

How the Community can Support People Living with Dementia, their Family, Friends, and Care Partners

A Dementia-Friendly Toolkit for the Community



A Member of the
Dementia Friendly
America Network

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Welcome!

Dementia Friendly Greater Pittsburgh (DFGP) is a collaboration built to create awareness and engagement throughout the community about dementia and how we can support those living with dementia and their care partners. Our vision is to make Greater Pittsburgh a region where those living with dementia and their care partners are able to live safe, engaged lives; where they are informed and included in the everyday life of their community.

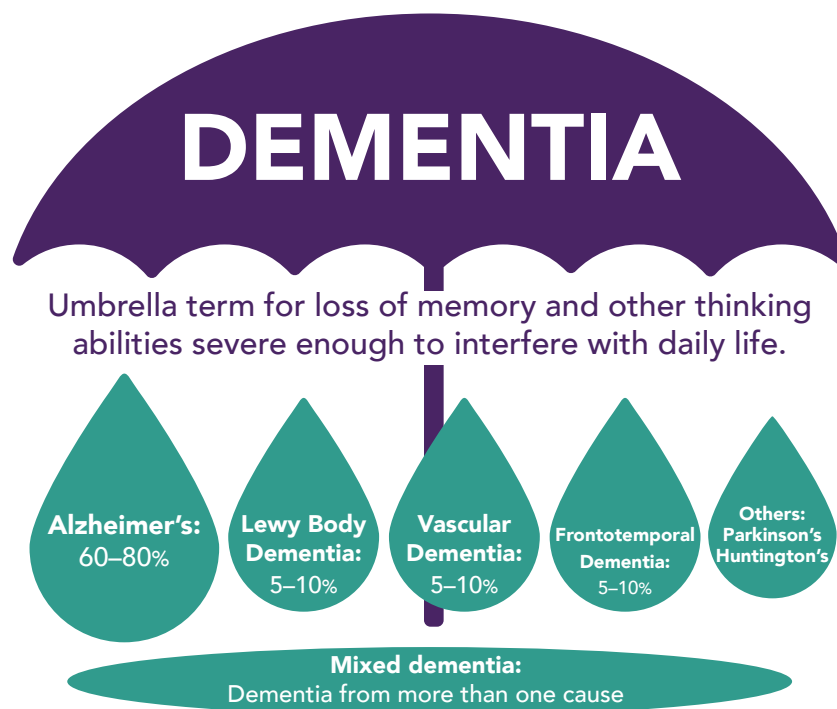
We hope this toolkit is helpful to begin or advance your efforts to usher in a culture of awareness and inclusion toward those living with dementia in our community. We are grateful for your partnership!

Thank you,
Dementia-Friendly Greater Pittsburgh

Prepare and Learn

What is Dementia?

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. Alzheimer's is the most common cause of dementia.



From the Alzheimer's Association, www.alz.org/alzheimers-dementia/what-is-dementia

Dementia is not a single disease; it's an overall term—like heart disease—that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings, and relationships.

What causes dementia?

Alzheimer's disease accounts for 60–80% of cases. Vascular dementia, which occurs because of microscopic bleeding and blood vessel blockage in the brain, is the second most common cause of dementia. Those who experience the brain changes of multiple types of dementia simultaneously have mixed dementia. There are many other conditions that can cause symptoms of dementia, including some that are reversible, such as thyroid problems and vitamin deficiencies.

Warning signs of dementia

The Alzheimer's Association has developed a brochure on the “Ten Warning Signs of Alzheimer's” or other dementia.¹ The warning signs are:

- **Memory loss that disrupts daily life**
- **Challenges in planning or solving problems**
- **Difficulty completing familiar tasks**
- **Confusion with time or place**
- **Trouble understanding visual images and spatial relationships**
- **New problems with words in speaking or writing**
- **Misplacing things and losing the ability to retrace steps**
- **Decreased or poor judgment**
- **Withdrawal from work or social activities**
- **Changes in mood and personality**

The worksheet on the following pages provides more information and examples for each warning sign.

1 https://www.alz.org/alzheimers-dementia/10_signs

10 Warning Signs of Alzheimer's

If you notice any of these signs, take action.

Use this form to note your concerns so you can address them with a friend, family member or doctor.

- 1. MEMORY LOSS THAT DISRUPTS DAILY LIFE.** One of the most common signs of Alzheimer's disease, especially in the early stage, is forgetting recently learned information. Others include forgetting important dates or events, asking the same question over and over again, or increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things the person used to handle on their own.

What's a typical age-related change? Sometimes forgetting names or appointments, but remembering them later.

- 2. CHALLENGES IN PLANNING OR SOLVING PROBLEMS.** Some people living with dementia may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What's a typical age-related change? Making occasional errors when managing finances or household bills.

- 3. DIFFICULTY COMPLETING FAMILIAR TASKS.** People living with Alzheimer's disease often find it hard to complete routine tasks. Sometimes they may have trouble driving to a familiar location, organizing a grocery list or remembering the rules of a favorite game.

What's a typical age-related change? Occasionally needing help to use microwave settings or to record a TV show.

- 4. CONFUSION WITH TIME OR PLACE.** People living with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What's a typical age-related change? Getting confused about the day of the week, but figuring it out later.

- 5. TROUBLE UNDERSTANDING VISUAL IMAGES AND SPATIAL RELATIONSHIPS.** For some people, vision problems are a sign of Alzheimer's. They may also have problems judging distance and determining color or contrast, causing issues with driving.

What's a typical age-related change? Vision changes related to cataracts.

6. NEW PROBLEMS WITH WORDS IN SPEAKING OR WRITING. People living with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or repeat themselves. They may struggle with vocabulary, have trouble naming a familiar object or use the wrong name.

What's a typical age-related change? Sometimes having trouble finding the right word.

7. MISPLACING THINGS AND LOSING THE ABILITY TO RETRACE STEPS. A person living with Alzheimer's may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. He or she may accuse others of stealing, especially as the disease progresses.

What's a typical age-related change? Misplacing things from time to time and retracing steps to find them.

8. DECREASED OR POOR JUDGMENT. Individuals may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, or pay less attention to grooming or keeping themselves clean.

What's a typical age-related change? Making a bad decision once in a while, like neglecting to change the oil in the car.

9. WITHDRAWAL FROM WORK OR SOCIAL ACTIVITIES. A person living with Alzheimer's may experience changes in the ability to hold or follow a conversation. As a result, he or she may withdraw from hobbies, social activities or other engagements. They may have trouble keeping up with a favorite team or activity.

What's a typical age-related change? Sometimes feeling uninterested in family or social obligations.

10. CHANGES IN MOOD AND PERSONALITY. Individuals living with Alzheimer's may experience mood and personality changes. They may be easily upset at home, at work, with friends or when out of their comfort zone.

What's a typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

WHAT'S NEXT?

If you're concerned that you or someone you know is displaying any of these signs, take action:

Talk to someone you trust. It can be helpful to confide in a friend or family member. For tips on how to have a conversation, visit alz.org/memoryconcerns.

See a doctor. Get a full medical evaluation to determine if it's Alzheimer's or something else. Early diagnosis gives you a chance to plan for the future, access support services and explore medication that may address some symptoms for a time. Visit alz.org/evaluatememory to learn what an evaluation may include.

Get support and information. Call the **Alzheimer's Association 24/7 Helpline (800.272.3900)** or visit alz.org/10signs.

Note: This list is for information only and not a substitute for a consultation with a qualified medical professional.

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2020 Alzheimer's Disease Facts and Figures



Alzheimer's disease is the leading cause of death in the United States

50%

of primary care physicians believe the medical profession is not ready for the growing number of people with Alzheimer's or other dementias



More than 5 million Americans are living with Alzheimer's

1 in 3 seniors dies with Alzheimer's or another dementia

It kills more than breast cancer and prostate cancer combined



16 million Americans provide unpaid care for people with Alzheimer's or other dementias



These caregivers provided an estimated 18.6 billion hours valued at nearly

\$244 billion



In 2020, Alzheimer's and other dementias will cost the nation \$305 billion — By 2050, these costs could rise as high as \$1.1 trillion

Between 2000 and 2018 deaths from heart disease have decreased

7.8% ↓

while deaths from Alzheimer's disease have increased

146% ↑



PENNSYLVANIA

ALZHEIMER'S STATISTICS

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

Year	65-74	75-84	85+	TOTAL
2020	42,000	120,000	130,000	280,000
2025	47,000	140,000	130,000	320,000

* Totals may not add due to rounding

Estimated percentage change



OF DEATHS FROM ALZHEIMER'S DISEASE (2018)

4,064

6th leading cause of death



GERIATRICIANS

of geriatricians in 2019 **278**
116% increase needed to meet Alzheimer's population needs in 2050

CAREGIVING (2019)

677,000

Number of Caregivers

771,000,000

Total Hours of Unpaid Care

\$10,104,000,000

Total Value of Unpaid Care

HOSPITALS (2017)

1,478

of emergency department visits per 1,000 people with dementia

18.6%

increase in emergency department visits since 2007

22.4%

dementia patient hospital readmission rate

HOSPICE (2017)

12,384

of people in hospice with a primary diagnosis of dementia

17%

of people in hospice have a primary diagnosis of dementia



MEDICARE

\$26,839

per capita Medicare spending on people with dementia (in 2019 dollars)

MEDICAID

\$3.658 BILLION

Medicaid costs of caring for people with Alzheimer's (2020)

10.2%

change in costs from 2020 to 2025



More than **5 million Americans** are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$305 billion** in 2020, increasing to more than **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.

For more information, view the **2020 Alzheimer's Disease Facts and Figures** report at alz.org/facts.

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Become a Dementia Friend

If you're in Pennsylvania and would like to learn more about dementia, attending an information session hosted by Dementia Friends Pennsylvania is a great place to start.



Join a growing movement of people like you who are helping fellow community members living with dementia. A little support can make a big difference. Be a Dementia Friend!

What Makes You a Dementia Friend?

You become a Dementia Friend by attending a one-hour informational session to learn about this worldwide movement, about living with dementia, and the simple things you can do to support someone living with the disease.



What Happens at the Information Session?

The one-hour session is a discussion led by a Dementia Friends Champion. It is not a training session. You'll learn what dementia is, what it's like to live with the disease, and some tips for communicating with people living with dementia. Everyone who attends is asked to turn their new understanding of dementia into a practical action that can help someone living in your community. The action can be as big or as small as you choose—every action counts!

Remember...

You don't need to be a dementia expert to become a Dementia Friend.
You don't need to know someone with dementia to become a Dementia Friend.

Learn more at www.dementiafriendspa.org

Dementia Friends is a global movement that is changing the way people think, act, and talk about dementia. Developed by the Alzheimer's Society in the United Kingdom, the Dementia Friends initiative is underway in Pennsylvania and across the United States. By helping everyone in a community understand what dementia is and how it affects families, each of us can make a difference for people touched by dementia.

Contact Us: info@dementiafriendspa.org

#DementiaFriendsPA



@DF_Pennsylvania

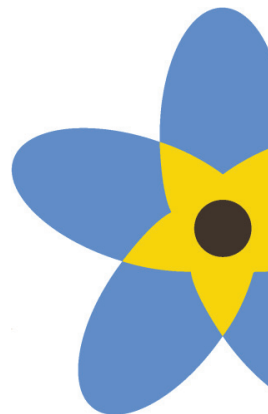


@DementiaFriendsPA



@DementiaFriendsPA

A program of the



Respond and Support

How Does a Community Support a Person Living with Dementia?

This section provides you with tips and best practices to help you support people living with dementia, their family, friends, and care partners in the community.

- **Treat the person living with dementia with dignity and respect.** Avoid talking past them as if they aren't there and don't ignore them either—say hello and make eye contact!
- **Be patient and supportive.** Let them know that you are listening and trying to understand. Show that you care about what they are saying and be careful not to interrupt. Give them time to respond to you.
- **Be understanding.** Show consideration to the person living with dementia and their care partners, especially if they may be having a difficult time. Ask how you can help them.
- **Be inclusive and flexible.** Involve the person living with dementia and their care partners in what is going on and be able to adapt to their needs. Get creative in finding ways to adjust activities and the environment so that they can be included and feel welcomed.

Communication Tips

- Approach from the front, identify yourself, and keep good eye contact. If the person is seated or reclined, go down to that level.
- Call the person by their preferred name to get their attention.
- Speak slowly and clearly. Use a gentle and relaxed tone.
- Do not correct them or point out that they can't remember or are wrong.
- Avoid arguing and reasoning. If the person says something you don't agree with. Let it be, or if possible, just go along with it.
- Make it positive—what you say, how you say it, AND how you look when you say it.
- Your job is to get into THEIR reality, not bring them back into yours. Once you accept this, you and they will have a lot less stress.
- Remove these words from your vocabulary: No.... Don't... Can't...
- Do not ask “Don't you remember?” or point out that they can't remember.
- Keep sentences and directions short ... 5 words or less.
- Break complex tasks down into smaller steps to help them to be successful.
- Offer choices instead of asking open ended questions. Instead of saying, “What do you want for a snack”, say “Do you want cookies or an apple?”
- Give them 60–90 seconds to respond.
- If they can't come up with a word, ask them to “Show me.”
- Tune out background noises if they are distracting to them.

Environmental Considerations

- Use appropriate signs with visual cues/symbols, i.e. signs for the bathroom and toilet, entrances/exits, etc.
- Make sure entrances and spaces are well-lit and make as much use of natural light as possible.
- Try to keep flooring and surfaces plain; bold patterns can cause problems to people with perceptual problems.
- Keep walkways clear and remove loose rugs and/or secure ends of carpet to avoid trips or falls.
- Keep in mind to utilize color contrast in various areas to help someone with visual problems, such as contrasting toilet seats, plates, stair edges, etc.
- Try to minimize loud music and background noises, which can be startling to someone living with dementia and make it difficult to hear. Consider having a “quiet space” where someone can go that is calming and relaxing.
- If possible, have a unisex or family bathroom for care partners to assist the person living with dementia without embarrassment.

Tips for Supporting the Caregiver and Family

- **Keep in touch.** Cards, calls, and visits to the family are always appreciated.
- **Do little things.** Cook and drop off a freezable meal. Ask the family members if you can pick up something for them while you run errands. Surprise the family with a gift certificate for dinner out and offer to help arrange care for their family member for that evening.
- **Care for and about the family caregiver.** Family caregivers are easily depleted, overwhelmed, and often feel alone. Let them know they are important to you, not just as caregivers, but also as themselves.
- **Remember all family members.** Alzheimer's and other dementias affect all family members. They may not seek out help because many families feel they should be able to "handle it" alone. Let them know that there is a community there for support and help.
- **Get the spiritual community involved.** Spiritual communities can sponsor group respite and family support programs; some may even offer to take on household chores such as weatherization and yard work.
- **Give them a break.** Offer to give the caregiver "a rest" by staying with the person living with dementia; the caregiver can get out of the house for a few hours of personal time while "off duty".
- **Ask the family for a To-Do list.** Family caregivers could often use a little help with chores like yard work, car repairs, grocery shopping and the like.
- **Be alert.** Learn about community resources and how to help the family find appropriate help for themselves and their family member living with dementia.
- **Listen.** Families may just need someone to talk to about their feelings and needs. You do not have to fix the problem for them—rather offer support and comfort.

Advocate and Volunteer

Alzheimer's Association Greater Pennsylvania Chapter

Join the fight against Alzheimer's disease by becoming an Alzheimer's Association Greater Pennsylvania volunteer. From planning an event to hosting a support group to providing office support, there are many ways to get involved. Read through the roles on the following pages to find the volunteer opportunities that best fit your interests and availability. If you'd like to learn more, contact the Alzheimer's Association Greater Pennsylvania Chapter at (412) 261-5040.

Support Group Facilitators

Support Group Facilitators create a safe, open environment where people share their feelings, thoughts and experiences in a combined effort to better cope with and manage the shared problems of dementia.

Key Activities

- Facilitate groups of caregivers or people living with dementia to provide social and educational support helping group members provide emotional support to one another.
- Present pertinent Association materials and information to group members and assure a positive experience for attendees.
- Connect people with additional Association services and volunteer opportunities by proactively making referrals to Alzheimer's Association programs & free 24/7 Helpline.

Faith Outreach Representatives

Alzheimer's Association Faith Outreach Representatives are community engagers that raise awareness of Alzheimer's Association programs, provide basic disease information, and link consumers to Alzheimer's Association services.

Key Activities

- Represent the Alzheimer's Association at a target of 12 faith events per year and distribute Alzheimer's literature at events or appearances in your faith community.
- Offer 20-minute Introduction to Alzheimer's presentations within your faith community or neighboring faith communities, congregations and denominations.
- Promote support groups, education programs, Alzheimer & Brain Awareness Month, Walk to End Alzheimer's, or The Longest Day using your local connections, bulletin boards, social media and physical displays in your community.
- Connect the Alzheimer's Association to new community organizations and connect people with additional Association services and volunteer opportunities.

Promotores

Alzheimer's Association Promotores are volunteer community engagers that raise awareness of Association programs, provide basic disease information, and link consumers to resources. Promotores are traditionally known as connectors, educators, mentors, counselors, peer leaders, patient navigators or health advocates and serve as liaisons between the Alzheimer's Association and the Hispanic/Latino community.

Key Activities

- Represent the Alzheimer's Association at a minimum of 12 events / per year distributing Alzheimer's Association literature at events or appearances in your local community.
- Offer 20-minute Introduction to Alzheimer's presentations within your community or neighboring Hispanic/Latino communities.
- Promote support groups, education programs, Alzheimer & Brain Awareness Month, Walk to End Alzheimer's, or The Longest Day using your local connections, bulletin boards, social media and physical displays in your community.
- Connect the Alzheimer's Association to new community organizations and connect people with additional Association services and volunteer opportunities.

Early Stage Social Engagement Leaders

Early Stage Social Engagement Leaders plan, implement and assure positive experience during social engagement events/activities for people living with memory loss and their care partners.

Key Activities

- In collaboration with staff and early stage advisors, schedule and implement social engagement events providing hospitality, support and volunteer oversight.
- Maintain clear communication with participants and early stage attendance rosters.
- Present pertinent Association materials and information to group members and assure a positive experience for attendees.
- Connect people with additional Association services and volunteer opportunities by proactively making referrals to Alzheimer's Association programs & free 24/7 Helpline.

Virtual Community Educators

Alzheimer's Association Virtual Community Educators are volunteer public speakers who provide Alzheimer's Association education programs through virtual platforms to community audiences.

Key Activities

- Deliver approximately 12 webinar-based presentations annually using prepared Alzheimer's Association evidence-based consumer education programs on a variety of care and support topics.
- Collaborate with local Association staff to expand programs by securing community partners, scheduling presentations, delivering the programs, and managing technology needs.
- Serve as virtual presenter for chapter-scheduled education programs and conferences.
- Connect people with additional Association services and volunteer opportunities by proactively making referrals to Alzheimer's Association programs & free 24/7 Helpline.

Virtual Community Representatives

Alzheimer's Association Community Representatives are community engagers that raise awareness of Alzheimer's Association programs, provide basic disease information, and link consumers to Alzheimer's Association services.

Key Activities

- Represent the Alzheimer's Association at a target of 12 community events / year in neighborhoods, rural counties, business and civic organizations or faith communities.
- Offer 20-minute Introduction to Alzheimer's presentations for community organizations, congregations, civic organizations, sororities / fraternities, clubs and other locations.
- Promote support groups, education programs, Alzheimer & Brain Awareness Month, Walk to End Alzheimer's, or The Longest Day using your local connections, bulletin boards, social media and physical displays in your community.
- Connect the Alzheimer's Association to new community organizations and connect people with additional Association services and volunteer opportunities.

Program Tech Support

Program Tech Support volunteers assist Alzheimer's Association staff and volunteers to provide support groups and education programs through virtual platforms and expand the reach of Alzheimer's Association programs in the community.

Key Activities

- Serve as host/moderator of web-based education programs or support groups offered through Zoom, BlueJeans, Google Meets. The programs are taught or facilitated by Alzheimer's Association staff or volunteers with specialized training in these topics.
- Mentor and coach Alzheimer's Association volunteer Community Educators and Support Group Facilitators in use of technology to maximize the constituent / user experience.
- Troubleshoot constituent access issues for caregivers to participate in groups. Monitor chat, mute microphones and cue up Q&A for volunteers to answer. Launch polling if part of the user experience in the platform.

Community Volunteer Leader

Alzheimer's Association Community Volunteer Leaders help the local chapter recruit program volunteers, network, build relationships, plan & promote local events, and evaluate community needs.

Key Activities

- Serve as a connector between the defined geography, underrepresented community, potential community partners, social group or business and the Alzheimer's Association.
- Discover opportunities for the Alzheimer's Association and coordinate appearances for local Association Community Representatives or Community Educators at community events.
- Help identify community needs by planning, implementing and hosting Community Forum events, promote events in community, build audience attendance.
- Frequently communicate with chapter about local volunteer needs and recruit prospective program volunteers that are both inclusive and represent the community demographics.
- Promote support groups, education programs, Alzheimer & Brain Awareness Month, Walk to End Alzheimer's, or The Longest Day using your local connections, bulletin boards, social media and physical displays in your community.
- Connect the Alzheimer's Association to new community organizations and connect people with additional Association services and volunteer opportunities.

Support Group Mentor

Support Group Mentors provide mentoring and training support for facilitators of early stage or caregiver groups.

Key Activities

- Collaborate with Association staff to provide hands-on assistance where needed to improve the quality and participation in Alzheimer's Association support groups.
- Provide co-training, ongoing consultation, mentoring support and assistance and evaluate successes, challenges and needs of the group.
- Provide annual quality assurance visits and review evaluation data with Facilitators to improve the constituent experience.
- Consult with support group leaders and staff to devise a plan to grow participation and expand the reach of support groups.
- Serve as a substitute for short-term facilitator absences or co-facilitator for virtual support groups during which time the Mentor assumes the temporary role of Facilitator.

Dementia-Friendly Greater Pittsburgh

Dementia-Friendly Greater Pittsburgh (DFGP) is available to help you champion dementia-friendly efforts! We are always looking for volunteers who would like to join our efforts and help us educate and engage the community, create awareness, and advocate for and support people living with dementia and their care partners.

DFGP is a member of the Dementia Friendly America network, sharing in a common mission of fostering dementia friendly communities throughout the U.S. We are a collaboration built to create awareness and engagement throughout the community about dementia and how we can support those living with dementia and their care partners. We are accomplishing this by providing education, creating opportunities for engagement, and advocating for the needs of those living with dementias and their care partners.

Please contact us by email if you are interested in volunteering with DFGP and keep updated on our current events and efforts on our website and through our Facebook page!

 DementiaFriendlyGreaterPgh@gmail.com

 www.swppa.org/DFGP

 [@DementiaFriendlyGreaterPgh](https://www.facebook.com/DementiaFriendlyGreaterPgh)

Local Resources



Dementia-Friendly Greater Pittsburgh
www.swppa.org/dfgp
DementiaFriendlyGreaterPgh@gmail.com



Dementia Friends Pennsylvania
www.dementiafriendspa.org



Alzheimer's Association—Greater Pennsylvania Chapter
www.alz.org/pa, 412-261-5040



UPMC Senior Services
www.upmc.com/services/seniors, 1-866-430-8742



Pennsylvania Area Agencies on Aging
www.aging.pa.gov/local-resources

National Resources



Dementia Friendly America

www.dfamerica.org



Alzheimer's Association

www.alz.org, 24-Hour Helpline: 1-800-272-3900



Alzheimer's Foundation of America

www.alzfdn.org, 1-866-232-8484



The Association for Frontotemporal Degeneration

www.theaftd.org, Helpline: 1-866-507-7222



American Stroke Association

A division of the American Heart Association.

American Stroke Association (Vascular Dementia)

www.stroke.org, 1-800-AHA-USA-1



Lewy Body Dementia Association

www.lbda.org, 1-877-206-1192



Family Caregiver Alliance

www.caregiver.org/caregiver-connect, 1-800-445-8106



Eldercare Locator

eldercare.acl.gov, 1-800-677-1116



Visit us online to learn more, and find ways to get involved!

 swppa.org/DFGP

 [@DementiaFriendlyGreaterPgh](https://www.facebook.com/DementiaFriendlyGreaterPgh)