

2017 Report
of the
New York State Coordinating Council
for Services Related to Alzheimer's Disease
and Other Dementias
to
Governor Andrew M. Cuomo
and the
New York State Legislature

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Section I. Background

New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Council) is established pursuant to Public Health Law § 2004-a as enacted by Chapter 58 of the Laws of 2007, Part B, § 24.

The Council was formed to facilitate interagency planning and policy-making, review specific agency initiatives for their impact on services related to the care of persons with Alzheimer's disease and other dementias (AD/D) and their families, and provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for AD/D. (See Attachment A for a list of Council members.)

The Council was charged with providing reports to the Governor and the Legislature beginning in 2009 and every two years thereafter. The reports must set forth the Council's recommendations for state policy relating to AD/D and include a review of services initiated and coordinated by public and private agencies to meet the needs of persons with AD/D and their families.

This is the fifth report by the Council. The Council has gathered advice from Council members and other experts in the field to inform the development of this report.

Council Activity

Quarterly meetings with the Council were held during 2016 and 2017, including one in-person meeting annually.

Dementia

AD/D or dementia, are umbrella terms that refer to a group of degenerative neurocognitive disorders. AD/D damages brain functioning, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive functioning), behavioral and psychiatric disorders (e.g., depression, delusion, agitation), and declines in activities of daily living (ADL) and independent functioning.¹

Alzheimer's Disease

Alzheimer's disease (AD) is the most common form of dementia; 60-80% of individuals with dementia have AD.² AD is a degenerative and ultimately fatal condition characterized by specific brain abnormalities, including amyloid plaques and neurofibrillary tangles. AD primarily occurs in adults with progressively increased frequency at older ages. Amyloid plaques and neurofibrillary tangles reflect a disruption in neuronal communication in the brain, which eventually causes cell death. There is currently no cure for AD. Available treatments that may temporarily improve or slow worsening symptoms do not alter the overall disease progression of AD. Symptoms of AD progressively worsen over time.

AD typically occurs in a progressive sequence of stages:

- According to the 2011 diagnostic guidelines for AD published by the National Institute on Aging (NIA), AD begins before the emergence of observable symptoms. The NIA identifies three stages of AD that occur on a spectrum: preclinical/presymptomatic Alzheimer's, mild cognitive impairment (MCI), and dementia due to AD.³ More information on the diagnostic guidelines can be viewed at http://www.alz.org/research/diagnostic_criteria.
- The Alzheimer's Association identifies three stages of dementia due to AD: early-stage, middle-stage, and late/final-stage.³ AD affects individuals in different ways, meaning that their presentation of the disease, symptoms they experience, and progression through these stages will be unique. These stages are a guideline. It may be difficult to place an individual in a specific stage because stages blend and may overlap.⁴

Descriptions of the stages identified by these two organizations follow:

Preclinical/Presymptomatic Alzheimer's Disease

Preclinical AD occurs before symptoms are present and an individual has measurable biomarkers for the disease. The preclinical stage can begin years, or even decades, before the symptoms of early-stage AD begin to occur. Studies suggest the possibility of subtle cognitive changes that could be detectable years before meeting the criteria for MCI.³

Mild Cognitive Impairment (MCI)

MCI is a clinical diagnosis that is determined by the judgment of a medical professional based on a medical evaluation that includes mental status screening, medical history, input from the patient and close family members, and assessment of daily activities. MCI causes cognitive changes that can affect memory, completion of tasks, reasoning, etc. "Amnesic MCI" affects memory and "non-amnesic MCI" affects thinking skills outside of memory, such as judgment.⁵ Individuals being evaluated for MCI should be screened and assessed for depression because this condition can exacerbate cognitive decline or its symptoms may mirror cognitive impairment.

The symptoms of MCI are significant enough to be noticed by the individual experiencing the change and/or by other people. However, these symptoms are typically not severe enough to interfere with daily life or independence.^{2, 5} MCI symptoms can be described as a range between the expected cognitive decline of normal aging and the more significant changes of AD/D.⁶

MCI is significant in the development and diagnosis of AD, but some individuals with MCI never develop AD. Studies indicate that as many as 15% to 20% of people over age 65 have MCI, and a review of 32 studies identified that a median of 31.5% of people with MCI progress to AD over five years.⁷ People with amnesic MCI are at greater risk of developing AD. If an individual presents with both MCI and the biomarkers for AD, there is a degree of certainty that he or she will develop AD.⁵ Limited information exists on the relationship between MCI and other dementias.

The causes of MCI are not fully understood, but there is significant evidence that MCI can be exacerbated by depression, certain medications, and/or co-occurring medical conditions, such as diabetes.⁶ For those individuals with MCI caused by treatable conditions, managing these conditions can eliminate the presence of MCI-like symptoms. This is particularly true among older adults with acute depression.⁸ Evidence indicates that people older than 70 years of age

with MCI and untreated depression are at twice the risk of developing AD than people with MCI without depression. While a correlation exists between depression, MCI, and AD/D, there is no definitive evidence that this is a causal relationship.⁹

Early-Stage Alzheimer's Disease

Individuals in the early stage of AD may have difficulty remembering recent information including places, names, events, and some personal information as the stage progresses; these symptoms are consistent with MCI progressing to AD.⁵ The Alzheimer's Association describes the following ten warning signs that may strongly indicate AD:

- memory loss that affects/disrupts daily life
- challenges in planning or solving problems
- difficulty completing familiar tasks at home, work, or at leisure
- confusion with time or place
- trouble understanding visual images and spatial relationships
- new problems with words in speaking or writing
- misplacing things and losing the ability to retrace steps
- decreased or poor judgment
- withdrawal from work or social activities
- changes in mood or behavior

When a person exhibits these warning signs, he or she should consult with a physician who will conduct tests to rule out the possibility of other reversible conditions with similar symptoms, such as delirium, depression, drug interactions, and normal pressure hydrocephalus.²

Middle-Stage Alzheimer's Disease

Individuals in the middle stage of the AD progression exhibit more pronounced symptoms of the disease. This stage generally begins with the development of more pronounced cognitive decline and difficulties. Individuals may develop behaviors such as wandering, personality changes, and increased agitation and/or aggression. Other changes in this stage include progressively increasing language difficulties, confusion, further memory loss, unstable mood, and difficulties with activities of daily living (ADLs).

Late-Stage Alzheimer's Disease

Individuals in the late stages of AD experience extremely debilitating symptoms which can be devastating for their caregivers and families. The symptoms of AD worsen over time. However, the rate of the disease's progression varies. A person with AD will live, on average, eight to ten years after diagnosis. However, in some cases, individuals with AD can live as long as 20 years.¹⁰

During the final stage of AD's progression, individuals lose awareness of recent experiences and surroundings and physical functioning. They have difficulty communicating and are vulnerable to infections such as pneumonia due to the inability to move around during late-stage Alzheimer's disease. They eventually lose the ability to swallow. Individuals in this stage will eventually require total care and dependence on caregivers. The disease will ultimately lead to death. Pneumonia is a common cause of death because impaired swallowing allows food or beverages to enter the lungs, where an infection can begin. Other common causes of death include dehydration, malnutrition and other infections.

Other Types of Dementia

Other types of dementia include vascular dementia; Lewy Body dementia (LBD); Parkinson's disease; Frontotemporal dementia (FTD); Huntington's disease; Creutzfeldt-Jakob disease (CJD); Wernicke-Korsakoff syndrome (WKS); chronic traumatic encephalitis (CTE); and human immunodeficiency virus (HIV) associated neurocognitive disorders (HAND). Causes and symptoms of the various types of dementia vary, with some of the neurodegenerative processes having common pathways.¹ In terms of clinical presentation and diagnosis, it is often difficult to distinguish between the different forms of dementia. (See Attachment B for additional information related to AD/D.)

In many cases, abnormalities characteristic of more than one type of dementia are found. This can lead to the clinical diagnosis of mixed dementia. Many researchers and experts in the field believe mixed dementia deserves more attention. According to an autopsy-based study conducted by the Rush Memory and Aging Project, more than 50% of people with AD experience a mixed presentation of dementia symptoms and pathology where abnormalities characteristic of more than one type occur concurrently.^{4, 11}

Despite evidence from autopsy studies of the high prevalence of mixed pathologies in older adults, mixed dementia is infrequently diagnosed, despite its significant impact on the development of the pathologies. The combination of two or more types of dementia-related brain changes may have a greater impact on the brain than one type alone and requires more complicated diagnostic procedures and treatments.

Mixed dementia is expressed differently in every patient. The most common form of mixed dementia exhibits the pathology of AD co-existing with blood vessel complications associated with vascular dementia. AD symptoms can also co-occur with Lewy bodies, the abnormal protein deposits characteristic of LBD. In some cases, a person may have brain changes linked to all three conditions: AD, vascular dementia, and LBD. For more information on mixed dementia; see https://www.alz.org/dementia/downloads/topicsheet_mixed.pdf.

Prevalence and Mortality

National

An estimated 5.5 million Americans live with AD; approximately 5.3 million of these individuals are over age 65.² One in nine Americans over the age of 65 has AD. This number is expected to triple by the year 2050 as the baby boom generation ages.² The rate of AD increases with age, with approximately one-third of people over age 85 are diagnosed with AD.¹² Although AD is typically diagnosed in people over age 65, it is estimated that at least 200,000 Americans between 30 to 60 years old are diagnosed with "younger/early onset."¹³ There is currently limited data addressing the prevalence and mortality of other forms of dementia.

AD is the fifth leading cause of death among individuals ages 65 and older and the sixth leading cause of death overall in the United States (US).² A research study conducted by the Centers for Disease Control and Prevention (CDC), which analyzed all resident death certificates filed from the 50 states and the District of Columbia, found an age-adjusted rate of 25.4 deaths from AD per 100,000 deaths for the year 2014; this is a 54.4% increase from the 1999 rate of 16.5 deaths per 100,000.¹⁴ However, prevalence and mortality rates for AD are not an accurate

representation of actual figures due to the lack of early detection and diagnosis and underreporting of AD on death certificates.¹⁵

Similarly, limited data related to other dementias could also contribute to their underrepresentation on death certificates. The CDC recognizes the cause of death based on what is listed on death certificates. Death certificates often list the acute illness, rather than the underlying cause of that illness, as the cause of death. For example, pneumonia may be listed as the cause of death when this acute illness resulted from complications from AD.¹⁶

The CDC, in collaboration with state health agencies, conducts the annual Behavioral Risk Factor Surveillance System (BRFSS) survey. The BRFSS has two modules related to AD: the perceived cognitive impairment and caregiver modules. National data from the perceived cognitive impairment module from the 2015 survey indicates that 11.1% Americans over the age of 45 are experiencing confusion or memory loss. Half of those who reported cognitive impairment also reported functional difficulties related to their confusion or memory loss. The Alzheimer's Association estimates that 78.1% of those with cognitive decline have not reported this condition to their health care providers.¹⁷

New York State (NYS)

The scope of AD has been difficult to project for multiple reasons including the following: many people remain undiagnosed because they do not share their symptoms with their medical providers; medical providers may be reluctant to give this diagnosis; cultural barriers may discourage individuals from seeking a diagnosis; the occurrence of delayed diagnosis and misdiagnosis; and increasingly longer lifespans.

An estimated 390,000 individuals in NYS have AD and that number is expected to increase to 460,000 by 2025. Comparable data for other dementias is not available.² The rise of the number of cases of the disease has far exceeded early expectations.

Similar to national figures, in NYS, 11.1% of individuals aged 45 and over reported confusion or memory loss in the 2015 BRFSS; 53.2% of them indicated that they have not reported the condition to their health care provider.¹⁷ Additional NYS-related BRFSS data is located at http://www.alz.org/publichealth/downloads/newyork_2015.pdf

Special Populations

The United States Department of Health and Human Services (HHS) recognizes that AD/D disproportionately impacts racial and ethnic minorities, individuals with younger onset AD/D, and those with Down syndrome. HHS has created the Task Force on Specific Populations to address the needs of these specific populations.¹⁸ The Task Force has issued a report with recommendations for these populations. This report is located at <http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf>.

Racial and Ethnic Minorities

Disparities are associated with the risk of developing of AD/D among certain racial, ethnic, and socioeconomic groups. Compared to older whites, older African Americans are two times and Hispanics are one and a half times more likely to have AD.² More research is needed to estimate the prevalence of AD/D in other racial and ethnic groups. However, a 2016 study which examined electronic health records of individuals from six different racial and ethnic groups found that dementia incidence was highest among African Americans and American Indians, intermediate among Latinos, Pacific Islanders, and whites, and lowest among Asian Americans.¹⁹

Research has shown that higher prevalence rates of AD/D in the African American and Hispanic populations are likely due to the higher number of individuals in these groups who have health conditions associated with AD/D.² These conditions include, but are not limited to, cardiovascular disease, diabetes, chronic kidney disease, and higher hemoglobin levels.^{20, 21} Increased risk of cardiovascular disease due to diabetes and heart disease also increases the risk of vascular dementia.²

In addition to lifestyle risk factors, researchers at Columbia University Medical Center and the Alzheimer's Disease Genetics Consortium have identified a variant of a gene (ABCA7) involved in cholesterol and lipid metabolism. This gene appears to be a stronger risk factor for late-onset AD in African Americans than in non-Hispanic Caucasians of European ancestry.²² Another study demonstrated that Hispanics, as compared to Caucasians, may have an earlier onset, while African Americans may have a later onset of the disease.¹² This research also found that upon initial diagnosis, African Americans and Hispanics had higher levels of cognitive impairment and dementia than non-Hispanic whites, and suggested that more research is required to determine the reason (e.g., differing cultural views regarding medical care and cognitive decline.)^{2, 20}

Women

Dementia disproportionately affects women -- both in disease prevalence and through caregiving burden. The disease contributes to growing rates of disability among women and impacts their emotional, physical, and financial well-being.

Women represent almost 66% of Americans with the disease.² Longevity alone might not be the only explanation for the higher prevalence of dementia among women.^{23, 24} Researchers are exploring this disparity by examining risk factors related to genetics (e.g., Apolipoprotein E (APOE)-ε4 genome), brain structure, disease progression, estrogen, and depression.²⁵ There is currently no definitive evidence of a causal relationship between these risk factors and AD/D. Health behavior, including cognitive development, education and physical activity throughout the lifespan might contribute to the difference in prevalence among men and women.^{26, 23, 24}

Women provide 65% of all paid and unpaid caregiving for individuals with AD/D.²⁷ Women are 2.3 times more likely than men to have provided care to someone with dementia for more than five years; this means that much of the financial, emotional, and physical burden of caregiving falls on them.^{27, 28} Women are more likely than men to reduce their hours to part-time or stop working altogether to be able to provide care. Twenty percent of female care partners have gone from working full-time to part-time, while only 3% of the men have had to do the same. This leaves women more vulnerable to being unable to support themselves later in life given a Social Security system based on number of years worked.^{23, 24, 29}

Early/Younger Onset Dementia

Early (also known as younger) onset dementia occurs when a person under the age of 65 is diagnosed with AD/D. There is limited data available on the number of Americans currently living with early onset dementia. A systematic review and meta-analysis published by the National Institutes of Health (NIH) in 2015 estimated that approximately 5.5% of individuals with dementia have an early onset form.³⁰ In 2006, the Alzheimer's Association calculated a tentative range of 200,000 to 640,000 individuals living with early onset AD/D in the US; this wide range is due, in part, to limited information about the number of individuals with early onset of dementias other than AD, and delayed diagnosis.¹³ In addition, other types of dementias mimic early onset AD including vascular dementia; Huntington's disease; Parkinson's disease; FTD; LBD; CTE; and HAND.

Many forms of early onset dementia are a type of familial disease that is inherited from a biological parent. Most cases of early onset familial AD result from inherited mutations on specific genes.³¹ Individuals with Down syndrome are at a strikingly increased risk of developing early onset AD.³² Other early onset dementias, such as Huntington's disease, FTD, and vascular dementia, also have familial forms. Huntington's disease is exclusively hereditary.³³ In addition, there are rare dementias caused by neuronal ceroid lipofuscinoses that affect children and young adults.^{34, 35}

Individuals with early onset AD/D and their caregivers face unique challenges when planning and managing the disease progression. Since AD/D is more prevalent in older individuals, obtaining an accurate diagnosis for a younger person can be difficult unless the individual has a known family history of a hereditary dementia. Delayed diagnosis and misdiagnosis limit access to research studies and mitigating interventions. Most individuals are not prepared for the negative financial impact of early onset AD/D due to job loss, cost of healthcare, difficulty obtaining Social Security Disability benefits, ineligibility for Medicare, and high cost of long-term care. Resources and community supports are limited because AD/D programs are typically designed for older adults. Individuals with early onset AD/D frequently have dependent children living at home. These factors exacerbate the financial demands and stress on their caregivers.¹³

Down Syndrome

Individuals with Down syndrome, an intellectual and developmental disability (ID/DD), are at increased risk for developing AD, particularly the early onset form of the disease, due to the accelerated aging process experienced by this population. These individuals have a partial or full third copy of the 21st chromosome. The 21st chromosome carries genes that are involved in the aging process and in producing the proteins that contribute to the development of AD. The properties of this chromosome set make AD a more acute concern for this population.³⁶

Most people with Down syndrome will develop significant levels of beta-amyloid plaques and tau tangles in their brains by the age of 40. According to the National Down Syndrome Disease Society, "Alzheimer's disease is not inevitable in people with Down syndrome. While all people with Down syndrome are at risk, many adults with Down syndrome will not manifest the changes of AD in their lifetime." It is estimated that about 30% of people with Down syndrome have AD in their 50s, and this number rises to 50% when they reach their 60s.³⁷

Although most individuals with Down syndrome develop the pathology of AD, not all exhibit the typical symptoms and decline associated with the disease. Researchers are focusing on individuals with Down syndrome who do not develop AD in order to identify differences and

protective qualities.³⁸ For this population, cognitive decline occurs more rapidly and can be aggressive, making early diagnosis crucial to providing better support.³⁹ Individuals with Down syndrome are more prone to co-occurring conditions such as sensory loss; hypothyroidism; obstructive sleep apnea; osteoarthritis; atlantoaxial instability; osteoporosis; and celiac disease. The presence of multiple co-occurring conditions makes diagnosis of and treatment for this population difficult because many dementia symptoms are associated with other conditions.³⁸

Due to the unique presentation of AD in individuals with Down syndrome, this population requires specialized care from formal and informal caregivers.⁴⁰ The National Task Group on Intellectual Disabilities and Dementia Practices recommends specific caregiver training, the use of respite services, environmental modifications, and collaboration with service agencies.³⁹ More information on the connection of Down syndrome and AD can be found at:

<http://www.ndss.org/Resources/Aging-Matters>, <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf> and <http://aadmd.org/NTG>.

Risk Factors

There currently is no exact known cause of AD. Research to understand the biological origins of the disease is critically needed. However, researchers have discovered several risk factors associated with AD: older age, family history and heredity, and lifestyle.

Old age is the most significant risk factor for AD. Three percent of individuals between the ages of 65-74, 17% of individuals between the ages 75-84, and 32% of individuals age 85 or older have AD.²

Genetics research suggests that certain combinations of APOE ϵ 2, ϵ 3, or ϵ 4 genes, inherited from both parents, increase an individual's risk of developing AD.^{2, 12, 41} This gene is responsible for providing the blueprint for a protein that transports cholesterol through the blood stream. Researchers estimate that as many as 67% of individuals with AD have at least one copy of APOE- ϵ 4. Research also supports the conclusion that mutations of several specific genes cause AD/D.¹²

Researchers are exploring the influence of lifestyle choices and health conditions on AD. For example:

- Research supports the importance of cardiovascular health, citing the high rates of AD in individuals with cardiovascular disease. Risk factors for cardiovascular disease include high cholesterol, obesity, diabetes, lack of physical activity, poor diet, and smoking.⁴²
- Research has supported the hypothesis that a higher level of education, which may increase or strengthen neural pathways, lowers the risk for, or slows the progression of, AD by creating a "cognitive reserve."⁴³ Other researchers believe the role of education is less important to brain function and explain this connection by the impact lower socioeconomic status has on access to medical care.⁴⁴
- Individuals with head injuries or moderate to severe traumatic brain injury (TBI) are at an increased risk for developing AD/D.^{2, 45}

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring AD/D.⁴⁶ This study compared two generations, one born in 1915 and the other in 1905. Those born in 1915 scored higher on two different cognitive tests at age 95

than those born in 1905 did at age 93. The only major differences found between these two groups were that the 1915 cohort had better diets and living conditions, including access to health care through a national health care system, higher incomes, and better access to housing and nursing care.

This research suggests that healthier individuals are less likely to have some of the risk factors associated with AD/D, and will therefore be less likely to develop the disease. A similar study in England and Wales compared two generations of randomly selected individuals age 65 and older in the same geographic areas.⁴⁷ The rate of AD/D in this study dropped 25% in the second generation studied. Individuals in the later generation presented reduced cardiovascular risk factors and were better educated, emphasizing the influence of education and health in the development of AD/D.

Further research regarding risk factors is essential to better understand causal relationships and to improve opportunities for the prevention of AD/D. Based on known risk factors, individuals can pursue many preventative life style changes to potentially lower their risk of developing AD/D. These strategies include:

- Exercise/physical activity – reduces inflammation, encourages generation of stem cells, helps maintain healthy weight, reduces stress and risk of many chronic conditions.
- Sleep – deep sleep is when the brain clears excess amyloid – target 7-8 hours per night.
- Diet – Mediterranean diet has been shown to have multiple benefits, and other approaches (i.e., increasing fruit and vegetable intake) have been shown to reduce inflammation and reduce risk of many chronic conditions.
- Keep moving – not just physically but intellectually and socially. Learning something new builds new synapses in the brain – an essential component of an active functioning brain.
- Manage stress – chronic increased stress produces toxic brain chemicals thought to accelerate dementia symptoms. Stress reducing and managing activity like exercise, meditation help reduce and control those chemicals.

Identification and Diagnosis

The NIA's 2011 diagnostic guidelines encourage the early detection of AD/D by recognizing the preclinical/presymptomatic stage of the disease.⁴⁸ Biomarker tests have the potential to identify changes 20 years before noticeable cognitive decline at the preclinical/presymptomatic stage and these tests are a possible future method of detecting AD/D.^{2, 48} A biomarker is a substance found in the body that can be measured to detect the presence, absence, or risk of a disease (e.g., beta-amyloids and tau in cerebrospinal fluid and certain proteins and/or mutations in blood tests).

Another form of biomarker analysis involves brain imaging technology. Magnetic resonance imaging (MRI) and computed tomography (CT) scans enable brain structural abnormalities, including tumors and regional brain shrinkage, to be detected. Positron emission tomography (PET) scans involve a tracer molecule injected into the blood that detects the abnormal presence of a specific pathological protein (amyloid or tau) in the brain or identifies brain regions with abnormal metabolic activity.

Combinations of these diagnostic methods may be used to distinguish AD from other forms of dementia with more precision. These new biomarker analyses may eventually enable definitive AD/D diagnoses to be made in the clinical setting.

AD/D cognitive screening tools are assessments that can determine a person's cognitive abilities, detect impairments, track functional/ADL decline, and monitor progression of MCI and AD/D. Cognitive screening tools alone do not provide enough information for formal diagnosis, but support the need for further, more extensive assessment and evaluation for diagnostic purposes. The Alzheimer's Association, the NIH, and Centers for Medicare and Medicaid Services (CMS) have recommended validated tools that are applicable in a range of settings. For example, these tools may be used in primary care offices and administered during annual physicals or used by other health and clinical professionals.⁴⁹ More than 40 screening tools are utilized to assess cognition and identify potential impairments.⁵⁰ Many of the recommended cognitive screening tools are easily accessed, implemented, and free to administer; however, they should be used only by those persons who have reason to know that they are competent to do so.

Additional information on the CMS/NIH recommendations is located at <http://aspe.hhs.gov/daltcp/napa/101512/Mtg6-Slides1.pdf>.

Additional information on the Alzheimer's Association's recommendations is located at http://www.alz.org/professionals_and_researchers_14899.asp or http://www.alz.org/documents_custom/The%20Cognitive%20Assessment%20Toolkit%20Copy_v1.pdf.

Additional information on assessing cognitive impairment is located at <https://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients> and <http://www.alz.org/health-care-professionals/cognitive-tests-patient-assessment.asp>.

Early Detection

NYSDOH, in addition to the *National Plan to Address Alzheimer's Disease*, the Alzheimer's Association, and *The Healthy Brain Initiative: the Public Health Road Map for State and National Partnership, 2013-2018* (Public Health Road Map), issued by the CDC and the Alzheimer's Association, recommend early detection of AD/D.⁵¹ Early detection is important for the individual with AD/D for a number of reasons including, but not limited to: accessing support services, planning and preparing for the future while they still have the capacity to do so, accessing treatments, and participating in clinical trials.²

Support services, including support groups, care consultation, and educational programs help individuals with AD/D connect with peers, and increase knowledge of the disease, caregiving options, and community resources.⁵² Individuals diagnosed with early-stage AD/D have the opportunity to engage in financial and advanced care planning and to determine and clearly express their wishes for the future.² Without such directives, families must make decisions based on what they believe the person would want. Making the decision to withhold or withdraw treatment is difficult, often leaving caregivers with a sense of guilt.⁵³

Early detection of AD/D allows for more effective management of some symptoms, and the overall advancement of other symptoms can possibly be slowed with medication. With early detection, other conditions can be ruled out or treated including depression, abnormal thyroid function, Wernicke encephalopathy, and vitamin B12 deficiencies which can intensify MCI.³³ In addition, other conditions mimic AD/D and may be reversible (e.g., normal pressure hydrocephalus and delirium).

Early detection is important and necessary for finding more effective treatments and developing prevention strategies.² Researchers are exploring early detection through biomarkers and genetic testing during the preclinical stage, before signs and symptoms appear.⁵⁴ Early detection provides individuals with the opportunity to participate in clinical trials that could be beneficial for treating or slowing AD/D in its early stages.

Barriers to early detection include the social stigma associated with AD/D and denial of observed changes and symptoms.⁵⁵ Social stigma persists despite the many attempts to reduce it. Strategies to overcome this barrier include educating the public on the disease and its progression, the benefits of early detection, and the impact of cultural norms on its diagnosis and treatment.

Research Update

Prevention

Research is a critical component of finding a method to prevent or cure AD/D and, given the growing number of individuals diagnosed with AD/D, time is of vital importance. The focus is on the prevention of AD/D and treatment in early stages, as research that has attempted to intervene in the later/clinical stages has been unsuccessful at changing the course of the disease. Currently, there are no clear prevention strategies for AD/D. However, there are steps that can be taken to recognize and mitigate risk factors.

The NIH report *Researching for a Cure: Alzheimer's Disease and Related Dementias Research at NIH Bypass Budget Proposal for Fiscal Year 2017* suggests that some of the most promising treatments under current investigation may be those focused on prevention by mitigating risk factors. Prevention strategies being studied focus on addressing risk factors such as cardiovascular health, physical activity, emotional well-being, intellectual stimulation, and social connections. Research suggests that improving an individual's vascular health has the potential to affect the development of AD/D.⁵⁴ Several unique and promising prevention research trials are exploring gene therapies and the influence of the endocrine system on preventing AD/D.

Researchers have been exploring ways to prevent or delay the build-up of two proteins: beta-amyloid and Tau. Build-up of beta-amyloid in the brain is associated with a disruption in cell communication. Beta-amyloid can be reduced by inhibiting the cleavage process that generates this small protein from a larger precursor. Inhibitors of the two cleaving enzymes involved in this process, BACE-1 and gamma-secretase, are among the strategies being tested to prevent or delay the onset of AD. Ongoing clinical trials are also testing whether antibodies to beta-amyloid can reduce the accumulation of beta-amyloid plaque in the brains of individuals to reduce, delay, or prevent symptoms.⁵⁴ The recent focus in these "amyloid vaccine" trials have been on very early intervention whereby the antibodies (or other anti-amyloid treatments) are administered some years before clinical symptoms arise. The individuals in these trials are selected because they are known to be at risk for AD due to genetic mutation or the presence of early amyloid deposits in the brain detected by neuroimaging.

Tau is a second protein implicated in AD and related "tauopathies," which is found in neurons where it normally facilitates communication of signals within the cell and between different neurons. In certain neurodegenerative diseases, including AD, these normal functions of tau become corrupted leading to the aggregation of tau into forms that are considered toxic to

neurons. Clinical trials are anticipated or underway to use a tau antibody vaccine or other approaches to reduce tau levels in AD. Most recently, a widening range of therapeutic approaches are in pre-clinical and clinical development to target other brain abnormalities in AD — inflammation and “cell waste recycling” to name a few. AD is increasingly recognized as a multifactorial disease that may require multiple treatment strategies to address optimally, including therapies targeting other brain processes besides tau or amyloid.

Treatments

Although there is no cure for AD/D, research focuses on non-pharmacological and pharmacological interventions that can decrease or slow symptoms associated with AD/D.

Non-pharmacological

Behavioral symptoms commonly associated with AD/D and early losses in functional independence are not always directly attributable to the underlying physiology of the disease. Precipitating factors of behavioral or psychological symptoms associated with AD/D must be understood, especially if symptoms are new onset. Careful history and assessment may reveal an underlying medical cause for behavioral symptoms which can be addressed and treated by a medical provider. Behavioral and psychological symptoms exhibited by individuals with AD/D should be fully assessed, given that communication with the patient is often difficult. Behavioral changes, including aggression, are often responses to unmet needs such as thirst, constipation, need to use the bathroom, fatigue, hunger, pain, or secondary symptoms.^{56, 57}

If there is no apparent underlying medical cause, basic and/or non-pharmacological approaches to AD/D care should be the first consideration for all medical and support personnel and formal or informal caregivers. Evidence shows that individuals living with AD/D are influenced significantly by fatigue, changes in routine, overwhelming sensory input, the need to integrate and respond to a demanding and busy environment and/or the misperceptions about that environment that are associated with disease-associated perceptual losses.⁵⁸ Often these situations can be prevented or reversed by focusing on caregiver approach and the environment of care as a first priority. This may avoid the use of medication and the risk for adverse events related to those medications.

Non-pharmaceutical interventions may require creativity and trial and error, but there are a number of suggested interventions that should be considered to alleviate behavioral symptoms for individuals with AD/D. Shortening activities (90 minutes or less), providing rest periods, and interspersing high stimulus activities with quieter moments will combat fatigue and mitigate adverse reactions. Caregivers can minimize an individual with AD/D's reactions to change by creating clear and consistent daily routines, minimizing environmental changes and unnecessary travel, and/or maintaining consistent caregivers and caregiver routines. Awareness of an individual with AD/D's response to large groups and noise and the importance of ensuring appropriately functioning glasses and hearing aids further reduce inappropriate sensory input. In addition, consistent use of a non-confrontational approach by caregivers that integrates positive use of body language and verbal instructions promotes positive understanding by the individual with AD/D.

Additional non-pharmacological treatments of AD/D include music therapy, reminiscence therapy, physical exercise, cognitive training, and collaborative care.^{2, 25, 59} The goal of these interventions is to maximize cognitive functioning and the individual's ability to perform ADLs, and/or enhance overall quality of life throughout the disease process. Best practices for AD/D

care include care models that are team-based and coordinate care across settings, including medical.⁵⁹

Pharmacological

Current medications address the symptoms of AD/D only, making memory appear clearer, reducing confusion and enhancing cognitive skills, such as the ability to reason. These medications also alter the chemicals in the brain required for nerve cells to function, if only temporarily in the disease course. These pharmacological treatments do not stop the progression of the disease or offer a cure to AD/D.

There are two types of medications available for use with AD/D. Cholinesterase inhibitors are medications often used to treat mild to moderate symptoms of AD; these medications include Donepezil (Aricept), Rivastigmine (Exelon), and Galantamine (Razadyne). Memantine (Namenda), the second type of medication available, is used for moderate to severe AD and is believed to mitigate glutamate levels in the brain that may lead to brain cell death.² Namzaric, a combination drug which is a branded generic, has been approved to treat moderate to severe AD and combines memantine hydrochloride extended-release (Namenda) and donepezil hydrochloride (Aricept), both of which are often prescribed in tandem.

Another avenue being explored by pharmaceutical companies is the development of drugs that rid the brain of amyloid or tau, as discussed in a previous section. However, at this time clinical trials of anti-amyloid treatment have not yielded positive results.^{54, 59} In addition to the new approaches to therapy being explored, as mentioned above, another alternative intervention under exploration by the NIH is testing existing drugs originally developed to address other diseases but have pharmacological properties suggesting that they may yield positive results for AD/D.²⁵ More information on medications can be found at <http://www.nia.nih.gov/Alzheimers/publication/Alzheimers-disease-medications-fact-sheet>.

Behavior management using non-pharmacological approaches should be the first goal of treatment; however, avoiding medication use may not be sufficient for every individual. Pharmaceutical therapies are available for addressing behavior symptoms that may occur with AD/D, treating pre-existing mental health disorders and managing co-existing chronic conditions. Psychotropic medication (e.g., anti-depressants, anxiolytics, and antipsychotics) can be used to address behavioral and emotional symptoms including, but not limited to, agitation, aggression, hallucinations, and delusions. However, none of these medications were developed for use in managing the behaviors associated with dementia and there are health risks associated with the “off-label” use of some of these medications in individuals with AD/D.^{2, 61}

Therefore, medications should be used judiciously for a short period of time and frequent assessment is important to ensure that the benefits of using these drugs outweigh the risks. A variety of agents with novel mechanisms of action compared to current anti-psychotics are under development to treat behavioral symptoms of AD/D, which are often a greater management problem for caregivers than memory loss. For example, a new class of antipsychotic agent, pimavanserin (Nuplazid), which is currently FDA approved only for Parkinson’s dementia with psychosis, is being evaluated for use to treat psychosis, agitation, and aggression in AD/D.

Individuals living with AD/D frequently have one or multiple chronic conditions that also need to be addressed by their primary care providers. Pharmacological treatment of any co-existing medical condition is likely to improve the effectiveness of AD/D treatment approach.⁵⁴

Palliative Care

Palliative care should be initiated from the time of diagnosis and may have a substantial impact on improving the quality of life for the individual with AD/D as well as the caregiver.⁵³ Palliative, or comfort care, aims to keep an individual comfortable and pain-free until life ends naturally.⁶²

Once the decision is made to pursue palliative care, clinicians should discuss treatment options with caregivers for the inevitable medical decline that will follow. Despite available treatments, there is currently no cure for AD/D, and the disease results in death.⁵³ Most individuals with late-stage AD/D are at an increased risk of aspiration pneumonia, development of pressure sores, recurrent urinary tract infections and possible urosepsis, poor oral intake affecting weight and nutrition, constipation, and delirium. Advanced care decisions should respect the person's values and wishes while maintaining comfort and dignity.⁶²

More information on palliative care can be found at http://caringkindnyc.org/_pdf/CaringKind-PalliativeCareGuidelines.pdf.

Caregiver Burden

Informal Caregivers

Millions of Americans are informal caregivers who provide unpaid care for individuals with AD/D. Nationally, informal caregivers for individuals with AD/D provide an estimated 18.2 billion hours of unpaid care.² The Alzheimer's Association reports that caregivers' unpaid care was valued at \$230 billion in 2016. This is nearly equal to the estimated cost of direct medical and long term care for AD/D.² In NYS, over one million caregivers provided 1.38 billion hours of unpaid care for individuals with AD/D, valued at \$14.69 billion.² Studies have found as many as 25% of individuals cared for by "sandwich generation caregivers" (caregivers who care for both an aging person and a dependent child) are individuals with AD/D.²

The role of an informal caregiver for a person with AD/D is intensely stressful. Caring for individuals with AD, especially in the later stages of the disease, can be extremely demanding. The chronic stressors of caregiving often affect the caregiver's financial stability, physical health, and emotional well-being. Caregivers are tasked with a wide range of responsibilities including, but not limited to, assisting with ADLs, advocacy, managing physical and behavioral symptoms, caring for other family members, identifying support services, paying for services, and, eventually, providing total care for the person with AD/D.

Most of the contemporary research indicates that the burden of caring for an individual with AD/D disproportionately affects women and minorities.⁶³ Women represent 65% of caregivers of individuals with AD and report taking on a higher burden of caregiving responsibilities. According to the *2017 Alzheimer's Association Facts and Figures* and a study conducted by AARP, Hispanic and African American caregivers report more time caregiving and higher intensity of caregiving burden compared to non-Hispanic white caregivers.^{2, 64} Other research identifies non-Hispanic white caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.⁶⁵

Research also demonstrates that providing caregivers with an array of support services alleviates caregiver burden, enhances the quality of life for both the individual with AD and the caregiver, delays institutional placement, and lowers healthcare costs. The most effective caregiver support strategies strive to improve the well-being of caregivers and consequently the outcomes for individuals with AD/D.^{66, 67, 68} The Alzheimer's Association recommends case management, psychoeducation, counseling, support groups, respite, psychotherapeutic approaches, multicomponent approaches, and training for caregivers of individuals with AD/D. Caregivers who receive support services can stave off negative impacts on their own health.⁶⁷

Formal Caregivers

Formal caregivers are paid staff who provide in-home or residential care. These caregivers often experience high levels of stress, leading to high turnover rates in this field. A 2005 study, which examined attitudes of direct care workers serving people with AD/D, found that stress levels are particularly high in facilities with specialized AD/D units.⁶⁹ Stress levels were also higher among male workers, younger workers, and staff working for less than two years.

The growing number of individuals with AD/D has created an urgent need for additional trained professional caregivers. It is important to develop effective strategies to attract and retain a more qualified workforce.⁷⁰ Workers who receive more AD/D training are more likely to have a person-centered attitude and report more job satisfaction.

Cost of Alzheimer's Disease and Other Dementias

Individuals with AD/D use a disproportionate amount of healthcare resources. A study funded by NIH found that health care costs for AD/D are greater than for any other disease. NIH reported that in the last five years of life, total health care spending for an individual with AD/D is more than \$341,651, greater than costs associated with this period from any other diseases.

The cost of health care, long-term care, and hospice services for individuals with AD/D makes dementia one of society's most costly chronic conditions.⁷² According to the *2017 Alzheimer's Association Facts and Figures*, the cost of care for Americans with AD/D is \$259 billion nationally. This includes an estimated \$131 billion covered by Medicare; \$44 billion covered by Medicaid; \$56 billion in-out-of-pocket expenses paid by individuals with AD/D and/or their caregivers; and \$28 billion covered by other sources, including private insurance and health organizations. It is also more common for a person with AD/D to be dually enrolled in Medicaid and Medicare. Twenty-seven percent of seniors with AD/D are dually enrolled, as compared to 11% of those without dementia. Average annual Medicaid payments for people with AD/D are 23 times greater than average Medicaid payments for dual enrollees who do not have this condition.²

Nationally, almost four million individuals who have AD/D also have at least one other chronic condition. These individuals are 5.5 times more likely to have six or more chronic conditions than a person without AD/D. According to the 2015 NYS BRFSS, 80% of respondents who reported subjective cognitive decline also reported having the following conditions: arthritis, asthma, chronic obstructive pulmonary disease, diabetes and/or cancer.

Other common chronic conditions associated with individuals with AD/D are heart disease, strokes, and kidney disease. The combination of AD/D and chronic health conditions complicates treatment and increases the cost of care. In 2013, 38% of Medicare beneficiaries

age 65 and older with dementia also had coronary artery disease, 37% also had diabetes, 28% also had congestive heart failure, 29% also had chronic kidney disease and 25% also had COPD.²

The average Medicare costs for seniors with AD/D and other chronic conditions are significantly higher than those individuals on Medicare who have a chronic condition without AD/D. According to a 2013 study, a senior with AD/D and diabetes costs Medicare 81% more than a senior with only diabetes. Individuals with multiple chronic conditions are more expensive to the Medicare system. This holds true for those with and without AD/D. A senior with one chronic condition and AD/D costs Medicare an average of 75% more than a senior with one chronic condition but no AD/D. This equates to \$16,775 as compared to \$9,523. Seniors with three chronic conditions and AD/D cost Medicare, on average, 25% more than a senior with three chronic conditions but no AD/D (\$27,097 compared to \$21,581).⁷³

Individuals with AD/D require more care (e.g., home care, long-term skilled nursing, etc.) than those experiencing normal aging. In a 2011 report based on data from the Medicare current beneficiary survey, 42% of individuals age 65 and older with AD/D lived in long-term care facilities as compared with 2% of individuals age 65 and older without AD/D.⁷³ A 2004 study estimated that individuals with AD/D are hospitalized two to three times more frequently than individuals of the same age without AD.^{1, 74} However, a 2013 study showed a decrease in hospital discharges for individuals with AD/D between 1999 and 2009. This could be due to increasing mortality rates for individuals with AD/D, as well as an increase in individuals with AD/D who are cared for in residential facilities rather than hospitals.⁷⁵

In addition to increased health care costs, the cost of AD/D to business and industry is substantial when considering lost wages and productivity resulting from absenteeism and the effects of presenteeism (the issue of workers being present on the job but, because of illness or other medical conditions, not fully functioning) for those caregivers able to remain in the workforce.⁷⁶ Many are forced to reduce hours or quit altogether due to their caregiving responsibilities. Loss of wages may also contribute to financial burden when an individual with AD/D needs to exit the workforce prematurely due to symptoms of AD/D, particularly early onset. More information is available at http://www.alz.org/documents_custom/2017-facts-and-figures.pdf.

The value of unpaid caregiving is also significant. Caregivers for individuals with AD/D spend an average of 92 hours per month fulfilling caregiving duties.⁷⁷ In 2016, there were 15.7 million caregivers of individuals with AD/D. Nationally, NYS has the fourth highest number of unpaid caregivers in the nation. According to data from the *2017 Alzheimer's Disease Facts and Figures*, over one million caregivers in NYS provided an estimated 1.16 billion hours of unpaid care valued at over \$14.6 billion.

Elder Justice for Individuals with AD/D

Elder justice is a broad term that, at its essence, means assuring that vulnerable older adults are protected from crime, abuse, neglect and financial exploitation. Elder justice also involves ensuring that vulnerable older adults have access to legal interventions and networks that provide or refer them to services and supports to address their needs. The Elder Justice Act (42 USCS § 3002) defines “elder justice” as follows: (A) used with respect to older individuals, collectively, means efforts to prevent, detect, treat, intervene in, and respond to elder abuse, neglect, and exploitation and to protect older individuals with diminished capacity while maximizing their autonomy and (B) used with respect to an individual who is an older individual, means the recognition of the individual's rights, including the right to be free of abuse, neglect, and exploitation.”

Abuse is a term that refers to knowingly, intentionally, or negligently acting in a manner that causes harm or a serious risk of harm to a susceptible person. Elder abuse occurs when a person is targeted due to vulnerabilities related to advanced age. This harm can be inflicted by anyone including a formal or informal caregiver, a family member, a friend, an acquaintance, a gatekeeper, or a stranger.

In NYS, elder abuse and exploitation cases referred to Adult Protective Services (APS) are tracked through the Adult Services Automation Program (ASAP.net) or APS.net in New York City. In addition, NYS has been participating with the federal government to provide statistical data to the National Adult Maltreatment Reporting System (NAMRS) since 2016.

The number of individuals suffering from elder abuse is severely underreported. According to the 2011 NYS Elder Abuse Prevalence study titled *Under the Radar: NYS Elder Abuse Prevalence Study*, for each reported case of abuse, as many as 24 cases are unreported. The most common forms of abuse are financial, emotional, physical, and neglect. While sexual abuse does occur, it is not as common as these other forms.⁷⁸ It is common for an abuser to inflict multiple types of abuse on a victim (e.g., a perpetrator is financially exploiting an elderly person, but also employs emotional and physical abuse to keep that person subservient).

Individuals with AD/D are especially susceptible to exploitation due to their difficulty recognizing, communicating, and/or defending themselves. In addition, perpetrators will exploit their cognitive impairment for personal gain at the expense of the victim. One of the most effective ways to protect an individual with AD/D from abuse is for an advocate, friend, family member, or caregiver who recognizes the warning signs to intervene or contact NYS APS for assistance.^{78, 79}

More information about recognizing elder abuse can be found at:

http://www.aoa.gov/AoA_programs/elder_rights/EA_prevention/whatisEA.aspx.

Financial Exploitation

As seen nationally, the number of financial exploitation cases in NYS is on the rise and is the most common form of elder abuse. Financial abuse is a broad term that includes, but is not limited to, the theft of money or property; coercing a person to adjust a will; using property without given permission; subjecting an individual to fraud and scams; overcharging for a service; or forging signatures. Poor cognition and increased dependence on others can create situations where the individual with AD/D is more vulnerable to this exploitation. In general, financial exploitation is difficult to prove due to underreporting and, often, lack of proof.

The gap in reporting is likely vast. The NYS Prevalence Study, which is based on an analysis of self-reports, found that only one in 44 cases of financial abuse is reported to authorities (i.e., APS or law enforcement).⁷⁸

<http://ocfs.ny.gov/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf>

Gatekeepers at banks and other financial institutions are in a unique position to recognize suspicious activity. Financial institutions and states recognize this growing problem and have developed policies and procedures to identify and address exploitation. In NYS, APS has the authority to examine bank records when indicated. The NYS Office of Children and Family Services (NYSOCFS) and Division of Financial Services (NYSDFS) have conducted numerous trainings on these topics for state and local staff as well as representatives of financial institutions.^{78, 79}

More information is available at:

<http://www.nij.gov/topics/crime/elder-abuse/pages/financial-exploitation.aspx>

http://www.preventelderabuse.org/elderabuse/fin_abuse.html

<http://ocfs.ny.gov/main/reports/Cost%20of%20Financial%20Exploitation%20Study%20FINAL%20May%202016.pdf>

Physical Abuse, Emotional Abuse, and Neglect

Individuals with AD/D are more vulnerable to abuse due to their limited ability to communicate, self-advocate, and recognize maltreatment. Correlations exist between caregiver stress and abuse. Physical abuse, emotional abuse (also referred to as psychological abuse), and neglect are the other most common forms of abuse. Physical abuse is physical force or violence that results in bodily injury, pain, or impairment. It includes assault, battery, and inappropriate restraint. Emotional abuse is the willful infliction of mental or emotional anguish by threat, humiliation, or other verbal or nonverbal conduct. Neglect is the failure of caregivers to fulfill their responsibilities to provide needed care. "Active" neglect refers to intentionally withholding care or necessities. "Passive" neglect refers to situations where caregiving is withheld as a result of illness, disability, stress, ignorance, lack of maturity, or lack of resources.

As with financial abuse, the best way to prevent physical or emotional abuse and neglect is to recognize the warning signs and intervene or contact APS.⁷⁹ NYSOCFS and NYSOFA have developed a new Gatekeeper Toolkit which is available to local APS and Offices for the Aging to provide local presentations to those in close contact with potential victims. More information is available at <http://www.preventelderabuse.org>.

Public Policy Initiatives: International and National

International

World Health Organization

The World Health Organization (WHO) recognizes AD/D as a priority condition and global public health challenge. WHO supports and encourages international efforts to address this growing issue by directing efforts to develop health and social systems; support informal care and caregivers; raise awareness and advocacy; and plan a way forward through strategic action by the international community to address the gaps in the previously mentioned areas.⁵⁸ In March

2015, WHO hosted the first Ministerial Conference on Global Action Against Dementia. The goal of this conference was to raise awareness of the socioeconomic burden of AD/D and to place AD/D high on the global health agenda.⁸⁰

National

The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships 2013-2018

The Alzheimer's Association and CDC have created *The Healthy Brain Initiative: The Public Health Road Map for the State and National Partnership* (Public Health Road Map), which seeks to increase public awareness of and action on AD/D as public health issues. The Public Health Road Map outlines recommendations related to cognitive decline and AD for state and local public health agencies and their partners. The two main objectives of the Public Health Road Map are to reduce the number of individuals who have undiagnosed AD and to reduce the number of avoidable hospitalizations due to AD. The Public Health Road Map includes recommendations in four major areas for action: monitoring and evaluating; educating and empowering the nation; developing policy and mobilizing partnerships; and assuring a competent workforce.⁵¹ The Public Health Road Map can be accessed at <http://www.alz.org/publichealth/2013-report/index.html>.

NYSDOH's Office of Health Insurance Programs' Division of Long Term Care's Bureau of Community Integration and Alzheimer's Disease leadership is participating in the development of the next Public Health Road Map which covers the period 2019 – 2024. A revised Public Health Road Map will be available in early 2018.

National Plan to Address Alzheimer's Disease

The National Alzheimer's Project Act (NAPA) was signed into law in early 2011 by President Barack Obama. NAPA requires the Secretary of HHS to create and maintain a national plan to address AD. The first *National Plan to Address Alzheimer's Disease* (National Plan) was released in May 2012, with the most recent update published in 2015. The National Plan coordinates federal research on AD; works to improve prevention, diagnosis, treatment, and care for AD, including health care services and long-term services and supports; and coordinates internationally on the fight against AD.⁶¹ The most recent version of the National Plan can be accessed at <http://aspe.hhs.gov/daltcp/napa/NatlPlan2015.pdf>.

National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers

The National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, convened a two-day meeting sponsored by the HHS and the Foundation at the National Institutes of Health on October 16-17, 2017, in Bethesda, MD.

The goal of this Summit was to identify what is known and what needs to be known to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The Summit was focused on research needed to improve quality of care and outcomes across care settings, including quality of life and the actual experience of persons with dementia and their caregivers (including family members, neighbors, friends, fictive kin, and formal, paid caregivers).

Information and video footage from the Summit can be found at:
<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>

The Science of Caregiving: Bringing Voices Together Summit

The National Institute of Nursing Research and partners convened *The Science of Caregiving: Bringing Voices Together* Summit on August 7-8, 2017. Caregiving experts convened at the NIH to gather insight and perspectives across the spectrum of caregiving, including the importance of caregiving across the lifespan as well as current and future directions for research to improve the health of patients and caregivers. Information and video footage from the summit can be found at:

<https://www.ninr.nih.gov/newsandinformation/newsandnotes/caregiving-summit-video>

Related Public Policy Initiatives: New York State

New York State Department of Health

The 2015-2016 NYS budget included Governor Cuomo's proposal for increased funding for services directed to individuals with AD/D and their caregivers. The budget dedicated \$26,426,000 for AD/D programs, the largest single state investment of its kind. With these funds, the NYSDOH has expanded and strengthened AD/D programs and developed new initiatives using evidenced-based strategies to support caregivers of and individuals with AD/D.

The initiative is based on evidence that demonstrates that providing an array of caregiver services in the community helps avoid unnecessary hospitalizations and emergency room visits, delays nursing home placement, and improves caregiver burden and mental health outcomes.

This initiative, one of many NYSDOH Medicaid Redesign Team (MRT) projects, addresses a myriad of needs of this community. A focus on improving early detection, quality of life, and quality of care includes palliative care, education of health care providers, and reduction unnecessary emergency department visits, hospitalizations, and nursing home placements. The investment has been accomplished primarily through competitive procurements.

Four major caregiver support initiatives have resulted from the increased state appropriation. The goal of these initiatives is to expand the safety net for caregivers of individuals with AD/D by recognizing and addressing the need for day-to-day caregiver supports and stress reduction. Benefits of these services include improved health and quality of life for both individuals with AD/D and their caregivers, reduced hospitalizations, and increased ability to maintain individuals with AD/D in the community. Programs which serve similar geographic regions collaborate with and reciprocally refer individuals with AD/D and their caregivers to each other to ensure the receipt of appropriate diagnosis, treatment, and support services.

More information on these initiatives, including an interactive NYS map listing county-specific services can be found at:

<https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/county/>

The statewide initiative has been featured both in *Newsweek*:

<http://www.newsweek.com/2017/06/09/rural-america-alzheimers-disease-states-help-619027.html> and the *New York Times*:
<https://www.nytimes.com/2017/08/04/health/caregiving-alzheimers-isolation.html?mcubz=1>

A description of each component of the initiative follows:

The Regional Caregiver Support Initiative

The Regional Caregiver Support Initiative provides \$15 million to fund a network of 10 organizations across NYS which deliver programs that support family caregivers who care for New Yorkers living with AD/D across NYS. These organizations each receive \$1.5 million annually to provide caregiver support services.

This statewide program provides:

- Care and family consultations
- Support groups
- Education and training programs
- Respite
- One or more additional caregiver support services including access services, caregiver companions, care support teams, caregiver wellness programs and joint enrichment opportunities

The Caregiver Support Initiative for Underserved Communities

The Caregiver Support Initiative for Underserved Communities provides \$1.5 million to 15 community-based organizations to provide caregiver support services in targeted traditionally underserved communities. These organizations each receive \$100,000 annually to reach caregivers of individuals with AD/D, either or both of whom are members of underserved communities. The programs recognize and address the need for culturally competent support strategies. Program models are designed to serve individuals who may experience challenges related to geographic isolation; English as a second language; minority or ethnic group membership; sexual orientation and gender identity; low socioeconomic status; or cultural isolation.

These programs offer:

- Extensive outreach to target communities
- Caregiver assessment and referrals
- Support groups
- Education and training
- Caregiver wellness
- Joint enrichment
- Respite

Centers of Excellence for Alzheimer's Disease

The Centers of Excellence for Alzheimer's Disease (CEAD) initiative provides \$4.7 million to a network of 10 medical centers and teaching hospitals, recognized nationally and by NYS as experts in the diagnosis and care of individuals living with Alzheimer's disease or other

dementias (AD/D). Each organization receives \$470,000 annually. The CEADs are at the forefront of research and clinical trials seeking effective treatments and a cure for AD/D.

The statewide CEAD program provides:

- Interdisciplinary and comprehensive medical services for the diagnosis of AD/D
- Coordinated treatment and care management for individuals living with AD/D
- Linkages to community-based services for patients and caregivers
- Expert training for physicians, health care professionals and students on the detection, diagnosis and management of AD/D
- Support for primary care providers to promote cognitive screening in community-based settings.
- Information on and access to current research and clinical trials.
- Resources to increase public awareness of AD/D and the importance of early screening

Alzheimer's Disease Community Assistance Program

The Alzheimer's Association, New York State Coalition is a not-for-profit organization that coordinates the Alzheimer's Disease Community Assistance Program (AlzCAP) in every region of NYS. The \$4.9 million statewide program, provided through eight subcontracts, delivers a comprehensive array of community-based services for individuals with AD/D and their caregivers. Each subcontractor receives between \$505,680 and \$1,148,400.

This statewide program provides:

- Professional care consultations conducted in-person, by phone or virtually depending on the person's needs
- Training and education for both caregivers and individuals with AD/D
- In-person and virtual support groups for caregivers and individuals with AD/D
- A 24-hour Helpline available in more than 200 languages
- Community education, awareness and outreach
- Training for professional caregivers, faith leaders and gatekeepers to create dementia-friendly and well-informed communities

Although not a direct replication, these initiatives reflect the evidence developed by Dr. Mary Mittelman at New York University and others.^{66, 67} Dr. Mittelman's research studies provide evidence that caregiver support and counseling can delay nursing home placement by a median of 1.5 years.⁶⁶ Dr. Mittelman describes the key factors of her successful approach in *Health Affairs*. In the article, she explains, "The intervention consisted of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling."⁶⁸ Dr. Mittelman's newer research demonstrates that the New York University Caregiver Intervention can result in 17% fewer AD/D deaths in nursing homes, and up to \$178.9 million in Medicaid savings over a 15-year period.⁸¹

A comprehensive, statewide, multi-level evaluation of the Alzheimer's Disease Caregiver Support Initiative is being carried out by researchers at the School of Public Health, University of Albany, State University of New York. This evaluation will examine the process and outcomes with an emphasis on how NYS has changed as a result.

In addition to documenting the effect of these expanded caregiver support services on a variety of patient, caregiver, and health system outcomes, the evaluation will significantly contribute to

the national evidence base related to Alzheimer's disease support services, and generate important evidence for future programmatic and policy decisions at both the state and national levels.

Other NYSDOH Initiatives

The Alzheimer's Workplace Alliance

The Alzheimer's Workplace Alliance (Alliance) is affiliated with the Alzheimer's Association. The Alliance raises awareness about the disease and the importance of early detection while providing help to those who are balancing work and caregiving responsibilities. The Alliance's work is a cost saving measure that supports employee well-being, work-life balance and retention.

The NYSDOH has joined the Alliance to provide critical information and support to employees across NYS who are caring for someone with AD/D. Due to the demands of caregiving, many NYSDOH employees face work-related challenges-depleting their time off accruals, needing to shorten their work day, or leaving employment entirely.

Public Health Live

Educational webcasts are produced on current evidenced-based information and interventions through a partnership between the NYSDOH and the University at Albany School of Public Health known as *Public Health Live!* Continuing education credits for viewing webcasts are available for professionals including physicians, nurses and social workers. Webcasts related to AD/D include:

- *Clinical and Ethical Indications for Cognitive Impairment Screening in Primary Care*
David Hoffman, D.P.S., C.C.E, Director, Bureau Community Integration and Alzheimer's Disease, NYSDOH
- *Alzheimer's Disease and Advance Directives: A Primer for Primary Care Physicians*
Wayne Shelton, PhD, MSW, Professor of Medicine and Bioethics, Alden March Bioethics Institute, Albany Medical College
Kevin Costello, MD, Assistant Professor of Medicine and Attending, Department of Medicine, Albany Medical College
- *Psychiatric Manifestations of Parkinson's Disease and Its Treatment*
Guy J. Swartz, MD, Assistant Clinical Professor of Neurology, Stony Brook University Medical Center
- *The Clinical and Cultural Challenges of Dementia in African American and Hispanic Communities*
Jennifer J. Manly, PhD Associate Professor, Department of Neurology, Columbia University
Teresa Santos, Center for the Aging Brain and the Memory Disorder Clinic, Montefiore Medical Center
- *Falls and their Prevention: A Geriatric and Pharmacological Imperative*

Bruce R. Troen, MD, Chief of the Division of Geriatrics and Palliative Medicine, Jacobs School of Medicine and Biomedical Sciences, SUNY Buffalo
Michael Brodeur, PharmD, Associate Professor of Pharmacy Practice, Albany College of Pharmacy and Health Sciences.

- *Determining Caregiver Needs and Well Being*
Elizabeth Smith-Boivin, MSHSA, Executive Director/CEO, Alzheimer's Association, NENY Chapter

New York State Office for the Aging (NYSOFA)

NYSOFA's mission is to help older New Yorkers be as independent as possible for as long as possible through advocacy, development and delivery of person-centered, consumer-oriented, and cost-effective policies, programs and services which support and empower older adults and their families, in partnership with the network of public and private organizations which serve them. These partnerships with community based organizations and state agencies result in beneficial outcomes for older adults in NYS, including individuals with AD/D and their caregivers.

Informal caregivers are an invaluable resource to their loved ones and to the health care system. Two federally funded programs administered by NYSOFA directly serve caregivers:

- The National Family Caregiver Support Act Title III, Part E, was established in the 2000 reauthorization of the Older American's Act (OAA) to address the needs of the growing number of informal caregivers. The National Family Caregiver Support Program assists informal caregivers - spouses, adult children, other family members, friends and neighbors - in their efforts to care for older persons who need help with everyday tasks. Services provided include:
 - information about available services and assistance in gaining access to services; individual counseling, support groups, and/or training to assist caregivers in the areas of health, nutrition and financial literacy and to make decisions and solve problems relating to their caregiver roles;
 - respite to temporarily relieve caregivers from their responsibilities by providing a short-term break through home care, overnight care in an adult home or nursing home, adult day care and other community-based care; and
 - supplemental services to complement the care provided by the caregiver, such as a Personal Emergency Response System, assistive technology, home modifications, home delivered meals, and transportation.
- The Lifespan Respite Program assists family caregivers to gain access to needed respite services, trains and recruits respite workers and volunteers, and enhances coordinated systems of community-based services for individual of all ages. The NYS Caregiving and Respite Coalition (NYSCRC) is helping to build volunteer respite capacity using the Respite Education and Support Tools (REST) model.

To date, NYSOFA and NYSCRC have expanded the REST model to include trainers within the past year. Additionally, through the Lifespan Respite Grant, mini-grants were

awarded to expand and enhance volunteer respite by inviting organizations to submit applications for replication and growth of successful volunteer respite programs in New York, as well as to offer REST training to meet training needs of respite volunteers.

NYSOFA makes available an online resource directory that includes respite and support services which provide relief for caregivers. The NY Connects Resource Directory includes an ongoing updating process. Additionally, the NYSCRC web site provides information and links to the NY Connects Resource Directory (<http://www.nyscrc.org/ny-connects>).

The NY Connects No Wrong Door screening tool now includes three questions for screening for memory problems that have been incorporated into the NY Connects screening process. These questions are used to refer to dementia-related services. NY Connects also can assist individuals with Medicaid applications, and referrals for other long-term services and supports.

AAAs contract with 67 Social Adult Day Service (SADS) programs utilizing a variety of federal and state funding. This service provides a safe, stimulating and affirming environment for individuals with AD/D, with many programs offering evidence based creative art therapies. The caregivers benefit from respite and caregiver support services. Sixteen SADS programs were directly funded by NYSOFA during State Fiscal Year (SFY) 2016-17 and 1,099 caregivers received services. Approximately seven of 10 participants who enroll in a program will continue for six months or longer, with an average length of stay of 41 months.

Elder Justice activities include:

- Legal assistance funded under the OAA addresses legal issues related to income, health care, nutrition, housing, utilities, protective services, guardianship avoidance, abuse, neglect, exploitation and age discrimination.
- The Office of Court Administration (OCA) convened a NYS Elder Justice Committee. This group, with NYSOFA's participation, has continued to collaborate to improve the way the court system addresses cases involving our state's older population.
- The Remote Access to Temporary Orders of Protection Program has been implemented in 15 counties statewide and new counties are being added each month. The Office of the Statewide Coordinating Judge for Family Violence Cases' goal is to make this program available in all 62 counties across New York State within the next two years. It allows for filing of a family offense petition to be done on-line and initial ex parte hearing can be held via Skype. This is a benefit to older adults who are not able to attend in person.

NYSOFA also operates adult abuse programs that protect and provide services to vulnerable adults, including individuals with AD/D:

- NYSOFA is working with NYS Office of Victim Services to expand interventions in a statewide project which provides a resource for professionals serving individuals within the target population (adults aged 60 and older) who show signs of elder abuse, including financial exploitation.
- NYSOFA operates adult abuse programs that protect and provide services to vulnerable adults, including individuals with AD/D, in care facilities. The Office of the State Long

Term Care Ombudsman provides advocacy and resources for people who reside in long-term care facilities including nursing homes, assisted living and adult care facilities.

New York State Education Department

The New York State Education Department (NYSED), under the authority and direction of the New York State Board of Regents, oversees the 55 professions licensed under Title VIII of the Education Law, including their requirements for education, conduct, and practice. NYSED has a vital function in providing a wide range of services to the public, including those individuals with AD/D.

Essentially all the professions require a generic core education for licensure that includes sufficient breadth and depth of content to enable licensees at entry level to address professional issues throughout the lifespan, as appropriate to the services and activities offered by the profession. As curricula develop through regulation or by amendment to the curricula of programs registered by NYSED, issues related to behavioral and social needs and ethics are becoming a fundamental requirement of professional education programs. In addition, many professions, such as medicine, psychology, and the social work and mental health practitioner professions, for example, have specifically included issues of cultural competence and health care disparities in mandated curricula. This is a significant development since, for persons with AD/D and their caregivers, the cultural customs and beliefs influence the way health and behavior is understood and health care and social living decisions are made.

While the core education requirements for these professions differ, all licensed professionals who provide services to persons with AD/D are required to ensure they are competent to provide the services before doing so. Many professions that provide services to persons with AD/D have mandated continuing education requirements approved by the Department that must be met for the licensees to be re-registered for practice. Course content regarding AD/D that is related to the practice of a profession may be accepted in these professions. Programs for Clinical Nurse Specialists in Adult Health may focus on the needs of those with AD/D.

The Department also provides guidance through Practice Alerts, Practice Guidelines, webinars for professionals, and recommendations to programs during the approval of course content for the degrees. In addition to the education, training, and experiential opportunities to gain such competence that is part of the mandated curriculum of a profession, many associations, employers and schools have recognized this need and offer training through various means, including online offerings. Many other professions, including nursing, offer non-mandated continuing education to licensees to address professional competence that may specifically focus on the healthcare, social, and behavioral needs of persons with AD/D.

Within the broad services of NYSED, other offices provide oversight of education and the provision of services. These include the Office of Adult Career and Continuing Education Services, which encompasses the areas of Vocational Rehabilitation (including Independent Living Administration); Adult Education; and the Bureau of Proprietary School Supervision (BPSS).

Several of the Independent Living Centers (ILC) in NYS operate as fiscal intermediaries under NYSDOH Medicaid Consumer Directed Personal Assistance Program (CDPAP) and provide self-directed services through surrogates. Surrogate-directed CDPAP for Medicaid eligible individuals helps individuals with AD/D remain at home, typically with family members and/or family caregivers. In addition, ILCs participate in providing New York State Office for Persons

with Developmental Disabilities with family support services and NYSOFA with self-directed personal care services. The New York Association on Independent Living, Inc. is partnered with Independent Living Centers across the State to provide the Open Doors Transition Center and Peer Outreach & Referral programs. This project, funded by the NYSDOH as part of the federal Money Follows the Person demonstration program, is designed to help Medicaid-eligible individuals who live in nursing homes return to the community. It also assists individuals with developmental disabilities living in large group homes and institutions (Intermediate Care Facilities and Developmental Centers) transition to smaller community settings or more integrated community programs.

The BPSS oversees the programs that follow the curriculum determined by NYSDOH. To the extent that AD/D is included in the Home Health Aide-Core Curriculum established by NYSDOH, BPSS ensures that the programs include these educational requirements and are presented by qualified instructors. These programs are also overseen by the Office of the Professions' Professional Education and Review Unit.

New York State Office of Child and Family Services (NYSOCFS)

NYSOCFS serves NYS by promoting the safety, permanency, and well-being of children, vulnerable adults, families, and communities.

With recent support from state and federal government legislative actions, the issue of financial exploitation of elderly and vulnerable adults is receiving increased attention. Changes in law, together with strong community involvement against this growing social and economic problem, will hopefully reverse the trend of elder abuse.

The NYSOCFS Bureau of Adult Services conducted the *New York State Cost of Financial Exploitation Study*, a research study to determine the cost of financial exploitation among vulnerable adults in NYS. The one-year information gathering period spanned from October 2012 through September 2013. Case information on 928 APS cases across NYS that were identified as having financial exploitation as a risk factor was provided by 31 participating counties and Lifespan of Greater Rochester, a non-profit elder services agency. This study can be found at:

<http://ocfs.ny.gov/main/reports/Cost%20of%20Financial%20Exploitation%20Study%20FINAL%20May%202016.pdf>

In this study, NYSOCFS examined the cost of funds and other property stolen from vulnerable elderly and dependent adults. In addition, the agency analyzed the cost of providing government benefits and services to victims of financial exploitation as well as the cost to agencies for the financial exploitation investigation and other related activities. To obtain a comprehensive picture of victims' situations, NYSOCFS examined other social factors including characteristics and relationships between perpetrators and victims.

Results of the study were issued in 2016. Across the 479 verified cases, over \$24 million was reported in lost assets. The most common loss was monetary, with 42% of verified cases reporting cash losses of nearly \$8 million. A statewide estimate indicates victim losses of about \$109 million. An additional \$14 million in costs were attributed to service agency and public benefit cost. The aforementioned *NYS Elder Abuse Prevalence Study* (2011), funded by NYSOCFS, suggests that there are 10 to 44 unreported incidents of financial exploitation for every case that is reported. Applying the data from the *NYS Cost of Financial Exploitation Study*,

low and high-end estimates of actual victim financial loss ranged from \$352 million to \$1.5 billion annually.

The most frequent methods used for financial exploitation were misappropriation of funds, larceny and power of attorney abuse. The cost of new or additional benefits that were put into place to keep the adult safe totaled over \$1 million in documented costs. The cost to involved agencies, including APS and law enforcement, totaled nearly \$1.2 million. The total figure of \$27 million is a mere fraction of the actual cost based on the 1:44 ratio of reported cases reported in the NYSOCFS-funded NYS Elder Abuse Prevalence Study.

The social characteristics found in this study were not surprising. For example, family members/spouses made up 67% of cases (36% were adult children). Eighty percent (80%) of victims were age 60 or older and 46% were age 81 or older. Seventy-six percent of all victims had one or more health concerns and 30% of them had signs of AD/D. Fifty-eight-percent of the victims required assistance with ADLs. Allegations of abuse/exploitation were more likely to be verified when clients were assessed as having dementia or difficulty managing finances due to dementia.

Most victims do not want to involve law enforcement. This is due in part to feelings of fear, shame or guilt, especially when a member of their family is the perpetrator. However, in approximately 24% of the cases, criminal action was taken. Only 1% of those cases resulted in the conviction of the perpetrators. A lower percentage of cases (7%) sought civil action and the victim saw some type of settlement in only 1% of those cases.

On October 1, 2015 Governor Andrew M. Cuomo announced that NYS would use a \$300,000 federal grant to crack down on the financial exploitation of older and vulnerable adults. The funding supports a two-year pilot program in Onondaga County and Queens. This model will serve as a blueprint for the rest of the state. The NYSOCFS Bureau of Adult Services, which oversees APS in all 62 counties, worked with a forensic accountant in consultation with a multi-agency advisory board to develop new investigative tools and templates for APS workers. The grant also enables APS in the pilot areas to move referrals to a forensic accounting consultant in complex cases. Training of pilot APS units on the use of the new investigation tools occurred in April 2017. The pilot units are currently field testing the new tools and processes. The grant also has a component for enhancement of APS data systems to better document the costs of financial exploitation of APS clients.

NYSOCFS also oversees the Family Type Home for Adults program (FTHAs). FTHAs are a small adult care facility of one to four residents who require personal care and/or supervision but not continuous medical care as provided by a nursing home. Most typically, residents reside with the operator in their homes. They receive meals, housekeeping, assistance with medication as well as ADL's. This small setting lends itself to low caregiver/resident ratios and residents receive care in environments similar to their own homes, rather than a facility. This model provides an alternative to institutional care and has been successful in maintaining many AD/D residents in community based settings with individualized care. NYSOCFS, through its local social service districts, has facilitated trainings of FTHA operators by Alzheimer's Association staff to improve quality of care for this population.

New York State Office of Mental Health

The New York State Office of Mental Health (NYSOMH) provides support for two psychiatric research institutes which study severely disabling mental disorders. The Nathan Kline Institute

for Psychiatric Research (NKI) and the New York State Psychiatric Institute (NYSPI) both conduct research programs on the causes, early diagnosis, and treatment of AD and related dementias. The major concentration of AD research within NYSOMH is conducted at the Center for Dementia Research (CDR).

Recognized internationally for influential advances toward innovative AD therapies, CDR researchers have been awarded over \$50 million in external research funding since 2011, mostly from the NIH. These awards include the renewal in 2017 of a five-year, \$12 million NIH Program Project grant supporting collaborative research by four NKI investigators and several other NYS scientists to continue their pioneering investigations on the causes of AD and the earliest stages of AD development. Their research has defined cellular abnormalities that arise decades before the earliest clinical symptoms and should yield new biomarkers of AD so that treatments can begin sooner. The further understanding of the biology underlying the earliest changes in the disease has identified new molecular targets for drug intervention at these early disease stages. Innovative lines of drug discovery, including approaches that have recently been awarded patents, are under development in the CDR, some in partnership with major pharmaceutical companies to accelerate the identification of new therapy candidates.

Researchers in NKI's Center for Brain Imaging and Modulation are investigating abnormal brain function, possibly heralding the future onset of AD, in symptom-free elderly individuals who are at higher genetic risk to develop the disease. Other new imaging techniques, initially perfected in AD model systems, are now being applied in patient populations with the goal of widening the window of prevention opportunity even further.

CDR programs have yielded over 300 peer reviewed publications in the past 10 years, including reports in the most prestigious scientific journals (*Cell*, *Proceedings of the National Academy of Sciences*, *Science*, *Nature Medicine*, and others), which have been cited by other investigators world-wide over 30,000 times. Attesting to the influence of CDR research in the research community, NKI has ranked in the top 1% of all research institutions nationwide in the number of citations per publication.

Ongoing programs include research to uncover mechanisms by which mutant genes accelerate the onset of AD. Major advances, for example, have been made at NKI in understanding the biology and possible treatment of AD in individuals with Down syndrome, a population representing the most common form of early onset AD. Additional patented technology is enabling an active program of genomic studies on individual neurons in the human brain with AD, an area of research pioneered in the CDR.

Individuals with AD decline faster if they also have vascular-related brain damage. Research in this area was catalyzed by the findings of an NKI scientist, who identified the first gene that causes a form of dementia related to AD and affects primarily the blood vessels. Subsequently, NKI scientists have developed unique laboratory models of the disease for drug screening and understanding further this important interaction of blood vessel disease with AD. Another major program is investigating the higher incidence of epilepsy in AD and its contribution to AD initiation progression.

An important mission of NYSOMH AD programs is to optimize the management of both memory and behavioral symptoms of people with AD/D. The elderly are highly prone to developing psychiatric disorders, probably because of age-related changes in the brain, physical disorders, as well as increased stress in later life. Besides trials of new memory-enhancing medications, these efforts at NKI's Geriatric Psychiatry Division and at the NYSPI's Memory Disorders unit

have included research into effective treatments for agitation, the most common symptom leading to hospitalization and residential nursing care of individuals with AD/D. Additional clinical research is addressing the adverse effects of commonly used medicines when taken by individuals with AD/D.

Both facilities offer access to cutting-edge clinical trials of diverse experimental compounds for the prevention and treatment of AD. An ongoing NCI program is designed to address important clinical needs of the elderly such as providing free cognitive assessments to individuals with memory complaints through the Memory Education and Research Initiative program. Clinical research studies at the Taub Institute at Columbia, involving investigators from the NYSPH, consist of investigational treatment studies for MCI and AD; brain imaging studies utilizing MRI and PET scanning with state-of-the-art technique and new radioactive tracers; genetic and family studies involving specific risk factors; and new biomarker approaches to make an early diagnosis of AD/D.

Section II. A Call to Action

AD/D poses one of the greatest threats to our physical and economic futures. As global, national, and state awareness of AD/D has increased, so has the urgency for public health, human service, long-term care and health systems to come together through public and private partnerships to actively address AD/D.⁸²

Section III. Recommendations

The Council has developed the following series of recommendations that members will use as both a roadmap for progress and a call for diverse groups to work together to achieve them.

The recommendations provide opportunities for government, healthcare and human service professionals and institutions, business and philanthropies to come together with a common set of goals and activities.

Recommendations of the New York State Coordinating Council for Services Related to Alzheimer’s Disease and Other Dementias (AD/D)

Recommendation Number	Responsible Parties	Action Description
Goal 1: Enhance Caregiver Health and Wellness		
Strategy 1-A: Ensuring Quality of Life and Quality of Care for Persons Living with Alzheimer’s Disease and Other Dementias (AD/D) and Their Families Across Care Settings		
	NYSDOH Initiatives, NYSOFA	Improve individual and family awareness of support services.
	NYSDOH Initiatives	Promote the importance of identifying and assessing the health and well-being of caregivers. Ensure the existence of support services and systems that provide caregivers with a thorough, person-specific assessment and use valid and evidence-based tools to assess caregiver burden and stress.
	NYSDOH Initiatives	Identify the unique needs of persons caring for someone diagnosed with dementia and establish systems to match these needs to accessible services and supports.
	NYSDOH Initiatives, Primary Care Providers	Develop a tool box of resources to assist primary care providers with best-practice approaches to the diagnosis and management of patients presenting with AD/D.
	NYSDOH, NYSOFA, Providers	Promote adult day services to improve quality of life for persons with AD/D with non-pharmacological and social approaches to brain health and wellness through participation in creative arts and therapeutic activities.
Strategy 1-B: Provide Education to Informal Caregivers		
	NYSDOH Initiatives	Train caregivers to appropriately implement evidence-based behavioral strategies and non-pharmacological approaches that will improve quality of life for individuals with AD/D and facilitate maintenance of home placement in the community.
	NYSDOH Initiatives, Primary Care Providers, Healthcare Providers, Support Services Providers, AAAs	Educate caregivers on how to effectively navigate the healthcare system and the importance of emergency preparedness to reduce avoidable emergency department visits, hospitalizations, and nursing home placements.
	NYSDOH Initiatives	Develop educational programs that highlight caregiver health and wellness and the impact of stress on their physical and mental health. Integrate these topics into all educational initiatives offered to the community.
Goal 2: Advance Early Detection of Alzheimer’s Disease and other Dementias		
Strategy 2-A: Improve Clinical Care for Persons with Dementia		
	NYSDOH	Enhance identification of cognitive impairment when patients present in opportunistic settings such as the

		emergency room and urgent care centers, by providing assessment tools and educational materials.
	NYSDOH	Increase awareness and implementation of cognitive screening that is now required during a Medicare annual wellness visit including assessment of a person's ability to receive a care plan and access services.
	NYSDOH Initiatives	Preserve and possibly expand funding to enhance existing, and increase the number of NYS Centers of Excellence for Alzheimer's Disease (CEAD) to improve the timeliness of, and access to, diagnostic care.
	NYSDOH	Insure that physicians, hospitals and diagnostic centers have access to and implement appropriate coding for advanced testing and care planning to maximize reimbursement of care.
	NYSDOH Initiatives	Embed appropriate care and management of AD/D in every setting where NYSDOH has regulatory authority: homecare, adult care facilities, nursing homes, hospitals, and medical adult day program settings.
	NYSDOH Initiatives	Identify barriers to persons with AD/D accessing appropriate medical and psychiatric treatment for behavioral symptoms accompanying their disease.
	NYSDOH, NYSOMH	Increase the availability of specialized neurobehavioral units in NYS and insure adequate funding and regulatory frameworks to support providers that establish this level of care.
	NYSDOH Initiatives	Conduct a public awareness campaign specific to the importance and benefits of early detection and diagnosis of AD/D.
	NYSDOH Initiatives	Inform the public about the importance of describing cognitive changes noticed in themselves or family/friends when visiting with healthcare providers.
	NYSDOH Initiatives	Provide education specific to individuals diagnosed with early-stage AD/D about early retirement, government assistance programs (Social Security, Medicare, Medicaid), and personal disability insurance.
	NYSDOH Centers of Excellence, American Society of Anesthesiologists, American College of Surgeons, American Society of General Surgeons, American Academy of Neurology, American Neurological Association	Educate medical providers, nursing staff and discharge planners regarding the evidence that cognitive impairment may often follow surgeries involving general anesthesia, especially in older patients and after lengthy surgical procedures. These effects on cognition, in some cases, may be prolonged and/or exacerbate pre-existing risks for dementia. Prolonged hospitalization represents an additional cause of cognitive impairment after discharge.
	American Society of General Surgeons,	Promote the development of guidelines for post-surgical cognitive screening and discharge planning that

	NYSDOH Centers of Excellence	appropriately address and manage cognitive issues often occurring post-surgery.
Strategy 2-B: Promote Clinical Trials		
	NYSDOH Initiatives	Increase awareness regarding the importance of enrolling in research and clinical trials.
	NYSDOH Centers of Excellence for Alzheimer's Disease	Identify strategies to increase enrollment of racial and ethnic groups in AD/D studies and clinical trials.
	NYSDOH Centers of Excellence for Alzheimer's Disease	Expand availability of early detection testing (imaging and biomarker studies) allowing greater numbers of individuals to be linked to clinical trials.
Strategy 2-C: Improve Care Planning		
	NYSDOH Initiatives, Health Care Providers, NYS Bar Association, Hospital-Based Medical/Legal Partnerships, NYSOFA	Encourage individuals with AD/D, their families, and caregivers to plan regarding healthcare, finances, and legal issues as early in the disease process as possible, so that the individual with AD/D can fully participate in this process. This includes advanced care planning; financial planning; selection of a power of attorney; drafting a will; and communication about these documents, thereby enabling them to be prepared when their use becomes necessary.
	NYSDOH Initiatives, NYSED, Primary Care Providers, Health Care Providers, Support Services Providers	Ensure high quality care planning efforts, performed by clinical providers, to include cognitive assessments, co-occurring conditions, systems navigation, and improved access to care that maintains the dignity and safety of persons with dementia.
		Enhance hospital discharge planning efforts by requiring evidence-based cognitive screening upon admission and appropriate discharge planning as soon as possible.
Goal 3: Ensure Access to Appropriate Housing and Supports		
Strategy 3-A: Improve the Ability for Persons with AD/D to Remain in Their Home		
	NYSDOH Initiatives	Inform caregivers on the importance of home modifications, county and community programs, and strategies to prevent injury and limit wandering.
	NYSDOH Initiatives	Ensure access to funding and services that make resources available to modify and repair caregivers' homes.
Strategy 3-B: Promote Dementia-Friendly Communities		
	NYSDOH Initiatives NYSOFA	Promote dementia-friendly, well-informed communities that focus on reducing stigma and the inclusion of people living with dementia. Train community members (including, but not limited to, pharmacists, shopkeepers, bank tellers, bus drivers, postal carriers, meter readers, customer service staff, faith-based communities, service providers, community leaders, financial planners, human resources professionals, EAP staff, volunteer outreach

		personnel such as Meals on Wheels volunteers, law enforcement and first responders) on how to (1) identify, offer meaningful assistance and to communicate effectively with individuals with AD/D; (2) appropriately prepare for and respond to hazards and emergencies; and (3) on appropriate related topics specific to their roles.
	NYSDOH	Inform communities about physical environment modifications that support dementia friendly communities such as: <ul style="list-style-type: none"> • Clear and legible signage placed at eye level. • Flat, wide and unobstructed sidewalks. • Clearly marked accessible washrooms in public spaces. • Landmarks, distinctive structures, open spaces and places of activity and rest.
Strategy 3-C: Improve Access to Assisted Living		
	NYSDOH	Promote policy changes, programs and initiatives that enhance access to and affordability of assisted living for those living with AD/D.
Strategy 3-D: Develop Strategic Regulatory Changes that Improve Access to Appropriate Housing		
	NYSDOH	Pursue regulatory change to eliminate unnecessary transitions to emergency rooms, hospitals or skilled nursing facilities.
Goal 4: Improve Rural Access to Care		
Strategy 4-A: Develop Networks to Improve Care Access		
	NYSDOH Initiatives	Develop and strengthen network adequacy in rural counties.
	NYSDOH Initiatives	Promote formal care provider networks to build capacity and collaboration to better reach isolated individuals living in rural communities.
	NYSDOT NYSDOH Initiatives	Provide resources to support programs that expand services in rural regions, such as transportation.
		Address the direct care workforce shortage in rural areas.
Strategy 4-B: Improve Access to Services to Improve Care		
	NYSDOH Initiatives, NYSOFA	Promote volunteer programs to build service delivery in rural areas, such as volunteer based respite and transportation models.
	NYSDOH	Promote efforts to expand use of telemedicine/ telepsychiatry in the home to facilitate physician care, cognitive assessments, and monitoring of treatment effectiveness.
Goal 5: Develop a Workforce That Supports Caregivers and Persons Living with AD/D		
Strategy 5-A: Ensure that the Financial and Justice System Recognize and Support Persons with Alzheimer's Disease and Other Dementias		
	NYS Division of Criminal Justice Services (NYSDCJS)	Mandate an on-line AD/D training for law enforcement personnel.

	Office of Court Administration (OCA), NYS Bar Association, NYSOPWDD, NYSOFA	Increase access to affordable legal assistance for persons with AD/D and their caregivers.
	NYSDOH NYSOFA, NYSOCFS	Educate staff of Expanded In-home Services for the Elderly and Protective Services for Adults (PSA) on the AD/D population and the risks of adult abuse.
	NYSDOH, NYSOCFS, NYSDFS	Educate financial services personnel on how to identify and report financial exploitation.
	NYSDOH	Advocate for enhanced quality of care and quality of life for individuals with AD/D who reside in skilled nursing and assisted living facilities.
	NYSOFA	Educate ombudsman on end of life comfort care for individuals with late stage AD/D.
	NYSDOH	Provide training for judges, court personnel, attorneys, and other legal professionals on protecting the legal rights of individuals with AD/D.
	NYSDOH Initiatives NYSOFA NYSOCFS NYSDCJS	Participate in interagency activities on elder abuse awareness, training and prevention (e.g., the Alzheimer's Association First Responder Training and PSA Training) released by the Coordinating Council on Police Services for the Elderly to its law enforcement network.
Strategy 5-B: Build a Skilled Healthcare Workforce to Provide High Quality Care		
	NYSDOH Initiatives NYSOFA	Train paraprofessional caregivers in both home and care settings to ensure that mechanisms exist to link trained caregivers to families needing services.
		Work towards pay equity, adequate skills training and increasing retention rates among the predominantly female paid dementia workforce.
	NYSED	Provide continuing education opportunities for all healthcare providers who take AD/D training classes as a part of their mandated continuing education in accordance with their scope of practice.
	NYSED	Provide licensed professionals with the opportunity to take an online examination that would require licensees to correctly answer questions on AD/D and, when all responses are correct, issue credit towards mandated continuing education in their professions.
	NYSDOH Initiatives	Explore programs and incentives that professionalize the dementia direct care workforce and expand opportunities for career growth.
	NYSDOH Initiatives	Expand the number of experts in the treatment of behavioral challenges associated with AD/D. Support efforts that increase the number of behavioral health clinicians, including geriatric psychiatrists and neurologists.

	NYSDOH	Promote dementia care specialty training among home care and long term care providers.
	NYSDOH Initiatives, NYSED	Provide training and education to medical providers and other healthcare professionals on critical topics and evidence-based tools that improve the quality of care of persons with AD/D and their caregivers. Topics to include, but not be limited to, understanding diagnostic guidelines; care management; pharmacological and non-pharmacological approaches to care; recognition of the role of health disparities; the implications of AD/D for women as persons with AD/D and caregivers; and the need for ongoing involvement in clinical trials.
	NYSED	Integrate a geriatric component into developmental curricula in elementary through secondary education to increase the level of awareness of differences between normal aging and AD/D.
	NYSED	Include the opportunity for certified teachers and licensed professionals to obtain coursework that addresses AD/D, and is approved for continuing education.
	NYSED	Highlight the full field of employment opportunities that provide care and services to the AD/D population in the joint efforts of the P-12 Education Office and the Office of the Professions to inform all students about future work and career opportunities.
Strategy 5-C: Educate and Support Employers to Better Understand the Effects of Alzheimer's Disease and Other Dementias		
	NYSDOH, NYS Governor's Office of Employee Relations, Business Council of NYS	Educate employers to recognize the economic cost of AD/D to the workplace and encourage them to offer caregiver support services and referrals through Employee Assistance Programs and personnel policies.
	NYSDOH	Promote initiatives that support caregivers in the workforce: encourage employers to embrace a dementia friendly workplace and to encourage policies that support caregiver retention in the workplace.
	NYSDOH	Encourage employers to adopt the standards of or join the Alzheimer's Workplace Alliance.
Goal 6: Address Disparities and Improve Health Equity		
Strategy 6-A: Improve Access to Care and Services for Underserved Populations Affected by Alzheimer's Disease and Other Dementias		
	NYSDOH Initiatives	Provide support services that target underserved communities including education on normal aging versus AD/D and the importance of timely diagnosis of AD/D.
	NYSDOH Initiatives	Promote initiatives that successfully build relationships and trust among underserved groups, incorporating partnerships with community-based organizations and gatekeepers which already provide care and services to target communities.

	NYSDOH Initiatives	Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.
	NYSDOH Initiatives NYSOFA	Identify gatekeepers, champions, and community leaders in underserved communities to promote awareness in their communities about issues related to AD/D, caregiver health and available support services.
	NYSDOH Initiatives	Enhance cultural competence in service provision by: <ul style="list-style-type: none"> • Identifying cultural practices that prevent or discourage people from seeking services for themselves or their care recipient. • Ensuring that educational programs and support services are culturally and linguistically appropriate (e.g., available in multiple languages). • Ensuring that care providers consider staffing patterns that reflect the target underserved community, both culturally and linguistically.
	NYSDOH Initiatives	Develop a methodology to ensure that providers of care are performing in a culturally competent manner, understanding the unique nature of diverse communities and cultures and directing outreach efforts (including promotional materials) that specifically reach the target underserved community.
	NYSDOH Initiatives	Address issues specific to economic disparities present in under-resourced communities: <ul style="list-style-type: none"> • Assist caregivers in understanding what they can afford, what services they qualify for and what government services might be available to meet their needs.
	NYSDOH Initiatives	Provide services to immigrant populations regardless of immigration status and eliminate any atmosphere of distrust and fear related to immigration and documented status.
Strategy 6-B: Improve Access to Services for Populations Facing Specific Care Challenges		
Early Onset		
	NYSDOH Initiatives	Educate individuals with early onset AD/D and their providers about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.
	NYSDOH Initiatives	Educate providers on the importance of individuals with early onset AD/D applying for benefits.
	NYSDOH Initiatives	Create appropriate support services so that individuals with early onset AD/D can have reasonable access to them.
	NYSDOH Initiatives	Explore effective support mechanisms for individuals with dementias other than AD/D.
	NYSOFA	Improve the availability of aging network services to support individuals with early onset AD/D.
Down Syndrome and Intellectual Disability/Developmental Disability (DD/ID)		

	NYSOPWDD NYSDOH Initiatives	Encourage families and caregivers of individuals with DD/ID who suspect memory problems and other symptoms to communicate this concern to the individual's healthcare provider. Ensure coordination with and support from NYSDOH Initiatives.
	NYSOPWDD	Encourage families and caregivers of individuals with AD and Down Syndrome or DD/ID to engage in early planning regarding AD/D.
	NYSOPWDD	Promote research on the connection between Down Syndrome and AD/D in NYS research institutes/NYSDOH Initiatives.
	NYSDOH Initiatives NYSOPWDD NYSOMH	Collect data and valid research on the relationship between concussion/acquired brain injury and AD/D for use in recognizing the effects of such injuries for treatment planning, the importance of developing injury avoidance measures, and the significance of such events in the diagnosis, behavior and treatment needs at a later stage in life.

Goal 7: Enhance Public Awareness and Engagement

Strategy 7-A: Implement Comprehensive Public Awareness Campaigns

	NYSDOH Initiatives Primary Care Providers The Council NYSED	<p>A public awareness campaign related to individuals with AD/D would accomplish the following:</p> <ul style="list-style-type: none"> • Raise awareness about the difference between AD/D and normal aging. • Encourage individuals with AD/D symptoms to be examined by healthcare providers when they experience the earliest symptoms. • Raise awareness of risk factors, prevention strategies, and the importance of early diagnosis of AD/D. • Reach those individuals most at risk of developing AD/D. • Address the impact of AD/D on women, both as caregivers and persons with the disease. • Promote early diagnosis and the benefits of an early differential diagnosis. • Promote increased access to support services, and advise people where they can go for help. • Promote increased awareness of the availability of palliative care for individuals living with AD/D. • Promote primary and secondary prevention by more clearly linking the relationship between a healthy lifestyle and brain health. • Raise public awareness of the impact of the stigma and stereotypes surrounding AD/D to the well-being and quality of life for those with dementia and their families by promoting understanding of the disease. • Educate the public about the latest research findings and clinical trials, including the benefits
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		of enrolling in clinical trials, using multi-media opportunities, public presentations, social networks and public television.
	NYSDOH Initiatives Primary Care Providers The Council NYSED NYSOFA	Components of a public awareness campaign specific to caregivers should include caregiver stress and the importance of caregivers maintaining optimal health and wellness and seeking support services.
Goal 8: Expand Collaborative Research to Obtain Quality Data		
Strategy 8-A: Collaborate with Federal and State Initiatives that Advance Progress in AD/D Research		
	NYS Research Institutes	Collaborate to accelerate progress in AD/D research, as follows: <ul style="list-style-type: none"> • Highlight research programs on the causes, diagnosis, and treatment of AD/D and related dementias, to match the urgent need. • Promote research opportunities related to caregiver health, AD/D financial implications on the caregiver and caregiver support services. • Promote research exploring the role of gender as a key health determinant of AD/D. • Continue collaborative research across institutes and incentivize development of cooperative inter-institutional programs. • Promote drug discovery initiatives and industry partnerships for drug discovery. • Continue to research biological effects of life style and drug-free approaches to lowering AD/D risk. • Develop a new generation of young investigators through training and seed grant opportunities. • Apply for federal funding.
	NYSDOH National Alzheimer's Association	Utilize public health surveillance systems to more accurately quantify burden of AD/D through aggregate data from electronic records, the BRFSS, and the Alzheimer's Association Facts and Figures document.
	NYS Research Institutes NYSDOH Initiatives	Maintain and facilitate research at a state and federal level to accelerate progress toward effective treatments for AD/D. <ul style="list-style-type: none"> • Leverage programs for early evaluation and care to expand knowledge and access to clinical trials and related clinical research. • Leverage state data bases for epidemiological and outcome research. • Interface with local Alzheimer's Association Chapters to synergize with research, awareness, and treatment efforts.
	NYS Research Institutes	Identify recognized and approved research studies throughout NYS on AD/D, and maintain an updated inventory for use by educators and researchers.

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Attachment A

**New York State Coordinating Council for Services Related to Alzheimer's Disease and
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Attachment B

Summary of Alzheimer’s Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
<p>Alzheimer’s disease (AD)</p>	<p>Characteristics: AD is a slowly progressive brain disease that begins well before symptoms emerge, and is fatal. There is no known cure or vaccine for this disease. AD is the most common type of dementia, accounting for an estimated 60 to 80% of cases.</p>
	<p>Symptoms:</p> <ul style="list-style-type: none"> • Early-stage: <ul style="list-style-type: none"> ○ Difficulty remembering recent conversations, names, or events ○ Confusion with time and place ○ Word finding issues ○ Difficulty performing familiar tasks in home, social, or work settings ○ Misplacing valuable items ○ Losses in planning, problem solving, and organizational abilities ○ Changes in mood or behavior ○ Withdrawal from work or social activities ○ Impaired judgment • Middle-stage: <ul style="list-style-type: none"> ○ Forgetting events in one’s personal history ○ Mood changes (apathy, depression, irritability) ○ Behavioral changes (agitation, wandering, aggression) ○ Increasing confusion related to date, time, and place ○ Difficulty maintaining continence ○ Disturbances in sleep, disruptions in sleep patterns ○ Increasing difficulties with ADLs, mobility, and functional independence • Late-stage: <ul style="list-style-type: none"> ○ Lack of awareness of recent experiences, surroundings, and physical functioning ○ Difficulty swallowing ○ At risk for infections, especially pneumonia ○ Further decline in physical ability and mobility ○ Significant dependence on caregivers for ADLs and personal care ○ Impaired verbal and receptive communication skills
	<p>Brain changes: Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain.</p>
	<p>Diagnosing: An AD diagnosis is based on a medical evaluation completed by a medical professional that includes a physical and neurological examination; interviews of the</p>

Summary of Alzheimer’s Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Alzheimer’s disease (AD) <i>(continued)</i>	patient and family member; mental status tests; functional assessments; and examinations to establish any differential diagnoses.
	Known risk factors: <ul style="list-style-type: none"> • Advancing age • Family history • Genetics, specifically the presence of the APOE-e4 gene or Down syndrome.
Diagnosis	Diagnostic Criteria
Chronic Traumatic Encephalitis (CTE)	Characteristics: CTE is a progressive degenerative brain disease associated with repetitive brain trauma and mild TBI. CTE can occur as a result of concussions often received in contact sports or non-concussive hits to the head over time.
	Symptoms: <ul style="list-style-type: none"> • Characteristics of dementia - memory loss, impaired judgment, confusion and agitation – appearing years after trauma • Depression and suicidal thoughts • Behavioral and mood changes • Impulse control problems and aggression
	Brain changes: The repetitive brain trauma triggers a progressive degeneration of brain tissue and the build-up of the abnormal protein called tau. These changes in the brain can begin months, years, or even decades after the last episode of trauma.
	Diagnosing: CTE is diagnosed through a physical and neurological examination, as well as a personal history that includes an assessment of past head trauma and involvement in contact sports. Brain imaging is also recommended.
	Known risk factors: <ul style="list-style-type: none"> • Repeated brain trauma • History of head injuries/TBIs
Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease (CJD)	Characteristics: CJD is the most common human form of a group of rare disorders categorized as Prion diseases. Prion diseases occur when prion proteins, found throughout the body and brain, begin misfolding into an abnormal three-dimensional shape. Cognitive changes with CJD are uncharacteristically rapid and severe. There are three main types of CJD: sporadic, familial, and transmitted/infectious. The most common form of CJD is sporadic.
	Symptoms: <ul style="list-style-type: none"> • Confusion and rapid decline in all areas of cognition • Involuntary muscle movements, twitches and/or stiffness • Difficulty walking

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease (CJD) <i>(continued)</i>	<ul style="list-style-type: none"> • Apathy, agitation and mood changes • Depression
	Brain changes: Results from misfolded prion protein throughout the body that progresses to the brain and leads to a destruction of brain cells.
	Diagnosing: CJD is diagnosed through a medical and personal history; a neurological exam; and spinal fluid testing via lumbar puncture to test for the presence of prion protein. Testing should also include an electroencephalogram and brain MRI. There is no known cause for sporadic CJD.
	Known risk factors: <ul style="list-style-type: none"> • Genetic variations • Exposure to external sources of abnormal prion protein (poorly sterilized medical equipment or infected meat)
Diagnosis	Diagnostic Criteria
Frontotemporal dementia (FTD)	Characteristics: FTD is an umbrella term that refers to a group of disorders that involve the frontal and temporal areas of the brain controlling personality, language, and movement. These diseases include behavioral variant FTD, temporal/frontal FTD, progressive non-fluent aphasia, semantic dementia, primary progressive aphasia, Pick's disease, corticobasal syndrome, progressive supranuclear palsy, FTD with parkinsonism, and FTD with amyotrophic lateral sclerosis (ALS). Persons with FTD are typically diagnosed in their 40s to 60s.
	Symptoms: <ul style="list-style-type: none"> • Behavior changes, such as impulsivity and inappropriateness, are often noted first. • Early difficulty with understanding speech or reading • Changes in personality and emotional reactions • Decline in motor function
	Brain changes: There is no distinguishing microscopic abnormality linked to all types of FTD. FTD primarily affects the frontal (forehead) and temporal (behind the ears) lobes of the brain. High levels of tau and Transactive Response Deoxyribonucleic Acid Protein-43 (TDP-43) have been found on autopsy. Individuals with FTD generally develop symptoms at a younger age than those with other forms of dementia, and survive for anywhere between 18 months to 20 years, with an average life expectancy of seven years.
	Diagnosing: The diagnosis of FTD requires an examination by a professional knowledgeable about this disorder. Evaluations should include a history of issues being experienced by the patient and a comprehensive neurological examination. Brain imaging, particularly MRIs and glucose PET scans, are helpful in determining the diagnosis of FTD.

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Frontotemporal dementia (FTD) <i>(continued)</i>	Known risk factors: <ul style="list-style-type: none"> • Family history (accounts for 1/3 of the cases)
Diagnosis	Diagnostic Criteria
HIV associated neurocognitive disorder (HAND)/Acquired immune deficiency syndrome (AIDS) dementia complex (ADC)	<p>Characteristics: HAND is an umbrella term for HIV-related dementias that include: Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder and HIV-Associated Dementia. The virus enters the central nervous system early in the course of the infection and causes several cognitive changes over the course of the disease.</p> <p>Symptoms:</p> <ul style="list-style-type: none"> • Forgetfulness, confusion, and other changes in cognition • Behavioral and personality changes • Headaches • Weakness and loss of sensation in arms and legs • Progressive motor dysfunction • Extremity pain due to nerve damage <p>Brain changes: The HIV virus penetrates the blood-brain barrier, and affects subcortical brain structures below the cerebral cortex. HIV has also been shown to alter brain size in the areas specific to learning and information processing. Although the virus doesn't directly invade or damage nerve cells in the brain, it impacts the health and function of these cells, causing an encephalitis (inflammation of the brain). Persons with advanced HIV infections are likely to develop ADC or HAND, leading to behavioral changes and a gradual decline in cognitive function.</p> <p>Diagnosing: HAND/ADC is diagnosed through a complete neurological examination, brain imaging, and potentially a lumbar puncture to assess cerebrospinal fluid. Cognitive testing is also recommended.</p> <p>Known risk factors:</p> <ul style="list-style-type: none"> • HIV Infection
Diagnosis	Diagnostic Criteria
Huntington's disease	<p>Characteristics: Huntington's disease is a progressive brain disorder caused by a single defective gene on Chromosome 4. This defect is hereditary and "dominant" meaning that if an individual has the gene then he/she will eventually develop the disease. Symptoms develop typically between the ages of 30 and 50.</p> <p>Symptoms:</p> <ul style="list-style-type: none"> • Unsteady gait and involuntary movements (chorea) involving all extremities • Forgetfulness and impaired judgment • Decline in thinking and reasoning skills including memory, concentration, judgment and ability to plan or organize

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Huntington's disease <i>(continued)</i>	<ul style="list-style-type: none"> • Personality changes, mood swings, anxiety, depression and uncharacteristic anger or irritability • Obsessive-compulsive tendencies
	Brain changes: The gene defect influences the abnormal production of "huntingtin" protein that, over time, leads to worsening symptoms.
	Diagnosing: A medical examination completed by a medical professional that includes a personal and family medical history, physical examination and neurological examination. Genetic testing and counseling is strongly recommended.
	Known risk factors: <ul style="list-style-type: none"> • Heredity and family history
Diagnosis	Diagnostic Criteria
Lewy body dementia (LBD)	Characteristics: LBD presents with cognitive symptoms similar to AD and movement symptoms typical of Parkinson's disease (muscle rigidity, shuffling gait, stooped posture, and difficulty initiating movement). Most experts estimate that LBD is the third most common cause of dementia after AD and vascular dementia.
	Symptoms: <ul style="list-style-type: none"> • Cognitive difficulties similar to AD, although memory loss of less severity • Periods of confusion and alertness that vary from one time of the day to another, or from one day to the next • Sleep disturbances, often acting out dreams • Well-formed visual hallucinations and delusions • Muscle rigidity or other Parkinsonian movement features • Autonomic nervous system changes • Difficulty with visual interpretations
	Brain changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also collects in the brains of people with Parkinson's disease, but the masses may appear in a pattern that is different from LBD.
	Diagnosis: A diagnosis of LBD is based on a medical evaluation completed by a medical professional that includes a physical, cognitive and neurological examination. Cognitive changes will be more significant in the areas of judgement, planning, and visual perception, likely less significant for memory. Well-formed hallucinations and delusions are likely. Movement symptoms typical of Parkinson's disease will be present, along with changes in autonomic nervous system function leading to drops in blood pressure, dizziness or repeated falls.
	Known risk factors: <ul style="list-style-type: none"> • Advanced age

Summary of Alzheimer’s Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Lewy body dementia (LBD) <i>(continued)</i>	<ul style="list-style-type: none"> • Male gender • Family member with history of LBD • Parkinson’s disease diagnosis
Diagnosis	Diagnostic Criteria
Mild Cognitive Impairment (MCI)	<p>Characteristics: MCI is characterized by cognitive changes that are significant enough to be noticeable by the person experiencing them and/or others, but not severe enough to interfere with daily life or independence. MCI is not cognitive decline related to normal aging. Individuals diagnosed with amnesic MCI are at a greater risk of developing AD/D but not all individuals with MCI progress to a dementia. The symptoms of other conditions, such as depression or a Vitamin B12 deficiency, may mimic those of MCI.</p> <p>Symptoms:</p> <ul style="list-style-type: none"> • MCI primarily affecting memory (“Amnesic”) <ul style="list-style-type: none"> ○ Short-term memory and re-call problems ○ Difficulty learning new information • MCI primarily affecting thinking (“Non-amnesic”) <ul style="list-style-type: none"> ○ Losses in executive thinking (planning, organization) ○ Lack of judgment ○ Difficulty completing complex tasks ○ Changes in visual perception • Presence of depression, irritability, anxiety, and/or apathy <p>Brain changes: Brain imaging has shown overall reductions in brain volume in persons with MCI, particularly in the area of the hippocampus, and an enlargement of the ventricles. Abnormal presences of beta-amyloid protein and microscopic clumps of tau may be found but in less significant amounts than seen with AD/D.</p> <p>Diagnosing: MCI is a clinical diagnosis based on a medical professional’s best judgment after considering the individual’s medical history, functional and ADL assessment, input from family, and/or mental status testing. Diagnosis may be enhanced with the use of biomarker testing (cerebrospinal fluid examinations and imaging).</p> <p>Known risk factors:</p> <ul style="list-style-type: none"> • Advancing age • Family history of AD/D • Conditions that increase a person’s risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)
Diagnosis	Diagnostic Criteria
Mixed Dementia	<p>Characteristics: Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of</p>

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Mixed Dementia <i>(continued)</i>	mixed dementia are AD with vascular dementia, AD with LBD, or characteristics of AD mixed with vascular and LBD.
	Symptoms: Symptoms vary and depend on the type of brain changes involved and regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of AD or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present.
	Brain changes: An individual with mixed dementia will have the pathology of the presenting combination of AD/D. For example, in an individual with both AD and vascular dementia, abnormal protein deposits associated with AD co-exist with blood vessel changes problems linked to vascular dementia.
	Diagnosing: Mixed dementia is diagnosed based on a medical evaluation that includes a physical and neurological examination, interviews of the patient and family member, mental status tests, functional assessments, and examinations to establish any differential diagnoses. Although mixed dementia is infrequently diagnosed, researchers believe it deserves more attention because the combination of two or more types of dementia-related brain changes may have a greater impact on individuals and increase their chances of developing symptoms.
	Risk Factors: <ul style="list-style-type: none"> • Risk factors are consistent with the types of dementia that comprise the mixed dementia diagnosis.
Diagnosis	Diagnostic Criteria
Parkinson's disease	Characteristics: Parkinson's disease occurs when abnormal aggregations (or clumps) of the protein alpha-synuclein occur in the brain. This protein forms Lewy bodies similar to those seen with LBD. As Parkinson's disease progresses, the brain changes gradually spread. These changes often begin to affect mental functions including memory, the ability to pay attention, make sound judgments, and plan the steps needed to complete a task. As Parkinson's disease progresses, it may result in a progressive dementia.
	Symptoms <ul style="list-style-type: none"> • Memory impairment with disruptions in judgment and ability to concentrate • Parkinsonian motor changes, such as: <ul style="list-style-type: none"> ○ Bradykinesia (slowed movements) ○ Tremors, mostly at rest ○ Muscle rigidity ○ Gait disturbances (shuffling, forward propelling, difficulty initiating movement) ○ Mask-like fascial expression

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
<p>Parkinson's disease (continued)</p>	<ul style="list-style-type: none"> ○ Abnormal posture ○ Micrographia ● Delusions and paranoid ideations ● Sleep disturbances ● Depression and anxiety ● Overall fatigue ● Low volume and muffled speech <p>Brain changes: Parkinson's disease begins in a region of the brain that plays a key role in movement. Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra; the deposits are called Lewy bodies. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.</p> <p>Diagnosing: Parkinson's disease is diagnosed by a medical professional trained in nervous system disorders and will include a medical history, complete physical and neurological examination, and a thorough assessment of cognitive function. Evaluation may include the use of a specialized imaging technique called a dopamine transporters scan (DaTscan) that captures dopamine in the brain.</p> <p>Known risk factors:</p> <ul style="list-style-type: none"> ● Age 60 or older ● Heredity ● Male gender ● Exposure to toxins (particularly herbicides and pesticides)
Diagnosis	Diagnostic Criteria
<p>Vascular dementia</p>	<p>Characteristics: Vascular dementia results from conditions that decrease or alter blood flow to the brain and leads to brain cell damage. Previously known as multi-infarct dementia, post-stroke or "mini-stroke" dementia, vascular dementia accounts for about 10% of dementia cases. Vascular dementia is the second most common dementia after AD.</p> <p>Symptoms: Symptoms of vascular dementia can vary depending on the area of the brain affected and the extent of damage caused by changes in blood flow to the brain. They may include:</p> <ul style="list-style-type: none"> ● Decrease in ability to organize thoughts and actions ● Confusion, disorientation, and poor attention span ● Impaired judgment and reasoning skills ● Difficulty with decision making ● Inability to complete complex, multiple step tasks ● Communication challenges related to losses in expressive and/or receptive language ● Changes to vision

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Vascular dementia <i>(continued)</i>	<ul style="list-style-type: none"> • Impairments in mobility and/or extremity weakness specific to the area of the brain affected
	<p>Brain changes: The location of vascular change in the brain and the extent of the damage will determine how the individual's thinking and physical functioning are affected. There are three criteria necessary for a vascular dementia diagnosis:</p> <ul style="list-style-type: none"> • A diagnosis of dementia or MCI; • Evidence of a stroke or other blood vessel changes that affect cause damage in the brain; and • No evidence that factors other than vascular changes caused the decline.
	<p>Diagnosing: Because vascular dementia may often go unrecognized, many experts recommend screening for everyone considered to be at high risk for this disorder. A diagnosis of vascular dementia is made after the completion of a professional screening to assess memory, thinking ability, and reasoning, in conjunction with a thorough neurological examination. Brain imaging may detect blood vessel changes that can relate to vascular dementia.</p>
	<p>Known risk factors:</p> <ul style="list-style-type: none"> • History of heart disease and stroke • Smoking • Poorly managed diabetes • Obesity and lack of exercise • Hypertension and high cholesterol
Diagnosis	Diagnostic Criteria
Wernicke-Korsakoff syndrome (WKS)	<p>Characteristics: WKS is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). It is most often associated with alcoholism but can be associated with AIDS, chronic infections, malnutrition, or other medical conditions. WKS is conceptually closely related to two syndromes: Wernicke encephalopathy, which is an acute phase of disease and potentially reversible, and Korsakoff dementia, which results from more chronic disease and is irreversible.</p>
	<p>Symptoms:</p> <ul style="list-style-type: none"> • Memory problems, both recent recall and long term, accompanying intact higher level cognitive and social skills • Difficulty learning new information • Tendency to confabulate and make up information that can't be recalled
	<p>Brain changes: Thiamine helps brain cells produce energy from sugar. When thiamine levels fall too low, brain cells cannot generate enough energy to function properly.</p>
	<p>Diagnosing: WKS is a clinical diagnosis representing a doctor's best professional judgment about the reason for a</p>

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
<p>Wernicke-Korsakoff syndrome (WKS) <i>(continued)</i></p>	<p>person's symptoms. There are no specific laboratory tests or neuroimaging procedures to confirm that a person has this disorder. Symptoms may be masked by other conditions associated with alcohol misuse. A complete medical workup for cognitive changes should include questions about an individual's alcohol use.</p>
	<p>Known risk factors:</p> <ul style="list-style-type: none"> • Alcohol misuse • Poor nutrition related to stringent dieting, fasting or anorexia • Presence of other diseases that lead to malnutrition such as AIDS, kidney dialysis, chronic infection, or cancer

Attachment C:

Acronyms

AAA	Area Agencies on Aging
AD	Alzheimer's disease
AD/D	Alzheimer's disease and other dementias
ADC	AIDS dementia complex
ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
AlzCAP	Coalition of Alzheimer's Association Chapters
APOE	Apolipoprotein E
APS	Adult Protective Services
BPSS	Bureau of Proprietary School Supervision
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CDPAP	Consumer Directed Personal Care Assistance Program
CDR	Center for Dementia Research
CEAD	Centers of Excellence for Alzheimer's Disease
CJD	Creutzfeldt-Jakob disease
CMS	Centers for Medicare and Medicaid Services
Council	New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias
E-MDT	Enhanced Multi-Disciplinary Teams
FTD	Frontotemporal Dementia
HAND	HIV associated neurocognitive disorder
HIV	Human Immunodeficiency Virus
ILC	Independent Living Centers
LBD	Lewy Body Dementia
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
NAPA	National Alzheimer's Project Act
NIA	National Institute in Aging
NIH	National Institutes of Health
NKI	Nathan Kline Institute for Psychiatric Research
NYS	New York State
NYSDCJS	New York State Division of Criminal Justice Services
NYSDOH	New York State Department of Health
NYSED	New York State Education Department
NYSOCFS	New York State Office for Child and Family Services
NYSOFA	New York State Office for the Aging
NYSCRC	New York State Coalition on Caregiving and Respite
NYSPI	New York State Psychiatry Institute
NYSOMH	New York State Office of Mental Health
NYUCI	New York University Caregiver Intervention
OAA	Older American's Act
PET	Positron Emission Tomography
PSA	Protective Services for Adults
Public Health Road Map	<i>The Healthy Brain Initiative: the Public Health Road Map for State and National Partnership, 2013-2018</i>
REST	Respite Education and Support Tools

SADS	Social Adult Day Service
SFY	State Fiscal Year
TBI	Traumatic Brain Injury
US	United States
WHO	World Health Organization
WKS	Wernicke-Korsakoff syndrome