

THE 2020 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: RECOMMENDATIONS AND ACTIVITIES

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. 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.

DEMENTIA STATE PLAN 2020-2024: BUILDING A DEMENTIA CAPABLE VIRGINIA

In December 2011, the Commission released the first Dementia State Plan. This was updated in 2015 and again in 2019. The Commission is now working to implement the *Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia*. 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.

COMMISSION RECOMMENDATIONS FOR 2021 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 (ADRD) and their caregivers.

Addressing the Impact of COVID-19 on Long-Term Care

Developing and Funding Dementia Care Management

Supporting the Public Health Approach to Dementia

2019-2020 ACCOMPLISHMENTS

DATA AND RESEARCH: The Dementia Services Coordinator presented the latest collection of statewide data on memory to the Commission in March 2020, and made it publicly available on alzpossible.org. Important data on memory impairment and caregiver stress was obtained through the annual public health Behavioral Risk Factor Surveillance System Survey in 2019 using the Caregiver and Cognitive Decline modules. The data will inform policy priorities into the next decade.

TRAINING: DARS received a Geriatric Training and Education (GTE) grant in 2019 to train 20 facilitators in the evidence-informed Dealing With Dementia workshops for family caregivers. Dementia Friends sessions led by more than 500 Dementia Friends Champions raise awareness about dementia and reduce stigma. Since the launch in 2018, over 5,000 people across the state have attended virtual or in-person sessions.

COORDINATED CARE: The GTE grant received in 2019 also supported the implementation of the Dealing With Dementia program in 12 of Virginia's 22 planning districts and allowed up to 780 family caregivers to attend workshops at no cost.

Addressing the Impact of COVID-19 on Long-term Care Facility Residents

The Commission recommends legislation to ensure residents of long-term care facilities (including assisted living and skilled nursing facilities) are appropriately supported during the COVID-19 pandemic. Roughly half the residents of skilled nursing facilities and 2 in 5 residents of all long-term care communities are living with some form of dementia. Residents with dementia are uniquely susceptible to COVID-19 due to their cognitive difficulties, age, increased likelihood of coexisting chronic conditions and the communal nature of their living environment. The Commission supports legislation that would address five immediate and long-term issues. All facilities must be required to **test** all residents and staff, necessitating the prioritization of testing supplies for long-term care facilities, and have the capability to ensure their communities remain free of infection. Any cases that do occur within these communities must be immediately and accurately **reported** while ensuring the privacy of individuals, and such reporting must be readily accessible by the public down to the facility level. Protocols must be established for steps long-term care facilities must take in case of outbreaks, and **surge activation** plans be in place including developing statewide strike teams to support communities with outbreaks, and designating long-term care ombudsman and CMS surveyors as essential, providing them priority access to personal protective equipment (PPE) and allowing them entry to long-term care communities. Long-term care communities must be **supported** in caring for their vulnerable residents and staff by ensuring priority access to PPE, requiring the dissemination of dementia care standards to help provisional staff deliver person-centered dementia care, and requiring measures to address social isolation and ensure communication between residents and family and friends. Finally, residents and staff of these communities must be given priority access to approved **vaccines** when available to minimize future infections and deaths.

Develop and Fund Interdisciplinary Memory Assessment Clinics with Dementia Care Managers

In 2019, the General Assembly approved funding to provide 100 families a year with dementia care management at the University of Virginia's Memory and Aging Care Clinic (UVA MACC). This funding was removed in response to the pandemic. The Commission believes that the pandemic heightens the need for appropriate care coordination, which can help increase the length of time that people living with dementia are able to remain in their homes and delay the need for facility-based long-term care. Additionally, studies have found that primary care providers are ill-equipped to provide comprehensive management or care coordination for individuals with dementia and their caregivers. Coordinated care programs using trained Dementia Care Managers (DCMs) embedded in memory assessment clinics 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. Federal grant funding for dementia care consultation at UVA MACC and Riverside's Center for Excellence in Aging and Lifelong Health (CEALH) will end in 2021, and many areas of the state have little or no access to such care coordination programs. The Commission recommends using state funding to continue interdisciplinary plans of care and dementia care management for individuals diagnosed with dementia at the existing sites with a vision to growing the program statewide.

Maintain the Public Health Approach to Alzheimer's Disease and Dementia

While Virginia's public health system understandably remains focused on responding to COVID-19, it is important to continue efforts to address the current and future burden of cognitive decline and dementia in the state. This can be achieved by fully implementing the Building Our Largest Dementia (BOLD) Infrastructure Act in Virginia. Legislation passed in 2020 gave lead responsibility to the Virginia Department of Health to educate and inform the public about dementia, to support the early detection and diagnosis of ADRD, to reduce the risk of hospitalization for people living with ADRD, to reduce the risks of developing cognitive decline and ADRD, and to support care planning and management for people living with ADRD. The impact of COVID-19 on long-term care communities highlights the need to support people living with ADRD to remain in the community and to reduce potentially avoidable hospitalizations and subsequent stays in long-term care facilities. The Commission recommends supporting this public health approach to address the needs of people living with cognitive decline and dementia in the Commonwealth.

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 AlzPossible.org or at vda.virginia.gov/dementia.htm

COVID-19 Pandemic: The Covid-19 pandemic affected activities supported by the Commission and the Dementia Services Coordinator. In-person trainings and workshops were suspended through much of 2020, and planned opportunities to raise awareness of the Dementia State Plan and other initiatives, such as presentations at the Virginia Governors Conference on Aging and the Southern Gerontological Society Conference were cancelled due to the pandemic. Information to assist caregivers of people living with dementia during the pandemic was made available on the DARS Dementia Services website vda.virginia.gov/dementia.htm.

Collaborative Efforts: The Commission and the DSC have worked together to broaden and deepen existing collaborative efforts with other stakeholders, and initiate new links where needed, including with the Geriatric Mental Health Partnership, the Virginia Caregiver Coalition, the Virginia Department of Health, LeadingAge Virginia, the Virginia Neuroscience Initiative, Virginia Navigator, and others. This type of capacity building and the relationships that result will be essential for ensuring the implementation of the Dementia State Plan. One partnership to highlight is with the Partners in Prayer & Prevention (P³) program at the Virginia Department of Health. The DSC has worked with Veronica Cosby, the P3 program coordinator, to raise awareness of the Dementia Friends information sessions and to promote the training of Dementia Friends Champions within faith communities.

Workforce Training and Education: The DSC has developed or adapted training modules to improve the dementia capability of certain sectors of the workforce. General dementia capability modules increase awareness and understanding of dementia including the ten warning signs of Alzheimer's disease, and of issues around cognitive decline such as the importance of early detection and diagnosis, risk factors for dementia, caregiving issues, treatment and management and the course of disease progression. The DSC adapted materials developed by the Eddy Alzheimer's Services in Cohoes, New York, supported by a grant from the Administration for Community Living on the Foundations of Dementia Care for individuals living with developmental disabilities (DD). To date the DSC has delivered this training to over 50 service providers.

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

Caregiver Education and Support: DARS received \$281,817 in federal funding to support the Virginia Lifespan Respite Voucher Program over three years. This program provides respite opportunities for family caregivers with a special focus on providing relief to those who provide care to an individual living with Alzheimer’s disease or a related dementia. Further information about this program is available on www.vda.virginia.gov/vlrv.htm.

DARS also received a Geriatric Training and Education grant from the Virginia Center on Aging to bring the evidence-informed Dealing With Dementia program developed by the Rosalynn Carter Institute for Caregiving to Virginia. This program was selected due to the robust content delivered during a four-hour workshop, the relatively small time commitment for busy caregivers, and the low cost of sustaining this program. The \$24,615 received under this grant supported the training of 20 workshop trainers embedded in Area Agencies on Aging and other agencies in 12 of Virginia’s 22 Planning and Service Areas (PSA) including every PSA west of the Blue Ridge mountains and each of the five counties in PSA 8 (Northern Virginia). It also covered the cost of materials to allow up to 780 caregivers to participate in the workshops at no cost.

Dementia Friendly Virginia: Communities across the state continue to join others across the United States in fostering dementia friendliness by affiliating with Dementia Friendly America. The last year has seen several more communities join Alexandria, Arlington, Charlottesville, Leesburg/Loudoun County and Lexington in the national network, and efforts are underway in other communities. The pandemic has impacted the expansion of these efforts, but local communities are using 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 new 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 500 Dementia Friends Champions have delivered 60-minute information sessions attended by more than 5,000 Virginians.

AlzPossible: The Commission, in collaboration with the Virginia Commonwealth University Department of Gerontology and World Events Forum, Inc., maintains the AlzPossible.org website. Aimed at providing professional and family caregivers in Virginia updated information on dementias and supporting the collaboration and sharing of knowledge by researchers in Virginia, the AlzPossible site hosts:

- The Commonwealth’s Dementia State Plan,
- A library of over seventy free webinars for professionals and caregivers on dementias and related topics,
- A map and listing of interdisciplinary memory assessment centers in Virginia to guide consumers to clinics that provide thorough and holistic diagnostic and treatment services for memory disorders,
- Information and links to available data sets for researchers in Virginia interested in dementia,
- Links to local, state, and national resources, including state agencies, Virginia Navigator, the Alzheimer's Association, and the federal ElderCare Locator and www.Alzheimers.gov.

CURRENT FOCUS

The Commission continues to partner with public and private partners throughout Virginia and at the national level to implement the Dementia State Plan. In the 2021 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. Additional information about the Commission may be found at: www.vda.virginia.gov/boardsandcouncils.html.