
Dementia Initiatives in Virginia

NEW RESOURCES AND SERVICES

Dementia 101 Session 2

George Worthington
Dementia Services Coordinator

Dementia definition

Changes in thinking, reasoning, memory, personality or other cognitive abilities that interfere with daily activities.



https://www.youtube.com/watch?v=7_kO6c2NfmE



Types of Dementia

BEYOND ALZHEIMER'S DISEASE

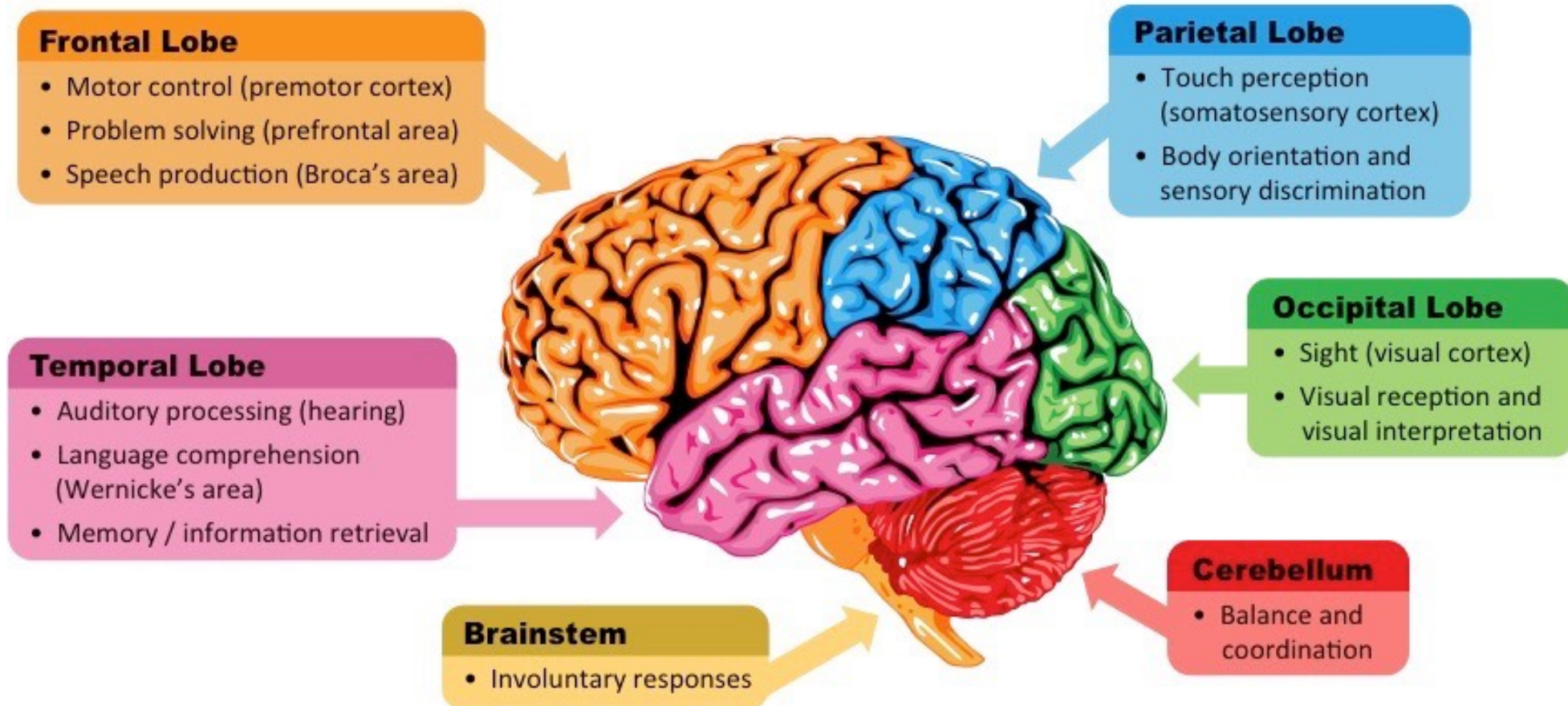
Dementia 101

George Worthington
Dementia Services Coordinator

Different types of dementias--prevalence

DISEASE	% of all dementias
Alzheimer's Disease	60-80%
Vascular Dementia	15-20%
Dementia with Lewy Bodies	5%
Parkinson's disease dementia	4%
Frontotemporal Degeneration	
Behavior Variant	1%
Primary Progressive Aphasia	1%
Posterior Cortical Atrophy	??

Brain Basics



Vascular Dementia

Caused by a single, major stroke or a series of very small strokes

- TIAs—transient ischemic attack (ischemia—reduced blood flow)
- Poor blood flow to the brain

Often occurs in combination with Alzheimer's disease (“mixed dementia”)

Symptoms are similar to Alzheimer's disease

- Often physical challenge accompanies cognitive decline

Stepwise decline rather than the gradual downward progression of Alzheimer's disease

Vascular Dementia Symptoms

Confusion, problems with planning/judgment

Trouble speaking or understanding; trouble finding the right words

Changes in mood including apathy, uncontrolled laughing or crying

Physical symptoms of stroke, numbness/paralysis

Problems with walking and balance

Vascular Dementia Risk Factors

Smoking

Uncontrolled
hypertension, high
cholesterol, blood
sugar

Poor diet

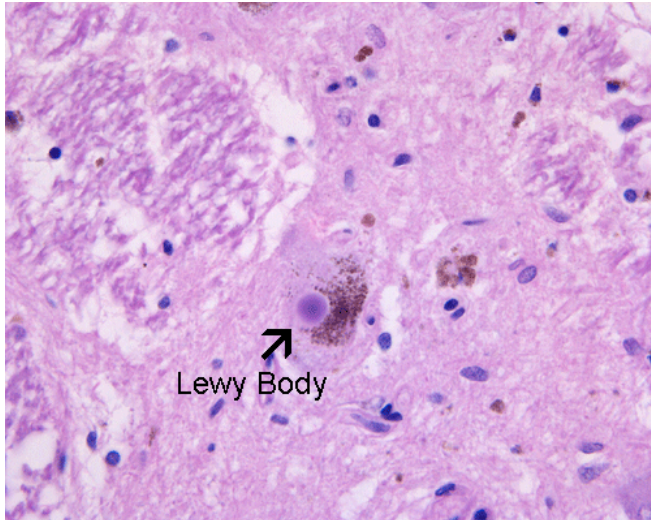
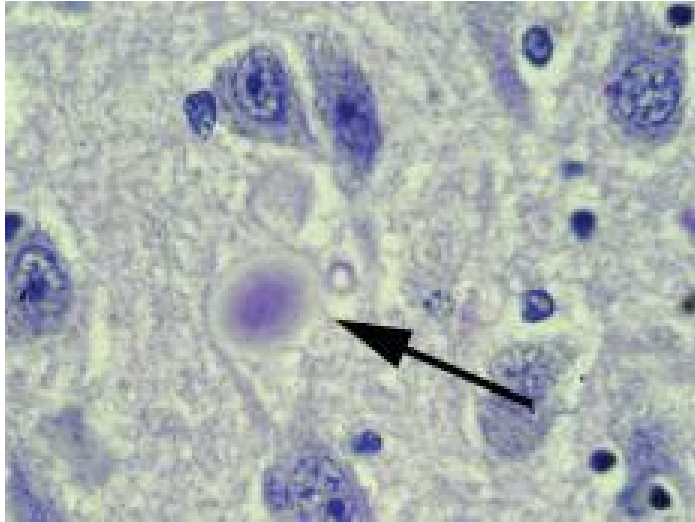
Lack of exercise

Overweight/obesity

More than
moderate alcohol
consumption



Dementia with Lewy Bodies



- Caused by protein deposits in the brain called Lewy bodies
- Often confused with other diseases, and can be difficult to diagnose
- Parkinson's disease dementia is caused by the same Lewy bodies in the brain

Lewy Body Symptoms



Visual hallucinations and delusions

Animals, people

Realistic and detailed

Typically not disturbing, may have insight



Physical changes

Muscle rigidity

Slow movement

Shuffling

Increase in falls



Difficulty sleeping

REM sleep disorder

Acting out dreams



Lewy Body Risk Factors

No specific causes identified

Most people diagnosed with DLB have no family history

No genes are proven to be linked with DLB



Frontotemporal Degeneration

- Caused by the shrinking of the frontal and temporal lobes of the brain
 - Progresses from front of brain to the back
- Earlier onset than other dementias – 40-70 y.o.
 - Much less common than Alzheimer's disease, but for 45-65 y.o., about the same prevalence as younger onset AD
- Changes in behavior and thinking
 - Often misdiagnosed as a psychiatric illness
- Memory problems are not the main symptom or concern

Variants of FTD

Behavioral Variant FTD (typically 50s/60s, but can appear in the 20s or as late as 80s)

- Disease affects areas of the brain responsible for conduct, judgment, empathy and foresight, impulse control

Primary Progressive Aphasia (normally appears in midlife)

- Semantic variant—lose the ability to understand or produce words in a spoken sentence
- Nonfluent/agrammatic variant—speaking is hesitant, labored and ungrammatical

ALS, Corticobasal syndrome, progressive supranuclear palsy

- Changes in muscle/motor function, with or without behavior or language problems

Symptoms of Frontotemporal Degeneration

Affected brain regions play a role in:

- Decision-making
- Behavioral control
- Emotion
- Personality
- Insight
- Empathy
- Language

Posterior Cortical Atrophy

Unknown whether this is a unique disease or a variant of AD

Amyloid plaques and tau tangles are present, but in the back of the brain

Some people show brain changes similar to dementia with Lewy Bodies

Typical onset at 50-65 y.o.

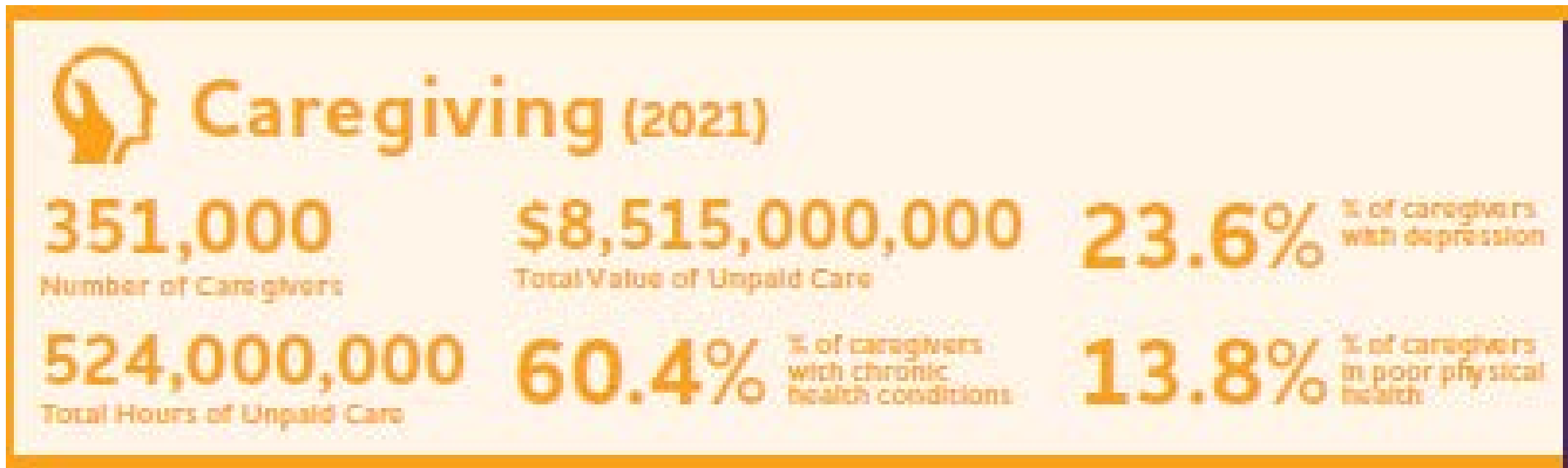
No standard definition, no established diagnostic criteria

Symptoms consistent with damage to the occipital cortex in the back of the brain

Dementia in Virginia

Virginia FFS Medicare beneficiaries with AD/D diagnosis (<i>CMS</i>)	
2015	2018
92,277	108,864
Virginians with Alzheimer's disease (<i>Alzheimer's Association</i>)	
2022	2025 (forecast)
150,000	190,000
Virginians experiencing Subjective Cognitive Decline (<i>BRFSS</i>)	
2015	2019
275,000	292,000

Caregivers in Virginia



Alzheimer's Association, *Facts and Figures 2022*

Virginia's Dementia Infrastructure



Virginia Dementia Infrastructure

Alzheimer's Disease and Related Disorders Commission

Dementia State Plan (updated every 4 years)

Dementia Services Coordinator (DSC)

Dementia Capable Virginia (new!)

Network of memory assessment centers

No Wrong Door network including AAAs



Dementia services

Dementia Care Coordination

- pilot project at UVA

Virginia Lifespan Respite Voucher Program vda.virginia.gov/vlrsv.htm

- Up to \$595 reimbursement for respite care

Dealing with Dementia workshops for caregivers

- Offered in several areas of Virginia



Dementia Capable Virginia

NEW BRANDING AND RESOURCES

Dementia Capable Virginia



New materials and resources for:

- Individuals living with dementia
- Caregivers of people living with dementia
- Service providers
- Primary care providers
- Researchers

<https://vda.virginia.gov/DementiaCapableVA.htm>

New webpage



OFFICE for AGING SERVICES
Division for Community Living

Providers' Portal

ENHANCED BY Google

About Us ▾ Find Local Services ▾ Community Living & Caregiving ▾ Health & Wellness ▾ Abuse & Fraud ▾ Resources DARS Homepage

Home / Community Living & Caregiving / Dementia / Dementia Capable Virginia

Dementia Capable Virginia



An initiative of the Alzheimer's Disease and Related Disorders Commission and the Department for Aging and Rehabilitative Services

I am providing care and support for a friend or family member

I am a health care professional

I am a researcher or interested in learning more about research

<https://vda.virginia.gov/DementiaCapableVA.htm>

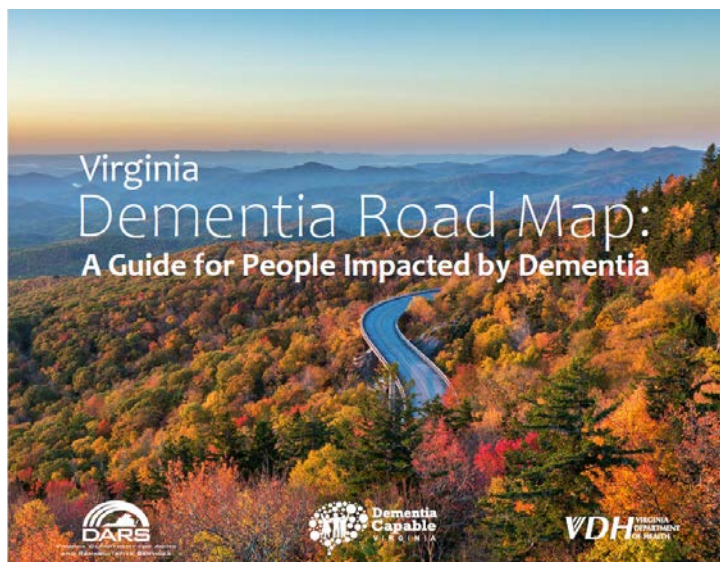
Dementia Capable Virginia

New webpage containing all DCV materials and more:

- Expanded resources and links
 - Dementia Road Map (new!)
 - Dementia Safety Information Toolkit (new!)
 - Dementia Fact Sheets
 - Primary Care Dementia Toolkit (new!)
- Training modules
 - Primary Care microlearning modules
 - Person-Centered Dementia Capable training modules for Area Agency on Aging staff
 - APS staff microlearning module (under development)
- Listing of memory assessment centers serving Virginians
- Dementia Friendly initiatives



Dementia Road Map



Virginia Dementia Road Map: A Guide for People Impacted by Dementia

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Virginia Dementia Road Map Overview

Wondering and Worried

- Is everything OK?
- Should I or my loved one be checked by a health care professional?
- Have I, or has my loved one, completed an annual cognitive evaluation?
- What if my loved one won't go to a health care professional?

Mild Cognitive Impairment (MCI)

- Where do we go to get memory loss checked out?
- How can I help my loved one with their memory and thinking?
- What can we do to promote our loved one's well-being?
- Can I share concerns privately with a health care professional?

Early-Stage Dementia

- Are there any medications, treatments or lifestyle changes that could help my, or my loved one's, memory and thinking?
- How can we help our loved one stay active and connected?
- Should I, or my loved one, still be driving?
- Is all our legal paperwork in order?

Mid-Stage Dementia

- What can I do to make the home safer?
- What can we do if our loved one won't stop driving?
- Where do we get help in coping with behaviors?
- What services might help and where do I find them?
- How can I make my loved one's life more enjoyable?

Late-Stage Dementia

- What can we do to promote quality of life?
- What kind of care is best for my loved one?
- What do we want in terms of medical care at the end of our loved one's life?

Adapted with permission from the Dementia Action Collaborative's *Dementia Road Map: A Guide for Family and Care Partners*

Alzheimer's Disease and Related Disorders Commission

This publication is illustrated with details taken from artworks created by people living with dementia participating in the Opening Minds Through Art program. See page 34 for more information on this program.

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Virginia Dementia Road Map
3

Dementia Road Map

Wondering and Worried



"Caregiving isn't just about the feeding, the changing of clothing, the medical appointments. It's about the special time you have with them. The one on one. It may not be a word spoken. It might just be holding hands. Let them feel your presence and your love."
—Janie S.

What should you expect in this stage?

You notice changes in your own or your loved one's memory, and thinking, but they may or may not affect daily life activities. For example, you may notice:

- Difficulty performing more than one task at a time.
- Difficulty solving complex problems or making decisions.
- Forgetting recent events or conversations.
- Taking longer to perform more difficult mental activities such as using the computer.
- Your loved one is likely concerned but may not discuss it. Other friends and family may or may not see or notice any changes.

You may be wondering

- Is everything OK?
- Should I or my loved one be checked by a health care professional?
- Have I, or has my loved one, completed an annual cognitive evaluation?
- What if my loved one won't go to a health care professional?

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Wondering and Worried

What you can do:

- Learn about normal changes with aging and those that indicate a need to get a check up. See the "10 Warning Signs" on page 23.
- If you're worried about changes in yourself, consider sharing your concerns with family, friends or your health care professional.
- Keep track of changes you notice. If your loved one doesn't bring it up, find the right time and a sensitive way to discuss these changes with them—get it out in the open.
- Ask your loved one to have a complete medical check-up. It's important to know if memory and thinking changes may be caused by something that could be treated or reversed. Even if not, it's best to know what you're dealing with.
- If your loved one is resistant to a medical check-up, enlist the help of trusted family or friends who may be able to encourage this.
- Call and ask your loved one's health care professional for the Medicare Annual Wellness exam (if they are on Medicare) that includes detection of cognitive impairments along with other screenings. Feel free to share with the professional what you've noticed either in person or in a letter.
- If you don't feel comfortable with your loved one's current health care professional, try to find a new one. Most primary care professionals can diagnose dementia. But

If you're looking for a specialist, contact the Alzheimer's Association to help identify providers in your area or check for a Memory Assessment Center on vda.virginia.gov/dementia_resources.htm

- Consider enrolling in a clinical trial or research study on dementia at a university or memory clinic. You and your loved one may advance our understanding of dementia.

ACTION STEPS

The following steps are important at this point:

- Obtain a medical assessment to find out what may be causing the problems.
- Complete health care planning documents. You and your loved one should have:
 - o A Health Care Directive (also called a "living will" or "advance directive" regarding treatment preferences); and
 - o A Durable Power of Attorney for Health Care, appointing a health care "agent."
- Complete a General Durable Power of Attorney document. In this document, you/your loved one appoints an "agent" to assist with financial and related matters.
- Complete an estate plan. Your loved one's estate plan may include legal documents such as a will or a trust that direct the disposition of their estate upon death.
- Have a family meeting to discuss what's happening and necessary next steps.

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Dementia Road Map

Caring for the Care Partner



"My daughters, they kept saying, "Mom, you need to get some help to come in to help you." And I was like, "I'm okay. I'm okay, right now." But last month, two... three weeks now, I did seek help. And that gives me a chance to go out. Run errands and whatever. As a matter of fact, went to a movie Saturday evening. It was awesome."
—Rosie H.

Caring for yourself is one of the most important things you can do as a care provider for your loved one. When your needs are taken care of, your loved one will benefit too. You can do this by asking family members or friends to help out, taking time to do things you enjoy, using respite services such as adult day programs, or getting help from a home health care agency. Taking these actions may provide you with relief and can help prevent you from getting ill or depressed.

Since the Covid-19 pandemic, many more services and supports are available virtually, such as virtual support groups, potentially giving you more options. Contact the agencies and referral sources on the next pages for more information

Resources



GENERAL ASSISTANCE AND REFERRALS

Virginia 2-1-1	211
Department for Aging and Rehabilitative Services	800-552-3402
Alzheimer's Association 24/7 Helpline	800-272-3900
Alzheimer's and related Dementias Education and Referral Center (ADEAR Center)	800-438-4380
DARS Dementia Services	804-662-9154

VIRGINIA'S NETWORK OF AREA AGENCIES ON AGING

Agency Name/Website	Counties/Cities served	Phone number
Appalachian Agency for Senior Citizens http://www.aasc.org/	Buchanan, Dickenson, Russell, Tazewell	276-964-4915 1-800-656-2272
Arlington Agency on Aging www.arlingtonva.us/aging	Arlington	703-228-1700
Bay Aging http://www.bayaging.org/	Essex, Gloucester, King and Queen, King William, Lancaster, Mathews, Middlesex, Northumberland, Richmond (County), Westmoreland	804-758-2386 866-758-2386
Central Virginia Alliance for Community Living (CVACL) https://www.cvocl.org	Amherst, Appomattox, Bedford, Campbell, Lynchburg	434-385-9070
City of Alexandria Aging and Adult Services https://www.alexandriava.gov/Aging	Alexandria	703.746.5999
Crater District Area Agency on Aging http://www.cdaaa.org	Colonial Heights, Dinwiddie, Emporia, Greenville, Hopewell, Petersburg, Prince George, Surry, Sussex	804-732-7020 888-732-7020
District Three Governmental Cooperative http://www.district-three.org	Bland, Bristol, Carroll, Galax, Grayson, Smyth, Washington, Wythe	276-783-8157 1 800 541 0933
Eastern Shore Area Agency on Aging/ Community Action Agency https://www.esaaa-caa.net/	Accomack, Northampton	757-442-9652 800-452-5977
Fairfax Area Department of Family Services https://www.fairfaxcounty.gov/familyservices/older-adults	Fairfax (City/ County), Falls Church	703-324-7948

Dementia Safety Information Toolkit




Safety Concerns for People Living with Dementia

Not all memory loss is due to dementia. Memory loss and/or confusion may be a result of many conditions, some of which are reversible. If you or someone you know has memory loss or confusion that's getting worse, it's important to talk with a health care professional about it. If it does turn out to be dementia, there are steps you can take to live well, and plan for a future with it.

Dementia affects each person differently, but symptoms typically include increasing memory loss, confusion, and disorientation. Changes in the brain can also impact how individuals interpret what they see, hear, feel, taste or smell, and their sense of time, place and judgment – each of which can impact safety.

The best environment for a person living with memory loss or dementia is one that helps them feel as independent and supported as possible. For people living with dementia wanting to stay at home, it's key to find the right balance between independence and safety – and to anticipate changes. With creativity and flexibility, it's possible to make adaptations that make the home safer and less stressful for all.



This "Info Kit" is a resource for family members and caregivers to assist in evaluating the home and taking steps to promote safety over the course of dementia. Materials highlight information and tips related to the following:

1. Home Safety
2. Falls Prevention
3. Driving
4. Wandering
5. Emergency Preparedness
6. Elder Abuse & Financial Exploitation

You may click on the links provided below each resource to view or print the information yourself. When a computer icon appears, the information is intended to be viewed online, and not in a printable format.

IT'S HELPFUL TO PLAN AHEAD: PUT SAFETY MEASURES IN PLACE BEFORE THEY'RE REALLY NEEDED

Adapted with permission from the Washington State Dementia Action Collaborative 9/2021

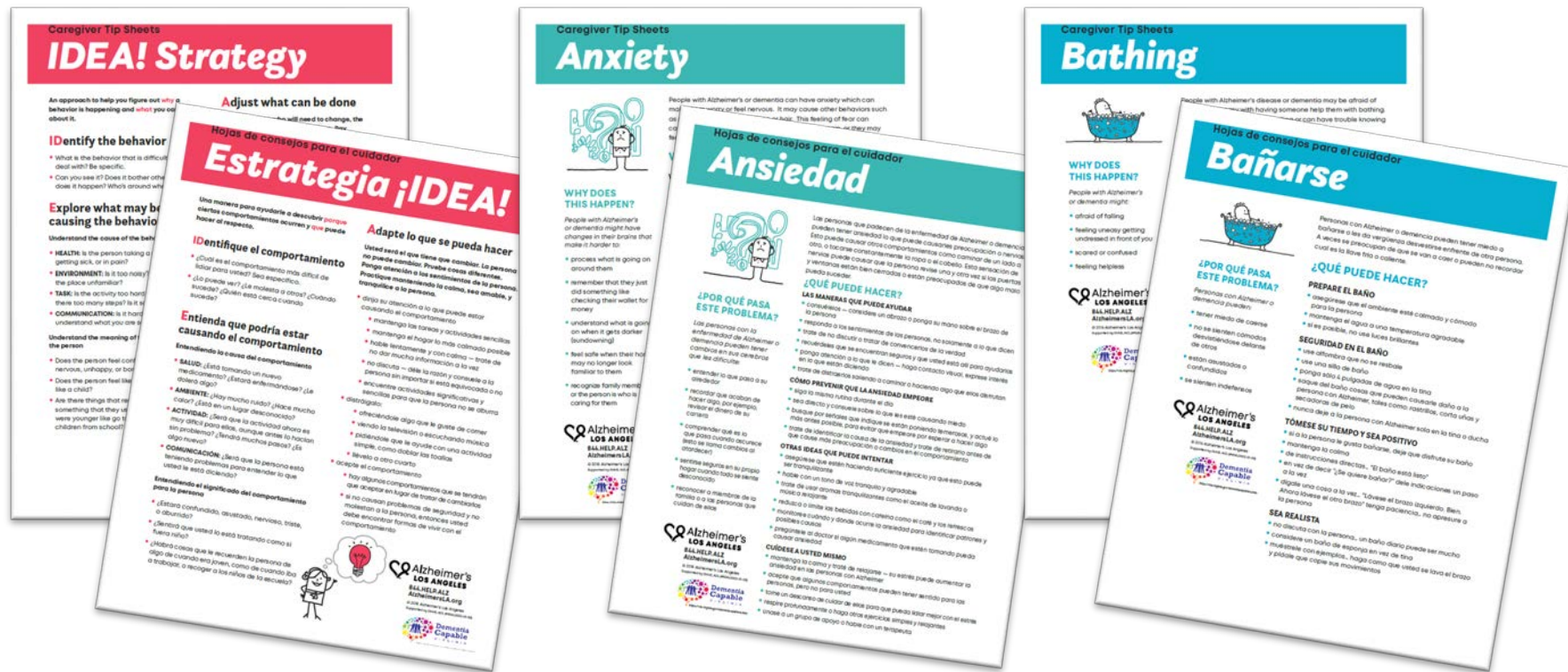
Information for families on keeping people living with dementia safe including:

- Home safety
- Falls prevention
- Driving
- Wandering
- Emergency preparedness
- Elder abuse and financial exploitation

Available on <https://vda.virginia.gov/dementia.htm>

Caregiver Tip Sheets

Addressing specific challenges for people living with dementia and caregivers



Resources on the web

Alz.org: Alzheimer's Association

- Many training and learning opportunities

Riverside CEALH: Caring for You, Mind Body and Soul (microlearning)

- <https://www.youtube.com/playlist?list=PLe-5WRxibSCnCxnlGwVtCspEl6JQ5vleH>

Teepa Snow Positive Approach to Care Teepasnow.com

- Many videos available on YouTube

Dementia Careblazers Careblazers.com

- on YouTube

Improv and dementia: Karen Stobbe: Team In the Moment

- <https://beinginthemoment.org/>
- https://www.youtube.com/watch?v=GciWltvLo_s&t=3s



Dementia Friendly Initiatives

HELPING RAISE AWARENESS AND REDUCE STIGMA

Why Dementia Friendly?

AWARENESS

STIGMA



Dementia Friendly Initiatives



A Member of the Dementia Friendly America Network



Dementia Friendly Communities



Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day to day living.

- A key component of dementia capability
- Led nationally by USAging
- AAAs often take a leading role or provide key support
- Statewide workshop in April 2018 to kick start Dementia Friendly Virginia
- LeadingAge Virginia and DARS leading the effort
- Can be one community, a county, a region

Dementia Friendly Communities



Brain Health Education

VIRGINIA BOLD PUBLIC HEALTH GRANT

Partners

VDH ALZHEIMER'S  **ASSOCIATION®**



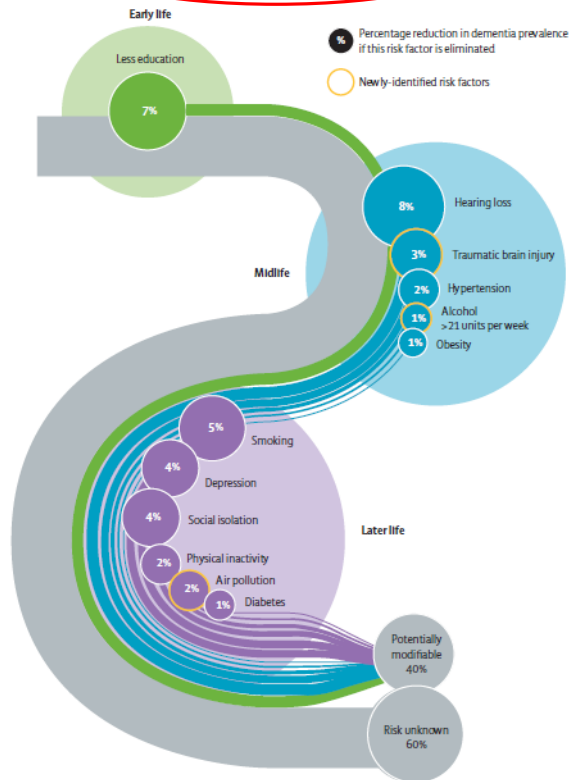
LeadingAge®
Virginia



Why is brain health important?

Risk factors for dementia

An update to the *Lancet* Commission on Dementia prevention, intervention, and care presents a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias



a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias

Risk factors for dementia

Early Life	(7%)	Less education (7%)
Midlife	(15%)	HEARING LOSS (8%) Traumatic brain injury (3%) Hypertension (2%) Alcohol (1%) >21 units per week Obesity (1%)
Later Life	(18%)	Smoking (5%) Depression (4%) Social Isolation (4%) Physical inactivity (2%) Air pollution (2%) Diabetes (1%)

Goal: Improve Virginia's Brain Health



- Revamping [Healthy Brain Virginia](https://vdh.virginia.gov/brain-health) website:
vdh.virginia.gov/brain-health
- Incorporating brain health information into existing public health campaigns
- Supporting early detection and diagnosis
- Mini-grants to foster local innovation
- Supporting dementia education and training



State and Local Public Health
Partnerships to Address Dementia:
The 2018-2023 Road Map



alzheimer's
association

Contact Details

George Worthington
Dementia Services Coordinator

george.worthington@dars.virginia.gov

804-662-9154

<https://vda.virginia.gov/dementia.htm>

<https://vda.virginia.gov/DementiaCapableVA.htm>