



# TERRY MOULTON



WISCONSIN STATE SENATOR

23<sup>RD</sup> SENATE DISTRICT

**From: Senator Terry Moulton**  
**To: Senate Committee on Workforce Development, Military Affairs and Senior Issues**  
**Re: Testimony on Senate Bill 527**  
**Relating to: Grants for Alzheimer's disease and dementia awareness**  
**Date: January 9, 2018**

Thank you Chairman Testin and members for allowing me to testify on Senate Bill 527 today.

Alzheimer's disease is the sixth leading cause of death in the United States and it is the only leading cause of death that has no known cure. Today, in Wisconsin, 110,000 people are living with Alzheimer's and nine new Wisconsinites are diagnosed every day. Unfortunately, all too often, there is a lack of awareness surrounding Alzheimer's and dementia. Many people don't know that they or someone they love is living with Alzheimer's or another form of dementia, and if they do, many don't know where to turn for help.

Senate Bill 527 addresses this problem by allowing the Department of Health Services to distribute up to \$500,000 in grants to community programs across Wisconsin that raise awareness about Alzheimer's and dementia and give families the tools they need to care for their loved ones. By increasing awareness about Alzheimer's we have the extraordinary opportunity to detect the disease earlier, giving families time to explore treatments, plan for the future and help patients maintain independence for longer.

Please vote to recommend passage of Senate Bill 527 and help us give families touched by Alzheimer's the answers they need.

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# MIKE ROHRKASTE

STATE REPRESENTATIVE • 55<sup>TH</sup> ASSEMBLY DISTRICT

## Senate Bill 527

Relating to: grants for Alzheimer's disease and dementia awareness and making an appropriation.

Testimony of State Representative Mike Rohrkaste

Senate Committee on Workforce Development, Military Affairs and Senior Issues

January 10<sup>th</sup>, 2018

Thank you, Chair Testin and members of the Senate Committee on Workforce Development, Military Affairs, and Senior Issues.

As many of you already know, Alzheimer's and dementia affect thousands of Wisconsinites every day. Many of us, including myself, have been impacted on a personal level, as we have had friends, family members, co-workers, or acquaintances either diagnosed with these diseases or are caring for someone living with these diseases. In fact, Alzheimer's is the 6<sup>th</sup> leading cause of death in Wisconsin and is the only cause of death in the top ten that is increasing.

Unfortunately, a very common theme surrounding Alzheimer's and dementia is a lack of awareness. Many Wisconsinites don't know that they or their loved one is living with Alzheimer's or another form of dementia, and if they do know, many don't know where to turn.

Senate Bill 527 directly addresses this problem by allowing DHS to distribute up to \$500,000 in grants to community programs across the state to raise awareness for Alzheimer's and dementia resources. There are many governmental and private resources throughout the state for those living with these diseases and their caregivers. These organizations offer different forms of assistance, but many of our fellow Wisconsinites are not aware of all options. By raising awareness, we are hoping to catch these diseases sooner and also to raise awareness for caregivers, co-workers, friends, and family about the resources available to them when caring for a loved one.

Thank you for your time and I encourage members of the committee to support Senate Bill 527.



Greater Wisconsin  
Agency on Aging Resources, Inc.



January 10, 2018

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

**Medical, Health Care, Research and Public Health Issues**

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



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

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

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

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

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

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

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

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

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



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# WESSELS

LAW OFFICE LLC  
ELDER & SPECIAL NEEDS LAW

January 9, 2018

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

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

Dear Senator Testin and Committee:

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

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

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



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

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

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

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

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

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

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

Very Truly yours,



Carol J. Wessels

Attorney at Law  
Cedarburg, Wisconsin