

THE 2022 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 Laura Bowser, 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 2023 General Assembly

Extend the sunset for the Alzheimer's Disease and Related Disorders Commission

Expand Dementia Care Management to Underserved Areas of Virginia

Increase Dementia Services Budget

Enhance Assisted Living Facility Affordability

Support Dementia Capable Training for First Responders

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

2021-2022 HIGHLIGHTS

DEMENTIA CAPABLE VIRGINIA:

A new initiative of the Commission and the Department for Aging and Rehabilitative Services, [Dementia Capable Virginia](#) brings together resources for families and caregivers, health care and service providers, and researchers (still under development) under uniform, recognizable branding. See p. 8 for more details.



DATA AND RESEARCH: The Data and Research Workgroup focused on building the research component of the Dementia Capable Virginia initiative, with a goal of increasing awareness of research and its importance, as well as participation, among underserved communities.

TRAINING: The Training Workgroup updated the [Primary Care Dementia Toolkit](#) and began work on developing two training videos, one to introduce the Toolkit and describe its utility, and a second, longer one to help practices integrate the Toolkit into their workflow.

COORDINATED CARE: Dementia Case Management services supported by state funds were offered through the University of Virginia's Memory Disorders Clinic. The Coordinated Care workgroup adapted the [Virginia Dementia Road Map](#), a resource for Virginians impacted by dementia, which was made available to the public in February 2022.

VIRGINIA'S DEMENTIA STATE PLAN

In December 2011, the Commission released the first Dementia State Plan. This was updated in 2015 and again in 2019. The Commission continues to work on implementing the [Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia](#) even as it begins work on the next iteration of the Plan, to be published in October 2023. The Plan maintains a focus on coordinated care through a network of memory assessment clinics and connections to public health initiatives. 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.

The goals of Virginia's *Dementia State Plan 2020-2024* are:

1. Coordinate quality dementia services to ensure dementia capability,
2. Use dementia-related data to improve public health,
3. Increase awareness and create dementia-specific training,
4. Provide access to quality coordinated care in the most integrated setting, and
5. Expand resources for translational research and evidence-based practices.

Virginia's *Dementia State Plan 2020-2024*, working in tandem with the National Alzheimer's Plan, provides the best opportunity for responding to dementia and providing support to the estimated 190,000 Virginians expected to be living with Alzheimer's disease by 2025, a 27% increase from 2020. This rapid growth highlights the importance of the Plan and the Commission's ongoing efforts.

Dementia State Plan: Update for 2023-2026

The Commission reconstituted the Dementia State Plan Workgroup in Spring 2022 to begin work on the fourth iteration of Virginia's Dementia State Plan. The Plan has gradually grown to include more than 70 recommendations under five goals that provided a blueprint for a fully dementia-capable state.

Since the publication of the current Plan, there has been a sharp increase in scientific knowledge and understanding of the importance of brain health, and of the possibility of reducing the incidence of dementia through addressing modifiable risk factors. According to the [Lancet Commission](#), up to 40% of the risks of developing dementia are potentially modifiable by, for example, controlling blood pressure or addressing hearing loss. The Commission will be seeking input from stakeholders in Virginia about how to incorporate this new knowledge into the Plan, whether by adding new recommendations under the existing goals or by developing an entirely new goal in line with the National Alzheimer's Project Act (National Plan).

COMMISSION MEMBERSHIP 2022

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The National Plan saw a new goal on brain health and dementia risk reduction added in January 2022, the first new goal since the Plan's inception a decade earlier.

Virginia Dementia Capable Summit: May 8, 2023

Stakeholders will have multiple ways of providing input into the next Dementia State Plan, such as a public comment period when the draft Plan is published in June 2023. In addition, the Commission is planning a one-day Virginia Dementia Capable Summit to bring together stakeholders from across the Commonwealth to learn more about the Dementia State Plan and workshop the five current goals as well as a potential sixth goal. The Summit will be held on May 8, 2023, in Richmond, and will be free to registrants. It will serve as a special pre-session of the 2023 Virginia Governor's Conference on Aging.

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](#))

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 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 as a whole, 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 6,800 Virginians.



COMMISSION RECOMMENDATIONS FOR 2023 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:

Extend the sunset for the Alzheimer's Disease and Related Disorders Commission

The Commission, composed of 15 members and established in 1982, serves in an advisory capacity to the Governor and the Secretary of Health and Human Resources and assists individuals with Alzheimer's disease or related disorders and their caregivers. The Code of Virginia § 51.5-154, which establishes the Commission, expires July 1, 2023. Recognizing the Commission's accomplishments to date and its proven track record of advocacy for the needs of individual living with dementia and their caregivers, and that efforts to meet the expected rise in the numbers of people living with dementia in the Commonwealth be supported at a state level, the Commission recommends extending its sunset by three years to July 1, 2026, to enable it to continue its work on updating, implementing and advocating for the Dementia State Plan. The next four-year update of the Dementia State Plan is due to be published October 1, 2023.

This is a legislative item that has no budgetary implications.

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). 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. This funding was removed in response to the COVID-19 pandemic, and later partially restored. A program to provide 50 families per year with dementia care management began on July 1, 2021, at the University of Virginia with participation by the Alzheimer's Disease and Related Disorders Association. This is now expanding to 83 families thanks to additional funding appropriated in 2022. Using an evidence-based program, dementia care management is expected to help reduce hospitalizations and emergency room visits, 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, and delay the need for facility-based long-term care.

Coordinated care programs using trained Dementia Care Managers (DCMs) are needed for successful community-based dementia care. Streamlining dementia care using DCMs would realize significant cost savings, decrease health care utilization, and improve health outcomes. Most areas of the state have little or no access to existing dementia care coordination programs at UVA and Riverside's Center for Excellence in Aging and Lifelong Health. The Commission recommends using \$1,000,000 in state funds to deliver a large-scale pilot of dementia care management in six additional areas of the state. In addition to providing care coordination for a total of at least 300 families, the dementia care managers would serve as subject matter experts to provide information and referral services, dementia-capability training to Area Agency on Aging (AAA) and partner agency staff, and offer community cognitive screening.

This is a budget item.

Increase Dementia Services Budget

A key recommendation to come out of the Aging Services workgroup that convened in 2022, and which has been reconstituted in 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 25% from an estimated 120,000 people to more than 150,000 people 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 helped bring more than \$2m in federal funding to Virginia to support new initiatives, some of which are being 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 and providers, 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.

This is a budget item.

Enhance Assisted Living Facility Affordability

An Auxiliary Grant is a supplement to income, available from local departments of social services, for recipients of Supplemental Security Income (SSI) and certain other aged, blind, or disabled individuals in assisted living, adult foster care, or other certified supportive housing. Funding for Auxiliary Grants is limited, especially compared to the growing need for affordable assisted living care. The Auxiliary Grant rate in 2022 is \$1609 per month, which is far too low to cover the cost of the services provided (a home, meals, medication management, and assistance with homemaking and personal care). The number of individuals receiving Auxiliary Grants has declined over the years because the number of participating providers has decreased due to the low reimbursement rate.

The Joint Commission on Health Care is engaged in a study of “Affordability of Assisted Living Facilities.” The study will examine challenges in the Auxiliary Grant Program, and other avenues for funding affordable assisted living, including Medicaid, as occurs in a number of other states. Urgent action is needed to promote realistic options for Virginians who need assisted living facility care.

This is a legislative and budget item. This is a recommendation from the Dementia State Plan and is a 2023 legislative priority for the Commonwealth Council on Aging, Northern Virginia Aging Network (NVAN) and Virginia Poverty Law Center (VPLC).

Support Dementia Capable Training for First Responders

The Commission supports efforts underway in communities in several areas across the Commonwealth to train first responders, including fire, police, emergency medical personnel and others in dementia capability. Often these efforts are in the context of Dementia Friendly Community initiatives, and they utilize programs such as Dementia Friendly @ Work, Dementia Friends, Approaching Alzheimer's: First Responder Training, and other sector-specific training modules. Sector-specific training can be supplemented with programs like Dementia Friends to provide these vital workers with the tools they need to confidently interact with this particularly vulnerable segment of the population.

The Commission recommends including basic dementia capability as an element of initial training programs for these professions. The Commission also recommends expanding the availability of these trainings to all areas of the Commonwealth, and supports their inclusion as programs that satisfy the respective continuing education requirements of these professions, where applicable.

This is a legislative recommendation that has no budgetary implications. It aligns with recommendations under Goal 3B of the Dementia State Plan.

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.

Since going live in April, the DCV website has received 749 visitors, a significant percentage of the 6,309 visitors to the main Dementia Services page (<https://vda.virginia.gov/dementia.htm>). The Virginia Dementia Road Map was the most downloaded file from the Division for Community Living site, with a total of 1,033 downloads through August 2022. The DSC and the Commission continue to seek ways of making this popular publication more available through the provision of a printed version, and 5,000 copies will be made available to Area Agencies on Aging and others thanks to support from Virginia Department of Health and the BOLD Act grant discussed highlighted on page 9. An additional nine Caregiver Tip Sheets were added to the existing suite of nine, providing practical, plain language guides to specific dementia-related challenges.

Part of the Resources for Individuals and Families section of the Dementia Capable Virginia webpage

Resources for Individuals and Families

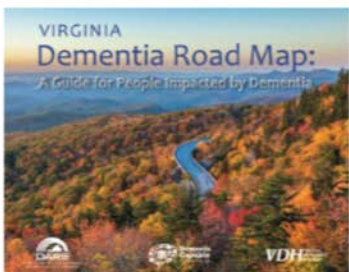
Resources that can help if you are experiencing cognitive changes, or when you are providing care and support for a friend or family member

Memory Assessment Centers Serving Virginians

There are several clinics that are either dedicated dementia and memory care clinics, or that include dementia and memory care services, that serve Virginians. Some of these may be located outside of the state.

Here is a list of clinics by location:

Dementia Road Map: A Guide for People Impacted by Dementia




This publication is a stage-by-stage guide to cognitive changes to help guide your journey:

- Information about Alzheimer's disease and dementia
- What you should expect at each stage
- What you can do at each stage
- Recommended **Action Steps**
- Communication tips
- Resources to support you and your loved one

You can [download the Road Map here](#).

Safety Concerns for People with Dementia




This publication contains information and resources to help you keep your loved one safe:

- Home Safety
- Falls Prevention
- Driving
- Wandering
- Emergency Preparedness
- Elder Abuse and Financial Exploitation

You can [download the Safety Concerns Toolkit here](#).

Dementia Fact Sheets

These Fact Sheets can help you address specific challenges that you may encounter with your loved one with dementia. Estas Fact Sheets pueden ayudarlo a abordar los desafíos específicos que puede encontrar con su ser querido con demencia.



COMMISSION ACTIVITIES

George Worthington is Virginia's Dementia Services Coordinator (DSC). The DSC is 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 DSC and review a copy of the current *Dementia State Plan 2020-2024* at vda.virginia.gov/dementia.htm.

COVID-19 Pandemic: The Covid-19 pandemic continued to affect activities supported by the Commission and the Dementia Services Coordinator in the past year. Participants remained relatively reluctant to attend in-person programs through the 2021-2022 period. However, the DSC and partners were able to offer a wide range of programming virtually, such as regular training and information sessions open to participants throughout the state. Information to assist caregivers of people living with dementia during the pandemic remains available on the DARS Dementia Services website vda.virginia.gov/dementia.htm.

Commission Workgroups: The Commission accomplishes much of its work through its various workgroups. Currently, there are five workgroups meeting in addition to the Legislative Committee that develops the Commission's annual legislative recommendations. Three 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), and Training (Goal 3). The Dementia State Plan workgroup is tasked with updating the Plan every four years, and additionally is managing the 2023 Virginia Dementia Capable Summit through its Summit Subcommittee. Finally, the Behavioral Risk Factor Surveillance System (BRFSS) Workgroup is tasked with analyzing and interpreting the results from the BRFSS Cognitive Decline and Caregiving modules that were asked in Virginia in 2019. 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.



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. 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](#)). Virginia was able to secure an enhanced grant thanks to the existing dementia infrastructure of the Commission, the DSC, and the Dementia State Plan.

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. In 2023, the grant will support the inclusion of the optional Cognitive Decline and Caregiving modules in the annual BRFSS survey conducted by VDH. The Commission and DSC have contributed to grant deliverables through providing dementia capable and dementia friendly training and education, through educating the public about the Commission and Dementia State Plan, and by providing input and assistance on projects like the redevelopment of the [Brain Health Virginia](#) website.

Workforce Training and Education: The DSC 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. In SFY 2022, the DSC delivered training and education sessions attended by a total of 654 individuals.

Although the pilot program for the Primary Care Dementia Toolkit that had been planned for the past year has not moved forward due to a lack of practices willing to commit resources to an unfunded pilot, the Toolkit is available to download on the Dementia Capable Virginia webpage. DARS and the Commission plan to continue publicizing its availability and are working on short training videos to support its usage. The Toolkit provides information on dementia screening tools and related training, diagnostic referrals and supports, follow up care planning and referrals to community-based supports and services as well as information on the billing codes that can support these activities.

Additionally, the DSC 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.

DARS continues to support Dealing With Dementia trainers who received training under a Virginia Center on Aging Geriatric Training and Education grant in early 2020. While in-person caregiver workshops are gradually returning, several agencies have seen staffing changes that have limited their ability to deliver these evidence-based workshops in future. DARS continues to support people completing this workshop at no cost through the provision of *Dealing With Dementia Guides* to workshop facilitators. Each *Guide* is worth that were purchased with grant funds.

CURRENT FOCUS: Virginia Dementia Capable Summit 2023 (May 8, 2023) and update of the Virginia Dementia State Plan for publication in November 2023.

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 2023 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 will be devoting significant time and effort to developing the fourth iteration of Virginia's Dementia State Plan, and is excited about the upcoming Virginia Dementia Capable Summit in May, 2023, that is intended to broaden awareness of the State Plan and encourage input from a broader range of stakeholders than in previous versions. Additional information about the Commission and its activities may be found at: www.vda.virginia.gov/boardsandcouncils.html.

Report prepared by George Worthington, Dementia Services Coordinator. Please contact George.worthington@dars.virginia.gov or 804-662-9154 with any questions or feedback.