



PATRICK SNYDER

STATE REPRESENTATIVE • 85th ASSEMBLY DISTRICT

Testimony in Support of AB 633 Establishing a Palliative Care Advisory Council

Thank you Chairman Tittl and fellow members of the Assembly Committee on Mental Health for allowing me to testify before you today on Assembly Bill 633, 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. Assembly Bill 633 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 AB 633 and would be happy to answer any questions you might have.



KEN SKOWRONSKI

STATE REPRESENTATIVE • 82nd ASSEMBLY DISTRICT

(608) 266-8590
Toll-Free: (888) 534-0082
Rep.Skowronski@legis.wi.gov

P.O. Box 8953
Madison, WI 53708-8953

Mr. Chairman and members of the Mental Health Committee,

Thank you for taking the time this morning to consider the series of bills before you today aimed at improving the lives of those with Alzheimer's, dementia, other significant diseases, those in need of palliative care and their caregivers.

While driving to the capitol today, I saw a billboard on East Washington Avenue that stated that 7,000 people in Dane County are living with Alzheimer's disease. In this county alone, there are 7,000 people who need care, or are already being take care of by a family member or in a dementia friendly facility. All of the counties in Wisconsin and all of our legislative districts have people suffering with this debilitating disease and all of our districts have family members are caring for them. All of us are touched by this disease, and that's why we're here today. Alzheimer's is the 6th leading cause of death in the United States, and it's the only one is incurable. More than 5 million Americans are currently living with Alzheimer's, which includes 110,000 Wisconsinites. Every 66 seconds, someone in the United States develops this disease and deaths from Alzheimer's disease have increased by 89% since 2000. Alzheimer's is the 6th leading cause of death in Wisconsin. In 2017, Alzheimer's and other dementias will cost this country \$259 billion. By 2050, these costs could rise as high as \$1.1 trillion as a projected 16 million people could be living with Alzheimer's.

The effects that this disease can devastate individuals and families and while we can't cure Alzheimer's and dementia here, we can ease the burden of the family members and improve care for those living with the disease.

Today's package of bills builds on the successful efforts of the legislators from the Speaker's Task Force on Alzheimer's and Dementia from the prior session. My staff and I have been working on this package of bills for many months now and have met with a variety of groups that advocate for senior citizens and aging populations, many health advocacy groups like those with Alzheimer's and dementia and cancer, pro-life groups, faith-based advocacy groups, as well as doctors in the palliative care field. With their help, we've crafted the package of bills that we're speaking about today. Many of those groups are here today, and you'll have a chance to speak and ask questions of those experts from organizations dedicated to helping these individuals.

The first bill I would like to speak on is Assembly Bill 629 Uniform Adult Guardianship Jurisdictions: Currently, 45 States, the District of Columbia, Puerto Rico and the US Virgin Islands have Uniform Adult Guardianship laws, making Wisconsin one of five states without them. Adult guardianship is the process

through which a court appoints a guardian for another adult, who is unable to make important decisions for themselves. Once appointed, the guardian may make decisions for the incapacitated person that relate to that person's health, well-being, and economic interest. However, in our increasingly mobile society, not all court-appointed guardians live in the same state as the person to which they are assigned. Differences in states' adult guardianship laws and limited communication between states and courts create a barrier to addressing caregiving issues. Adult Guardian Jurisdictional questions may arise in situations involving snowbirds, long-distance caregiving arrangements, even the rare incident of elderly kidnapping. Adding Wisconsin to the list of states with Uniform Adult Guardianship laws will simplify the process for determining jurisdiction between multiple states, and establishes a framework that allows state court judges in different states to communicate with each other.

Wisconsin's Silver Alert has been issued nearly 200 times and has been successful in ensuring that 96% of people are returned to their home, to their families or their caregivers safely. Assembly Bill 628 is a small fix to the Silver Alert similar to a bill that passed the Assembly last session but did not make it to the Governor's desk. This bill would allow the Department of Transportation to do a follow up to situations where a credible Silver Alert is placed on someone who is driving to investigate whether. This fix would make the Silver Alert maintain the integrity of the Silver Alert program and more useful and successful.

Assembly Bill 630 would create a 40-hour voluntary certification for CNAs, nurses and assisted living center administrators with the goal of improving caregiving for individuals with Alzheimer's and dementia, creating new opportunities for professional development and helping facilities attract and retain new workers. This bill would ensure that everyone using the term "Certified Dementia Specialists" would have a standard knowledge base. Those looking to place their loved ones in care facilities would know that a "Certified Dementia Specialist" completed a state-sponsored training program. A certified dementia specialist would be trained in the challenging behaviors and situations that often arise with a patient with Alzheimer's and dementia. The goal of this bill is twofold, providing care for those with Alzheimer's and dementia and allowing professional caregivers to develop a stronger skill set to improve their careers. This bill was part of the Speakers Task Force package last session but did not make it to the governor's desk.

Across the country, 15 million Americans provide unpaid care for people with Alzheimer's and other dementias, that is more people than the number of people who are employed by Walmart, the country's largest single employer. These caregivers provide an estimated 18.2 billion hours of care, valued over \$230 billion.



KEN SKOWRONSKI

STATE REPRESENTATIVE • 82nd ASSEMBLY DISTRICT

(608) 266-8590
Toll-Free: (888) 534-0082
Rep.Skowronski@legis.wi.gov

P.O. Box 8953
Madison, WI 53708-8953

And that's just for Alzheimer's. Those numbers grow even higher when accounting for family members caring for loved ones with other devastating illnesses. Imagine if the cost of that caregiving was to fall on the backs of our government and taxpayers instead of on those families.

Caregiving is physically, mentally and financially exhausting but family members often must step up and take care of their aging relatives as the cost of professional nursing home care is even more burdensome and cost prohibitive than at home care. Individuals who leave the workforce to care for a sick or dying family member lose hundreds of thousands of dollars in salary and benefits.

Assembly Bill 631 would allow caregivers to claim up to \$1,000 in caregiving expenses on their taxes if their income is below \$75,000 as a single person or \$150,000 as a married couple filing jointly to help ease the burden of caregiving on families.

While we recognize that the fiscal note on this bill is high, we're glad we're starting this discussion. We believe that returning some money for caregiving to the caregivers will help them better take care of their loved ones, improve their financial situation and return that money to the economy.

Thank you for your consideration on these bills as well as the others that are being discussed here today.



TERRY MOULTON



WISCONSIN STATE SENATOR

23RD SENATE DISTRICT

From: Senator Terry Moulton
To: Assembly Committee on Mental Health
Re: Testimony on Assembly Bill 633
Relating to: establishing a palliative care council
Date: December 12, 2017

Thank you Chairman Tittl and members for allowing me to testify on Assembly Bill 633 this morning. 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 whose illness is no longer responsive to curative treatment. Care includes 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. Palliative care does not hasten or postpone death, rather it affirms life by improving quality of life for patients facing a non-curable condition.

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.

Assembly Bill 633 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.

Assembly Bill 633 is a wonderful opportunity to join the efforts of 21 other states and the federal government in proactively assessing palliative care, its growing need, and its impact on Wisconsin. Please vote to recommend passage of Assembly Bill 633 and help us serve Wisconsin families by taking this issue head on.

Serving the 23rd Senate District

**Testimony Provided to
Wisconsin Assembly Committee on Mental Health
Madison Wisconsin
December 12, 2017**



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

Chairman Tittl, Vice-Chair Jagler and members of the Committee,

Thank you for inviting 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 other two Alzheimer's Association Chapters, The Greater Wisconsin Chapter and the South Central Chapter. Together we support Alzheimer's Association programs and services, awareness activity, advocacy and research support 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 that 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.

Alzheimer's and Dementia

Dementia is a medical term used to describe a series of symptoms related to cognitive performance that impacts with daily living in areas such as memory, judgment, planning, decision making, emotional control, and language. Dementia itself is not a diagnosis. There are many causes of dementia in older adults. Some of the causes of dementia are treatable such as urinary tract infections, vitamin and thyroid deficiencies, medication interactions, and other health concerns. Alzheimer's disease is the leading cause of dementia, accounting for over 70 percent of all cases, followed by Vascular Dementia which is related to circulatory problems such as stroke, Lewy Body Dementia, Frontal Temporal Dementia, Creutzfeldt-Jakob Disease and others. All of the non-treatable dementias destroy brain tissue, are fatal and result in death. Alzheimer's disease by itself is the 6th leading cause of death in the United States. Alzheimer's disease is irreversible and always fatal. There is currently no proven way to prevent, treat or even slow the disease progression of Alzheimer's disease.



Diagnosis, Symptoms and Warning signs

Currently in the US, the average age of diagnosis is in the early to mid-70's, Persons with the diagnosis and their care partners face a long journey that has been referred to as the long goodbye. A major national goal of the Alzheimer's Association is to identify and treat persons with Alzheimer's and dementia as early as possible in the disease process, where the person and their care partners can become better connected to resources and better prepared for the years ahead. Early detection matters.

Family Caregiving

The majority of unpaid caregivers are the sons and daughters of the diagnosed individual, the so-called "sandwich generation," and 81 percent report being employed at the start of caregiving. 15 percent of dementia caregivers had to take a leave of absence, 13 percent had to go from full to part time, and 9 percent quit their jobs completely after assuming caregiving roles.

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the physical strain and emotional stress of dementia care provision is much higher than caregiving for an older adult without dementia, and increases the caregiver's susceptibility to disease and other health complications.

Emotional and practical support, counseling, resource information and educational programs about Alzheimer's disease all help a caregiver provide the best possible care for a loved one. Through training, caregivers can learn how to manage challenging behaviors, improve communication skills and keep the person with Alzheimer's safe. Research shows that caregivers experience lower stress and better health when they learn skills through caregiver training and participate in support groups, online or in person. Participation in these programs and groups can allow the person with the diagnosis to remain at home for a longer period of time.

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.

In closing, there are many promising practices in regard to dementia care and support in Wisconsin today.

- Dementia Care Specialists are in place in many counties, with more to be added in the coming months,
- Family Care MCO's have developed dementia lead staff persons and enhanced the dementia capabilities of their provider networks,
- The Dementia Friendly Communities Toolkit and Dementia Friendly Employers Toolkit produced by DHS are being used all over the State to reduce stigma and foster local efforts to support people in need,
- The Partnership to Improve Dementia Care in nursing homes has lowered the reliance on dangerous medications as a form of behavior control,
- The Music and Memory program brings the power of music into 250 Wisconsin nursing homes improving care and augmenting activity therapy,
- Grants made by the Division of Quality Assurance under the Civil Monetary Penalties program has made possible vital training programs for Wisconsin long term care facilities,
- To augment in-person training, the two Wisconsin long term care provider organizations, Wisconsin Health Care Association and LeadingAge Wisconsin, have made the Alzheimer's Association CARES® online dementia care training and certification programs available to all their member facilities, and
- Partnerships with law enforcement and other first responders are blossoming all over the State, ensuring that these vital community professionals have the tools and interventions they need when they come upon crisis situations in our communities.

In regard to remaining gaps and concerns, the Alzheimer's Association would like to see:

- 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
- 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

- Review and adjust our robust Guardianship Laws to allow Wisconsin courts to effectively communicate with other courts when a jurisdictional issue arises
- Dementia Specialist Certification program that would help in improving the caregiving for individuals with dementia and create new opportunities for professional development
- 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.
- A silver Alert referral program where when a credible Silver Alert has been issued for someone who has gone missing in a vehicle they be referred for a driving review

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

L!fe

WISCONSIN RIGHT TO LIFE

Chelsea Duffy, Legislative Director, Wisconsin Right to Life

Assembly Committee on Mental Health

AB 633, relating to: establishing a palliative care council.

Tuesday, December 12, 2017

Thank you to Chairman Tittl and members of the Assembly Committee on Health 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 and Rep. Ken Skowronski 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



Chairman Tittl
Assembly Committee on Mental Health
Public Hearing, Assembly Bill 633
Tuesday, December 12, 2017

Thank you Representative Tittl and members of this committee for the opportunity to testify today. My name is Sara Sahli and I am the Wisconsin Government Relations 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 Assembly Bill 633 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 sponsors 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 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 AB 633 is key to do this, and in fact 20 other states have passed similar legislation.

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

Thank you for the opportunity to testify, and I urge you to vote yes on AB 633.

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

December 12, 2017

Chairman Tittl
Assembly Committee on Mental Health
Public Hearing, Assembly Bill 633

I am here today to express my support for Assembly Bill 633, which seeks to improve health care quality through the establishment of a state advisory council on palliative care. Thank you to Chairman Tittl, Representative Snyder as the lead sponsor, the co-sponsors, 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. I am also an oncologist, a clinician scientist, and an educator. The UW training program and our clinical programs are national programs of excellence including a 2017 Citation of Honor from the American Hospital Association's Circle of Life program for innovation in palliative care. My specialty of Palliative care focuses on improving the quality of life of patients with serious illnesses and their families. 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 a serious illness about the relative value of different treatment options. Sometimes people mistakenly think about palliative care as in search of a good death. I have cared for thousands of people who have died over my 15 years in this career and I have rarely witnessed a "good death." Even when peaceful it is sad and tragic and leaves behind a wake of grief and despair. No, we are not pursuing a good death; we are all about helping people live a good life. Palliative Care is about living well.

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...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. The goal of such services is to promote optimal well-being in the face of serious, life-threatening illness for patients and families. This should include access to specialized palliative care providers and services, including hospice and home-based palliative care.

There is already a rich, and growing, 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 palliative care along with standard oncologic care it showed that patients anxiety and depression was better, the quality of life was better, 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 drug, it would be a billion dollar blockbuster.

Yet specialized palliative care clinicians are in short supply and yet there is increased demand and access as our field moves earlier into the course of a serious illness by seeing patients outside the hospital in clinics, homes, and nursing homes. As the United States and Wisconsin move towards value-based payment models for healthcare, access to palliative care must be preserved which requires financing and payment methods. This is particularly applicable to home-based palliative care and hospice programs.

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. However, the experience in other states with PC Advisory Councils is mixed. AB 633 can be improved with minor modifications to its current form, particularly in section 5, which stipulates what measures the committee should report on. To establish Wisconsin as the national leader in population-based palliative care we require data that provides a picture of our population's well-being in the face of serious illness. I encourage modification of AB 633 to allow the council leeway and authority to collect the data they deem necessary to accurately provide 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 AB 633.

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.



Greater Wisconsin
Agency on Aging Resources, Inc.



December 12, 2017

To: Representative Tittl, Chair
Members, Assembly Committee on Mental Health

From: Greater Wisconsin Agency on Aging Resources, Inc. & the Wisconsin Aging Advocacy Network

Re: Support for Alzheimer's and Caregiver Bill Package – AB 628, AB 629, AB 630, AB 631,
AB 632 & AB 633

Greetings, Chairman Tittl, Vice Chair Jagler 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 the Alzheimer's and Caregiver Bill package (AB 628 – AB 633) which is specifically aimed at improving the lives of those with Alzheimer's and related dementias, those with life-threatening illnesses, and the caregivers who support them.

With over half a million family caregivers in Wisconsin – and over 40 million nationwide – it is very likely many of us know someone who is or was providing care for a family member or are involved in caregiving ourselves. I have worked in the aging field for over thirty years and have been caregiver for multiple family members. These bills address much of what I have encountered personally and professionally.

The Silver Alert Referral (AB 628) bill will help connect caregivers to their local Aging & Disability Resources Centers (ADRC), if they have not already done so, to learn of the valuable information and resources available at there. Though I have been a caregiver multiple times, no two situations were the same and new resources were needed. The local ADRC was able to help me find what I needed each time. Knowledge is power and caregivers are better equipped to provide the care and support their family members need when they feel informed. Several other bills in this package also relate to information. The Alzheimer's Awareness Grants (AB 632) will help increase awareness of Alzheimer's disease and dementia in rural and underserved urban areas. This will help people living with dementia to be more informed and seek earlier diagnosis, so they and their family members can be connected to resources and be given the opportunity to plan and prepare. The Palliative Care Council (AB 633) bill will help with the development of an information and education program about palliative care and a system to help

facilitate access to appropriate palliative care services to help manage the pain and stress experienced by individuals with serious illness and improve their quality of life. The Dementia Specialist Certification (AB 630) bill not only creates new professional development opportunities for workers to obtain specialized skill and training in working with people with dementia, but also has the potential to serve as a measure of information for people with dementia and their caregivers regarding the level of training a worker has if they are using this title. To be most useful for consumers, it is recommended that anyone using this title not only complete the instructional program outlined, but also a specified number of hours of specialized training. This would ensure that all workers using the dementia specialist certification have no less than the base-level of training hours completed specific to dementia care training. Without the hours specified, some could complete, for example, an 8-hour class while others a 40-hour course and the certification would not mean the same thing in each example. Training is a measure of quality and commitment.

The last bill I would like to specifically address is the Caregiver Tax Credit (AB 631). 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. Offering a state income tax credit for family caregivers sends a message that Wisconsin recognizes the valuable service provided by these women and men and will offer some help to ease the financial burden of family caregiving.

Thank you, Chairman Tittl, for this opportunity to offer testimony in support of the Alzheimer's and Caregiver Bill package. I am happy to respond to any questions that you or the Committee may have.

Testimony
Assembly Committee on Mental health
Helen Marks Dicks
December 12, 2017

Good Afternoon. My name is Helen Marks Dicks and I am the State Issues Advocacy Director for AARP Wisconsin.

AARP Wisconsin has over 840,000 members over the age of 50 in Wisconsin. AARP looks at the impact of legislation on the 50+ population. Today we are supporting the package of bills before you with slight modifications to one bill. We do so because AARP Wisconsin has a strong interest in supporting Wisconsin 578,000 unpaid Family Caregivers. They are Wisconsin's unsung heroes that make it possible for so many people to remain in their homes until the end of life.

I will address the bills in the order they appear on the agenda except for the Caregiver Tax Credit. This is the most important bill in the group for AARP Wisconsin and I will leave it to be emphasized at the end of my testimony.

The use of the Silver Alert has been successful and we support the portion of this bill that provides referral to the Aging and Disability Resource Centers (ADRCs). We object to the automatic referral to the Department of Transportation (DOT) for license review. Law enforcement is already empowered to make such a referral at their discretion and making the referral automatic is inappropriate. The totality of the circumstances will guide the officer and mandatory referral is unnecessary.

The Uniform Adult Guardianship Jurisdiction Act brings us in line with other states in dealing across state lines on issues of guardianship without compromising our unique protective system. We thank the Elder Law Section of the Bar for working on this.

Caring for people with dementia is challenging even for a professional caregiver and we support the need for specialized training in this area. The grants for dementia awareness compliment the work already being done on dementia awareness within the Dementia Friendly Communities and Age Friendly Communities movements, both efforts supported by AARP Wisconsin.

The Palliative Care Council might benefit from greater consumer involvement and it is a good idea as more people need to live with chronic conditions as the impact of palliative care reaches beyond just the end of life process.

These are good bills but the best bill, and the one we give our most enthusiastic support to, is the Caregiver Tax Credit. I have attached to my testimony an infographic about the costs to families in caring for a loved one. The out of pocket costs average around \$7,000 a year if you are reasonably nearby and close to \$12,000 if you are doing long distance caregiving. Few people realize that except for Family Care/IRIS, which helps low income people and long-term care (LTC) Insurance which is not affordable for all, there are no programs that help people stay in their homes as they age and require to assistance to maintain their independence. Traditionally, government programs fund institutional care, which is expensive and often more care than a person needs. By supporting caregivers who are helping their family members stay in their homes, the care recipient, the caregiver, and the state all win. The caregiver is supported because the expense is a little less burdensome and the recognition of their difficult task is important, the care recipient because they get to age in their homes as they wish, and the state because it keeps people off taxpayer-supported programs.

Caregiving is truly a nonpartisan, nonpolitical issue. We are all going to be caregivers or care recipients at some time in our lives. A modest tax credit will recognize and support these unsung heroes while softening the financial impact of their efforts.

The need for this bill is best told by the stories of the caregivers themselves. Noreen Holmes, one of our AARP Advocates from La Crosse who was a caregiver, will be sharing her story.

I would like to conclude my testimony by acknowledging the work that this committee and the authors of these bills have done over the last two sessions for people with dementia and their caregivers. It is a partnership we hope continues into the future.

If you have questions about this or any other legislative position taken by AARP Wisconsin, please feel free to contact me at 608-286-6337 or by email at hmdicks@aarp.org.

From: Carol Wessels [mailto:Carol@wesselsllc.com]

Sent: Sunday, December 10, 2017 12:47 PM

To: Hall, Steve <Steve.Hall@legis.wisconsin.gov>

Subject: Written testimony for Mental Health Committee hearing on December 12

Dear Representative Tittl:

I am writing to express my support for the package of bills that is before the Committee on December 12. All of 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. As an elder law attorney, I work on a daily basis with families who are facing the challenges of Alzheimer's and other conditions. As an advocate, I hope to see an end to this disease in my lifetime. I simply wish to highlight some of the bills before the committee.

1. **Caregiver Credit:** 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 AB 631/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.

2. **Uniform Guardianship:** The bill related to uniform guardianship jurisdiction (AB 629/SB518) 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. It also provides a process where a guardianship entered in Wisconsin can be recognized in another state. 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

3. **Dementia Specialist Training: (AB 630)** This bill would encourage caregivers to receive a professional training course that would improve their ability to care for people with Dementia. Unfortunately, the care situation for people with Dementia is currently one of voluntary participation. Assisted living facilities who call themselves "memory care" facilities do not need any special training or certification. Also, aides and others working in those facilities do not need special training. The amount of training is purely up to the facilities and individuals, whichever the case may be. This certification will motivate caregivers to participate in the training and will be an incentive for facilities to improve the level of training. It will also provide a benefit to other professionals and individuals who are motivated to complete the training in order to improve their ability to serve people with dementia.
4. **Palliative Care Council (AB 633):** Not enough people use palliative care appropriately. It is care to provide 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. 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.

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

Carol J. Wessels
Attorney at Law

Wessels Law Office LLC
11649 N. Port Washington Rd. Suite #210
Mequon, Wisconsin 53092

Phone: 262-264-7702
Fax: 262-264-7706

Web: www.Wesselslawoffice.com
Blog: www.Wesselselderlaw.wordpress.com

From: Carrie [mailto:cp9333@gmail.com]
Sent: Friday, December 08, 2017 3:43 PM
To: Hall, Steve <Steve.Hall@legis.wisconsin.gov>
Subject: Alzheimer's and Caregiver bill testimony

Rep. Tittl,

For about 18 months, I was one of many caregivers for my father who was diagnosed with dementia and shortly after, terminal cancer. He passed away in July.

I work in the field of aging, but even with that expertise, caregiving, navigating treatments, insurance, financial decisions, and finding appropriate care at all levels of need was challenging.

The entire package of Alzheimer's and Caregiver bills will benefit residents of the state. In particular, I'd like to speak to Three.

My experience with my dad was my first with palliative care. Having assistance from the palliative care doctor throughout the whole disease progression, which was complicated by the dementia, enabled us to better understand and accept quality of life vs. quantity and treat accordingly to maximize quality and reduce pain. Palliative care is a healthy way to look at end of life - something we don't often discuss or want to talk about. We need to encourage more palliative care and the advisory council is a great start. I look forward to raising awareness of this critical part of end of life care.

My grandmother passed away from Alzheimer's disease over 3 years ago. One of the most heart-warming scenes I witnessed during the many years of caregiving was the interaction between my daughter and her great-grandmother. She seemed to intuitively know how to interact with the behaviors of the disease - but many kids are frightened or don't know how to respond. The Alzheimer's awareness grants will benefit communities, caregivers and people with dementia and can help teach children how to interact with people with dementia. I am involved with the dementia friendly community initiative as a trainer in Portage County. While these efforts are a good start, there is more to be done. We need to erase the stigma of behaviors people with dementia exhibit, learn why, and mitigate them as much as possible. The experience of the virtual dementia tour was powerful and made me realize why people with dementia act the way they do.

Caregiver tax credits are important assistance because all the care costs incurred by the family are not always covered by long term care insurance or other funding. This credit can help ease some of the financial worry so the quality of life of that whole person - and not just the costs of their disease can be addressed.

Please accept this written testimony for the Dec. 12 hearing as I am unable to attend. There is so much more that needs to be done, but this package of bills is a start. Not one solution will help every caregiver because their situation is not like anyone else's. We need to tackle this disease, and the strain on families that caregiving often causes, together.

Thank you.

Carrie Porter Diamond
810 Fifth Street, Plover
920-574-6665

-----Original Message-----

From: Mary Kolberg [mailto:marykolberg@ymail.com]

Sent: Monday, December 11, 2017 12:19 PM

To: Rep.Tittl <Rep.Tittl@legis.wisconsin.gov>

Subject: Alzheimer's Testimony

Dear Chairman Tittl,

I am writing to you today on behalf of the upcoming hearing on Tuesday in regards to the caregiver bills. I have attached my written testimony that I would love to be shared with the committee. I realize the hearing is tomorrow so I hope that I am not too late in sending this to you.

Thank you for your support.

Please reach out if I can help in any other way.

Thank you,

Mary Kolberg

To whom this may concern:

My name is Mary Kolberg; I am 23 years old and live in Mukwonago. I am caregiver to my 63-year-old mother who has Alzheimer's disease. I am an active volunteer for the Alzheimer's Association and that is how I became aware of this opportunity to share my story.

My mom has had early-onset Alzheimer's for the past 10 years and today, she rapidly decreases. My mom worked as a nurse at Froedtert Hospital for 30 years. She spent 30 years taking care of other people and now, she can't get any help for herself. She is on Medicare and her only source of income is social security. My father and I do what we can to take care of her but we struggle greatly. We are part of the under served community of people who make just enough money to not qualify for any assistance, but we do not make enough to actually pay for assistance. Someday, I hope to see this changed.

My mom's disease has and continues to progress rapidly. Our situation will continue to worsen, and unfortunately, there is nothing anyone can do for us at this present time. My family and I have accepted the situation we were dealt, but that does not mean that we aren't in pain each and every single day.

I write this today because I want to see the changes. I NEED to see the changes. The things my family and me have to endure and have to feel are terrible, terrible things.

I grieve every day for the loss of my mom because every day I lose more and more of her. It affects me in more ways than I am too proud to say. But, my father and I are part of the 35% of caregivers whose health has gotten worse due to responsibilities and stress. My mom requires constant around the clock care. My dad spends his entire day taking care of my mom and keeping her safe. When I get home I am responsible for the daily household necessities. Cleaning, laundry, dinners and shopping. It is quite difficult to take my mom shopping because she has developed an extreme anxiety when in unfamiliar public situations so it is impossible for my dad to go with her anywhere throughout the day. I work full time during the day and then I come home and have to work full time there.

I no longer have a mom, and I haven't for a very long time. The hardest part for me is that when the Alzheimer's began to show signs in my mom, I was 15 years old and one, didn't know that she actually had a problem and two, didn't really care. I was a 15-year-old girl who cared more about her social life than her mother. That eats at me every single day. I lost YEARS with my mom and I will never get it back. I wish I could have my mom back for even a minute just to tell her that I love her and she was a good mom.

I have dedicated my life to taking care of my mom. My dad and I split the responsibilities because it is literally impossible for one person to do. I am not a professional caregiver, but I am grateful for the care that we are able to provide her. I know that others are not in the same position. I wish there were more resources and help for people like us from the Government. Maybe one day there will be, but unfortunately, I know that it will come too late to help our family.

I am an advocate 100% for these bills, and while they might not help my family, they certainly will help others. The change has to begin somewhere.

From: Elizabeth Stevens [mailto:estevens@portagelawyers.com]
Sent: Monday, December 11, 2017 1:44 PM
To: Hall, Steve <Steve.Hall@legis.wisconsin.gov>
Subject: Alzheimer's bills considered by Mental Health Committee

Dear Representative Tittl:

I am writing to express my support for the package of bills that is before the Committee on December 12. All of 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 as an elder law attorney. I work on a daily basis with families who are facing the challenges of Alzheimer's and other conditions. As an advocate, I hope to see an end to this disease in my lifetime. I simply wish to highlight some of the bills before the committee.

1. **Caregiver Credit:** 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 AB 631/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. 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 like modifying their home to accommodate an adult with special needs, hiring an aide to help while the caregiver needs to be away and buying supplies the person needs. 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.
2. **Uniform Guardianship:** The bill related to uniform guardianship jurisdiction (AB 629/SB518) 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. 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. It also provides a process where a guardianship entered in Wisconsin can be recognized in another state. Most other states have already adopted this legislation.
3. **Dementia Specialist Training:** (AB 630) This bill would encourage caregivers to receive a professional training course that would improve their ability to care for people with Dementia. Unfortunately, the care situation for people with Dementia is currently one of voluntary participation. Assisted living facilities who call themselves "memory care"

facilities do not need any special training or certification. Also, aides and others working in those facilities do not need special training. The amount of training is purely up to the facilities and individuals, whichever the case may be. This certification will motivate caregivers to participate in the training and will be an incentive for facilities to improve the level of training. It will also provide a benefit to other professionals and individuals who are motivated to complete the training in order to improve their ability to serve people with dementia.

4. Palliative Care Council (AB 633): Not enough people use palliative care appropriately. It is care to provide 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. 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.

I support these bills as well as the rest of the package and encourage your committee to do so as well.

Sincerely,

Attorney Elizabeth A.H. Stevens
Miller and Miller, LLC
311 DeWitt Street
PO Box 200
Portage, WI 53901
608-742-8585
fax-742-2501

From: Ron Duerkop [mailto:carod@att.net]
Sent: Sunday, December 10, 2017 7:02 PM
To: Hall, Steve <Steve.Hall@legis.wisconsin.gov>
Subject: Written Testimony on Alzheimer's and Caregiver Bills for 12/12/17 Assembly Committee on Mental Health Public Hearing
Importance: High

Representative Tittl, Chair of the Assembly Mental Health Committee,

Having worked for over 40 years with older adults challenged by various aging related issues including Alzheimer' and other dementias, I support all efforts to positively intervene to assist those negatively impacted, both individuals and their caregivers.

AB-628 Silver Alert Referrals. This modification is very important to ensure that ADRCs are alerted in every situation in order to offer/provide the intervention necessary to protect persons with cognitive deficits. If a vehicle was involved it is also a good idea to require that the DOT be notified to determine if any driving restrictions are appropriate. This is good and helpful legislation. Please support it and pass it on in the legislative process so that it becomes law.

AB-629 Uniform Adult Guardianship Jurisdiction. Having worked in APS (Adult Protective Services) for all of those 40 + years, I support this effort to make court jurisdiction issues for adult guardians acting across state lines more clearly defined and less time consuming. This has been an area of much wasted time and effort under current statutes. This is good and helpful legislation. Please support it and pass it on in the legislative process so that it becomes law.

AB-630 Dementia Specialist Certification. While this is simply "title protection" in terms of the use of the title "dementia specialist" or "certified dementia specialist", it does require some basic training (40 hours) in dementia to use the title. Many more hours of training/experience are necessary to do a good job but this ensures some basics for those who want to use the "title". Hopefully, this legislation is supportive of the need for every county ADRC to have at least one designated "dementia specialist" on staff.

AB-631 Caregiver Tax Credit. It is a well-known fact that family caregivers provide the vast majority of care/supervision to those challenged with dementia. This caregiver tax credit to allow for a maximum tax credit of \$1,000 for out of pocket caregiver expenses is a helpful step in the right direction to encourage and support these valuable "tax saving" care providers. This is good and helpful legislation. Please support it and pass it on in the legislative process so that it becomes law.

AB-632 Alzheimer's Awareness Grants. In spite of all the information that is already available related to Alzheimer's and dementia resources, most do not seek out that information until there is some crisis that demands intervention. The \$500,000 in grants to community programs to raise awareness, unfortunately, is needed to be more proactive with early intervention. This

is good and helpful legislation. Please support it and pass it on in the legislative process so that it becomes law.

AB-633 Palliative Care Advisory Council. Palliative care is misunderstood and underutilized. This effort to make consumer and professional information/education more readily available is a step in the right direction. This is good and helpful legislation. Please support it and pass it on in the legislative process so that it becomes law.

Thank you for allowing me to provide input on this important group of bills.

Ron Duerkop (former direct service social worker and supervisor of Older Adult Services at Winnebago County DSS/DHS and ADRC)
1600 Brentwood Dr.
Oshkosh WI 54904
920-231-6691

From: Eric Duncan [mailto:eduncanlaw@gmail.com]
Sent: Monday, December 11, 2017 2:38 PM
To: Hall, Steve <Steve.Hall@legis.wisconsin.gov>
Subject:

Dear Representative Tittl:

I am writing to express my support for the package of bills that is before the Committee on December 12. All of 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 have seen two of four grandparents struggle with the disease for many years before their deaths, as well as the disruption caused in the lives of my mother and aunt, who assumed the primary roles in caring for them. As an elder law attorney, I work on a daily basis with families who are facing the challenges of Alzheimer's and other conditions. As an advocate, I hope to see an end to this disease in my lifetime. I simply wish to highlight some of the bills before the committee.

1. **Caregiver Credit:** 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 AB 631/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.

2. **Uniform Guardianship:** The bill related to uniform guardianship jurisdiction (AB 629/SB518) 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. Typically, an attorney will need to start an entirely new guardianship where a person moved from out of state, and it is often impossible 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. It also provides a process where a guardianship entered in Wisconsin can be recognized in another state. Most other states have already adopted this legislation. As a member of the Elder Law Section of the State Bar of Wisconsin, I supported a group of elder law attorneys who 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.
3. **Dementia Specialist Training:** (AB 630) This bill would encourage caregivers to receive a professional training course that would improve their ability to care for people with Dementia. Unfortunately, the care situation for people with Dementia is currently one of voluntary participation. Assisted living facilities who

call themselves "memory care" facilities do not need any special training or certification. Also, aides and others working in those facilities do not need special training. The amount of training is purely up to the facilities and individuals, whichever the case may be. This certification will motivate caregivers to participate in the training and will be an incentive for facilities to improve the level of training. It will also provide a benefit to other professionals and individuals who are motivated to complete the training in order to improve their ability to serve people with dementia.

4. Palliative Care Council (AB 633): Not enough people use palliative care appropriately. It is care to provide 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. 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.

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

Thanks,

Eric Duncan
Duncan Law LLC
416 George Street
De Pere, WI 54115
414-531-1614
eduncanlaw@gmail.com



Rob Gundermann, Public Policy Director
Gundermann@alzwissc.org 608-232-3408

December 12, 2017

Alzheimer's and Dementia Alliance of Wisconsin testimony in support of

Good morning Chair Tittl and members of the committee. Thank you for the opportunity to speak today. I'm Rob Gundermann, the Public Policy Director for the ADAW and I'm speaking in favor of AB 628, 629, 630, 631, 632 and 633. I'm not going to speak to each bill but we do support the entire package.

We all know the number of people with dementia in our state is growing dramatically and that growth is going to continue. The bills before you address challenges we are facing today and prepares us for challenges we will face in the future. I know there are a lot of people testifying today so I will be brief but I want to mention a few things you might not hear from others.

First, AB 628, the Silver Alert bill, would ensure that follow up actions are taken when a Silver Alert is issued. We have people who have had more than one Silver Alert issued for them and we want to make sure nobody is falling through the cracks. We're especially concerned about those individuals living alone in the community who may not have anyone looking out for them. Every time a Silver Alert is issued the person for whom the alert is issued is at risk. This bill aims to reduce that risk.

AB 630 would create a Certified Dementia Specialist position, which would help to address the issue of challenging behaviors and would help us deal with those situations in place. We believe this bill would also help address the staffing crisis nursing homes are dealing with today by creating a career path for CNAs, making it more likely that they will remain in the field.

Lastly, I want to express our support for AB 632, the Alzheimer's Awareness Grants bill. This bill is very important to the ADAW as we have opened three new offices this year as part of our planned expansion and we want people to know we are here to help. We can put all the resources in the world into our local communities but if people aren't aware of what services are available they won't be able to access them.

Thank you for your time and consideration and I'm happy to try to answer any questions.



WISCONSIN CATHOLIC MEDICAL GUILDS

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

December 12, 2017

To: Members, Assembly Committee on Mental Health

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

RE: Assembly Bill 633 – 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.”

Assembly bill 633 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.

Good morning Chairman Tittl and distinguished members of the Assembly Committee on Mental Health.

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 Assembly Bill 633.

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 obstanenance.

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 Assembly Bill 633.

Thank you.

Jeffrey Bremer
5 Greystone Circle
Middleton, WI

Good morning Chairman Tittl and distinguished members of the Assembly Committee on Mental Health. My name is Linda DeGarmo and I live in Chaseburg, Wisconsin. Thank you for the opportunity to speak with you today in support of Assembly Bill 633 – 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 Assembly Bill 633. 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
S958 Schultz Ln
Chaseburg, WI 54621

12/12/17 Testimony in Opposition to AB 633/Palliative Care Council

Bill AB633 establishes:

- 1) state sponsored website to promote palliative care and
- 2) an appointed ~20 member palliative care council with 1 position open to a non-palliative care physician, to advise the legislators on various matters.

Introduced with bipartisan support and perhaps, even the hoped-for effect of decreasing the push for formal “physician-assisted suicide”, it is well-intentioned, but there are red flags. I am representing myself. As a board certified, licensed physician anesthesiologist who for 25+ practice years had focused on patient safety and relief of pain and suffering, including 6 years on a regional and acute pain service, I oppose AB633.

Palliative Care Medicine is a relatively new specialty (recognized by American Board of Medical Specialties in 2006. Dr. Capone, board certified in Hospice and Palliative Care Medicine writes, “In hospice and palliative care settings, the administration of intentionally larger doses of analgesia beyond what is necessary to diminish pain, is sometimes done to intentionally end patients’ lives. **This is not a secret within the medical profession.**” (bold emphasis in original, underline mine)¹

Wis. legislative definitions 50.90

Definitions. Subchapters:

“(3) “Palliative care” means management and support provided for the reduction or abatement of pain, for other physical symptoms and for psychosocial or spiritual needs of individuals with terminal illness and includes physician services, skilled nursing care, medical social services, services of volunteers and bereavement services. “Palliative care” does not mean treatment provided in order to cure a medical condition or disease or to artificially prolong life.”

(5) “Terminal illness” means a medical prognosis that an individual's life expectancy is less than 12 months. (emphasis mine)

Medical definition:

“Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.”² (underline emphasis mine)

1) NB Difference between legislative definition is that “treatment” of medical conditions is explicitly excluded and focuses on symptoms, whereas in this medical definition palliative care can be, but not necessarily provided along with curative treatment. The legislative definition may only include terminally ill, but the medical practice does not limit it to terminally ill.

2) It is accepted medical practice that “treatment” of underlying conditions is done precisely to relieve symptoms not just for sake of a cure. In addition, symptom management is also basic principle of good medicine, but without killing the patient. Even if not successfully “curative”, some treatments themselves may lessen pain and discomfort, even in a terminally or “seriously ill” patient. E.g. Discomfort from urinary tract or other infections, heart failure, asthma, broken bones, some obstructions, etc.

¹ “Hospice and Palliative Care Medicine: Is It Losing Its Soul? from Human Life Alliance “Imposed Death - Euthanasia and Assisted Suicide, p. 10 author Ralph Capone, MD FACP, http://www.imposeddeath.org/Articles/11_Hospice.htm

² <https://getpalliativecare.org/whatis/>

3) Terminal patients may have a “terminal” or “serious” illness, but also coincident with other reversible, life-threatening problems that can be treated successfully. We are all terminal in a sense. I have known of a patient in her 80’s, initially denied surgery to fix a diaphragmatic hernia, a certain death sentence. A retired physician advocated for her, she was operated on, and lived well for another several years, only to be put into hospice for an unknown reason and was soon dead.

4) The expansion of palliative care to patients who are not terminally ill is being promoted by palliative care personnel. Almost anyone could qualify. See attached “Triggers to Refer for palliative care” which include:

- Declining ability to complete activities of daily living.
- Weight loss
- Patient or family requests for “futile” care.
- Limited social support and a serious illness (e.g. homeless, chronic mental illness)
- Patient or family psychological or spiritual distress, ...

According to a recent article in the Journal of Palliative Medicine, palliative care is not just for terminally ill but seriously ill patients. Who are the “seriously ill” in need of palliative medicine? The authors state, “Conceptually, “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.” They recommend targeting high-cost and high-need patients.³ Again, this could apply to many of us. Why is caregiver strain a reason to sedate another person, possibly to death?

My concern is not a dearth of “palliative care” for citizens but denial of “treatments” of treatable medical conditions, if not immediately, over the long-term based on recommendations from a palliative care council, heavily weighted/biased by palliative medicine team members advising our legislators. There is only 1 other spot for another physician specialist.

“Anesthesiologists have been among the very pioneers of patient safety. According to a definition by Charles Vincent, patient safety is ‘the avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare’ (p. 31) [1], rather than from the patient’s underlying medical condition [2]. During the last decades, the risks associated with anesthetic care have been dramatically reduced [3].”⁴

“In 1999, the Institute of Medicine report “To Err is Human” singled out the medical specialty of anesthesiology for its significant improvements in patient safety. “Few professional societies or groups have demonstrated a visible commitment to reducing errors in health care and improving patient safety. Although it is believed that the commitment exists among their members, there has been little collective action. The exception most often cited is the work that has been done by anesthesiologists to improve safety and outcomes for patients.”^{5, 6}

Anesthesiologists use many of the same drugs in the Palliative Medicine protocols. Yet, they are not represented on this council. There are significant concerns for patient safety and well-being.

³ Kelley, Amy & Bollens-Lund, Evan. (2017). Identifying the Population with Serious Illness: The “Denominator” Challenge. Journal of Palliative Medicine. . 10.1089/jpm.2017.0548. <https://www.ncbi.nlm.nih.gov/pubmed/29125784>

⁴ Wacker, J., & Staender, S. (2014). The role of the anesthesiologist in perioperative patient safety. *Current Opinion in Anaesthesiology*, 27(6), 649–656. <http://doi.org/10.1097/ACO.000000000000124>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4232292/>

⁵ <https://www.kevinmd.com/blog/2015/01/american-society-anesthesiologists-deep-roots-patient-safety.html>

⁶ Institute of Medicine (US) Committee on Quality of Health Care in America; Kohn LT, Corrigan JM, Donaldson MS, editors. To Err is Human: Building a Safer Health System. Washington (DC): National Academies Press (US); 2000. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK225182/doi:10.17226/9728>

E.g. Versed 5 mg loading dose, then a continuous infusion. This is a high dose. Commonly 1-2 mg are given to prevent the patient from remembering even going into the operating room. Versed is now being avoided more often in elderly patients given concerns about cognitive dysfunction. It does NOT relieve pain. It causes amnesia and relieves anxiety.

The endpoints of sedation in the PC protocols can essentially be general anesthesia (“Unarousable: no response to voice or physical stimuli”) but without safety monitoring: painless, non-invasive monitors, e.g., a pulse oximeter.

E.g. Infusions of Propofol; Fentanyl – a narcotic ~50-100 times as potent as morphine. Some drugs given as infusions and/or in combination may take hours for blood levels to decrease even when discontinued for hrs.

E.g. “Other” triggers for drug administration could include just about any movement, facial expression, sound, made by the patient, etc. Unless silent and motionless, the patient may get more drugs that lead not just to “comfort” but possibly death. “Intention” is hard to prove and unlikely to be challenged.

E.g. Agitation – Common cause could be low oxygen in the blood. Anesthesiologists know this so they rule it out, often by simply checking a painless, non-invasive monitor, e.g. pulse oximeter or administer oxygen. The very drugs that are given in response to agitation could worsen agitation. Essentially the side effects of these medicines are considered indications for upping the dose or adding other drugs that can cause the same problems without ruling out treatable problems. NB The definition of palliative care is not “treatment”.

E.g. Titrating drugs to respiratory rate may ignore depth of breaths. Insufficient breaths in rate or volume can result in high levels of carbon dioxide in the blood leading to more sedation and low oxygen.

E.g. Constipation – Side effect of all narcotics to which tolerance is unlikely to occur. This is uncomfortable, yet the protocol may be to give more of the same or just to possibly consider avoiding constipating drugs. It is the patient who should be given the option of taking/declining definite “treatments”. Perhaps it is not, because the concept of “treatment” of “medical conditions” has been abandoned.

There seems to be large use of narcotics and sedative/hypnotics, benzodiazepines, and antipsychotics when other areas of medicine are using multimodal approaches to treat pain/and specifically to avoid narcotics and their many negative side effects. It is not just because of the opioid crisis, but because narcotics have avoidable unpleasant, even dangerous side effects:

Narcotics do not necessarily relieve all pain, especially if movement is desired (like sitting up and visiting with family). Pain with temporary movements for repositioning may not be relieved even with high doses of narcotic. Yet, if given more medication, then when left undisturbed they **may not breath well or even stop breathing**. Narcotics and other drugs can cause **dysphoria**, not necessarily euphoria, especially in elderly; but **patient may not be able to tell you they are really uncomfortable** inside. With these protocols, if they did, they might just get more or stronger drugs to “make them comfortable”. Morphine can cause nausea but also **low blood pressure**, which can also be associated with nausea. **Nausea, +/- regurgitation and itching** (pruritis) may not be able to be communicated by the patient who is “uncomfortable” but too weak to speak up. Narcotics may **prevent the patient from swallowing and clearing their secretions, or coughing effectively**, thus **having secretions go down the windpipe**, which isn’t a comfortable feeling, again, which they may not be able to express. Narcotics also depress white blood cells that help the immune system.

Yet, with death, not necessarily wanting to be avoided, what is the incentive to monitor for or avoid side effects that can hasten death?

Please see the attached list, Triggers for palliative care from a PC website. Just about all of us could qualify. Even if this law limits PC to “terminally ill” now what is to prevent the PC advisory council from recommending expansion; and how reliable is a “terminal” prognosis anyway? Once on certain drug regimens death becomes a self-fulfilling prognosis.⁷

The ethical principle of double effect (which has 4-5 conditions that get lost in most discussions!) may be used to justify giving drugs which may shorten life with a condition of having only intending the good, but this principle loosely and widely misapplied. How can one really know the “intentions” of any caregiver or prove that they went against a stated definition or goal not to hasten or cause death?

Legislative definitions may be helpful, but will not likely change practice or professional organizations’ definitions of care. More likely with advisory councils in this bill, the laws will be changed sooner or later to reflect and protect medical practice, not necessarily to protect and preserve individual patients’ lives.

In the Catechism of the Catholic Church there is mention of “palliative care” but it is neither defined nor described. CCC 2279 “Even IF death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity IF death is not willed as either an end or a means, but only foreseen and tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged.” (emphasis mine) Yet, details are important. Not only competence and caring attitude but proper “intention of all” those working with the sick person from Doctor to Nurse to any caregivers, especially those deciding when/how much drug(s) to give.

Quotes of Pope Pius XII regarding treatment at the approach of death to relieve pain that deprive the person of consciousness have moral conditions.

"It is not right to deprive the dying person of consciousness without a serious reason."

"If no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties: Yes." (emphasis mine)

Pius XII, Address of February 24, 1957: AAS 49 (1957), p. 147.

Pius XII, Ibid., p. 145; cf. Address of September 9, 1958: AAS 50 (1958), p. 694.

This bill gives the Palliative Care Medicine specialty a legislative access advantage at taxpayers’ expense estimated at >\$100,000 for promotion of its specialty via a state website and its council advisory role.

Citizens who don’t want any part of palliative care but may want “treatment” are not given equal voice. Patients if they survive, or family members with bad experiences may be too traumatized to speak up. Others may be trusting and not realize the medical implications of what was done or denied having only sought “comfort” for their loved ones. Others may still want and ask for physician-assisted suicide.

I ask whether would there be a need for state-sponsored i.e., essentially promotion of palliative care if it offered significant advantages such that other doctors saw the benefit for their patients and referred.

This bill sets a precedent for other physicians’ specialties to get taxpayer-funded websites, promotion, and special advisory role access to legislators. There are many specialties that may rightly claim to be deserving and underrepresented to patients. Shortages of physicians exist in many areas. E.g., As good as regional anesthesia and nerve blocks may be for many patients having surgery, imagine anesthesiologists getting a state-sponsored, taxpayer funded website to promote pain-relieving regional anesthesia and a regional anesthesia specialty advisory council to legislators to “help them” promote regional

⁷ <https://getpalliativecare.org/resources/clinicians/>

anesthesia to patients. Anesthesiologists stand on their merits and work with surgical colleagues, patients/their surrogates, do research, as should others, Palliative Medicine specialists included.

This bill seems to put legislators very close to practicing medicine.

What are the advisory matters of this council to legislators? They include:

- E.g., disclosure requirements for informed consent

(There are already documented problems with patients being unaware of other end-of-life advance directives executed without truly informed consent e.g., POLST which even the Wis. Bishops have cautioned against. There are health care providers criticized for providing information (“interference”) that resulted in a patient choosing to be treated and go on living, NB Case in point by Nancy Valko, RN -

http://www.imposeddeath.org/Articles/02_Euthanasia.htm) Worse, other providers may be intimidated with false charges of “assault” were they to speak to patients about welcomed treatment choices that preserve and protect their life.

- E.g. whether a palliative team member can approach patients without their physician’s knowledge (i.e., a request for consultation by specialist), etc.

(Is this so some “team member” can walk into a vulnerable patient’s room or contact them without being invited, neither asked by the attending physician nor the patient/surrogate? Will their medical records have been screened or profiled in some way?)

- E.g. only 1 non-palliative care physician slot open;

(There is no multidisciplinary inclusion of other specialty MDs which is common now in medicine, especially those who are familiar with protocol treatment drugs. There are no requirements for:

- Psychiatrists, experts in mental health (who also prescribe some of the drugs used in PC protocols);

- Anesthesiologists, experts in pain, acute and chronic,(who also prescribe many of the analgesic/sedative/hypnotic drugs used in PC protocols)

- Pain clinic physicians or psychologists

- Physical medicine and rehab physicians

- Physical or occupational or speech therapists

- Integrative medicine or alternative medicine specialists (acupuncture, nutritionists; et al.)?

I oppose AB 633 and urge you to vote against. I think others would, too, if they had more information. It does not protect the life, health, or well-being of any Wisconsin citizen.

Respectfully, 

Christine M. Zainer, M.D.

737 N. Robertson St.

Wauwatosa, WI 53213

Phone and fax: 414 771-7962

Mobile: 414 807-8604

Email: czainermd@wi.rr.com

Triggers to refer for palliative care

- Declining ability to complete activities of daily living
- Weight loss
- Multiple hospitalizations
- Difficult to control physical or emotional symptoms related to serious medical illness
- Patient, family or physician uncertainty regarding prognosis
- Patient, family or physician uncertainty regarding goal
- Patient or family requests for futile care
- DNR order conflicts
- Use of tube feeding in cognitively impaired or seriously ill patients
- Limited social support and a serious illness (e.g., homeless, chronic mental illness)
- Patient, family or physician request for information regarding hospice appropriateness
- Patient or family psychological or spiritual distress

<www.getpalliativecare.org>



WISCONSIN CATHOLIC CONFERENCE

TESTIMONY ON AB 633: PALLIATIVE CARE COUNCIL Presented to the Assembly Committee on Mental Health December 12, 2017

Thank you for the opportunity to testify for information on the creation of a palliative care council through Assembly Bill 633. My name is Kim Wadas and I am the Executive Director of 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 individual to hasten the end of his or her life. Therefore, we respectfully request that the

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

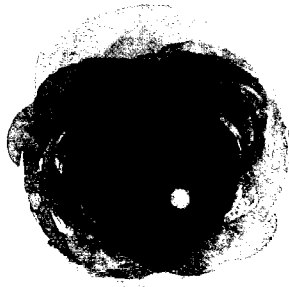
definition of palliative care, as referenced in AB 633, specifically exclude any attempts to assist in or intentionally hasten death.

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, AB 633, 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 AB 633 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.



ProLife
LOVE. FOR LIFE. WI.

**Testimony / Assembly Bill 633: establishing a palliative care council
Assembly Committee on Mental Health
By Matt Sande, Director of Legislation / December 12, 2017**

Good morning Chairman Tittl 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 Assembly Bill 633, legislation that would establish a Palliative Care Council within the Department of Health Services.

Pro-Life Wisconsin has serious concerns with AB 633 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 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 discuss 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. Carlin 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 AB 633 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 Assembly Bill 633.

Thank you for your consideration.