

Virginia Dementia State Plan 2024-2027

Building a Dementia Capable Virginia

Virginia Alzheimer's Disease and Related
Disorders Commission

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List of Acronyms

ADRD:	Alzheimer's Disease and Related Disorders
ADPI:	Alzheimer's Disease Program Initiative
AHEC:	Area Health Education Center
ARDRAF:	Alzheimer's and Related Diseases Research Award Fund
BOLD:	Building Our Largest Dementia (Infrastructure)
BRFSS:	Behavioral Risk Factor Surveillance System
CSB:	Community Services Boards
DARS:	Department for Aging and Rehabilitative Services
DBHDS:	Department for Behavioral Health and Developmental Services
DD:	Developmental Disabilities
DMAS:	Department of Medical Assistance Services
DSS:	Department of Social Services
HCBS:	Home and Community Based Services
IADRP:	International Alzheimer's Disease Research Portfolio\
MCI:	Mild Cognitive Impairment
PACE:	Program of All-Inclusive Care of the Elderly
VDH:	Virginia Department of Health
VMP:	Virginia Memory Project



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January 1, 2024

The Honorable Glenn Youngkin and Members of the Virginia General Assembly:

The Alzheimer's Disease and Related Disorders Commission is pleased to present the *Dementia State Plan 2024-2027: Building a Dementia-Capable Virginia*.

The Commission has revised and updated the Dementia State Plan in collaboration with researchers and stakeholders, and through a statewide Dementia Capable Summit. Additionally, the Commission accepted comments from the public by phone, mail, and e-mail from August 1, 2023, through August 31, 2023.

An estimated 150,000 Virginians were living with Alzheimer's disease or another form of dementia in 2020, and this number is forecast to rise to 190,000 by 2025. A fully realized Plan would ensure the services and supports they will need are available. This Plan also contains a new, sixth goal to address brain health and dementia risk reduction that should help prevent some of the projected increase in dementia over coming decades. The six goals offer a comprehensive vision of a dementia-capable Virginia:

1. Coordinate quality dementia services to ensure dementia-capability.
2. Use dementia-related data to support policy development and service provision, and to improve public health outcomes.
3. Increase awareness and promote dementia-specific training.
4. Provide access to quality coordinated care for individuals living with dementia in the most integrated setting.
5. Expand resources for dementia-specific translational research and evidence-based practices.
6. Enhance brain health and address modifiable risk factors for dementia.

To continue building a dementia-capable Virginia, the Commission has developed recommendations and strategies that will be overseen by focused workgroups based within the Commission to facilitate the realization of the six goals. The Commission will evaluate and track progress on the recommendations and looks forward to reporting accomplishments under the Plan in the future. Although achieving the vision contained in the Plan will likely require additional resources, progress toward the goals can also be made through innovation and collaboration with stakeholders across the Commonwealth. We welcome your thoughts and ideas. To share them with the Commission, please contact any of the Commission members or staff at the Virginia Department for Aging and Rehabilitative Services.

Sincerely,

Lana Sargent, Chair
Alzheimer's Disease and Related Disorders Commission

Vision

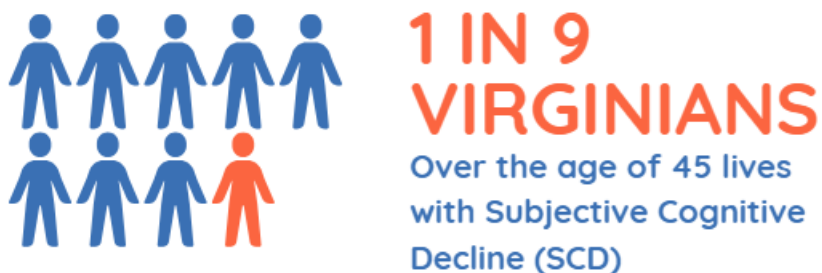
The Alzheimer’s Disease and Related Disorders Commission, and its partners, envision a dementia-capable Virginia that provides ethical, person-centered, evidence-based, and high-quality care across the continuum of the disease through a coordinated system that meets the needs of individuals of any age living with dementia and their caregivers. Through raising understanding of the importance of addressing brain health and the modifiable risk factors for dementia, the Commission strives to reduce the future burden of dementia in the Commonwealth.



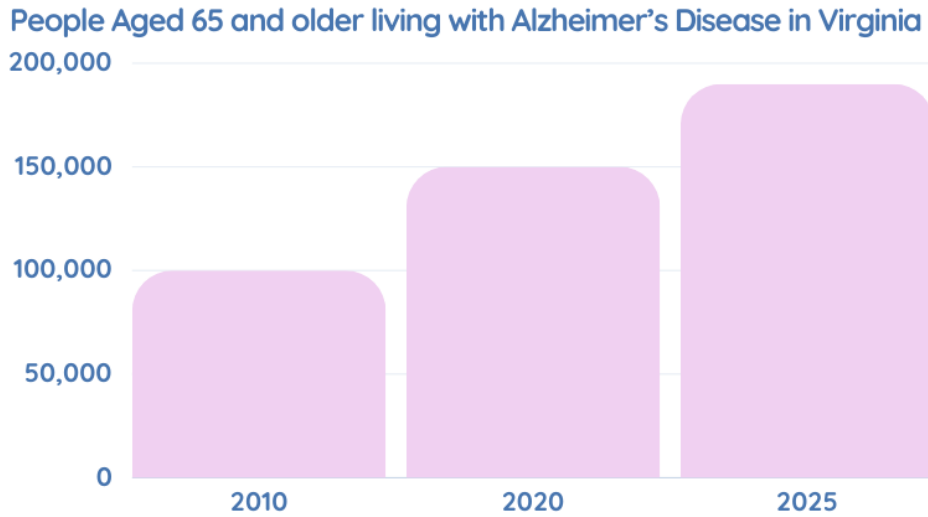
Plan History

Since 1982, the Alzheimer’s Disease and Related Disorders Commission (the Commission), has advised the Governor and the General Assembly on the needs of Virginians living with dementia and their caregivers, and on policies to meet those needs. The Commission has a total of twenty appointed and ex-officio members and has the powers and duties described in the Code of Virginia [§ 51.5-154](#) (see page 46). In 2011, the Commission published Virginia’s first Dementia State Plan as a blueprint for fully meeting the needs of Virginians of all ages living with dementia, their families, and their care partners.

This version of the Plan, covering 2024-2027, is the fourth iteration, and reflects the many developments in services, treatments and prevention since



the first Plan was published. It also seeks to support the increase in the number of Virginians living with dementia since 2011. That rose from an estimated 100,000 Virginians over the age of 65 living with Alzheimer’s disease in 2010 to 150,000 in 2020, and that number is expected to reach 190,000 by 2025 (Alzheimer’s Association, 2023a). In 2019, roughly 300,000, or 1 in 9, Virginians over the age of 45 reported that they were living with changes to their thinking or memory that they felt were getting worse over time, known as Subjective Cognitive Decline (SCD, CDC, 2021). Many more Virginians under the age of 45 are also living with dementia, including young children, people living with Down syndrome or Trisomy-21, and those affected by younger-onset Alzheimer’s disease (see box *Dementia at Any Age*). These numbers speak to the importance of implementing the Dementia State Plan.



Source: Alzheimer's Association, 2023a.

The Dementia State Plan provides a blueprint for a fully dementia capable state. The concept of **dementia capability** means being skilled in identifying people with possible dementia and working effectively with them and their care partners or caregivers through the stages of their disease (Alzheimer's Association, 2019). Guided by the Plan, the Commission has achieved much over the past thirteen years to improve Virginia's dementia capability and ultimately to improve the quality of life for those who are living with this condition.

For example, the first strategy of the first Dementia State Plan was to create the position of Dementia Services Coordinator (DSC). Since 2013, when the General Assembly first funded this position at the Department for Aging and Rehabilitative Services (DARS), the DSC has supported the Commission in its efforts to realize the Plan, increased grant funding to support new programs that help individuals living with dementia and their caregivers and care partners, and spearheaded efforts to expand knowledge and awareness of dementia and related issues among all sectors of the community, from first responders supporting people in moments of crisis, to community members worried about their neighbors.

Dementia at Any Age

The symptoms of dementia can affect people at any age. While they are most common in older people, children with rare genetic conditions, people living with Trisomy 21 (Down syndrome) and those affected by younger onset Alzheimer's disease experience symptoms at much younger ages.

Childhood dementias, although rare, are devastating neurological disorders that affect the cognitive and physical abilities of children. These disorders, also known as pediatric neurodegenerative diseases, lead to the progressive degeneration of brain function, resulting in severe impairment of memory, thinking, behavior, and motor skills. Managing childhood dementias poses significant challenges for families and healthcare providers. Research into these disorders is ongoing, aiming to understand their underlying causes and develop potential treatments to improve the quality of life for affected children and their families.

Down syndrome dementia, also known as Alzheimer's disease in individuals with Down syndrome (DS-AD), occurs earlier and more frequently in people with Down syndrome due to an extra chromosome 21. Symptoms mirror Alzheimer's but often appear in their 40s-50s, including memory loss, personality changes, and difficulty with daily tasks. The progression can be rapid, impacting their independence and requiring specialized care. Families and caregivers face unique challenges due to communication barriers and specific needs. Supportive environments, early detection, and tailored interventions, like cognitive therapies, aim to enhance their quality of life and comfort while managing the complexities of DS-AD.

Younger onset dementia affects individuals under 65, challenging careers, relationships, and independence. Symptoms vary but often include memory loss, mood swings, and difficulty with daily tasks. The impact on families can be profound, disrupting financial stability and caregiving roles prematurely. Diagnosis delays are common due to rarity and misattributed symptoms, adding strain to coping mechanisms. Support groups and specialized services address unique needs, promoting social connection and tailored care. Early diagnosis aids in planning and accessing appropriate resources, aiming to sustain quality of life and dignity while navigating the complexities of dementia at a younger age.

Supporting Virginians Living with Dementia

Innovative programs to support both individuals living with dementia and their caregivers have been devised or adapted and piloted in Virginia using a mix of federal, state, local and private funding, and the DSC continually looks for opportunities to increase the range of evidence-based and evidence-informed programs available in the state. Efforts to train the workforce help increase the awareness and understanding of dementia-related issues that first responders, healthcare workers, service providers and others may encounter. The DSC has identified and utilized data sources such as the annual Behavioral Risk Factor Surveillance System (BRFSS) to better inform policy at the state and local levels. Like most other states, Virginia now regularly includes the optional Cognitive Decline and Caregiving modules in this survey that examines health risks generally. Analysis of the data permits a greater understanding of the health profile of people living with dementia and their caregivers.

The DSC also supports and maintains the [Dementia Capable Virginia](https://vda.virginia.gov/dementia.htm) webpage (<https://vda.virginia.gov/dementia.htm>), which offers a range of high-quality resources for individuals, unpaid and paid caregivers, primary care and other health providers, community support providers, and researchers. This page, launched in 2022, adds to the range of information and resources available through DARS Dementia Services (see box on next page).

The Commission sees **care coordination and care navigation** services as vital in Virginia for providing a link between individuals and families living with dementia, and the range of care, supports and services available to them. Navigating the array of health care options and home and community-based services is difficult as the system is fragmented and complex. Many people do not know where to start. The model on page 15 of a **lifecourse approach to dementia**, starting with the preclinical stage and moving through mild cognitive impairment and the various stages of dementia, seeks to respond to the needs of individuals and families at each step. Of particular concern is the behavioral crisis stage, which not all individuals will encounter, but which often marks a sharp shift in support options available.

Resources on Dementia Capable Virginia

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



Dementia Capable Virginia is Virginia’s website for dementia-related resources aimed at individuals and families, providers, and research participants and researchers. The page is broken into three sections: Resources for Individuals and Families, Resources for Providers (including healthcare and community services providers) and Resources for Researchers.

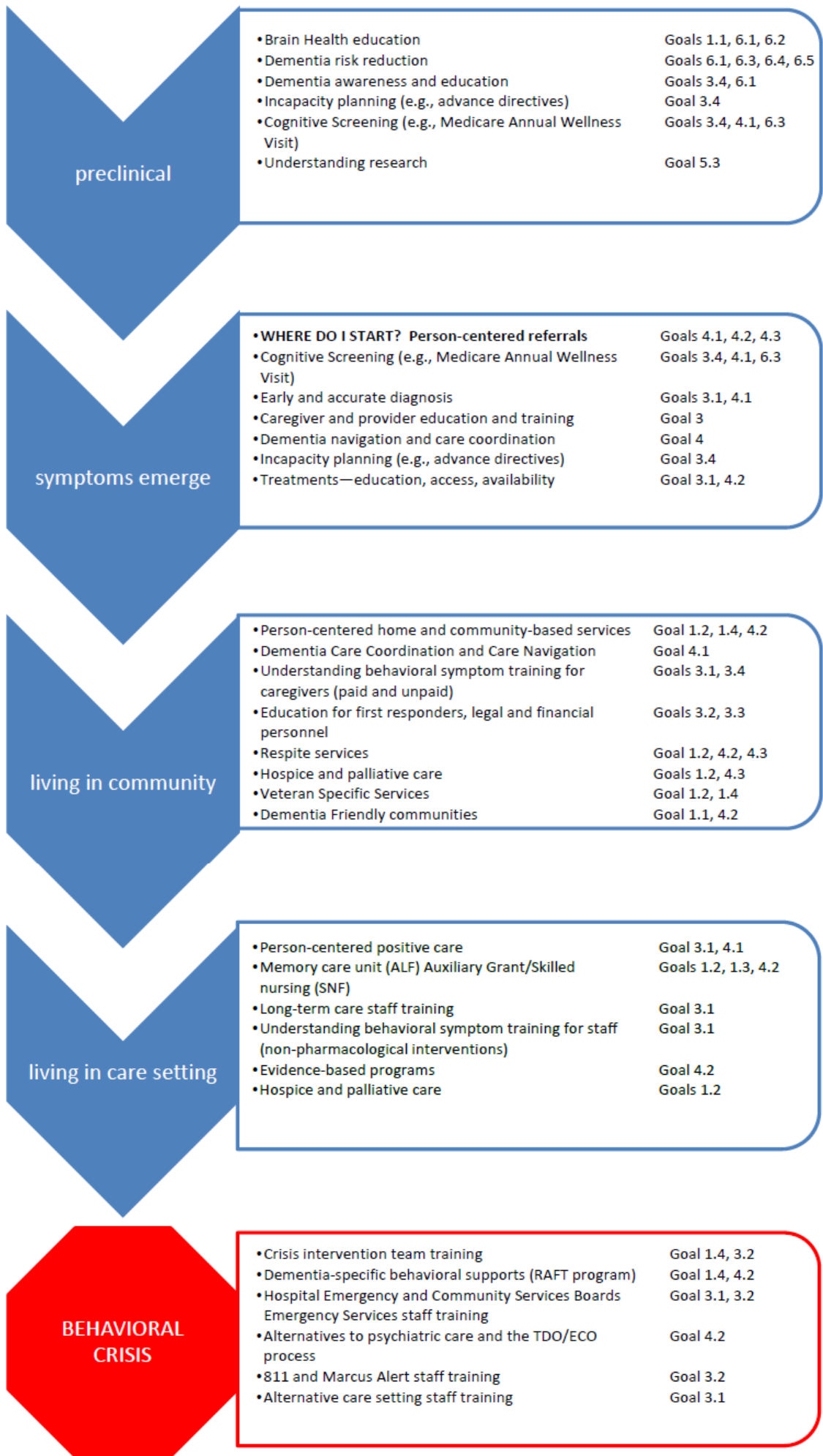
Since launching in April 2022, Dementia Capable Virginia has seen strong demand for its resources for individuals. These include the ***Virginia Dementia Road Map***, an adaptation of a similar publication from Washington State. The Road Map contains a stage-by-stage guide to dementia, including what to expect, what you can do, and recommended, concrete action steps at each stage. Virginia added a caregiver self-care section and information about younger-onset Alzheimer’s disease, among other things. Highlighting the potential for a good quality of life with dementia, all the art in the Road Map was created by people living with dementia through an evidence-based program called Opening Minds Through Art.

Additionally, Dementia Capable Virginia offers eighteen caregiver information sheets covering specific topics such as wandering, driving and agitation. There is a home safety information toolkit that includes information about elder abuse, exploitation and neglect in addition to information for keeping loved ones safe from wandering, driving and falls. In 2023, a set of four cobranded guides to advance planning for health care, financial planning, care planning and supported decision making was added to Dementia Capable Virginia. These guides were developed by the National Alzheimer’s Disease Resource Center supported by the Administration for Community Living.

The **Alzheimer’s and Related Diseases Research Award Fund (ARDRAF)**, administered by the Virginia Center on Aging, helps make Virginia a leader in supporting vital research into the diseases that cause the symptoms of dementia, such as Alzheimer’s disease, and into services and supports that can improve the quality of life for those living with dementia and their caregivers. This program has been funding pilot research projects across the Commonwealth since 1982 that have often gone on to secure federal funding for larger research efforts. The \$5.33 million awarded to date by ARDRAF has seeded a further \$45.6 million in further research funding, earning a return of nearly \$10 for every \$1 invested by the General Assembly, and resulted in 313 scientific and professional publications.



Lifecourse Model: Dementia Awareness, Supports and Services



Dementia and Public Health

The previous Plan published in 2019 incorporated strategies and objectives to bring a public health lens to dementia as a chronic condition. Public health focuses on four levels of prevention: primordial, primary, secondary and tertiary. Primordial prevention involves intervening at a societal level to reduce risks of developing a disease through a focus on social and environmental conditions. Primary prevention involves intervening before any symptoms occur with an emphasis on particularly at-risk populations. Secondary prevention focuses on early detection and diagnosis, through measures such as screenings. Finally, tertiary prevention is aimed at treating or reducing the effects of an established disease (Kisling & Das, 2023).

In the context of dementia, primordial prevention involves addressing social determinants of health that can increase future risk of developing dementia, particularly education, physical activity and nutrition. Primary prevention involves educating the public, and particularly groups with a higher incidence of dementia (see Risk factors below), on brain health and lifestyle changes that can reduce dementia risks. Secondary prevention involves regular cognitive screenings and supporting optimal health through regular visits to physicians and understanding the importance of, for example, cardiovascular health given its implications for future dementia risk. Tertiary prevention will increasingly involve treatments for people at all stages of the disease process (though current treatments are typically aimed only at people in the earliest stages of cognitive decline, see box on page 22) and ensuring a high standard of care, services, and supports is available to everyone living with cognitive decline and dementia, and their caregivers and care partners.

The Covid-19 pandemic demonstrated the importance of the public health system, particularly for people living with dementia. Public health measures, such as closing long-term care facilities to visitors to protect their residents, often had unintended consequences, such as depriving people living with dementia of much-needed social engagement and the extra care tasks that may be provided by unpaid caregivers. The pandemic had a disproportionate impact on people living with dementia, with deaths among this population surging in 2020 and 2021 (see box on next page).

Covid-19 and Dementia

The COVID-19 pandemic disproportionately impacted people living with dementia. As a vulnerable population, individuals living with dementia faced increased risks due to their age and underlying health conditions, and the death rate of people living with dementia surged as a result. The pandemic also disrupted their routines and access to essential services, leading to heightened confusion, anxiety, and distress. Covid-19 has also been implicated as a dementia risk factor, with the disease having the potential to add to long-term cognitive decline, and possibly worsening any predisposition to dementia (Pyne & Brickman, 2021).

Social isolation measures, crucial for containing the virus, resulted in decreased social interactions, exacerbating feelings of loneliness among people living with dementia. Caregivers, often family members, faced unprecedented challenges as day care centers and support services closed, placing additional stress on both the caregivers and their loved ones.

Additionally, the pandemic strained healthcare systems, affecting timely diagnosis and medical care for people experiencing the changes associated with dementia. Access to vital resources such as respite care and mental health support became limited, impacting the overall well-being of both individuals and their caregivers.

Furthermore, the shift towards telemedicine, while essential for minimizing virus transmission, posed difficulties for individuals living with dementia, many of whom struggle with technology. This digital divide hindered access to medical consultations and support services.

Brain Health and Dementia Risk Reduction

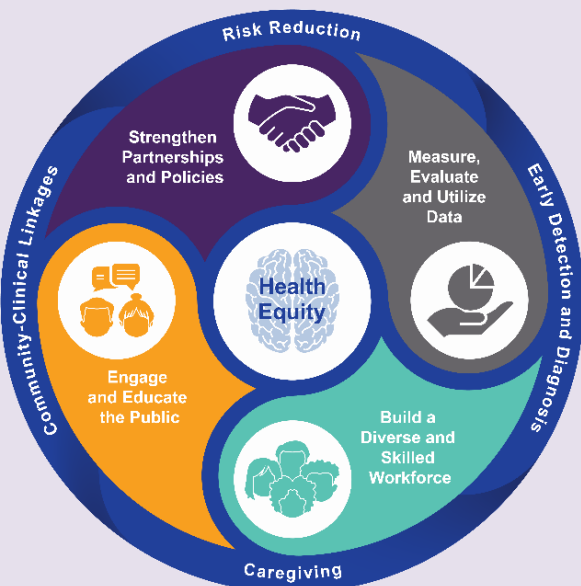
This Dementia State Plan incorporates a rapid increase in knowledge and understanding about brain health and dementia risk reduction. At a national level, the Alzheimer’s Association and Center for Disease Control and Prevention’s (CDC) Healthy Brain Initiative (HBI, see box on next page) and the associated Building Our Largest Dementia (BOLD) Infrastructure act are supporting efforts to reduce the future prevalence of dementia through addressing the modifiable risk factors of dementia and improving brain health. Virginia was one of five states to receive an enhanced award in the initial funding round in 2020. That three-year project, led by the Virginia Department of Health as the state’s public health agency, in partnership with DARS and the Alzheimer’s Association, ended in 2023, and Virginia received a further five years of funding for 2023-2028 to continue drive these efforts.

The Healthy Brain Initiative and the BOLD Infrastructure Act

The [Healthy Brain Initiative](#), established in collaboration between the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association (Alzheimer's Association and CDC, 2023), is a nationwide effort focusing on public health actions to address cognitive health as a vital component of aging. Launched in 2005, this initiative promotes policies and programs that encourage brain health, raise awareness about cognitive impairment, and support those affected by Alzheimer's disease and related dementias.

To help implement the Healthy Brain Initiative, the CDC introduced the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act grant opportunities in 2019. The Virginia Department of Health, the state's public health agency, has received two BOLD awards, a three-year award in 2019 and a five-year award in 2023. The funds are enhancing the state's capacity in addressing Alzheimer's and dementia-related public health issues. These grants support early detection and diagnosis, caregiver support, and the implementation of evidence-based interventions to promote brain health. BOLD grants also facilitate the development of supportive communities, ensuring access to resources and services for individuals living with dementia and their families.

Conceptual Framework for the Healthy Brain Initiative



Source: Centers for Disease Control and Prevention (CDC)

The combination of the Healthy Brain Initiative and BOLD grants highlights the significant commitment to public health strategies to address dementia. These initiatives encourage communities to take proactive measures in promoting brain health and supporting those affected by dementia, thereby fostering a more dementia-capable society.

The Healthy Brain Initiative Roadmap includes 24 actions in the four domains shown in the conceptual framework below: Strengthen Partnerships and Policies (P); Measure, Evaluate and Utilize Data (M); Build a Diverse and Skilled Workforce (W); and Engage and Educate the Public (E). These actions are listed on page 44 and are referenced throughout the Dementia State Plan to highlight the many areas where the Roadmap and the Plan align.

The focus on brain health driven by these efforts, and by studies that provide clear evidence of the impact of addressing the modifiable risk factors in reducing the chances of developing dementia (and/or slowing the progression of established disease), have prompted the inclusion of a new goal in the Dementia State Plan for the first time since its creation. This mirrors the addition of a similar goal in the National Alzheimer’s Plan in 2022 (United States Department of Health and Human Services, 2022). The new sixth goal addressing brain health and dementia risk reduction adds to the five standing goals that address state-level coordination of services; data collection; workforce and community training and education; coordinated care of people living with dementia and caregiver supports; and research.

In developing the Dementia State Plan, the Commission has taken an approach that addresses both the different stages of disease, from asymptomatic through to late-stage dementia, and the life stage model of risk reduction (see page 15), with interventions to address different risk factors particularly effective at certain points of the lifespan. For example, early in life, the main modifiable risk factor is education, with more years of formal education being associated with a reduced risk of developing dementia at any age (in addition to being protective by slowing the progression of disease). While the State Plan does not directly include strategies specifically aimed at helping support people to study for longer, it does include strategies such as incorporating brain health and dementia awareness education into middle- and high-school curricula.



What is dementia?

Dementia is an umbrella term referring to a collection of symptoms affecting thinking and memory caused by many different diseases. Some of these are progressive, neurodegenerative conditions such as Alzheimer’s disease and frontotemporal degeneration that currently have no effective treatments or cures. Others are potentially treatable, curable and reversible, such as hyperthyroidism, a vitamin deficiency, or a urinary tract infection (UTI). Additionally, the symptoms of dementia are sometimes approximated or mimicked by depression or delirium. As such, it is important to get symptoms checked out when they are noticed, as they may be treatable and reversible. Symptoms of dementia vary widely by individual and by the specific disease that is causing them, but typically include significant impairment in at least two of the following areas: memory, language and communication, ability to focus and pay attention, reasoning and judgment, and visual perception (Alzheimer’s Association, 2023b). When these impairments are severe enough to affect daily life (for example, paying bills), then dementia is present. Less severe impairment that is measurable but does not interfere with daily living is called **Mild Cognitive Impairment (MCI)**. MCI is a risk factor for dementia.



Alzheimer’s disease is the most common cause of dementia, accounting for 60-80% of all dementia cases (Alzheimer’s Association, 2023a). Other common diseases that cause dementia include vascular dementia, frontotemporal degeneration, dementia with Lewy bodies, and Parkinson’s disease dementia. As diagnostic tools improve, it has become clear that many people are experiencing multiple pathologies that are causing the symptoms, such as Alzheimer’s disease overlaid with vascular disease. These diseases are alike in that they attack and kill brain cells, resulting in a loss in brain volume and a progressive decline in abilities. Ultimately, these diseases are fatal, with Alzheimer’s disease the sixth leading cause of death in Virginia and the United States. Throughout this document, dementia will refer to

Alzheimer’s disease and related disorders that cause progressive declines in abilities resulting in death, rather than treatable, often reversible conditions that also cause the symptoms of dementia.

Risk Factors for Dementia

Risk factors for dementia may be modifiable or non-modifiable. According to *Dementia Prevention, Intervention, and Care: 2020 Report of the Lancet Commission* (2020), 60% of dementia risks at a population level are non-modifiable. Age is the most important non-modifiable risk factor, while others are genetic (e.g., APOE-e4 gene), family history, mild cognitive impairment (MCI), and environmental. However, up to 40% of worldwide dementias could be prevented by addressing the twelve modifiable risk factors summarized in the table below. At the same time, experience over the last few decades has borne this out to some degree. Hudomiet, Hurd and Rohwedder (2022) showed a decline in the age-adjusted prevalence of dementia in the United States from 12.2% in 2000 to 8.5% in 2016 using data from the national Health and Retirement Survey. The authors noted that more average years of education in the 2016 sample likely accounted for nearly half of the reduction in prevalence. These declines in prevalence were seen across populations, including non-Hispanic Black, non-Hispanic White and

Potentially Modifiable Risk Factors for Dementia

Stage of Life	Modifiable Risk Factor
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%)

Note: Percentages are population level risk levels.

Source: *Dementia Prevention, Intervention and Care: 2020 Report of the Lancet*

Hispanic individuals. Encouragingly, the declines were steeper for populations with higher prevalence such as non-Hispanic Black and Hispanic individuals.

Despite these declines in prevalence, the absolute numbers of individuals living with dementia is expected to continue to increase reflecting the rapid rise in the population aged 65 and over. There are also concerns that Covid-19 may prove to be a risk factor for dementia, potentially increasing future prevalence. In the US, the fastest growing segment of the population is the aged 85 and over cohort, where dementia affects between one in two or one in three people.

New treatments for Alzheimer's disease

Alzheimer's disease is the sixth leading cause of death in the United States and in Virginia, and the only one of the top ten causes that currently has no cure or treatment that can halt the progress of the disease.

Between 2020 and 2023, significant strides have been made in Alzheimer's disease treatments, offering a ray of hope to millions of patients worldwide. One notable breakthrough is the development of monoclonal antibody therapies. Since the previous Plan was published, two new monoclonal antibodies that have been shown to be successful at reducing the beta-amyloid plaques in the brain associated with Alzheimer's disease were approved for use by the Food and Drug Administration (FDA). While these do not stop the progression of Alzheimer's disease, they have been shown to slow its progression through clearing beta-amyloid plaque. These treatments are believed to show the most benefit for people who are early in the disease process, such as those experiencing Mild Cognitive Impairment or early-stage Alzheimer's disease.

Other potential disease-modifying treatments are in the pipeline, such as monoclonal antibodies that attack the tau pathology that is also associated with Alzheimer's disease. Researchers are hopeful that more disease modifying treatments will become available in the next few years, but caution that a multi-pronged approach using a cocktail of therapies will likely be necessary to stop or even cure neurodegenerative diseases such as Alzheimer's disease.

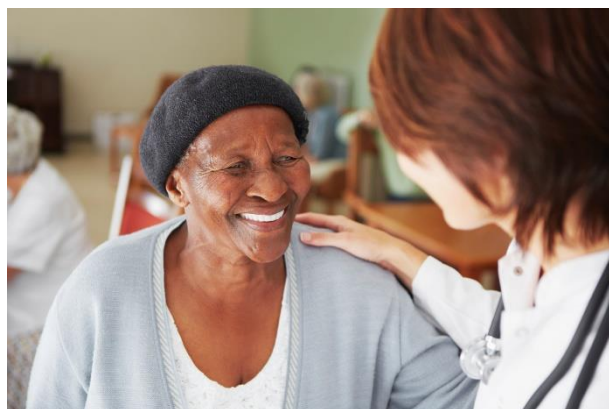
Dementia in Virginia

How many Virginians are living with dementia in 2024? The answer is not yet straightforward thanks to difficulties in collecting comprehensive data. Does this include only people with a diagnosis, or all of those experiencing changes in their cognitive skills? The Commission prefers an inclusive approach that considers all people experiencing cognitive changes related to dementia, many of whom will not have a diagnosis. The most comprehensive data source is the annual Behavioral Risk Factor Surveillance System (BRFSS) conducted by the Virginia Department of Health. According to the Cognitive Decline module, roughly one in nine Virginians over the age of 45 reported changes in their thinking or memory skills that were getting worse over time (CDC, 2021). This phenomenon is called Subjective Cognitive Decline (SCD). Roughly half of these people had not talked to a healthcare professional about the changes they reported experiencing.

These questions are included in the BRFSS only every three years on average and are only asked to people over the age of 45. The extrapolation to roughly 300,000 Virginians thus excludes anyone under the age of 45, such as those living with younger-onset Alzheimer’s disease, childhood dementias, or dementia related to developmental disabilities.

In 2022, the Virginia Memory Project launched an Alzheimer’s and Related Disorders registry and is working on improving data collection to provide answers to questions such as ‘how many Virginians are living with dementia’, ‘where are the areas of greatest need’ and others that can help drive policy implementation and better focus resources, services and supports.

The Alzheimer’s Association provides annual estimates of the number of people living with Alzheimer’s disease, caregiving statistics and other information in its annual Facts and Figures (Alzheimer’s Association, 2023a).



Dementia Friendly Virginia

DARS collaborates with LeadingAge Virginia as state co-leads for dementia friendly efforts through the Dementia Friendly Virginia initiative. Dementia friendliness is a key component of a robust dementia capable structure, as it includes efforts to help people living with dementia and their caregivers thrive in their communities, which can support their needs thanks to efforts to improve dementia capability.

Communities across the state continue to join others across the United States in fostering dementia friendliness by affiliating with Dementia Friendly America. While the pandemic hit the expansion of Dementia Friendly efforts and curtailed activities in many of the existing initiatives, one new community joined the national network in 2022 (Harrisonburg/Rockingham). Local communities continue to use virtual training and webinars to continue raising awareness and reducing stigma.

Dementia Friendly America provides tool kits, webinars, and other resources, but each community decides what it needs to do to better support people with dementia and their caregivers. Businesses and government agencies also can learn how to make their offices and stores safer and more inviting for people with dementia at www.dfamerica.org. The Commission included support for Dementia Friendly Communities in the Dementia State Plan 2020-2024 in recognition of this initiative's role in helping to achieve full dementia capability.

Dementia Friendly Communities and the allied Dementia Friends initiative help raise awareness of dementia and reduce stigma in the community, thereby helping to improve the quality of life for individuals living with dementia, their families and care partners. Since launching [Dementia Friends Virginia](#) in 2018, more than 650 Dementia Friends Champions have delivered 60-minute information sessions attended by more than 7,500 Virginians.



Plan Implementation and Evaluation

Implementation of the Dementia State Plan 2024 will be guided by the Alzheimer’s Disease and Related Disorders Commission, through workgroups tied directly to the Plan’s goals: Care Coordination (Goals 1 & 4), Data and Research (Goals 2 & 5), Training (Goal 3), and Brain Health (Goal 6). As part of the newly-funded BOLD project, in 2024 the workgroups will be collaborating with relevant state agencies including DARS and VDH to develop a workplan for the Plan that will include measurable outcomes. The Commission expects that this workplan will focus on strategies that are achievable within the Plan period (2024-2027), while progress on medium to longer-term strategies will also be monitored.

This is the first effort to tie Virginia’s Plan strategies directly to outcomes, and it is expected to serve as a model for Plan development and implementation in years to come. More information about Plan implementation and evaluation will be provided in the Commission’s Annual Report to the Governor and General Assembly that is published each year by October 1. This report is available through Virginia’s Legislative Information System (LIS) and on the DARS Boards and Commission’s webpage (<https://vda.virginia.gov/boardsandcouncils.htm>).



Key Accomplishments 2020-2023

Overarching

- In 2022, the ADRD Commission launched Dementia Capable Virginia, an initiative to present a single brand associated with high-quality dementia-related resources, services and supports, to replace alzpossible.org.
- In 2020, the Virginia Department of Health (VDH) received a three-year enhanced BOLD grant from the Centers for Disease Control and Prevention. Key partners in the effort to implement the Healthy Brain Initiative and embed brain health and dementia risk reduction messaging and awareness in the public health system included DARS and the Alzheimer's Association.
- Using funds from the BOLD grant, VDH, DARS and the Alzheimer's Association updated and relaunched the Brain Health Virginia website.
- Supported by VDH, the Virginia Center on Aging, and DARS, the ADRD Commission held the 2023 Virginia Dementia Capable Summit, the first statewide gathering of dementia stakeholder to learn about, and provide input into, the Dementia State Plan. A key topic was the development of the Plan's newest goal to address brain health and the modifiable risk factors for dementia.
- In 2023, the Virginia Department of Health received a further five-year BOLD grant to continue efforts to implement the Healthy Brain Initiative. The grant will fund the development of an implementation plan for the Dementia State Plan among other activities in partnership with the ADRD Commission and DARS.

Coordinated Care

- In 2019, DARS received a Geriatric Training and Education grant from the Virginia Center on Aging to train 20 facilitators in the evidence-based Dealing With Dementia workshops for family caregivers. The grant additionally supported the purchase of workshop materials to permit 780 family caregivers to attend the sessions at no cost.
- In 2021, the General Assembly funded a pilot program of Dementia Care Management at the University of Virginia's Memory and Aging Care Clinic in collaboration with the Alzheimer's Association. Funding was increased from \$150,000 to \$262,500 per year in 2022 to support 88 families annually in the program, which uses the evidence-based Benjamin Rose Institute Care Consultation intervention. The ADRD Commission and the Alzheimer's Association support increased funding to make this service available in more areas of the Commonwealth.
- The ADRD Commission adapted Washington State's Dementia Road Map for use in Virginia. The *Virginia Dementia Road Map: A Guide for People Impacted by Dementia*, was made available on the Dementia Capable Virginia

website. Printed copies were made available with the support of the Virginia Department of Health through the BOLD grant.

- In 2021, DARS received federal funding of \$1,349,480 to support the Virginia Lifespan Respite Voucher Program over five years.

Training

- In partnership with LeadingAge Virginia, the Dementia Friends initiative was rolled out across Virginia. Since 2018, more than 650 Dementia Friends Champions have been trained and more than 7,500 people have attended the one-hour information sessions to raise awareness and reduce stigma, including more than 1,500 people who attended Information Sessions led by the DSC.
- The ADRD Commission developed and published a Primary Care Dementia Toolkit to support primary care clinics in the detection, support and care of people living with dementia and their caregivers.
- The DSC provided Dementia Awareness training to seven cohorts of Virginia State Police Academy recruits totaling 278 participants.
- Through lifelong learning institutes and others, the DSC provided community education on dementia resources to 129 people, brain health and dementia risk reduction to 278 people.
- The DSC provided training on dementia capability to 115 professional caregivers in underserved areas of Virginia, and to 47 providers of services for people living with developmental disabilities.
- Dementia-specific training modules available on Dementia Capable Virginia developed for Area Agency on Aging staff were accessed more than 100 times, including by many from other service providers.

Data and Research

- In 2019 and 2022, Virginia included the optional Cognitive Decline module in the annual BRFSS survey.
- In 2019 and 2022, Virginia included the optional Caregiver module in the annual BRFSS survey.
- In 2019, the DSC reviewed data sources providing insight into dementia-related issues and updated the Interagency Data Collaboration report initially published in 2014.
- The ADRD Commission formed a special BRFSS workgroup to analyze and disseminate the results of the 2019 Cognitive Decline and Caregiver optional modules.

Dementia State Plan Goals and Objectives



GOAL 1 Coordinate quality dementia services in the Commonwealth to ensure dementia capability.

- Objective 1.1** Support and maintain the Dementia Services Coordinator position at the Department for Aging and Rehabilitative Services to oversee Virginia’s dementia capability.
- Objective 1.2** Expand availability of and access to dementia-capable Medicaid and other state-level administered services.
- Objective 1.3** Review state legislation and regulations for licensing of professions, facilities, and providers.
- Objective 1.4** Ensure state-funded services adopt person-centered, dementia-capable approaches and policies.



GOAL 2 Use dementia-related data to support policy development and service provision, and to improve public health outcomes.

- Objective 2.1** Collect and monitor data related to the impact of dementia on Virginians.
- Objective 2.2** Support the Virginia Memory Project (VMP) as it builds the Pathway to Care ADRD registry.
- Objective 2.3** Support data collection and analysis to demonstrate the benefits of care coordination for people living with dementia.



GOAL 3 Increase awareness and promote dementia-specific training.

- Objective 3.1** Promote dementia-specific training for medical, health, and social services workers to ensure dementia capability.
- Objective 3.2** Promote dementia-specific training for first responders.
- Objective 3.3** Promote dementia-specific training for legal and financial services personnel.
- Objective 3.4** Support care partners, family members, people living with dementia, and community members by providing educational information about dementia and available resources and services.



GOAL 4 Provide access to quality coordinated care for individuals living with dementia in the most integrated setting.

- Objective 4.1** Promote and support access to dementia care navigation services.
- Objective 4.2** Provide a system of integrated, coordinated, and diverse services to meet the needs of individuals living with dementia and care partners during the disease trajectory.
- Objective 4.3** Identify and coordinate supports for unpaid care partners to enhance well-being.



GOAL 5 Expand resources for dementia-specific translational research and evidence-based practices.

- Objective 5.1** Support Virginia's Alzheimer's and Related Diseases Research Award Fund (ARDRAF), especially projects that have a specific emphasis on "methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth" (§ 51.5-153).
- Objective 5.2** Provide support to researchers and interested stakeholders across Virginia.
- Objective 5.3** Promote the advancement of translational research, evidence-based practices, and research participation in Virginia.



GOAL 6 Enhance brain health and address modifiable risk factors for dementia.

- Objective 6.1** Work collaboratively with the Virginia Department of Health to implement the Healthy Brain Initiative.
- Objective 6.2** Support statewide and local initiatives to improve brain health measures and reduce the modifiable risks for dementia at the population and individual levels.
- Objective 6.3** Embed brain health and dementia risk reduction messaging and education across the lifespan.

GOAL 1 Coordinate quality dementia services in the Commonwealth to ensure dementia capability

Objective 1.1 Support and maintain the Dementia Services Coordinator position at the Department for Aging and Rehabilitative Services to oversee Virginia's dementia capability. (HBI P-1, P-3, P-5, P-6, P-7, M-4, M-5)*

Strategies

- Recommend policy and coordinate statewide data collection, research and analysis, and training and awareness efforts with the ADRD Commission.
- Collaborate and coordinate with the Brain Health Coordinator at the Virginia Department of Health to support a public health approach towards brain health and dementia across the lifespan.
- Support, maintain, and extend the resources, training, and information available through the [Dementia Capable Virginia](#) website and promote the Dementia Capable Virginia initiative statewide.
- Coordinate services and activities of state and local agencies, service providers, advocacy groups, first responders, law enforcement, and other entities throughout the state that engage individuals living with dementia and their care partners.
- Disseminate information on the Dementia State Plan and systems, services, and related activities for individuals living with ADRD through the DARS [Dementia Services](#) or [Dementia Capable Virginia](#) websites.
- Coordinate and provide support for ADRD Commission activities.
- Expand public engagement with the ADRD Commission through wider participation in committees and workgroups.
- Survey existing and new comprehensive memory assessment centers, share information about them with the public and provide professional development opportunities for center staff.
- Coordinate with LeadingAge Virginia to support and encourage creating Dementia Friendly communities across the state.

**Healthy Brain Initiative (HBI) Roadmap Actions are listed on page 44.*

Objective 1.2 Expand availability of and access to dementia-capable Medicaid and other state-level administered services. (HBI P-4, P-5, P-6, P-7)

Strategies

- Monitor and support the dementia capability of care coordination services provided by Cardinal Care Managed Care.
- Expand awareness, accessibility, and availability of adult day services, hospice, and palliative programs, the Program of All-Inclusive Care for the Elderly (PACE), and similar services.
- Increase funding for the [Virginia Lifespan Respite Voucher](#) program.
- Increase funding for home and community-based services (HCBS) offered through Area Agencies on Aging.
- Increase the payment rate of the Auxiliary Grant to cover the actual cost of care.
- Promote the awareness and use of Virginia's Long-Term Care Partnership Program.
- Increase funding for Virginia's State Long-Term Care Ombudsman program.
- Ensure the demand for public guardians is fully met.
- Promote the Virginia State Loan Repayment Program and advocate for a similar loan forgiveness program or tuition assistance for geriatric specialties.
- Promote awareness of the expanding network of Virginia [Veterans Care Centers](#).

Objective 1.3 Review state legislation and regulations for licensing of professions, facilities, and providers. (HBI W-3)

Strategies

- Review licensing and survey standards or protocols for long-term facilities and identify opportunities to improve dementia capability and quality through actions such as acuity-based staffing.
- As regulations are open for review, advocate and recommend that expected dementia care practice components be standard for assessments, service delivery, and training and oversight of medical and health professionals and paraprofessionals engaged in caregiving.
- Increase the availability of information on licensed professions, facilities, and providers for consumers, including information on dementia-specific training and programming.
- Review the overlapping requirements for licensing residential facilities, assisted living facilities, and nursing facilities to clarify the different levels of services and clarify the differences in admission disclosure documents.

Objective 1.4 Ensure state-funded services adopt person-centered, dementia-capable approaches and policies. (HBI P-3)

Strategies

- Ensure individuals living with dementia experiencing behavioral challenges have access to 24/7 crisis stabilization services. Partner with local Community Services Boards (CSBs), Area Agencies on Aging, DBHDS, and other stakeholders to deliver innovative crisis stabilization services in the most appropriate setting for people living with dementia.
- Expand programs like RAFT and the RAFT Dementia Support Program to all areas of the Commonwealth to support paid and unpaid caregivers in understanding and appropriately responding to challenging dementia-related behaviors.
- Integrate the Alzheimer’s Association [Dementia Care Practice Recommendations](#) into the development, delivery, and evaluation of services provided in Virginia.
- Ensure that Virginia’s No Wrong Door network is dementia capable.
- Incorporate dementia education into developmental disability (DD) services and provider training, and review waiver regulations and policies to accommodate the growing population of individuals with DD, including Trisomy 21 (Down Syndrome), and dementia who are served through state-funded programs.
- Support and promote collaborative efforts between Area Agencies on Aging, Community Services Boards, and Local Departments of Health and Social Services to address dementia-related challenges.
- Support increasing the number of diseases that can result in childhood dementia included in Virginia’s Newborn Screening Program.
- Conduct veteran specific outreach efforts in partnership with the Virginia Department of Veterans Services.
- Collaborate with the Department of Corrections to identify areas of support needed for incarcerated persons living with dementia.

GOAL 2 Use dementia-related data to support policy development and service provision, and to improve public health outcomes

Objective 2.1 Collect and monitor data related to the impact of dementia on Virginians. (HBI M-1, M2, M-5)

Strategies

- Monitor identified data sources, and identify and monitor new sources, to better understand the prevalence of dementia and its impact on families and specific populations in Virginia.
- Regularly share data findings with the public through infographics and other accessible formats.
- Support the regular implementation of the Behavioral Risk Factor Surveillance System's (BRFSS) Cognitive Decline and Caregiving modules.
- Coordinate with state licensing agencies to collect data on dementia prevalence, trends, and the characteristics of professions, facilities, and providers. Consider the extent to which internal agency policies could mandate data collection that captures the presence or absence of ADRD or offer financial incentives for entities that fully complete forms or assessments.

Objective 2.2 Support the Virginia Memory Project (VMP) as it builds the Pathway to Care ADRD registry. (HBI M-2)

Strategies

- Advocate for legislation to codify Virginia's ADRD registry.
- Collaborate with VMP to increase awareness and understanding of the need for and uses of a statewide ADRD registry.
- Utilize data from the VMP to inform program and service development and delivery.

Objective 2.3 Support data collection and analysis to demonstrate the benefits of care coordination for people living with dementia. (HBI M-2)

Strategy

- Track health outcomes and service utilization of persons living with dementia and their care partners to assess and analyze effectiveness and cost, including money saved through coordinated care.

GOAL 3 Increase awareness and promote dementia-specific training

Objective 3.1 Promote best-practice, dementia-specific training for medical, health, social services, and long-term care workers to ensure dementia capability. (HBI W-1, W-4)

A suggested topic list for dementia capable trainings is on page 42.

Strategies

- Collaborate with Area Health Education Centers (AHECs) and the Virginia Health Workforce Development Authority to incorporate required dementia-specific training into relevant professions' training curricula.
- Integrate dementia-specific training modules into existing trainings offered by agencies, including DARS, DBHDS, DMAS, DSS and VDH, and ensure their completion fulfills continuing education requirements.
- Promote the use of Project ECHO to improve dementia-related knowledge and capabilities of rural and regional healthcare workers, emphasizing accurate and early detection and diagnosis/referral.
- Promote virtual dementia tours or similar experiential training for all health care and long-term care workers.
- Collaborate with VDH to support dementia-specific training for community health workers.
- Collaborate with LeadingAge Virginia to promote the Dementia Friends Virginia initiative to health care and long-term care workers.
- Promote the use of the Advanced Certified Nurse Aide curriculum.
- Promote the use of the Certified Dementia Practitioner or similar designation.

Objective 3.2 Promote best-practice dementia-specific training for first responders. (HBI W-5)

Strategies

- Support funding for local and statewide efforts to deliver dementia-specific training to police, fire, emergency medical services, behavioral crisis response, and search and rescue personnel.
- Ensure that first responder training includes specific information on how interactions with people living with dementia may vary by type of dementia.
- Raise awareness and understanding of technology and services that can help prevent wandering, including Project Lifesaver.
- Provide dementia awareness training for the Virginia State Police.

Objective 3.3 Promote best-practice dementia-specific training for legal and financial services personnel.

Strategies

- Source and implement dementia-specific training suitable for legal services personnel, including general practice attorneys, prosecutors, judges, magistrates, victim advocates, and court clerks.
- Source and implement dementia-specific training suitable for financial services personnel, including bank tellers, accountants, financial advisors, loan officers, and collectors.

Objective 3.4 Support unpaid care partners, family members, people living with dementia, community members and community organizations by providing educational information about dementia and available resources and services. (HBI E-6, E-7)

Strategies

- Pursue a community-consultative approach to selecting or developing training and similar programs.
- Support [Dementia Capable Virginia](#) as a primary source for resources and information about ADRD.
- Link unpaid care partners to information and education about dementia and the caregiving process, including staying healthy, coordinating legal and financial issues, and locating and using respite care services, among other topics.
- Support best-practice, culturally-appropriate training programs for unpaid caregivers.
- Support Dementia Care Navigators in their role as community educators.
- Support family caregivers in coping with dementia-related behavioral challenges through person-centered education and training.
- Promote inclusive, culturally-appropriate caregiver support groups and link them with information and resources to share with participants.
- Consider the use of dementia-specific advance directives that could be used routinely in Virginia.
- Increase awareness and use of cognitive screening available through Medicare and other settings.
- Collaborate with LeadingAge Virginia to support and promote the Dementia Friends Virginia initiative to deliver dementia awareness education and reduce stigma.

GOAL 4 Provide access to quality coordinated care for individuals living with dementia in the most integrated setting

Objective 4.1 Promote and support access to dementia care navigation services.

Strategies

- Promote awareness of interdisciplinary memory assessment centers that serve Virginians through [Dementia Capable Virginia](#).
- Within interdisciplinary memory centers or community partners, establish and fund Dementia Care Navigators who provide care coordination services in addition to community screening and education.

Objective 4.2 Provide a system of integrated, coordinated, and diverse services to meet the needs of individuals living with dementia and care partners during the disease trajectory.

Strategies

- Promote the use of standardized protocols for referrals and follow-up care after screening or diagnosis of ADRD through [Dementia Capable Virginia](#).
- Support systems that promote integrated care between primary, acute, and long-term care settings and the transitions between them, with an emphasis on minimizing transitions, repeat hospitalizations, and emergency department visits.
- Support equitable access to effective treatments for Alzheimer's disease and other neurodegenerative conditions.
- Promote collaboration between primary care and care coordination or care navigator programs.
- Promote the implementation of regular medication reviews and reconciliation for people living with cognitive decline.
- Identify and remove barriers to community integration for people living with dementia in part by promoting and supporting dementia-friendly efforts.
- Promote geriatric emergency departments in hospitals.
- Advocate for accessible and innovative transportation systems.
- Promote and advocate for long-term care services that establish person-centered, homelike environments that incorporate the latest design research, such as that relating to acoustic and visual environmental impacts on people living with dementia.
- Support increased availability of Medicaid waiver services for children living with dementia.

Objective 4.3 Identify and coordinate supports for unpaid care partners to enhance well-being. (HBI E-7)

Strategies

- Identify and deliver, or support the delivery of successful, evidence-based programs that support family care partners through education, counseling referrals, respite, and other related supports.
- Through [Dementia Capable Virginia](#), provide information about financing the costs of long-term care through grants, insurance, and other programs.
- Through [Dementia Capable Virginia](#), provide information about the different services and supports available in the community, including the range of long-term services and supports, hospice and palliative care.
- Encourage the use of [Dementia Capable Virginia](#) and similar resources by employee assistance programs to help support individuals and family caregivers.
- Support the use of tax incentives to support caregivers with the purchase of technology, respite care services, and other costs associated with providing care in the home.

GOAL 5 Expand resources for dementia-specific translational research and evidence-based practices

Objective 5.1 Support Virginia’s Alzheimer’s and Related Diseases Research Award Fund (ARDRAF), especially projects that have a specific emphasis on “methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth” (§ 51.5-153).

Strategies

- Support an increased focus on translational projects, including those that
 - Utilize epidemiological methods.
 - Advance translational or clinical methods that identify evidence-based practices for service delivery and take them from bench to bedside.
 - Identify costs associated with the delivery of programs and services to individuals living with dementia and care partners.
 - Develop high-tech and low-tech assistive devices that adapt to everyday environments for people living with dementia.
 - Assess the quality of services and facilities for individuals living with dementia and their care partners including factors such as acoustic and visual environments that can affect dementia-related behaviors.
- Support a lifespan approach to research on treatments and supports for people living with dementia.
- Explore projects that attempt to understand ADRD in diverse settings and communities better.
- Disseminate research findings, especially translational research findings, through [Dementia Capable Virginia](#).

Objective 5.2 Provide support to researchers and interested stakeholders across Virginia.

Strategies

- In collaboration with researchers, develop a research consortium network and provide networking opportunities for researchers and interested stakeholders in Virginia.
 - Periodically disseminate information about studies in need of participants and funding opportunities, which may include federal grant opportunities from the US National Institutes of Health as well as from the Alzheimer's Disease Programs Initiative (ADPI) within the Administration for Community Living and the US Centers for Medicare and Medicaid Services Innovation grants, Civil Money Penalty funding and pilot demonstrations.
 - Use [Dementia Capable Virginia](#) and the International Alzheimer's Disease Research Portfolio (IADRP) on iadrp.nia.nih.gov to link researchers interested in dementia research.
- Direct researchers to dementia and caregiving-related data sources to support funding applications.

Objective 5.3 Promote the advancement of translational research, evidence-based practices, and research participation in Virginia.

Strategies

- Promote training to improve awareness of the value of research participation.
- Develop incentives, such as research partnering and communication of study results, for medical and health professionals who encourage research participation in the community.
- Support efforts to increase participant recruitment and participation in research studies in underrepresented and at-risk communities in Virginia.
- Foster university-community partnerships to further research and development, address community needs and promote research opportunities.
- Use [Dementia Capable Virginia](#) to link to additional resources related to research.
- Promote awareness and use of existing mechanisms to link potential participants with research opportunities (such as clinicaltrials.gov and TrialMatch).

GOAL 6 Enhance brain health and address modifiable risk factors for dementia

Objective 6.1 Work collaboratively with the Virginia Department of Health to implement the Healthy Brain Initiative. (HBI P-5, P-6, E-1, E-2, E-3)

Strategies

- Enhance collaboration between the DSC and the VDH Brain Health Coordinator to expand outreach, education, and resources to support brain health and dementia risk reduction across Virginia.
- Embed information on brain health and modifiable risk factors of dementia in public health campaigns and raise awareness and understanding of dementia to reduce the incidence of Alzheimer's disease and related dementias in coming decades.
- Collaborate with VDH on initiatives supported by BOLD Act funding and other sources to embed brain health awareness within the public health system.
- Collaborate with VDH to enhance and raise awareness about the Brain Health Virginia initiative.
- In collaboration with the Virginia Department of Health (VDH) and local health departments, integrate dementia and brain health into public health strategies and reports.
- Educate public health and healthcare professionals on sources and uses of reliable information about brain health and dementia prevalence.

Objective 6.2 Support statewide and local initiatives to improve brain health measures and reduce the modifiable risks for dementia at the population and individual levels. (HBI M-1, M-5, E-1, E-2, E-3, E-4, E-6)

Strategies

- Use the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with subjective cognitive decline in Virginia and analyze and apply the findings to improve dementia capability.
- Collaborate with related public health efforts (e.g., diet, exercise, co-morbid conditions, etc.) to improve treatment adherence and encourage risk-reduction strategies, including lifestyle changes.
- Promote awareness of the importance of controlling vascular risk factors to reduce dementia risk.
- Promote awareness of the importance of regular hearing screening, and the use of hearing aids among those with hearing loss, to reduce dementia risk.
- Promote efforts to improve treatment adherence among those experiencing subjective cognitive decline (SCD) living with at least one chronic condition.
- Encourage participation in the Chronic Disease Self-Management Education (CDSME) program by persons experiencing subjective cognitive decline, persons living with dementia, and caregivers. Continue to expand this program to make it available in all areas of Virginia.
- Promote awareness of the benefits of consulting health care providers about brain health and the modifiable risk factors for dementia by people experiencing subjective cognitive decline.

Objective 6.3 Embed brain health and dementia risk reduction messaging and education across the lifespan. (HBI E-3, E-4, E-5)

Strategies

- Encourage and promote regular cognitive screening.
- Develop infographics and social media posts to promote cognitive health.
- Promote awareness and education campaigns working with higher-risk populations.
- Promote and support efforts to incorporate brain health and dementia awareness education in schools (K-12, post-secondary) in Virginia.

Dementia Capable Training Topics (Goal 3)

Dementia-capable training should cover a wide range of topics to ensure that individuals and organizations are equipped to provide appropriate care and support to people living with dementia. By covering these topics comprehensively, dementia-capable training programs can prepare individuals and organizations to provide compassionate, respectful, and effective care to people living with dementia.

Here are some key topics that should be included in dementia-capable training programs:

1. **Understanding Dementia:** Trainees should learn about different types of dementia, their causes, progression, and symptoms. Understanding the basics of dementia is essential for providing effective care.
2. **Communication Skills:** Effective communication techniques are crucial when interacting with individuals living with dementia. Training should cover how to communicate clearly, patiently, and empathetically, considering the cognitive and sensory challenges faced by people with dementia.
3. **Person-Centered Care:** Dementia-capable training should emphasize the importance of person-centered care, focusing on the individual's preferences, background, and personal history. This approach helps in creating a supportive and respectful environment.
4. **Behavioral Management:** Dementia can lead to challenging behaviors. Training should cover strategies for managing difficult behaviors, such as aggression, agitation, and wandering, in a compassionate and non-restrictive manner.
5. **Safety and Environment:** Understanding safety measures, including fall prevention, home modifications, and creating dementia-friendly environments, is crucial. Training should teach participants how to adapt surroundings to enhance safety and minimize confusion.
6. **Legal and Ethical Issues:** Trainees should be aware of legal and ethical considerations related to dementia care, including informed consent, decision-making capacity, and the rights of individuals with dementia. Additionally, trainees should understand how to honor the individual's advance care choices, including the understanding of advance directives and powers of attorney.
7. **Caregiver Support:** Dementia-capable training should address the needs of family caregivers, providing information on respite care, support services, and coping strategies. Supporting caregivers is essential for maintaining the well-being of both the person living with dementia and their family. Training should also inform trainees about [Dementia Capable Virginia](#), [Virginia Navigator](#), [No Wrong Door](#) and the network of [Area Agencies on Aging](#), and the [Alzheimer's Association](#) to connect individuals and caregivers to services and supports.

8. **Cultural Competency:** Understanding cultural differences and how they can impact perceptions and approaches to dementia is important. Training should address cultural competence to ensure that care is respectful and inclusive of diverse backgrounds.
9. **Medication Management:** Training programs should cover common medications used in dementia treatment, their side effects, and proper administration techniques.
10. **Promoting Independence:** Strategies for promoting independence and empowering individuals with dementia to engage in meaningful activities should be included. This can enhance their quality of life and overall well-being.
11. **Dementia and Coexisting Conditions:** Many individuals with dementia have coexisting health conditions. Training should cover common health issues and their management to provide comprehensive care.
12. **End-of-Life Care:** Training should address end-of-life considerations, including palliative and hospice care, as well as emotional support for both the person with dementia and their loved ones.
13. **Continuous Professional Development:** Dementia care practices and research are continually evolving. Training programs should emphasize the importance of ongoing learning and staying updated with the latest advancements in dementia care.

Healthy Brain Initiative Roadmap Actions

<https://www.cdc.gov/aging/healthybrain/roadmap.htm>

P: STRENGTHEN PARTNERSHIPS AND POLICIES

Increase community partnerships

P-1 Convene and leverage diverse and inclusive multi-sector coalitions to strengthen supportive, equitable policies within communities, workplaces and health care settings across the life course of brain health.

P-2 Utilize community-clinical linkages to improve equitable access to community-based chronic disease prevention, dementia support and healthy aging programs.

P-3 Partner across the community to promote equitable access to services, supports and quality care for people living with dementia and their caregivers.

P-4 Partner with public and private health plans to implement evidence-informed policies and programs that impact social determinants of health related to brain health and cognitive impairment.

Increase integration with other chronic disease efforts

P-5 Build on existing state and local public health chronic disease, healthy aging, and disability programs and policies to address social determinants of health and improve health equity related to brain health.

Increase policy action and implementation

P-6 Equip policymakers with information on risk factors, the stigma associated with cognitive impairment and the impact of social determinants of health; and offer evidence-informed policy options across the life course.

P-7 Join ongoing coalitions and partnerships to prevent or remediate abuse, neglect and exploitation of people living with dementia.

M: MEASURE, EVALUATE AND UTILIZE DATA

Increase data availability, quality and utilization

M-1 Support implementation of the Behavioral Risk Factor Surveillance System (BRFSS) optional modules for Cognitive Decline and Caregiving and use the data to develop and inform programs and policies.

M-2 Supplement existing state, local and BRFSS data with data from health systems, health plans, pharmacies, and other health care providers and community organizations to better understand disparities and opportunities for improving equity.

M-3 Evaluate implementation of the HBI Road Map actions to identify successes and needed improvements.

Increase data-informed decision making and action

M-4 Translate data analyses and evaluation findings into state and community strategic and health improvement plans that support brain health across the life course and quality of life for people living with dementia and their caregivers.

M-5 Share findings with community organizations, agencies, policymakers and provider associations to help focus and inform community awareness efforts, resource needs, programs and policies, particularly for populations most impacted.

W: BUILD A DIVERSE AND SKILLED WORKFORCE

Reduce stigma and bias about cognitive decline

W-1 Provide evidence-informed training and informational resources for primary health care providers to facilitate culturally sensitive conversations about brain health with patients and caregivers across the life course.

Increase knowledge and skills of current and future workforce

W-2 Train current and future public health professionals about risk factors for cognitive decline and dementia and ways to integrate this information with other chronic disease prevention strategies.

W-3 Promote inclusion of the life course approach to brain health in licensing, certification and continuing education requirements for health care and allied professionals.

W-4 Strengthen training of community health and direct service workers about brain health across the life course to improve equitable care and quality of life for those living with cognitive decline and to support caregivers.

W-5 Partner with public safety and emergency response agencies to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.

E: ENGAGE AND EDUCATE THE PUBLIC

Increase public knowledge about brain health, risk factors for dementia and benefits of early detection and diagnosis

E-1 Engage diverse audiences to develop culturally responsive messaging about brain health, cognitive decline, healthy aging and caregiving.

E-2 Disseminate culturally responsive messaging to encourage conversations about brain health, cognitive decline, healthy aging and caregiving.

E-3 Engage with communities, especially those at highest risk, about risk factors for dementia and how people living with dementia can best thrive in their communities.

E-4 Embed cognitive decline risk factors into evidence-informed health promotion and chronic disease prevention awareness and education campaigns.

E-5 Partner with educational systems (K-12 and post-secondary) to include brain health and dementia in their curricula.

Increase public knowledge and use of services for people living with dementia and their caregivers

E-6 Enhance communication with people living with dementia, their families and caregivers about how to access services, care and social supports.

E-7 Ensure caregivers have information, tools and resources about their vital role and ways to maintain their own health and well-being.

Development Process

The Commonwealth of Virginia's Alzheimer's Disease and Related Disorders Commission was established in 1982. The Commission serves as an advisory board in the executive branch of Virginia's state government and aims to assist people living with Alzheimer's disease and related disorders and their care partners.

Under the Code of Virginia § 51.5-154, the Commission has the power and duty to:

1. Examine the needs of persons with Alzheimer's disease and related disorders, as well as the needs of their caregivers, and ways that state government can most effectively and efficiently assist in meeting those needs;
2. Develop and promote strategies to encourage brain health and reduce cognitive decline;
3. Advise the Governor and General Assembly on policy, funding, regulatory, and other issues related to persons living with Alzheimer's disease and related disorders and their caregivers;
4. Develop the Commonwealth's plan for meeting the needs of people living with Alzheimer's disease and related disorders and their caregivers, and advocate for such plan;
5. Submit to the Governor, General Assembly, and Department by October 1 of each year an electronic report regarding the activities and recommendations of the Commission, which shall be posted on the Department's website; and
6. Establish priorities for programs among state agencies related to Alzheimer's disease and related disorders and criteria to evaluate these programs.

To guide the process, a Dementia State Plan Work Group, chaired by Margie Shaver, was appointed in 2022. As was the case in the development of Virginia's 2011, 2015 and 2019 Dementia State Plans, the Work Group reviewed state plans from other states, particularly those created by other BOLD grant recipients, reviewed accomplishments achieved under the previous Plan, and considered changes in the legal and regulatory environment. Most notably, the Commission began to consider adopting a new goal (Goal 6) for the first time since the Plan was published.

To obtain stakeholder input, the Commission held the Virginia Dementia Capable Summit on May 10, 2023, in coordination with the Virginia Governor's Conference on Aging. Additionally, the draft Plan was available for public comment and feedback during August 2023. Comments were received from professionals and family caregivers via mail, telephone and email.

The Commission intends that the Dementia State Plan be a living document always responsive to the needs of Virginians. The intent is to continue updating it every four years to ensure that it adapts to changing circumstances, and that it makes use of cutting-edge research and standards. The Commission welcomes your thoughts via email at dementia@dars.virginia.gov.

Contributions and Acknowledgments

The Virginia Alzheimer's Disease and Related Disorders Commission would like to recognize its current members who contributed to the Dementia State Plan:

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Lastly, the Commission expresses immense gratitude to the many individuals living with dementia, their care partners, family members and friends, and professionals who participated in the Dementia Summit or offered comments by mail, telephone or email. Their invaluable first-hand input has meaningfully informed the Dementia State Plan. It is the Commission's sincere hope that the Dementia State Plan reflects the needs, concerns and priorities of Virginians.

Glossary

ARDRAF In 1982, the Virginia General Assembly established a research award fund entitled the Alzheimer’s and Related Diseases Research Award Fund (ARDRAF). “The awards shall be given annually to scientists in Virginia in order to support research into the causes of Alzheimer’s disease and related disorders, methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the of the Commonwealth.” <https://vcoa.chp.vcu.edu/grant/ardraf/>

Auxiliary Grant (AG) is an income supplement for individuals who receive Supplemental Security Income (SSI) and certain other aged, blind, or disabled individuals who reside in a licensed assisted living facility (ALF) or an approved adult foster care home. <https://www.dss.virginia.gov/printer/family/as/auxgrant.cgi>

Behavioral Risk Factor Surveillance System (BRFSS) is an annual survey of Virginia’s adult population about individual behaviors that relate to chronic disease and injury. The national BRFSS is coordinated by the Centers for Disease Control and Prevention (CDC) and is the primary source of state-based information on health risk behaviors among adult populations. Typically, the survey includes the optional Cognitive Decline and Caregiver modules every three years. <https://www.vdh.virginia.gov/brfss/>

BOLD (Building Our Largest Dementia Care) Infrastructure Act (2018) became law on December 31, 2018. The activities outlined in BOLD are designed to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of CDC’s Healthy Brain Initiative. Competitive grants to state public health agencies were first funded in 2021, with the Virginia Department of Health (VDH) receiving a three-year enhanced grant. A second round of funding was offered in 2023, and VDH received a further five years of funding. Many strategies contained in this project relate to the ADRD Commission and implementation of the Dementia State Plan.

Care Partner/Caregiver refer to anyone who supports another person who is, in some degree, incapacitated and needs help. Informal care partner/caregiver and family care partner/caregiver are terms that refer to unpaid individuals such as family members, friends and neighbors who provide support. These individuals can be primary or secondary care partners, full time or part time, and can live with or apart from the person being supported. In the Dementia State Plan, the term ‘unpaid caregiver’ is used.

Cardinal Care (Medicaid) provides services to older adults and individuals with physical disabilities living in a community setting to prevent the premature institutionalization of seniors and physically disabled individuals. The waiver allows for consumer direction of personal assistance services and respite care services, meaning they can choose who provides the service. Spouses and legal guardians may not be hired, but adult children, friends and other select relatives can be compensated for their care activities. Services include medical and behavioral health, adult day health care, personal care assistance, respite care, assistive technology, home and vehicle modifications, personal emergency response systems (PERS), skilled private duty nursing and transition services. <https://www.dmas.virginia.gov/for-members/cardinal-care/>

Culturally Appropriate refers to actions, behaviors, or practices that align with and respect the beliefs, values, customs, and needs of a particular cultural group or community. It involves acknowledging diverse backgrounds and adapting services, interventions, or interactions to be sensitive and relevant to the cultural context. This approach ensures that practices are respectful, inclusive, and effective, considering the nuances and preferences within different cultural frameworks to provide equitable and meaningful experiences or services for individuals or communities.

Cultural Competence is the application of skills and knowledge to effectively deliver services to culturally diverse individuals by tailoring programs and interventions to their behaviors, beliefs, values and linguistic needs. Professionals who exhibit cultural competence work successfully with persons from varying cultures because they demonstrate understanding and respect of their unique background, keeping in mind these differences when providing education and planning, implementing and evaluating programs.

Dementia is a syndrome characterized by impairments in at least two areas of cognitive function such as memory, judgment, or planning, that are severe enough to affect daily functioning. Dementia is not a diagnosable disease, but describes the symptoms that are caused by diseases such as Alzheimer’s disease or Lewy Body dementia.

Dementia Capable means being skilled in identifying people with possible dementia and working effectively with them and their care partners, being knowledgeable about the kinds of services needed, and being able to inform or refer to agencies and individuals that provide such services. It typically includes increasing the knowledge and skills of those who care for or interact with people living with dementia and their supporters, identifying gaps in services and providing long-term services and supports to meet the needs of people living with dementia and their care partners. (Alzheimer’s Association, 2019).

Dementia Friendly is often used in the context of community. Dementia friendly indicates a community that makes intentional changes to ensure the safety and accessibility for people living with dementia, as well as to support people living with dementia and their caregivers to remain engaged and participate in the life of the community (Alzheimer’s Association, 2019).

Dementia-related behaviors describe a large group of symptoms associated with Alzheimer’s disease and related disorders including sleep disturbances, agitation (physical or verbal aggression, general emotional distress, restlessness, pacing, shredding paper or tissues and/or yelling), delusions (firmly held belief in things that are not real) and hallucinations (seeing, hearing or feeling things that are not there). These symptoms may be caused by things like pain, drug interactions, or changes in the environment or routine among others. It is important to try non-pharmacologic strategies to address behaviors before adding medications. (Alzheimer’s Association, 2021).

Evidence-Based means based on research, especially those projects involving a randomized controlled trial (RCT). Evidence-based programming translates tested program models or interventions into practical, effective programs that can provide proven health benefits to participants. When an evidence-based program is implemented, there is proof that the program works.

Evidence-Informed reflects the deliberate and systematic use of the best available evidence. This is combined with a distillation of the experience of experts where that evidence is not available, to inform clinical decision-making and evaluation, program development and policy creation.

Formal/Professional Care Partner/Caregiver; Paid Caregiver are professionals or paraprofessionals who are paid in exchange for providing care.

Home and Community Based Services (HCBS) comprise assistance provided to individuals so they can remain in their homes and communities. Services could include case management, homemaker services, home health, adult day services, personal care, respite care, as well as other related activities.

Hospice Care is designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home, such as freestanding facilities, nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient’s emotional, social, and spiritual needs, as well as medical symptoms as part of treating the whole person.

International Alzheimer’s Disease and Related Dementias Research Portfolio (IADRP) is a database supported by a collaboration between the National Institute on Aging and the Alzheimer’s Association. It provides access to information about research projects focused on Alzheimer’s disease and related disorders and facilitates collaboration and coordination between researchers. All research projects supported by the ARDRAF are available using this link: https://iadrp.nia.nih.gov/search?cadro=All&funding_organization%5B0%5D=88088&funding_year=All&f%5B0%5D=fa_f_org%3A60719.

Informal Care Partner/Caregiver; Unpaid Caregiver are individuals, usually family members, friends, neighbors or volunteers who provide unpaid support and care. Unpaid caregivers make up the vast majority of those providing care for individuals living with dementia in the United States.

Interdisciplinary Memory Assessment Centers have multi-disciplinary teams that provide a comprehensive dementia assessment and diagnosis, continuing care for individuals diagnosed with dementia, access to support groups, and opportunities to join clinical trials. A list of Centers serving Virginians is available on [Dementia Capable Virginia](#).

Long-Term Care (LTC)/Long-Term Supports and Services (LTSS) encompasses a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community (e.g., adult day services), in assisted living or in nursing homes. People may need long-term care at any age.

Medicaid is state-based health insurance available to certain people and families who have limited income and resources. Eligibility may also depend on how old you are and whether you are pregnant, whether you are blind or have other disabilities, and whether you are a US citizen or a lawfully admitted immigrant. People with Medicaid may also get coverage for services such as nursing home care and home and community-based services.

Medicaid Waivers were developed to encourage people with disabilities and the elderly to access services in their homes and communities. Medicaid is a joint federal-state program. Through Medicaid Waivers, states can “waive” certain requirements including the requirement that individuals live in institutions to receive Medicaid funding. Medicaid Waivers provide funding to provide people who are eligible for long-term care in institutions such as hospitals, nursing facilities, and intermediate-care facilities to access home and community-based services.

Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD). The different parts of Medicare help cover specific services. Part A covers inpatient hospital stays, short-term care in a skilled nursing facility, hospice care and some short-term home health care. Part B covers certain doctors' services, outpatient care, medical supplies and preventive services. Part C (Medicare Advantage Plans) is a type of Medicare health plan offered by private companies that contract with Medicare to provide all Part A and Part B benefits. Part D plans offered by private companies cover prescription drugs. Through the Virginia Insurance Counseling and Assistance Program, Virginia offers free, unbiased, confidential counseling on Medicare and related insurance programs (call 800-552-3402 for more information).

Mild Cognitive Impairment (MCI) describes the presence of measurable changes in cognitive functioning that are not severe enough to affect daily functioning. It is a risk factor for dementia.

Person-Centered Care empowers staff to be a resident advocate and honors each person's dignity, rights, self-respect, and independence. It allows individuals to make choices and requires staff to respect the wishes of the individual receiving services. It requires involving the person in decision making to provide the person with control of their own life.

Program of All-Inclusive Care for the Elderly (PACE) provides the following services: adult day care, physical, occupational and recreational therapies, meals, nutritional counseling, social work, personal care, home health care, necessary prescription drugs, social services, medical specialties, respite care and hospital and nursing home care when necessary. Recipients must be at least 55 years of age, live in the PACE service area, be screened by a care team and found to meet the nursing facility level of care, and be able to live safely in a community setting at time of enrollment.

Respite Care is the provision of relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned breaks for family and other unpaid care partners. There is much evidence demonstrating the benefits of respite for both the care recipient and care partners.

Skilled Nursing Facility (SNF), also known as nursing homes, provide housing, meals, skilled and intensive medical care, personal care, social services, and social activities to people who have physical or behavioral conditions that prevent them from living alone. Medicare and private insurance typically cover short-term nursing home stays for skilled care needs, but they do not cover long-term stays.

Subjective Cognitive Decline is self-reported memory problems that have been getting worse over the previous twelve months. Subjective cognitive decline is a risk factor for developing mild cognitive impairment or dementia but does not necessarily develop into those conditions. People experiencing subjective cognitive decline should discuss their concerns with a healthcare provider. The BRFSS Cognitive Decline module provides data on the prevalence and impact of subjective cognitive decline.

Translational Research takes the findings from basic science and applies them to enhance the health of people, particularly through the development and implementation of treatment options.

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This publication is available to download on
DARS Dementia Services page.

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

Resources for individuals, families, providers and
researchers are available on Dementia Capable Virginia

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



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