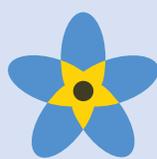




# Dementia Friends Wisconsin: A Guide for Getting Started



**Dementia  
Friends  
Wisconsin**   
A Dementia Friendly America initiative



**Wisconsin Alzheimer's Institute**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH



Wisconsin Alzheimer's Institute  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

# Dementia Friends Wisconsin: A Guide to Getting Started

©2019 Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health

This guide is a product of the Wisconsin Dementia Resource Network (WDRN), a statewide collaboration led by the Wisconsin Alzheimer's Institute at the University of Wisconsin School of Medicine and Public Health, with funding support provided by The Helen Daniels Bader Fund of Bader Philanthropies, and the University of Wisconsin School of Medicine and Public Health.

**Primary Author:** Kate Kowalski, Education Outreach Manager, Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health

**Contributing Author:** Kathleen Smith, Rural Outreach Manager, Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health

**Layout and Design:** Heidi Pophal, Education Program Manager, Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health

**Contact information:**

Wisconsin Alzheimer's Institute

610 Walnut Street, Suite 957

Madison, Wisconsin 53719

Phone: 608-265-3885

Fax: 608-265-9122

Email: [kmkowalski@wisc.edu](mailto:kmkowalski@wisc.edu)

Web: [wai.wisc.edu/publichealth/guides.html](http://wai.wisc.edu/publichealth/guides.html)

# Dementia Friends Wisconsin: A Guide to Getting Started

**Spring 2019**

History of the Dementia Friends Program.....	4
Overview of the Dementia Friends Program .....	5
What is a Dementia Friend?.....	5
How Do I Become a Dementia Friend?.....	6
What Happens at a Dementia Friends Information Sessions? .....	6-7
What is a Dementia Champion?.....	8
Should I Become a Dementia Friend or a Champion?.....	9
Getting Started with Dementia Friends in Your Community .....	9
What Happens During Champions Trainings?.....	10
I've Been Trained as a Champion, What Happens Next? .....	10
How Are Champions Supported? .....	11
Engaging Youth to Become Dementia Friends .....	11
Engaging Diverse Communities .....	11-12
Dementia Friends in Communities that are Already Dementia Friendly .....	12
Master Trainer Comments.....	12
Summary .....	12



The information contained in this guide is adapted from resources made available through Dementia Friends USA, ACT on Alzheimer's, and the global Dementia Friends network.

[dementiafriendsusa.org](http://dementiafriendsusa.org)  
[www.actonalz.org](http://www.actonalz.org)  
[www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

## History of the Dementia Friends Program

Dementia Friends is a global social action movement established with the goal of changing the way people think, act, and talk about dementia. Inspired by Japan’s Dementia Supporters program, the Alzheimer’s Society developed Dementia Friends in the United Kingdom following a 2012 survey of 850,000 people living with dementia. The survey indicated that 61% of respondents believed their community did not understand how to help them live well with dementia. Respondents further indicated a need for “better understanding and less social stigma”; “more public awareness of the condition”; “more activities /opportunities to socialize”; “more tolerance and patience”; and “more community spirit.” The survey led the Alzheimer’s Society to develop the Dementia Friends program and curriculum to raise awareness, reduce the stigma of dementia, and encourage individual action.

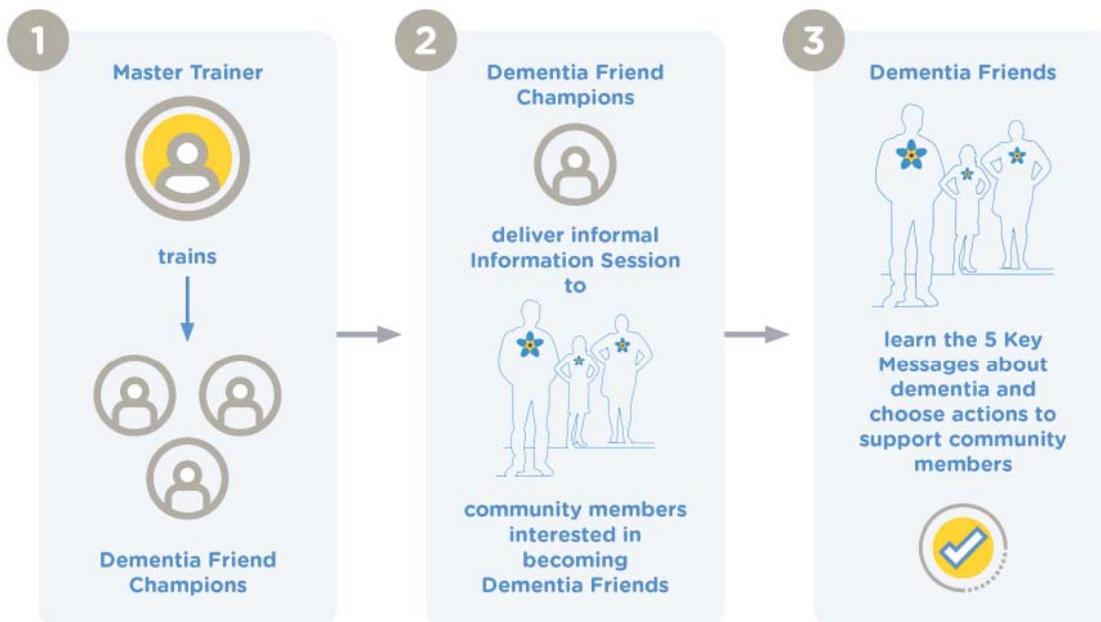
With the success of Dementia Friends in the UK, the Alzheimer’s Society made a commitment to share the program with other countries interested in adopting it. As of 2019, **36 countries** comprise the Global Dementia Friends Network, with nearly **15 million Dementia Friends worldwide**.



The Dementia Friends Program was initially brought to the United States in 2015 by the state of Minnesota as part of the state’s ACT on Alzheimer’s Initiative. Given Minnesota’s success, the National Association of Area Agencies on Aging (n4a) formed a license agreement with the Alzheimer’s Society in 2017 allowing n4a to make the program available in the United States as part of their oversight of Dementia Friendly America. In spring of 2018, the Wisconsin Alzheimer’s Institute (WAI) at the University of Wisconsin School of Medicine and Public Health submitted an application to become the licensee for the State of Wisconsin. Only one organization per state is allowed to host Dementia Friends on behalf of the state. Before applying, WAI consulted with numerous partners and stakeholders to ensure consensus that WAI was the appropriate organization to host the program. With the overwhelming support of stakeholders, WAI was granted the license for Wisconsin and the Dementia Friends initiative was launched in the fall of 2018. As of early 2019, 20 states have adopted Dementia Friends nationwide.

## Overview of the Dementia Friends Program

The Dementia Friends Program engages individuals interested in improving the lives of people living with dementia in their communities. Where many dementia friendly community efforts focus on training businesses, government entities, and community-based organizations, Dementia Friends is designed for individual community members. Here's how it works... using a train-the-trainer approach, a select group of Master Trainers train Champions to provide informal, no-cost, in-person Dementia Friends Information Sessions to interested community members. Champions are provided access to all of the materials necessary to conduct the Information Sessions in their communities.



The purpose of this guide is to offer an overview of the Dementia Friends Wisconsin initiative and to help those interested in bringing the program to their communities. The guide will provide a thorough explanation of the program and step-by-step information for getting started. To learn more, visit the Dementia Friends Wisconsin website at [www.wai.wisc.edu/dementiafriendswi](http://www.wai.wisc.edu/dementiafriendswi), or contact the state leader for Dementia Friends Wisconsin at [kmkowalski@wisc.edu](mailto:kmkowalski@wisc.edu).

## What is a Dementia Friend

Being a Dementia Friend means being part of a global movement to help communities become more friendly, welcoming, and respectful places for people living with dementia. By taking the time to attend an Information Session, understand the content, and identify a personal action, individuals are demonstrating their commitment to making a positive difference in the lives of people living with dementia in their communities. Virtually anyone, young to old, can become a Dementia Friend.



## How Do I Become a Dementia Friend?

There are two ways to become a Dementia Friend. The preferred way is to attend the one-hour in-person Dementia Friends Information Session described earlier. Wisconsin has a rich and growing network of Dementia Champions who have been trained to conduct these informal sessions.

For those unable to attend an in-person session, the other option is to go online at [dementiafriendsusa.org](http://dementiafriendsusa.org) and watch a series of videos that provide information about dementia, how to recognize the signs, and ways people can help.



## What Happens at a Dementia Friends Information Session?

During the one-hour Information Sessions, individuals becoming Dementia Friends learn the following:

- 5 Key Messages about dementia
- 10 Early Signs and Symptoms of Alzheimer's ([www.alz.org/alzheimers-dementia/10\\_signs](http://www.alz.org/alzheimers-dementia/10_signs))
- Communication strategies
- Community resources available to assist people with dementia and their care partners
- Ways they can make a difference in the lives of people living with dementia

Information Sessions are not formal trainings. Rather, they are gatherings of community members interested in making a difference. The format includes presentation, discussion, and activities. Information Sessions can be held for groups of varying sizes and age groups. Specially adapted materials are available for young people in grades 2-6, and for middle and high school grades 7-12. Materials have also been translated into Spanish, Portuguese, Mandarin, and Hmong. Additionally, there are suggestions for adaptations for Tribal and African American communities.

At the end of a Dementia Friends Information Session participants are asked to commit to one action they will take to make a difference in their community. The actions are determined by each individual based upon their own interests, abilities, and time. All actions can make a difference and no action is too small. On the following page are examples of actions people in Wisconsin have committed to thus far. Together we can all make a difference!

*“The Dementia Friends Information Session not only provides an educational opportunity for the general public to learn about dementia and the 5 key messages, but is a powerful ‘call to action’ for all that attend. There is a definite benefit in providing dementia awareness and education, but empowering people to make a commitment to making real change is what makes Dementia Friends exceptional. The Dementia Friends Information Session has replaced my community Dementia Awareness presentation.”*

Randy Kohl, MS, CTRS, CPRP, CBIS  
Dementia Care Specialist, Waukesha County ADRC

## Examples of Actions Committed to by Dementia Friends in Wisconsin

- Give a smile and say “hello” to someone with dementia
- Help others learn to communicate, understand verbal and non-verbal communication with someone with dementia
- Make a purposeful effort to spend more time with individuals with dementia, engaging them in social and recreational activities
- Tell people about resources for dementia
- Inform caregivers of the resources to help with caregiver burnout
- Encourage people to educate themselves on dementia and take time to know someone with dementia
- Reach out to a new caregiver whose mom was recently diagnosed with support, resources, and listening ear
- Be an advocate for someone living with dementia
- Support and educate my friend whose father has dementia
- I will call my grandma who has dementia more frequently
- Try to start a conversation with church community regarding supporting parishioners living with dementia
- Tell one other person what I learned here today
- Share and promote the 5 Key Messages
- Bring Dementia Friends to our county
- Provide information to my ADRC committee
- Educate others about Dementia Friends
- Learn more about becoming a presenter and getting trained to offer presentations in the community



- Campaign for change by participating in local advocacy events
- Volunteer/join an organization in my community
- Talk about Dementia Friends with community partners
- Support dementia friendly efforts in my community
- Promote dementia friendly business training in my community
- Continue to teach local businesses about being dementia friendly; reach out to schools about Dementia Friends

## What is a Dementia Champion?

Dementia Champions are professionals or volunteers trained by Master Trainers to offer the one-hour in-person Information Sessions. The goal of the Information Session is to encourage participants to understand dementia and to take action to help their communities become a more welcoming place for people living with dementia. During the training, Champions are provided all of the materials they will need to conduct the Information Sessions. The Master Trainer will also model an Information Session, providing tips and suggestions along the way, so Champions are not only hearing about, but experiencing the material presented. Following the training, participants register themselves as Champions on the Dementia Friends Wisconsin website, after which, they are sent a link to all of the materials needed to conduct their own Information Sessions.

Champions agree to:

- Act as an ambassador for Dementia Friends and support the program throughout their networks and communities
- Conduct a minimum of 2 to 3 Dementia Friends Information Sessions per year
- Follow the training guide and materials provided by the Wisconsin Alzheimer's Institute
- Adapt the "Resources in Your Community" section of the workbook to reflect local resources
- Maintain logos of Dementia Friends Wisconsin and the Wisconsin Alzheimer's Institute on the shared materials. Sponsoring agencies and organizations are encouraged to add their logos
- Report completed Information Sessions, including the number of Dementia Friends engaged, on the Dementia Friends Wisconsin website



*"As people in community, we rely on the everyday kindness shown by others to have a more positive day. We can quickly feel when people are irritated or impatient with us. This is where the Dementia Friends key messages and information can make such an impact. Someone doesn't have to own a business or be part of an organization to get involved, raise awareness, and take action. It is a personal response and a vital part of dementia friendly communities."*

Kathy Jeans Glaser  
Dementia Care Specialist, Aging and  
Disability Resource Center of Ozaukee County



## Should I Become a Dementia Friend or a Champion?

A key consideration for deciding whether to become a Champion or a Dementia Friend is the level of commitment you feel you can realistically make. As previously discussed, there are specific expectations of Dementia Champions. Another consideration is your personal comfort level with public speaking. The materials include a step-by-step comprehensive guide that will walk you through the session, but it's helpful to feel at least somewhat at ease speaking to a group. A good way to determine if becoming a Champion is right for you is to start by participating in a Dementia Friends Information Session and observing the Champion in action. If you can see yourself as a Champion and feel you have the time to commit to arranging and conducting Sessions, then definitely sign up for a Champions training.

## Getting Started with Dementia Friends in Your Community

The first step to bringing the program to your community is to identify a Master Trainer to train Champions. Wisconsin has taken a unique approach to the role of Master Trainers relative to other states. Where most states assign a very limited number of people as Master Trainers, Wisconsin has an expansive team of individuals trained as Master Trainers to assure comprehensive availability of Dementia Friends across the state. A list of Master Trainers, their contact information, and the geographic regions and program sectors they cover, can be found on the Dementia Friends Wisconsin website at [www.wai.wisc.edu/dementiafriendswi](http://www.wai.wisc.edu/dementiafriendswi).

Once you review the list and identify a Master Trainer for your community, you are encouraged to contact that individual to discuss a Champions training. Details to address will include:

- Number of Champions to be trained
- How Champions will be identified
- Who will handle the logistics (scheduling, location, registration, printing materials, and other details)

Once these details are sorted out, the Master Trainer can move ahead with conducting the Champions training with interested volunteers.



## What Happens During Champions Trainings?

Champions trainings follow a structured curriculum and typically last approximately one-and-a-half to two hours. The trainings include the Master Trainer(s) modeling a Dementia Friends Information Session, including tips and suggestions for hosting successful sessions. Champions are provided with the following materials during the training:

- Dementia Friends Wisconsin Champions Guide, a 33-page detailed document that provides information necessary to successfully conduct Information Sessions in their communities
- An 8-page Information Session Workbook to be given to Information Session participants
- An abbreviated Participant Packet that can be used as an alternative to the 8-page Workbook
- Other materials to assist with the session (eg: signs, certificates, action slips, business cards, etc.)

Newly trained Champions are asked to register as Champions on the Dementia Friends Wisconsin website at [wai.wisc.edu/dementiafriendswi](http://wai.wisc.edu/dementiafriendswi), and to commit to holding 2-3 Information Sessions in their communities. Once registered, Champions receive an email that includes a link to the curriculum materials needed to conduct Information Sessions. At that point, Champions will be equipped to schedule and present their own sessions.

*"I have been implementing Dementia Friends Information Sessions as a means to recruit Champions and have taught the course independently and with Kate Kowalski. I became a Master Trainer to educate communities in addition to pre-health profession students."*

Sue Wenker, PhD, PT  
Professor, Department of Family Medicine and Community Health,  
University of Wisconsin School of Medicine and Public Health

## I've Been Trained as a Champion, What Happens Next?

Once trained and registered on the Dementia Friends Wisconsin website, Champions are welcome to begin scheduling Information Sessions. Sessions can either be public, meaning they are open to all community members, or private, for specific groups or audiences. For public sessions, it will be important to consider a marketing plan for making the public aware of what a Dementia Friends Information Session is, how to register, and the logistical details regarding time and location. Public Information Sessions can also be registered on the Dementia Friends Wisconsin website. In this case, individuals seeking to find an Information Session will know when and where they are being offered around the state. In order to post a public Information Session on the website, Champions complete a simple online form at [wai.wisc.edu/dementiafriendswi](http://wai.wisc.edu/dementiafriendswi).

Champions are also welcome and encouraged to inform existing community groups of their availability to conduct private Dementia Friends Information Sessions for their members. Examples of groups may include civic organizations, faith communities, book clubs, school groups, youth organizations, scouts, arts organizations, and the like.

## How Are Champions Supported?

As previously mentioned, Champions receive access to all of the materials necessary to provide Dementia Friends Information Sessions in their communities. Key to these materials is the Champions Guide. This 33-page document provides step-by-step instructions to guide Champions through Information Sessions. Champions' names are also added to a dedicated listserv that has been set up to facilitate communication and resource sharing. Quarterly conference calls are an additional support mechanism. Finally, the statewide lead for Dementia Friends Wisconsin, Kate Kowalski, is available to respond to individual questions or concerns. Kate can be reached via email at [kmkowalski@wisc.edu](mailto:kmkowalski@wisc.edu).



## Engaging Youth to Become Dementia Friends

Many people around the world are finding Dementia Friends to be a wonderful way to engage youth to learn about dementia and the small actions they can take to make a positive difference in the lives of people living with dementia. The Dementia Friends program offers specialized curriculum materials that have been adapted for youth in grades 2-6, and for older grade levels, 7-12. Like the main curriculum, the youth-specific materials provide step-by-step instructions for hosting Information Sessions for these younger audiences.

*“The Dementia Friends Information Session has been a wonderful tool as I work with high school students. It provides a great introduction to dementia while creating awareness, building empathy and involving the students in a national effort. Students are able to not only take the information they learn home to share with their families but also into their careers. The call to action component of the session is a great way to empower students to get involved in the capacity that they feel comfortable, which may include volunteering with a Music & Memory Certified organization.”*

Julie Hyland  
Director, Wisconsin Music & Memory Student Program

## Engaging Diverse Communities

Since bringing Dementia Friends to the United States, Dementia Friends USA has worked to provide culturally-tailored adaptations to the Dementia Friends curriculum. This includes collaborating with a number of states to translate the curriculum materials into Spanish, Portuguese, Hmong, and Mandarin. In addition to the language translations, there are suggestions offered for adapting the Information Sessions and/or



materials to be more culturally relatable for Native American and African American communities. These tips and adaptations are addressed as part of the Champions training, and all Champions are encouraged to consider them when introducing Dementia Friends especially within underrepresented communities.

## **Dementia Friends in Communities that are Already Dementia Friendly**

Numerous Wisconsin communities are already advanced in their dementia friendly efforts, making some people wonder whether Dementia Friends would be of benefit. The answer among those who have already adopted the program is a resounding “yes.” While some communities introduce Dementia Friends as a first step to becoming dementia friendly, the program can also be a useful additional tool for communities already engaged in dementia friendly efforts. Where many of these initiatives focus on training businesses and government entities, Dementia Friends engages individuals wishing to make a positive difference. It is also effective for introducing dementia content to young people who might not otherwise be included in dementia friendly community programs.

*“I think this is a great first step on the journey to creating a Dementia Friendly Community! There are so many big goals to achieving public awareness and creating a friendly community, and the Dementia Friends initiative is a perfect starting point for people to become more aware and contribute to the cause in an easy, duplicable format.”*

Kelsey Flock, CTRS  
Dementia Care Specialist, La Crosse County ADRC

## **Master Trainer Comments**

One of the many things people like about Dementia Friends is that a curriculum is provided. This allows those interested in the program to adopt it with relative ease. The Champions guide provides step-by-step instructions for hosting Information Sessions, and Master Trainers offer guidance based upon their own training, expertise, and experiences. In bringing Dementia Friends to Wisconsin, the Wisconsin Alzheimer’s Institute has been intentional in inviting partners from across the state to become Master Trainers in order to reflect the geographic, cultural, and programmatic diversity of Wisconsin. WAI encourages Master Trainers to engage and train a diverse pool of Champions to introduce the program in their home communities.

Throughout this guide are comments from several Wisconsin Master Trainers regarding their rationale for implementing Dementia Friends, along with their personal perspectives on how they are or plan to employ the program.

## **Summary**

As more Wisconsin communities commit to becoming Dementia Friendly, it is helpful to have readily accessible and affordable tools to help raise awareness and reduce the stigma of dementia. Dementia Friends is one such tool. By helping individuals understand the experience of those living with dementia, learning effective communication strategies, and encouraging people to take small actions in their own lives to make a difference, Dementia Friends can provide a starting point for a dementia friendly community effort, or can be a useful addition to existing dementia friendly community activities. Either way, it can be a powerful force for good.