

WORK IN PROGRESS

Virginia's Commission on Alzheimer's Disease and Related Disorders Strategic Plan

BACKGROUND AND RATIONALE

Life expectancy of the oldest-old is increasing, while the prevalence of dementia increases nearly exponentially beyond age 65. The number of people being affected by Alzheimer's disease (AD), the most prevalent form of dementia, is growing at a faster rate than the progress being made in discovering the means to cope with the emerging epidemic. In other words, the pace of developing interventions to delay the symptoms of disease is not adequate to overcome the demographic forces, which are increasing the total number of affected individuals. The approaching crisis in the national health care system stems from not only the growing number of older people at risk for prolonged disabilities such as cognitive impairment due to dementia but also the rising cost of labor intensive care. Neither the general public nor its policy makers appreciates the magnitude of the pending public health disaster.

Alzheimer's disease, the most prevalent form of dementia, currently costs nearly \$100 billion a year, reflecting medical charges, institutionalization, and informal care costs. The average annual cost of care is estimated to be between \$40,000 to \$60,000 per patient, per year, with nearly 500,000 new patients every year. The statistics indicate that by the year 2050, US will have more than 16 million individuals, up from five million today, affected by Alzheimer's disease and requiring medical care and institutionalization.

The patterns of demographic, economic, and sociologic changes in society are going to effect profoundly how care is provided for people with Alzheimer's disease. These patterns will have their full impact as the "baby-boom" generation ages into late life 20 to 30 years from now. These trends, which foretell the devastating toll of dementia, have already begun to shape the future strategic plans of many public and private organizations. Not only the families of the people with the disease but also the whole population of the Commonwealth of Virginia, and the country as a whole will feel the projected changes.

At the same time, remarkable progress has been made since 1978 in understanding Alzheimer's disease. Now the field has access to a rich array of talents, tools, ideas, knowledge, and experiences from diverse disciplines, providing unique opportunities for quantum leaps in uncovering cause(s), early detection, treatments, and new models of care. New discoveries and leads have begun to provide some measure of hope for interventions that could delay the onset of disabling symptoms and enable

- Americans fear Alzheimer's more than heart disease, stroke, or diabetes
- Those over 55 fear the disease more than any other – even more than cancer.
- Almost 5 million Americans have Alzheimer's, including almost half those over 85.
- Every 72 seconds another American joins their ranks
- The number of people with Alzheimer's doubles every 5 years beyond age 65.
- Cases expected to triple over coming generation as baby boomers age.
- Half of all nursing home residents suffer from Alzheimer's.
- CDC lists Alzheimer's as the 7th leading cause of death in America.
- There are no cures; there are no remissions.
- Alzheimer's costs the federal government alone more than \$100B per year.
- Healthcare for Alzheimer's patients is three times as expensive as for those without.

patients to continue functioning independently for longer periods. It is estimated that a modest delay in the onset of symptoms by five years for all age groups over 65 would reduce nearly half the total number of individuals with the disease.

It is on this background that the Commonwealth brings together a Commission which focuses its mission and goals on Virginia's individuals with Alzheimer's disease and related disorders, as well as on their caregivers.

MISSION AND ORGANIZATION

The Virginia's Commission on Alzheimer's Disease and Related Disorders serves in an advisory capacity to the Virginia Governor and the Secretary of Health and Human Resources (HHR), and exists to assist individuals with Alzheimer's disease or related disorders, as well as their caregivers.

The overarching aim of the Commission is to support a convergence of all relevant public and private stakeholders or a statewide "call to action" targeting the improvement of care and the development of effective treatments for the individuals with Alzheimer's disease.

The Commission is legislatively mandated to have the following powers and duties:

1. **Examine the needs** of persons with Alzheimer's disease and related disorders, as well as the needs of their caregivers, and ways that state government can most effectively and efficiently assist in meeting those needs;
2. **Advise the Governor and General Assembly** on policy, funding, regulatory and other issues related to persons suffering from Alzheimer's disease and related disorders and their caregivers;
3. **Develop the Commonwealth's plan** for meeting the needs of patients with Alzheimer's disease and related disorders and their caregivers, and advocate for such plan;
4. **Submit a report**, including an executive summary, by October 1 of each year to the Governor and General Assembly regarding the activities and recommendations of the Commission; and
5. **Establish priorities for programs** among state agencies related to Alzheimer's disease and related disorders and criteria to evaluate these programs.

The Commission consists of 15 non-legislative citizen members, appointed as follows:

- Three members are appointed by the Speaker of the House of Delegates;
- Two members are appointed by the Senate Committee on Privileges and Elections; and
- Ten members are appointed by the Governor. Of these ten, seven are appointed from the board members, staff members and volunteers of the Virginia Chapters of the Alzheimer's Disease and Related Disorders Association. The other three members are appointed from the public at large.

The Commission elects a Chairman from among its membership. View a current list of [Commission members](#).¹

The Commission meets quarterly and all meetings are open to the public. Meetings of the Commission are announced in advance on the [Commonwealth Calendar](#). Minutes of Commission meetings are also available on the Calendar.

The Commission's operative arm is the Virginia Alzheimer's Commission AlzPossible Initiative (VACAPI), through which it had created an infrastructure to facilitate delivery of Alzheimer's disease-relevant services to targeted constituencies. The following VACAPI services are currently available throughout the Commonwealth:

- *The Education, Outreach, and Information Core* has launched an interactive forum, monthly newsletter and live webinar series designed to address questions posed and issues faced by Virginia citizens with Alzheimer's disease, as well as their caregivers;
- *The Services Core* has established a Telemedicine Memory Disorders Clinic, staffed by Alzheimer's disease specialists at the University of Virginia School of Medicine and partly supported through a federal grant, that provides consultative advice to physicians and other health care workers caring for Alzheimer's patients throughout the state;
- *The Research Core* is creating a registry comprised of children of Alzheimer's disease patients, which will serve as a resource for Virginia scientists studying aging and Alzheimer's disease; and
- *The Administrative Core* has successfully created and maintained an official website accessible to Virginia citizens wishing to learn more about the Commonwealth's commitment to those affected directly (patients) or indirectly (caregivers) by Alzheimer's disease.

The Commission prepares an annual report for the Secretary of Health and Human Resources which is available at the following link: [Commission's current report \(www.vda.virginia.gov/pdfdocs/adrdcommannualrpt.pdf\)](http://www.vda.virginia.gov/pdfdocs/adrdcommannualrpt.pdf).

GOALS and OBJECTIVES

To better meet the needs of patients with Alzheimer's disease and related disorders and their caregivers, the Commission has developed the following goals and objectives:

¹ View a complete description of the selection process of Commission members and their respective terms of service. Visit the [Virginia General Assembly's Code of Virginia](#) page. Type "2.2-720" in the box under the words "Enter search phrase and press submit", then press the "submit" button.

1. **Review the current quality and effectiveness of public and private programs** and Federal, state, and local government involvement in the delivery of services to individuals with Alzheimer's disease and related disorders, while identifying unmet needs and barriers to services.
2. **Formulate policy options** that could be implemented by public and private providers and Federal, state, and local governments to integrate the use of effective treatments and services, enhance coordination among service providers, and improve community support.
3. **Promote education and disseminate information** on services and related activities for individuals with Alzheimer's disease and related disorders to the medical and healthcare communities, academia, family caregivers, advocacy groups and the public-at-large.
4. **Support the collaboration** and coordination of services and activities across state agencies as well as relevant groups and associations.
5. **Recommend short-term and long-term actions** designed to benefit individuals with Alzheimer's disease and related disorders and their caregivers.
6. **Advocate for coordinated research and education** across the Commonwealth.
7. Ensure that **Alzheimer's disease research** under the Alzheimer's and Related Diseases Research Award Fund (ARDRAF) **is maintained as a line item** in the state budget.
8. **Create additional funding** for statewide Alzheimer's disease projects and programs.
9. Maintain and further develop the Commission's **AlzPossible website**.