



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – Joshua M. Sharfstein, M.D., Secretary

January 7, 2013

The Honorable Martin O'Malley, Governor
State House
100 State Circle
Annapolis, MD 21401-1925

Re: Comprehensive Evaluation of Alzheimer's Disease and Related Disorders in Maryland

Dear Governor O'Malley:

Executive Order 01.01.2011.21 established Maryland's Virginia I. Jones Commission on Alzheimer's Disease and Related Disorders. Executive Order 01.01.2011.21 requires the Commission to submit a comprehensive evaluation of Alzheimer's Disease and Related Disorders (ADRD) in Maryland and makes recommendations for a State plan to address the needs of individuals with ADRD, their families, and caregivers.

I hope that you find this information useful. If you have any questions or need more information on this subject, please contact Dr. Laura Herrera at 410-767-6525 or Dr. James Lett at 301-770-8473.

Sincerely,

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Maryland's Virginia I. Jones Commission
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Enclosure

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Maryland State Plan on Alzheimer's Disease and Related Disorders



Governor Martin O'Malley
Lieutenant Governor Anthony Brown

December 2012

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Executive Summary

Individuals and their families face enormous challenges – both in terms of their health and well-being and finances – when faced with a diagnosis of Alzheimer’s disease and related disorders (ADRD). Approximately 100,000 people are expected to have Alzheimer’s disease in Maryland by 2025, and a disproportionate number of these individuals will represent racial and ethnic minorities. To help address this growing public health problem, Governor Martin O’Malley issued Executive Order 01.01.2011.21 establishing the Maryland Alzheimer’s Disease and Related Disorders Commission, a state-wide public-private panel, and asked it to develop this state plan to address the growing burden of ADRD in Maryland.

Persons living with ADRD face special challenges in many areas. Some notable ones include:

- Access to clinical centers for early diagnosis and treatment;
- High risk for adverse outcomes in care transitions;
- Ethical issues, particularly in the area of advance directives;
- Training clinicians, caregivers and facilities to provide optimal care and a reimbursement for these services; and
- Protection from predatory behavior from untrustworthy individuals.

A special debt is owed to those in the care circle of persons living with ADRD: spouses, family, significant others, neighbors, friends and generous others who form an unofficial safety net. Much of the care provided is uncompensated. It exacts a toll not only in time and personal resources, but in loss of health and lifespan.

The goal of the commission is to take the next step in closing gaps in knowledge and care for both those individuals with ADRD and those secondarily affected by it, and to strengthen their support system. This public health issue, already of enormous import, will only intensify as our population ages.

Introduction

Background and Charge

In December 2010, a report entitled “Services for Individuals with Alzheimer’s Disease and Related Disorders” was sent to the Maryland General Assembly. In the report, three recommendations were made:

- Recommendation 1: Increase data collection capabilities;
- Recommendation 2: Establish a state-wide public-private commission dedicated to Alzheimer’s disease and related disorders (ADRD); and
- Recommendation 3: Increase public awareness and outreach for ADRD and the need for health care and other decision making through the course and development of ADRD, including at the end of life. Special attention should be devoted to underserved and minority communities.

In November 2011, Governor Martin O’Malley issued Executive Order 01.01.2011.2.1 establishing the Maryland Alzheimer’s Disease and Related Disorders Commission, a state-wide public-private commission dedicated to ADRD. The order tasked the Commission with developing a state plan that would address the recommendations made in 2010.

Since the Governor’s executive order was signed, several national initiatives have been established that highlight the importance of the work of the Commission. In January 2011, President Barack Obama signed the National Alzheimer’s Project Act (NAPA), which required the United States Department of Health and Human Services (HHS) to establish a national Alzheimer’s project to coordinate federal programs and resources and develop a national plan to improve ADRD outcomes and reduce the cost of care. This plan, released in March 2012, requires engagement from multiple stakeholders, including state and local partners. This Maryland state plan is modeled after the national plan and makes several recommendations that support the national goals.

Alzheimer’s Disease in Maryland

Alzheimer’s disease (AD) is a distinctive disease of enormous magnitude and immeasurable suffering for individuals, their families and loved ones. Other types of dementia exist, including but not limited to vascular dementias, frontotemporal disease and Lewy body disease. It is sometimes difficult, if not impossible, to distinguish between Alzheimer’s disease from other dementing diseases based upon clinical presentation and course of the illness. Ultimately those afflicted with dementia, their families, and caregivers must surmount similar difficulties in locating continuing, appropriate and timely care. Given these shared challenges, for the purposes of this report when the term Alzheimer’s disease is used it refers to the entire array of dementias.

As a disease associated with aging, the escalation in Alzheimer’s incidence reflects the rise in average population age in Maryland and the United States. Currently there are five million Americans living with Alzheimer’s, and this number is projected to rise between 13 to 16 million by 2050. The economic impact of Alzheimer’s is significant. In today’s dollars and assuming current prevalence estimates, the cumulative costs for caring for Alzheimer’s in the United States will exceed \$20 trillion between now and 2050.¹ In Maryland, an estimated 100,000 people are expected to have AD by 2025.²

Disparities in Alzheimer's and Other Dementias

Maryland has a higher percentage of racial and ethnic minorities than the rest of the United States. Caucasians represent 61 percent of the Maryland population, compared to 78 percent of the United States population. Nearly one-third of Marylanders are black, compared to 13 percent nationwide. Hispanics are another significant minority, at approximately eight percent of the Maryland population. They proportionally make up a smaller percent of the Maryland population than the U.S. population, which is about 17 percent Hispanic.³

These demographic differences are important when considering that blacks, and to a lesser extent Hispanics, have higher rates of Alzheimer's disease and other dementias than whites. Based on an analysis of existing studies, the Alzheimer's Association estimates that the prevalence of AD is two times higher for blacks compared to whites, while Hispanics have a rate 1.5 times greater than whites.⁴ In addition, blacks have been shown to have a much higher rate of vascular dementias than whites.⁵ A range of risk factors may be contributing to these differences, including co-morbid chronic diseases, genetics, and social and cultural factors.

Strategic Goals for Reducing the Burden of ADRD in Maryland

Goal 1: Support Prevention and Early Identification of ADRD
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Cognitive functioning in older adults has become an increasingly important focus among health care providers and researchers. This is due in part to the increasing longevity of older adults, which has resulted in increased incidence of cognitive functioning decline. Epidemiologic studies indicate that as people live longer, the prevalence of ADRD also increases.⁶

Given the large numbers of older adults who will develop ADRD and the health and financial consequences of the disease, early identification of dementia and pre-dementia conditions through cognitive screening tools is essential. Early identification of dementia provides the opportunity to engage in more comprehensive disease management and life planning, both for the person living with ADRD and his or her loved ones. It may also help avoid complications that can speed decline in persons with dementia and result in unnecessary health care spending.

Strategy 1: Identify early stages of Alzheimer's disease

Alzheimer's disease is a progressive, insidious disorder. The progression of the disease is generally linear, although there may be some within-stage fluctuations of symptoms. Early detection of dementia is often the result of a patient presenting with mild cognitive impairment (MCI). MCI is a syndrome in which the patient has a singular cognitive deficit (usually memory). There is a large body of evidence supporting the idea that MCI is a precursor of dementia or a pre-dementia phase. In the typical MCI presentation, the patient has a memory deficit, but otherwise generally normal cognitive functions, can generally maintain normal daily activities of living, and is not demented. At least 60 percent of MCI patients will develop dementia, and most of these cases will be AD. MCI patients convert annually to AD six to ten times more often than cognitively normal older people.

Early identification of dementia can provide essential information for disease management and life planning. For our health system to be more successful in early detection, we must develop and provide effective cognitive screening tools, make them available to those providers, and motivate providers to use them. The first step is to ensure that screening tools have adequate sensitivity and specificity in detecting cognitive impairment. This issue was specifically addressed in the U.S. Preventive Services Task Force's statement on dementia screening tools (2003), which concluded that the pool of available screening tools was generally weak. Since their opinion was published, a newer generation of screening tools has been developed and published that meet acceptable standards. Three of these are the Brief Cognitive Assessment Tool (BCAT & BCAT- Short Form), the Montreal Cognitive Assessment (MoCA), and the Saint Louis University Mental Status Examination (SLUMS) (see *Appendix A*). All three are sensitive to MCI versus dementia and meet sensitivity and specificity standards.

For health care providers to successfully integrate cognitive screening into their practices, the instruments must be brief, sensitive, able to detect MCI versus dementia, and should be administered by either licensed professionals or technicians. A substantial body of evidence indicates that primary care providers, who are most likely to see patients at the MCI or early dementia phase, do not routinely administer cognitive screening tools, even when there is a subjective or objective memory complaint. There is little literature concerning best practices for implementing effective screening programs. More information about how public and private health programs can do a better job of screening may be forthcoming through the *Healthy Brain Initiative*, a joint project between the CDC and the Alzheimer's Association in creating a road map for meeting the ongoing needs of an aging society from a health perspective.

While the dominant paradigm for integrating effective cognitive screening into our health care system focuses on the primary care provider as the pivot point, other creative programs are beginning to emerge. Many persons living with ADRD do not have a primary care physician, but have their care managed by specialists. Others see no clinician at all, making it very hard to reach some ADRD sufferers. In Orange County, California, the Vital Aging Program has been developed to better link older patients to appropriate community health care providers. They are using an online portal and a memory self-assessment tool. The patient is directed to appropriate resources based on their assessment results.

Strategy 2: Address chronic disease risk factors contributing to disparities in Alzheimer's disease

Higher rates of chronic diseases known to be associated with dementia development in racial and ethnic minorities may also contribute to disparities in ADRD. Blacks and Hispanics have considerably higher rates of vascular dementias than whites.⁷ Research suggests that vascular dementias are associated with previous incidence of stroke,⁸ and Blacks and Hispanics have rates of stroke that are two or more times greater than whites.⁹ Blacks also have a higher prevalence of hypertension, which places them at higher risk for neurovascular pathology often found in patients diagnosed with Alzheimer's disease, such as cerebral amyloid angiopathy and white matter lesions.¹⁰ In addition, a history of myocardial infarction and coronary artery disease are associated with the presence of diffuse plaques in the brain, and blacks and Hispanics have higher rates of these cardiac conditions.¹¹ Studies assessing the relationship between diabetes mellitus and dementias have produced conflicting results and there is no scientific consensus on the underlying mechanisms; some researchers believe any association is due to comorbid cardiovascular and/or cerebrovascular disease.¹²

Like racial and ethnic disparities in other medical conditions, differences in socioeconomic status (SES), education, and other social factors are contributors to disparities in ADRD.¹³ Multiple studies have shown that a higher level of education and a higher degree of cognitive challenge in an individual's occupation are associated with a lower incidence of the development of dementias.^{14, 15} Minorities tend to have fewer years of education and work in jobs that on average are less cognitive and more physical in nature.¹⁶ Cultural beliefs and customs may also contribute to disparities. Blacks are significantly more

likely than whites to believe that AD symptoms are a normal consequence of aging,¹⁷ which may contribute to delayed assessment, referral, and treatment for dementia in the black population.¹⁸ Overall reduced access to care among minorities – including preventive care – also results in delayed care for dementias.¹⁹ Delayed diagnosis in minorities may also result in underestimation of the true depth of racial and ethnic disparities in ADRD.²⁰

Several existing initiatives in the state are aimed at preventing the development of these kinds of risk factors. First, the Maryland General Assembly passed SB 234, Chapter 3, in 2012 to establish Health Enterprise Zones (HEZs) in areas with poor health outcomes that reflect unacceptable health disparities. To qualify to become an HEZ, a community led coalition must set specific goals on health outcomes, health utilization, and costs and then propose a comprehensive plan and budget to meet these targets. Tools available to community coalitions include grant funding, state income tax credits, Loan Assistance Repayment Program (LARP), and additional tax incentives for hiring staff. Community based organizations that lead HEZs will forge partnerships between hospitals, local health departments, nonprofit organizations, and other stakeholders and develop creative, collaborative, community-driven plans to improve health outcomes and reduce disparities. Two to four pilot HEZs will be established with state funding in late 2012.

In addition, the Maryland Department of Health and Mental Hygiene was awarded a Community Transformation Grant (CTG) in 2011 from the Centers for Disease Control and Prevention that will target the chronic disease risk factors that studies show are associated with ADRD. The program, Healthiest Maryland, expands efforts in tobacco-free living, active living and healthy eating, and quality clinical and other preventive services (i.e., improving control of hypertension and high cholesterol) as part of a statewide movement to transform communities into healthy environments for all. Local health departments provide the backbone for intensive, community interventions. As such, the CTG is a vehicle for local action teams to implement initiatives to prevent and control chronic disease through these kinds of primary prevention efforts. The CTG has a particular focus on racial, ethnic and economic subgroups experiencing health disparities.

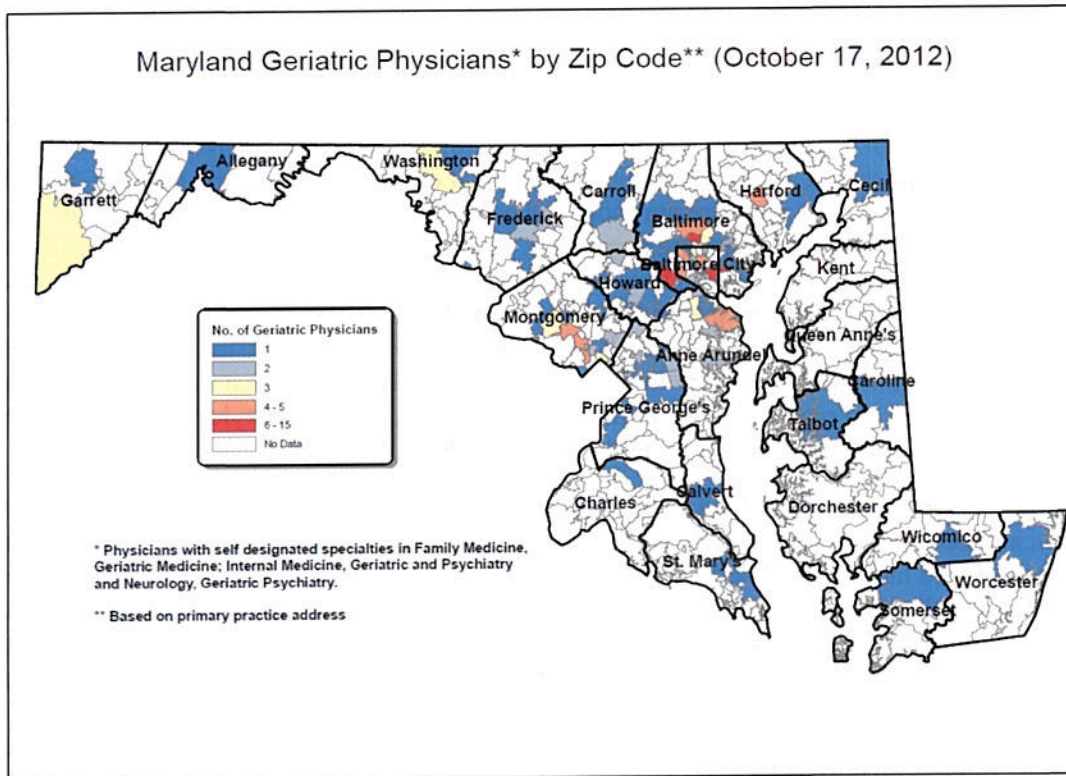
Finally, the Maryland Department of Aging, in partnership with other state and local agencies, will create a statewide coordinated chronic disease self-management program called the Maryland Living Well Project (MLWP). The goal is to enable seniors, caregivers and adults with disabilities to have easy access to MLWP by providing services to at least 5,000 persons (50% minority) over the course of the project. The Maryland Living Well Project is offered as a six-week workshop that is highly structured and intensively interactive for participants. The program has been proven to help participants become more self-sufficient in managing the kinds of chronic conditions that are risk factors for ADRD. It has also been shown to improve physical and emotional health and reduce health care costs.

Goal 2: Enhance the Quality of Care

Strategy 1: Build a workforce with ADRD training and skills to provide high quality care

Maryland faces a shortage of physicians trained to provide care to persons living with ADRD. According to the Maryland Board of Physicians, there are 257 physicians with self-designated specialties in geriatric medicine and geriatric psychiatry. This means that of the more than 28,000 licensed physicians in Maryland, only one percent is dedicated to the practice of geriatric medicine. This clearly represents a significant shortage of physicians well-equipped to treat ADRD. The geographic distribution of these physicians is shown in *Figure 1*.

FIGURE 1



There are two geriatric fellowships programs for physicians in Maryland, both of which are sponsored by academic medical centers. Both programs include extensive research training and provide fellows the opportunity to learn alongside leading experts in geriatrics. However, with both focused on training future physician-researchers, there are no geriatric fellowships in Maryland that focus primarily on delivery of services in the community. The number of slots for geriatric fellows should increase and the focus should include the delivery of geriatric care. Moreover, residency programs in primary care should include additional training focused on older populations, cognitive decline, and the treatment of ADRD.

There is also a shortage of nurse practitioners prepared to effectively treat ADRD. In 2012, the National Council of State Boards of Nursing Advanced Practice Registered Nurses (APRN) Advisory Committee eliminated the official gerontological nurse practitioner track and its associated certification exam. Nursing schools are dropping their gerontology programs and/or combining them with adult NP programs. Maryland nursing schools are strongly encouraged to maintain strong gerontology programs and incorporate training and education on screening, diagnosis, and treatment of ADRD.

Strategy 2: Educate primary care providers on best practices

The research literature on best practices for diagnosis and treatment of ADRD is constantly growing and evolving. It is a challenge for health care providers – whether physicians, nurses, social workers, or another field, – to keep up with the latest findings and translate them into care processes in their practices. There are regular continuing medical education (CME) courses for physicians on ADRD best practices in Maryland, including online CME courses related to ADRD. Clinicians that see persons living with ADRD, especially primary care physicians who may have limited training on ADRD, should be strongly encouraged to participate in these programs. As noted before, they will likely play a larger and larger role in identifying ADRD in its early stages.

Strategy 3: Promote ADRD care guidelines and patient-centered approaches in nursing homes and assisted living facilities

Maryland has a significant number of long-term care beds. There are 233 licensed nursing home facilities, with a total of 27,493 beds. Of these, three facilities (182 beds) are private pay only and 22 facilities (1,131 beds) do not accept Medicaid. The annual cost of nursing home care for ADRD is estimated to be \$81,000 for a semi-private room and nearly \$92,000 for a private room. These costs are prohibitive for many considering nursing home care. In addition, Maryland has 1,368 licensed assisted living facilities, totaling 19,750 beds. These facilities have emerged as a residential option for persons living with ADRD. They range in size and style from small group homes with 2-15 residents to larger hospitality model facilities that have hundreds of residents. The cost of assisted living care in Maryland ranges from \$1,000 per month in a very limited number of smaller homes that accept individuals with social security and SSI to over \$12,000 per month in the larger, concierge style facilities.²¹ Only a few of these facilities specialize in caring for individuals with ADRD.

Patient-centered care. The Alzheimer's Association estimates that more than half of all nursing home and assisted living residents have some form of dementia.²² Given this high prevalence, it is critical that long-term care facilities utilize best practices in ADRD care. Despite their cognitive impairment, persons living with ADRD are still able to enjoy meaningful activities, experience positive emotions, and continue personal growth. An important factor for persons living with ADRD who reside in assisted living or nursing homes is the quality of care that they receive from their direct care staff and the nature of their relationships with them. Good dementia care involves a comprehensive assessment of the resident's abilities, an appropriate care plan that includes strategies for addressing behavioral and communication difficulties, and adequate staffing patterns to meet the resident's growing needs. Such assessments should also involve gathering and using information about a resident's life, including past experiences, family life, preferences, hobbies, and routines, so that a person-centered approach can ensure that care is tailored to each resident's particular needs.

Long-term care facilities of all types are adopting practices that move the culture of the facility from a focus on the institution to a focus on the individual. Thirty-two states – not including Maryland – have functioning Culture Change Coalitions that work to advance practices that transform the traditional long-term care environment to home settings. These coalitions promote environments that respect the residents and those who care for them by promoting choice, self-expression, dignity, self-determination, and purposeful living. The ultimate goal is to ensure that staff and family together act as “care partners” to ensure optimal function and high quality of life for each resident, minimizing unnecessary medications, and reducing transfers in and out of hospitals and nursing facilities. The development of a Culture Change Coalition in Maryland should be a priority.

Care guidelines. Despite the growing body of knowledge on best practices in long-term care facilities, there are significant gaps in the quality of services being provided. This is largely because we lack uniform standards of care beyond the basic requirements for assisted living that are set forth in Maryland regulations. In 2006, the Alzheimer's Association developed *Dementia Care Practice Recommendations* for nursing homes and assisted living facilities. The recommendations are evidenced based and are endorsed by 28+ national organizations. They promote person-centered care that is tailored to the abilities and changing needs of each resident and include a comprehensive assessment and care planning as well as an understanding of behavior and effective communications. The strategies focus on fundamental components of quality of life and quality of care, including food and fluid consumption, pain management, engaging in meaningful activities, wandering, falls, physical restraint free care, and end of life care. They also include practical tips and examples that “rely on having effective staff approaches and an environment conducive to carrying out recommended care practices.” However, many facilities are not aware that this document exists. Requiring facilities to implement these core practice recommendations would enhance services to individuals with ADRD and improve quality of care.

Strategy 4: Promote the Patient-Centered Medical Home Model

A medical home is an enhanced model of primary care that provides patients with access to comprehensive and integrated health care. The focus is on quality and safety through ongoing relationships with and oversight by medical providers. Its goal is to allow the primary care provider to serve as the quarterback of a team of health professionals that focus on coordinating care and rewards clinicians for keeping their patients healthier. This approach is highly relevant to addressing the multi-faceted health care needs associated with ADRD.

In March 2010, the Maryland General Assembly passed House Bill 929, Chapter 6, “Patient-Centered Medical Home Program (PCMH),” which directed the Maryland Health Care Commission (MHCC) to establish a medical home program. The intent was for medical homes to promote the delivery of higher quality health care that could also slow the rising costs seen in Maryland. The PCMH is designed to proactively anticipate and resolve barriers to a seamless provision of care. In addition, for those medical practices that are successful in keeping their patients out of the emergency department or from being hospitalized, they will receive a percentage of the shared savings. The program also utilizes care plans by nurse case managers that can track patients across settings and time.

In 2011, CareFirst Blue Cross Blue Shield launched its primary care medical home program. Based on lessons learned in their medical home pilot, the program incentivizes primary care providers to focus on the needs of chronic patients and those at greatest risk for chronic diseases. Incentives are similarly based on a fixed component for setting and monitoring care plans as well as shared savings based on quality and cost outcomes. The CareFirst model includes care managers as well as a sophisticated care management software tool to track patients across the health system.

Through this team-based approach, PCMH models have the potential to provide high quality care to persons living with ADRD patients in the primary care setting. Persons living with ADRD often have comorbid conditions that make their already complex health care needs that much more significant. They make frequent visits to medical specialists and may also have unique social and behavioral needs that require other health professionals such as social workers. PCMH case managers may guide patients and their families through the health care system, coordinate care among the various specialists and other health professionals, and ensure that the patient’s unique, complex needs are being met. When carried out effectively, this approach may help persons living with ADRD remain at home longer and result in better quality of life for the individual and his or her loved ones.

Goal 3: Enhance Supports for Persons Living with ADRD and Their Families

Services and supports for persons living with Alzheimer’s disease in Maryland can be divided into two categories -- formal services provided by agencies and facilities and informal supports provided mostly by unpaid caregivers, such as family, friends, and the extended faith based community.

Strategy 1: Promote and expand home and community-based support programs

While many persons living with ADRD eventually end up requiring institutional care, less than 6% of the older population actually resides in nursing homes. Assisted living facilities have emerged as an alternative to nursing home placement for persons with mild or moderate dementia. However, the rising cost, of specialized assisted living care for individuals with Alzheimer’s may deter placement. The end result is high stress, high risk caregiving in the community for persons living with ADRD. In addition, most individuals prefer to stay in their home environment, so caregivers may face a significant

amount of guilt when considering placement in a 24-hour living arrangement. As a result, home- and community-based care options are frequently considered more desirable.

Informal caregiving. Most caregiving in the community is provided by unpaid, untrained caregivers, such as family members, friends and neighbors, and through faith-based organizations. These informal services may include meal preparation, shopping, driving to appointments, housekeeping, and medication reminders, as well as assistance with bathing, dressing, toileting, and eating. In many instances, unless the person living with ADRD has family staying in the home with them full-time, these services are sporadic, leaving the individual unattended much of the day, increasing the risk for medication errors, falling, wandering, and financial exploitation. These informal caregivers are often without the necessary resources to maintain the health of their loved one and their own personal health and well-being. The Maryland Access Point (MAP), discussed on pages 11 and 12, is a clearinghouse of resources and information for informal caregivers.

The Alzheimer's Association Disease Facts and Figures Factsheet for 2012 states that:

- More than 1 in 7 individuals with Alzheimer's disease (an estimated 800,000 individuals) live alone at home. Over half of these individuals have no identifiable caregivers.
- In Maryland last year, 278,490 caregivers provided more than 317 million hours of care.
- Nationally, in 2011, 15.2 million family and friends provided 17.4 billion hours of unpaid care to those with Alzheimer's, valued at \$210.5 billion.
- More than 60% of caregivers rate the emotional stress of caregiving as high or very high and one-third report symptoms of depression.
- Due to physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$8.7 billion in additional health care costs in 2011.

As the dementia progresses, informal supports are frequently no longer sufficient and formal support options must be introduced into the mix. While Maryland offers an array of formal support services for individuals with ADRD, there is significant fragmentation and variation in the availability, quality, and cost of these services throughout the state. Some regions have multiple resources of a given type, while other areas, particularly rural counties and inner cities, have very limited options. In addition, many of the care options that individuals might need are not affordable for people without financial means.

Maryland offers a limited array of home and community-based services, such as adult medical day care, senior center plus, social day respite programs, and in-home personal care through various Medicaid waivers. These options allow individuals with Alzheimer's to remain in their home environment for a longer period of time, while offering caregivers a reprieve (respite) from their caregiving responsibilities. Payment for home and community services is primarily through private means. While Maryland offers several home and community based waivers, all of them, with the exception of the Medical Day Care Waiver, have significantly limited slots and are at full capacity. As a result, access to these services for individuals without private funds is frequently only available after being on a long waiting list.

Adult medical day care. There are approximately 120 licensed adult medical day care (AMDC) programs in the State of Maryland. Adult medical day care programs offer a comprehensive array of services, which includes transportation to and from home, nursing care, medication administration, personal care, meals, and structured activities. Adult medical day care centers provide care for individuals with mild, moderate, and even advanced stages of dementia, as well as individuals with other health conditions or disabilities. The cost of adult medical day care averages approximately \$72 per day, and is covered as a Medicaid waiver service for individuals who demonstrate both medical and financial need. Most adult medical day care centers are open Monday through Friday between the hours of 7am –

6pm, and some operate 7 days per week. All centers have wheelchair accessible transportation services that pick up and drop off the client. In addition, caregivers are able to bring their loved one in at a time that is more convenient. These centers are licensed by the Office of Health Care Quality. With costs of adult medical day care being considerably lower than residential programs, they are a viable option for many families. Unfortunately, these programs are frequently underutilized because the public is unaware that they exist. In addition, social service agencies frequently direct ADRD caregivers to utilize assisted living or nursing home placement in lieu of adult medical day care. Raising awareness of adult medical day care should be included in the public outreach campaign.

Senior Center Plus. This program was implemented by the Maryland Department of Aging (MDoA) to meet the needs of individuals with mild dementia who do not need the more structured environment of an adult medical day care. This program is frequently run out of existing senior centers and offers staff supports to direct individuals with mild memory loss through the day. It does not offer hands-on assistance with activities of daily living. Availability is limited to certain areas of the State, so access is an issue. The cost of this service is supplemented by MDoA for individuals with financial need, and typically ranges from \$12 - \$35 dollars per day. However, there is only limited funding available and transportation is not available with this service. As the prevalence of mild dementia continues to grow, increased funding and transportation services for this program should be considered.

Social day respite programs. Respite programs, which provide activities for mildly impaired patients and allow caregivers respite, are available at the local level across the state. These programs typically operate two or three days per week and offer an array of social activities for individuals with memory loss while providing much needed respite to caregivers. Most programs charge minimal fees that are based on the caregiver's income.

Over the past 10 years, Maryland has made steady progress toward enhancing and improving home and community-based service options for individuals in need of long term services and supports (LTSS). The Department of Health and Mental Hygiene has an overall rebalancing vision that improves access to home and community-based services (HCBS) and shifts the focus from institutional settings. Along with a State Plan personal care program, Maryland currently has nine Medicaid home and community-based services waiver programs serving over 25,000 people as an alternative to institutionalization.

Maryland is also participating in the Money Follows the Person Rebalancing Demonstration (MFP), which is a federal initiative that focuses on home and community services by streamlining and supporting transitions from institutions to the community. Maryland's MFP developed a peer-based outreach system to educate individuals with disabilities and older adults, in nursing facilities, about the option to receive long-term supports and services in the community. Recognizing the need for additional community-based services, it added many services and established a flexible funds account for services needed for transitions. MFP supported the development of the statewide network of Aging and Disability Resource Center sites, known as the Maryland Access Point (MAP). The MFP demonstration was extended through the Affordable Care Act.

The Balancing Incentive Program (BIP), created by the Affordable Care Act and offered by the Centers for Medicare and Medicaid Services (CMS), provides financial incentives to states to increase community-based services as an alternative to institutional services. To receive these incentives, states must spend at least 50% of their LTSS budget on home and community-based supports and implement three structural changes: a no wrong door/single entry point system, a core standardized assessment, and a conflict-free case management system. Maryland applied to participate in the BIP program in February of 2012 and was the second state to be approved to begin collecting enhanced FMAP as of April 1, 2012.

The no wrong door/single entry point was accomplished by developing the Maryland Access Point (MAP) sites, a one stop shop for information about community LTSS, eligibility determination, and program enrollment. In conjunction with stakeholders, the Department selected the interRAI-HC tool as the core standardized assessment (CSA) instrument for home and community-based services requiring a nursing home level of care and support with activities of daily living. Conflict free case management seeks to mitigate financial or other incentives for the over or under utilization of services by separating eligibility, planning, assessment, and funding activities from direct service provision. The Department is reviewing all case management practices to identify and remediate any conflicts.

The Affordable Care Act added a new section to the Social Security Act to create Community First Choice (CFC), which offers the option of person-centered home and community-based services and supports through the Medicaid State Plan for individuals who require a nursing home level of care. This new State Plan option is designed to assist individuals with activities of daily living and health related tasks. The Department will continue developing the CFC program with the assistance of the Implementation Council.

Strategy 2: Promote Maryland Access Point (MAP)

Given the fragmentation of formal and informal services and the challenge in finding information, it is critical to promote public awareness and usage of the Maryland Access Point (MAP). Maryland currently has twenty MAP sites providing statewide assistance for consumers seeking information, referral and program support for long-term care services in multiple settings. The state's seven regional Centers for Independent Living (CILs) are primary partners in all sites.

MAP is part of the federal Aging and Disability Resource Center (ADRC) initiative, which is a joint effort of the Administration for Community Living, the Centers for Medicare and Medicaid Services, and the Department of Veterans Affairs. The national vision is to establish Aging and Disability Resource Centers like MAP in *every* community, serving as highly visible and trusted places where people of all incomes and ages can turn for information on the full range of long-term support options and a single point of entry for access to public long-term support programs and benefits. The federal initiative began with 12 states including Maryland in 2003; the program is now in 54 states and territories. The core functions of an ADRC are information, referral, assistance and streamlined eligibility for public programs. These services are commonly referred to as "options counseling."

In addition to 20 local sites, MAP provides a statewide public searchable resource directory²³ to serve the public and professionals in identifying, connecting and accessing private and public resources. The MAP website has several options for searching for services which include selecting a county and program type, a self-assessment tool, and a quick search. Individuals can use the website to directly find and contact service providers or they can find an appropriate agency in their local area to contact for counseling and assistance.

Maryland's MAP has established partnerships among state and local agencies and organizations while welcoming new partners and roles. MAP staff work with advocacy groups to develop searchable data resources for different constituent groups. The MAP website is under constant review for accuracy and ease of search, as well as to ensure the inclusion of information relevant to different consumer groups. MAP will continue to:

- Review current resources listed in the searchable database;

- Review current search functions for services that may be supportive for individuals dealing with cognitive dementia;
- Provide a “Learn About” on cognitive loss and dementia for the website;
- Work to include an on-line screening instrument for cognitive impairment; and
- Develop a process for on-going input from stakeholders serving persons living with ADRD and their caregivers and support networks.

Maryland Access Point has become a one stop shop resource tool for consumers looking for services and support for current and future needs. It is a major element in Maryland’s rebalancing initiative to allow persons to age in place and, where possible, return to their communities. MAP can play an important role in informing professionals of resources and assist the public in accessing transportation, home repair, financial assistance, and other personal needs. As an ongoing effort, local and state agencies are working together to expand and grow the MAP initiative in hopes to reach the public beyond just the aging and disabled populations. The MAP network offers an opportunity to expand knowledge of the availability of dementia services through existing resources. Awareness of this valuable resource should be raised during the public outreach campaign.

Strategy 3: Assist families in planning for future care needs

The Alzheimer’s Association (www.alz.org) has published national guidelines to assist in the care of patients in the home and in assisted living and nursing facilities. The core elements of the practice guidelines include decision-making and advance planning, personal care, pain management, eating and drinking, falls, wandering, home safety, social relationships, meaningful interaction, and end-of-life care.

Decision-making and advance planning. Decision-making and advance planning constitute areas of dementia care that need to be addressed by persons living with ADRD, their families, and providers. It is paramount that providers inform family caregivers of individuals with cognitive loss about the signs and symptoms of dementia, the natural history of the disease (including dementia as a fatal illness) behavioral disturbances, home safety, appropriate care, and community resources such as the Alzheimer’s Association. This knowledge will facilitate and encourage persons living with ADRD and their family caregivers to begin the process of advance planning, especially while those with AD are still capable of making decisions about their health care and are able to designate another person (proxy) to act on their behalf when they lose the ability to make decisions. A key reason for early detection of a dementing disease is to allow the involved person the right to determine how the remainder of life, and the approach to death, is to be embraced. This extends the patient-centered philosophy to its rightful place in dementia care.

Advance directives (living wills and durable powers of attorney for health care or health care proxies) are formal, written documents intended to guide care when an individual is no longer able to make health care decisions, especially in end-of-life situations. Advance care planning may also include an individual’s oral statement to a physician leaving instructions or appointing an agent. The state of Maryland recognizes and supports the use of these aforementioned advance directives when individuals have already executed them or when they are planning future health care issues. The primary method to document an individual’s decisions in an actionable order is the Maryland Medical Orders for Life-Sustaining Treatment (MOLST). The MOLST program translates the individual’s personal wishes, including those in an advance directive, into a physician’s or nurse practitioner’s order that must be followed at every site of care and in the community in Maryland.

End-of-life planning. It is important to determine the individual’s wishes while the person is still able to make their own decisions so that compassionate and informed end-of-life care can be provided

that meets the individual's needs and choices. Medical providers should educate the person and family caregivers about the end result of this terminal disease. This includes education about the signs and symptoms of the dying process. This will allow the person and family to anticipate crises and avoid undesirable, futile medical treatments and unnecessary hospitalizations when the individual no longer benefits from such interventions. Likewise, it is essential that caregivers be educated about alternative care options, such as hospice and palliative care. Hospice care involves an interdisciplinary team who provide pain and symptom management as well as emotional and spiritual support to individuals with terminal illnesses and their families. Hospice services are reimbursed through Medicare, Medicaid, and some insurance carriers when a physician certifies that the individual has no more than six months of life remaining if the disease runs its normal course. Palliative care is not a specific program, but a philosophy of care that focuses on alleviating pain and suffering, whether physical or emotional.

Everyone involved in decision-making needs to be educated about informed consent and honoring an individual's wishes. A number of factors enter into the discussion about end-of-life issues, including:

- It is crucial to address pain alleviation, comfort, and dignity at the end-of-life.
- Families should understand that patients who are actively dying may not require the same amount of food and fluids for sustenance, as the body is slowing down and preparing to die. A person who is dying from dementia generally is not uncomfortable during the end stages of the illness.
- Personal care and hygiene are not only essential to maintain the patient's comfort, but are dignity issues that must be addressed. Mouth care, nail care, incontinence care, skin care, and odor control all contribute to the overall comfort and dignity of the dying person.
- Emotional and spiritual support for both the patient and their loved ones and caregivers are very important during the dying process. Family members and caregivers benefit from education and reassurance during the person's illness, the dying process, and after their loved one has passed away.

The overall goal of end-of-life care is to minimize the person's physical, emotional, and spiritual distress while maximizing comfort, choice, well-being and dignity. Advance care planning, including the development of advance directives and completion of the Maryland MOLST form, is crucial for individuals to direct their own health care, especially at the end-of-life.

Goal 4: Enhance Public Awareness

While public awareness of Alzheimer's disease has increased in recent years, there still exists much misinformation among the general public. In 2011 the Alzheimer's Association hosted 132 public input sessions in 42 states, including 5 in Maryland, to solicit opinions on leading challenges that should be addressed in a National Alzheimer's Plan. A lack of public awareness of the disease was one of the top ten challenges that emerged. This included "a lack of knowledge and widespread misunderstanding about Alzheimer's, significant stigma and negative experiences, and a poor understanding of the scope of the disease." Many still do not recognize that Alzheimer's is a fatal disease and that is not a normal part of aging. Unfortunately, lack of knowledge, denial and stigma exist in the general public, in families dealing with the dementia and in health care professionals. This lack of awareness hampers early

detection and diagnosis, support for family caregivers and research investment at a level that is consistent with the scope of the disease, thus increasing healthcare costs.

Even less is known and understood about the challenges faced by those with younger onset dementias. In the United States, an estimated 400,000 Americans have dementias that developed under age 65, in their 30s, 40s and 50s. People with younger onset dementia are more likely to be misdiagnosed and have less access to supportive services, long term care and participation in research studies. Many are fired from jobs and lose access to income, retirement benefits and health care coverage. Almost one-third of people with early onset dementia have no health insurance. They do not automatically qualify for Medicare, so families are financially burdened. They may have children in school and a spouse who is working to help support the family. Family dynamics change and social isolation increases. Family members and other care partners often lack the information and support they need to provide care to their loved ones.

Strategy 1 : Conduct a campaign to educate the public on risk factors for dementia, the importance of screening and available support services and resources

All State offices and local public agencies involved in the care of older adults, including the Department of Health and Mental Hygiene, Department of Aging and Department of Human Resources, should collaborate in an effort to educate and inform their constituents about ADRD. This may include revising public education materials and programs, including content in personnel training and education programs, strengthening dementia-related areas when reviewing regulations and updating websites. The State will partner with the Alzheimer's Association and other organizations for dementia training for State employees in appropriate positions. The State and agencies will run an educational campaign and public awareness events during September, World Alzheimer's Month, to complement national awareness efforts. State employees may wear purple or buttons or State landmarks may be in purple lighting.

The State will collaborate with other organizations to promote current public awareness efforts. The Alzheimer's Association's Alzheimer's Early Detection Alliance (AEDA) program builds partnerships with businesses and organizations to educate as many people as possible about the warning signs of Alzheimer's disease and the importance of early detection. Alzheimer's Awareness Purple Sunday involves faith-based organizations in spreading the message about early detection and supportive services for caregivers. The Alzheimer's Association's Workplace Champions program develops strategic partnerships among employee groups to create awareness.

Faith Based Initiatives

In many neighborhoods, the religious center acts as the thought leader and knowledge dissemination base for the community. This is a vibrant, extant network for ADRD information dissemination as well as for best practices and expectations. For example, at the 2005 Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss, participants felt that the faith-based community should expand their outreach. Over the next six years, letters were sent to pastors inviting them and their congregations to participate in an education and outreach initiative designed to increase public awareness of Alzheimer's disease and its impact on the African American community. In 2011, pastors and church leaders throughout the Baltimore area were asked to host a program entitled "Alzheimer's Awareness Purple Sunday." This program asks church leaders to distribute literature on AD and discuss its impact on the African American community. Congregations are encouraged to participate in the annual forum. To date, sixty-eight (68) churches have participated reaching more than 9,000 congregants.

Goal 5: Improve Data Capacity to Track Progress

Strategy 1: Promote existing data resources and identify opportunities to expand

Several data resources on ADRD in Maryland are available from the Department of Health and Mental Hygiene. This information is vital to understanding the prevalence, geographic distribution, and other important information related to ADRD.

Primary Data Sources

Behavioral Risk Factor Surveillance System. The Maryland Behavioral Risk Factor Surveillance System (BRFSS) is a statewide landline and cell phone survey. Maryland BRFSS annually conducts approximately 12,000 Maryland resident interviews on a variety of health variables. All states, the District of Columbia, and three territories collect BRFSS data; therefore Maryland's state data can be compared to other states and the nation. In 2011 and 2012, Maryland BRFSS has collected data on 10 cognitive impairment questions (see Appendix B). The new 10 item Impact of Cognitive Impairment Module gathers information about individuals affected by cognitive impairment, the impact of cognitive impairment on activities outside the home, the need for assistance and care giving and healthcare seeking behaviors. Maryland is one of 23 states currently using the module.

The data from these questions can be accessed in an online data application.²⁴ Cognitive impairment questions can be stratified in this data application by demographic variables, including age, gender, race, Hispanic or Latino origin, home ownership, education level, employment status, income level and marital status, as well as geographically by county and region. State level data obtained from BRFSS will be helpful for understanding the impact of cognitive impairment among adults in Maryland which will be instrumental in guiding current and future programmatic and resource planning.

Vital Statistics. The Vital Statistics Administration manages Maryland's Alzheimer's disease mortality data and records from 1970 to 2011. Alzheimer's disease mortality data is available by age, gender, race, Hispanic origin, education level, marital status, autopsy, where death occurred and location of residence (including census tract, zip code, and county). Data can be requested by resident data (includes all births and deaths among Maryland residents regardless of place of occurrence), resident-recorded data (includes births and deaths occurring within Maryland to residents of the state; does not include births and deaths among Maryland residents occurring in other states or in the District of Columbia), Maryland recorded data (includes all events occurring in Maryland, regardless of place of residence), and out-of-state data (includes Maryland resident births and deaths occurring outside Maryland). Data can be accessed in the Maryland Annual Vital Statistics Reports on the Department of Health and Mental Hygiene's Vital Statistics Administration website²⁵ or by contacting the Vital Statistics Administration.

Secondary Data Sources

Maryland Assessment Tool Community Health (MATCH). Data that are utilized or displayed in a format different than the primary source are known as secondary data. Secondary data sources of Alzheimer's disease are available through the Department of Health and Mental Hygiene. MATCH application provides Vital Statistics death data in a query format for Alzheimer's data from 2000 to 2010. Data can be accessed online²⁶ and are available for stratification by demographic variables, including age, gender, race, and Hispanic origin, as well as geographically by county. Maps may be created as well

through the MATCH application.

State Health Improvement Process. Another secondary data source is the State Health Improvement Process (SHIP). SHIP provides a framework for accountability, local action, and public engagement to advance the health of Marylanders by tracking thirty-nine critical health measures. SHIP measure #35 is aimed at reducing the proportion of hospitalizations related to Alzheimer's disease and other dementias. Utilizing Maryland Health Services Cost Review Commission (HSCRC) data, SHIP tracks the rate of inpatient hospitalizations for Alzheimer's and other dementias for adults, ages 65 years and older. The overall rate is available as well as the rate for specific races. Currently, only 2010 data are available and can be accessed on the SHIP website.²⁷ These measures are linked to national rankings and Healthy People 2020.

Recommendations

- Request that the Governor extend the Maryland's Virginia I. Jones Commission on Alzheimer's Disease and Related Disorders for an additional year through December 31, 2013, specifically to collect data, conduct research, and implement recommendations in this report. The Commission will pursue the establishment of a permanent ADRD Council through the legislative process.
- Include information and education about dementia (including best practices and guidelines on dementia care) and the needs of individuals with dementia, in the training of all professions who are involved in their care and treatment. Consider requiring continuing education about dementia as part of professional licensure, certification, and other similar renewal requirements.
- Designate Maryland Access Point as a clearing house for dementia information including, but not limited to:
 - o Serving as a starting point for those affected by newly diagnosed dementia;
 - o A source of information on Alzheimer's Disease and Related Disorders;
 - o Guidelines on dementia care;
 - o Best practices regarding dementia care;
 - o Current research on dementia causes, treatments and potential cures;
 - o Organizations offering services and education related to dementia;
 - o Dementia support groups; and
 - o Dementia treatment programs.
- Review current Maryland statutes and regulations that affect people living with dementia to promote:
 - o Their right to have as productive a life as practical;
 - o Protection from personal and financial abuse and neglect;
 - o Their safety while recognizing special patient-centered needs; and
 - o Recognition of the ethical challenges and needs of people living with dementia and their circle of care.

Appendices

Appendix A: Cognitive Assessment Instruments

The following cognitive assessment instruments were selected for inclusion in this table if they met these criteria: 1) demonstrated reliability and validity; 2) brief to administer; 3) can be administered by any member of the health care team with appropriate training.

Name of Instrument	Brief Description	Publication Data	Additional Information
Brief Cognitive Assessment Tool (BCAT)	The BCAT can be completed in approximately 10-15 minutes; differentiate among Mild Cognitive Impairment (MCI), mild dementia, and moderate dementia; contains strong verbal recall components; has a complex executive function component; and predicts Instrumental Activities of Daily Living (IADL) performance.	Mansbach WE, MacDougall EE, Rosenzweig AS. The Brief Cognitive Assessment Tool (BCAT): a new test emphasizing contextual memory, executive functions, attentional capacity, and the prediction of instrumental activities of daily living. (2012). <u>J Clin Exp Neuropsychol</u> ;34(2):183-94.	http://thebcat.com/
BCAT Short Form	The BCAT Short Form can be administered in 3-4 minutes and was designed for primary care settings in particular.	Mansbach, WE. & MacDougall, EE. Development and Validation of the short form of the Brief Cognitive Assessment Tools (BCAT-SF). (2012). <u>Aging and Mental Health</u> , Vol 16 (8), 1065-1071.	
The Montreal Cognitive Assessment (MoCA)	The MoCA is a brief cognitive screening tool (10 minutes) with high sensitivity and specificity for detecting MCI as currently conceptualized in patients performing in the normal range on the Mini Mental Status Examination.	Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. <u>J Am Geriatr</u>	http://www.mocatest.org/

		Soc. 2005 Apr;53(4):695-9. Koski, L., Xie, H., & Finch, L. (January 01, 2009). Measuring Cognition in a Geriatric Outpatient Clinic: Rasch Analysis of the Montreal Cognitive Assessment. <i>Journal of Geriatric Psychiatry and Neurology</i>, 22, 3, 151-160.	http://www.bami.us/Neuro/MiniCog.html
Mini-Cog	The Mini-Cog takes about 3 minutes to administer. The Mini-Cog is not influenced by education, culture or language. Simple, short training is required to perform the Mini-Cog accurately. The Mini-Cog adds a three-word recall test to the Clock Drawing Test, thus improving memory testing.²¹ The result obtained is that cognitive impairment is absent or present, rather than a numerical scale. This adds to its simplicity as a screening test, but means the test has no value in either monitoring disease progression or rating severity.	Borson, S., Scanlan, J.M., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. <i>International Journal of Geriatric Psychiatry</i>, 15(11), 1021-1027. Borson, S., Scanlan, J.M., Chen, P., & Ganguli, M. (2003). The Mini-Cog as a screen for dementia: Validation in a population-based sample. <i>JAGS</i>, 51(10), 1451-1454.	
St. Louis University Mental Status Examination (SLUMS)	The SLUMS takes 7-10 minutes to administer. SLUMS and MMSE have comparable sensitivities, specificities, and area under the curve in detecting dementia, but the SLUMS is possibly better at detecting mild neuro-cognitive disorder.	SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. <i>J Am Geriatric Psych</i> 14(11):900-910, November 2006.	

Memory Impairment Screen (MIS)	MIS is a 4-minute, four-item, delayed free- and cued-recall test of memory impairment that uses controlled learning to ensure attention, induce specific semantic processing, and optimize encoding specificity to improve detection of dementia. The Albert Einstein College of Medicine owns the copyright to the MIS; it makes the test available as a service to the research community but licenses it for commercial use.	Buschke, et al. <i>Neurology</i> . 1999;52:231	https://gill.crab.org/SELWBdocs/manual/form312.pdf
Rowland Universal Dementia Assessment Scale (RUDAS)	RUDAS is a short cognitive screening instrument designed to minimize the effects of cultural learning and language diversity on the assessment of baseline cognitive performance. RUDAS takes less than 4 minutes to administer to a patient and is valid across cultures, portable and easily administered by primary health care clinicians.	The Rowland Universal Dementia Assessment Scale (RUDAS) and the Folstein MMSE in a multicultural cohort of elderly persons. <i>International Psychogeriatrics</i> (2006), 18:1, 111-120. The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale. <i>International Psychogeriatrics</i> (2004), 16:1, 13-31.	http://www.fightdementia.org.au/common/files/NA_T/20110311_2011NSWR_UDASscoring_sheet.pdf

Appendix B: Maryland Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Impairment Questions

- 1) Cognitive Impairment: As a result of your or the other persons confusion or memory loss, in which of the following four areas need the most assistance?
 - a. Safety – Turn off the stove or falling
 - b. Transportation – Getting to doctors' appointments
 - c. Household Activities – Managing money, housekeeping
 - d. Personal Care – Eating or bathing
 - e. Needs Assistance, but not in those areas
 - f. Does not need assistance in any area
- 2) Cognitive Impairment: During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?
 - a. Yes
 - b. No
- 3) Cognitive Impairment: During the past 12 months, how often has confusion or memory loss interfered with your or this person's ability to work, volunteer, or engage in social activities?
 - a. Always
 - b. Usually
 - c. Sometimes
 - d. Rarely
 - e. Never
- 4) Cognitive Impairment: During the past 12 months, how often have you or this person given up household activities or chores because of confusion or memory loss that is happening more often or is getting worse?
 - a. Always
 - b. Usually
 - c. Sometimes
 - d. Rarely
 - e. Never
- 5) Cognitive Impairment: During the past 30 days, how often have you or a family member or friend provided any care or assistance for you or the other person because of confusion or memory loss?
 - a. Always
 - b. Usually
 - c. Sometimes
 - d. Rarely
 - e. Never

- 6) Cognitive Impairment: Has a health care professional ever said that you have or this person has Alzheimer's disease or some other form of dementia?
- a. Yes, Alzheimer's disease
 - b. Yes, other form of dementia, not Alzheimer's disease
 - c. No diagnosis has been given
- 7) Cognitive Impairment: Has anyone discussed with a health care professional increases in your or this person's confusion or memory loss?
- a. Yes
 - b. No
- 8) Cognitive Impairment: Have you or this person received treatment such as therapy or medications for confusion or memory loss?
- a. Yes
 - b. No
- 9) Cognitive Impairment: How many adults 18 or older in your household experienced confusion or memory loss that is happening more often or is getting worse during the past 12 months?
- a. One
 - b. Two
 - c. Three
 - d. Four or more
 - e. None
- 10) Cognitive Impairment: Of these people, please select the person who had the most recent birthday, how old is this person?
- a. Age 18-29
 - b. Age 30-39
 - c. Age 40-49
 - d. Age 50-59
 - e. Age 60-69
 - f. Age 70-79
 - g. Age 80-89
 - h. Age 90+

Appendix C: Policy Study on Alzheimer's Disease Care

In 2004, the Attorney General issued a report focused on State law and policy affecting people with Alzheimer's disease and their caregivers. The report identifies the legal and policy environment in which care is delivered.

The report is available in separate chapters and covers issues from guardianship and advance planning to driving and abuse and exploitation. The overview and chapters can be accessed at:
<http://www.oag.state.md.us/Healthpol/Alzheimers.htm>:

Overview	Cover, Table of Contents, Preface, and Summary of Recommendations
Chapter 1	Alzheimer's Disease: Assessing Its Impact and Its Policy
Chapter 2	Health Care Decisions: Patient Capacity and Proxy Decision Making
Chapter 3	Guardianship
Chapter 4	Advance Planning: Health Care Choices and Research Participation
Chapter 5	Advance Planning-Financial Matters
Chapter 6	Access to Appropriate Health Care Services - The Role of the State Medicaid Program
Chapter 7	Facility Regulation and Quality Care of AD Patients
Chapter 8	Patient Abuse and Exploitation
Chapter 9	Genetic Discrimination
Chapter 10	Driving and Other Transportation Issues

Appendix D: Resources

Alzheimer's Disease and Related Disorders Sites

http://www.alz.org	Alzheimer's Association
http://www.parkinson.org	National Parkinson Foundation
http://www.americanheart.org	Includes American Stroke Association
http://www.theaftd.org/	Association for Frontotemporal Degeneration
http://www.lbda.org	Lewy Body Dementia Association

Maryland Community-Based Services

Maryland Access Point - <http://www.marylandaccesspoint.info/>
Housing options- <http://www.mdoa.state.md.us/housing.html>
U.S. Administration on Aging, Eldercare Locator www.eldercare.gov
Alzheimer's Association Support Groups and education programs www.alz.org/maryland
Maryland Department of Aging www.aging.maryland.gov/senior.html
Retirement Living SourceBook <http://www.retirement-living.com>

Facilities' Resources

Maryland Office of Health Care Quality <http://dhmh.state.md.us/ohcq/>
(includes nursing homes, assisted living facilities, adult day programs, and in-home care)
Assisted Living in Maryland <http://www.aging.maryland.gov/documents/ALGuide.pdf>
Report on the State of Nursing Homes in Maryland 2010
<http://mhcc.dhmh.maryland.gov/ltc/Pages/longtermcare/default.aspx>
Retirement Living Sourcebook – online version <http://www.retirement-living.com>

Other Resources

Ask Medicare <http://www.medicare.gov/caregivers>

Caregiving Resources

Family Caregiver Alliance <http://www.caregiver.org>

Legal Issues

Advance Directives <http://www.oag.state.md.us/Healthpol/adirective.pdf>

Financial Issues

Taxes and Alzheimer's Disease http://www.alz.org/living_with_alzheimers_5455.asp

AARP Tax Aide Program http://assets.aarp.org/external_sites/google/overview.html

BenefitsCheckUp (Comprehensive web-based service from the National Institute on Aging to identify benefit programs for seniors with limited income and resources) <http://www.benefitscheckup.org>

Dementia and Driving Resource Center

Four six-minute films show how four families deal with different issues related to dementia and driving.
http://www.alz.org/safetycenter/we_can_help_safety_driving.asp

On-line Message Boards

On the Alzheimer's Association's national website anyone can participate in multiple message boards. These enable both caregivers and people with Alzheimer's to easily communicate with others in similar situations around the country.
http://www.alz.org/living_with_alzheimers_message_boards_lwa.asp?type=homepage

Resources in Other Languages

Spanish Language Version www.alz.org/espanol/overview-espanol.asp

Asian Portal Alzheimer's Association web site:

- [中文/Chinese](http://www.alz.org/asian/overview.asp?nL=ZH&dL=ZH)
www.alz.org/asian/overview.asp?nL=ZH&dL=ZH
- [한국어/Korean](http://www.alz.org/asian/overview.asp?nL=KO&dL=KO)
www.alz.org/asian/overview.asp?nL=KO&dL=KO

- Tiếng Việt/Vietnamese www.alz.org/asian/overview.asp?nL=VI&dL=VI
 - 日本語/Japanese
www.alz.org/asian/overview.asp?nL=JA&dL=EN
-

Free Publications

Alzheimer's Association www.alz.org

National Institute on Aging, Alzheimer's Disease Education and Referral Center
<http://www.nia.nih.gov/alzheimers>

Alzheimer's Association 24 Hour Helpline: 800.272.3900

**Appendix E: Maryland State Regulations for Health Care Facilities and Programs
Related to Alzheimer’s Disease and Related Disorders**

Program Type	COMAR	Topic
Adult Medical Day Care	10.12.04.12	Participant Rights
Adult Medical Day Care	10.12.04.13	Staff Training
Assisted Living Facility	10.07.14.35	Resident’s Rights
Assisted Living Facility	10.07.14.15	Assisted Living Manager
Assisted Living Facility	10.07.14.16	Assisted Living Managers – Training Requirements
Assisted Living Facility	10.07.14.17	Assisted Living Managers – Training, Basic Courses
Assisted Living Facility	10.07.14.18	Alternate Assisted Living Manager
Assisted Living Facility	10.07.14.19	Other Staff – Qualifications
Hospice	10.07.21.21	Patient’s Rights
Hospice	10.07.21.08	Personnel
Home Health Agencies	10.07.10.13	Patient’s Bill of Rights
Home Health Agencies	10.07.10.10	Staff Supervision and Training
Nursing Home	10.07.09	Patient’s Rights
Nursing Home	10.07.02.07-1	Employee Training on Cognitive Impairment and Mental Illness

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