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# THE 2014 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 Lynne Seward, 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 and National Alzheimer's Plan

In December 2011, the Commission released the *Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers*. This plan serves to advise policy makers, legislators, other public officials, health and human services professionals, advocates, and other interested people about best practices and strategies as the Commission and all public and private partners work together to better serve individuals with dementias and their family members, friends, and care providers. The five goals of the state plan establish a comprehensive vision for:

1. Coordinating quality dementia services to ensure a dementia-capable services system,
2. Using dementia-related data to improve public health,
3. Increasing awareness and creating dementia-specific training,
4. Providing access to quality coordinated care in the most integrated setting, and
5. Expanding resources for translational research and evidence-based practices.

On May 15, 2012, the federal government released the country's first National Alzheimer's Plan (Plan). It is the result of a mandate in the National Alzheimer's Project Act (NAPA), which Congress passed unanimously in December 2010. The Plan, which will result in important progress when fully implemented, seeks to prevent and effectively treat Alzheimer's by 2025.

These concerted state and federal planning efforts will provide the best chance of overcoming Alzheimer's disease and related disorders. 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.

## COMMISSION RECOMMENDATIONS FOR 2015 GENERAL ASSEMBLY ACTION TO IMPLEMENT THE DEMENTIA STATE PLAN

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The 2014 General Assembly recognized the Commission's accomplishments, proven track record of advocacy, and the Dementia State Plan work that remains to be done by expanding State Long-Term Care Ombudsman access to the records of community providers, providing an increase in public guardianship funding, and extending the Commission until July 1, 2017, ensuring the Commission can continue its invaluable work. This year, the following items serve as the Commission's 2015 policy recommendations.

### FACTS ABOUT ALZHEIMER'S DISEASE

- According to the Virginia Center on Aging estimates, 131,000 Virginians were living with Alzheimer's disease and related dementias (ADRD) in 2012.
- In 2012, 91,517 Medicare beneficiaries in Virginia had ADRD (CMS Chronic Conditions, 2014). Yet, the prevalence is likely much higher because many do not receive a confirmed diagnosis (Alzheimer's Association, 2014; USPSTF, 2014).
- In calendar year 2012, 12.5% of adults age 45 and older surveyed by Virginia Department of Health (VDH) reported having experienced increased confusion or memory loss in the last 12 months. Of those adults, only 1 in 4 discussed it with a health care professional (VDH BRFS 2012).

### ACCOMPLISHING THE GOALS OUTLINED IN THE DEMENTIA STATE PLAN 2011-2014

**COORDINATED CARE:** The Commission developed an interdisciplinary memory assessment center listing for consumers and posted it on [www.AlzPossible.org](http://www.AlzPossible.org).

**DATA AND RESEARCH:** The Commission continued collecting and analyzing data, including prevalence estimates and use of public services, and identified data sets for Virginia researchers.

**TRAINING:** The Commission received GTE funding in 2011-2013 for training webinars on ADRD and participated in the statewide Crisis Intervention Team conference in May 2014 presenting to first responders on Alzheimer's disease and related dementias.



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## Dementia Training Funding for First Responders and Law Enforcement

Virginia needs to develop training standards and modules for communicating with and facilitating the safe return of persons with ADRD and fund statewide such training efforts.

The Commission seeks dedicated funding to provide dementia training to first responders and law enforcement. The Department of Criminal Justice Services has the duty to establish training standards and a model policy for law-enforcement personnel in communicating with and facilitating the safe return of individuals diagnosed with ADRD pursuant to Code of Virginia § 9.1-102. Yet, in 2010, the funding for dementia training was cut. Six in 10 people with dementia will wander at some point during the disease process. If not found within the first 24 hours, anywhere from one-third to one-half may die (ABC News, 2014). Training first responders on how to identify, communicate with, and locate an individual with ADRD will prove to not only save lives, but also minimize the costs associated with implementing a major search and rescue effort. With minimal funding, such training needs can once again be met in Virginia.

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## Alzheimer's Waiver Definition Revision to Include Other Related Dementias

While Alzheimer's disease is the leading cause of dementia, as many as 40% of dementias are caused by other disorders (WHO, 2012).

The Commission calls for a revision to the definition of Alzheimer's disease for the 1915(c) Alzheimer's Assisted Living (AAL) Waiver program through the Virginia Department of Medical Assistance Services (DMAS). Started in 2006, the AAL Waiver provides community-based care options for individuals with Alzheimer's disease in assisted living facilities who meet the nursing facility level of care and are currently receiving an Auxiliary Grant. However, the current narrow eligibility criteria do not recognize the similar needs of individuals with other dementias. Studies estimate the prevalence of vascular dementia to be 20-30% and Lewy body dementia to be anywhere from 5-30%, with mixed dementia occurring in about 35% of individuals with diagnosed Alzheimer's disease (Stephan & Brayne, 2008, WHO, 2012; Alzheimer's Disease International, 2009). In order to allow more individuals to receive services through the AAL waiver, the Commission urges DMAS to adopt the language of "serious cognitive impairment" as defined in 22VAC40-72-10 within the Standards for Licensed Assisted Living Facilities, thereby ensuring a truly inclusive and person-centered approach to community-based services for Virginians with ADRD.

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## Commitment from Virginia Department of Health to Collect Data on Caregivers

In 2013, an estimated 447,000 family caregivers in Virginia provided 509 million hours of unpaid care valued at over \$6.342 billion (Alzheimer's Association's 2014 Facts and Figures at [www.alz.org](http://www.alz.org)).

The Commission seeks a commitment from the Virginia Department of Health to implement the Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module to collect data on caregivers in 2015 and 2016. The 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. It is common for caregivers to report high emotion and physical stress that negatively impact their own health care utilization, employment, and even mortality (Alzheimer's Association, 2014). Combined with the 2012 and 2013 results from the BRFSS Cognitive Impairment Module, the Caregiver Module results will give agencies a clearer picture of need and allow for continued coordinated efforts to address the ADRD and caregiving needs in the Commonwealth.

## COMMISSION ACTIVITIES

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**Dementia Care Best Practices:** In 2014, DARS was asked to do a study of dementia care “best practices” in the Commonwealth and ways to expand and encourage such practices across all levels of care and settings with a final report date of October 1, 2014. Charlotte Arbogast, MSG, Virginia’s first Dementia Services Coordinator (DSC) at DARS, is serving as the lead on the Best Practices study. Persons may contact the DSC through the AlzPossible website ([www.AlzPossible.org](http://www.AlzPossible.org)).

**AlzPossible:** The Commission, in collaboration with the Virginia Commonwealth University Department of Gerontology and World Events Forum, Inc., has recently unveiled a new look for its AlzPossible website. Aimed at providing professional caregivers in Virginia updated information on ADRD, the innovative AlzPossible site hosts:

- ❖ The Commonwealth’s Dementia State Plan,
- ❖ A library of free webinars for professionals and caregivers on ADRD 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 ADRD,
- ❖ The results of research being conducted in the Commonwealth and information on Virginia Alzheimer’s and Related Disorders Research Award Fund (ARDRAF) applications and deadlines, and
- ❖ Links to local, state, and national resources, including state agencies, Senior Navigator, the Alzheimer’s Association, and the federal ElderCare Locator and Alzheimer’s.gov.

**Training Events:** The Commission received funding through the Virginia Center on Aging’s Geriatric Training and Education Initiative (GTE) to implement a series of free webinar training events using AlzPossible entitled, *The Other Dementias: Virtual Training and Active Learning on Non-Alzheimer’s Dementias*. Across the series, attendees came from 26 states, including Virginia, and 99.8% of attendees reported that they would recommend the virtual trainings to their colleagues. The courses held were:

General Dementia Overview	Vascular and Mixed Dementia	Parkinson’s Disease Dementia	Lewy Body Dementia
<ul style="list-style-type: none"><li>• Pre-recorded</li><li>• Served as a prerequisite</li></ul>	<ul style="list-style-type: none"><li>• Live webinar held March 17, 2014</li><li>• 329 Attendees</li></ul>	<ul style="list-style-type: none"><li>• Live webinar held April 3, 2014</li><li>• 337 Attendees</li></ul>	<ul style="list-style-type: none"><li>• Live webinar held May 29, 2014</li><li>• 189 Attendees</li></ul>

An additional live webinar on August 29, 2014 provided training on Oral Health Care and Dementia, drawing 143 attendees from 11 states with 100% of attendees reporting that they would recommend the webinar to their colleagues.

## CURRENT FOCUS

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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 2015 General Assembly session, the Commission will promote its recommendations, which advocate for continued data collection, expanded support for people with varying dementias, and enhanced training of first responders. Additional information about the Commission may be found at: <http://www.vda.virginia.gov/alzcommission.asp>.

The Commission is currently in the process of updating the Dementia State Plan. While taking an inventory of the successes in making Virginia more dementia-capable in the last four years, the Commission is also examining activities that still need to be accomplished and new objectives and strategies that have been identified. The Commission will be diligently working in 2015 to craft and update the Dementia State Plan, ensuring it reflects the needs of individuals with ADRD and their dedicated caregivers and identifies initiatives to address those needs.