

**Alzheimer's Disease and Related Disorders Commission**

# **DEMENTIA STATE PLAN:**

**Virginia's Response to the Needs of  
Individuals with Dementia  
and their Caregivers**



# Table of Contents

**Letter to the Governor and General Assembly , 3**

**Overview of Goals, 4**

**What is Dementia?**

**Definition and Causes, 5**

**Symptoms of Alzheimer’s Disease, 5**

**Diagnosis of Alzheimer’s Disease, 6**

**Causes of Alzheimer’s Disease, 7**

**Risk Factors, 8**

**Treatment , 10**

**Recommendations**

**I. Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia Capability, 11**

**II. Use Dementia Related Data to Improve Public Health, 13**

**III. Increase Awareness and Create Dementia Specific Training, 15**

**IV. Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting, 17**

**V. Expand Resources for Dementia Specific Translational Research and Evidence-Based Practices , 18**

**Appendices**

**How We Got Here, 20**

**Statistical Sheet, 21**

**Resources, 22**

**Glossary, 25**



**COMMONWEALTH OF VIRGINIA**  
*Alzheimer's Disease and Related Disorders Commission*

December 7, 2011

The Honorable Robert F. McDonnell and Members of the Virginia General Assembly,

The Alzheimer's Disease and Related Disorders Commission is pleased to present the *Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers*. The Commission has worked diligently to develop this plan through collaboration with researchers and clinicians and through a statewide series of public hearings providing valuable input from individuals with dementia and family caregivers. These hearings were facilitated by organizations such as the four chapters of the Alzheimer's Association serving Virginia, and an online public comment period was publicized through a network of health and trade organizations.

Approximately one in eight older adults is affected with Alzheimer's disease, the fifth leading cause of death, and the number affected is expected to triple by 2050. Planning now is essential. The five goals of the plan provide a comprehensive vision to:

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
5. Expand Resources for Translational Research and Evidence-Based Practices

The Commission has developed associated recommendations and formed workgroups to facilitate realization of each goal. The Commission will evaluate and track progress on these recommendations and looks forward to reporting accomplishments in the future.

While achieving this vision will likely require additional resources, progress can also be made through innovation and collaboration. If you would like to share your thoughts and ideas with the Commission, please contact any of the Commission members or the staff at the Virginia Department for the Aging.

Sincerely,

A handwritten signature in black ink that reads 'Patricia W. Slattum'.

Patricia W. Slattum, Chair  
Alzheimer's Disease and Related Disorders Commission

*Patricia W. Slattum, Pharm.D.,  
Ph.D., Chair*

*Martha Watkins, Vice Chair*

*Charlotte Arbogast*

*Vivian Bagby, RN, MS*

*Kae H. Chung, Ph.D.*

*Constance L. Coogle, Ph.D.*

*Julia T. Dillon*

*W. Thomas Hudson*

*Maxcine C. Maxfield, Ph.D.*

*Robert Schaefer*

*Lynne Seward*

*Faith C. Shartzler, RN*

*Courtney S. Tierney, MSW*

*George Vradenburg*

*Kevin P. Walsh, DC*

[www.alzpossible.org](http://www.alzpossible.org)

[vda.virginia.gov/alzcommission.asp](http://vda.virginia.gov/alzcommission.asp)

*Virginia Department for the Aging*

*1610 Forest Avenue, Suite 100*

*Richmond, Virginia 23229*

[aging@vda.virginia.gov](mailto:aging@vda.virginia.gov)

*(804) 662-9333*

*Fax (804) 662-7035*

# Overview of Goals

## **GOAL I: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia Capability**

- A. Create a dementia services coordinator.
- B. Expand availability and access of dementia capable Medicaid and other state-level services.
- C. Create a statewide network of memory disorders clinics to assess and treat persons with dementia.

## **GOAL II: Use Dementia Related Data to Improve Public Health Outcomes**

- A. Collect and monitor data related to dementia's impact on the people of the Commonwealth.
- B. Remove barriers for community integration for persons with dementia.
- C. Collaborate with related public health efforts to encourage possible risk-reduction strategies.

## **GOAL III: Increase Awareness and Create Dementia Specific Training**

- A. Provide standardized dementia specific training to individuals in the health-related field and require demonstrated competency.
- B. Provide dementia specific training to professional first responders, financial services personnel, and the legal profession.
- C. Link caregivers, family members and individuals with dementia to information about dementia services.

## **GOAL IV: Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting**

- A. Advocate for and increase awareness of integrated systems of care coordination that effectively support improved health outcomes for individuals with dementias and their families and loved ones.
- B. Explore tax incentives for family caregiving, respite care, long term care insurance purchases, locator devices, and additional long term care services.
- C. Advocate for accessible transportation systems.

## **GOAL V: Expand Resources for Dementia Specific Translational Research and Evidence-Based Practices**

- A. Increase funding for the Alzheimer's and Related Diseases Research Award Fund.
- B. Provide support to researchers across the Commonwealth through data sources and networking opportunities.
- C. Promote research participation in Virginia.

# What Is Dementia?

## DEFINITION AND CAUSES

When making a diagnosis of dementia, physicians commonly refer to the criteria given in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). To meet DSM-IV criteria for dementia, the following are required:

- **Symptoms must include decline in memory and in at least one of the following cognitive abilities:**
  1. Ability to generate coherent speech or understand spoken or written language;
  2. Ability to recognize or identify objects, assuming intact sensory function;
  3. Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and
  4. Ability to think abstractly, make sound judgments and plan and carry out complex tasks.
- **The decline in cognitive abilities must be severe enough to interfere with daily life.**

It is important for a physician to determine the cause of memory loss or other dementia-like symptoms. Some symptoms can be reversed if they are caused by conditions such as depression, delirium, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies. If not, a physician must conduct further assessments to identify the disorder, most commonly Alzheimer's Disease, that is causing symptoms. Different disorders are associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. These disorders include, but are not limited to, primary neurodegenerative dementias, such as dementia with Lewy Bodies and other Parkinsonian syndromes with dementia, vascular dementia, and frontotemporal dementias including Pick's Disease.

Although Alzheimer's disease is the most common type of dementia, increasing evidence from long-term observational and autopsy studies indicates that many people with dementia have brain abnormalities associated with more than one type of dementia.

## SYMPTOMS of Alzheimer's Disease

The warning signs of Alzheimer's disease are illustrated on the next page.

Individuals progress from mild Alzheimer's disease to moderate and severe disease at different rates. As the disease progresses, the individual's cognitive and functional abilities decline.

In advanced Alzheimer's, people need help with basic activities of daily living, such as bathing, dressing, using the bathroom and eating.

Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on around-the-clock care.

# What Is Dementia? (cont.)

In late-stage Alzheimer's disease, the inability to move around can make a person more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer's disease is ultimately fatal, and Alzheimer-related pneumonia is often the cause.

Although families generally prefer to keep the person with Alzheimer's at home as long as appropriate, most people with the disease eventually move into a nursing home or another residence where around-the-clock professional care is available.

## DIAGNOSIS of Alzheimer's Disease

A diagnosis of Alzheimer's disease is most commonly made by an individual's primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. Ideally, a family member or other individual close to the patient is available to provide input. The physician also conducts cognitive tests and physical and neurologic examinations. In addition, the patient may undergo magnetic resonance imaging (MRI) scans to identify brain changes that have occurred so the physician can rule out other possible causes of cognitive decline.



# What Is Dementia? (cont.)

## CAUSES of Alzheimer's Disease

Alzheimer's disease was first identified more than 100 years ago, but research into its symptoms, causes, risk factors and treatment has only gained momentum in the last 30 years. While research has revealed a great deal about Alzheimer's, with the exception of certain inherited forms of the disease, the cause or causes of Alzheimer's disease remain unknown.

Among the brain changes believed to contribute to the development of Alzheimer's are the accumulation of the protein beta-amyloid outside nerve cells (neurons) in the brain and the accumulation of the protein tau inside neurons. A healthy adult brain has 100 billion neurons, each with long, branching extensions. These long, branching extensions enable individual neurons to form specialized connections with other neurons. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and detected by the receiving neuron. The brain contains 100 trillion synapses. They allow signals to travel rapidly and constantly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

In Alzheimer's disease, information transfer at synapses begins to fail, the number of synapses declines and neurons eventually die. The accumulation of beta-amyloid outside these synapses is believed to interfere with neuron-to-neuron communication and contribute to cell death. Inside the neuron, abnormally high levels of tau form tangles that block the transport of nutrients and other essential molecules throughout the cell. This is also believed to contribute to cell death. Brains with advanced Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

One known cause of Alzheimer's is genetic mutation. A small percentage of Alzheimer's disease cases, probably less than 1 percent, are caused by rare genetic mutations. These mutations involve the gene for the amyloid precursor protein on chromosome 21, the gene for the presenilin 1 protein on chromosome 14 and the gene for the presenilin 2 protein on chromosome 1. Inheriting any of these genetic mutations guarantees that an individual will develop Alzheimer's disease. In such individuals, the disease tends to develop before age 65, sometimes in individuals as young as 30. These people are said to have "familial" Alzheimer's disease.

# What Is Dementia? (cont.)

## RISK FACTORS

The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most Americans with Alzheimer's disease are aged 65 or older. These individuals are said to have late-onset Alzheimer's disease. However, people younger than age 65 can also develop the disease. When Alzheimer's occurs in a person younger than 65 who does not have familial Alzheimer's disease, it is referred to as "younger-onset" (formerly known as "early-onset" Alzheimer's). Advancing age is not the only risk factor for Alzheimer's disease. The following sections describe other prominent risk factors.

### Family History

Family history is another risk factor for Alzheimer's disease. Individuals with a parent, brother or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's. Those with more than one first-degree relative with Alzheimer's are at even higher risk of developing the disease. When diseases run in families, heredity (genetics), environmental factors or both may play a role.

A genetic factor in late-onset Alzheimer's disease is Apolipoprotein E-e4 (APOE-e4). APOE-e4 is one of three common forms (e2, e3 and e4) of the

APOE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream.

Everyone inherits one form of the APOE gene from each parent. Those who inherit one APOE-e4 gene have increased risk of developing Alzheimer's disease and of developing it at an earlier age than those who inherit the e2 or e3 forms of the APOE gene. Those who inherit two APOE-e4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's.

### Mild Cognitive Impairment (MCI)

Another established risk factor for Alzheimer's disease is MCI, a condition in which a person has problems with memory, language or another essential cognitive ability that are severe enough to be noticeable to others and show up on cognitive tests, but not severe enough to interfere with daily life. Studies indicate that as many as 10 to 20 percent of people aged 65 and older have MCI. People whose MCI symptoms cause them enough concern to visit a physician appear to have a high-

er risk of developing dementia. It's estimated that as many as 15 percent of these individuals progress from MCI to dementia each year. From this estimate, nearly half of all people who have visited a physician about MCI symptoms will develop dementia in three or four years. It is unclear why some people with MCI develop dementia while others do not. MCI may in some cases represent a transitional state between normal aging and the earliest symptoms of Alzheimer's.



# What Is Dementia? (cont.)

## Cardiovascular Disease Risk Factors

A growing body of evidence suggests that the health of the brain is closely linked to the overall health of the heart and blood vessels. The brain is nourished by one of the body's richest networks of blood vessels. A healthy heart helps ensure that enough blood is pumped through these blood vessels, and healthy blood vessels help ensure that the brain is supplied with the oxygen- and nutrient-rich blood it needs to function normally. Some data indicate that cardiovascular disease risk factors, such as high cholesterol (especially in midlife), Type 2 diabetes, high blood pressure

(especially in midlife), physical inactivity, smoking and obesity, are associated with a higher risk of developing Alzheimer's and other dementias. Unlike genetic risk factors, many of these cardiovascular disease risk factors are modifiable — that is, they can be changed to decrease the likelihood of developing cardiovascular disease and, possibly, the cognitive decline associated with Alzheimer's and other forms of dementia. More limited data suggest that other modifiable factors, such as remaining mentally active and consuming a diet low in saturated fats and rich in vegetables, may support brain health.

## Head Trauma and Traumatic Brain Injury

Moderate and severe head trauma, head injury and traumatic brain injury are associated with an increased risk of Alzheimer's disease and dementia. If the head injury results in loss of consciousness or post-traumatic amnesia lasting more than 30 minutes, the injury is considered moderate; if either of these lasts more than 24 hours, the injury is considered severe. Data indicate that moderate head injuries are associated with twice the risk of developing Alzheimer's compared with no head injuries, and severe head injuries are associated with 4.5 times the risk. These increased risks have not been shown for individuals experi-

encing mild head injury or any number of common mishaps such as bumping one's head while exiting a car. Groups that experience repeated head injuries, such as boxers, football players and combat veterans, may be at increased risk of dementia, late-life cognitive impairment and evidence of tau tangles (a hallmark of Alzheimer's) at autopsy. Some studies suggest that APOE-e4 carriers who experience moderate or severe head injury are at increased risk of developing Alzheimer's compared with APOE-e4 carriers who do not have a history of moderate or severe head injury.

# What Is Dementia? (cont.)

## TREATMENT

No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration has approved five drugs that temporarily slow worsening of symptoms for about six to 12 months. They are effective for only about half of the individuals who take them. However, researchers around the world are studying numerous treatment strategies that may have the potential to change the course of the disease.

Approximately 75 to 100 experimental therapies aimed at slowing or stopping the progression of Alzheimer's are in clinical testing in human volunteers. Researchers believe that treatments to slow or stop the progression of Alzheimer's disease and preserve brain function will be most effective when administered early in the course of the disease. The brain changes in individuals with Alzheimer's are thought to begin 10 years or more before such symptoms as memory loss appear, and this may be the period during which future Alzheimer drugs will first be given. Much research in recent years has focused on identifying biomarkers that will aid in early detection and tell physicians which patients should receive treatment during these very beginning stages of Alzheimer's. (A biomarker is a naturally occurring, measurable substance or condition that reliably indicates the presence or absence of disease or the risk of later developing a disease; for example, blood glucose levels are a biomarker of diabetes, and cholesterol levels are a biomarker of cardiovascular disease risk.)

To aid in early detection and in diagnosis of Alzheimer's disease from its earliest signs to its eventual impact on mental and physical function, in 2009 the National Institute on Aging and the Alzheimer's Association convened three workgroups to explore the need for new diagnostic criteria that better reflect the full continuum of the disease. In 2010, these workgroups proposed recommendations to update the diagnostic criteria for Alzheimer's dementia and MCI. The workgroup recommendations also include criteria for "preclinical Alzheimer's disease," a new diagnostic category representing the earliest changes that occur even before symptoms such as memory loss or the symptoms associated with MCI. All of the recommendations incorporate the use of biomarkers for diagnosis. Among the biomarkers being considered are brain volume, level of glucose metabolism in the brain, presence of beta-amyloid in the brain and levels of beta-amyloid and tau in cerebrospinal fluid. These recommendations would currently be used only in research settings. Their accuracy must be confirmed in research studies before they can be used in clinical practice, such as during a visit to a physician.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for individuals with Alzheimer's and their caregivers. Active management includes

- (1) appropriate use of available treatment options,
- (2) effective integration of coexisting conditions into the treatment plan,
- (3) coordination of care among physicians, other healthcare professionals and lay caregivers and
- (4) use of activity and support groups, adult day care programs and supportive services such as counseling.

# Goal I: Recommendations

## **GOAL I: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia Capability**

The system of services provided by the Commonwealth is not designed to serve persons with dementia. Each department within Health and Human Resources created, slowly over time, their own programs for long-term care including dementia related services and supports, but without any clear oversight or coordination of policy goals and implementation. Virginia needs to make a comprehensive review of these programs in order to ensure better services and more efficient use of state funds.

The Dementia Services Coordinator described in this plan would review the existing programs and work with the agencies to create a dementia capable service delivery system. The coordinator would identify gaps in Medicaid (and other state services) and reduce duplication of existing services.

In order to get the maximum benefit from a better coordinated system, Virginians will need access to early detection and treatment of dementia. Memory Disorders Clinics that use an interdisciplinary team approach to assess and treat persons with dementia would provide the citizens of the Commonwealth with screening services and treatment. Early identification and aggressive treatment of Alzheimer's and other related dementias offer the greatest opportunity to decrease cost and progression of the disease.

### **A. Create a dementia services coordinator**

1. Create a position and obtain specific funding to hire a full time Dementia Services Coordinator (DSC) to coordinate the services provided to persons with Alzheimer's disease and Related Dementia working in conjunction with the Alzheimer's Commission.
  - 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, academic community, primary family caregivers, advocacy associations and general public.
  - c. The DSC will establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups and other entities throughout the State 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, the Area Agencies on Aging, and other groups invested in dementia research and care.
  - d. The DSC will coordinate and provide support for Commission activities.

# Goal I: Recommendations

- e. The DSC will oversee and promote services for all stages and types of dementia including younger onset.
- f. The DSC will ensure that the Aging and Disability Resource Centers are dementia capable.

## **B. Expand availability and access of dementia capable Medicaid and other state-level services**

1. Increase respite services for caregivers of people with dementia
2. Restore funding to maintain the Virginia Caregivers Grant and the Virginia Respite Care Grant
3. Revise the current definition, eligibility and service requirements for the provision of respite to make the above mentioned programs more flexible.
4. Expand the accessibility and availability of PACE (Program of the All-inclusive Care for the Elderly) and Adult Day Services, the Elderly or Disabled Consumer Direction (EDCD) waiver, and hospice programs.
5. Expand the Medicaid waiver specific to Alzheimer's disease and related dementias to include other home and community based services.
6. Explore changes needed to ensure Medicaid eligibility for younger onset (formerly known as "early onset") dementia.
7. Increase the payment rate of the Auxiliary Grant to cover the actual cost of care in an assisted living facility.
8. Expand the use of Virginia's Long-Term Care Partnership Insurance Program.
9. Increase funding for Home and Community Based Services.
10. Review the overlapping requirements for the licensing of residential facilities, assisted living facilities, and skilled nursing facilities to further clarify the different levels of services.
11. Increase the funding for the Virginia Long-term Care Ombudsman Program to meet the required one ombudsman for every 2000 long-term care beds.
12. Review all state-funded services to ensure "dementia capable" approaches and policies, based on principles derived from the Person-Centered Care and Culture Change movements.

## **C. Create a statewide network of memory disorders clinics to assess and treat persons with dementia**

1. Create a network of memory disorder clinics that use an interdisciplinary team approach to assess and treat persons with dementia.

# Goal II: Recommendations

## **GOAL II: Use Dementia Related Data to Improve Public Health**

Public health data collection is essential to understand the scope and extent of dementia impact on Virginians. State agencies such as DSS, DMAS, DBHDS, and VDA do collect some general information related to specific programs, but the information is not aggregated or sorted by the Commonwealth to inform state policy decisions related to dementia care. Currently the Commonwealth has no effective statewide tool to regularly gather and analyze information on dementia disease diagnoses, risk factors or disease patterns. This lack of data leads to a fragmented service delivery system that does not meet the needs of persons with Alzheimer's disease.

The Dementia Services Coordinator described in this plan would review existing data and create a system to incorporate that data into a meaningful tool to inform state policy makers. A careful study of the data would allow the Commonwealth to identify barriers to serving more people with dementia in their homes and ultimately make recommendations that will reduce the reliance on expensive nursing home care thus allowing Virginia to meet its community integration goals on the Olmstead v. L.C. court decision. Additionally, the data can be used to target risk reduction strategies and reduce the overall cost of dementia on Virginia.

### **A. Collect and monitor data related to dementia's impact on the people of the Commonwealth.**

1. Require the DSC to develop, implement and coordinate a statewide data collection system (including Behavioral Risk Factor Surveillance System data) through the VACAPI (Virginia Alzheimer's Commission AlzPossible Initiative) website ([www.alzpossible.org](http://www.alzpossible.org)). The website could provide a clearinghouse of links to the state agencies or groups with relevant, up-to-date, and available data on dementia.
2. The DSC should collect and monitor data with the following themes in mind:
  - a. The prevalence of dementia related diseases across the Commonwealth.
  - b. The prevalence of dementia related diseases by city and county, rural communities and ethnic and racial minorities.
  - c. The prevalence of younger onset (formerly known as "early onset") dementia related diseases across the Commonwealth.
  - d. The prevalence of inpatient geriatric psychiatry beds.
  - e. The prevalence of dementia related diseases among incar-

# Goal II: Recommendations

cerated populations

- f. The availability of geriatric services and specialists.
- g. The availability of dementia related services and supports.
- h. The availability of assessment services for Alzheimer's and dementia.
- i. The number and location of Virginians who are currently providing care in their home to a family member with Alzheimer's disease and dementia.
- j. The cost of caring for a person with dementia.

## **B. Remove barriers for community integration for persons with dementia**

- 1. With appropriate stakeholders, develop, collect and implement a protocol of appropriate placement options based on the stages of Alzheimer's and dementia related diseases, and available community resources.

## **C. Collaborate with related public health efforts to encourage possible risk-reduction strategies**

- 1. Use the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with Alzheimer's disease and dementia in Virginia.
- 2. Collaborate with related public health efforts (e.g. diet, exercise, comorbid conditions, etc.) to encourage possible risk-reduction strategies.

# Goal III: Recommendations

## **GOAL III: Increase Awareness and Create Dementia Specific Training**

Many families can anticipate up to a 20 year progression when faced with a dementia diagnosis, encountering a wide variety of care providers along the way. Despite the current demographic predictions, there is a startling dearth of training for care providers across all disciplines, professional and licensure levels regarding detection, diagnosis, care, treatment and general best practices in dementia. The dementia knowledge gap leaves patients and families at risk. Families are left to fend for themselves.

Dementia specific training is essential to ensure quality care across the continuum of care. Coordination and expansion of existing training models is key to ensuring a dementia-ready workforce.

### **A. Provide standardized dementia specific training to individuals in the health-related field and require demonstrated competency**

- a. Develop or collect and deliver dementia specific training for physicians and encourage practical experience in geriatrics for medical students.
- b. Develop or collect and deliver dementia specific training for professionals working in the health professions, such as gerontologists, physical therapists, occupational therapists, nurses, pharmacists, rehabilitation counselors, social workers, etc.
- c. Emphasize the unique role and knowledge of the informal or family caregiver and encourage physicians to utilize their expertise.
- d. Develop or collect and deliver evidence-based training curriculum and implementation strategy for the Department of Behavioral Health and Developmental Services and the Community Services Boards.
- e. Develop or collect and deliver an evidence-based training curriculum and implementation strategies for Long Term Care facilities and home and community based providers.
- f. Require mandatory dementia specific training for emergency room staff including nurses, physicians and related services technicians such as radiology.
- g. Incorporate evidence-based dementia practices into all existing training offered through the Department of Social Services, the Department for the Aging, the Department for Behavioral Health and Disability Services, the Department of Rehabilitation Services, and their contractors.

# Goal III: Recommendations

## **B. Provide dementia specific training to professional first responders (police, fire, EMS and Search & Rescue personnel), financial services personnel, and the legal profession**

1. Develop, collect and implement training on dementia related disorders for various stakeholders.
  - a. Continue to develop relationships and implement training with state and local first responders (police, fire, EMS and Search & Rescue personnel) and emergency personnel.
  - b. Continue work with first responders (police, fire, EMS and Search & Rescue personnel) to ensure a coordinated protocol for swift and appropriate action upon report of a missing adult with dementia.
  - c. Develop, collect and implement dementia specific training for financial services personnel.
  - d. Develop, collect and implement dementia specific training for judges, magistrates, prosecutors, and general practice attorneys.
  - e. Increase training for Department of Social Services adult protective services workers on Alzheimer's disease and dementia.
  - f. Develop or collect and implement dementia specific training for Department of Corrections personnel
2. Develop or collect and deliver a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias.

## **C. Link caregivers, family members and individuals with dementia to information about dementia services**

1. Train and link family and informal caregivers to information and education about dementia and the caregiving process (through coordination with the Alzheimer's Association, Area Agencies on Aging, and similar organizations and agencies). This should provide the caregivers information about dementia as well as information on how caregivers can stay healthy, organize the various legal issues associated with a loved one's dementia diagnosis (such as Advanced Medical Directives, Power of Attorneys, etc.), and how caregivers can locate and make use of resources for respite care services. This could be accomplished through a combination of efforts, including use of the VACAPI (Virginia Alzheimer's Commission AlzPossible Initiative) website.
2. Develop or collect and deliver a strategy to reach out to rural communities, racial and ethnic minorities, and faith-based communities. This could include a combined effort with the Alzheimer's Association to increase the availability and use of education materials tailored to these groups.
3. With appropriate stakeholders, develop or collect and implement evidence-based protocol for appropriate interaction with individuals with Alzheimer's and related dementias and their family and loved ones.



# Goal IV: Recommendations

## **GOAL IV: Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting**

Currently 80-85% of care is provided by family members. It is safe to say that our current health care system is dependent on family care. While caregivers express commitment and devotion to their loved ones, the emotional and physical strain can be devastating. It is well documented that the person with dementia often outlives their caregiver as the caregiver's physical and emotional needs take a back seat to daily demands. In addition, caregiving often takes a significant financial toll on families as well as industry due to lost wages, poor work performance, and absenteeism. Adequate support for families can preserve caregiver physical, emotional, and financial health, improve care of persons with dementia, postpone costly residential placement, and maintain caregivers as valuable contributors to the workforce.

The Commonwealth must support, fund, and expand availability of professional care coordination to help families navigate our complex eldercare system. In order to survive, families need dementia friendly solutions for their safety, services, and behavioral concerns, including: assessment and diagnosis, counseling and support services, care management, respite care, assistive technologies and home modification, transportation, and payment options including long term care insurance.

- A. Advocate for and increase awareness of integrated systems of care coordination that effectively support improved health outcomes for individuals with dementias and their families and loved ones.**
  - 1. With the appropriate stakeholders, support a pilot demonstration project to improve transitional care and address the problem of lack of placement and facility discharge for residents exhibiting disruptive behavior.
  - 2. Foster University-Community partnerships to address community needs and promote mutually beneficial participatory research opportunities.
- B. Explore tax incentives for family caregiving, respite care, long term care insurance purchases, locator devices, and additional long term care services.**
  - 1. Offer tax credits for families for the purchase of locator devices and other related expenses.
- C. Advocate for accessible transportation systems.**

# Goal V: Recommendations

## **GOAL V: Expand Resources for Dementia Specific Translational Research and Evidence- Based Practices**

Key to Virginia's response to dementia will be continued support for research aimed at disease modification, prevention, and elimination, as well as the translational, evidence-based, and behavioral research developments that improve the quality of life and care for those impacted by dementia. Through a combination of partnerships spanning the scientific, academic, public, and private sector communities, Virginia must encourage research participation at all levels of service delivery while also facilitating information sharing and networking opportunities for researchers. With increased funding for the Alzheimer's and Related Disease Research Award Fund and support for the progression of evidence-informed practices to evidence-based practices, Virginia will ensure that it is prepared to meet the research needs of its residents.

### **A. Increase funding for the Alzheimer's and Related Diseases Research Award Fund.**

1. Increase funding for the Alzheimer's and Related Diseases Research Award Fund.

- a. Restore and expand funding to increase investment in research on the biomedical and psychosocial aspects of dementia, including cell biology, caregiving, and animal modeling dementia prevention, modification, treatment cures, and best practices for dementia.
- b. Disseminate research findings, especially translational research findings, on the VACAPI (Virginia Alzheimer's Commission AlzPossible Initiative) website ([www.alzpossible.org](http://www.alzpossible.org)).

### **B. Provide support to researchers across the Commonwealth through data sources and networking opportunities.**

1. Provide networking opportunities for researchers in Virginia.

- a. Disseminate funding opportunities.
- b. Use VACAPI website as a forum to link researchers interested in Alzheimer's disease research.
- c. Use a webinar, survey or live format to assess the needs of Alzheimer's disease research in Virginia and explore options to further support participant recruitment.

2. Direct researchers to data sources for statistics regarding Alzheimer's disease and dementia in Virginia so that they can better write research funding applications.

### **C. Promote research participation in Virginia.**

1. Develop training for gatekeepers (physicians, nurses, office managers,

# Goal V: Recommendations

and other health professionals) on Alzheimer's disease and the value of research participation.

2. Develop incentives, such as care coordination, research partnering and communications of study results, for health professionals who encourage research participation in the community.
  - a. Foster university-community partnerships to address community needs and promote mutually beneficial participatory research opportunities.
  - b. Post white paper on barriers to research participation and solicit suggestions to overcome them through the VACAPI website.
  - c. Serve as a resource for university institutional review boards as they develop consistent methods for assessing and approving dementia research studies.
  - d. Use the VACAPI website to link to additional resources related to research.
3. Direct the Commission and VACAPI to serve as a resource to evaluate dementia capable services and risk reduction strategies through the development of evidence-based protocols.
  - a. Evaluate the effectiveness of common methods used to disseminate and translate evidence-based practices, and apply the results in Virginia.
  - b. Implement promising practices and programs statewide and promote the incorporation of evidence-based practices into existing programs that are merely evidence-informed at the present time.

# How We Got Here

The Commonwealth of Virginia's Alzheimer's Disease and Related Disorders Commission was created in 1982. The Commission serves as an advisory board in the executive branch of state government and aims to assist people with Alzheimer's disease and related disorders and their caregivers. Under the Code of Virginia § 2.2-720:

The Commission has 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. Develop and promote strategies to encourage brain health and reduce cognitive decline;
3. 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;
4. 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;
5. Submit to the Governor, General Assembly, and Department, by October 1 of each year, an electronic report regarding the activities and recommendations of the Commission, which shall be posted on the Department's website; and
6. Establish priorities for programs among state agencies related to Alzheimer's disease and related disorders and criteria to evaluate these programs.

Throughout the years the Commission has served as an advisory vehicle and information hub across the Commonwealth. In 2009, in conjunction with other state plan initiatives, the Commission began reviewing other existing state plans for dementia with the intent of more formally creating a plan for action to improve the lives of Virginians affected by Alzheimer's disease and related disorders. The Commission conducted Public Listening sessions in five locations across the Commonwealth. These sessions were attended by over 90 people and were followed by extensive review by Commission members and community stakeholders. Once input was gathered, the Commission, guided by optimal aging theory and stress and coping theory, drafted the plan. The Commission intends that this will be a living document always responsive to the population we serve.

The Commission partnered with stakeholders throughout Virginia who contributed to the development and who ultimately will work with the Commission to implement the plan. The Commission thanks all who contributed to the development of the plan and provided comments on earlier versions of the plan. The final version reflects these contributions and specific issues raised have been referred to the work groups who work to implement the recommendations in this plan.

# Virginia Statistics

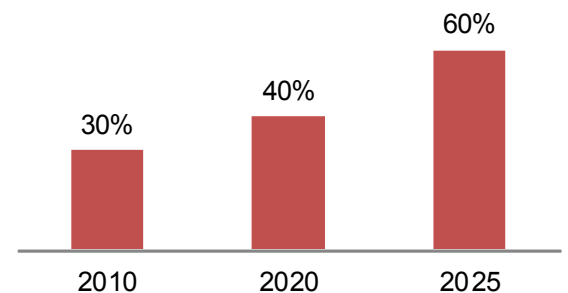
In the United States, an estimated 5.4 million people are living with Alzheimer's disease, and someone develops the disease every 69 seconds. Unless something is done, as many as 16 million Americans will have Alzheimer's in 2050 and someone will develop the disease every 33 seconds. In 2010, 14.9 million family members and friends provided 17 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at \$202.6 billion.

For Virginia, these statistics are:

## Virginians Aged 65 and Older with Alzheimer's by Age

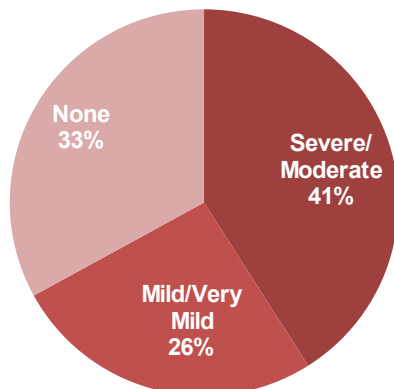
YEAR	65-74	75-84	85+	Total	% Change from 2000
2000	7,100	56,000	41,000	100,000	
2010	6,600	59,000	61,000	130,000	30%
2020	8,900	64,000	67,000	140,000	40%
2025	10,000	77,000	71,000	160,000	60%

Percentage Change in Numbers of Virginians with Alzheimer's Disease Compared to 2000



YEAR	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care
2008	250,025	215,821,226	2,395,615,613
2009	280,043	318,912,890	3,667,298,236
2010	422,116	480,706,197	5,734,824,927

Cognitive Impairment in Virginia Nursing Home Residents, 2008



2008 Virginia Nursing Home Residents

**72,214**

# Resources

## ALZHEIMER'S ASSOCIATION CHAPTERS

1-800-272-3900

### CENTRAL & WESTERN VIRGINIA

[www.alz.org/cwva/](http://www.alz.org/cwva/)

#### **Charlottesville Office**

1160 Pepsi Place, Suite 306  
Charlottesville, VA 22901  
Phone: 1-800-272-3900  
Email: [alzcvva@alz.org](mailto:alzcvva@alz.org)

#### **Danville Office**

308 Craghead St, Suite 104  
Danville, VA 24541  
Phone: 434-792-3700 Ext. 237

#### **Lynchburg Office**

1022 Commerce Street  
Lynchburg, VA 24504  
Phone: 434-845-8540

#### **Roanoke Office**

3959 Electric Rd, Suite 357  
Roanoke, VA 24018  
Phone: 540-345-7600

### GREATER RICHMOND

[www.alz.org/grva/](http://www.alz.org/grva/)

#### **Richmond Office**

4600 Cox Road, Suite 130  
Glen Allen, VA 23060  
Phone: 804-967-2580; Fax: 804-967-2588

#### **Fredericksburg Office**

2217 Princess Anne St., Ste. 106-1F  
Fredericksburg, VA 22401  
Phone: 540-370-0835; Fax: 540-370-4976

#### **Middle Peninsula/Northern Neck Office**

6650 Main Street  
Gloucester, VA 23061  
Phone: 804-695-9382; Fax: 804-695-9278

#### **Tri-Cities Office**

201 Temple Ave., Suite E  
Colonial Heights, VA 23834  
Phone: 804-526-2359; Fax: 804-526-4128

### NATIONAL CAPITAL AREA

[www.alz.org/nca/](http://www.alz.org/nca/)

#### **Northern Virginia Office**

3701 Pender Drive, Suite 400  
Fairfax, VA 22030  
Phone: 703-359-4440

### SOUTHEASTERN VIRGINIA

[www.alz.org/seva/](http://www.alz.org/seva/)

#### **Southeastern Virginia Office**

6350 Center Drive, Suite 102  
Norfolk, VA 23502  
Phone: 1-800-272-3900

#### **Eastern Shore Branch Office**

5432 Bayside Road  
Exmore, VA 23350  
Phone: 1-800-272-3900

#### **Williamsburg Branch Office**

213 McLaws Circle, Suite 2-B  
Williamsburg, VA 23185  
Phone: 1-800-272-3900

## AREA AGENCIES ON AGING

### 1—Mountain Empire Older Citizens, Inc.

P.O. Box 888  
Big Stone Gap, VA 24219-0888  
Marilyn Maxwell, Executive Director  
Phone: 276-523-4202 or 1-800-252-6362  
FAX: 276-523-4208  
Email: [mmaxwell@meoc.org](mailto:mmaxwell@meoc.org)  
*Counties of Lee, Wise, & Scott. City of Norton*

### 2—Appalachian Agency for Senior Citizens, Inc.

P.O. Box 765  
Cedar Bluff, VA 24609-0765  
Regina Sayers, Executive Director  
Phone: 276-964-4915 or 1-800-656-2272  
FAX: 276-963-0130  
Email: [aasc@aasc.org](mailto:aasc@aasc.org)  
*Counties of Dickenson, Buchanan, Tazewell, & Russell.*

### 3—District Three Governmental Cooperative

4453 Lee Highway  
Marion, VA 24354-4270  
Mike Guy, Executive Director  
Phone: 276-783-8150 or 1-800-541-0933  
FAX: 276-783-3003  
Email: [district-three@smyth.net](mailto:district-three@smyth.net)  
*Counties of Washington, Smyth, Wythe, Bland, Grayson, & Carroll. Cities of Galax & Brisol*

### 4—New River Valley Agency on Aging

141 East Main Street, Suite 500  
Pulaski, VA 24301  
Tina King, Executive Director  
Phone: 540-980-7720 FAX: 540-980-7724  
Email: [nrvaoa@nrvaoa.org](mailto:nrvaoa@nrvaoa.org)  
*Counties of Giles, Floyd, Pulaski and Montgomery, City of Radford*

### 5—LOA-Area Agency on Aging, Inc.

P.O. Box 14205  
Roanoke, Virginia 24038-4205  
Susan Williams, Executive Director  
Phone: 540-345-0451 / Fax: 540-981-1487  
Email: [sbwloa@loaa.org](mailto:sbwloa@loaa.org)  
*Counties of Roanoke, Craig, Botetourt, & Alleghany. Cities of Salem, Roanoke, Clifton Forge, & Covington*

### 6—Valley Program for Aging Services, Inc.

P.O. Box 14205  
Waynesboro, VA 22980-0603  
Paul Lavigne, Executive Director  
Phone: 540-949-7141 or 1-800-868-8727  
FAX: 540-949-7143  
Email: [vpas@ntelos.net](mailto:vpas@ntelos.net)  
*Counties of Rockingham, Rockbridge, Augusta, Highland, & Bath. Cities of Buena Vista, Lexington, Waynesboro, & Harrisonburg*

### 7—Shenandoah Area Agency on Aging, Inc.

207 Mosby Lane  
Front Royal, VA 22630-2611  
Cindy Palmer, Director  
Phone: 540-635-7141 or 1-800-883-4122  
FAX: 540-636-7810  
Email: [cindy.palmer@shenandoahaaa.com](mailto:cindy.palmer@shenandoahaaa.com)  
*Counties of Page, Shenandoah, Warren, Clarke, & Frederick. City of Winchester*

### 8A—Alexandria Office of Aging & Adult Services

2525 Mount Vernon Avenue  
Alexandria, VA 22301-1159  
MaryAnn Griffin - Director  
Phone: 703.746.5692; Fax: 703.746.5975  
Email: [Maryann.Griffin@alexandriava.gov](mailto:Maryann.Griffin@alexandriava.gov)  
Website: [www.AlexandriaVA.gov](http://www.AlexandriaVA.gov)  
*City of Alexandria*

### 8B—Arlington Agency on Aging

2100 Washington Boulevard, 4th Floor  
Arlington, VA 22204  
Terri Lynch, Director  
Phone: 703-228-1700 FAX: 703-228-1174  
TTY: 703-228-1788  
Email: [arlaaa@arlingtonva.us](mailto:arlaaa@arlingtonva.us)  
*County of Arlington*

### 8C—Fairfax Area Agency on Aging

12011 Government Center Parkway, Suite 720  
Fairfax, VA 22035  
Sharon Lynn, Director  
Phone: 703-324-5411 FAX: 703-449-9552  
Email: [Sharon.lynn@fairfaxcounty.gov](mailto:Sharon.lynn@fairfaxcounty.gov)  
*County of Fairfax, Cities of Fairfax and Falls Church*

### 8D—Loudoun County Area Agency on Aging

215 Depot Court, SE, Suite 231 78 A  
Leesburg, VA 20175  
Lynn A. Reid, Administrator  
Phone: 703-777-0257 FAX: 703-771-5161  
Email: [aaa@loudoun.gov](mailto:aaa@loudoun.gov)  
*County of Loudoun*

### 8E—Prince William Area Agency on Aging

5 County Complex, Suite 240  
Woodbridge, VA 22192  
Courtney Tierney, Director  
Phone: 703-792-6400 FAX: 703-792-4734  
Email: [CTierney@pwcgov.org](mailto:CTierney@pwcgov.org)  
*County of Prince William. Cities of Manassas, Manassas Park, & Woodbridge*

# Resources

## 9—Rappahannock-Rapidan Community Services

P.O. Box 1568  
Culpeper, VA 22701  
Ray Parks, Director of Aging & Transp Services  
Phone: 540-825-3100 FAX: 540-825-6245  
Email: rrcsb@rrcsb.org  
*Counties of Culpeper, Fauquier, Madison, Orange, & Rappahannock*

## 10—Jefferson Area Board for Aging

674 Hillsdale Drive, Suite 9  
Charlottesville, VA 22901  
Gordon Walker, CEO  
Phone: 434-817-5222; FAX: 434-817-5230  
Email: info@jabacares.org  
*Counties of Nelson, Albemarle, Louisa, Fluvanna, & Greene. City of Charlottesville*

## 11—Central Virginia Area Agency on Aging, Inc.

501 12th Street, Suite A  
Lynchburg, VA 24504  
Deborah Silverman, Executive Director  
Phone: 434-385-9070; FAX: 434-385-9209  
Email: cvaaa@cvaaa.com  
*Counties of Bedford, Amherst, Campbell, & Appomattox. Cities of Bedford & Lynchburg*

## 12—Southern Area Agency on Aging, Inc.

204 Cleveland Avenue  
Martinsville, VA 24112-4228  
Teresa Carter, Executive Director  
Phone: 276-632-6442 FAX: 276-632-6252  
Email: saaa@southernaaa.org  
*Counties of Patrick Henry, Franklin, & Pittsylvania. Cities of Martinsville & Danville*

## 13—Lake Country Area Agency on Aging

1105 West Danville St  
South Hill, Virginia 23970-3501  
Gwen Hinzman, President/CEO  
Phone: 434-447-7661 FAX: 434-447-4074  
Email: lakecaaaa@lcaaaa.org  
*Counties of Halifax, Mecklenburg, & Brunswick. City of South Boston*

## 14—Piedmont Senior Resources Area Agency on Aging, Inc.

P.O. Box 398  
Burkeville, Virginia 23922-0398  
Ronald Dunn, Executive Director  
Phone: 434-767-5588 or 800-995-6918  
FAX: 434-767-2529  
Email: psraaaa@embarqmail.com  
*Counties of Nottoway, Prince Edward, Charlotte, Lunenburg, Cumberland, Buckingham, & Amelia*

## 15—Senior Connections

24 East Cary Street  
Richmond, VA 23219  
Thelma Bland Watson, Executive Director  
Phone: 804-343-3000 or 800-995-6918  
FAX: 804-649-2258  
Email: gstevens@youraaa.org  
*Counties of Charles City, Henrico, Goochland, Powhatan, Chesterfield, Hanover, & New Kent. City of Richmond*

## 16—Rappahannock Area Agency on Aging, Inc.

171 Warrenton Road  
Fredericksburg, VA 22405  
Jim Schaefer, Executive Director  
Phone: 540-371-3375 or 800-262-4012  
FAX: 540-371-3384  
Email: info@raaa16.org  
*Counties of Caroline, Spotsylvania, Stafford, & King George. City of Fredericksburg*

## 17/18—Bay Aging

P.O. Box 610  
Urbanna, VA 23175  
Kathy Vesley, President  
Phone: 804-758-2386 FAX: 804-758-5773  
Email: info@bayaging.org  
*Counties of Westmoreland, Northumberland, Richmond, Lancaster, Essex, Middlesex, Mathews, King & Queen. King William, & Gloucester*

## 19—Crater District Area Agency On Aging

23 Seyler Drive  
Petersburg, VA 23805  
David Sadowski, Executive Director  
Phone: 804-732-7020 FAX: 804-732-7232  
Email: director@cdaaa.org  
*Counties of Dinwiddie, Sussex, Greensville, Surry, & Prince George. Cities of Petersburg, Hopewell, Emporia, & Colonial Heights*

## 20—Senior Services of Southeastern Virginia

5 Interstate Corporate Center  
6350 Center Drive, Suite 101  
Norfolk, Virginia 23502  
John Skirven, Executive Director  
Phone: 757-461-9481 FAX: 757-461-1068  
Email: services@sseva.org  
*Counties of Southampton & Isle of Wight. Cities of Franklin, Suffolk, Portsmouth, Chesapeake, Virginia Beach, & Norfolk*

## 21—Peninsula Agency on Aging, Inc.

739 Thimble Shoals Boulevard  
Building 1000, Suite 1006  
Newport News, VA 23606  
William Massey, CEO  
Phone: 757-873-0541 FAX: 757-872-1437  
Email: information@paainc.org  
*Counties of James City & York. Cities of Williamsburg Newport News, Hampton, & Poquoson*

## 22—Eastern Shore Area Agency on Aging-Community Action Agency, Inc.

P.O. Box 415  
Belle Haven, Virginia 23306  
Diane Musso, CEO  
Phone: 757-442-9652 or 800-452-5977  
FAX: 757-442-9303  
Email: esaaa@aol.com  
*Counties of Accomack & Northampton*

## CENTER FOR EXCELLENCE IN AGING AND GERIATRIC HEALTH

[www.excellenceinaging.org/](http://www.excellenceinaging.org/)

## EASTERN VIRGINIA MEDICAL SCHOOL Glennon Center for Geriatrics & Gerontology

[www.evms.edu/evms-centers-of-excellence/glennan-center-for-geriatrics-gerontology.html](http://www.evms.edu/evms-centers-of-excellence/glennan-center-for-geriatrics-gerontology.html)

## JAMES MADISON UNIVERSITY Caregivers Community Network

[www.socwork.jmu.edu/Caregivers/](http://www.socwork.jmu.edu/Caregivers/)

## LYNCHBURG COLLEGE

**Beard Center on Aging**  
[www.lyncburg.edu/beard](http://www.lyncburg.edu/beard)

## UNIVERSITY OF VIRGINIA

**Memory Commons**  
[www.memorycommons.org](http://www.memorycommons.org)  
**Memory Disorders Clinic**  
500 Ray C. Hunt Drive  
Charlottesville, VA 22943  
Tel: 434-924-8668; Research: 434-243-5898

## VIRGINIA ALZHEIMER'S COMMISSION ALZPOSSIBLE INITIATIVE (VACAPI)

[www.alzpossible.org](http://www.alzpossible.org)

## VIRGINIA CAREGIVER COALITION

Ellen M. Nau, Program Coordinator  
Virginia Department for the Aging  
Phone: 804-662-9340

## VIRGINIA COMMONWEALTH UNIVERSITY

**Department of Gerontology**  
[www.sahp.vcu.edu/gerontology/](http://www.sahp.vcu.edu/gerontology/)  
**Parkinson's Disease Center**  
[www.parkinsons.vcu.edu](http://www.parkinsons.vcu.edu)  
**Virginia Center on Aging**  
[www.vcu.edu/vcoa/](http://www.vcu.edu/vcoa/)

# Resources

---

## **VIRGINIA DEPARTMENT FOR THE AGING**

1610 Forest Avenue, Suite 100  
Richmond, VA 23229  
Phone: 804-662-9333  
Toll Free 1-800-552-3402 FAX: 804-662-9354  
[www.vda.virginia.gov](http://www.vda.virginia.gov)

## **VIRGINIA EASY ACCESS**

[easyaccess.virginia.gov/](http://easyaccess.virginia.gov/)

## **VIRGINIA SENIORNAVIGATOR**

[www.seniornavigator.com/](http://www.seniornavigator.com/)

## **VIRGINIA TECH**

**Center for Gerontology**  
[www.gerontology.vt.edu/](http://www.gerontology.vt.edu/)



# Glossary

## **AG - Auxiliary Grant**

An Auxiliary Grant is an income supplement for individuals who receive Supplemental Security Income (SSI) and certain other aged, blind, or disabled individuals who reside in a licensed assisted living facility (ALF) or an approved adult foster care (AFC) home. An AG payment is issued to an individual monthly, to be used with a designated amount of their monthly income to pay an ALF or AFC a maximum monthly rate. This rate is determined by the Virginia General Assembly and is adjusted periodically. The AG Program is 80 percent state funded and 20 percent locally funded and is administered by the Virginia Department of Social Services. It is only for individuals who reside in an ALF licensed by the Virginia Department of Social Services' Division of Licensing Programs or in an AFC home approved by their local department of social services.

## **Assisted Living**

Assisted living is a licensed residential setting that provides 24-hour care and supervision to seniors and people with disabilities who need assistance, but do not require around the clock nursing care. Assisted living facilities provide assistance with Activities of Daily Living (ADLs), medication management, social activities, housekeeping, meals, and may offer dementia care programs.

## **ALF - Assisted Living Facility**

Assisted Living Facility (ALF) means any congregate residential setting that provides or coordinates personal and health care services, 24-hour supervision, and assistance (scheduled and unscheduled) for the maintenance or care of four or more adults who are aged, infirm or disabled and who are cared for in a primarily residential setting. Included in this definition are any two or more places, establishments or institutions owned or operated by a single entity and providing maintenance or care to a combined total of four or more aged, infirm or disabled adults. Maintenance or care means the protection, general supervision and oversight of the physical and mental well-being of an aged, infirm or disabled individual.

## **APS - Adult Protective Services**

Adult Protective Services investigates reports of abuse, neglect, and exploitation of adults 60 years of age or older and incapacitated adults age 18 or older. If protective services are needed and accepted by the individual, local Adult Protective Services social workers may arrange for a wide variety of health, housing, social and legal services to stop the mistreatment or prevent further mistreatment. Services offered may include home-based care, transportation, adult day services, adult foster care, nutrition services and legal intervention in order to protect the adult. Services may also be arranged for individuals in emergency situations who lack the capacity to consent to services.

## **BRFSS – Behavioral Risk Factor Surveillance System**

The Virginia BRFSS is an annual survey of Virginia's adult population about individual behaviors that relate to chronic disease and injury. The BRFSS is the primary source of state-based information on health risk behaviors among adult populations.

## **Caregiver**

The term caregiver refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help. *Informal caregiver* and *family caregiver* are terms that refer to unpaid individuals such as family members, friends and neighbors who provide care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately.

## **Culture Change**

Culture change is the common name given to the national movement for the transformation of older adult services, based on person-directed values and practices where the voices of elders and those working with them are considered and respected. Core person-directed values are choice, dignity, respect, self-determination and purposeful living.

# Glossary (cont.)

## **Dementia Capable**

Dementia capable indicates the attribute of being tailor-made to the unique needs of persons with dementia stemming from conditions such as Alzheimer's disease and related disorders, and their caregivers.

## **EDCD Waiver**

The Elderly or Disabled Consumer Direction (EDCD) Waiver serves the elderly and persons of all ages with disabilities. The individual may receive this service through a service provider or through consumer direction in which he or she directs his or her own care, or a parent, spouse, adult child or other responsible adult can direct care on behalf of the individual. Services include Adult Day Services, Medication Monitoring, Personal Care – Agency and Consumer-Directed, Personal Emergency Response System (PERS), Respite Care – Agency and Consumer-Directed, Transition Coordination, Transitional Services.

## **Hospice Care**

Hospice care is designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home—in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs as well as medical symptoms as part of treating the whole person.

## **Long-term care**

Long-term care encompasses a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community, in assisted living or in nursing homes. It is important to remember that you may need longterm care at any age.

## **Medicaid**

Medicaid is health insurance available to certain people and families who have limited income and resources. Eligibility may also depend on how old you are and whether you are pregnant, whether you are blind or have other disabilities, and whether you are a U.S. citizen or a lawfully admitted immigrant. People with Medicaid may also get coverage for services such as nursing home care and waiver services.

## **Medicaid Waivers**

Medicaid Waivers were developed to encourage people with disabilities and the elderly to access services in their homes and communities. Medicaid is a joint federal-state program. Medicaid Waivers provide funding to serve people who are eligible for long-term care in institutions such as hospitals, nursing facilities, and intermediate-care facilities. Through Medicaid Waivers, states can "waive" certain requirements including the requirement that individuals live in institutions in order to receive Medicaid funding.

## **(MDC) - Memory Disorders Clinic**

In 1996, a dedicated Memory Disorders Clinic was established at the University of Virginia (UVA) Health System. The clinic pooled appropriate expertise within the UVA Department of Neurology. This expertise included (but was not limited to) two cognitive disorders sub-specialist neurologists, a neuropsychologist, a dedicated nurse coordinator, and social worker. Multiple members of the group were experienced in the conduct of AD drug trials. Since its inception, the UVA MDC has fulfilled essential clinical, educational, and investigational services to the Commonwealth. Physicians in internal medicine, psychiatry, and neurology residency/fellowship training programs regularly rotate through the clinic as part of their post-graduate medical training. Clinic staff is regularly recruited for continuing medical education and patient education events. Because of its large patient base and professional resources, the MDC has been asked to participate in numerous industry and federally sponsored AD and vascular dementia drug trials. Here in the Commonwealth, it serves as the principle gateway of dementing individuals to experimental therapies.

# Glossary (cont.)

## **Olmstead v. LC**

The United States Supreme Court decided in an Opinion issued on June 22, 1999 that a State is required under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. § 12132, to provide community-based treatment for persons with mental disabilities 1) when the State's treatment professionals determine that such placement is appropriate, 2) the affected persons do not oppose such placement, and 3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with disabilities. The Court further stated that nothing in the ADA or its implementing regulations requires community placements for persons unable to handle or benefit from community settings.

## **Optimal Aging Theory PACE**

Optimal aging is the capacity to function across many domains—physical, functional, cognitive, emotional, social, and spiritual – to one's satisfaction and in spite of one's medical conditions

The Program of All-Inclusive Care for the Elderly (PACE) provides the following services: Adult Day Care, Home Health Care, Hospital Patient Care, Meals, Nursing Facility Care, Nutritional Counseling, Outpatient Medical Services, Personal Care, Prescribed Medications, Primary/Specialty Care, Nursing, Respite Care, Social Services, Transportation and All other Medicare and Medicaid Services. Recipients must meet the following criteria: at least 55 years of age, and reside in a PACE provider area, and be eligible for Nursing Home Care, and be screened and assessed by the PACE team, and have a safe service plan and have an income equal to or less than 300% of Social Security Income.

## **Person Centered Care**

Person Centered Care is personal attention to individuals in the Long Term Care system. It empowers staff to be a resident advocate and honors each person's dignity, rights, self-respect, and independence. It allows individuals to make choices, and requires staff to respect the wishes of the individual receiving services. It requires involving them in decision making process, giving them the control of their life.

## **Respite Care**

Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned short-term and time-limited breaks for families and other unpaid care givers of children with a developmental delay and adults with an intellectual disability in order to support and maintain the primary care giving relationship.

## **Skilled Nursing Facility**

Skilled nursing facilities (also known as nursing homes) provide housing, meals, skilled and intensive medical care, personal care, social services, and social activities to people who have physical or behavioral conditions that prevent them from living alone. Medicare and private insurance typically cover short-term nursing home stays for skilled care needs, but they do not cover long-term stays.

## **Stress and Coping Theory**

The Stress and Coping Theory asserts that adaptive behavior occurs primarily in response to stress, defined as problems or hardships that threaten an individual's well-being.

## **VACAPI - Virginia Alzheimer's Commission AlzPossible Initiative**

In 2004, the Virginia Alzheimer's Disease and Related Disorders Commission created a statewide "Virtual Alzheimer's Disease Center." To date, this work has received financial support from a federal grant obtained by the Virginia Department of Aging (The Alzheimer's Disease Demonstration Grants to States Program). In 2006, however, the Commission has refined this effort so that over the long term it will create a centralized mechanism for ascertaining patient needs and mounting coordinated responses to those needs before they reach crisis proportions. This effort has been formally titled the "Virginia Alzheimer's Disease AlzPossible Initiative" (VACAPI). VACAPI is established as a virtual center or a center without walls. The virtual center concept is a hybrid organization designed to leverage *intellectual assets*, rather than *physical assets*, to attain its corporate objectives.

[www.alzpossible.org](http://www.alzpossible.org)

*Cover photographs courtesy of Ray Moore and the Mountain Empire Older Citizens, Inc.*

*From top left, clockwise:*

*VINADA BRICKEY AND HUSBAND, MACK BRICKEY, WEBER CITY —“I am grateful for each day with my wife and would not trade this experience for anything. There could be no greater love than my love for her.” —Mack Brickey*

*MARY SCHAUER AND MOTHER, INA DUFF, PENNINGTON GAP —“My mother is my best friend.” —Mary Schauer*

*ALBERTA MITCHELL AND MOTHER, ILLINOISE MITCHELL, BIG STONE GAP — “This experience has afforded me an opportunity to do for my mother and give back to her for all she has done for me in my life. It makes me feel so blessed to have her for a mother, she is so precious to me!” —Alberta Mitchell*