

THE 2012 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: ACTIVITIES AND RECOMMENDATIONS

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 activities and recommendations of the Commission. The Commission, chaired by Dr. Patricia W. Slattum, advises the Commonwealth on the care of individuals with Alzheimer's disease and other dementias, and how to assist their caregivers.

Dementia State 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 we work to better serve individuals with dementias and their family members, friends, and care providers. The five goals of the state plan provide a comprehensive vision to:

1. Coordinate quality dementia services to ensure a dementia-capable services system
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
5. Expand resources for translational research and evidence-based practices

National Alzheimer's Plan

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, also sets out five goals:

1. Prevent and effectively treat Alzheimer's by 2025,
2. Optimize care quality and efficiency,
3. Expand support for people with the disease and their caregivers,
4. Enhance public awareness and engagement, and
5. Improve data to track progress.

Because of the Plan, the National Institutes of Health committed an additional \$50 million this year for Alzheimer's research, and another \$6 million is being spent by the federal government on increasing public awareness and educating health care professionals. The next important step is for Congress to approve the Plan's additional funding for 2013. Specifically, Congress needs to provide an additional \$100 million in the fight against Alzheimer's for 2013 – \$80 million for research, \$10.5 million for caregiver support, and \$9.5 million for public awareness, physician education, and data collection.

ALZHEIMER'S DISEASE FACTS AND FIGURES:

Statistics published in the Alzheimer's Association's 2012: *Alzheimer's Disease Fact and Figures* found at www.alz.org document the rapidly growing Alzheimer's crisis:

- 5.4 million Americans are living with Alzheimer's disease—5.2 million aged 65 and over, and 200,000 under the age of 65.
- One in eight older Americans has Alzheimer's disease.
- Alzheimer's disease is the 6th leading cause of death in the United States and the only cause of death among the top 10 in the United States that cannot be prevented, cured or even slowed.
- More than 15 million Americans provide unpaid care valued at \$210 billion for persons with Alzheimer's and other dementias.
- Payments for care are estimated to be \$200 billion in 2012, including \$140 billion in Medicare and Medicaid costs.
- Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent.
- Another American develops Alzheimer's disease every 68 seconds.
- An estimated 800,000 individuals with Alzheimer's (more than 1 in 7) live alone and, of these, up to half of them do not have an identifiable caretaker.
- Due to the physical and emotional toll of care giving on their own health, caregivers of individuals with Alzheimer's and other dementias had \$8.7 billion in additional health care costs in 2011.
- Deaths from Alzheimer's increased 66 percent between 2000 and 2008, while deaths from other major diseases, including the number one cause of death (heart disease) decreased.
- In 2008, 66% of residents of Virginia nursing facilities had cognitive impairment related to dementia.

When both the state and federal plans are fully implemented, important progress will be realized in the fight against Alzheimer's disease and related disorders. Concerted efforts in national and state planning will provide the best chance of overcoming this dreaded disease. Acting in its advisory capacity and to further these goals, the Commission recommends actions to enhance Virginia's ability to effectively and efficiently serve individuals with Alzheimer's disease and other dementias and their caregivers.

COMMISSION RECOMMENDATIONS FOR 2013 GENERAL ASSEMBLY ACTION TO IMPLEMENT THE DEMENTIA STATE PLAN



Create and fully fund a Dementia Services Coordinator (DSC).

Create a position and hire a full-time **Dementia Services Coordinator (DSC)** to coordinate the services provided to individuals with Alzheimer's disease .

Each agency within the Health and Human Resources Secretariat has created its own long-term care program for dementia-related services and supports without coordinating policy goals and implementation. The DSC in the Department for Aging and Rehabilitative Services would review existing programs and work with agencies to create a dementia-capable service delivery system. The DSC would identify gaps in Medicaid and other state services and reduce duplication of existing services.

- a. The job responsibilities should include policy, research and coordination of services.
- b. The DSC should disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academia, primary caregivers, advocacy organizations and the general public.
- c. The DSC should establish a strategy to link and coordinate services and activities of state agencies, other service providers, advocacy groups, and other entities throughout Virginia such as emergency personnel, police, universities, and attorneys and other staff associated with the legal system. This could include partnerships with the Alzheimer's Association, Area Agencies on Aging, and other groups involved with dementia research and care.
- d. The DSC should coordinate and provide support for Commission activities.
- e. The DSC should oversee and promote services for all types and states of Alzheimer's and related dementias, including younger individuals with early onset dementias.
- f. The DSC should support the Aging and Disability Resource Centers in becoming dementia capable.

Designate the Department for Aging and Rehabilitative Services as the lead state agency for Alzheimer's disease and related disorders.

DARS becomes lead state agency for Alzheimer's disease and related disorders.

Building on the momentum of the *Dementia State Plan* and the *National Alzheimer's Plan*, the General Assembly should designate DARS as the lead agency for carrying out the *Dementia State Plan*, and have DARS, in conjunction with the Commission, propose initiatives and identify the sources and amounts of resources needed to implement the plan. The lead agency and the Commission should oversee the implementation of the plan. The lead agency should identify workable and effective organizational structures at the state and regional or local levels to implement the goals in the plan. The Commission's annual report should identify any new initiatives and the resources necessary to implement them to enhance the Commonwealth's efforts in the fight against Alzheimer's disease and related dementias.

Increase funding for the Alzheimer's and Related Diseases Research Award Fund (ARDRAF).

Double ARDRAF funding.

The General Assembly should double funding for the ARDRAF to increase investment in research on the biomedical and psychosocial aspects of dementia, including cell biology, caregiving, animal modeling dementia prevention, modification, treatment cures, and best practices for dementia.

The Virginia Center on Aging (VCoA) at Virginia Commonwealth University administers ARDRAF, which is the country's most productive state-based seed grant program to stimulate research on dementia. The ARDRAF (*Code of Virginia § 51.5-153*) was established in 1982 to stimulate biomedical and psychosocial research on dementia, which affects more than one-third of all Virginians above age 85. To date, the ARDRAF has supported 131 pilot studies, which have produced more than 242 scientific publications and a documented \$22.29 million in subsequent funding from non-state grantors. The return on Virginia investment is \$9 for every \$1 appropriated.

The ARDRAF's many practical results include clinical tools to help physicians diagnose dementia, web-based help for family caregivers, improved drug regimens for treatment, and a search-and-rescue protocol used around the world to find confused wanderers.

LONGER TERM RECOMMENDATIONS FOR IMPLEMENTING THE DEMENTIA STATE PLAN

The Virginia Alzheimer's Disease and Related Disorders Commission partnered with stakeholders throughout Virginia who contributed to the development of and who will ultimately work with the Commission over time to implement the Dementia State Plan. The Commission has disseminated the plan widely, including hosting a webinar on the VACAPI (Virginia Alzheimer's Commission AlzPossible Initiative) website (www.alzpossible.org) on December 15, 2011. VACAPI is an online platform dedicated to learning, sharing, and formulating concrete solutions to the problems involved in Alzheimer's disease caregiving.

The Commission received funding in 2011 through VCoA's Geriatric Training and Education Initiative to implement a series of webinar training events based on the results from previously-funded ARDRAF projects that targeted Virginia professional service and care providers:

Improving Short-Term Memory Loss in Patients with Alzheimer's Dementia Using Smartphone Application for Capturing Daily Life

Live webinar held November 10, 2011

The Triad in Dementia Care: Methods for Strengthening the Partnership

Live webinar held December 2, 2011

End-of-Life Care Experiences for Individuals with Alzheimer's Disease and their Family Caregivers

Live webinar held February 15, 2012

Caring for a Spouse with Mild Cognitive Impairment: Daily Challenges, Marital Relations, and Physiological Indicators of Health

Live webinar held April 2, 2012

Family Quality of Life in Dementia: Key Concepts in Dementia Care

Live webinar held July 30, 2012

Through VACAPI, the Commission promotes public access to the results of research being conducted in the Commonwealth and clearly demonstrates that the research is effective. The Commission will continue to use the VACAPI website also as a forum to link researchers interested in Alzheimer's disease research.

As part of its ongoing longer term recommendations for the future, the Commission recommends promoting research and developing new treatments that prevent and effectively treat the disease, expanding support for people with the disease and their families, and enhancing care quality and coordination in addressing the rapidly mounting Alzheimer's crisis.