



KEN SKOWRONSKI

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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.



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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.



Rob Gundermann, Public Policy Director
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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.

**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.



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 AAPR 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.

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From: kstark@co.winnebago.wi.us [mailto:kstark@co.winnebago.wi.us]
Sent: Thursday, December 07, 2017 10:13 AM
To: 'Steve.Hall@legis.wisconsin.gov' <Steve.Hall@legis.wisconsin.gov>
Cc: Nagler, Brian <BNagler@co.winnebago.wi.us>; Culp, Beth <BCulp@co.winnebago.wi.us>
Subject: Testimony for 12/12/17

**Assembly Committee on Mental Health
Public Hearing on 12-12-2017**

Representative Tittl, Chair of the Assembly Mental Health Committee

I am submitting my written testimony for consideration at the public hearing on December 12, 2017 to the Assembly Committee on Mental Health.

- **AB-628 - Silver Alert Referral** - This modification to the Silver Alert program ensures that if a credible Silver Alert has been issued the law enforcement agency that has issued the alert for the missing adult at risk, commonly known as a "Silver Alert," to refer the person making the report and any guardian of the missing person to a local Aging and Disability Resource Center. If the subject of such an alert was driving a vehicle when he or she was reported missing, this bill also requires the law enforcement agency to notify the Department of Transportation (DOT). If DOT receives such a notification, DOT must review the driver's license of the person to determine if restrictions should be imposed on the person's license for the safety of the person or the public.

Enacting this referral provision will serve to protect the public by providing a point of intervention to a potentially dangerous driver, and also enable the person driving to be assessed for further assistance from medical and community support services. It is a front-line, logical response to this particular situation.

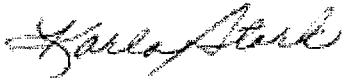
- **AB-630 - Dementia Specialist Certification** - creates a 40-hour voluntary dementia specialist certification program. Prohibits any person from using the title "dementia specialist" or "certified dementia specialist" without the certification.

The key part of this bill is that it prohibits any person from using the title erroneously. The public presumes that if someone uses this title that they have a special knowledge base. This is currently not the case.

- **AB-632 - Alzheimer's Awareness Grants** – Allows the state Department of Health Services (DHS) to distribute up to \$500,000 in grants to community programs across the state to raise awareness for Alzheimer's and dementia resources.

One of the areas identified in recent state sponsored trainings is a lack of awareness of community resources for those affected. When someone receives a diagnosis of a mild cognitive impairment or other type of dementia, they hopefully will seek out information, education and resources. Marketing of ADRC's as a primary point of community/county contact would be a part of this equation, as would having a specific person/persons within that agency as a dementia specialist. As a person serving on a community committee to bring dementia awareness to our area, grant funds would do so much to bring ideas to fruition that would improve the quality of life for not only the person with dementia, but the community as a whole.

This is my testimony sworn and true.



Karla Stark, CSW
Information and Referral Specialist

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"The Best Work of Life, Service to Humanity"

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
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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



December 12, 2017

Chairman Tittl and Members of the Assembly Committee on Mental Health,

Thank you for the opportunity to offer our perspective on the legislative package before you today. Our associations represent skilled nursing and assisted living providers from every corner of Wisconsin.

Wisconsin's long-term care (LTC) providers are in the midst of a workforce shortage crisis that has left skilled nursing and assisted living facilities across the state with fewer frontline caregivers, unfilled staff hours, and an inability to admit new patients or residents. Currently, 1 in 7 caregiver positions remains vacant and 18% of the state's LTC providers report they have been forced to deny admissions in the past year due to insufficient staffing.

We would like to thank those Wisconsin leaders who have taken on the noble task of carrying forward the important work of last session's Speaker's Task Force on Alzheimer's and Dementia. Representative Rohrkaste and Representative Hesselbein, chair and vice chair of the task force, continue to provide great leadership, and Representatives Skowronski and Snyder, along with many others here in this room today, show great dedication to finding solutions to benefit Wisconsin residents who live with dementia.

We believe many of today's bills help advance the quality of life of Wisconsin dementia patients and help provide resources for families and loved ones.

While we appreciate the author's interest in ensuring quality care for dementia patients, we are concerned that Assembly Bill 630 will undermine the care quality that Wisconsin's care providers deliver every day.

The bill as written disregards potentially decades of work experience for current caregivers who are, for all relevant purposes, dementia specialists. AB 630 prohibits anyone who has not completed the training program from using the title "dementia specialist" or "certified dementia specialist". Many caregivers across the state have years of real-life experience working with dementia patients and could probably teach the course. An individual with no on-site experience with dementia patients who completes this training program would be considered a dementia specialist, while a seasoned caregiver with a depth of practical experience who has not completed the training program would not be considered a dementia specialist.

Wisconsin's LTC providers take their responsibility of caring for Wisconsin's most vulnerable residents very seriously. We are committed to providing round-the-clock care to our residents, who deserve the best care quality possible.

Thank you again for your time and consideration of our concerns. We are more than willing to meet with bill authors to discuss these concerns further. Please do not hesitate to contact us with any questions you may have.

Contacts: Sarah Bass – Wisconsin Assisted Living Association: 608.288.0246; sbass@ewala.org
John Sauer – LeadingAge Wisconsin: 608.255.7060; jsauer@leadingagewi.org
John Vander Meer – WHCA/WiCAL: 608.257.0125 john@whcawical.org

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 Titil:

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.

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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
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