



**Testimony Provided to  
Speaker's Legislative Task Force on Alzheimer's and Dementia  
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**Chairman Rohrkaste, Vice-Chair Hesselbein, and Members of the Task Force:**

Thank you for inviting me to speak today, and thank you also to Assembly Speaker Robin Vos for calling for this important Task Force. I am Tom Hlavacek, Executive Director of the Alzheimer's Association, Southeastern Wisconsin Chapter. I am speaking today on behalf of the other two Wisconsin Alzheimer's Association chapters, the Greater Wisconsin Chapter and the South Central Wisconsin Chapter. Together we support Alzheimer's Association programs and services, awareness activity, advocacy, and research support in every county of the State of Wisconsin. The full array of programs and services provided by the Association are described in more detail in the packet of information made available to each Task Force member.

It is not an exaggeration to state that Wisconsin, like every State in the US, is facing a crisis when it comes to Alzheimer's disease and related dementias. There are currently over 115,000 people with the disease in Wisconsin, out of 5.3 million nationally, and the Department of Health Services predicts the number in Wisconsin will grow by 68% in less than 20 years to over 190,000. As we shall discuss, this growth is due to several factors including increased longevity, the aging of the 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 interferes 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 6<sup>th</sup> leading cause of death in the United States. There is currently no proven way to prevent Alzheimer's or slow the disease process.

**Diagnosis, Symptoms and Warning Signs**

Until about ten years ago, the only way to make an accurate diagnosis of Alzheimer's disease was through autopsy. Today, with new and advanced diagnostic approaches, the diagnosis can be made with great accuracy in most cases, especially when the person is in the middle or later stages of the



disease. Through the use of advanced scanning techniques it is now possible to see the characteristic plaques and tangles associated with the disease process and which are associated with cell death. Currently in the US, the average age of diagnosis is in the early to mid-70's, the person is in the middle stages of the disease, and the rest of the disease course will take more than seven years until death. 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, when the medications we now have work best, and where the person and their care partners can become better connected to resources and better prepared for the years ahead. Early detection matters.

Epidemiologic studies indicate that 50 percent of affected people are undiagnosed or misdiagnosed, and that an additional number of people who are diagnosed are not told of their diagnosis by the medical provider. These practices and issues reflect the social and medical issues we face today. Stigma keeps people and families from seeking a diagnosis, and a lack of effective treatments results in some doctors not telling patients their findings. The end result, as we will discuss, is that the only way many people with Alzheimer's and dementia are discovered is at the point of crisis.

Symptoms include memory changes that disrupt daily life, challenges in problem solving and planning, difficulty completing familiar tasks, confusion with time and place, new problems with words in speaking and writing, misplacing things and losing the ability to retrace steps, decreased or poor judgment, withdrawal from work or social activities, and changes in mood or personality. Risk factors include age; the presence of co-occurring disorders such as hypertension, diabetes and depression; low education levels; and history of brain injury. Alzheimer's disease is irreversible and always fatal. There is yet to be a first survivor of Alzheimer's disease.

### **Prevalence and Demographics**

The lifetime risk for developing Alzheimer's at age 65 is one in six for men and one in 11 for women, but this changes as we age. By age 85 the percentage of people with Alzheimer's increases to almost 50%.

The disease has a disparate impact on women and minority group members. Women account for two-thirds of all seniors with the diagnosis. After age 71, 16 percent of women have Alzheimer's compared to 11 percent of men. Women in their 60's are about twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer. Not all of the differences in prevalence in women over men can be accounted for by longevity alone. African Americans have approximately twice the incidence of Alzheimer's as Caucasians. US Latinos have 1.5 times the incidence and develop symptoms of the disease, on average, seven years earlier in life. Wisconsin's population is becoming more diverse and with that will come greater numbers of people with Alzheimer's disease.

The greatest impact on the future of Alzheimer's and dementia will be the Baby Boom generation. There are more than 76 million baby boomers, and the oldest, those born in 1946, turn 70 next year. In July 2015, the Lewin Group released a report estimating that in the absence of a disease modifying scientific breakthrough, 28 million baby boomers will develop Alzheimer's between 2015 and 2050, and by 2040, 10.3 million baby boomers will have the disease, nearly twice as many as the total number of people with Alzheimers in the US today.

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.

### **Stigma**

Facing stigma is often a primary concern of people living with Alzheimer's and their care partners. Those with the disease report being misunderstood because of the myths and misconceptions others have about the disease. Stigma around Alzheimer's disease can interfere with receiving an early diagnosis or any diagnosis at all, living the best quality of life possible for as long as possible, making plans for the future, benefitting from available treatments, and developing a support system. When coupled with the isolation described above and the low numbers of people with the disease who have received an accurate diagnosis, it is not surprising that we only learn about many people with diagnosis when a crisis occurs.

### **Family Caregiving**

Studies estimate that Alzheimer's disease is called a family disease, because the chronic stress of watching a loved one slowly decline affects everyone. Eighty percent of people with Alzheimer's live at home and are supported by family caregivers, only 10 percent reside in nursing homes, and only 20 percent are in any publicly funded health or social service program. These numbers indicate that families for people with Alzheimer's definitely care for their own, but not without major economic, physical and emotional costs. In 2014 caregivers of people with Alzheimer's and other dementias provided an estimated 17.9 billion hours of unpaid assistance, valued at \$217.7 billion. This is approximately 46 percent of the net value of Walmart sales, and nearly eight times the total revenue of McDonalds, in 2013.

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 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.

In a very bright spot for Wisconsin, I am proud to share that we are a national leader in Alzheimer's research. We have outstanding researchers in several parts of the State, including here at the UW School of Public Health Alzheimer's Disease Research Center and the Wisconsin Alzheimer's Institute, as well as in Milwaukee at Froedtert and the Medical College, Marquette University and UW Milwaukee, among other research locations. The Alzheimer's Association is the largest non-profit funder of Alzheimer's disease research in the world. We recently released \$20 million in new research grants, bringing to \$80 million the total amount of current actively funded Association research projects. A significant number of Wisconsin Alzheimer's researchers are either now or were in the past Alzheimer's Association research grant awardees, and have been at the front lines of important breakthroughs and scientific advancements. State funding for Alzheimer's research at UW is embedded in the base funding for the system, helping to solidify these studies and ensure they will continue into the future.

### **Difficult Behaviors and Crisis**

As indicated, we only learn about many people with dementia through crisis, and the precipitating factor that leads to crisis for both family and professional caregivers are often the behavioral and psychological symptoms of dementia, or what are sometimes referred to as challenging behaviors, since they are a challenge to everyone involved. These behaviors are not uncommon; in fact the literature indicates that

between 65 and 90 percent of people with dementia will exhibit difficult behaviors at some point in the disease process.

Behaviors oftentimes precipitate interactions between the person with Alzheimer's disease and various aspects of the legal and human service systems. Law enforcement, adult protective services, the courts, public defenders and corporation counsel become involved in incompetency hearings, guardianship proceedings, involuntary treatment and protective placements. These interactions were brought into sharp detail in the 2012 *Fond du Lac County v. Helen EF* Supreme Court decision. The Alzheimer's Association submitted an amicus brief in that case and remains in support of utilizing Chapter 55 as the statutory framework when involuntary treatment and emergency protective placement and protective services are required.

Regardless of the statutory framework, dementia-specific resources for crisis intervention and emergency placement are not sufficiently developed and coordinated to meet the current and emerging needs of people with Alzheimers and dementia. For example, counties have been required under Chapter 55 to develop emergency protective placement capacity for people with dementia and other lifelong disabilities, but in many parts of the State this capacity does not exist. In terms of legal proceedings, there are significant differences in how Chapter 55, and for that matter Chapter 51, are utilized in counties. Significant problems occur between hospital and long term care service providers in this area of concern. In the absence of a clearly defined and strongly supported crisis intervention system, we see too many instances where the situation is dealt with through the use of dangerous antipsychotic medications, all of which carry FDA "black box" warnings against their use in people with Alzheimer's and dementia. While these medications have a limited role in Alzheimer's treatment and care, they are not intended and should not be used as a form of chemical restraint. We also have evidence that alternative methods to behavior intervention work. Wisconsin's recent experience with the CMS National Partnership to Improve Dementia Care in Nursing Homes reveals that in Wisconsin homes, the use of these drugs has significantly been reduced. In the latest CMA Rankings, Wisconsin is the 5<sup>th</sup> best state in the nation in terms of the lowest use of these medications to treat behaviors.

In regard to crisis system reform, the Alzheimer's Association participated in and strongly supported the work of a recent Legislative Council Study Committee chaired by Rep. Dan Knodl and former Rep. Penny Bernard-Schaber that attempted to address these issues. We also strongly support the Department of Health Services attempt to address crisis more broadly through the Plan for a Dementia Capable Wisconsin, which Department staff will describe in more detail next. Both efforts have been laudatory and yet many gaps remain, especially in rural communities, and it is our hope that this Task Force will attempt to address them.

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,
- Family Care MCO's have developed dementia lead staff persons and enhanced the dementia capabilities of their provider networks,

- The Dementia Friendly Communities Toolkit produced by DHS is 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 to the Alzheimer's Association 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.

You will hear more signs of progress in the Department's presentation on our Dementia State Plan. In regard to remaining gaps and concerns, the Alzheimer's Association would like to see:

- The expansion of dementia-capable mobile crisis systems and interventions designed to treat crises in place and minimize to the fewest possible the number of people who need to go through legal interventions and proceedings,
- Expansion and creation of dementia-specific crisis treatment facilities that combine up to date geriatric medical and behavioral interventions, and that are linked to after-care facilities so people do not remain hospitalized longer than necessary,
- Expanded public health efforts that are aimed at early identification and intervention, and that address physician and other healthcare provider education and outreach, as well as the lack of medical professionals in key areas such as Geriatrics,
- Heightened coordination between health and long term care systems, especially in the area of care transitions between hospitals and care facilities.
- Finally we are concerned that changes to Family Care and IRIS in the last State budget could potentially undo progress that has been made in recent years to develop dementia-specific and capable care networks.

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