

# THE 2018 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 2015-2019

In 2015, the Commission issued an updated *Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers 2015-2019*. The plan focuses 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, working in tandem with the National Alzheimer's Plan, provides the best chance of responding to the challenge of dementia and providing the care and support to the estimated 140,000 Virginians with Alzheimer's disease.

## AWARD WINNING DEMENTIA CARE COORDINATION

In 2015, DARS received a nearly \$1 million federal grant to pilot a coordinated care system for persons with dementia and their caregivers that concludes in August 2018. The grant project bridges the gap between clinical and community-based supports through a partnership between the University of Virginia's Memory and Aging Care Clinic and the Jefferson Area Board for Aging (JABA) for dementia care services. In 2018, the program won a Best Practices Award from the Virginia Commonwealth Council on Aging and was recognized by the National Association of Area Agencies on Aging (n4a) as one of the top four highest-scoring Aging Innovation Award winners.

## COMMISSION RECOMMENDATIONS FOR 2019 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.

Develop and Fund  
Interdisciplinary  
Memory Assessment  
Clinics with Dementia  
Care Coordination

Commitment from VDH to  
collect cognitive  
impairment and caregiver  
data

Assess family caregivers  
in developing managed  
long term services and  
support care plans

## Develop and Fund Interdisciplinary Memory Assessment Clinics with Dementia Care Coordination

Studies have found that primary care providers are ill-equipped to provide comprehensive management or care coordination for individuals with dementia and their caregivers. Dementia care coordination programs using trained Care Coordinators (CC) embedded in the memory assessment clinics are needed for successful dementia care. Streamlining dementia care using CCs would realize significant cost savings, decrease health care utilization, and improve health outcomes. The CCs undergo specialized dementia training and provide the services of options counseling with understanding the unique evolving needs of persons with dementia and their caregivers. Since 2015, the Dementia Care Coordination Program, a three-year grant funded partnership between DARS, the University of Virginia's Memory and Aging Care Clinic, and JABA, will result in a replicable best practice for care coordination for individuals with dementia and their caregivers. With the grant coming to an end in 2018, the Commission recommends using state funding to continue interdisciplinary plans of care and dementia care coordination for individuals diagnosed with dementia with a vision to growing the program statewide.

### Commitment from VDH to collect cognitive impairment and caregiver data

The Commission seeks a commitment from the Virginia Department of Health (VDH) to implement the Behavioral Risk Factor Surveillance System (BRFSS) optional Cognitive Impairment and Caregiver Modules to collect Virginia data on cognitive impairment and caregiving and future public health service needs. BRFSS is a data collection tool to assist states with gathering data on health, disease prevalence, and health behaviors nationally through the Centers for Disease Control and Prevention. VDH last implemented the BRFSS Cognitive Impairment Module in 2015. During 2015, 24 states, including Virginia, included the Caregiver Module on their BRFSS. According to *From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Crisis* ([http://www.caregiving.org/wp-content/uploads/2018/01/From-Insight-to-Advocacy\\_2017\\_FINAL.pdf](http://www.caregiving.org/wp-content/uploads/2018/01/From-Insight-to-Advocacy_2017_FINAL.pdf)), "Surveillance data on public health topics is critical because it provides an evidence base upon which to make informed decisions about allocating resources, targeting programs, and developing policy." The Commission believes the collection of this BRFSS data will give government agencies and providers a clearer picture of need and allow for continued coordinated efforts to address the dementia and caregiving needs in the Commonwealth.

### Assess family caregivers in managed long term services and support care plans

As Virginia Medicaid shifts to Managed Long Term Services and Supports (MLTSS), a key component must not be left out of the equation: family caregivers. A report released by the AARP Public Policy Institute in November 2016 emphasizes that caregivers are an invaluable part of the care team and often make the difference between a beneficiary remaining in the community or being institutionalized. [http://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080\\_FSandMLTSS\\_REPORT\\_WEB.pdf](http://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080_FSandMLTSS_REPORT_WEB.pdf) In Medicaid, many states formally or informally assess family caregivers as part of the process for developing long term services and supports care plans. The assessment is an opportunity to ask caregivers how they are doing and determine what information and assistance they need. Experts frequently cite caregivers as the backbone of our long-term care system. The Commission recommends recognizing and supporting family caregivers as the Commonwealth transitions to MLTSS for Medicaid recipients and other populations.

## COMMISSION ACTIVITIES

**Dementia Services Coordinator:** 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 [www.AlzPossible.org](http://www.AlzPossible.org).

**Caregiver Grants:** In 2014, DARS received \$441,131 for a three-year grant from the federal Administration for Community Living (ACL) to establish Virginia as dementia-capable and implement a caregiver program called FAMILIES in the greater Charlottesville and Williamsburg areas. The caregiver program aims to help family or informal caregivers feel more confident in their role, build a support network, and help caregivers assess and comfortably respond to behaviors that can sometimes affect people with dementia. A \$276,127 expansion grant was also awarded to achieve statewide coverage of the caregiver program using telehealth and increased in-person delivery. The ACL-funded FAMILIES grant concludes in August 2018 and sustainability planning is underway. In 2016, DARS won a \$900,000 grant from ACL to partner with the Alzheimer's Association chapters in Virginia to expand Virginia's chronic disease management program, "You Can! Live Well, Virginia!" to include individuals with early-stage dementia and their caregivers, and it will provide training on dementia to those who coordinate and lead the workshops at the local level.

**Dementia Friendly Virginia:** DARS and LeadingAge Virginia co-sponsored a statewide kick off workshop on April 20, 2018 for the Dementia Friendly Virginia Learning Collaborative that was followed up by a webinar in May 2018 that included a presentation on the Dementia State Plan by Commission Chair Lory Phillippo. Communities across the country, including Herndon, Virginia, are fostering dementia friendliness by affiliating with Dementia Friendly America. This national group 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. <http://www.dfamerica.org/>

**Collaboration with the Department of Criminal Justice Services on First Responder Training:** Through an RFP process, DCJS contracted with Niagara University of New York to develop a train-the-trainer curriculum which focuses on preparing law enforcement for interactions with special populations including persons with dementia. The \$50,000 allocated annually by Virginia for first responder training on Alzheimer's disease and dementia led to the development of an eight-hours dementia-specific module.

**AlzPossible:** The Commission, in collaboration with the Virginia Commonwealth University Department of Gerontology and World Events Forum, Inc., maintains the AlzPossible 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, Senior Navigator, the Alzheimer's Association, and the federal ElderCare Locator and 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 2019 General Assembly session, the Commission will promote its recommendations for expanded support for people with dementias and their caregivers and facilitating dementia research and access to services. Additional information about the Commission may be found at: <https://www.vda.virginia.gov/boardsandcouncils.htm>