

THE 2019 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: RECOMMENDATIONS AND ACTIVITIES

Pursuant to 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 Lory Phillippo, 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.

VIRGINIA DEMENTIA STATE PLAN 2020-2024

In December 2011, the Commission released the first Dementia State Plan, and this was updated in 2015. The Commission is pleased to present a newly updated *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 five goals of the Virginia Dementia State Plan 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 2019. This rapid growth highlights the importance of the Plan and the Commission's ongoing efforts.

COMMISSION RECOMMENDATIONS FOR 2020 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 other dementias and their caregivers.

BOLD Infrastructure for Alzheimer's Act implementation

Develop and fund interdisciplinary Memory Assessment Clinics with Dementia Care Coordination

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

2018-2019 ACCOMPLISHMENTS

DATA AND RESEARCH: In 2019, Virginia is again collecting important data on memory impairment and caregiver stress through the annual public health Behavioral Risk Factor Surveillance System Survey using the Caregiver and Cognitive Decline modules. The data will inform policy priorities into the next decade.

TRAINING: A federal grant supported the creation of five modules on dementia for the primary care workforce, available on alzpossible.org. Dementia Friends sessions to raise awareness and reduce stigma have been attended by over 1,000 people across the state since mid-2018.

COORDINATED CARE: In 2018, DARS received a GTE grant to train an additional 15 counselors to deliver the FAMILIES program in more areas of Virginia. This program can reduce depression and improve self-efficacy for family caregivers of individuals living with dementia.

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

The Commission recommends legislation to ensure that Virginia is prepared to implement initiatives described in the federal BOLD Infrastructure for Alzheimer's Act passed in 2018. The proposed bill would give lead responsibility to the Virginia Department of Health, in consultation with the Virginia Department for Aging and Rehabilitation, for educating and informing the public, based on evidence-based public health and research and data, about Alzheimer's disease and related dementias, for supporting early detection and diagnosis of Alzheimer's disease and related dementias, for supporting risk reduction of cognitive decline, and for supporting care planning and management for individuals living with Alzheimer's disease or a related dementia. These activities would help achieve Goals 2B (Collaborate with related public health efforts and encourage possible risk-reduction strategies) and 3C (Support care partners, family members and people living with dementia by providing educational information about dementia and available resources and services) of the Dementia State Plan 2020-2024, and help meet several objectives of the Centers for Disease Control and Prevention's *Healthy Brain Initiative 2018-2023 Road Map*.

Develop and Fund Interdisciplinary Memory Assessment Clinics with Dementia Care Managers

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 dementia care. Streamlining dementia care using DCMs would realize significant cost savings, decrease health care utilization, and improve health outcomes. In 2015, DARS received a nearly \$1 million federal grant to pilot a coordinated care system for persons with dementia and their caregivers. The grant project bridged the gap between clinical and community-based supports through a partnership between the University of Virginia's Memory and Aging Care Clinic (UVA MACC) and the Jefferson Area Board for Aging (JABA) for dementia care services. Although this grant ended in 2018, the importance of care coordination has been recognized by both UVA MACC and Riverside Center for Excellence in Aging and Lifelong Health (CEALH), who are delivering care consultation in their areas supported by additional federal grant funding. However, care coordination programs such as this remain unavailable in many areas of the state. The Commission recommends using state funding to continue interdisciplinary plans of care and dementia care management for individuals diagnosed with dementia with a vision to growing the program statewide.

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. Code of Virginia §51.5-154, which establishes the Commission, expires July 1, 2020. 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, 2023 to enable it to carry out the goals of the Dementia State Plan 2020-2024.

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 updated Dementia State Plan at AlzPossible.org or at www.vadars.org/cbs/dementiaservices.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.

Caregiver Education and Support: DARS also 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 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/vlr.htm. The Commission is also beginning work on adapting resources available to families in other states to provide information and referrals on Alzheimer's disease and dementia with a goal of making this available to families starting in 2021.

Dementia Friendly Virginia: Communities across the state, starting with Herndon, are joining others across the United States in fostering dementia friendliness by affiliating with Dementia Friendly America. Since a statewide workshop was held by DARS and LeadingAge Virginia in 2018 to kick start the initiative in Virginia, Alexandria, Arlington, Charlottesville, Leesburg/Loudon County and Lexington have now joined the national network. 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. Commission members attended a one-hour Dementia Friends information session in March 2019 and support efforts by DARS to partner with the Virginia Department of Health's Partners in Prayer and Prevention (P³) to embed the Dementia Friends sessions in faith-based communities across the state.

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 caregivers in Virginia updated information on dementias, the innovative AlzPossible site hosts:

- The Commonwealth's Dementia State Plan,
- A library of 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 2020 General Assembly session, the Commission will promote its recommendations for expanded support for people with dementias 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.