

Virginia Alzheimer's  
Disease and Related  
Disorders Commission

# DEMENTIA STATE PLAN

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

2015-2019

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

# Table of Contents

LETTER FROM THE CHAIR TO THE GOVERNOR AND GENERAL ASSEMBLY	3
VISION	4
DEMENTIA	5
DEMENTIA IN VIRGINIA	9
ACCOMPLISHMENTS: 2011-2015	12
OVERVIEW OF GOALS	15
Goal 1	16
Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia-Capability	
Goal 2	19
Use Dementia Related Data to Improve Public Health	
Goal 3	21
Increase Awareness and Create Dementia Specific Training	
Goal 4	24
Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting	
Goal 5	27
Expand Resources for Dementia Specific Translational Research and Evidence-Based Practices	
DEMENTIA STATE PLAN DEVELOPMENT PROCESS	30
CONTRIBUTIONS AND ACKNOWLEDGMENTS	31
GLOSSARY	32
REFERENCES	37



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

*Courtney S. Tierney, MSW, Chair*

*Lory Phillippo, MPH, OTR/L*

*Laura Adkins*

*Vivian Bagby, RN, MS*

*Laura Bowser*

*Sharon E. Davis*

*Chris Desimone, Esq.*

*Julia Trivett Dillon*

*Valerie Hopson-Bell, B.A., C.M.C.*

*W. Thomas Hudson, Esq.*

*Janet L. Honeycutt*

*Carol Manning, Ph.D, ABPP-CN*

*Lynne Seward*

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

*Kevin P. Walsh, DC*

October 1, 2015

The Honorable Terence R. McAuliffe and Members of the Virginia General Assembly:

The Alzheimer's Disease and Related Disorders Commission is pleased to present the *2015-2019 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 listening sessions with individuals with dementia, their families and services providers. The sessions provided valuable input. Over 100 Virginians attended the public listening sessions, which were conducted in partnership with the four chapters of the Alzheimer's Association serving Virginia and Mountain Empire Older Citizens in Big Stone Gap. The Commission received additional comments by telephone, mail, and e-mail.

An estimated 130,000 Virginians have Alzheimer's disease and related dementias. 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 recommendations and strategies to further the Commonwealth's dementia-capability, which will be overseen by focused workgroups to facilitate realization of the goals. 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 Aging and Rehabilitative Services.

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

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

*Department for Aging and  
Rehabilitative Services*

*Virginia Division for the Aging*

*1610 Forest Avenue, Suite 100*

*Richmond, Virginia 23229*

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

*(804) 662-9333*

*Fax (804) 662-7035*

Sincerely,

A handwritten signature in blue ink that reads "Courtney S. Tierney".

Courtney S. Tierney, Chair  
Alzheimer's Disease and Related Disorders Commission

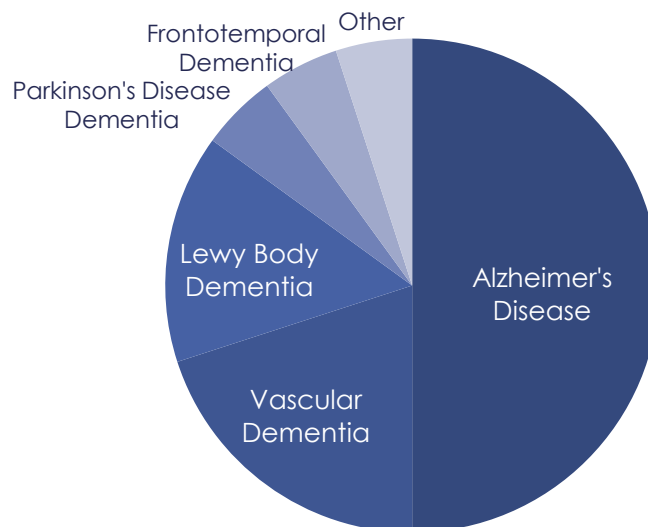
With the Dementia State Plan as a strategic plan for policy, the Alzheimer's Disease and Related Disorders Commission (the Commission) and its partners envision a dementia-capable Virginia that provides ethical, person-centered, evidence-based, and high quality care across the continuum of the disease through a coordinated system that meets the needs of individuals with dementia, regardless of age, and their caregivers.

## WHAT IS DEMENTIA?

Dementia is a progressive and ultimately fatal collection of neurodegenerative diseases, which affect cognition and memory (Alzheimer's Association, 2014). Over time dementia can cause changes in memory, thought, navigation, language, behavior, mood and personality (AlzPossible webinar, 2011). Behavioral changes observed during the onset of dementia can include poor judgment, difficulty with problem solving, the inability to manage finances, misplacing items and disconnection from the date or season.

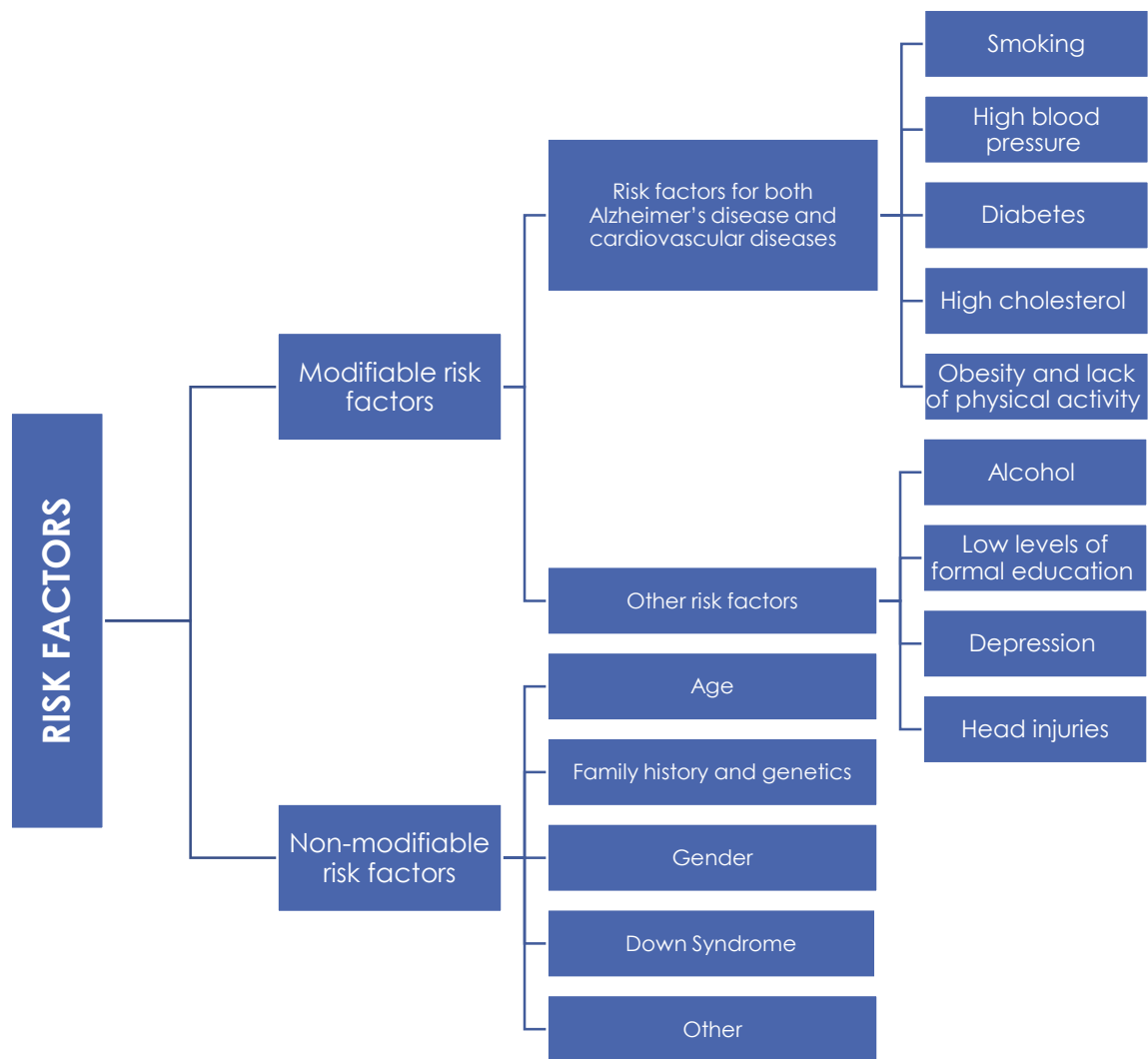
According to the American Psychiatric Association (APA), dementia can be categorized as mild or major. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) released in 2013 states that mild dementia involves modest cognitive decline recognized by cognitive testing, which causes the performance of everyday tasks to require greater effort. Major dementia involves substantial cognitive decline recognized by cognitive testing and assistance is required to complete daily activities (American Psychiatric Association, 2013).

Irreversible forms of dementia can be categorized as cortical or sub-cortical. Cortical dementia involves disorders affecting the cerebral cortex, the outer layers of the brain, and causes impairment in memory and language. Common cortical dementias include Alzheimer's disease, frontotemporal dementia, vascular dementia and Creutzfeldt-Jakob disease (AlzPossible webinar, 2011). Alzheimer's disease is the most common form of dementia representing approximately 60 to 80 percent of dementia cases and is the sixth-leading cause of death in the United States (Alzheimer's Association, 2014). Sub-cortical dementia affects portions of the brain below the cortex causing changes in attention span and personality. Types of sub-cortical dementia include dementia caused by Huntington's disease, dementia caused by Parkinson's disease, alcohol-induced persisting dementia, and Lewy body dementia (AlzPossible webinar, 2011). It is not uncommon for individuals to have two or more types of dementia. In fact, in the United States, 75 percent of individuals with dementia aged 75 years and older have mixed pathologies or multiple conditions (Middleton, 2014).



Age is the biggest risk factor for Alzheimer's disease and is reflected in Alzheimer's disease prevalence because of the aging baby boomer generation and longer life expectancies. Between two to ten percent of dementia cases are found among individuals under the age of 65, known as younger-onset Alzheimer's disease, with prevalence doubling at each five-year increment after the age of 65 (World Health Organization, 2012). Nationally, it is estimated that one-third of individuals aged 85 and older are affected by Alzheimer's disease (Alzheimer's Association, 2014). In 2010, approximately one out of eight Virginians was aged 65 or older and there were approximately 125,000 individuals 85 or older in Virginia (Tippett, 2011). That figure will only continue to grow in the coming years.

Other risk factors include: family history, APOE 34 gene, mild cognitive impairment (MCI), cardiovascular risk factors, social and cognitive engagement, education, and traumatic brain injury (Alzheimer's Association, 2014).



No treatments are currently available to slow or stop Alzheimer's disease nor is there a cure (Alzheimer's Association, 2014). Providers, individuals with Alzheimer's disease and caregivers are encouraged to discuss potential medications with medical and pharmacy staff to ensure that they are appropriate. Medications with the ability to stop dementia

have not yet been developed, but the U.S. Food and Drug Administration has approved several prescription drugs to assist with some of the symptoms throughout the stages of the disease. It is important to have a thorough and clear diagnosis since medications are not universal for all dementias, with some potentially causing negative side effects. Non-pharmacological interventions, therapies not involving medication, have been successfully implemented to improve quality of life for individuals with dementia (Alzheimer's Association, 2014). These interventions provide individuals with dementia opportunities to participate in cognitive, physical and social activities, which may result in a reduction of dementia associated symptoms.

Lastly, it is important to note that although dementia is generally irreversible, in some instances the cause and symptoms can be reversed. Reversible or pseudodementia can be caused by alcohol consumption, drugs, depression, delirium, medication interactions, tumors, infections, nutritional deficiencies, emotional disorders, eye or ear impairments, and metabolic disorders (AlzPossible webinar, 2011). A recent review of current research indicated that nine percent of individuals with dementia-like symptoms were only mimicking dementia and the symptoms could potentially be reversed (Alzheimer's Association, 2014).

## SPECIAL FOCUS:

### **Dementia and Intellectual and Developmental Disabilities (ID/DD)**

Much research remains to be done on the exact relationship between Alzheimer's disease and ID/DD, such as Down syndrome, cerebral palsy, epilepsy, and more. Current research efforts have determined stronger linkages between Alzheimer's disease and Down syndrome than some of the other intellectual and developmental disabilities. Studies on other disabilities have "found varying results—some with rates greater than the general population and others with rates similar to the general population" (Gordon et al, 2015, p. 6). According to the Alzheimer's Association, "autopsy studies show that by age 40, brains of almost all individuals with Down syndrome have significant levels of plaques and tangles, which are abnormal protein deposits considered hallmarks of Alzheimer's disease" (Alzheimer's Association, 2015a, p. 2). In comparison to those without Down syndrome, the rate of developing Alzheimer's is almost 6 times higher, and of those 65 and older with Down syndrome, about 75% have Alzheimer's disease (Alzheimer's Association, 2015a).

Determining changes in cognition caused by dementia, however, can prove challenging. There are specific, validated screening and diagnostic tools that professionals can use to arrive at a clinical diagnosis (Gordon et al, 2015). Providers of services and programs will need to be aware of and educated about dementia in order to be prepared to provide quality, person-centered care to individuals with disabilities and Alzheimer's disease. In general, the Alzheimer's Association (2015a, p.3) recommends the following:

- Document baseline adult function by age 35.
- Watch for changes in day-to-day function.
- Consider professional assessment by a dementia expert.
- Rule out other causes of symptoms.

## SPECIAL FOCUS: **Younger-Onset Dementia**

An estimated five percent of individuals with Alzheimer's disease have a specific type, referred to as younger-onset Alzheimer's disease, which was previously called early-onset Alzheimer's disease. For a small subset of individuals with younger-onset, the cause has been directly linked to rare, inherited genes. For most individuals with younger-onset Alzheimer's disease, however, clinicians and researchers have not found a direct genetic link and are unsure why "symptoms appear at an unusually young age" (Alzheimer's Association, 2011a, p.1). More research is certainly needed, particularly as experts are finding physical evidence of Alzheimer's disease often years prior to individuals showing any clinical signs or symptoms.

Younger-onset Alzheimer's disease presents a unique set of challenges often not found in later-onset Alzheimer's disease. Many individuals with younger-onset are still in the workforce and raising young or teenage children (Alzheimer's Association, 2011a). They are at risk of losing their jobs and health insurance, and may "have difficulty obtaining a timely and accurate diagnosis, support services, and income support through disability payments" (U.S. H.H.S., 2013, p. 2). For individuals diagnosed with younger-onset Alzheimer's disease and their families, it is important to plan for the future and make arrangements for legal and financial issues as well as end-of-life care.

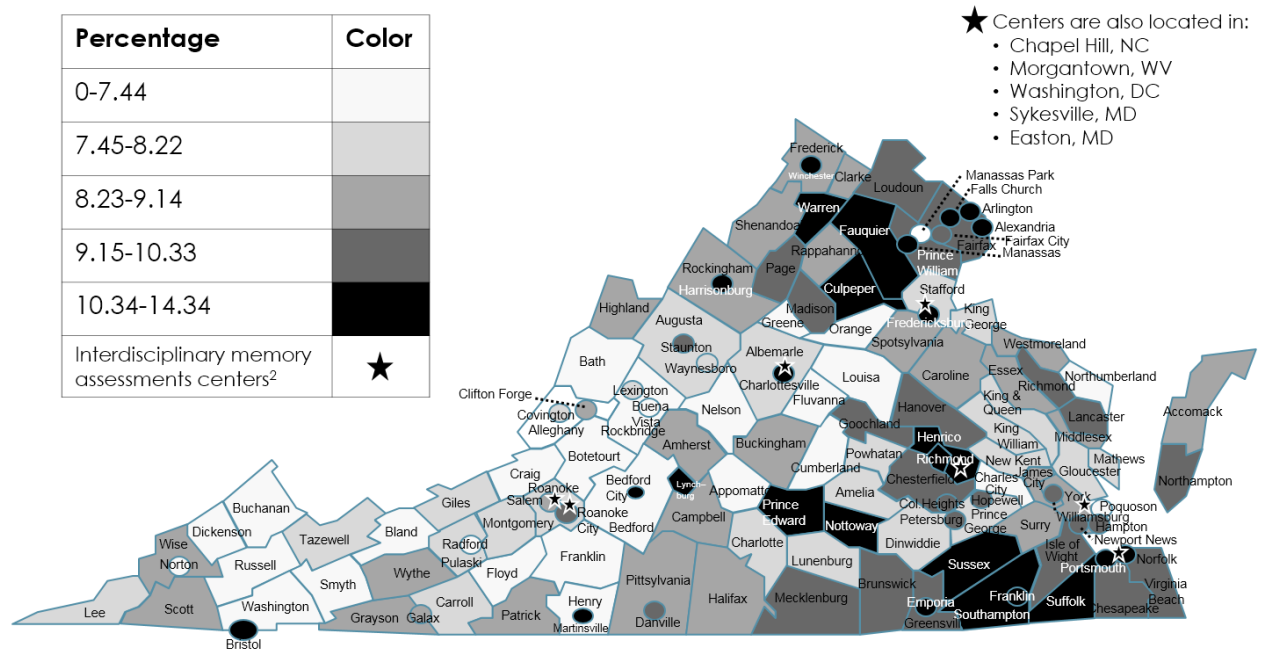


# Dementia in Virginia

In Virginia, an **estimated** 130,000 older adults aged 65 and older are currently affected by Alzheimer's disease with an expected increase to 190,000 by 2025 (Alzheimer's Association, 2015b). Further, according to data from the Centers for Medicare and Medicaid Services (CMS), 91,517 fee-for-service or traditional Medicare beneficiaries in Virginia had received a **clinical diagnosis** of Alzheimer's disease or a related dementia in 2012 (U.S. CMS Chronic Conditions, 2012).

However, experts expect that the figure in Virginia is much higher for several reasons. Anywhere from 29 to 76 percent of individuals in the community have not received a clinical diagnosis from their primary care provider and not all of those who receive a clinical diagnosis of Alzheimer's disease or dementia are enrolled in Medicare, thus accounting for the differences between the 91,517 clinically diagnosed Virginians and the 130,000 estimated Virginians with dementia (Alzheimer's Association, 2014; Moyer, 2014). For more details on this data, including the prevalence rates for Medicare beneficiaries within cities and counties in Virginia, please visit: [www.AlzPossible.org](http://www.AlzPossible.org).

### Virginia CMS Chronic Conditions: Percentage fee-for-service Medicare beneficiaries diagnosed with Alzheimer's disease and dementia, 2012



<sup>1</sup>Data not available for Manassas Park City and Alleghany County

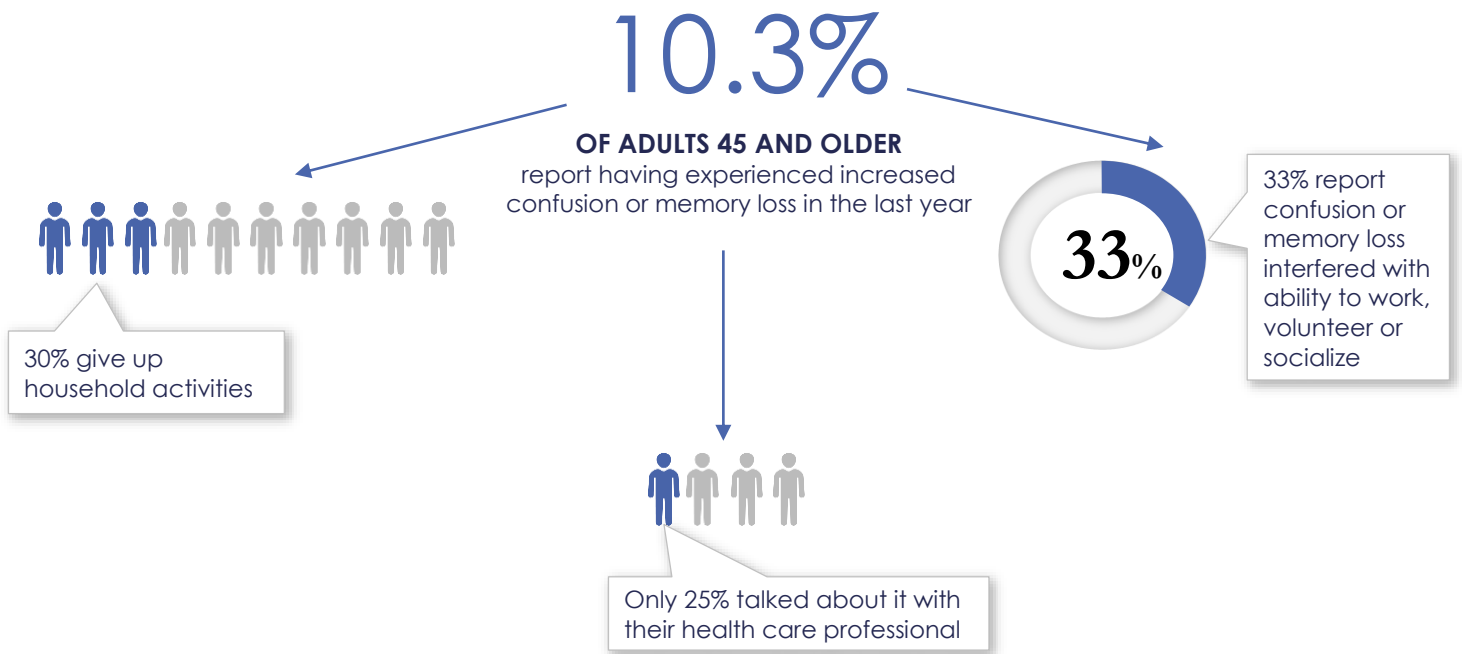
<sup>2</sup>More information on the interdisciplinary memory assessment centers is available on [www.AlzPossible.org](http://www.AlzPossible.org)

Data from <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/>

### Estimated Number of People Aged 65 and Older with Alzheimer's disease by Age

Year	65-74	75-84	85+	Total	% Increase from 2014
2015	21,000	58,000	53,000	130,000	
2020	26,000	69,000	59,000	150,000	15%
2025	29,000	89,000	68,000	190,000	46%

In 2012 and 2013, the optional Cognitive Impairment Module was included in the annual Behavioral Risk Factor Surveillance System (BRFSS), allowing the Commonwealth to get an idea of widespread cognitive issues as reported by Virginians. The results provide state health and human resource agencies a deeper perspective of cognitive impairment issues and how they may interfere with functioning. Among the findings are: in 2012, 10.3 percent of adults age 45 and older surveyed by the Virginia Department of Health (VDH) reported having experienced increased confusion or memory loss in the last 12 months. Of those adults, 30 percent have given up household activities or chores that they used to do and 33 percent reported that confusion or memory loss interfered with their ability to work, volunteer or engage in social activities. Perhaps most troublesome, however, is the finding that of those who reported confusion or memory loss, only 25 percent had talked about it with a health care professional (Alzheimer's Association, 2014b).



## Considerations for Special Populations in Virginia

When considering responses to dementia in the Commonwealth, it is important to note the specific needs of low income, women and minority Virginians as well as those living in rural areas. Additional analysis from the National Center on Aging (NCOA) using American Community Survey (ACS) data estimates that in 2012, there were 11,101 Virginians enrolled in Medicare with household incomes below 150 percent of the federal poverty threshold who also reported having a cognitive difficulty or disability (NCOA, 2014). In addition, there were 123.3 women per 100 men aged 60 and over living in Virginia as of 2011 and approximately two thirds of individuals with Alzheimer's disease are women (Alzheimer's Association, 2014; Lombard, 2013).

Virginia is ethnically diverse with one in every ten residents having been born in another country (Lombard, 2013). The proportion of Hispanic Virginians almost doubled during the decade of 2000 to 2010. As of 2011, 2.4 percent of the 60 and older population was Hispanic (AOA AGID, 2011). For African Americans, this figure was 15.3 percent (Lombard, 2013). Comparing nationally estimated prevalence between ethnicities, aging Hispanics

are one and one-half times more likely and African Americans are twice as likely to be diagnosed with Alzheimer's disease in comparison to Caucasians and Asians (Alzheimer's Association, 2014).

Older adults living in rural areas of Virginia also represent a population vulnerable to the impacts of dementia. They often have decreased access to specialists, community supports, and educational resources, which impede diagnosis and treatment (Teel, 2004). In 2010, there were 1.4 million Virginians aged 60 and older living in rural areas of the state (Lombard, 2013).

## Dementia and Caregiving

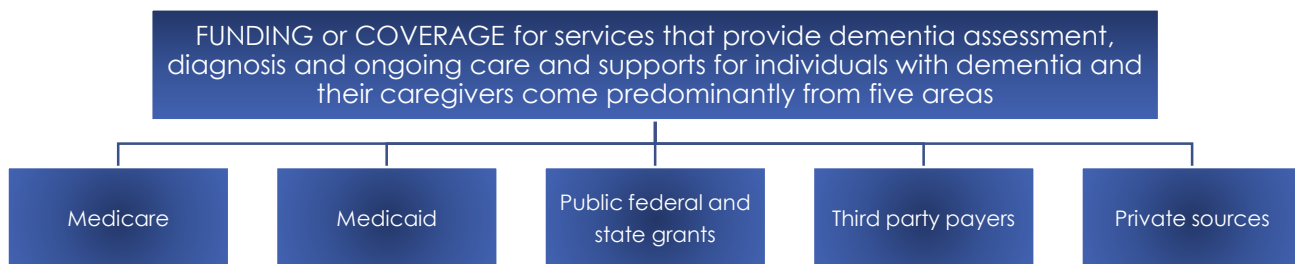
Given the debilitating nature of dementia, caregiving is generally required in both an informal and formal setting. Caregivers are essential partners when managing the health of individuals with dementia and are critical to the implementation of interventions not involving medications (Odenheimer et al, 2013). Caregivers provide assistance with instrumental activities of daily living (IADLs) and activities of daily living (ADLs) in addition to assistance with treatment and medication recommendations.

Caregivers in Virginia, estimated to be around 452,000 individuals in 2014, provided 514 million hours of unpaid care valued at \$6.3 billion to individuals with Alzheimer's disease or another form of dementia (Alzheimer's Association, 2015b). While the majority of individuals with dementia live in the community, by the age of 80, 75 percent of individuals with Alzheimer's disease have been transferred to a nursing facility as compared to four percent for those without the disease (Alzheimer's Association, 2011b).



## Funding for Dementia Care

Funding or coverage for services that provide dementia assessment, diagnosis, and ongoing care and supports for individuals with dementia and their caregivers come predominantly from five areas: Medicare; Medicaid; public federal and state grants; third party payers, such as health insurance and long-term care insurance; and private sources, such as an individual's own financial resources, donations, scholarships, in-kind resources, volunteer commitments, etc.



## 2011-2015

---

In December 2011, Virginia published its first comprehensive Dementia State Plan after a year of study, public listening sessions, and development. The Dementia State Plan is a reflection of a strong sentiment that has spread across the United States. The vision for this nationwide movement asserts that states are primed to offer a unique perspective on dementia issues and their accompanying solutions, many of which can be envisioned and implemented most effectively at a state-level.

With a focus on state-based programs and state oversight and infrastructure, Virginia's 2011 Dementia State Plan has offered numerous opportunities to improve the quality of life for individuals with dementia and their dedicated caregivers in a strategic and measured manner over the last four years. Since the first Dementia State Plan, Commission members paid particular attention to scanning available data and improving data collection and analysis moving forward.

In preparing for an update to the Dementia State Plan, the Virginia Alzheimer's Disease and Related Disorders Commission (the Commission) members are pleased to review the many policy and programmatic successes that were achieved with the first Dementia State Plan as a guide and in partnership with state agencies and organizations like the Alzheimer's Association.

The following are considered accomplishments in dementia policy and programming from 2011 through 2015 and serve as tangible evidence of Virginia's increased dementia-capability. The list is not exhaustive, but rather highlights major triumphs in advancing data collection, analysis and research; quality, coordinated care and support; and training and workforce development, all of which can improve the lives of individuals with dementia and their caregivers.

### **Overarching Accomplishments**

1. With funding and support from the General Assembly, Virginia hired the Commonwealth's first Dementia Services Coordinator (DSC), a full-time state-level position that coordinates dementia-focused efforts among state agencies and organizations to improve service delivery, identify gaps and duplication, administer grants, and recommend policy that ensures Virginia's dementia-capability.
2. With the unanimous support of stakeholders from state agencies, providers, experts and advocates in Virginia, DARS published a report on Dementia Care Best Practices, which highlights programs and practices in Virginia and recommendations for encouraging and expanding them across the Commonwealth. The report is available on [www.AlzPossible.org](http://www.AlzPossible.org).
3. Through the amendment of § 51.5-152, Virginia codified the specific responsibilities of the Virginia Department for Aging and Rehabilitative Services (DARS) as they relate to Virginia's response to Alzheimer's disease and related disorders.

4. Virginia modified the Department of Medical Assistance Services (DMAS) Alzheimer's Assisted Living Waiver program to allow individuals with related dementias to receive services and bring the eligibility definition in line with the standards for licensed assisted living facilities, creating a truly inclusive and person-centered approach to community-based services.
5. Virginia increased funding for the Public Guardianship program by \$599,700, which will increase the reach in order to meet the demand across the Commonwealth.
6. Through changes to § 51.5-150, Virginia codified the requirement that DARS develop and implement person-centered guardianship regulations that govern practices and procedures for Public Guardianship programs, which serves individuals with dementia, among others.
7. Virginia amended the Code of Virginia to expand the State Long-Term Care Ombudsman Program's access to records of providers of community based services to fulfill their programmatic responsibilities as Virginia continues to modernize the system of long-term care services from a focus on institutional to community-based care.

## **Data and Research Accomplishments**

1. For the first time ever, Virginia accessed and analyzed data from the 2012 Medicare Chronic Conditions database, resulting in the development of publically accessible maps and spreadsheets that provide data on fee-for-service or traditional Medicare beneficiaries who have received a clinical diagnosis of Alzheimer's disease or dementia by city and county in the Commonwealth.
2. Virginia increased funding for the Alzheimer's and Related Diseases Research Award Fund (ARDRAF) by \$125,000, an increase of just over 60% in ARDRAF's budget, which helped to increase the number and size of awards given to Virginia-based researchers to stimulate innovative research in a variety of fields.
3. Virginia implemented and collected data from the 2012 and 2013 BRFSS optional Cognitive Impairment module of survey questions, and has planned to implement and collect data from the 2015 optional Cognitive Decline and Caregiver modules.
4. Virginia collected and analyzed available data from state-based data systems and published the findings in a report available on [www.AlzPossible.org](http://www.AlzPossible.org).
5. Virginia aligned the application process for the ARDRAF to encourage researchers to think critically about how proposed projects fit within the goals of the Dementia State Plan.
6. Virginia engaged in ongoing conversations with state-based researchers on ways to increase and improve research, including participation, study approvals, funding, and coordination, while sharing information with them on available funding sources and tools developed at the state and federal levels on [www.AlzPossible.org](http://www.AlzPossible.org).

## **Coordinated Care Accomplishments**

1. Recognizing the importance of interdisciplinary clinical assessments and diagnoses, Virginia identified and surveyed interdisciplinary memory assessment centers from Virginia and neighboring states and then shared information about their services with partners and for consumers on [www.AlzPossible.org](http://www.AlzPossible.org).
2. In 2014, Virginia received a three-year federal Administration for Community Living (ACL) Alzheimer's Disease and Supportive Services Program (ADSSP) grant to advance the dementia-capability of Virginia's aging network and Aging and Disability Resource Connection, and to implement F.A.M.I.L.I.E.S., Family Access to Memory Impairment and Loss Information, Engagement and Supports in the greater Charlottesville and Williamsburg regions.
3. Virginia has continued an open and informal discussion on dementia services and training needs through the interdisciplinary, multi-agency Virginia Geriatric Mental Health Partnership (GMHP), which includes a focus on the U.S. Centers for Medicare and Medicaid Services (CMS) Partnership to Improve Dementia Care in Nursing Homes and reduce unnecessary antipsychotic medications.

## **Training and Workforce Development Accomplishments**

1. Virginia budgeted for a designated and consistent funding source for training law enforcement and first responders on communicating with individuals with dementia, locating individuals with dementia who have wandered through coordinated search and rescue efforts, and many other related topics through the Virginia Department of Criminal Justice Services (DCJS).
2. Since 2011 and with support from partners, Virginia developed over 25 excellent webinars on dementia-related topics that were accessed by over 2,000 formal and informal caregivers across the Commonwealth through [www.AlzPossible.org](http://www.AlzPossible.org).

## GOALS

---

### **Goal I: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia-Capability.**

- A. Support and maintain a dementia services coordinator (DSC) who oversees Virginia's dementia-capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.
- B. Expand availability and access of dementia-capable Medicaid and other state-level administered services.
- C. 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.

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

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

### **Goal III: Increase Awareness and Create Dementia Specific Training.**

- A. Provide standardized dementia specific training to individuals in the medical, health- and social services-related fields and require demonstrated competency.
- B. Provide dementia specific training to professional first responders (police, fire, EMS and search & rescue personnel), financial services personnel, and the legal profession.
- C. Support caregivers, family members and people with dementia by providing educational information about dementia and available resources and services.

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

- A. Create a statewide network of interdisciplinary memory assessment centers with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life.
- B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals with dementia and caregivers during the disease trajectory.
- C. Identify needed supports for informal and family caregivers and coordinate them to ensure positive caregiving experiences.

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

- A. Support Alzheimer's and Related Diseases Research Award Fund (ARDRAF), especially projects that have a specific emphasis on "methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth" (§ 51.5-153).
- B. Provide support to researchers and interested stakeholders across the Commonwealth through data sources and networking opportunities.
- C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.

## COORDINATE QUALITY DEMENTIA SERVICES IN THE COMMONWEALTH TO ENSURE DEMENTIA-CAPABILITY

---

There are dozens of state and local contributors that have the potential to enhance and strengthen Virginia's dementia-capability. Yet, with all of the Commonwealth's Health and Human Resource agencies combined with several agencies under Public Safety and Homeland Security having direct contact with individuals with dementia and their caregivers, the system is vulnerable to a silo effect.

Evolving evidence on the manifestation and treatment of behavioral and psychological symptoms of dementia, such as depression, anxiety, apathy and aggression, continues to blur the lines of cognitive impairment and mental health, leaving the system muddled.

Further changes in the delivery of long-term care have shifted the roles of nursing and assisted living facilities, with nursing facilities moving away from more custodial care and into step-down, rehabilitative care and assisted living facilities serving a resident base with increasingly complex care needs.

With all of these public agencies and private providers (many of which receive public funding) involved in dementia care it is imperative that a coordinated, state-level response is needed to ensure Virginians receive the care they need, when they need it, in an appropriate place, and from an appropriate provider.

**A. Support and maintain a Dementia Services Coordinator (DSC) who oversees Virginia's dementia-capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.**

1. The DSC shall disseminate information on systems, services and related activities for individuals with Alzheimer's disease and related dementias, the medical and healthcare community, academic community, primary family caregivers, advocacy associations, and the general public.
2. The DSC shall coordinate services and activities of state and local agencies, service providers, advocacy groups, first responders and law enforcement, as well as other entities throughout the state that engage the person with dementia and caregivers, specifically the Alzheimer's Association, Area Agencies on Aging (AAAs), and Adult Protective Services (APS).
3. The DSC shall coordinate and provide support for Commission activities.
4. The DSC shall continue to identify interdisciplinary memory assessment centers, share information about them with consumers, and provide professional development opportunities for center staff.



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

1. Increase respite services for caregivers of people with dementia.
2. Expand the accessibility and availability of PACE (Program of the All-inclusive Care for the Elderly) and adult day health care, the Elderly or Disabled with Consumer Direction (EDCD) waiver, and hospice programs.
3. Review the Medicaid waiver specific to Alzheimer's disease and related dementias for opportunities to increase enrollment and dementia-capability and ways to expand it to include other Home and Community-Based Services (HCBS).
4. Increase funding for Home and Community-Based Services (HCBS).
5. Increase the payment rate of Auxiliary Grant to cover the actual cost of care in an assisted living facility.
6. Promote the use of Virginia's Long-Term Care Partnership Insurance Program.
7. Increase the funding for Virginia State Long-Term Care Ombudsman Program.
8. Monitor Medicaid care coordination demonstrations for dementia-capability.
9. Continue to evaluate and improve Virginia's advance directives and emergency custody orders (ECOs) temporary detention orders (TDOs), and commitment laws to more easily allow persons with dementia to access needed and appropriate behavioral health services.
10. Increase the geographic reach and meet the unmet demand for public guardians.
11. Create a student loan forgiveness program or tuition assistance for medical, nursing and other allied health students specializing in geriatrics.
12. Review state legislation and regulations for licensing of professions, facilities and providers.
  - a. Review licensing and survey standards or protocols for long-term care facilities and identify opportunities to improve dementia-capability and quality through actions such as acuity-based staffing.
  - b. As regulations are open for review, advocate and recommend that expected dementia care practice components be standard for assessments, service delivery, and training and oversight of medical and health professionals and paraprofessionals engaged in caregiving.
  - c. Increase the availability of information on licensed professions, facilities and providers for consumers, including information on dementia specific training and programming.

**C. 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.**

1. Integrate the Dementia Care Best Practices report guiding principles and evidence-based practices into the development, delivery and evaluation of services provided in Virginia, including the development and implementation of the Commonwealth's Four-Year Plan for Aging Services.
2. Partner with DARS APS Division, the Virginia League of Social Service Executives, Virginia's AAAs, the Virginia Department of Behavioral Health and Developmental Services (DBHDS), Community Services Boards (CSBs), and the Geriatric Mental Health Partnership (GMHP) to identify solutions and promote best practices for providing crisis stabilization for individuals with dementia who have Behavioral and Psychological Symptoms of Dementia (BPSD).
3. Review the overlapping requirements for the licensing of residential facilities, assisted living facilities, and nursing facilities to further clarify the different levels of services and clarify the differences in admission disclosure documents.
4. Ensure that the Aging and Disability Resource Centers are dementia-capable, with a specific focus on education and training for information and referral specialists, options counselors, and care transition coaches.
5. Incorporate dementia education into intellectual and developmental (ID/DD) services and provider training, and review waiver regulations and policies to accommodate the growing population of individuals with ID/DD, including Down syndrome, and dementia who are served through state-based programs.
6. Conduct veteran-specific outreach efforts in partnership with the Virginia Department of Veterans Services and through the Virginia Veterans Care Centers.

## USE DEMENTIA RELATED DATA TO IMPROVE PUBLIC HEALTH

---

Having spent a large portion of the last four years focused on inventorying state agency data, with the findings available at <http://alzpossible.org/tools/data/>, data remains a priority. While it is clear that Alzheimer's disease and dementia continue to affect populations throughout the Commonwealth, an examination of the available data has revealed limitations in its applicability to policy and programming.

Elements designed to capture Alzheimer's disease, dementia, or cognitive impairment are not always required and many state-based data sources are designed to track claims and reimbursement rather than diagnoses or prevalence. Valid and reliable data has the potential to increase the efficacy of service delivery, allowing Virginia to target resources to those areas and populations with the greatest unmet needs.

Furthermore, as research continues to shed light on the interconnectedness of Alzheimer's disease and other dementias with chronic conditions, such as hypertension, hyperlipidemia, diabetes and obesity, coordinated public health efforts could improve health outcomes and reduce health care costs.

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

1. Develop, implement and coordinate statewide data collection and regularly share the findings through the AlzPossible website, which should serve as a clearinghouse of links to state, federal and private entities with relevant, up-to-date, and available data on dementia. Such data findings should include the results of the BRFSS caregiver and cognitive decline modules as well as Medicare data on beneficiaries and individuals who are dually eligible for Medicare and Medicaid.
2. Coordinate with state licensing agencies to collect data on dementia prevalence, trends, and the characteristics of professions, facilities and providers.
  - a. Consider the extent to which internal agency policies could mandate fields that capture the presence or absence of Alzheimer's disease and dementia.
  - b. Consider potential financial incentives for entities that fully complete forms or assessments.
3. The DSC should inventory and monitor data with the following themes in mind:
  - a. The prevalence of dementia related diseases across the Commonwealth, including by locality, across rural and urban communities, gender, ethnic and racial minorities, younger onset, individuals with intellectual and developmental disabilities, and other special populations or unique characteristics;
  - b. The availability of dementia related services and supports;
  - c. The availability of diagnostic and assessment services for Alzheimer's and dementia;

- d. The number and location of Virginians who are currently providing care to a family member or friend with dementia;
  - e. The cost of caring for persons with dementia; and
  - f. The prevalence of dementia among incarcerated populations.
4. With collected data, apply the findings to policy development and implementation so that such policies can target geographic areas and populations with identified unmet or higher needs.

**B. Collaborate with related public health efforts and encourage possible risk-reduction strategies.**

1. Use the BRFSS to collect health outcomes data for persons with Alzheimer's disease and dementia and their caregivers in Virginia, and analyze and apply the findings to improve dementia-capability.
2. Collaborate with related public health efforts (e.g. diet, exercise, co-morbid conditions, etc.) to improve treatment adherence and encourage possible risk-reduction strategies.
3. Encourage caregiver participation in the Chronic Disease Self-Management Education (CDSME) program and adapt it so that it can be used successfully with persons with dementia.
4. In collaboration with VDH and local health departments, integrate dementia and cognitive health into public health strategies and reports.

## INCREASE AWARENESS AND CREATE DEMENTIA SPECIFIC TRAINING

---

An estimated 447,000 caregivers, 65% of whom were women, provided 509 million hours of unpaid care for individuals with Alzheimer's disease and dementias in 2013 in Virginia (Alzheimer's Association, 2014). Both, informal or family caregivers report needing referrals to resources as well as education about dementia, general health care and mental health care (Black et al., 2013). These caregivers are also providing complex care on a daily basis, supporting individuals experiencing BPSD, such as depression and anxiety, and performing medical and nursing tasks, such as managing medications and operating durable medical equipment. In some cases caregivers even provide wound and IV care (Reinhard et al., 2014).

Both informal or family caregivers and formal or professional caregivers and direct care staff need high-quality, tangible education on dementia, including information on disease progression, home safety, wandering and driving concerns, interactions with other chronic conditions, advance directives and end-of-life care, among many other topics. Moreover, working to provide training to ancillary professions, such as those spanning law enforcement and first responders, legal, and financial personnel, has the potential to mitigate abuse, neglect and financial exploitation and ensure that individuals potentially experiencing a dementia disease are referred to appropriate resources.

### **A. Provide standardized dementia specific training to individuals in the medical, health- and social services-related fields and require demonstrated competency.**

1. Develop or collect and deliver dementia-specific, evidence-based trainings that include an emphasis on the differences between dementias and their disease trajectories, BPSD, referral protocols and resources, non-pharmacological interventions, care planning and advance directives, cultural and linguistic competence, and the needs of and supports for family and informal caregivers, among others.
  - a. Such dementia-specific, evidence-based trainings should be part of regular offerings and require demonstrated competencies for medical and health professions, including physicians, physician assistants, nurses of all licensing levels, gerontologists, psychologists, occupational, physical, and speech therapists, pharmacists, rehabilitation counselors, and social workers, and other health- and social services-related professionals across all professional care settings.
  - b. Integrate the dementia-specific, evidence-based trainings modules into the existing trainings offered through VDH, Virginia Department of Social Services (DSS), DARS, DBHDS, and their local entities and contractors, including AAAs, CSBs, local health departments and local departments of social services.
  - c. Integrate the dementia-specific, evidence-based trainings modules into the curriculums and trainings for long-term care facilities and HCBS providers.

2. Promote the continued and expanded use of the Advanced Nurse Aide Certification and encourage employers to reward such additional education with increased salaries.
3. Develop or catalog and deliver a portable certification program for direct care staff with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias.
4. Coordinate training opportunities with the GMHP and the Virginia Alcohol and Aging Awareness Group (AAAG), specifically with issues such as cognitive impairment and mental health, substance use, and polypharmacy.

**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 or catalog and deliver dementia-specific, evidence-based trainings with dedicated funding that include an emphasis on BPSD, detention orders, driving safety, wandering issues and resources, advance directives and other legal tools, and risks and signs for abuse, neglect, and financial exploitation, among others.
  - a. In partnership with the Virginia Department of Criminal Justice Services (DSCJ), Virginia State Police (VSP), Virginia Department for Emergency Management (VDEM), and Virginia Department of Corrections (DOC) continue to develop relationships and implement coordinated, dementia-specific, evidence-based trainings with state and local first responders (police, fire, EMS, and search & rescue personnel), emergency and disaster response personnel, and correctional personnel.
  - b. In partnership with DSCJ, VSP and VDEM, 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, to include the appropriate use of Senior Alert, Project Lifesaver, and other wandering prevention and response tools.
  - c. In partnership with statewide and local legal groups and associations, implement the dementia-specific, evidence-based trainings for general practice attorneys, prosecutors, judges, magistrates, victim advocates, and court clerks.
  - d. In partnership with the VSP, Virginia State Corporation Commission (SCC) and industry representatives, implement dementia-specific, evidence-based trainings for financial services personnel, including bank tellers, accountants, financial advisers, loan officers and collectors.
2. Coordinate dementia specific outreach and training efforts with the Virginia Office of the Attorney General (OAG) and its Senior-focused Triad and SALT (Seniors and Law Enforcement Together) initiatives.

**C. Support caregivers, family members and people with dementia by providing educational information about dementia and available resources and services.**

1. Expand AlzPossible resources and its free library of quality trainings and online materials available to address dementia care and research needs in Virginia, to include:
  - a. Dementia and caregiving data for tracking trends in the Commonwealth;
  - b. Interdisciplinary memory assessment centers;
  - c. Best practices for dementia assessment and diagnosis, care and caregiving support and a clearinghouse of evidence-based and evidence-informed dementia care interventions and therapies not involving medications;
  - d. Cognitive assessment instruments;
  - e. A comprehensive listing of available, evidence-based and evidence-informed trainings for professional caregivers;
  - f. A listing and explanation of the roles of state agencies; and
  - g. The diagnostic criteria summaries for the dementias and the stages of Alzheimer's disease with frequently used services associated with each stage.
2. In partnership with the Alzheimer's Association and other state agencies and their contractors, train and link informal or family caregivers to information and education about dementia and the caregiving process that is culturally and linguistically appropriate, including how caregivers can stay healthy, prepare for driving and wandering issues, coordinate legal and financial issues, and locate and use respite care services, among other topics.
3. Develop or collect and deliver a statewide, culturally-appropriate awareness strategy that has tailored components for the unique needs of rural communities, racial and ethnic minorities, non-English speaking individuals, veterans, individuals with younger-onset Alzheimer's disease, individuals with intellectual and developmental disabilities, members of the LGBT community, and individuals with traumatic brain injuries (TBI). As appropriate, such a strategy could be in partnership with faith-based communities and the Alzheimer's Association to increase the availability and use of education materials tailored to these groups.
4. With appropriate stakeholders, develop or collect and implement an evidence-based protocol for appropriate interaction with individuals with dementia and their family and caregivers, with specific information on BPSD.
5. Advocate for and increase awareness of and inclusion of advance directives and end-of-life planning, including knowledge of Virginia-specific laws governing such practices, in routine care for all older adults, with particular emphasis on individuals with Alzheimer's disease and dementia and caregivers.
6. Increase awareness of the Annual Wellness Visit, which includes an assessment of cognitive function, offered to Medicare beneficiaries.
7. Incorporate dementia awareness and information about resources into the state employee wellness program for the Commonwealth of Virginia.

## PROVIDE ACCESS TO QUALITY COORDINATED CARE FOR INDIVIDUALS WITH DEMENTIA IN THE MOST INTEGRATED SETTING

---

Our health care delivery system fails to identify and treat individuals with dementia effectively and to support caregivers appropriately, if at all. Quality care for individuals with dementia is hindered by a lack of clinical assessments and diagnoses, uncoordinated care transitions, and rising costs that leave care out of reach for many. According to a recent study conducted by Kotagal et al. (2015), an estimated 55% of Americans with dementia have not received a cognitive evaluation by a physician. From an acute care perspective, research on hospitalizations has noted that cognitive impairment, with delirium and without, in hospitals is “under-recognized, impacts care, and increases risk for adverse health outcomes” (Boustain et al., 2010). Long-term care costs continue to climb; according to a 2014 Genworth Financial survey, the average annual cost of assisted living facility care has increased 5 percent annually while nursing home care has risen 4.5 percent annually for the last five years.

Nonetheless, a coordinated delivery system with entry points focused in memory assessment clinics and in partnership with the aging network has the potential to break down barriers and remove obstacles to excellent care. Modeled after a patient navigation model from Boone and Braun (2012), an integrated network of memory assessment centers with patient navigators who are trained in dementia and caregiving can provide Virginians with the information, tools and referrals they need as the disease progresses from diagnosis to end-of-life.

### **A. Create a statewide network of interdisciplinary memory assessment clinics with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life.**

1. Create a statewide network of memory assessment clinics that use an interdisciplinary team approach to assess and treat persons with dementia.
2. Identify the typical pathways to assistance for individuals with dementia, possibly through a study, and develop a system of entry based on coordinated memory assessment centers for individuals with dementia and their caregivers.
3. Within the interdisciplinary memory assessment clinics and community partners, establish and fund dementia coordination centers that are staffed by credentialed patient navigators who can help persons with dementia and their caregivers and offer such services as:
  - a. Assessing and developing care plans in conjunction with the person with dementia and their caregivers and family;
  - b. Identifying and making referrals or arranging appropriate clinical care;



- c. Identifying and making referrals or arranging long-term care services and programs, including HCBS, long-term care facilities, hospice programs, PACE, and others;
  - d. Identifying and making referrals or arranging supportive services, such as transportation, meals, home modifications, respite care, counseling, and support groups, and others;
  - e. Educating the persons with dementia and their caregivers about the disease, interactions with chronic conditions, care options, driving assessments, legal and financial issues, including end-of-life wishes and advance directives, etc.; and
  - f. Accessing public and private benefit program and insurance claims.
4. Integrate data collection and track health outcomes and service utilization of persons with dementia and caregivers in the memory assessment center network to analyze prevalence and trends, effectiveness, and cost, including money saved through coordinated care.

**B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals with dementia and caregivers during the disease trajectory.**

1. Standardize the protocol followed after an individual receives a diagnosis of dementia, to include referrals for further evaluation by an interdisciplinary team with expertise in cognitive impairment and dementia at a memory assessment center and referrals to the local Alzheimer's Association chapter.
2. With appropriate stakeholders, identify current protocols, and develop and implement improved protocols for appropriate placement options and available community resources based on the stages of Alzheimer's and dementia related diseases.
3. Support systems that promote integrated care between primary, acute and long-term care settings and the transitions between them, with an emphasis on minimizing transitions, repeat hospitalizations, emergency department visits, and improving medication reconciliation.
4. Identify and remove barriers for community integration for persons with dementia.
5. In coordination with AAAs and CSBs, establish cross-setting teams and provide supports to long-term care facilities and family caregivers to manage BPSD in a safe and appropriate manner.
6. Promote research participation and university-community partnerships to address community needs and promote mutually beneficial participatory research opportunities in diagnosis, treatment, long-term care services and supports, and caregiver supports.

7. Track health outcomes and service utilization of persons with dementia and caregivers to assess and analyze effectiveness and cost, including money saved through coordinated care.
8. Promote geriatric emergency departments in hospitals to assure safety and best outcomes for elder patients, to include trained staff and a thorough evaluation of adults presenting with possible delirium and dementia.
9. Advocate for accessible transportation systems.
10. Promote and advocate for long-term care services that are modeled after Culture Change (including Green Houses, Eden Alternatives, Household Models, etc.) and other related initiatives that establish person-centered, home-like environments.
11. Identify opportunities and barriers to the increased and successful use of telemedicine and telehealth services that meet the needs of individuals with dementia and caregivers, particularly in rural areas.
12. Identify and deliver, possibly through pilot demonstrations, evidence-based programs that support caregivers through education, counseling, referrals, respite, and other related supports.

**C. Identify needed supports for informal and family caregivers and coordinate them to ensure positive caregiving experiences.**

1. Offer business and individual tax incentives to promote family caregiving and for the purchase of locator devices, respite care services, and other related expenses.
2. Encourage the development and implementation of employee assistance programs that identify the needs of caregivers and resources available to support them, which may include educational materials, onsite respite care and support groups.
3. Provide information about long-term care insurance policies and other related programs that help offset the financial expenses associated with long-term care.

## EXPAND RESOURCES FOR DEMENTIA SPECIFIC TRANSLATIONAL RESEARCH AND EVIDENCE-BASED PRACTICES

---

Since 2011 and in line with the growing numbers of individuals affected by dementia, research funding and attention has drastically accelerated at the national and international levels. Virginia certainly followed suit when it increased the funding for ARDRAF by \$125,000 in 2013, an increase of just over 60% in ARDRAF's budget. With this increase in funding and an ever-present demand for research on the causes of and possible treatments and cures for dementia, Virginia is well positioned to contribute to the body of research on dementias. More specifically, Virginia is poised to add to state-focused research on the prevalence of dementia in specific areas and populations and the costs to state-funded programs and family caregivers.

However, all the research in the world will do absolutely nothing if it is not disseminated and applied to practice and delivery to benefit individuals and their families. In order to disseminate and apply research findings, researchers in Virginia report needs related to: opportunities for in-person and virtual networking, assistance and support with recruitment and research participation, and technical assistance on applications for Institutional Review Boards (IRBs). Therefore, a statewide response to these identified research needs is essential.

**A. Support ARDRAF, especially projects that have a specific emphasis on “methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth” (§ 51.5-153).**

1. Support an increased focus and balance on translational projects, to include those that:
  - a. Utilize epidemiological methods.
  - b. Advance translational or clinical methods that identify evidence-based practices for service delivery and take them from bench to bedside.
  - c. Identify costs associated with the delivery of programs and services to individuals with dementia and caregivers.
  - d. Develop both high-tech and low-tech assistive devices that adapt everyday environments for people with dementia.
  - e. Assess the quality of services and facilities for individuals with dementia and their caregivers.
2. Explore projects that attempt to better understand Alzheimer's disease and dementias in rural communities, racial and ethnic minorities, non-English speaking individuals, veterans, individuals with younger-onset Alzheimer's disease, individuals with intellectual and developmental disabilities, members of the LGBT community, individuals with TBI, and individuals experiencing BPSD and co-occurring serious mental illness.

3. Disseminate research findings, especially translational research findings, on the AlzPossible website.

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

1. Develop a research consortium network and provide networking opportunities for researchers and interested stakeholders in Virginia.
  - a. Periodically disseminate information about studies in need of participants and funding opportunities, which may include federal grant opportunities from the U.S. National Institutes of Health (NIH) as well as from the Alzheimer's Disease Supportive Services Program (ADSSP) within the Administration for Community Living (ACL) and the U.S. Centers for Medicare and Medicaid Services (CMS) Innovation grants and pilot demonstrations.
  - b. Use the AlzPossible website as a forum to link researchers interested in dementia research.
2. Direct researchers to dementia and caregiving-related data sources so that they can better write research funding applications.

**C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.**

1. Develop training for gatekeepers (primary care providers, physicians, nurses, office managers, and other health professionals) on dementia and the value of research participation.
2. Develop incentives, such as care coordination, research partnering and communication of study results, for medical and health professionals who encourage research participation in the community.
  - a. Explore options to further support participant recruitment and participation in research studies in Virginia, specifically with diverse populations such as ethnic and racial minority populations, rural and underserved communities, individuals with younger onset Alzheimer's disease, individuals with intellectual and developmental disabilities, and other special populations or unique characteristics.
  - b. Foster university-community partnerships to further research and development, address community needs, and promote mutually beneficial participatory research opportunities.
  - c. Develop and share resources for university IRBs as they develop consistent methods for assessing and approving dementia and caregiving research studies, to include information on informed consent allowances as outlined in § 32.1-162.16 through § 32.1-162.20.
  - d. Use the AlzPossible website to link to additional resources related to research.

3. Further dementia-capability with the use evidence-based practices and use AlzPossible as a resource to evaluate and share dementia-capable services, evidence-based practices, and risk reduction strategies.
  - a. With additional study and subsequent positive outcomes, identify opportunities for continued and expanded use of evidence-informed programs in Virginia, including the shift of quality evidence-informed programs into evidence-based programs.
  - b. Evaluate the effectiveness of common methods used to disseminate and translate evidence-based practices, and apply the results in Virginia.
  - c. 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.

## DEMENTIA STATE PLAN DEVELOPMENT PROCESS

---

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

Under the Code of Virginia § 51.5-154, the Commission has the power and duty to:

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.

As was the case in the development of Virginia's 2011 Dementia State Plan, the Commission reviewed state plans from other states, particularly those that had been drafted in recent years. Having recently identified Guiding Principles, Best Practices and Recommendations for dementia care in the 2014 study managed by the Dementia Services Coordinator within the Virginia Department for Aging and Rehabilitative Services (DARS), the Commission integrated the findings of the report into the Dementia State Plan's development. Once a draft of the updated Dementia State Plan was in place, Commission members hosted five public listening sessions around the Commonwealth in Big Stone Gap, Roanoke, Virginia Beach, Fairfax and Richmond. These sessions were attended by over 100 people. Additionally, the DSC conducted electronic outreach to members of the Virginia Geriatrics Society and received many comments from professionals and family caregivers by mail, telephone and email through DARS.

Once input was gathered, the Commission, guided by optimal aging theory and stress and coping theory, drafted the Dementia State Plan. The Commission intends that this will be a living document always responsive to the needs of Virginians. The intent is to update it every four years to ensure that it is adaptive and that it makes use of cutting-edge research and standards.

# Contributions and Acknowledgments

The Virginia Alzheimer's Disease and Related Disorders Commission would like to recognize its **current members who contributed to the Dementia State Plan**:

Courtney S. Tierney, MSW, *Chair*  
Lory Phillippo, MPH, OTR/L, *Vice Chair*  
Laura Adkins  
Vivian Bagby, RN, MS  
Laura Bowser  
Sharon E. Davis  
Christopher Desimone, Esq.  
Julia Trivett Dillon

Valerie Hopson-Bell, BA, CMC  
W. Thomas Hudson, Esq.  
Janet L. Honeycutt  
Carol Manning, PhD, ABPP-CN  
Lynne Seward, *Former Chair*  
Patricia W. Slattum, PharmD, PhD  
Kevin P. Walsh, DC

The Commission also thanks **former members** as well as **Commission work group members**, including:

Sonya Barsness, MSG  
Constance L. Coogle, PhD  
Andrew Heck, PsyD, ABPP

Shannon Jarrott, PhD  
Martha Watkins  
George Vradenburg

The Commission would also like to thank the following **individuals** who lent their time and expertise to the development of the Dementia State Plan and assisted with planning and hosting public listening sessions:

Virginia Alzheimer's Association  
Chapters

Carter Harrison  
John Christopher Broullire  
Gino Colombara  
Sue Friedman, MS  
Marie Kolendo  
Sherry Peterson, MSW  
Cindy Schelhorn  
Patricia Farish Lacey, MBA  
Ellen Phipps, CTRS, MSG  
Annette Clark, MSG

The Memory Center (Virginia Beach)

Kevin DiBona  
Kathryn Bennett

Mountain Empire Older Citizens  
(Big Stone Gap)

Michael Wampler

Virginia Department for Aging and  
Rehabilitative Services

Charlotte Arbogast, MSG  
Amy Marschean, JD

Lastly, the Commission expresses immense gratitude to the **many individuals with dementia, their caregivers, family members and friends, as well as professionals** who took time out of their busy schedules to participate in the public listening sessions or offer comments by mail, telephone or email. Their invaluable first-hand input has meaningfully informed the Dementia State Plan. It is the Commission's sincere hope that the Dementia State Plan reflects the needs, concerns and priorities of Virginians.

**Adult Day Health Care (ADHC)**

Adult day health care is a community-based, non-residential service that supports the health, nutritional, social, emotional, cognitive, recreational and daily living needs of adults in a professionally staffed, protective group setting for individuals who cannot be left alone during the day. Services and supports are based on individual assessment of needs, strengths and preferences to develop and maintain a current, written, person-centered plan of care for each participant. Adult day health care also meets the needs of family caregivers for support and education, allowing them to work without distraction or worry, and meeting their need for respite from 24 hour responsibility for caregiving.

**Adult Protective Services (APS)**

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 professionals 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 health care, 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.

**AlzPossible**

AlzPossible is established as a virtual center or a center without walls. The mission of AlzPossible is to promote workforce development through education and training in person-centered, ethical dementia care and to ensure the development of a broad range of well-integrated programs, services and research designed to reduce the burden of the disease on the citizens of the Commonwealth of Virginia. AlzPossible disseminates prevalence data, information for researchers, and information about dementia and effective interventions that maintain and/or extend the independent functioning of people with the disease.

**Assisted Living Facility (ALF)**

Assisted Living Facility 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. Assisted Living Facilities provide assistance with Activities of Daily Living (ADLs), medication management, social activities, housekeeping, meals, and may offer dementia care programs. 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.

**Auxiliary Grant (AG)**

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 for Aging and Rehabilitative 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.

**Behavioral and Psychological Symptoms of Dementia (BPSD)**

Describes the range of non-cognitive symptoms that often occur or manifest with dementia. These symptoms include, but are not limited to, apathy, verbal and physical aggression, agitation, wandering, decreased inhibition, anxiety, hallucinations and delusions, sleep disturbances, irritability, and depression.

**Behavioral Risk Factor Surveillance System (BRFSS)**

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 long-term care services, based on person-directed values and practices where the voices of those receiving services and those working with them are considered and respected. Core person-directed values are choice, dignity, respect, self-determination and purposeful living.

**Cultural Competence**

Cultural competence is the application of skills and knowledge to effectively deliver services to culturally diverse individuals by tailoring programs and interventions to their behaviors, beliefs, values and linguistic needs. Professionals who exhibit cultural competence work successfully with persons from varying cultures because they demonstrate understanding and respect of their unique background, keeping in mind these differences when providing education and planning, implementing and evaluating programs.

**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. A dementia-capable system: 1) identifies those with a possible dementia and recommends follow up with a physician or other trained professional; 2) ensures that the staff they encounter have appropriate training, understand the unique needs and the services available as well as knowledge of how to communicate with them; and 3) provides quality, person-centered services that help them remain independent and safe in their communities. A dementia-capable system also

involves family caregivers when they are available and it is appropriate.

**Elderly or Disabled with Consumer Direction (EDCD) Waiver**

The EDCD Waiver serves as an alternative to nursing facility care for 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 health care, medication monitoring, personal care (agency and consumer-directed), personal emergency response system (PERS), respite care (agency and consumer-directed), transition coordination, and translational services.

**Evidence-Based**

Based on research. Evidence-based programming translates tested program models or interventions into practical, effective programs that can provide proven health benefits to participants. When an evidence-based program is implemented with fidelity, there is proof that the program works.

**Evidence-Informed**

Reflects the deliberate and systematic use of the best available evidence. This is combined with a distillation of the experience of experts where that evidence is not available, to inform clinical decision-making and evaluation, program development and policy creation.

**Formal Caregiver**

Professionals or paraprofessionals who are paid in exchange for providing care.

**Home and Community Based Services (HCBS)**

Assistance provided to individuals so they can remain in their homes and communities. Services could include case management, adult day health care, homemaker, home health, personal care, respite care, as well as other related activities.

**Hospice Care**

Hospice care is designed to give person-centered, 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. 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.

**Informal Caregiver**

Individuals, usually family members, friends, neighbors or volunteers who provide unpaid care.

**Interdisciplinary Memory Assessment Clinic**

These clinics have multi-disciplinary teams that provide a comprehensive dementia assessment and diagnosis, continuing care for individuals diagnosed with dementia, access to support groups, and opportunities to join clinical trials.

**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.

## **Medicaid**

Medicaid is a joint federal-state program. 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 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.

## **Medicare**

Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD). The different parts of Medicare help cover specific services. Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care. Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services. Part C services as a type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Part A and Part B benefits. Lastly, Part D adds prescription drug coverage to the offerings.

## **Olmstead v. L.C.**

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**

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.

## **Person-Centered Care**

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.

**Program of All-Inclusive Care for the Elderly (PACE)**

PACE provides the following services: adult day health 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; reside in a PACE provider area; be eligible for Nursing Home Care; be screened and assessed by the PACE team; have a safe service plan; and have an income equal to or less than 300% of Social Security Income.

**Respite Care**

Respite care is the provision of short-term, intermittent, 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.

**Nursing Facility**

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.

**Translational Research**

Taking the findings from basic science and applying them to enhance the health of humans, particularly through the development and implementation of treatment options.

# References

- Administration on Aging, & AGing Integrated Database (AGID) (2011). *Profile of state OAA programs: Virginia*. Retrieved from [www.agid.acl.gov/StateProfiles/Profile/Pre/?id=49&topic=0&startyear=2011&endyear=2011](http://www.agid.acl.gov/StateProfiles/Profile/Pre/?id=49&topic=0&startyear=2011&endyear=2011)
- Alzheimer's Association (2011a). Younger-onset Alzheimer's: I'm too young to have Alzheimer's disease. Retrieved from [https://www.alz.org/national/documents/brochure\\_earlyonset.pdf](https://www.alz.org/national/documents/brochure_earlyonset.pdf)
- Alzheimer's Association (2011b). *Generation Alzheimer's: the defining disease of the baby boomers*. Retrieved from [www.alz.org/boomers/](http://www.alz.org/boomers/)
- Alzheimer's Association (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 10(2), 1 - 80. Retrieved from [www.alz.org/downloads/facts\\_figures\\_2014.pdf](http://www.alz.org/downloads/facts_figures_2014.pdf)
- Alzheimer's Association. (2014b). Cognitive decline in Virginia. Retrieved from <http://alzpossible.org/wp-content/uploads/2014/06/Cognitive-Divine-in-Virginia.pdf>
- Alzheimer's Association. (2015a). Down syndrome and Alzheimer's disease. Retrieved from [http://www.alz.org/dementia/downloads/topicsheet\\_downsyndrome.pdf](http://www.alz.org/dementia/downloads/topicsheet_downsyndrome.pdf)
- Alzheimer's Association. (2015b). 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 11(3), p. 332-384. Retrieved from [http://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](http://www.alz.org/facts/downloads/facts_figures_2015.pdf)
- AlzPossible (2011, May 9). General dementia knowledge [Video file]. Retrieved from [www.alzpossible.org/wordpress-3.1.4/wordpress/webinars-2/general-dementia-knowledge](http://www.alzpossible.org/wordpress-3.1.4/wordpress/webinars-2/general-dementia-knowledge)
- American Psychiatric Association. (2013). Neurocognitive Disorders. In *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed., pp. 602-605). Washington, D.C: American Psychiatric Association.
- Gordon, K., McGinn-Shapiro, M., Gould, E., Shuman, S. B. & Wiender, J. M. (2015). IDD and dementia. Retrieved from [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/IDD-and-Dementia.pdf](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/IDD-and-Dementia.pdf)
- Lombard, H. (2013, November 21). Migration patterns and aging among Virginia's regions. *Census Brief: Demographics Research Group*, (1), 1 - 2. Retrieved from [www.coopercenter.org/demographics/publications/aging-and-migration-in-Virginia](http://www.coopercenter.org/demographics/publications/aging-and-migration-in-Virginia)
- Middleton, L. (2014, June 24). Barriers and opportunities for investment in research to find a cure for dementia by 2025: funding the scientific challenge ahead [PowerPoint Presentation]. Retrieved from <http://dementiachallenge.dh.gov.uk/2014/06/24/slide-packs/>
- Moyer, V. A. (2014). Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 1 - 7. Retrieved from <http://annals.org/>
- National Center on Aging (NCOA). (2014). Disabilities and Difficulties in the Low-Income Medicare Population. Retrieved from [www.ncoa.org/enhance-economic-security/center-for-benefits/disabilities-and-difficulties-map.html](http://www.ncoa.org/enhance-economic-security/center-for-benefits/disabilities-and-difficulties-map.html)
- Odenheimer, G., Borson, S., Sanders, A. E., Swain-Eng, R. J., Kyomen, H. H., Tierney, S., . . . Johnson, J. (2013). Quality improvement in neurology: dementia management quality measures. *Journal of the American Geriatrics Society*, 62, 558 - 561. doi:10.1111/jgs.12630
- Teel, C. S. (2004). Rural practitioners' experiences in dementia diagnosis and treatment. *Aging & Mental Health*, 8(5), 422 - 429. doi:10.1080/13607860410001725018
- Tippett, R. M. (2011, September 21). Virginia's changing population. *The Column: Newsletter of the Virginia Institute of Government*, 1 - 4. Retrieved from [www.coopercenter.org/demographics/publications/column-virginias-changing-population](http://www.coopercenter.org/demographics/publications/column-virginias-changing-population)
- U.S. Centers for Medicare and Medicaid. 2012 Chronic Conditions Medicare beneficiaries data available at <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/index.html> and [www.alzpossible.org](http://www.alzpossible.org)
- U.S. Department of Health and Human Services (HHS). (2013). Improving care for populations disproportionately affected by Alzheimer's disease and related dementias: Report from the task force on special populations. Retrieved from <http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf>
- World Health Organization, & Alzheimer's Disease International (2012). *Dementia: a public health priority*. Retrieved from [www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/)