



Alzheimer's Disease and Related Disorders Commission Annual Report

Report to

Governor of Virginia and the Virginia General Assembly

Richmond

October 1, 2024

THE 2024 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION

RECOMMENDATIONS AND ACTIVITIES

Authority: Pursuant to the Code of Virginia § 51.5-154, the Virginia Alzheimer's Disease and Related Disorders Commission (Commission) must submit to the Governor, General Assembly, and Department for Aging and Rehabilitative Services (DARS) a report regarding the recommendations and activities of the Commission each year. The Commission, chaired by Lana Sargent, develops and oversees the implementation of the Commonwealth's Plan for meeting the needs of individuals with Alzheimer's disease and related disorders and their caregivers.

Commission Recommendations for the 2025 General Assembly

Expand Dementia Care Management to Underserved Areas of Virginia

Dementia Services Budget Increase

Replicating RAFT dementia training beyond Northern Virginia

Funding for Virginia Lifespan Respite Voucher Program

2023-2024 HIGHLIGHTS



VIRGINIA DEMENTIA STATE PLAN 2024-2027: The new [Virginia Dementia State Plan 2024-2027](#) was published on January 2, 2024. The updated Plan was expanded to include a new high-level goal (taking the total to six) addressing brain health and dementia risk reduction. Previous plans included strategies to address these under the data goal, but increased knowledge and understanding of the benefits of lifestyle and health choices in preventing dementia, and the solid work being undertaken in the Commonwealth in this area, in part through the Virginia Department of Health's BOLD funding (see page 7), merited the elevation of this topic to its own goal. The other goals of the Plan address statewide coordination or services, data collection and interpretation, training for those interacting with people living with dementia, coordinated care services and research. For the first time, measurable goals will be attached to selected strategies of the Plan, allowing See page 2 for more information.

Details of the recommendations are found starting on page 4 of this report.

VIRGINIA'S DEMENTIA STATE PLAN 2024-2027

In December 2011, the Commission released the first Dementia State Plan. This was updated in 2015, 2019 and again in 2023. The Commission will continue its work through implementing the [Virginia Dementia State Plan 2024-2027: Building a Dementia-Capable Virginia](#) published on January 2, 2024. The Plan maintains a focus on coordinated care through a network of memory assessment clinics and connections to public health initiatives, but this year added, in line with the National Alzheimer's Plan, a new sixth goal related to brain health and dementia risk reduction. Elevating brain health and risk reduction in this way recognizes both the dramatic increase in knowledge in recent years that supports dementia prevention efforts, and the ongoing BOLD grant-funded activity by the Virginia Department of Health, DARS and other partners.

The Plan guides legislators, other public officials, health and human services professionals, advocates, and other interested people on best practices and specific strategies for dementia-focused data collection, care, training, and research and prevention.

The goals of the *Virginia Dementia State Plan 2024-2027* are:

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

The *Virginia Dementia State Plan 2024-2027*, working in tandem with the National Alzheimer's Plan, provides the best guide to responding to dementia and providing support to the increasing number of Virginians living with the disease and their care providers, whether paid or unpaid. In 2020, there were an estimated 164,000 Virginians living with Alzheimer's disease, and data from the Virginia Department of Health showed that 9.9% of people over the age of 45 are living with some form of cognitive decline that is felt to be getting worse over time. That translates to roughly 300,000 people, and as the number of people over 45 continues to rise, and especially reflecting the rapid increase expected in the over 85 range, this number is also expected to grow steadily in coming years. This growth highlights the importance of the Plan and the Commission's ongoing efforts, and especially of addressing brain health and improving efforts to prevent future dementias.

COMMISSION MEMBERSHIP 2024

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Tara Ragland, DSS

Developing the Dementia State Plan 2024

The Commission reconstituted the Dementia State Plan Workgroup in Spring 2022 to begin work on the fourth iteration of Virginia's Dementia State Plan, and held the Virginia Dementia Capable Summit in May, 2023. The draft Plan was put out for public comment in August 2023, and received several comments informing different areas of the Plan. The Commission felt that additional time was required to ensure that the input received was considered and incorporated into the Plan, and approved the final version at its meeting in December 2023.

The most obvious change to the Plan was the inclusion of the new sixth goal, elevating measures to address brain health, modifiable risk reduction and dementia prevention. Knowledge of these risk factors continues to increase, with the Lancet Commission updating the number of potentially modifiable risk factors from nine in 2018 to twelve in 2020 to fourteen in 2024 reflecting the increasing evidence from research projects. If all fourteen risk factors were fully addressed at a population level, up to 45% of all dementias could be prevented. That is a sobering statistic that highlights the importance of the new goal and the efforts to raise awareness and understanding among Virginians of how to support brain health. These modifiable risk factors include several that are addressed by established public health programs in Virginia, including diabetes, hypertension, smoking and physical inactivity, while others require new and innovative efforts.

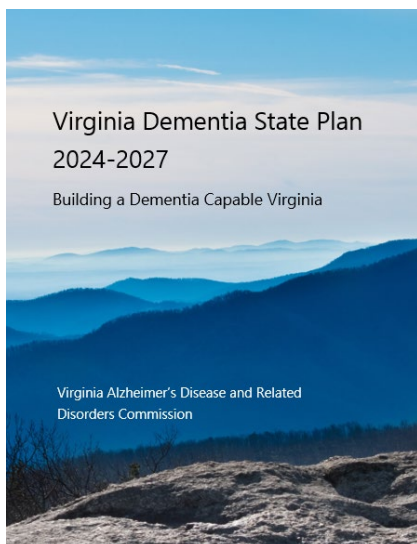
For the first time, using funds that had been raised for the Dementia Summit in 2023, the Commission printed bound copies of the Plan for distribution to the members of the General Assembly and other stakeholders. Early in 2024, the Dementia Services Director delivered presentations about the updated Plan to several groups including the Virginia Association of Area Agencies on Aging, the Commonwealth Council on Aging, the Hanover Council on Aging and a webinar through the Virginia Governor's Conference on Aging, informing stakeholders about changes and new initiatives.

Definitions

Dementia Capable: 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.

Dementia Friendly: being accessible to people living with dementia and their care partners, and enabling their continued engagement with their community.

([Alzheimer's Association, 2016](#))



The *Virginia Dementia State Plan 2024-2027* can be downloaded from <https://vda.virginia.gov/dementia.htm>.

COMMISSION RECOMMENDATIONS FOR 2025 GENERAL ASSEMBLY

Acting in its advisory capacity and to further the Dementia State Plan goals, the Commission recommends the following actions to effectively and efficiently serve individuals with Alzheimer's disease and related dementias (ARD) and their caregivers:

Expand Dementia Care Management to Underserved Areas of Virginia

Virginia's Dementia State Plan provides a blueprint for a fully dementia capable state. A key component of that is the availability of quality, person-centered care management services to families living with dementia (Goal 4). The latest Behavioral Risk Factor Surveillance System showed that roughly 1 in 10, or about 300,000, Virginians over the age of 45 are experiencing changes to their memory or thinking that are getting worse over time. More than a quarter report that they need assistance with day-to-day activities, and over half have not spoken to their doctor about their cognitive concerns.

In 2019, the General Assembly approved funding to provide 100 families a year with dementia care management at the University of Virginia's Memory Disorders Clinic in Charlottesville. Due to the pandemic and other factors, funding is currently set to support 88 families per year with dementia care management at the University of Virginia with participation by the Alzheimer's Disease and Related Disorders Association. Additional funding was appropriated in 2024 to provide dementia care management services for 100 families at Riverside Health Services' Martha W. Goodson Center in Williamsburg. Using evidence-based or evidence-informed interventions, dementia care management has been shown to reduce unplanned hospitalizations and emergency room visits, and reduce depression and anxiety while improving quality of life. Informal caregivers receiving care management are better able to cope with challenging dementia-related behaviors, so potentially reducing the risk of involuntary psychiatric admissions and helping reduce the burden on private and public psychiatric hospitals. Care coordination can increase the length of time that people living with dementia are able to remain safely in their homes, delaying the need for facility-based long-term care.

There is a clear need for clinic-based dementia care management, as the Centers for Medicare and Medicaid Services (CMS) has recognized through the introduction of an 8-year demonstration project, the Guiding and Improved Dementia Experience (GUIDE) model. This model is now being implemented by several health systems across Virginia, extending the clinical model of dementia care management to several previously unserved or underserved areas of the state such as Norfolk, Richmond, Northern Virginia, Roanoke and Lynchburg.

However, capacity constraints at specialty providers in Virginia mean that most people living with Alzheimer's disease or another form of dementia will never interact with a dedicated memory clinic or other health service offering clinical dementia care management services. Often, they will only need guidance at certain points during the disease trajectory rather than extended case management services. Other states provide examples of the benefits of dementia care navigators housed in community-based

organizations. They can provide short-term case management, dementia-specific information and referrals, community education and cognitive screenings, and serve as subject matter experts for their local communities.

The Alzheimer's Disease and Related Disorders Commission recommends using \$1,000,000 in state funds to deliver a large-scale pilot of dementia care navigation in at least eight underserved areas of the state (suggested areas include Eastern Shore, Southwest Virginia, Shenandoah Valley, Fredericksburg, New River Valley, Western Tidewater, and Southside). This sum would support hiring eight full-time dementia care navigators and costs for program development and implementation. In addition to providing care navigation services for several hundred families, the dementia care navigators would serve as subject matter experts to provide dementia-capability training to Area Agency on Aging (AAA) and partner agency staff, community education and screening, and support for local dementia-friendly initiatives. The dementia care navigators would also be able to leverage the newly dementia-capable No Wrong Door system funded by the General Assembly in 2024 to provide dementia-specific person-centered referrals to over 26,000 supports and services in Virginia.

This is a **legislative and/or budgetary request**. This proposal aligns with recommendations under Objective 4.1 of the Virginia Dementia State Plan 2024-2027.

Dementia Services Budget Increase

A key finding from the Aging Services workgroup that convened in 2022 and 2023 was the need for more resources (staff and funding) to serve the growing numbers of people living with dementia in the Commonwealth. Since 2013, when funding to establish the Dementia Services Coordinator role was initiated, the number of people living with Alzheimer's disease (60-80% of all dementias) in Virginia has risen by 37% from an estimated 120,000 people to more than 164,000 people in 2020, and is expected to rise further to 190,000 in 2025. Data from the Virginia Department of Health indicates that roughly 300,000 Virginians over the age of 45 are experiencing some level of cognitive decline that is worsening. Despite the sharp increase in people living with dementia, the funding for dementia services has remained unchanged at \$100,000 per annum since 2013.

The Dementia Services Coordinator (DSC) role has been successful in advancing supports and services for Virginians using federal and other grant funds. The DSC has directly and indirectly helped bring more than \$3m in federal funding to Virginia to support new initiatives, some of which are sustained with state and local funding. Sustaining these programs is difficult without additional state funding. A case in point is the evidence-based Dealing with Dementia program, which the DSC helped establish in most areas of the state using a \$25,000 Geriatric Training and Education grant from the Virginia Center on Aging. Despite strong support from local agencies, providers and program participants, the program has proven difficult to sustain due to competing demands for local agencies' limited funds.

Providing dementia services with additional funding would allow the DSC to support and sustain evidence-based educational and other programs for people living with dementia and their caregivers, potentially delaying the need for a long-term care placement. The ADRDC recommends that \$100,000 be

appropriated for the support of new and existing dementia programs, and to support dementia-related resource development and dissemination.

This is a **budgetary request**. This proposal aligns with recommendations under Objective 1.2 of the Virginia Dementia State Plan 2024-2027.

Replicate RAFT Training Program Across Virginia

Many persons living with Alzheimer’s disease or a related dementia are likely to experience behavioral challenges as their disease progresses. The inability of unpaid caregivers to cope with these challenges is often the proximate cause for placement of the individual in a long-term care facility, often at great financial and emotional cost to those involved. Dementia-specific supports currently only exist in Northern Virginia.

The Regional Older Adults Facility Team (RAFT) has been operating in the five counties of Northern Virginia since 2008 to support older adults with mental illness and dementia to achieve and maintain successful community-based placements. Team members train and support staff in assisted living and skilled nursing facilities to enable them to better care for people experiencing behavioral challenges because of their dementia or related conditions. The RAFT Dementia Support Program launched in 2023 to support people living with dementia who are being cared for in their homes. The program is aimed at preventing expensive and often traumatic psychiatric hospitalizations, and to provide education and strategies to improve caregiver resilience and support the safety and stability of in-home care situations. The program has a proven track record not only of helping people continue to be cared for at home, but also of collaborating with other community-based organizations to ensure that families have access to resources and have a well-developed action plan in place to manage behavioral challenges that may occur with dementia. In 2023, the program supported 73 individuals, none of whom experienced a psychiatric admission while receiving services. Additionally, validated measures noted a reduction in caregiver distress related to behavioral challenges of the person living with dementia.

The Commission supports replicating efforts to provide training specific to dementia-related challenging behaviors to both paid and unpaid caregivers. The second strategy under Objective 1.3 of the 2024-2027 Virginia Dementia State Plan calls for expanding “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.” Potential outcomes of expanding these services would be a reduction in inappropriate psychiatric admissions, improved caregiver resilience and coping skills, and an improvement in the quality of life of people living with dementia.

The Commission recommends setting up similar services in each of the four remaining behavioral health regions of Virginia, and recommends encouraging the use of telehealth by these services to meet needs across large geographical areas. This is a **budgetary request** and aligns with strategies under Objective 1.3 of the Virginia Dementia State Plan 2024-2027.

Funding for Virginia Lifespan Respite Voucher Program

For caregivers of people living with dementia, respite is often the number one service request, reflecting the prolonged and demanding experience typical of this type of caregiving. However, paying for respite services, whether in home or out of home, poses an additional financial burden that many families struggle to meet. Typical costs for adult day programs are \$80 per day or \$40-50 per half day, while in-home companion care typically costs \$25-30 per hour. The Virginia Lifespan Respite Voucher Program helps households with a \$595 reimbursement for spending on respite services. This program has been funded entirely by federal grants, with demand for services beginning to outstrip available funding.

The Alzheimer's Commission recommends allocating \$500,000 annually to the Virginia Lifespan Respite Voucher Program to supplement the federal grant funds, support additional capacity building and direct additional resources to respite services for unpaid caregivers of people living with dementia. This is a **budgetary request** that would fulfil a strategy under Objective 1.2 of the Virginia Dementia State Plan 2024-2027.



Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act

In 2020, the Virginia Department of Health (VDH) was awarded a BOLD Public Health Programs Enhanced grant for a three-year period, in partnership with DARS and the Alzheimer's Association. After being one of five states to receive an enhanced grant in 2021, Virginia received a further five years of funding in 2023. The main purpose of this grant funding is 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.” ([CDC, 2021](#)).

This grant project has supported Commission efforts such as the Dementia Capable Virginia initiative and materials developed or adapted through that initiative such as the Virginia Dementia Road Map, the Primary Care Dementia Toolkit, and others. The new grant project has three required strategies that require close alignment with the ADRD Commission, whose members approved this in 2023. These are to expand the diversity and breadth of the Commission, mainly through recruiting additional workgroup members, to develop an implementation plan for the Dementia State Plan and monitor its progress, and to develop and implement an educational program for the Commission members and public.

Workgroup membership has expanded dramatically, with many new stakeholders and partners taking an active role in the Commission's work. A regular survey will be distributed to workgroup and Commission members to evaluate the diversity of the membership. The Commission and workgroups spent the first six months of 2024 developing the Implementation Plan, which was provisionally approved by the Commission and the Virginia Department of Health. The educational program is getting underway, with the first programming scheduled for the September Commission meeting with presentations on geriatric emergency departments and the Wisconsin Dementia Care Specialist program. Commission meetings have returned to four hours to accommodate the additional programming.

Dementia Capable Virginia Initiative

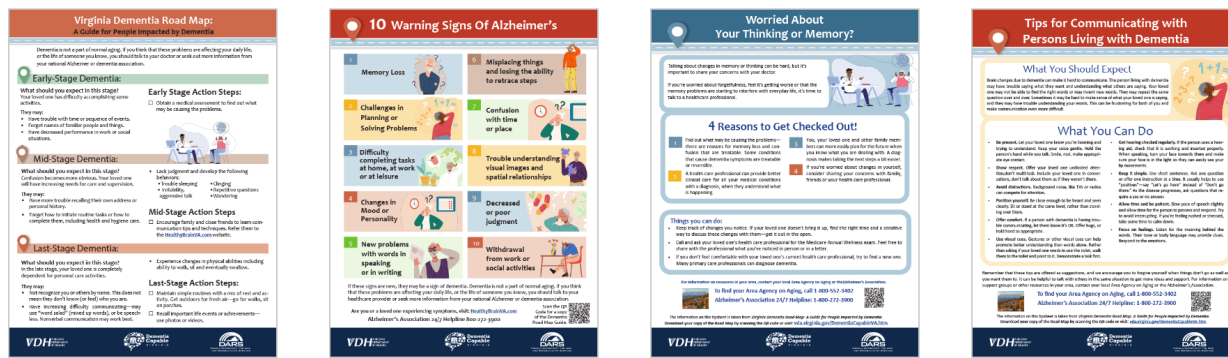


Dementia Capable Virginia brings together resources available for the public and for providers under one unified and recognizable brand: <https://vda.virginia.gov/DementiaCapableVA.htm>. The page is broken into three sections: Resources for Individuals and Families, Resources for Providers (including healthcare and community services providers) and Resources for Researchers.

In the latest fiscal year, the DCV web page received 9,183 visitors, a significant percentage of the 11,451 visitors to the main Dementia Services page (<https://vda.virginia.gov/dementia.htm>). The *Virginia Dementia Road Map* remains the most downloaded document from the Division for Aging Services site, reflecting the need for quality resources and guides to the dementia caregiving journey. The Dementia Services Director and the Commission continue to seek ways of making this popular publication more available through the provision of a printed version. The Virginia Department of Health has printed copies of the *Road Map* and made copies available through Area Agencies on Aging, Local Departments of Health, and others with support from the BOLD Act grant highlighted on page 7. The most recent addition to the Dementia Capable Virginia website is a series of one page documents developed by the Virginia Department of Health to supplement the *Virginia Dementia Road Map*.

New additions to the Resources for Individuals and Families section of the Dementia Capable Virginia webpage

Dementia Roadmap one-pagers



Healthy Brain Virginia one-pagers



COMMISSION ACTIVITIES

George Worthington is Virginia's Dementia Services Director. This role was a critical recommendation of the Commission's first Dementia State Plan to work towards creating a dementia-capable service delivery system in the Commonwealth. Persons may contact the Director and review a copy of the current *Virginia Dementia State Plan 2020-2024* at vda.virginia.gov/dementia.htm.

Commission Workgroups: The Commission accomplishes much of its work through its various workgroups. Currently, there are five workgroups in addition to the Legislative Committee that develops the Commission's annual legislative recommendations. Four of the workgroups are tied to the five goals of the Dementia State Plan: Coordinated Care (Goals 1 and 4), Data and Research (Goals 2 and 5), Training (Goal 3), and Brain Health (Goal 6). The Dementia State Plan workgroup has focused on updating the Plan every four years, and with the adoption of the Implementation Plan, will continue to meet on a regular basis to review progress and provide guidance on next steps. The workgroups could not effectively do their work without the participation of members from outside of the Commission who volunteer their time and expertise to support Commission activities:

Melissa Andrews

Dan Bluestein

Denise Butler

Connie Coogle

Stephani Curry

Kimberly Davis

Jessica Frederickson

Kathy Guisewhite

Missy Harden

Patricia Heyn

Kim Ivey

Tracey Lewis

Melissa Long

Theresa Mandela

Guy Mayer

Melicent Miller

Josh Myers

Sharon Napper

Annie Rhodes

Karen Roberto

Amy Sanders

Ashley Staton

Stephen Towns

Lindsey Vajpeyi

Chazley Williams

Workforce Training and Education: The Dementia Services Director continues to identify training opportunities to support a dementia-capable workforce in Virginia, and to deliver trainings to direct service workers, such as long-term care facility staff and workers supporting people living with intellectual and developmental disabilities at risk of dementia. The Director also provides community education opportunities. In SFY 2024, the Director delivered more than 40 training and education sessions attended by a total of 1,241 individuals.

Additionally, the Director works with the Virginia State Police Academy to provide dementia awareness training for each cohort of cadets and has collected training materials to share with first responders across the Commonwealth.

Caregiver Education and Support: In 2021, DARS received new federal grant funding of \$1,349,480 in federal funding to support the Virginia Lifespan Respite Voucher Program over five years. This program provides respite opportunities for family caregivers who are caring for someone with a chronic condition, such as Alzheimer's disease or a related dementia. Further information about this program is available on www.vda.virginia.gov/vlr.htm.

CURRENT FOCUS: Implementation of the Virginia Dementia State Plan 2024-2027

The Commission continues to partner with public and private partners throughout Virginia and at the national level to implement the Dementia State Plan. Ahead of and during the 2025 General Assembly session, the Commission will promote its recommendations for expanded support for people with dementia and their caregivers and facilitating dementia education and access to services. The Commission has devoted significant time and effort to developing a workplan including measurable outcomes that is attached to the fourth iteration of Virginia's Dementia State Plan, and will be focused on working to achieve those through its workgroups and other community partnerships. Additional information about the Commission and its activities may be found at: www.vda.virginia.gov/boardsandcouncils.html.

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. Expansion since the pandemic has slowed, with only two new communities joining existing efforts in the reporting period. In total, there are ten affiliated communities in Virginia. Some local efforts have also expanded their reach, such as Dementia Friendly Central Virginia which now includes Dementia Friendly Fauquier and Dementia Friendly Madison in addition to efforts already underway in Charlottesville and Albemarle and Culpeper Counties. Several local communities are providing regular virtual programs to help to raise awareness and reduce stigma that are accessible across the state.

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 continues to support Dementia Friendly Communities through the new *Virginia Dementia State Plan 2024-2027* in recognition of this initiative's role in dementia capability.

Dementia Friendly Communities and the allied Dementia Friends initiative help raise awareness of dementia and reduce stigma, 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 750 Dementia Friends Champions have delivered 60-minute information sessions attended by more than 10,000 Virginians.

