



TERRY MOULTON



WISCONSIN STATE SENATOR

23RD SENATE DISTRICT

From: Senator Terry Moulton
To: Senate Committee on Workforce Development, Military Affairs and Senior Issues
Re: Testimony on Senate Bill 548
Relating to: Establishing a palliative care council
Date: January 9, 2018

Thank you Chairman Testin and members for allowing me to testify on Senate Bill 548 today. I am grateful for the opportunity to work with Representative Snyder on this important piece of legislation.

Palliative care is care given to an individual with a terminal illness that is no longer responsive to curative treatment. Care can include services from doctors and skilled nurses, as well as medical social services and bereavement services. Physicians, staff and volunteers work with patients and their family to reduce pain and other physical symptoms and care for patient's psychological and spiritual needs. The goal of palliative care is neither to hasten nor postpone death, rather palliative care affirms life by improving the quality of life for patients facing non-curable conditions.

Palliative care is a growing need in Wisconsin and as our population ages, so does the need for patients, family and caregivers to understand palliative care and the options that exist for them or their loved ones.

Senate Bill 548 would allow Wisconsin to join 21 other states in establishing a Palliative Care Advisory Council of doctors, healthcare professionals, patients and advocates. The Palliative Care Advisory Council would work directly with the Department of Health Services to evaluate palliative care in Wisconsin, assess palliative care's impact on patients and their families, and discuss ways that palliative care can be improved. The Council would submit a biennial report to the Wisconsin Legislature and work directly with the Department of Health Services in an advisory capacity to improve patient awareness and understanding of palliative care.

Senate Bill 548 is a wonderful opportunity to join the efforts of 21 other states and the federal government to proactively assess palliative care, its growing need, and its impact on Wisconsin. Please vote to recommend passage of Senate Bill 548 and help us serve Wisconsin families by taking this issue head on.

Serving the 23rd Senate District



PATRICK SNYDER

STATE REPRESENTATIVE • 85th ASSEMBLY DISTRICT

Testimony in Support of SB 548 Establishing a Palliative Care Advisory Council

Thank you Chairman Testin and fellow members of the Senate Committee on Workforce Development, Military Affairs, and Senior Issues for allowing me to submit testimony on Senate Bill 548, a bill that will establish a Palliative Care Advisory Council in our state. It has been an honor working with Senator Moulton on legislation that will improve the quality of life for those who are suffering from a chronic or terminal illness.

Palliative care is specialized medical care that works to reduce pain and improve the quality of life for a patient and their loved ones. As patients and their doctors have begun to see how effective palliative care can be, it has become a growing part of our medical treatment systems. In 2015, the Center to Advance Palliative Care found that 67 percent of U.S. hospitals with fifty or more beds have palliative care teams, up from 63 percent in 2011 and 53 percent in 2008. Provided in conjunction with other appropriate medical treatments, including curative care, palliative care has been proven to be cost effective by lowering overall health care costs and improving health care outcomes for patients. A study published in Health Affairs healthcare journal found that in four New York state hospitals, Medicaid patients who received palliative care incurred nearly \$7,000 less in hospital costs per admission than patients who didn't receive palliative care. As the demand for this specialty continues to grow, it is important our state proactively examines ways to improve access to palliative care for patients who are in need.

Modeled after legislation introduced by many states across our country, including our Midwestern neighbors in Minnesota, Indiana, and Ohio, this proposal creates a Palliative Care Advisory Council tasked with evaluating the impact of palliative care and areas in which it can be improved. The council will consist of physicians, healthcare professionals, advocates, hospital administrators, and medical students that will consult with and make policy recommendations to the Department of Health Services and the legislature through a biennial report. The council will meet at least twice a year and, when possible, hold their meetings in different geographical areas across the state, both urban and rural, to better learn about access to palliative care and quality in all communities.

As Wisconsin's population continues to age, it is critical we begin to have these important conversations now. A Palliative Care Advisory Council will ensure our state is working to provide the highest quality of life for as long as possible for those who are suffering from disease and illness. Senate Bill 548 is an opportunity to join with the many states across our country to examine and assess access to palliative care and its impact on Wisconsin's patients. I ask you to join me in supporting SB548 and would be happy to answer any questions you might have.



Chairman Testin
Senate Committee on Workforce Development, Military Affairs and Senior Issues
Public Hearing, Senate Bill 548
Wednesday, January 10, 2018

Thank you Senator Testin and members of this committee for the opportunity to testify today. My name is Sara Sahli, Wisconsin Director of the American Cancer Society Cancer Action Network. ACS CAN is the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society. We support evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem.

I am here today to express our support for Senate Bill 548 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 want to recognize and thank Senator Moulton and Representative Snyder as the lead sponsors as well as members on this committee who are among bi-partisan cosponsors on SB 548.

We recognize that treatment for cancer is more than just ridding patients of the disease. It involves making sure the whole patient is considered when surviving cancer. Nearly two-thirds of people who are diagnosed with cancer are surviving more than 5 years, and there are nearly 15 million cancer survivors in the United States. That's why improving palliative care is a priority for us.

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 particular case, the goal is to improve quality of life and help reduce health care costs.

According to a 2010 study published in the New England Journal of Medicine, early palliative care provided alongside cancer treatment resulted in patients living longer. The study examined introducing routine palliative care evaluations and ongoing support for patients newly diagnosed with lung cancer. The results were that patients felt better, were less depressed, were less likely to die in the hospital, and were less likely to be in the hospital in their last month of life. Patients who got palliative care at the same time as their cancer treatment lived nearly 3 months longer than similar patients getting only cancer care but not receiving palliative care¹. Four other studies have shown that when palliative care teams work together with oncologists, patients are able to remain at home – they don't end up in the ER and hospital with pain and symptom crises. As a result, they go through fewer unnecessary tests and procedures, which in turn leads to lower costs. In short, palliative care programs provide higher-quality care for patients and a better bottom line.

While palliative care is a rapidly growing specialty, it is still not found in all areas of the state, which is why it's important to identify existing barriers to this care and ensure that accurate, comprehensive information and education about it is made available to the public, health care providers and health care facilities. ACS CAN contends that SB 548 is key in 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 SB 548.

¹ Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine* 2010;363;741-9

Thank you, Chairman Testin and members of the Senate Committee on Workforce Development, Military Affairs, and Senior Issues for the opportunity to speak before you today in support of Senate Bill 548 to establish a palliative care advisory council. My name is Hillary Kirking. I'm a volunteer with the American Cancer Society Cancer Action Network (ACS CAN). I grew up north of Sparta where my parents still live. Today, Edgerton is my home. I'm a nurse, and I work in an ICU. Full disclosure, I worked the last two nights, and if I stumble over my words, I'll attribute it to that.

Seven years ago, my dad, Gary, was diagnosed with a rare cancer called a soft tissue sarcoma (leiomyosarcoma) which consisted of a large tumor in his thigh. My dad is energetic and hard-working, and he lives by two mottos: 25/8--live as if there were 25 hours in a day and eight days in a week-- and *Carpe diem*-- seize the day. Stoicism is his other defining characteristic. Raised on a dairy farm near Viroqua, my dad learned to put mind over matter at a young age. He passed on that important life lesson-- mind over matter, and by sheer will complete the job at hand.

Cancer is a disease that saps your energy and erodes your mental control over your body. It was very important for my dad to continue working throughout his cancer treatment. During his radiation treatments, my dad couldn't go into the office as often as he liked, so he often worked from home. When I called, he always sounded upbeat and when I asked how he was doing, he recounted the jokes he made with his physician and described the nurses' reactions when he arrived for a treatment dressed as Elvis-- a look complete with rhinestones, a wig, and a cape.

He never spoke about his pain.

In between rounds of radiation, my dad came to Madison for work and spent a night with me. He was unusually quiet during dinner. Back at my apartment, my dad stretched out on the couch. He rolled up his pant leg and asked me to change the dressing wrapped around his thigh. I was not a nurse then. I gingerly peeled back the bandage. His skin was black and severely burned, and layers of skin came off while I changed his bandage. Before re-wrapping his leg, I paused to collect to myself. My dad remained motionless, silent, still breathing in and out, in and out, but clearly experiencing intense pain.

Several weeks later surgeons removed the large mass along with numerous lymph nodes and blood vessels. I'm happy and very grateful to say that my dad is doing well for the most part. He does suffer from lymphedema as a result of the removal of his lymph nodes. However, he is still working and enjoys visits his grandchildren. For a recent Star Wars themed birthday party, grandpa dressed up as Chewbacca.

My dad received great cancer treatment, but he could have received better palliative care to relieve his pain and to provide additional support for him and our family. Palliative care is patient centered and coincides with curative treatment. Palliative care practitioners learn about patients' experiences and goals and focus on relieving the pain, symptoms, and stress that accompany a serious illness. This allows patients to actively direct their care and their lives at a time when they can't control their disease. For patients like my dad, who refuse to slow down no matter what, palliative care would make a world of a difference in their quality of life while undergoing treatment.

Senate bill SB548 is important because its proposed Palliative Care Council will assess what is going well regarding palliative care in Wisconsin and how it can be better. The council will increase public awareness of palliative care and ensure that quality palliative care is offered to all patients, especially for those like my dad, who are too stoic to talk about their pain and symptoms. And, palliative care is a team sport-- the council's interprofessional make up and the inclusion of patient advocates

ensures all needed expertise sits on the council.

Thank you again for the opportunity to speak with you today and for all your hard work and dedication. All patients and families have a right to quality, patient-centered care, and palliative care is an essential component. For these reasons and my family's experiences, I respectfully ask that you vote in favor of Senate Bill 548.

Hillary Kirking
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**Senate Committee on Workforce Development, Military Affairs and Senior Issues****RE: Support for Senate Bill 548****Testimony provided by Toby Campbell, MD****January 10, 2018**

Dear Chairman Testin and members of the committee:

I am here today to express my support for Senate Bill 548 (SB-548), which seeks to improve health care quality through the establishment of a state advisory council on palliative care. Thank you to Chairman Testin, Senator Moulton as the lead author, the co-sponsors in the Assembly and Senate, and the members of this committee for the opportunity to share my perspective regarding care for those with serious illness.

My name is Dr. Toby Campbell and I am the Chief of Palliative Care and the Ellen and Peter O. Johnson Chair in Palliative Care at the University of Wisconsin School of Medicine and Public Health.

I arrive today with some good news and some bad news. First, the good news: we are living longer—considerably longer—than ever before in human history. In 1900, the average life expectancy in the USA at birth was 47 years. By 1950, it was 20 years longer, 68, and today the average life span is nearly 80. The bad news? We are living longer...but with chronic illness. Every day, approximately 10,000 people qualify for Medicare and approximately 17% of Wisconsinites are Medicare recipients. An essential task before us is creating a healthcare system that provides empathetic, coordinated, high-quality health care for people living with a serious illness for prolonged periods including functional impairment. The goal of this legislation, in essence, is to create a council charged with measuring and encouraging good population-based palliative care throughout the state. This should include access to specialized palliative care providers and services, including hospice and home-based palliative care.

As you consider SB-548, I think it's important to provide you with some insight into what it's like to have my job. In palliative care we break seriously bad news every day. I empathize with people who are in utter despair. I listen as they try and make sense of a new reality or cope with life altering news. I witness and respond to intense emotion. I relieve crippling pain or suffocating shortness of breath. I support colleagues who struggle with "a really tough case." We improve patients and families' lives, we unburden colleagues, and we improve health system outcomes. While palliative care clinicians often work with people who are nearing the end of their life, our focus is on extracting as much value from the time remaining as we can. Our work is not about helping someone die. We work with seriously ill and dying people to *live well* in the face of illness. Palliative Care focuses on patient-centered outcomes like symptom burden, caregiver burden, quality of life, and bereavement. We have open and honest discussions with people facing a serious illness about the relative value of different treatment options.

There is a rich evidence base to support the broad use of palliative care, particularly hospice at the end of life and early, integrated, palliative care concurrent with usual medical care. Studies show that palliative care improves quality of life, improves symptom burden, prolongs life, and improves caregiver burden all while saving the system money largely by helping patients avoid unnecessary and unwanted intensive procedures and treatments. In a famous study in patients

with lung cancer who received early palliative care along with standard oncology treatment, findings showed an impact on both quality of life and quantity of life: they reported less anxiety and depression and they lived longer.

In a very recent major study with early palliative care in patients receiving a bone marrow transplant, patients saw improved depression and PTSD after the transplant. In the ICU, we see that palliative care improves satisfaction while reducing costs without impacting likelihood of dying. This means that expert palliative care does not alter the outcome of a serious illness but it does significantly impact the patients and families experience of living with that illness. Bottom line, palliative care has never shown to be harmful and the positive benefits shown impact patients, families, health care systems, and populations. If Palliative Care was a medication, it would be a billion dollar blockbuster.

As the United States and Wisconsin move towards value-based payment models for healthcare, access to palliative care must be preserved but this requires attention and planning to payment models and design. My assessment is that the proposed Palliative Care Advisory Council is an important step towards ensuring the people of Wisconsin have access to palliative care. I support the legislation but encourage minor modification chiefly to allow the council leeway and authority to collect the data they deem appropriate to meet the objectives of providing the legislature with a report on the impact of palliative care throughout our state. For example, these data might include measures such as time spent in the preferred settings of care in the final month of life, symptom burden, caregiver burden, the financial impacts of serious illness, insurer-provided hospice benefits, barriers to family leave to care for the dying, and programs that promote advance care planning. To be effective, this committee must have the authority to measure what matters related to population-based palliative care and to exercise their judgment to modify those measures over time.

Thank you for the opportunity to testify. I recommend a yes vote on SB-548 and I would be happy to take your questions at this time.

References:

1. Temel J, et al Early Palliative Care for patients with metastatic non-small cell lung cancer. NEJM 2010; 363;741-9.
2. El-Jawahri A, et al. Effect of Inpatient Palliative Care on Quality of Life 2 weeks after hematopoietic stem cell transplantation: a randomized clinical trial. JAMA 2016; 316(20): 2094-2103.
3. El-Jawahri A, et al. Effect of Inpatient Palliative Care during stem-cell transplant on psychological distress 6 months after transplant. JCO 2017; 35 (32): 3714-21.
4. Casarett D, et al. Why Population Health and Palliative Care Need Each Other. JAMA 2016; 316 (1): 27-28.

Chairman Testin

Senate Committee on Workforce Development, Military Affairs and Senior Issues

Public Hearing, Senate Bill 548

Wednesday, January 10, 2018

I would like to start by thanking Senator Testin and members of this committee for this great opportunity to provide testimony in support of some of our most vulnerable patients. My name is Dr. Tim Jessick. I am a Family Physician now specializing in Palliative Care. I am also Chair of the Palliative Care Network of Wisconsin, a statewide palliative and hospice organization formed to help provide education and support for the healthcare clinicians caring and advocating for patients with serious, life limiting illnesses.

I am here today to express our support for Senate Bill 548, which seeks to improve health care quality and delivery by establishing a state advisory council on palliative care. We would like to thank and recognize Senator Moulton and Representative Snyder as the lead sponsors as well as members of this committee.

As a Palliative Care specialist, I have seen how healthcare has become silo'd, especially for those patients with life limiting illnesses. Few clinicians have the time nor the expertise to treat severe symptoms such as pain, nausea or shortness of breath. Most clinicians have not had communication training to help patients and their families make decisions regarding their own healthcare, especially after being hospitalized.

So what do Palliative Care specialists provide that is different than other doctors? Our expertise is in communication skills and symptom management. Our ability to meet patients and their families where they are is imperative in a healthcare delivery system that lacks continuity or familiarity with the patient. Our job is to better realize a patient's understanding of their disease, their future goals for care and what really matters most to them.

This patient centered care approach allows us to serve as advocates for our patients in a system that tends to focus on organ systems and specific diseases instead of people. This specialized care really helps the most vulnerable and underserved of our community including our elderly patients, seriously ill patients and even those individuals that have been marginalized due to their disabilities. In the process, this leads to improved patient and family satisfaction while meeting the goals of quadruple aim- better health, lower costs, better experience and improved clinician job satisfaction.

I think we all have had loved ones that have suffered from their medical problems. Palliative care is part of the solution.

Studies tell us that 20% of all patients admitted to the hospital have some sort of unmet palliative need such as symptom problems or lack of goals of care

discussions. Currently, we are short about 4000-8000 palliative providers nation wide so we can't see all of these patients with unmet needs. This will continue to be a problem for patients, especially as they continue to get older.

A Palliative Care Advisory Council could help promote education on palliative care to the public and healthcare communities throughout Wisconsin, it could also support increased training opportunities for clinicians. The council would also be influential in assessing palliative care needs throughout the state while setting minimum standards for palliative care.

Thank you for this time to testify. I would recommend a yes vote on Senate Bill 548.



WISCONSIN CATHOLIC CONFERENCE

TESTIMONY ON SB 548: PALLIATIVE CARE COUNCIL

Presented to the Senate Committee on Workforce Development,
Military Affairs and Senior Issues
January 10, 2018

Thank you for the opportunity to testify for information on the creation of a palliative care council through Senate Bill 548. My name is Larry Haas and I am the Associate Director for Education and Health Care at the Wisconsin Catholic Conference (WCC), which serves as the public policy voice for the Catholic Bishops of Wisconsin.

The Catholic Church supports the use of quality palliative care for those who are facing significant health issues. 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

Human life is a sacred gift from God and an inalienable right, deserving of protection. This is not merely a “Catholic” proposition, nor a uniquely Christian one. It is, rather, a “self-evident” proposition, recognized as such by the Founders of our nation. While as a society we cannot cure every illness, we can and must show compassion and support for each and every person suffering grave illness.

Quality palliative care that supports those who are seriously ill, with the goal of improving that person’s life and that of their loved ones, is the proper response to human suffering and disease. Recent 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. We support and encourage efforts to provide more quality palliative care options for patients in Wisconsin.

However, any public policy designed to aid those who are vulnerable and facing serious illness must emphasize principles that benefit both the individual and our society. The provision of palliative care 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 pressure on an

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

individual to hasten the end of his or her life. Therefore, we respectfully request that the definition of palliative care, as referenced in SB 548, specifically exclude any attempts to assist in or intentionally hasten death.

Also, as the goal of palliative care is to prevent the relief of both the symptoms and stress of serious illness, the design of the palliative care council should include representatives who can address not only the medical, but also the familial, emotional, financial, societal, and other needs of those facing illness. We therefore request that the committee consider altering the council's statutory design to include greater representation from among those who have personally experienced serious illness or their caregivers and advocates.

Finally, SB 548, under a proposed s. 146.695(5)(c), requires the palliative care council to submit a report analyzing the policies, practices, and protocols concerning patients' rights related to palliative care. This analysis would include the practices and protocols used for discussion of life-sustaining treatment and advance directives, as well as informed consent and disclosure. While having insight from palliative care professionals and advocates on these practices is necessary and important, conversations regarding these issues are broached in numerous settings, including family gatherings, houses of worship, and in consultation with legal counsel. It would therefore seem more appropriate that these policy discussions regarding best practices and protocols take place among a wider variety of stakeholders.

As palliative care is about the alleviation of symptoms, its benefits extend beyond those facing death. Wisconsin has made incredible progress in providing palliative care, but there remains the need for greater collaboration and training among health care professionals and others who aid those facing serious illness. 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. For all these reasons, the WCC requests that SB 548 be altered to ensure that those who suffer are comforted and reassured by our state's commitment to their care.

I hope these insights are helpful to you. Thank you for the opportunity to offer them.

Dear Chairman Testin and distinguished members of the Senate Committee on Workforce Development, Military Affairs, and Senior Issues,

My name is Linda DeGarmo and I live in Chaseburg, Wisconsin. Thank you for the opportunity to speak with you today in support of Senate Bill 548 – which would establish a Palliative Care Advisory Council.

I have been a volunteer with the American Cancer Society since 1990, active in Relay for Life and Run/Walks. Twelve years ago, I helped to found the Sole Burner of Chaseburg. Sole Burner is a fundraiser for the American Cancer Society. We raise money for cancer research and services for cancer patients and their families. This year, we hit \$1 million raised since we started the event! If you wonder how a town of 259 people can raise so much, it's because we are all only one degree from cancer. We all have our stories of how cancer had impacted us. I want to tell you mine.

Valentine's Day 1978 will forever be one of the worst days of my life. Our precious 9-year-old daughter was diagnosed with ALL, Acute Lymphocytic Leukemia. I was 28 years old and had a great husband, Tammi our daughter and Paul, our 3-year-old son. Our doctor suggested that we take Tammi to the University of Minnesota in Minneapolis for treatment. The very next day, we arrived at the hospital. After a short examination, they started Tammi on chemotherapy. We were terrified.

The second day we were there, the questions started about how we were going to pay for Tammi's medical treatment. My husband had just started a new job, and was still in his probationary period for health insurance. So here we were, away from home with a daughter who was given a 40% chance of surviving her disease, no money, and no insurance. We worried constantly about how we would pay the bills, over the four months it took to hear that we were approved to receive assistance from the state. We were split in two, worrying about her care and its cost.

Tammi went into remission before Easter that spring, but by May the cancer came back again and we had to spend more time in Minneapolis. It was especially tough on our three-year-old son. He was too young to understand what was going on, he only knew that mom was gone all the time, Tammi was gone too, and he didn't know why. It broke my heart every time I had to leave him, and then again when I had to leave Tammi at the hospital in Minneapolis. Again, we were split in two.

Those days were some of the hardest of our lives. In August, doctors told us there was nothing more that they could do for Tammi except put her on experimental drugs. She went back to school in the fall in the fourth grade, making the most of life, spending time with her friends and family. By the middle of October, we knew we were fighting a losing battle with the leukemia. Tammi died on November 28, which I can say was the absolute darkest day of my whole life. It wasn't until the anniversary of her death that I truly realized she was not coming back.

I look at those two years now, and I wonder how we did it. We just existed. There was no one to help us get through this time. She went through this treatment, she died and we were just expected to go on with our lives without her. We had each other, our families and friends, but no one trained to help us.

I wonder how palliative care could have helped during the darkest days of our lives. What if we had a team of trained palliative care providers to walk beside us from the point of diagnosis, to help us manage the side effects of treatment (pain, nausea, exhaustion), to assist with insurance questions, how to get to treatment, emotional and spiritual support, and to answer all the questions and unknowns – to keep the goals of our daughter and our family at the center of our cancer care. To help us in the end. The outcome may have been the same, but the experience could have been different. That matters.

I do not want anyone else to go through what we went through, which is why it is so important that we establish a palliative care advisory council to determine how to raise awareness and expand access to palliative care in Wisconsin.

Please vote yes on Senate Bill 548. It would mean the world of difference to any family facing a chronic illness. Instead of feeling completely lost and alone as we did, families can feel supported and have the help they need to get through each day.

Thank you for your time.

Linda DeGarmo
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Dear Chairman Testin and distinguished members of Senate Committee on Workforce Development, Military Affairs, and Senior Issues,

My name is Jeff Bremer. I am resident of Middleton, a volunteer with the American Cancer Society Cancer Action Network (ACSCAN), and a past care giver for family members who battled cancer. I believe all chronically ill patients, and their families, should have access to the benefits of palliative care and thus I am here to speak in support of Senate Bill 548.

My first experience with palliative care came in July of 2009 when my dad was nearing the end of his courageous fight with bladder cancer. He had been admitted to the Intensive Care Unit (ICU) and the doctors were encouraging my mother to speak with the palliative care coordinator. Our family had no prior experience with palliative care and it was not adequately explained to us what palliative care is and is not. We assumed palliative care was just about end of life care, and in our minds we thought accepting palliative care meant we were giving up and conceding that dad would die. We actually went out of our way to avoid the palliative care coordinator.

When my dad passed away a few days later, I was left with a great sense of guilt that he had experienced more pain and discomfort than was necessary because we had not engaged palliative care. I vowed to never make that mistake again.

Just two years later, my vow was tested when my brother Bob was diagnosed with lymphoma.

Just as my dad had done, Bob fought his battle with exceptional strength, courage, and perseverance. My sisters and I were Bob's primary caregivers and we fought with him and for him; we advocated for him; and we did our best to protect him.

While in the hospital preparing for a stem cell transplant, Bob developed an infection and ended up in the Intensive Care Unit. This time around there was no discussion of palliative care but the ICU doctors began talking to us about ending treatment.

As a family we were confused, scared, frustrated and angry about the whole situation. The ICU doctors were not connecting with us – emotionally or intellectually. They didn't truly know Bob. They didn't know how far Bob had come, how much he had endured already, and how hard of a fighter he was. We didn't know what to do and so we turned to one of the hospitalists on Bob's medical team, Dr. Linda.

Bob and our family had made a connection with "Dr. Linda" during Bob's previous hospital stays. She seemed to be the only doctor that truly understood us. She was our rock and we relied on her to guide us through Bob's final days.

Honestly, I don't think Dr. Linda told us anything different than the ICU doctors did about Bob's condition or prognosis, but rather it was how she explained it that made the difference. She was the only doctor who had training in palliative medicine and you could tell.

Dr. Linda spoke with much more compassion and understanding. Her palliative care fellowship shaped her overall approach to medicine and enabled her to develop a rapport with Bob and our family from

the start. She was able to minimize Bob's suffering and at the same time provide much needed counsel, support and compassion to myself and our entire family.

Unfortunately, Bob lost his battle – one year and one day after his diagnosis.

When my brother passed away, I felt like I had lived up to the vow I made after my dad's passing of not allowing another loved one to suffer more than necessary at the end.

Yet it wasn't until I became involved with ACS CAN that I realized there was still more to learn about palliative medicine. Despite being a caregiver for two chronically ill family members, and two encounters with palliative care at two different hospitals, I still did not fully understand what palliative care is truly all about. At that time, I continued to view palliative medicine simply as an end of life issue. It has only been through my volunteer work with ACS CAN, that I now understand that it can and should be coordinated into a patient's overall care.

Today, as I talk with friends, co-workers, and neighbors who have a loved one who is fighting cancer or other serious health issue, I always encourage them to seek out palliative care and I explain the benefits to the patient and the family. Unfortunately, I typically get met with the same response that my family had back in 2009 – a look of fear and obstanence.

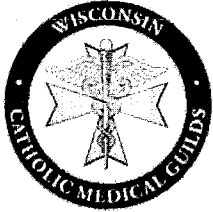
I am left wondering why the medical team treating their loved ones have not proactively engaged in palliative medicine alongside their curative treatment. Why hasn't someone in the medical community helped these patients and their families? Many of these patients are being treated at the largest and best hospitals in our state. Why is palliative care so misunderstood? How can we make it available to everyone who would benefit from it? Why aren't there more palliative care specialists? How can we get the medical community to proactively embrace it early in a patient's treatment? These questions, and many more, are things that I believe a palliative care advisory council can and should address.

The advisory council is a meaningful step towards ensuring that all Wisconsinites have ready access to palliative care, even if they do not yet understand what it is, or know enough to ask for it.

I respectfully request that you support Senate Bill 548.

Thank you.

Jeffrey Bremer
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WISCONSIN CATHOLIC MEDICAL GUILDS

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

January 10, 2018

To: Members, Senate Committee on Workforce Development, Military Affairs and Senior Issues

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

RE: Senate Bill 548 – to establish a Palliative Care Council under Department of Health Services

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.”

Senate Bill 548 seeks to establish a Palliative Care Council. Evaluating the availability and need for Palliative care resources in Wisconsin is important. However, the bill as currently written has some very concerning components. The make-up of the committee is heavily weighted to almost exclusively 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, therefore, that for the safety of patients, any definition of palliative care needs to include that it does not intentionally hasten, assist in, or cause hastened death. Palliative care and hospice utilize very powerful sedating medicines and high dose opioids that can be helpful to terminal cancer patients who are in severe pain, but also constitute a blunt instrument that can end lives. The danger is, when all you have is a hammer, everything starts to look like a nail.

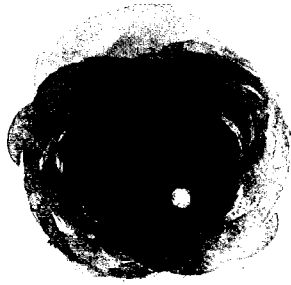
The committee also has little opportunity for primary care physicians to be involved. These are the physicians who know their patients’ medical, emotional, and psychological condition, as well as their end-of-life wishes, the best. In fact, the current bill would potentially allow a palliative care team member to approach a patient, without even notifying or involving the patient’s primary care 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. Such discussions are negatively-biased, and neglect the fact that without this, you die. These non-physician activities cannot constitute informed consent.

As representatives of the Wisconsin Catholic Medical Guilds, we urge you to amend the bill to include in its 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. Ideally, we would strongly support a study committee to evaluate the current need for palliative care resources and its safety before establishing a palliative care council.



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Testimony / Senate Bill 548: establishing a palliative care council
Senate Committee on Workforce Development, Military Affairs & Senior Issues
By Matt Sande, Director of Legislation / January 10, 2018

Good morning Chairman Testin 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 speak with you about Senate Bill (SB) 548, legislation that would establish a Palliative Care Council within the Department of Health Services.

Pro-Life Wisconsin has serious concerns with SB 548 as currently drafted but is confident that, working with the bill authors and committee members, these concerns can be alleviated through the amendment process. To be sure, we do not at all question the intentions of the authors in forwarding this legislation - we know they are good and noble.

Our first impression of the legislation is that it is not the place of the state 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 organize a study committee to assess the need for appropriate palliative care and its safety. But if the legislature is to proceed with establishing a government council, we ask you to hear and address our concerns.

It is critical that palliative medicine be understood and defined as managing pain, not hastening death – or rather, helping dying patients live well, not helping patients die. According to hospice physician and Duke University professor Farr Curlin, many families have said that when “hospice and palliative medicine (HPM) professionals became involved in their care, their loved ones were put on powerful drugs, became unconscious and unresponsive, and were soon dead. These stories are clearly shared within communities and powerfully shape people's perceptions of HPM, which many see as a sophisticated and seductive way of getting people to die.”

(Excerpts from Farr A. Curlin, MD Hospice and Palliative Medicine's Attempt at an Art of Dying, ch 4 in Dying in the Twenty-First Century, edited by Lydia Dugdale, MD, MIT Press 2015)

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

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 hastened death.

It is imperative that palliative care be collaborative and integrated. Palliative care physicians and practitioners must work with primary care doctors to ensure full knowledge of patient medical history and patient end-of-life wishes so as to provide the most appropriate type and level of care. We believe the current makeup of the council as proposed in SB 548 is too heavily weighted toward palliative care doctors and specialists. We support amending the bill to include primary care doctors, anesthesiologists, health care professionals that have pain relief and symptom management work experience, more patient advocates, and patients themselves.

We oppose section 146.695(5)(c) concerning policies, practices, and protocols concerning patient's rights related to palliative care, particularly lines 15,16 concerning "whether a palliative care team member may introduce palliative care options to a patient without the consent of the patient's attending physician." That is clearly not collaborative medicine.

In sum, if our shared goal is to promote good palliative care, we must understand and employ it as pain management promoting activity and interaction, not sedation inducing premature death. We believe this goal can be achieved by properly amending SB 548.

Thank you for your consideration.



Chelsea Duffy, Legislative Director, Wisconsin Right to Life

Senate Committee on Workforce Development, Military Affairs and Senior Issues

SB 548, relating to: establishing a palliative care council.

Wednesday, January 10, 2018

Thank you to Chairman Testin and members of the Senate Committee on Workforce Development, Military Affairs and Senior Issues for your time today.

My name is Chelsea Duffy, and I am the Legislative Director of Wisconsin Right to Life.

Wisconsin Right to Life completely supports better education on palliative care as a life-affirming alternative to physician assisted suicide. We applaud the efforts of Sen. Terry Moulton, Rep. Ken Skowronski, and Rep. Patrick Snyder for bringing forward this legislation as a good faith effort to improve education in this important area of healthcare.

With that said, at this time Wisconsin Right to Life has a few minor concerns with the legislation as written. We have sadly seen in too many states great medical organizations and advisory bodies hijacked by the pro-assisted suicide movement. Often, the tactic is to bring up assisted suicide in the conversations of a council or organization that is not actually dedicated to discussing that issue, to push for it to take a position on assisted suicide.

Since conversations about palliative care can be so closely tied to other end-of-life conversations, we believe there may be a chance for assisted suicide advocates to try a similar sort of sabotage for the Council being discussed today, even though the goal of the Palliative Care Council is laudable.

Therefore, we ask for the following changes to be considered:

- 1.) That the definition of palliative care be amended to exclude assisted suicide.
- 2.) That the Council be prohibited from discussing assisted suicide.

- 3.) That the voices within the Council be diversified to include patient advocates, non-medical personnel, and primary care physicians who also have a stake in this issue and can offer real-life scenarios that should be addressed for palliative care in this state to improve.

We know the intent of this bill is to have this Council be a vehicle for better education on palliative care. With these changes, we hope that excellent goal will be protected from any derailment by assisted suicide activists.

Thank you very much for your time,

Chelsea Duffy



Greater Wisconsin
Agency on Aging Resources, Inc.



January 10, 2018

To: Senator Testin, Chair
Members, Senate Committee on Workforce Development, Military Affairs and Seniors Issues

From: Janet Zander, Advocacy & Public Policy Coordinator
Greater Wisconsin Agency on Aging Resources, Inc. & the Wisconsin Aging Advocacy Network

Re: Support for Supported Decision-Making Agreements Bill – SB 552 & Support for Alzheimer's
and Caregiver Bills – SB 518, SB 527, SB 528, & SB 548

Good day, Chairman Testin, Vice Chair Feyen and members of the Committee. I am Janet Zander, Advocacy & Public Policy Coordinator for the Greater Wisconsin Agency on Aging Resources (GWAAR), one of three Area Agencies on Aging in Wisconsin. I am also here representing the Wisconsin Aging Advocacy Network (WAAN), a collaborative group of individuals and associations – including Wisconsin's three Area Agencies on Aging and other professional associations representing Wisconsin's senior centers, nutrition directors, aging units and Aging & Disability Resource Centers (ADRCs), Benefit Specialists, Adult Day Services, the Alzheimer's Association and the Wisconsin Institute for Healthy Aging (WIHA). This network of older adults and professionals work with and for Wisconsin's older adults to shape public policy that improves the quality of life of older people throughout the state.

I am speaking today in support of SB 552 regarding supported decision-making agreements, as well as in support of all four of the Alzheimer's and Caregiver Bills on the agenda for today's hearing – SB 518 regarding uniform adult guardianship jurisdiction, SB 527 regarding grants for Alzheimer's disease and dementia awareness, SB 528 regarding creation of a state caregiver tax credit, and SB 548 regarding establishing a palliative care council.

Our ability and capacity to make decisions changes over time. For some those changes are due to maturity, for others the changes may be due to functional impairments resulting from illness, injury, or conditions in which change may occur through the rehabilitation processes or progressive conditions. The Supported Decision-Making Agreements bill (SB 552) provides a legally recognized option for older adults and people with disabilities to remain fully in charge of making some or all of their own life-decisions by creating agreements that can easily be put into place by an older adult or person with a disability in response to their changing needs. These agreements with a trusted "Supporter" (of their choosing) allow individuals to receive any needed assistance with the decision-making process such as gathering information, understanding available options, and/or communicating their decisions. These agreements are flexible and as needs and circumstances change, so can the type and amount of agreements an individual chooses to have. Supported decision-making agreements do not replace Wisconsin's existing guardianship system; instead they can be used in combination with other legal arrangements such as limited guardianship or Power-of-Attorney.

With over half a million family caregivers in Wisconsin, and over 40 million nationwide, it is very likely many of us know someone who was/is providing care for a family member or we are involved in caregiving ourselves. I have worked in the aging network for over thirty years and have also been a caregiver for multiple family members. Family caregivers contribute great value to our society. The Alzheimer's and Caregiver bills recognize and support the vital role of family caregivers and work to improve the lives of those with Alzheimer's and related dementias and those with life-threatening illnesses.

The Uniform Adult Guardianship Jurisdiction bill (SB 518) would adopt the Uniform Guardianship Jurisdiction Act (passed in some version by 50 states and territories) into Wisconsin law and improve communication with people and courts in other states. This bill will clarify guardianship jurisdiction across state lines and offer vulnerable people additional protections from abuse and exploitation.

Currently over 115,000 people are living with Alzheimer's disease and related dementias in Wisconsin. This number is expected to increase to over 190,000 people in the next 20 years. The Alzheimer's Disease and Dementia Awareness Grants (SB 527) will help increase awareness of Alzheimer's disease and dementia in rural and underserved urban areas. This increase in outreach and awareness can help lead to a higher level of dementia screening, diagnosis, and treatment. Connecting individuals with Alzheimer's disease and their family members to information and resources early on, gives them the much-needed opportunity to plan and prepare.

More than three-quarters of all family caregivers experience out-of-pocket expenses related to their caregiving. On average, they spend about \$7,000 per year on caregiving expenses. For those who have needed to cut back on their work hours due to caregiving responsibilities, this can be especially financially challenging. For those who must leave the labor force early because of caregiving duties, the costs are much greater when caregiver expenses are combined with lost wages, lower Social Security benefits, and reduced pensions. The Caregiver Tax Credit (SB 528) creates a state income tax credit for family caregivers who have spent their own funds to meet the care needs of a family member. This bill sends a message that Wisconsin recognizes the valuable service provided by these caregivers and will offer some help to ease the financial burden of family caregiving.

Palliative care is a rapidly growing specialty. Unfortunately, this type of care focused on providing people with serious health conditions relief from the symptoms and stress of their illness, is not available in all parts of the state. The Palliative Care Council bill (SB 548) establishes a palliative care council that can evaluate the palliative care system in Wisconsin and make policy recommendations to the legislature on how to improve it, so that improved quality of life through palliative care can be available to patients with serious illness and their families no matter where they live in the state.

Thank you for this opportunity to offer testimony in support of the Supported Decision-Making Agreements bill (SB 552) as well as the Alzheimer's and Caregiver Bills (SB 518, SB 527, SB 528, and SB 548). I am happy to respond to any questions that you may have.



**Testimony Provided to Wisconsin Senate Committee on Workforce Development
Military Affairs and Senior Issues
Madison, Wisconsin
January 10, 2018**

**Tim Harrington,
Development Coordinator- Workplace Relations and Advocacy Focus
Alzheimer's Association of Southeastern Wisconsin**

Chairman Testin, Vice-Chair Feyen and members of the Committee,

Thank you for allowing me to speak today around this important package of legislation aimed at making Wisconsin a more dementia capable State. I am Tim Harrington, Advocacy lead for the Alzheimer's Association in Wisconsin. I am speaking today on behalf of the three Alzheimer's Association Chapters in Wisconsin. We support care and support for Wisconsinites impacted by Alzheimer's and dementia, raise concern awareness of the disease, advocate the rights in the best interest of those impacted and offer support of research in every county of the State of Wisconsin.

It is not an exaggeration to say the State of Wisconsin, like every in the U.S., is facing a public health crisis when it comes to Alzheimer's disease and related dementias. There are currently over 115,000 people living with the disease in Wisconsin, out of over 5 million nationally, and the Department of Health Services predicts this number will grow by 68% in less than 20 years to over 190,000. These demographic numbers play out in different ways in different parts of our State. For example, currently only two counties, Door and Vilas have more than 27% of the population over the age of 65, mainly due to a higher concentration of retired people. By 2035 however, 25% of the population will be over 65 in the entire northern tier of counties, and no Wisconsin county will have less than 20% of the population over 65. This poses issues across the State, but especially in rural Wisconsin. As the children in a family go off to school and find jobs elsewhere, older adults can become increasingly isolated. Recent surveys indicate that as many as 30 percent of Wisconsinites with Alzheimer's live alone in their communities.

This growth is due to several factors including increased longevity, the aging Baby Boomer population and the increasing racial and ethnic diversity of our State.

Medical, Health Care, Research and Public Health Issues

The medical treatments available for Alzheimer's today only work on the symptom of memory loss and do not slow the underlying disease process. As indicated earlier, diagnostic rates for Alzheimer's disease are not consistent with the number of people with cognitive decline, partly due to stigma and partly due to the difficulty of making an accurate diagnosis and the lack of effective treatments. The unfortunate consequence is that many people do not seek help, and many doctors may not make a thorough assessment even when they suspect a problem. This can lead to reversible forms of dementia that go untreated, and can also make it more difficult for the person and the family to begin financial and legal planning to prepare for the future.



Scientists now know that for the person who develops the symptoms of Alzheimer's by age 70, brain changes were occurring for at least 20 years. In the future, we hope to have effective treatments that slow or reverse the course of the disease, and a reliable biomarker that helps identify the people who are developing the disease, even when they are still largely asymptomatic. Coupling those two advances would lead to the ability to prevent or substantially delay the most difficult stages of the disease.

Until that day arrives the Alzheimer's Association is encouraging states to see Alzheimer's disease as a public health issue, and to take public health steps to raise awareness in local communities that can lead to a higher level of dementia screening, diagnosis and treatment. We are very encouraged that Wisconsin is a leader in participating in the Public Health Road map for Alzheimer's disease, and with the Alzheimer's Association and AARP Wisconsin, has produced the Dementia Friendly Communities Toolkit and the Dementia Friendly Employers Toolkit.

Wisconsin has been ahead of many states in these efforts starting with the convening of a task force put together by Former Secretary of Health Services, Kitty Rhodes, who brought together key stake holders to set the platform for and implement our Wisconsin State Alzheimer's plan, followed by the Speakers Task force in the Assembly on Alzheimer's and Dementia that introduced a comprehensive package of bills that addressed many areas of need, then furthered even more by the legislature's insistence on continuing and expanding the funding for the Dementia Care Specialist position in the ADRC's around the state.

The bills before you today are another example of Wisconsin's dedication to staying ahead of what is being termed the Silver Tsunami, the rise in numbers of the baby boomer generation who are living longer and as such are more likely to develop Alzheimer's or a related dementia.

In regard to remaining gaps and concerns, the Alzheimer's Association would like to ask for your support of the following bills that are certain to keep us moving to become a truly dementia capable state:

- (SB 527) A State wide awareness campaign that aims to catch Alzheimer's and dementia sooner in those living with and also raise awareness for caregivers, co-workers, friends and family about the resources available to them while caring for a loved one targeting areas and demographics in the state that are currently underserved
- (SB 528) The creation for a caregiver tax credit for families who are caring for a loved one and accruing large out of pocket costs while doing so, an estimate from a Met Life study showed this could be as high as \$15,000 on average for an individual caregiver.
- (SB 518) Review and adjust our robust Guardianship Laws to allow Wisconsin courts to effectively communicate with other courts when a jurisdictional issue arises and transfer guardianship across state lines.
- (SB 548) Create a palliative care advisory council made up to help guide The Department of Health Services to evaluate the impact Palliative Care has on families, experiences of families

that have used Palliative Care services, practices and protocol of doctors within the Palliative care field and in areas where Palliative Care can be improved.

- (SB 552) Allows adults with functional impairment to create a SDM agreement to allow another person, referred to as a "supporter", to assist the adult with certain decision-making by providing assistance with understanding options, accessing and obtaining needed information, understanding information once it is obtained, and/or communicating the adult's Decision(s) to the appropriate people

Thank you again for the opportunity to address you today and I would be happy to entertain any questions.



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January 9, 2018

Senator Patrick Testin
Senate Committee on Workforce Development, Military Affairs and
Senior Issues.

Re: Written Testimony for Committee Hearing on January 10, 2018

Dear Senator Testin and Committee:

I am writing to express my support for bills that are before the Committee on January 10, 2018. These bills advance the dire need to provide care and support to individual with Alzheimer's and other dementias. Some go even farther to provide support to individuals with disabling or terminal conditions of any kind.

My connection with the devastating condition that is Alzheimer's is on a variety of levels. I – along with my brothers - was the caregiver for my mother, Velma who had the disease for 15 years until her death in January 2015. Also, as an elder law attorney, I work on a daily basis with families who are facing the challenges of Alzheimer's and other conditions. Finally, as an advocate, I hope to see an end to this disease in my lifetime.

1. Caregiver Credit SB 528: As I work with families who are providing care, I see the financial toll it takes on them as individuals. (It takes a toll on the health of the caregiver as well.) That is why SB 528 is a critical step in the right direction to provide some financial relief. According to the Alzheimer's Association, in Wisconsin alone, there are an estimated 193,000 people providing unpaid care for someone with Alzheimer's or dementia. These unpaid caregivers put in 219,000,000 (that's two hundred and nineteen MILLION) hours of unpaid care. If this care were valued it would be worth \$2,775,000,000. (That's two TRILLION 775 million dollars.) Caregivers make financial sacrifices – 48 percent cut back on spending for themselves and 43 percent cut back on saving because of the out-of-pocket cost of caring for someone with dementia. The bill would allow a tax credit for qualifying expenses:

- Spending \$800 to have a grab bar installed in the shower of your home would get a tax credit of \$400.
- Paying \$1500 in a year for an aide who comes in when you need to be away from your loved one would net a credit of \$750.
- Spending \$2000 on legal fees related to your loved one would allow a credit of \$1000.
- Spending \$500 on incontinence supplies such as Depends in a year would provide a \$250 tax credit.

The credit would put some money back in the pockets of caregivers, which quite frankly they would most likely use for more costs related to their loved ones. This bill, if enacted, would not only benefit families of people with Alzheimer's, but also parents caring for adult children with disabling conditions, and similarly situated families.

2. Uniform Guardianship: The bill related to uniform guardianship jurisdiction (AB 629/SB 518) would provide much-needed solutions to a problem that I see as an Elder Law Attorney. Where guardianship has been entered in one state and needs to be transferred to Wisconsin because the ward is moving, the process is so difficult under current law that usually it is necessary to start a whole new proceeding, adding time and costs. I personally have had to start entirely new guardianships where a person moved from out of state and we were not able to get the out of state court to provide the documentation required under Wisconsin's existing law. Families are frustrated by this since they already had to go through the stress and turmoil of a proceeding once, they should not be subjected to the entire process a second time. It should be a streamlined process that eliminates unnecessary repetition. This bill achieves that by facilitating the transfer process in the proposed Chapter 53. It also provides a process where a guardianship entered in Wisconsin can be recognized in another state. This is critical as well. I work with parents who are the guardians of adult children with disabling conditions. As the parents age, they look to siblings as the logical successor guardians. In many cases, siblings live in another state. The new Chapter 53 will make the transfer a much smoother process at a time where the family is already going through upheaval and transition. Most other states have already adopted this legislation.

As a member of the Elder Law Section of the State Bar of Wisconsin, I and a group of other attorneys worked directly with the drafter to make sure that this uniform bill had language that would allow it to dovetail correctly with Wisconsin's existing guardianship and protective placement law. One of the lawyers who had participated in the committee raised what I believe to be largely unsubstantiated issues about this proposed legislation in testimony before the Assembly Mental Health Committee. The majority of

the committee members involved in the drafting recommendations, myself included, feel that this bill is essential to the smooth functioning of our judicial system when it comes to the issue of interstate guardianships.

3. Palliative Care Council (SB 548 / AB 633): Not enough people use palliative care appropriately. Palliative care provides comfort and pain management, and while it is often used in Hospice situations, it does not need to be confined to a person in Hospice. People with chronic conditions can benefit greatly from the use of palliate care. Providing ongoing pain management and comfort can help stabilize an ongoing condition and avoid acute / emergency situations. Creating a council to study and positively impact the policies regarding palliative care will help maximize the ways in which people are able to make use of this benefit. It is a timely step in the right direction toward increased awareness and effective use of this treatment.
4. Awareness Grants (SB 527): According to the Alzheimer's Association 2017 Facts and Figures report, there will be an increase of 20,000 in the number of people living with Alzheimer's between now and 2025. The grant to provide education regarding community services and Alzheimer's issues will help those 20,000 newly-diagnosed people to find the services they need, or to become sufficiently educated so as to be able to obtain a needed diagnosis in order to plan for the future. Increasing awareness will also help the 110,000 people already living with the disease in our state to connect with available support and services and to understand the disease better.

I support these bills and encourage your committee to do so as well. Please do not hesitate to contact me if anything further is needed.

Very Truly yours,



Carol J. Wessels

Attorney at Law
Cedarburg, Wisconsin