

A Dementia Friendly Toolkit for the Lehigh Valley Building a Community to Support People Living with Dementia and Their Care Partners



Mission

The Mission of DFLV is to raise awareness and reduce stigma related to Alzheimer's Disease and Related Disorders (ADRD) among community members and encourage the Lehigh Valley community to become more accessible and supportive for individuals affected by ADRD and their caregivers.

Vision

To create a greater community that embraces and encourages people with Alzheimer's Disease and Related Disorders by cultivating dignity, empowerment, and autonomy. We envision a community of organizations and individuals equipped to support people living with dementia so they can remain in the community and engage and thrive in day-to-day living.

Goals

- To raise awareness and reduce stigma through education and outreach endeavors
- Cultivate and confirm commitments from stakeholders and partners
- Leverage existing dementia-friendly community resources
- Share information about best practices with the broader community

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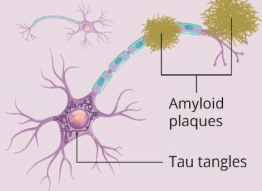
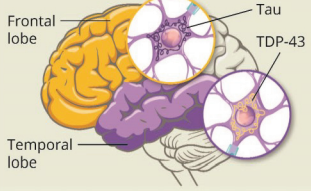
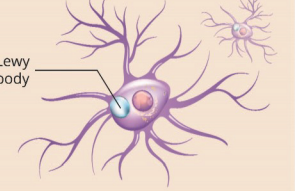
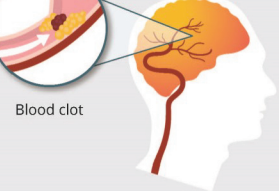


Understanding Different Types of Dementia

Dementia is not a specific disease, but rather an “umbrella” term for chronic impairment of brain function that affects thinking. There are numerous types of dementia described below, and Alzheimer’s dementia is one of them. Today there are over 7 million Americans living with Alzheimer’s disease.



TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?*			
<p>Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain.</p>  <p>Amyloid plaques Tau tangles</p>	<p>Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes.</p>  <p>Frontal lobe Temporal lobe Tau TDP-43</p>	<p>Abnormal deposits of the alpha-synuclein protein, called “Lewy bodies,” affect the brain’s chemical messengers.</p>  <p>Lewy body</p>	<p>Conditions, such as blood clots, disrupt blood flow in the brain.</p>  <p>Blood clot</p>

*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.

Symptoms			
<p>Mild</p> <ul style="list-style-type: none"> Wandering and getting lost Repeating questions <p>Moderate</p> <ul style="list-style-type: none"> Problems recognizing friends and family Impulsive behavior <p>Severe</p> <ul style="list-style-type: none"> Cannot communicate 	<p>Behavioral and Emotional</p> <ul style="list-style-type: none"> Difficulty planning and organizing Impulsive behaviors Emotional flatness or excessive emotions <p>Movement Problems</p> <ul style="list-style-type: none"> Shaky hands Problems with balance and walking <p>Language Problems</p> <ul style="list-style-type: none"> Difficulty making or understanding speech <p><i>There are several types of frontotemporal disorders, and symptoms can vary by type.</i></p>	<p>Cognitive Decline</p> <ul style="list-style-type: none"> Inability to concentrate, pay attention, or stay alert Disorganized or illogical ideas <p>Movement Problems</p> <ul style="list-style-type: none"> Muscle rigidity Loss of coordination Reduced facial expression <p>Sleep Disorders</p> <ul style="list-style-type: none"> Insomnia Excessive daytime sleepiness <p>Visual Hallucinations</p>	<ul style="list-style-type: none"> Forgetting current or past events Misplacing items Trouble following instructions or learning new information Hallucinations or delusions Poor judgment
Typical Age of Diagnosis			
Mid 60s and above, with some cases in mid-30s to 60s	Between 45 and 64	50 or older	Over 65
Diagnosis			

Symptoms can be similar among different types of dementia, and some people have more than one form of dementia, which can make an accurate diagnosis difficult. Symptoms can also vary from person to person. Doctors may ask for a medical history, complete a physical exam, and order neurological and laboratory tests to help diagnose dementia.

Treatment

There is currently no cure for these types of dementia, but some treatments are available. Speak with your doctor to find out what might work best for you.

Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit www.nia.nih.gov/health/what-is-dementia.

10 Early Signs Alzheimer's Worksheet

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. NOTE: It's possible for individuals to experience one or more of these signs in varying degrees. It is not necessary to experience every sign in order to raise concern.

1. MEMORY LOSS THAT DISRUPTS DAILY LIFE. One of the most common signs of Alzheimer's disease, especially in the early stages, 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. This may lead to difficulty with balance or trouble reading. 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 disease may experience changes in the ability to hold or follow a conversation. As a result, they 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 OR PERSONALITY. Individuals living with Alzheimer's may experience mood or 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.

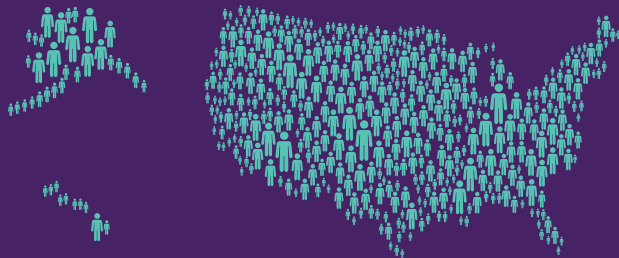
WHAT'S NEXT? If you're concerned that you or someone you know is displaying any of these signs, take action:

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 treatment options. To learn more about the diagnostic process, **visit alz.org/evaluatememory.**

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

2025 ALZHEIMER'S DISEASE FACTS AND FIGURES



Over

7 MILLION

Americans are living with Alzheimer's

1 IN 3

older adults dies
with Alzheimer's or
another dementia



IT KILLS MORE THAN

breast cancer



prostate cancer

COMBINED

Between
2000 and
2022 deaths
from heart
disease have
decreased

2.1%



while deaths
from
Alzheimer's
disease have
increased

142%

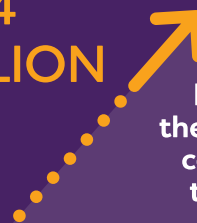


In 2025, Alzheimer's
and other dementias
will cost the nation

\$384 BILLION

By 2050,
these costs
could rise
to nearly

\$1 TRILLION



The lifetime
risk for Alzheimer's
at age 45 is

1

IN

5

for
women

1

IN

10

for
men



NEARLY 12 MILLION

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

These caregivers
provided more than
19 billion hours
valued at nearly

\$413 BILLION



UP TO 4 IN 5

Americans feel
optimistic about new
Alzheimer's treatments
in the next decade



92%

of Americans would
want a medication to
slow the progression
of Alzheimer's following
a diagnosis

For more information, visit alz.org/facts

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ALZHEIMER'S  ASSOCIATION®

2025 PENNSYLVANIA

ALZHEIMER'S STATISTICS



PREVALENCE

Number of People
Aged 65 and Older
with Alzheimer's (2020)

282,100

% of Adults Over 65
with Alzheimer's

11.5%

WORKFORCE

of Geriatricians
in 2021

455

of Home Health
and Personal Care
Aides in 2022

188,340

Increase Needed to
Meet 2032 Demand

15.3%

CAREGIVING

of Caregivers

470,000

Total Hours
of Unpaid Care

831M

Total Value
of Unpaid Care

\$15.9B

Caregivers with Chronic
Health Conditions

76.6%

Caregivers
with Depression

32.5%

Caregivers in
Poor Physical Health

16.0%

HEALTH CARE

of People in Hospice
(2017) with a Primary
Diagnosis of Dementia

12,384

Hospice Residents
with a Primary Diagnosis
of Dementia

17%

of Emergency
Department Visits per
1,000 People with
Dementia (2018)

1,470

Dementia Patient
Hospital Readmission
Rate (2018)

22.0%

Medicaid Costs of
Caring for People with
Alzheimer's (2025)

\$4.4B

Per Capita Medicare
Spending on People with
Dementia in 2024 Dollars

\$32,271

More than **7 million**
Americans are living
with Alzheimer's,
and nearly **12 million**
provide their unpaid
care. The cost of
caring for those
with Alzheimer's
and other dementias
is estimated to total
\$384 billion in 2025,
increasing to nearly
\$1 trillion
(in today's dollars)
by mid-century.

For more
information, view
the *2025 Alzheimer's
Disease Facts and
Figures* report at
alz.org/facts.



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Association is a
not-for-profit 501(c)(3)
organization.

MORTALITY

of Deaths from
Alzheimer's Disease (2022)

4,011



**Changing the way we
think, act and talk
about dementia.**

Join a growing movement of people like you who are making a positive difference in the lives of people living with dementia

What makes you a Dementia Friend?

You become a Dementia Friend by attending an interactive 60-minute Information Session to learn about living with dementia and the small things you can do to show support to members of your community.

As a Dementia Friend you will turn your understanding into a practical action that can help someone with dementia living in your community. The action can be as big or small as you choose because every action counts!

Please understand...

You don't need to be a dementia expert, have prior knowledge, or know someone living with dementia to become a Dementia Friend.

**Become a
Dementia
Friend!**

What happens at the Information Session?

- Describe dementia
- Know the most common type of dementia
- Understand five key messages about dementia
- Learn ways to effectively communicate with a person living with dementia
- Choose a small dementia-friendly action

To schedule an in-person or virtual session visit us at:

www.dementiafriendspa.org

Supported by



Communication



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might have changes in their brains that cause them to:

- have a tough time finding the right word
- lose their train of thought
- have problems following a conversation
- not be able to understand what you are saying
- speak only in their native or first language



844.HELP.ALZ
AlzheimersLA.org

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People with Alzheimer's or dementia can lose their ability to speak clearly and understand what you are saying. This can be frustrating both for the person with Alzheimer's and for you.

WHAT CAN YOU DO?

USE SHORT SENTENCES & SIMPLE WORDS

- give short, one sentence answers
- offer one step directions
- slowly repeat instructions or sentences if not understood the first time
- be patient and positive, even when it takes a long time to answer
- try not to remind them that they forgot or already told you something
- ask a question and offer a simple choice of answers such as "What do you want for dinner? Fish or chicken?"
- ask questions that can be answered with yes or no
- try not to use "baby talk" or a "baby voice"
- avoid negative words. Instead of "Don't go out that door!" try "Let's go this way!" and gently guide the person away

FOCUS THEIR ATTENTION ON YOU

- get on their eye level
- call the person by name
- remove distractions — turn off TV, go to a quiet room
- pay attention to your tone, how loudly you are speaking and your body language — which often "speak" louder than words
- be an active listener — make eye contact, nod your head

OTHER IDEAS TO TRY

- put up signs or pictures to explain what is in the room or cabinet
- have the person's hearing tested to make sure they can hear
- use a chalk or white board to write the schedule for the day or the answers to frequently asked questions
- respond to the person's feelings or emotions, not only to words
- if conversation is hard but you want to do something together, try listening to music or looking at old family photos

Anxiety



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might have changes in their brains that make it harder to:

- process what is going on around them
- remember that they just did something like checking their wallet for money
- understand what is going on when it gets darker (sundowning)
- feel safe when their home may no longer look familiar to them
- recognize family members or the person is who is caring for them

People with Alzheimer's or dementia can have anxiety which can make them worry or feel nervous. It may cause other behaviors such as pacing or picking at clothing or hair. This feeling of fear can cause the person to check things over and over again, or they may feel worried that something bad is going to happen.

WHAT CAN YOU DO?

WAYS TO HELP

- be comforting — consider a hug or place your hand on the person's arm
- respond to the person's feelings, not only to what they say
- try not to argue or convince them of the truth
- remind the person that they're safe and you are there to help
- be an active listener — make eye contact, express interest in what they are saying
- try to distract them with a walk or something they enjoy

HOW TO PREVENT ANXIETY FROM GETTING WORSE

- follow a routine for the day
- be matter of fact and comforting about what is causing them fear
- look for signs that they are becoming fearful and try not to let it get worse by waiting to act
- try to identify what is causing the anxiety and try to remove it before it causes the worry or behavior

OTHER IDEAS TO TRY

- make sure they get enough exercise as this can be calming
- speak in a calm, gentle voice
- try using calming smells such as lavender oil or relaxing music
- reduce or limit drinks that have caffeine like coffee and soda
- track when/where anxiety occurs to look for patterns
- ask the doctor if any of their medications can cause anxiety

TAKE CARE OF YOURSELF

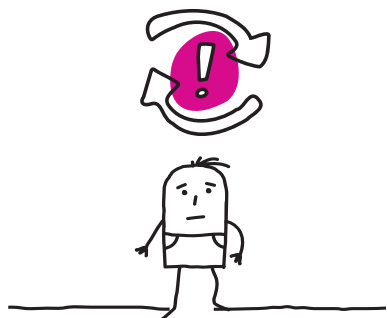
- slow down and try to relax — your stress can add to the anxiety
- accept that some behaviors may make sense to the person but not to you
- take a break from caregiving so you are better able to cope with the stress
- practice deep breathing or other simple relaxing exercises
- join a support group or speak with a therapist



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Repeating



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- having problems remembering what they just said or what just happened
- repeating questions or stories because they feel nervous or afraid
- having trouble saying what they need or want



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People with Alzheimer's or dementia often ask questions or tell stories over and over. While frustrating, it is not harmful. They are not doing this on purpose. This behavior is caused by changes in the brain.

WHAT CAN YOU DO?

THINK ABOUT WHY

- new place? new people? somewhere they find scary?
- they forget that the question was asked and/or answered
- they want your attention... to feel a connection with you
- maybe they are trying to tell you about a need... hunger, concern about someone or something, urge to go to the bathroom

ACCEPT THE BEHAVIOR

- stay calm and be patient, they can't change so you will need to
- don't argue or try to correct them
- breathe... and remember the disease is the reason
- calmly answer the question every time it's asked
- smile at the story every time it's told

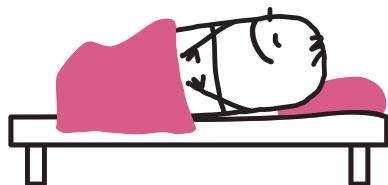
TRY REMINDERS

- use clocks or photos of items or objects to help with questions that are repeated
- post notes or a daily schedule in a place they often look
- get a big "white board" so you can write and erase information

WAYS TO HELP

- listen to music, watch TV, take a walk, or find something they like to do to get their mind on something else
- think first about how they are feeling and remind yourself it's not their fault
- wait until just beforehand to tell them about things that make them nervous like doctor's visits, bathing, or going out
- if you are tired and might react, and they are safe, go to another room for a bit to breathe

Sleeping



WHY DOES THIS HAPPEN?

Changes in sleep can happen for many reasons:

- changes in the brain may cause the body's natural "clock" to change – the body can feel awake during the night and sleepy during the day
- pain from arthritis or other illnesses can wake the person
- the person needs to go to the bathroom
- the person may have problems breathing while they sleep; this can cause loud snoring
- feeling very sad or nervous can wake the person

Sleeping problems are common for people living with Alzheimer's or other dementias. Many people are restless at night and feel tired during the day. Poor sleep can also lead to other health problems.

WHAT CAN YOU DO?

KEEP A REGULAR SCHEDULE

- begin each morning at the same time and the same way
- keep them as active as possible during the day-walks, gardening, and other daytime activity is good
- avoid naps later in the day
- make sure to keep the same relaxing routine before bedtime

OTHER THINGS YOU CAN DO

- provide as much bright light as possible during the day
- if they really want to be up at night, do not force them to be in bed or to sleep
- keep everything quiet and dark at nights
- help them avoid drinking coffee, tea, or soda with caffeine after 2PM
- give less liquids in the evening
- keep a light on in the bathroom to avoid accidents
- massages may help some people

SPEAK WITH A DOCTOR IF:

- they have pain
- they snore badly
- they go to the bathroom a lot
- they seem very sad or nervous

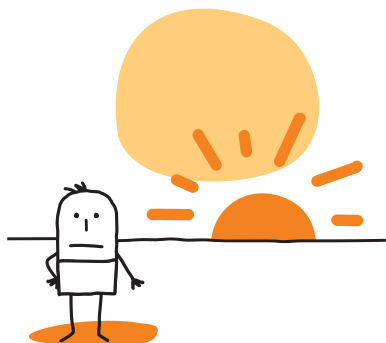
Don't use sleep medicines of any kind without speaking with a doctor first. Sleep medicines can cause confusion and falls.



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Sundowning



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- more tired in the late afternoon
- confused by changing amounts of light
- scared by shadows
- reacting to your feelings of being tired



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People with Alzheimer's or dementia may become more confused or nervous later in the day, often as the sun sets. This is called sundowning. They may see or hear things that are not there. They may accuse people of things that are not true, like stealing or lying, and may pace or walk back and forth. This is not done on purpose, and people with dementia cannot control it.

WHAT CAN YOU DO?

MAKE CHANGES AT HOME

- turn lights on early in the afternoon to make the house brighter
- turn down (or turn off) the television or radio
- turn on soothing music
- avoid loud or confusing noises
- clear a path for the person to walk back and forth

PAY ATTENTION TO MEALS AND SNACKS

- provide a large meal at lunch and a light meal at dinner
- allow less caffeine, sugar, coffee, tea, and soda after 3 PM
- remove access to alcohol and cigarettes

KEEP A SCHEDULE

- make going to bed and waking up at the same time every day
- take walks or dance to use up extra energy
- plan doctor visits, outings, baths in the morning

OTHER IDEAS

- be calm and reassuring
- be flexible... if one idea doesn't work, try another
- comfort her and say or do something to calm her fears
- try a new activity, like sorting coins or dancing

Memory Cafés



Betty Ann's Memory Cafe, sponsored by Care Patrol, is held the 1st Thursday of each month from 10 AM - 12 Noon at Bethany Church located at 1208 Brookside Road in Allentown, PA. Light refreshments served; safe, calm, inclusive space. Call 610.597.6842 or Email cfrawley@carepatrol.com.



The Morningstar Memory Café by Senior Solutions is held the 2nd and 4th Thursday of each month from 10 AM-12 Noon at the Advent Moravian Church located at 3730 Jacksonville Road in Bethlehem, PA. Register to attend by calling Senior Solutions at **610.258.0700**.

Support Groups

Alzheimers' Association

Visit www.alz.org

Arden Courts ProMedica Memory Care, Allentown, PA

First Thursday of each month...Call 610.366.9010

Bradbury-Sullivan LGBT Community Center

"Sharing Our Stories" Dementia Support Group...Call 610.347.9988

Fleming Memory Center at Lehigh Valley Hospital, 17th Street Allentown, PA

Call 610.969.3390

Heather Glen

Call 610.841.4478

Moravian Hall Square at 175 W. North Street, Nazareth, PA

Call 610.746.1000

Northampton County Area on Aging Caregiver Support Group

2801 Emrick Blvd. Bethlehem, PA 18020. First Thursday of each month, 2:15-3:30 PM
Call 610.829.4540

South Mountain Memory Care Caregiver Support Group

Call 484.460.6842 or email csteele@southmountainmemorycare.com

YMCA Bethlehem

Email Donna Scrafano at donnascrafano@gmail.com

Local Resources



Dementia Friendly Lehigh Valley

www.dementialv.org



St. Luke's Center for Positive Aging

St. Luke's—Comprehensive Geriatric Assessments

www.slnh.org/senior-health/services



LVPG Fleming Memory Center

Comprehensive Geriatric Assessment and Community Support Services—Lehigh Valley Health Network

www.lvhn.org/locations/fleming-memory-center



Lehigh County Aging and Adult Services

Lehigh County Area Agency on Aging

www.lehighcounty.org



Northampton County Area Agency on Aging

www.northamptoncounty.org

Local Resources



United Way Greater Lehigh Valley

www.unitedwayglv.org/dementia-caregiver-support



Meals on Wheels Greater Lehigh Valley

Provides homebound seniors and adults with disabilities with home-delivered meals

www.mowglv.org



Department of Human Services

www.dhs.pa.gov



Dementia Friends Pennsylvania

www.dementiafriendspa.org



Alzheimer's Association—Greater Pennsylvania Chapter

www.alz.org/pa



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



Alzheimer's Foundation of America

1-866-232-8484

www.alzfdn.org



The Association for Frontotemporal Degeneration

1-866-507-7222

www.theaftd.org



American Stroke Association (Vascular Dementia)

1-800-AHA-USA-1

www.stroke.org



Lewy Body Dementia Association

1-877-206-1192

www.lbda.org

CDC Five Brain Health Tips

This Brain Awareness Month, the CDC reminds us that simple lifestyle choices can make a big difference in keeping our minds strong as we age.

From staying active to staying connected, taking care of your brain is a lifelong commitment—and it's never too early (or too late) to start! 🧠

Dementia Friendly Pennsylvania makes it easy to stay connected and increase your knowledge! Visit the Dementia Friendly Calendar to explore events in your part of Pennsylvania- <https://www.dementiafriendlypa.org/calendar-events>
#BrainHealthMonth #StayConnected #Pennsylvania #dementiafriendlypa

Small changes can make a big difference to lower your risk of dementia.

Here are five lifestyle habits to keep your brain healthy!

- 01 Stay physically active**

- 02 Prevent or manage diabetes.**

- 03 Manage your blood pressure.**

- 04 Prevent or correct hearing loss.**

- 05 Try to limit or avoid drinking alcohol & smoking.**






To learn more and find ways to get involved!



www.dementialv.org



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