



Wisconsin Dementia Care System Redesign:

Reflecting on the Accomplishments



Dedication to Secretary Kitty Rhoades

Kitty was a true leader and was committed to the Department of Health Services (DHS) and the citizens of Wisconsin. One of her passions was changing the way state residents with Alzheimer’s disease and other dementias are cared for in Wisconsin. Her legacy includes the redesign of Wisconsin’s dementia care system as well as bringing the Music & Memory™ Program to Wisconsin.

Kitty recognized that the most effective way to make change is by working together and that our collective path to successfully meeting our mission lies in always acting true to our shared conviction. She incorporated this philosophy into the DHS mission and guiding principles and could be frequently heard saying, “We’re all in this together.”

We remain committed to moving forward with Kitty’s vision of redesigning the way we care for people with Alzheimer’s disease and other dementias in Wisconsin.



April 7, 1951 – June 18, 2016

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INTRODUCTION

An estimated 110,000 individuals in Wisconsin have Alzheimer’s disease or a related dementia in 2016.¹ By 2040, that number is expected to grow to 242,000.² The large numbers of people affected, the personal impact on individuals with dementia and their families, and the cost of providing care that can stretch over many years are all compelling reasons for re-examining and improving the dementia care system in Wisconsin.

In 2013, Department of Health Services (DHS) Secretary Kitty Rhoades launched a redesign of the system of dementia care in Wisconsin. It was clear from the start that success would depend on cooperation and coordination among many partners. The redesign effort started with a Dementia Care Stakeholder Summit in October 2013. The summit brought 33 key stakeholders together to identify priorities for moving Wisconsin toward a more “dementia-capable” state. Summit participants identified top strategies that were then used to guide the development of a “[Wisconsin Dementia Care System Redesign Plan](#)” (referred to as the Plan), which was published by DHS in February 2014.

The Plan was developed to serve as a living document, one that would evolve to reflect progress made and lessons learned along the way. In the first two years of implementing the Plan, DHS and its many partners have helped foster a statewide conversation about dementia and stressed the importance of creating dementia-friendly communities, workplaces and living environments throughout the state. While there is much work yet to be done, it is evident that Wisconsin is moving closer to achieving the vision of providing the highest possible quality of life for all Wisconsin residents with dementia. This document highlights some of the many successes so far.

OVERVIEW

The original Plan for strengthening Wisconsin’s dementia care system was organized into five broad categories. This report presents progress in the following key topic areas: community awareness and services, facility-based long-term care, capacity for dementia-related crisis response and stabilization, dementia care guiding principles and training, and research and data.

¹ Alzheimer’s Association. “2016 Alzheimer’s Association Facts and Figures,” pg 20.

² <https://www.dhs.wisconsin.gov/publications/p01159.pdf>

COMMUNITY AWARENESS AND SERVICES

Alzheimer’s disease and other dementias typically progress slowly; people often live with the symptoms of the disease for 10 to 20 years. Individuals with dementia typically spend the majority of this time living at home in the community. As a result, community support is a critical resource in the lives of individuals with dementia and their family caregivers.

The focus of this component of the Plan has been on increasing community awareness and community-based services to help improve the quality of life for people with dementia and their families living in community settings. Outreach under this component has helped foster community conversations about dementia, with the goal of reducing stigma and helping increase community connections and quality of life for people with dementia. The following section describes some of the accomplishments under the Plan and provides examples of ways in which Wisconsin communities are becoming more dementia friendly.

Promoting Dementia-Friendly Communities

Communities that are becoming dementia-friendly are helping to make living with dementia less isolating for individuals with dementia, as well as their family caregivers. Several communities have successfully organized community-wide responses to dementia. Community members have been trained to recognize the signs of dementia, to communicate effectively with people with dementia, and to locate resources for assistance. In order to expand these efforts, state and local public health agencies have become engaged in Wisconsin’s dementia initiative.

In April of 2014, DHS received a one-year grant for the Healthy Brain Initiative from the National Association of Chronic Disease Directors with funding from the Centers for Disease Control and Prevention (CDC). The overall purpose of the grant was to implement local and state public health strategies focused on priority actions from [The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013 – 2018](#). Wisconsin’s project focused on three main areas:

- Creating partnerships with existing Wisconsin dementia-friendly communities.
- Developing a Wisconsin-specific, dementia-friendly communities toolkit.
- Conducting education efforts to promote and engage local health departments in dementia-friendly community initiatives.

The Alzheimer's Association of Southeastern Wisconsin and the American Association of Retired Persons (AARP) were key partners in this project. AARP collaborated with DHS to host three tele-town hall sessions to provide education on dementia and to promote the concept of dementia-friendly communities. These sessions reached over 42,000 AARP members.

In June of 2015, the toolkit for [Building Dementia-Friendly Communities](#) (referred to as the Toolkit in this section) was released. The Toolkit provides information, resources, lessons learned, and steps for building a dementia-friendly community. It is designed to be a user-friendly resource guide for implementing and sustaining dementia-friendly community efforts. The Toolkit also features several Wisconsin communities' dementia-friendly programs. Specific sections include information for use by professionals, businesses, public health, families, and individuals with dementia and include resources and services available from Wisconsin organizations and programs. The Toolkit is unique to Wisconsin, drawing from the direct experiences of local and state partners and agencies that are currently working on projects to improve the quality of life for those with Alzheimer's disease and related dementias and their caregivers.

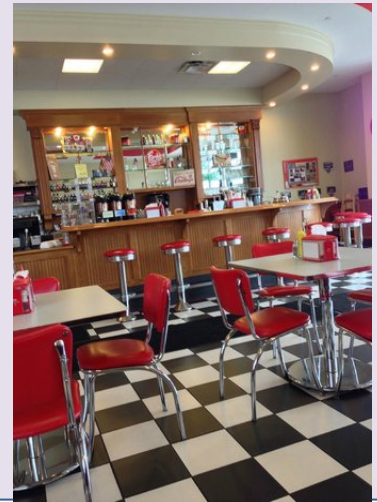
The release of the Toolkit coincided with DHS providing recognition for one of the first dementia-friendly community efforts in the state. The [Fox Valley Memory Project](#) received the Secretary's Award in June 2015, for pioneering work on dementia-friendly communities in Wisconsin. One innovative program that the Fox Valley Memory Project implemented in their region was the Memory Cafe.

Memory Cafes are places where people naturally gather to enjoy social activities, such as coffee shops, restaurants, libraries, nature centers, community centers, places of worship and others. Memory Cafes are not support groups, but are social gatherings convened on a regular basis for people in the early stages of dementia or memory loss and their families and friends. An important part of being a dementia-friendly community is to include people living with dementia and their families and friends in community life. Staying active and engaged is beneficial for people with dementia as well as their caregivers. An important piece of every dementia-friendly community is providing social activities where people can come together without fear of embarrassment from symptoms of dementia.

Ferch's Malt Shoppe & Grille Memory Cafe in Greendale

Ferch's provides a safe and comfortable space, free of charge, in a nostalgic setting where people with memory loss and their caregivers can laugh, learn, and remain socially engaged with others traveling on the same journey. The Wurlitzer Jukebox playing the old '45 tunes, tin ceilings, black and white tile floors, wooden booths and a marble bar with red stools all spark memories for participants in Ferch's Memory Cafe.

When reflecting on her experience, owner Betty Ferchoff stated, "You could see it on their faces as they walked through the door. It brought back those warm memories that they experienced growing up..."



In June of 2015, as part of the Healthy Brain Initiative, DHS awarded 15 one-time mini-grants to local health departments. These mini-grants focused on implementing the strategies laid out in the Toolkit and provided resources needed to address dementia within community health improvement plans. The grants explored public health's involvement with issues related to dementia in the community. They also helped to define the roles of public health in prevention and health promotion, community education, and engagement of coalitions and partnerships. Successes included a variety of local initiatives across the state raising awareness of dementia as a public health issue.

Ozaukee County Dementia-Friendly Community Efforts

The groundwork for Ozaukee County to become dementia friendly was laid out at an aging consortium meeting. The community was invited to hear about the dementia-friendly community initiative. Attendees included senior programs and service professionals, government representatives, caregivers, and advocates.

A workgroup was formed to assess where to start and who to involve. In addition to starting two Memory Cafes, the workgroup addressed the underutilization of the Wanderers Registry, a free service to county residents that includes a database for those who may be at risk if they live alone. The application and information was revised and is now called the Safety Registry and includes all information necessary to issue a Silver Alert, which is a public notification system to broadcast information about missing persons, especially seniors. After crafting new language for the Safety Registry, the county had a 400% increase in people enrolling from 2014 to 2015.



Including local businesses is an important component of creating a dementia-friendly community. Having the distinction of being a dementia-friendly business means that management and frontline employees are trained to recognize and assist customers with dementia. Businesses are also encouraged to consider environmental changes (e.g., lighting, signage, layout) that are sensitive to the needs of people with dementia.

Festival Foods Grocery Store in Eau Claire: A Dementia-Friendly Business

At Festival Foods in Eau Claire, employees are trained on how to assist community members who have dementia. Teresa Henrickson, the assistant store director said they starting to see the impact of the dementia-friendly community training and it is making a difference for customers with dementia. The customers know the store is safe place to shop and that they will receive the assistance they need.



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Henrickson said, “We’re able to give an associate to them and say, ‘Hey, we’re going to help you shop. Let’s just go through the store.’ We go through each aisle and they leave with a smile on their face.”

Expanding the Dementia Care Specialist Program

Aging and Disability Resource Centers (ADRCs) offer the general public a single source for information and assistance on issues affecting older people and people with disabilities, regardless of their income. These resource centers are welcoming and convenient places for people with dementia and their caregivers to get information, advice, and access to a wide variety of services. In 2013, DHS piloted a new program to enhance the capacity of ADRCs to work with individuals and families living with dementia. This program funded Dementia Care Specialist positions in five ADRCs. As part of the Plan, the pilot project was expanded in 2014 to 11 additional ADRCs. Dementia Care Specialist positions were also funded in three Wisconsin tribes to serve the Native American population and in two counties to serve the African American population.

Everyone’s experience with dementia is unique, and connecting people with dementia to a community-based dementia specialist can ensure that supports and services are tailored to the needs of each individual. Dementia care specialists are trained to perform memory screens for individuals to determine a need for clinical follow-up with a primary physician or other health care professional. They also provide information and assistance to people with dementia and

their caregivers and connect them with support and options for home help, long-term care, and other needs.

Dementia care specialists have been effective catalysts in promoting dementia-friendly communities. They work with businesses, employers, local organizations, and the community to increase awareness of the unique needs of individuals with dementia and their caregivers. Dementia care specialists provide community education; mobilize community resources; and consult with law enforcement, adult protective services (APS), crisis response teams, medical providers, and others who need information regarding dementia-related issues. Dementia care specialists facilitate and lead efforts to make local communities safe and welcoming for people with dementia. In 2015, dementia care specialists attended 1,669 community outreach events, reaching nearly 31,000 people.³ Outreach events included health fairs, information booths, public speeches, content-expert presentations, radio shows, and discussion panels.

Dementia care specialists also provide opportunities for individuals and family caregivers to participate in evidence-based programs to improve the experience and outcomes of both caregivers and people with dementia. Two of these opportunities include the Memory Care Connections (MCC) and the Language-Enriched Exercise Plus Socialization (LEEPS) programs. MCC is an evidence-based program (known elsewhere as the New York University Caregiver Intervention program) that provides family caregivers with the tools to care for their loved ones. The MCC program has been shown to help families care for loved ones at home an average of 18 months longer than without the support of the program. The LEEPS program provides opportunities for people in the early stages of Alzheimer's disease or mild dementia to engage in exercise and social opportunities. LEEPS has been shown to help individuals with dementia improve their physical fitness and mood as well as maintain functional ability.

³ <https://www.dhs.wisconsin.gov/publications/p01284.pdf>

Location of Dementia Care Specialists in Wisconsin in 2014



Enhancing the Dementia-Related Services of Managed Care Organizations (MCOs)

Publicly funded long-term care programs, such as Family Care, can also support families in providing care at home. Most Family Care members live in home and community settings, with Managed Care Organizations (MCOs) contracting with a wide variety of care providers. Therefore, MCOs have an important role to play in promoting dementia-capable community services. The MCO is able to ensure appropriate, dementia-capable care for MCO members by using its relationship with its provider network to improve the dementia care available to the community at large.

As part of the redesign effort, each Family Care MCO has designated a dementia care lead who is trained to conduct memory screens and support members with dementia. MCOs have developed screening guidelines to ensure Family Care members are being screened consistently for cognitive issues. The dementia care leads act as internal resources to MCO staff in addressing how to best support members with dementia, their families, and professional caregivers. Each MCO has a dementia initiative work plan that identifies specific interventions, outreach activities, and trainings that will be accomplished each year.

Facilitating Early Identification and Screening

Community-based memory screening can help people take action quickly when they have concerns about memory loss or increased confusion. Memory screening is used to identify deficits in one or more areas of cognitive function including: memory, abstract thinking, attention, and reasoning. Screening can identify early signs of dementia, along with other potentially treatable causes of memory impairment. Facilitating early identification of cognitive issues allows for interventions and lifestyle changes at a stage when they have the greatest potential impact on the disease process.

Hot Air Affair: Increasing Awareness in the Hudson Community

The Hudson Hot Air Affair is the premier winter ballooning event and winter festival in the Midwest. Thousands of visitors head to the St. Croix Valley in west central Wisconsin on the first full weekend in February to enjoy family-friendly events. In 2016, one of the 36 balloons carried the banner, "LIVING with Dementia." The "LIVING with Dementia" balloon sponsors, brought together by the dementia care specialist of the St. Croix ADRC, wanted to share the story of living with dementia through a passenger ride experience.



Craig Smith and his daughter Emily were selected to ride in the balloon but unfortunately, due to weather conditions, the balloons couldn't fly. Instead, Craig, a former firefighter, and Emily were able to participate by riding on a fire truck during the parade and engaging the crowd about the importance of early identification of dementia. Craig, Emily, and Nancy Abrahamson, the dementia care specialist, handed out over 500 postcards at Hot Air Affair events with information on dementia and services available through the ADRC.

By the age of 52, Craig Smith had been diagnosed with frontal temporal dementia, a deterioration of the area of the brain that controls decision-making and behavior. The disease forced him to leave his jobs as an iron worker and volunteer firefighter. However, the disease has not stopped him from remaining engaged and living life to the fullest.

As previously stated, existing resources for memory screening now include ADRC and MCO staff. Additionally, DHS has engaged in information exchanges with Aurora Health Systems and the UW Hospital and Clinics about ways to encourage health care professionals to regularly conduct screenings when memory issues are noted and to provide diagnoses when applicable.

If a dementia diagnosis is obtained, the individual and family can be connected to appropriate services and supports, including the ADRCs.

Providing Support for Family Caregivers

Eighty-three percent of care provided to people with dementia living in the community is provided by unpaid caregivers, most often family members.⁴ Acknowledgement and support for caregivers is essential to the Dementia System Redesign. Family caregivers often lack sufficient understanding to be able to appropriately respond to the needs of a family member with dementia or to recognize their own need for support. Many spouses and adult children whose parents develop dementia do not think of themselves as caregivers. They are often unaware of the physical and mental stress that being a caregiver has placed on them.

The Wisconsin Alzheimer's Family Caregiver Support Program (AFCSP) was created 30 years ago in response to the stress and needs of families caring for someone with Alzheimer's disease or a related dementia. The purpose of AFCSP is to make an array of community services available to families in hopes of relieving some of the stress on caregivers and helping to keep people in their homes as long as possible. Funds are available in each county for qualified individuals to purchase goods and services needed to care for someone with irreversible dementia. Supporting families who provide care for a family member with dementia can help them feel confident and competent in continuing to provide care as dementia progresses.

In 2015, DHS drafted an AFCSP Policy and Best Practices Manual to help support local programs. The new manual provides guidance to county and tribal coordinators about program requirements as well as best practices for reaching out to and serving families of people with dementia. The new manual is currently being updated to reflect changes to the program as a result of legislation passed in March 2016. The new provisions increase AFCSP respite care funding, change income eligibility requirements for participation, and include tribes as administering agencies at the local level.

Caregiving creates many life changes for caregivers. Serving as a caregiver can impact a person's physical health, create financial strain, and increase general stress levels, which can also lead to depression. These changes have the potential to affect an employee's job performance, but with the proper workplace support, employed caregivers can successfully manage both their

⁴ Alzheimer's Association "2016 Alzheimer's Association Facts and Figures," pg 32.

caregiving and workplace responsibilities. With help from many partners, DHS designed a web-based [Dementia-Friendly Employers Toolkit](#) (referred to as the Employers Toolkit in this section) to provide employers with the knowledge and tools needed to successfully support employees caring for a loved one with dementia. The Employers Toolkit explains the benefits that employers gain by being supportive of working caregivers. It includes information on an anonymous survey to help employers gauge the number of working caregivers in a company and offers suggestions for how to meet their employees' needs. The Employers Toolkit also provides a comprehensive list of caregiver support programs and classes available from local Alzheimer's groups, ADRCs, and other local agencies and groups that serve families with dementia. The Employers Toolkit was launched in October 2015 at an [event in Lake Geneva](#) that included Governor Walker, Secretary Rhoades, Former Governor Schreiber, and key partners.

Dementia-Friendly Employers Toolkit in Appleton

The Mayor of Appleton, Tim Hanna, has a personal connection with dementia. Both his sister and his mother were diagnosed with dementia and he has been active as his mother's caregiver and power of attorney for many years. At the Regional Public Meeting for Dementia-Capable Wisconsin in Appleton, Mayor Hanna shared, "I love the fact that we are talking about caring for the caregivers in our workplaces...I've struggled with it personally. I've talked to other people in our workplace that are going through the same thing with siblings or parents or other family members. So to have a resource, a toolkit to use as an employer, it's a very valuable thing and now we need to make people aware of it."

Hanna continued, "There is a stigma around behavior that makes people uncomfortable and stigma around being able to admit that you are caring for someone who has dementia. And we really need to push through that because when we push through that, that's when we rally those resources to provide the best care."



Developing Culturally Competent Innovative Programs

Minority communities are at an increased risk for developing dementia and face unique challenges that must be addressed to ensure that all communities have equal access to appropriate dementia care and services tailored to their needs. The Plan includes a goal of

developing innovative programs for engaging underserved populations and provides specialized dementia programming.

In September of 2014, DHS received two three-year grants from the U.S. Department of Health and Human Services Administration for Community Living (ACL) that support this goal including: the Alzheimer’s Disease Initiative–Specialized Supportive Services (ADI–SSS) grant and the Alzheimer’s Disease Supportive Services Program (ADSSP) grant. The primary focus of the grants is funding activities designed to enable people with dementia to live at home for as long as possible. The grants provide innovative programming and interventions for people with dementia who live alone, the African American communities in Dane and Milwaukee counties, people with intellectual and developmental disabilities (IDD), and caregivers of individuals with challenging behaviors. Interventions include:

- Expanding and enhancing the Share the Care™ program to create networks of family members, friends, neighbors, and volunteers to provide support for people with dementia who live alone.
- Providing outreach, screening, training, consultation, and other support for family caregivers and professional non-medical staff who support people with IDD and dementia.
- Developing awareness and expertise in the medical community concerning diagnosing dementia in individuals with IDD.
- Developing an online behavior management training course for family caregivers.
- Implementing the Music & Memory program (an innovative program that provides personalized music to people with dementia) in tribal community homes.
- Expanding the evidence-based Memory Care Connections program to African American communities.

In 2014, DHS released a competitive grant to fund three tribal dementia care specialists. The Oneida, Menominee, and St. Croix Chippewa were the three tribes who were awarded the funding. The goal of the tribal dementia care specialist project is to develop culturally appropriate dementia care services and family caregiver supports in tribal communities, as well as to aid tribes in becoming dementia capable and dementia friendly. The tribal dementia care specialists also provide support for the Tribal Music & Memory Program and help DHS to better understand dementia in tribal communities.

Engaging Students by Promoting the Department of Public Instruction Dementia Curriculum

A partnership between DHS and the Department of Public Instruction (DPI) resulted in the development of a dementia Brain Health curriculum for middle and high school health classes. The curriculum was piloted in partnership with the Clark Street Community School in Middleton, the Wisconsin Alzheimer's Institute, the DHS Music & Memory program, and the Wisconsin Alzheimer's Disease Research Center. After a successful pilot experience, DPI published the [Brain Health Mini-Unit Guidance Document](#) on their website for use by middle and high schools across the state.

Clark Street Community School Brain Health Curriculum Pilot

The Assembly Speaker's Task Force on Alzheimer's and Dementia, a group of state legislators created to make recommendations on policy initiatives related to dementia, visited a Clark Street Community School classroom to discuss the Brain Health curriculum with the students and teachers. Students shared their experiences with the curriculum and how dementia has touched their lives through members of their families. The principal and teachers described the importance of the curriculum and how community engagement opportunities provided valuable experiences for the students. The final report from the Speaker's Task Force included the recommendation to promote the Brain Health curriculum for use in classrooms across the state.



FACILITY-BASED LONG-TERM CARE

Approximately one in four Wisconsin residents with dementia is cared for in a facility-based setting: a nursing home, community-based residential facility, or adult family home. Residential

care apartment complexes are intended for a more independent population but may admit or retain residents with dementia under limited circumstances.

Nursing homes and assisted living facilities are regulated by the Division of Quality Assurance (DQA) at DHS. The responsibilities of DQA include licensing and certifying facilities as well as conducting periodic regulatory reviews. If problems are found during a review, DQA may require the provider to submit and comply with a plan of correction, obtain consultation or pay a fine or a Civil Money Penalty (CMP). Concern about the potential for regulatory violations and enforcement remedies have created a perceived barrier that prevents some facilities from admitting residents with challenging dementia-related behaviors.

The focus of this component of the Plan has been on identifying, sharing, and implementing promising practices to enhance the overall quality of life for facility residents with dementia. In addition, the Plan concentrates on identifying key factors leading to citations and providing guidance on how to prevent or reduce them.

Addressing Citations and Guidance on Reducing Their Incidence

To help address the barriers that may deter some facilities from admitting and providing ongoing care for residents with dementia who exhibit challenging behaviors, DQA developed strategies and best practice guidelines. These guidelines identify what facilities can do to provide good care, meet the needs of residents, and avoid the type of violations that typically result in enforcement action. DHS published the themes and guidance in [Nursing Home Strategies to Enhance Quality of Life for Residents with Dementia](#) and [Assisted Living Strategies to Enhance Resident Care](#).

Promoting Promising Practices in Facility-Based Care for Individuals with Dementia

DQA encourages nursing homes and nursing home stakeholders to apply for grants of Civil Money Penalty (CMP) funds to use for projects that will benefit nursing home residents. Grants are available to qualified entities to fund proposals designed to improve the quality of life, care, and treatment of persons living in Wisconsin nursing homes.

Recommendations for CMP-funded grants are made to the Secretary of DHS by the [Quality Assurance and Improvement Committee \(QAIC\)](#). QAIC is a cross section of long-term care stakeholders appointed to the Committee by the Secretary and includes nursing home staff members, nursing home residents, advocates, trade representatives, physicians, and nurses. DHS staff worked with QAIC, nursing home representatives, and other stakeholders to

encourage and facilitate requests for CMP money to fund training and programs to benefit nursing home residents with Alzheimer’s disease or related dementias.

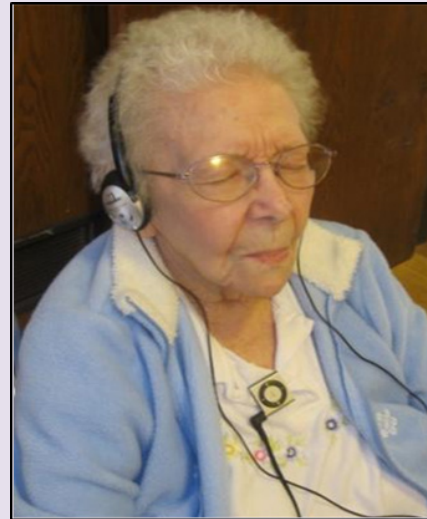
DHS used CMP grant funding to create and expand the Wisconsin Music & Memory program to bring personalized music to individuals diagnosed with Alzheimer’s disease and related dementias. Wisconsin’s program is based on the Music & Memory™ program founded by Dan Cohen in New York. Facility staff members work with family caregivers to create a personalized music playlist on an iPod for each person with dementia who chooses to participate. Personalized music provides an enjoyable activity for people with dementia, increases cooperation and attention, reduces resistance to care and agitation, enhances engagement and socialization, and provides a valuable tool to reduce reliance on antipsychotic medications.

The program has been expanded to over 300 Wisconsin facilities certified in Music & Memory™ serving over 3,500 people in nursing homes and assisted living communities. The success has spurred other states to promote similar programs. The [Wisconsin Music & Memory](#) program website provides more information.

Music & Memory with Margaret

Margaret’s days in the nursing home were often spent in her room alone. During her activity interview, she only expressed that she had a passion for music.

Her life changed after she was enrolled in the Music & Memory Program. When Andrea Bocelli began to sing in Italian, Margaret’s world stopped as her eyes shut and her head and body moved to the music. She went from spending time alone in her room, to visiting and being social during each meal. Margaret said, “Music makes me feel dreamy, you know, nice. It sends me, it’s like I’m gone with the music.”



CMP grants were provided for the following additional programs to help improve care and services for nursing home residents with dementia as well as reduce the use of antipsychotic medications:

- Chair Yoga program: Yoga poses are done seated on a chair or the chair is used for support during standing and balancing poses

- Namaste Care: End-of-life care for people with advanced dementia based on loving touch, aroma therapy, and other strategies to improve quality of life
- SNOEZELEN Multi-Sensory Environment room: A relaxing space that helps reduce agitation and anxiety, increase engagement, stimulate reactions, and encourage communication for the person with dementia
- Training for nursing home staff to increase skills and competency in approaches to prevent and manage residents with challenging behaviors
- Developing and implementing a comprehensive train-the-trainer education program regarding sexuality and intimacy in dementia care
- Dementia-related training for facility staff, using the curriculum developed by the UW-Oshkosh Center for Career Development & Employability Training (UWO-CCDET)

Efforts by Wisconsin nursing homes to become more dementia capable are exemplified by Wisconsin being one of the states leading the nation to reduce antipsychotic medications for residents with dementia. In a [report](#) on the third quarter of 2015, the [National Partnership to Improve Dementia Care in Nursing Homes](#) shows Wisconsin ranked sixth lowest in the nation in the use of antipsychotic medications for nursing home residents.

DHS staff members from the Dementia Care System Redesign team have visited seven nursing homes identified as providing high-quality dementia care to learn about their programs, innovative practices, and suggestions for improving the system. The facilities visited included private for-profit, not-for-profit, and publicly owned homes. Each visit included a tour of the facility and an open-ended discussion with facility staff to gain their perspectives on how best to care for elders with dementia. A number of promising practices were identified, with the overriding principle being a facility culture that is conducive to providing quality dementia care. These practices included: hiring caregivers who are empathic, patient, and flexible; involving direct care staff in decisions about resident care; addressing the underlying cause, rather than focusing on control of behaviors; recognizing and planning for the fact that many residents with dementia may have incidents of challenging behaviors; having regular access to psychiatric and behavioral consultation; and having crisis plans in place.

CAPACITY FOR CRISIS RESPONSE AND STABILIZATION

The Plan noted gaps in the current care delivery infrastructure in crisis response for people with Alzheimer’s disease and related dementias. The Dementia Crisis Response Team focused on creating a model for dementia-capable mobile crisis response that includes treating people in place when possible, clarifying roles and responsibilities for crisis response and stabilization,

and addressing the need for appropriate placement options for people with dementia in crisis. Dementia-capable crisis response also requires a care system that is built around having trained staff and using care planning as a crisis prevention strategy to increase the success of stabilization efforts and reduce relocations of individuals during crisis.

Learning from Local Efforts

DHS staff consulted with counties and county consortia and visited long-term care facilities to learn about local efforts and challenges. These interviews helped guide the development of two surveys that were conducted to gain a better understanding of current practices across the state.

In November 2014, DHS received survey responses from 54 county crisis units regarding their capacity for responding to crises that involve people with dementia. A report titled, [Wisconsin's Crisis Response System: Capacity for Serving Persons with Dementia](#), summarizes the status of crisis programs in the responding counties and provides information about training and resource needs for serving people with dementia in crisis. The key takeaway from the survey is that county crisis units are ill prepared because they lack dementia-specific training, tools to screen or assess people in crisis for dementia, clinicians who specialize in aging or care of older adults, and stabilization facilities for people with dementia in crisis.

In February 2015, DHS received survey responses from county adult protective service (APS) units in 72 counties and one tribe regarding how emergency protective placements are used for people with dementia. A report, [Chapter 55 Emergency Protective Placements for Persons with Dementia in Crisis](#), was written based on survey responses. The report describes the results of the survey and how DHS will use the results to identify what is working well and where to focus efforts to improve the dementia capability of Wisconsin's crisis systems. The key takeaway is that almost all counties (90%) reported they do not have access to a sufficient number of facilities willing to accept emergency protective placements of people with dementia exhibiting challenging behaviors.

The results indicate that dementia-related crisis response varies considerably, with approaches differing in terms of agency configuration, relationships among partners, and the level of dementia expertise and capacity in the crisis response system. Effective solutions, when found, have been developed locally, and have typically involved cooperation among a variety of stakeholders including county APS and crisis response systems, care facilities, law enforcement, managed care organizations, and others. Also important are adequate training, an understanding that behavior is often a way to communicate needs, and planning with

prevention in mind. The findings from both surveys have helped inform the need for continuing local collaborative efforts to address problems related to responding to people with dementia in crisis and to emergency protective placements for this population.

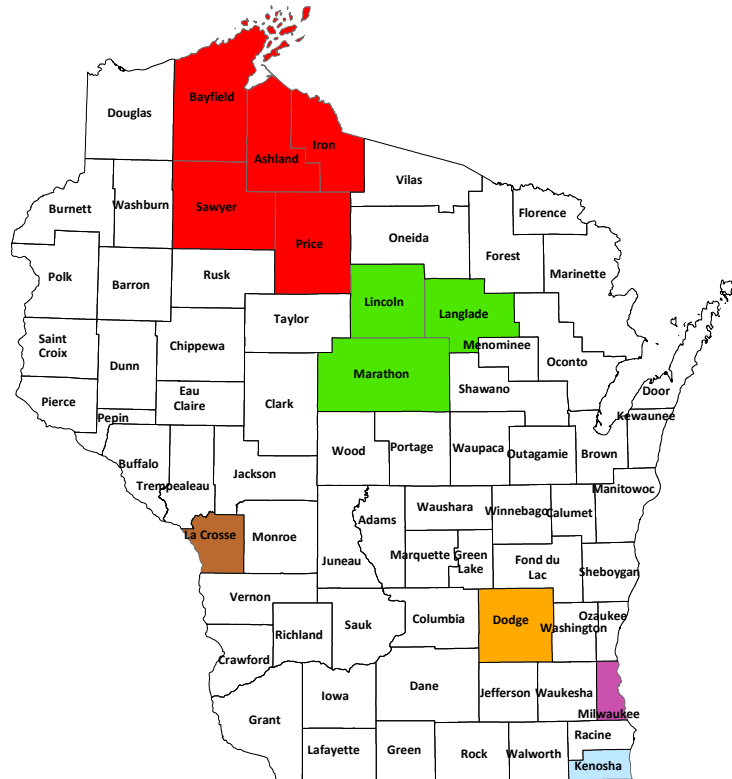
Building Collaborative Dementia-Capable Crisis Response

In October 2015, DHS offered a competitive funding opportunity for interested counties or consortia with a goal of building a more dementia-capable crisis response system. The applicants were encouraged to develop systems that would create the following in their proposals:

- A coordinated, dementia-capable approach to supporting people with dementia in crisis.
- An understanding of how to assess and plan for people with dementia as a way to avoid or de-escalate crises.
- Shared strategies to anticipate and capably respond to a crisis in the best interest of the individual.
- Local and regional care and crisis systems that emphasize stabilization-in-place and use emergency transfers as a last resort for people with dementia in crisis.
- Collaboration, communication, and trust among all parties who have a role to play in responding to and caring for people with dementia in crisis.

Six grantees, representing 12 counties, were awarded funds.

Counties and County Consortia that Received Dementia Crisis Innovation Grants



GUIDING PRINCIPLES AND TRAINING

In order to have a dementia-capable system of care, the Plan recognized that there must be a widely shared understanding of what constitutes appropriate and high-quality care for people with dementia. It is also important for providers to subscribe to that shared vision and to have a competent, well-trained workforce to provide needed care.

The Guiding Principles were developed through a contract with the UWO–CCDET. The project included a review of international and national standards as well as a process to gather ideas from Wisconsin stakeholders. The Guiding Principles supplement existing resources and provide common terminology and values that can be shared across stakeholder groups.

In May 2015, DHS finalized 10 principles for use in guiding the Wisconsin Dementia Care System. The [Wisconsin Dementia Care Guiding Principles](#) describe the values and practices necessary to provide high-quality, effective care and support for all people living with dementia. They also include a strong emphasis on prevention or mitigation of crisis situations that may

arise, and on the importance of consumer awareness, person-centered care, and community engagement.

In addition to posting the Wisconsin Dementia Care Guiding Principles booklet and an accompanying poster of the Ten Guiding Principles on the DHS Dementia-Capable Wisconsin website, DHS held regional presentations in the fall of 2015. The purpose of these presentations was to increase awareness of the Guiding Principles and other resources, to facilitate the sharing of stories of the Guiding Principles in action in communities around the state, and to promote grassroots engagement in making communities dementia-friendly.

O’Connell Pharmacy Adopts the Wisconsin Dementia Care Guiding Principles

O’Connell Pharmacy in Sun Prairie includes a retail location and a long-term care pharmacy, both with the mission to keep people at home and independent for as long as possible. O’Connell Pharmacy incorporated the Wisconsin Dementia Care Guiding Principles into their business model to better achieve this mission. By having the majority of their staff trained in dementia-friendly principles, they are able to serve their customers better and promote community awareness.

Their pharmacists are able to screen for cognitive impairment and refer to primary care physicians or specialized memory clinics, if needed. The pharmacy supports maximum independence and choice through their prescription delivery service,



monthly medication sync program, “med box” program, and medication therapy management. These programs have shown improvement in medication adherence and health outcomes for patients. O’Connell Pharmacy provides individualized care and services by being flexible in regard to patients’ needs and coordinates with local organizations to provide additional services.

DHS also contracted with the UWO–CCDET to create affordable and accessible dementia care training for a wide audience including: family caregivers; community members; nursing home and assisted living facility staff; police, fire and emergency personnel; and county crisis workers. After receiving extensive stakeholder input and working with a group of experts, UWO–CCDET initiated the creation of [online dementia trainings](#) on a variety of topics and a registry to record people who have successfully completed the trainings.

Recognizing that many additional training opportunities are needed for professionals and family members who care for with people with dementia, DHS created a catalog of dementia trainings

and posted it to the [Dementia-Capable Wisconsin website](#) in the form of a searchable list. For each of the trainings included on the list, there is a brief description of the intended audience, content, cost, availability, and contact information. The intended audiences include professionals in health care, social services or public health; paid caregivers; family caregivers; guardians (corporate, volunteer or family); powers of attorney; law enforcement, adult protective services, and other crisis workers.

Trainings are updated as new information fitting these requirements is submitted to DHS.

RESEARCH AND DATA COLLECTION

The Plan identified the need for data collection to facilitate quality measurement related to dementia care. The initial step was to estimate the Wisconsin population with dementia and identify the subset of that population served by Wisconsin's Medicaid program. A summary of the findings titled, [Dementia Care System Redesign Data: Estimated and Projected Wisconsin Dementia Population](#), was published on the DHS website.

DHS also developed measures to monitor the impact of the dementia initiative. These measures included psychotropic medication use, hospitalizations, long-term care enrollment, and moves in and out of institutional and residential placements. For each measure, baseline data was analyzed and will be compared to data collected on a yearly basis.

CONCLUSION

The accomplishments described in this document highlight only some of the many achievements across the state. Since the Plan was initiated in 2013, these efforts have helped improve the quality of life and care for individuals with dementia. The momentum from the expanding conversation and focus on increasing Wisconsin's dementia-capability continued to grow into the creation of the Speaker's Task Force on Alzheimer's and Dementia.

Looking Ahead: The Wisconsin Cares Legislative Package

The Speaker's Task Force on Alzheimer's and Dementia, created in 2015, highlighted the need for education and resources for individuals with dementia and their family caregivers. This legislative group conducted public hearings throughout Wisconsin, resulting in the introduction of 10 dementia-related bills named the Wisconsin Cares Legislative Package. Out of the 10 Wisconsin Cares bills, three of them were passed by the Legislature in 2016 and signed into law. The Task Force published a [Report of the Speaker's Task Force on Alzheimer's and Dementia](#) that summarizes the work of the Task Force and includes recommendations for future legislative action.



DHS would like to thank all of the community partners and stakeholders for their many contributions in promoting the development of a more dementia-capable system of care in Wisconsin. Many exciting changes are happening in our state to reach our goal of every person with Alzheimer's disease and dementia having the highest quality of life possible in Wisconsin. We are all in this together and DHS looks forward to future collaboration in the coming years with partners and stakeholders in this exciting endeavor.