



Dementia Friends Pennsylvania

A Guide for Getting Started



Dementia Friends Pennsylvania: A Guide to Getting Started

Adapted from Dementia Friends Wisconsin, developed by Wisconsin Alzheimer's Institute and University of Wisconsin School of Medicine and Public Health

Contact information:

Dementia Friends Pennsylvania
Jewish Healthcare Foundation
625 Liberty Avenue, Suite 2500
Pittsburgh, PA 15222

Email: info@dementiafriendspa.org

Web: www.dementiafriendspa.org

   [#DementiaFriendsPA](https://www.instagram.com/dementiafriendspa/)

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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.

www.dementiafriendsusa.org

www.actonalz.org

www.dementiafriends.org.uk

History of the Dementia Friends Program

Dementia Friends is a global social 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. Additionally, respondents felt there was a need for better understanding, less social stigma, increased public awareness of dementia, increased activities/opportunities to socialize, more tolerance and patience and community spirit. The survey led the Alzheimer's Society to develop the Dementia Friends program to raise awareness, reduce the stigma surrounding dementia and encourage individual action.

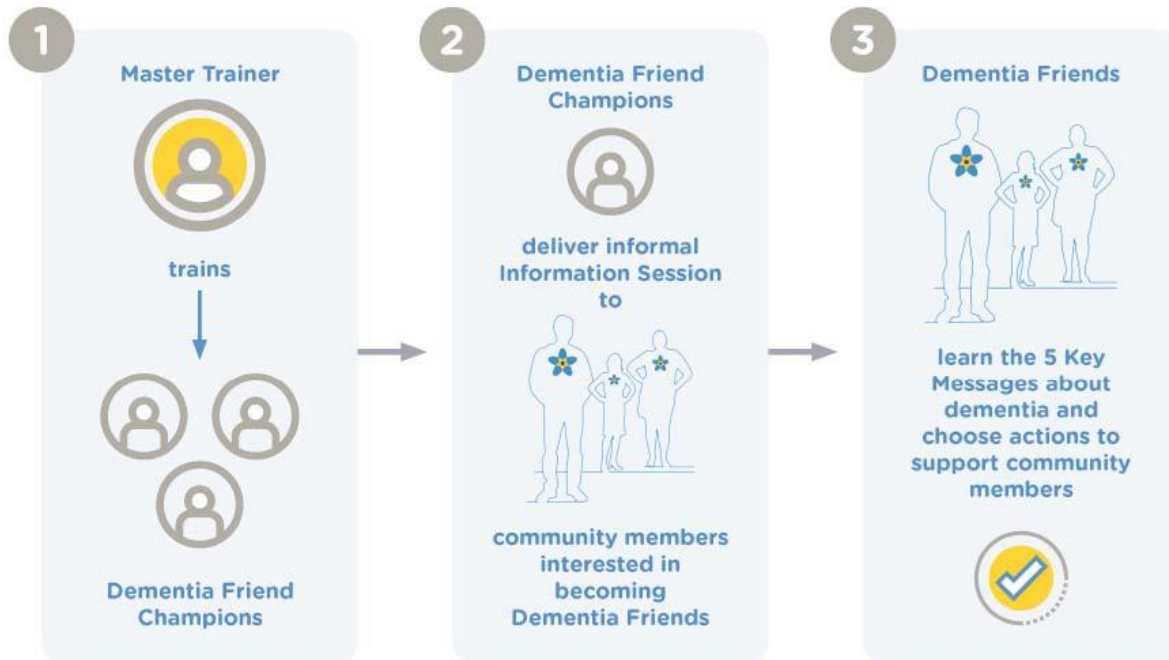
With the success of Dementia Friends, the Alzheimer's Society committed to sharing the program with other countries interested in adopting it. As of 2021, **62 countries** comprise the Global Dementia Friends Network, with more than **20 million Dementia Friends worldwide**.



The Dementia Friends Program was brought to the United States in 2015 by the state of Minnesota as part of the [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 across the United States as part of their oversight of Dementia Friendly America. In the spring of 2018, the Jewish Healthcare Foundation applied to become the licensee for the Commonwealth of Pennsylvania. One organization per state holds the license and is responsible for spreading the initiative across the state. Before applying, JHF developed an implementation plan that included numerous partners and stakeholders to ensure the ability of statewide reach. Based on over 25 years of relentless work, JHF has created an army of partners, change agents and quality improvement leaders across the Pennsylvania. With overwhelming support, JHF was granted the license and Dementia Friends Pennsylvania was launched in July 2018. As of early 2021, 26 states and territories have adopted Dementia Friends nationwide.

Overview of the Dementia Friends Program

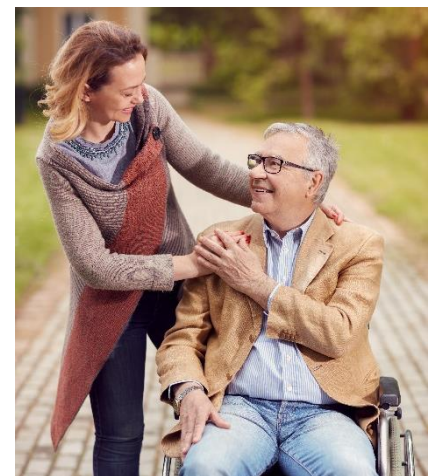
The Dementia Friends Program engages individuals interested in improving the lives of people living with dementia in their communities. Where many dementia friendly community efforts focus on training businesses, government entities and community-based organizations, Dementia Friends is designed for individual community members. Using a train-the-trainer approach, a select group of Master Trainers train Champions to provide informal, no-cost, in-person, or live interactive virtual Dementia Friends Information Session to interested community members. Once trained, Champions gain access to all the materials needed to conduct the Information Sessions in their communities.



The purpose of this guide is to offer an overview of the Dementia Friends Pennsylvania initiative and to help bring the program to your community. This guide provides a thorough explanation of the program and the step to take to get started. To learn more, visit the Dementia Friends Pennsylvania website at www.dementiafriendspa.org or contact the state leads at info@dementiafriendspa.org

What is a Dementia Friend?

A Dementia Friend is part of a global movement that is helping 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. Anyone, of any age 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 a one-hour in-person or live virtual Dementia Friends Information Session led by a Dementia Friends Champion. Pennsylvania has a rich and growing network of Champions who have been trained to conduct these informal sessions. The Dementia Friends Pennsylvania website lists all the upcoming Information Sessions. If you do not find one that fits your schedule you can contact the Master Champions who will work with you to plan a session that does.



What Happens at a Dementia Friends Information Session?

During the one-hour Information Session, community members learn:

- How to describe dementia
- Early signs and symptoms
- Five key messages about dementia
- How to effectively communicate with persons living with dementia
- Community resources available to assist people living with dementia, their family and 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 ages. There is curriculum for grades 1-3, 4-5, middle school and high school. Materials have also been translated into several languages including the top six most common languages spoken in Pennsylvania: Spanish, Chinese, Tagalog, Vietnamese, Arabic and French.

"From my work with family caregivers, I see family members caring for their loved ones struggling at times with understanding dementia and how to communicate. I love the Dementia Friends information Session because it helps families and community members achieve a general understanding of dementia, know the common types and warning signs, learn practical communication tips, and commit to an action on how to make the community supportive and dementia friendly."

Deanna Page, MSCP, LPC, NCC, CDP,
Dementia Care Coordinator
Pittsburgh, PA

At the end of a Dementia Friends Information Session participants are asked to commit to a personal dementia friendly action and make a difference in their community. Big or small, every action will make a difference. Check out some examples from Pennsylvania Friends on the next page.

Together we can make a difference in Pennsylvania. I will...

- Help a friend whose grandfather is living with dementia.
- Become a Dementia Friends Champion
- Encourage others to become a Dementia Friend.
- Start and/or support dementia friendly efforts in my community.
- Get in touch and stay in touch with someone I know living with dementia.
- Volunteer for an organization that helps people living with dementia.
- Change how I talk about dementia by saying “living with dementia” rather than “suffering with dementia”.
- Smile and say hello instead of avoiding a person living with dementia.
- Be more patient with my mom who is living with dementia.
- Talk to my church about hosting a Dementia Friends Information Session.
- Organize dementia friendly services at my church.
- Be more patient with my 86-year-old grandfather.
- Ask my doctor for a cognitive assessment during my annual physical exam.
- Work to ensure caregivers and other staff I work with are equipped with dementia friendly knowledge and best practices.



- Participate in the annual local Alzheimer's Association Walk.
- Talk about Dementia Friends with my colleagues.
- Be kind and friendly to individuals living with dementia.

What is a Dementia Friends Champion?

Dementia Friends Champions are 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 friendly and welcoming place for people living with dementia, their family and care partners. To become a Champion, you must first attend an in-person or live virtual Dementia Friends Information Session. During the training, Champions are provided the necessary materials needed to conduct the Information Sessions. Master Trainers will offer tips and suggestions along the way, so Champions are prepared. Following the training, participants will register as Champions on the Dementia Friends Pennsylvania website. Once approved, Champions will have access to all the materials needed to conduct their own Information Sessions.

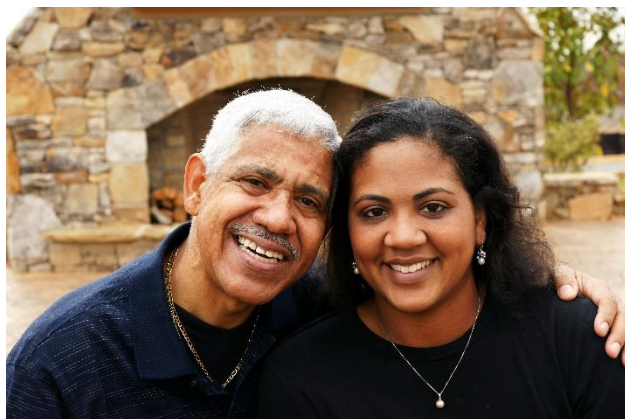


“Working in healthcare for most of my adult life, I found the Dementia Friends program provides easy and understandable information and guidance for people of all ages. Both of my parents have experienced living with dementia. They are my rock and I want to do more to help others. I have been able to utilize the information to help families and friends figure out what they can do for their loved ones living with dementia.”

Julie Fenton
Director of Outreach, Education and Community
Services
Area Agency on Aging, Clearfield County, PA

Champions agree to:

- Act as an ambassador for Dementia Friends promoting the program throughout their networks and communities.
- Conduct a minimum of **four** Dementia Friends Information Sessions per year.
- Follow the Champion’s Guide and Session Workbook when providing sessions.
- Describe and advertise Dementia Friends Sessions as Information Sessions rather than “trainings,” so participants will have accurate expectations.
- Maintain logos of Dementia Friends Pennsylvania on all materials.
- Promptly record completed Information Sessions, including number of Dementia Friends, sectors and counties represented during the session.
- Contact Master Trainers with any questions or if you no longer wish to volunteer.



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 Friends Champions. Another consideration is your personal comfort level with public speaking. The materials include a step-by-step comprehensive guide including a script that will walk you through the session. It is helpful to feel somewhat at ease speaking to a group. A good way to determine if becoming a Champion is right for you by attending a Dementia Friends Information Session and observing. If you can see yourself as a Champion and feel you have the time to commit to providing Sessions, then definitely register for a Champion Training.



Getting Started with Dementia Friends in Your Community

The first step to bringing the program to your community is to connect with a Master Trainer who can train Champions. Pennsylvania requires all Champions to attend an in-person or live virtual Dementia Friends Information Session prior to training as a Dementia Friends Champion. You can find all upcoming session advertised on the Dementia Friends Pennsylvania [website](https://www.dementiafriendspa.org). If you can not find a session that fits your schedule, please email info@dementiafriendspa.org to work with the Master Trainers to schedule a session.

Once you have become a Dementia Friend, the next step is to register for a Dementia Friends Champion Training. These are offered in-person or a live virtual training. You can find all upcoming Champion Trainings on the website. If you can not find a session that fits your schedule, please email the Master Trainers to schedule.



What happens during a Champions Training?

Champions trainings follow a structured curriculum led by a Master Trainer and typically last one-and-a-half hours. The training will equip volunteers with the knowledge and activities necessary to provide the Dementia Friends Information Session. The Master Trainer will instruct Champions on how to prepare and provide tips for delivering a successful session. Champions are provided with the following materials during the training:

- Champion Roles and Responsibilities
- How Dementia Friends Works Infographic
- Champion Training Presentation Slides
- Session Checklist
- Champion's Guide
- Session Reporting Tool
- Dementia Friends Pennsylvania Website User Guide
- Tips for Offering Dementia Friends to Cultural Communities

Upon completion of the training, newly trained Champions are asked to register on the Dementia Friends Pennsylvania website and commit to providing **four** Information Sessions in their communities. Once registered, Champions will receive an email that welcomes them to log in and gain access to all the Dementia Friends Pennsylvania materials on the website. At that point, Champions are ready to schedule and present their own sessions.

"I have been presenting Dementia Friends Information Sessions during our All Day Inservice for employees. I believe 'flipping the negative' is important in so many aspects of life. Changing the negative stigma about dementia is a big initiative, and I wanted to be part of that change."

Vicki Gilchrist
Director of Home Care and Share Care
Brevillier Village, Erie, PA

I have been trained as a Champion, what happens next?

Once trained and registered on the Dementia Friends Pennsylvania website, Champions are welcome to begin scheduling and providing Information Sessions. Sessions can be open, meaning they are open to all community members or closed, private for specific groups or audiences. For open sessions you will want to have a marketing and advertising plan to make the public aware of what a Dementia Friends Information Session is, how to register and the logistical details regarding location and time. This plan should include posting the Sessions on the Dementia Friends Pennsylvania website. Directions for posting on the website are including in the User Guide Champions receive during their training.

Champions are welcome and encouraged to inform community groups of their availability to conduct closed Sessions for their members. Examples may include civic organizations, faith communities, book clubs, school groups, youth organizations, arts organizations to name a few.

How are Champions Supported?

Champions receive access to all the materials necessary to provide Dementia Friends Information Sessions in their communities. The most important document is the Champions Guide. This is a 25-page handbook provides step-by-step instructions that will guide the Champion through the Information Session. Champions are also added to a dedicated listserv that has been set up to facilitate communication, resource sharing and delivery of a monthly newsletter. Optional quarterly conference calls are scheduled as an additional support mechanism. Finally, the statewide leads for Dementia Friends Pennsylvania are available to respond to individual questions or concerns. They can be reached via email at info@dementiafriendspa.org.



“As a program coordinator, my favorite part of my work is supporting family caregivers and their loved ones. I was impressed with what I learned and the helpfulness during a Dementia Friends Information Session. I knew I wanted to become a Champion and be able to share the information with others in our County. Our agency has a goal to become a Dementia Friendly Community and plan to use the Dementia Friends curriculum to help meet that goal.”

Heidi Farmery, Administrative Programs
Coordinator
Aging Service, Inc
Indiana County, PA

Engaging Youth to become Dementia Friends

Many people around the world are finding Dementia Friends 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 that has been adapted for youth in grades 1-3, 4-5, middle school and high school aged students. Like the adult curriculum, the youth-specific materials provide step-by-step instructions for delivering an Information Session to younger audiences.

Engaging Diverse Communities

Since Dementia Friends arrived in the United States, Dementia Friends USA has worked to include culturally tailored adaptations to the curriculum. This includes collaborating with other states to translate the materials into several commonly spoken languages, including Spanish, Chinese, Tagalog, Vietnamese, Arabic and French. There are also suggestions for adapting Information Sessions and materials to be more culturally relatable for American Indians and African American communities. All Champions are encouraged to consider adaptations when providing Dementia Friends Information Sessions in the community.



Dementia Friends in Communities that are already Dementia Friendly

Several Pennsylvania communities are already advancing 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 efforts. Where many of the dementia friendly community 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. Dementia Friends can be the vehicle through which a community works to become dementia friendly.

“Many of our clients are living with or caring for someone living with a form of dementia. We have always looked at ways to educate our community about elder law issues and found it was time to go further and share knowledge and awareness around dementia. We felt that by becoming part of the Dementia Friends movement it would help us to bring awareness to different sectors of our community. We want to reach as much of our community as possible. Our vision is to build a Dementia Friendly Community.”

Karrie L. Sarisky
Elder Care Coordinator
Kreisher Marshall & Associates, LLC
Bloomsburg, PA

Master Trainer Comments

One of the many things people like about Dementia Friends is the standard curriculum that 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. Master Trainers offer guidance based upon their own training and experiences. In bringing Dementia Friends to Pennsylvania, the Jewish Healthcare Foundation has been intentional in inviting partners from across the state to become Champions to reflect the geographic, cultural, and programmatic diversity of Pennsylvania. The goal is to make Dementia Friends accessible to everyone in Pennsylvania. Throughout this guide, several Dementia Friends and Dementia Friends Champions comments are shared to provide personal perspectives on how important this program is to Pennsylvania, people living with dementia, their family and care partners.

Summary

As more Pennsylvania communities commit to becoming Dementia Friendly, it is helpful to have readily accessible and affordable tools that can raise awareness and reduce the stigma surrounding 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 an addition to existing dementia friendly community activities. Looking forward to becoming Friends!