.

Dear Chairman Moses and Members of Assembly Health Aging and Long-Term Care Committee,

On behalf of the Wisconsin Nurses Association, the association with membership open to any Wisconsin Registered Nurse, I want to share our support for the establishment of a Palliative Care Council. The Council will be administered by the State of Wisconsin Department of Health Services which has demonstrated experience in supporting the work of other legislative established councils related to the health of Wisconsinites.

The consensus-based definition of palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.ⁱ The type of medical conditions that can be supported by palliative care include cancer, cardiac disease such as heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, Parkinson's, and Amyotrophic Lateral Sclerosis (ALS).

For Wisconsinites, the benefits of an established palliative care council include the following: **Improved access**

A state palliative care council can help ensure that palliative care is available across the state's health care system.

Reduced stigma

A state palliative care council can help reduce stigma around palliative care, which can prevent patients and families from seeking care.

Improved outcomes

A state palliative care council can help improve outcomes for patients by ensuring that palliative care is integrated into the health care system.

These benefits reflect the principles of the Wisconsin Nurses Association (WNA) that are addressed in our Public Policy Agenda for the 2025-27 Legislative Biennium. AB 23 addresses the important responsibilities that a council needs to examine and reflect the identified common

"7 C's" of palliative careⁱⁱ which are; Compassion, Communication, Collaboration, Coordination, Continuity of care, Continued Learning, and Care in the Dying Phase.

WNA supports the membership of the council as it reflects a patient-centered team-based care approach. The life of a patient who is receiving palliative care services does need a team of health care providers throughout their period of care.

It is important to include both Advanced Practice Nurse Prescribers and Registered Nurses to be included as members of the Council. For nurses, palliative nursing reflects a holistic philosophy of care and services for patients and families who face serious or life-threatening illness in a wide variety of settings and conditions. Palliative nurses work side-by-side with patients and their families as well as with numerous interdisciplinary colleagues and provide consistent responsibility for the round-the-clock care of palliative patients. Attending to the patient's end-of-life physiological and psychological responses and requirements as well as to the social and cultural factors and the spiritual aspects of care is the essence of palliative nursing. ⁱⁱⁱ

As Wisconsin's continuing to see the rise of chronic health conditions and the growing population of older adults so will the need for compassionate and competent care delivery will be needed. Palliative care is an effective solution to these current and future needs. The establishment of a State of Wisconsin Palliative Care Council will support and communicate best-practices in the care of these vulnerable Wisconsinites.

WNA requests the Committee to vote in favor of AB 23 and to vote out of Committee as soon as possible.

Sincerely,

gina Donnik - Champeian

Gina Dennik-Champion, MSN, RN, MSHA WNA Executive Director

References

¹ Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Munyoro EC, Centeno C, Cleary J, Connor S, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khan QT, Larkin P, Leng M, Luyirika E, Marston J, Moine S, Osman H, Pettus K, Puchalski C, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining Palliative Care-A New Consensus-Based Definition. J Pain Symptom Manage. 2020 Oct;60(4):754-764. doi: 10.1016/j.jpainsymman.2020.04.027. Epub 2020 May 6. PMID: 32387576; PMCID: PMC8096724.

 ⁱⁱ Hall, Sue & Goddard, Cassie & Stewart, Frances & Higginson, Irene. (2011). Implementing a quality improvement programme in palliative care in care homes: A qualitative study. BMC geriatrics. 11. 31. 10.1186/1471-2318-11-31.
 ⁱⁱⁱ American Nurses Association. Hospice and Palliative Nursing : Scope and Standards of Practice / Hospice and Palliative Nurses Association [and] American Nurses Association. [4th ed.]. Silver Spring, Md: American Nurses Association, 2007. Print.