2025 Report

of the

New York State Coordinating Council

for Services Related to Alzheimer's Disease

and Other Dementia

to

the Governor

and the

New York State Legislature

Table of Contents

Introduction

Section I. Background

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

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

The Council was formed to facilitate interagency planning and policymaking, review of specific agency initiatives for their impact on services related to the care of persons living with Alzheimer's disease and other dementias and their families, and to provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for Alzheimer's disease and related dementias. Please refer to **Attachment A** for the full 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. Reports must set forth the Council's recommendations for state policy relating to Alzheimer's disease and related dementias and include a review of services initiated and coordinated by New York State agencies to meet the needs of persons living with Alzheimer's disease and related dementias and their families. This is the ninth report prepared by the Council and covers calendar years 2023-2024. The Council has gathered advice from Council members and other experts in the field to facilitate the development of this report.

The Council has developed a series of goals and 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, businesses, and philanthropies to come together with a common set of goals and activities.

The Council has determined the top three priorities for calendar years 2025-2026 will include:

1. Risk reduction and early detection/diagnosis of Alzheimer's and related dementia.
2. Increase and support for the direct care workforce.
3. Support for informal caregivers of persons living with Alzheimer's disease and related dementia.

The Council's aforementioned goals and recommendations are as follows:

Goal 1: Enhance Public Awareness and Disease Understanding in order to Advance Early Detection of Alzheimer's Disease and All Other Dementia

1. Implement public awareness and education activities that are designed to enhance health and wellness and their relationship to Alzheimer's disease and related dementia:

    - Encourage individuals with Alzheimer's disease and related dementia symptoms to be examined by healthcare providers when they experience the earliest symptoms and raise awareness about the difference between Alzheimer's disease and related dementia and normal aging.

    - Promote brain health and raise awareness of risk factors, prevention strategies, and the importance of early differential diagnosis of Alzheimer's disease and related dementia.

    - Reach those individuals, based on current research, most at risk of developing Alzheimer's disease and related dementia.

    - Address the impact of Alzheimer's disease and related dementia on women, both as caregivers and persons with the disease.

    - Promote increased awareness of the availability of palliative care for individuals living with Alzheimer's disease and related dementia.

    - Promote primary and secondary prevention by clearly linking the relationship between a healthy lifestyle and brain health.

    - Provide funding for a public awareness campaign, that includes the warning signs, referral information for supports and services, and adopting healthy brain habits.

2. Increase public awareness about evolving treatments for Alzheimer's disease and related dementia, including new, existing, and evolving disease targeting medications.

3. Identify barriers to persons with Alzheimer's disease and related dementia accessing appropriate medical and psychiatric treatment for behavioral symptoms accompanying their disease.

Goal 2: Improve Clinical Care for Alzheimer's Disease and Other Dementia

4. Train primary care providers to utilize best-practice approaches for the screening, diagnosis, and care management/treatment of individuals presenting with Alzheimer's disease and related dementia and their caregivers. Expand this to include training the medical community, in general.

5. Increase public awareness about evolving treatments for Alzheimer's disease and related dementia, including new, existing, and evolving disease targeting medications.

6. Enhance identification of cognitive impairment when patients present in opportunistic settings, such as the emergency room and urgent care centers, by promoting the use of appropriate assessment tools and providing educational materials.

7. Increase awareness and implementation of cognitive screening during the Medicare annual wellness visit, including assessment of a person's ability to implement a care plan and access services.

8. Increase the number and funding of New York State Centers of Excellence for Alzheimer's Disease to improve the timeliness of, and access to, diagnostic care.
9. Ensure that physicians, hospitals, and diagnostic centers have access to, and implement appropriate coding for advanced testing and care planning to maximize reimbursement of care.

10. Train primary care physicians in the appropriate management of the evolving new treatments and disease targeting medications for Alzheimer's disease and related dementia.

11. Promote the importance of early planning for individuals with Alzheimer's disease and related dementia, their families and caregivers, including planning for healthcare, finances, and legal issues as early in the disease process as possible, so that the individual with Alzheimer's disease and related dementia can fully participate in these processes. This includes advance 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.

12. Support the availability of, and reimbursement for, telehealth services for diagnostic and care management services to improve access to and timeliness of an accurate diagnosis.

Goal 3: <u>Ensure Access to Housing and Supports that Promote Living in the Least Restrictive Environment. Support Formal Caregivers in These Settings.</u>

13. Promote age/dementia-friendly, well-informed communities that focus on reducing stigma, and the inclusion of people living with dementia. Train community members on how to:

    - Identify, offer meaningful assistance, and to communicate effectively with individuals with Alzheimer's disease and related dementia.

    - Appropriately prepare for and respond to hazards and emergencies.

    - Make physical environment modifications that support age/dementia-friendly communities.

    - Ensure access to housing, community-based supports, and/or high-quality long-term care settings.

    - Promote living in the least restrictive environment whenever possible.

14. Promote policy changes, programs, and initiatives that enhance access to, and affordability of, assisted living for those living with Alzheimer's disease and related dementia, including expansion of the Special Needs Assisted Living Residence Voucher Demonstration Program for Persons with Dementia.

15. Promote efforts to expand use of telemedicine/telepsychiatry in the home to facilitate physician care, cognitive assessments, and monitoring of treatment effectiveness.

16. Support the development of a dementia-capable workforce by advancing evidenced based/informed professional education across the professions and supporting ongoing training of formal caregivers across all settings.
17. Develop effective strategies to recruit and retain medical providers, professionals, and formal caregivers.

Goal 4: <u>Supporting Informal Caregivers and Persons Living with Alzheimer's Disease and Related Dementia</u>

18. Promote the importance of identifying and assessing the health and well-being of informal caregivers. Ensure the existence of in-person and virtual support services and systems that provide caregivers with a thorough, person-specific assessment and use of valid and evidence-based tools to assess caregiver burden and stress.

19. Train informal caregivers to appropriately implement evidence-based behavioral strategies and non-pharmacological approaches that will improve quality-of-life for both the caregivers and individuals with Alzheimer's disease and related dementia.

20. Educate informal caregivers on how to effectively navigate the healthcare system, which includes long-term care, and how to access Alzheimer's disease and related dementia resources and services.

21. Ensure that the financial and justice system recognize and support persons with Alzheimer's disease and related dementia by:

    - Providing an on-line Alzheimer's disease and related dementia training for law enforcement personnel.

    - Educating financial services personnel on how to identify and report financial exploitation.

    - Providing training for judges, court personnel, attorneys, and other legal professionals on protecting the legal rights of individuals with Alzheimer's disease and related dementia.

22. Provide continuing education opportunities on Alzheimer's disease and related dementia for all healthcare providers.

23. Support employers to better understand the effects of Alzheimer's disease and related dementia by educating them to recognize the economic cost of Alzheimer's disease and

related dementia to the workplace, and promoting initiatives, including support services and referrals through Employee Assistance Programs and personnel policies.

24. Increase the requirements for evidence-based Alzheimer's disease and related dementia education and training in all long-term care settings.

25. Utilize public health data collection systems such as Behavioral Risk Factor Surveillance System, health data from the National Institutes of Health, the New York State Department of Health, Alzheimer's Disease Program, and from the Alzheimer's Association Facts and Figures document to highlight caregiver health and stress and to quantify the burden of Alzheimer's disease and related dementia more accurately through aggregate data.

Goal 5: <u>Address Disparities and Improve Health Equity</u>

26. Provide support services that target underserved communities, including education on normal aging versus Alzheimer's disease and related dementia and the importance of timely diagnosis of Alzheimer's disease and related dementia.

27. Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.

    - 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.

    - Ensuring regionally appropriate services in rural areas.

28. Educate individuals with early onset Alzheimer's disease and related dementia and their providers about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.

29. Improve the availability of aging network services to support individuals with early onset Alzheimer's disease and related dementia.

30. Encourage families and caregivers of individuals with intellectual disability/developmental disability who suspect memory problems and other symptoms to communicate this concern and request assessment by the individual's healthcare provider and engage in early planning regarding Alzheimer's disease and related dementia. Ensure coordination with, and support from, current New York State Department of Health Initiatives.

Goal 6: <u>Promote Research, Prevention, and Risk Reduction Strategies</u>

31. Using public health data, promote the importance of lifestyle changes to improve the health, wellness, and quality-of-life of individuals with Alzheimer's disease and related dementia

and their caregivers, including best practice approaches for implementing strategies to potentially reduce the risk of developing Alzheimer's disease and related dementia.

32. Increase awareness, reaching patients with the disease, as well as healthy volunteers, regarding the importance of enrolling in Alzheimer's disease and related dementia research and clinical trials.

33. Promote research on the connection between Down syndrome and Alzheimer's disease and related dementia in New York State research institutes/New York State Office of People with Developmental Disabilities/New York State Department of Health initiatives.

Lessons Learned from the 2020 COVID-19 Pandemic

With the declaration of a worldwide pandemic and in response to COVID-19 closures in March 2020, contractors under the New York State Department of Health Alzheimer's Disease Caregiver Support Initiative were required to adapt to delivering services differently. Contractor staff across all funded programs quickly established systems to engage in telehealth patient and family visits, or virtual service delivery.

Caregiver support services continue to be offered through various virtual platforms. Outreach efforts on behalf of the caregiver and the person living with dementia resulted in stronger communication and collaboration among other community-based organizations.

Studies indicated caregivers of those living with Alzheimer's disease and related dementias experienced higher levels of stress during the pandemic than the rest of the population.[82] Early in the pandemic, studies suggested the removal of supports and services at the onset of the pandemic caused a substantial increase on caregiver workload and stress.[83, 84] As stated above, contractors under the New York State Department of Health, Alzheimer's Disease Caregiver Support Initiative, quickly adapted to virtual and telehealth services to ensure there was no gap in delivery of service. A study conducted by the New York University (NYU) Langone, Alzheimer's Disease and Related Disorders Family Support Program, indicated caregivers were able to transition to online services with little difficulty, which allowed them to benefit from the availability of online services. Some caregivers reported satisfaction with the increased convenience of virtual programming.

With the public health emergency ending on May 11, 2023, contractors, community services providers, and Centers of Excellence for Alzheimer's Disease, continue to provide some services virtually, such as support groups and education programs, in order to ensure safety for caregivers, persons with dementia, and staff, to reduce fear of COVID-19, continue accessibility for caregivers with access concerns, and decrease travel time so that staff can dedicate more time to clients.

COVID-19 significantly complicated the health and safety of older adults, particularly those experiencing cognitive impairment, and their caregivers. Advanced age, multiple chronic conditions, and disability are well recognized risk factors for greater morbidity and mortality due to COVID-19, making people with dementia one of the most at-risk groups. Actions under the National Plan are supporting increased research into the impacts of COVID-19 and post-COVID conditions on brain health, cognition and Alzheimer's disease and related dementia. Particularly, efforts are looking at the long-term effects of COVID-19 infections through the Researching COVID to Enhance Recovery (RECOVER) Initiative. This initiative is examining the clinical outcomes seen with long-COVID affecting both cognition and the risk of developing Alzheimer's

disease and related dementia. The National Institutes of Health was joined by the National Institute on Aging to support research specific to the social, behavioral, and economic impacts of COVID-19 on aging and vulnerable populations, including those with cognitive impairment and dementia.

Dementia

Dementia is an umbrella term that refers to a group of degenerative neurocognitive disorders. Alzheimer's disease and related dementia reflects an impairment of 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 an individual's ability to perform activities of daily living and independent functioning.[1]

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia: 60-80% of individuals with dementia have Alzheimer's disease.[2] Alzheimer's disease is a degenerative and ultimately fatal condition characterized by diagnostic brain abnormalities, amyloid plaques and neurofibrillary tangles, and extensive loss of synapses (the connections between neurons that maintain circuits subserving memory and other brain functions). Amyloid plaques and neurofibrillary tangles contribute to this disruption in neuronal communication in the brain, which eventually causes brain cell death. There is currently no cure for Alzheimer's disease. Until recent years, available treatments that may temporarily improve or slow worsening symptoms did not alter the overall disease progression of Alzheimer's disease. However, in 2021, the Food and Drug Administration approved the first disease targeting therapy designed to remove amyloid from the brain. In July of 2023 a second disease targeting therapy to treat Alzheimer's disease in the early, mild stages was approved. An additional disease targeting therapy was approved in July 2024. Like the previous approved therapy, this medication acts on the amyloid plaques and has been shown to slow the progression of the disease in clinical trials.

Alzheimer's disease typically occurs in a progressive sequence of stages. According to the 2011 diagnostic guidelines for Alzheimer's disease published by the National Institute on Aging, Alzheimer's disease begins before the emergence of observable symptoms.

The National Institute on Aging identifies three stages of Alzheimer's disease that occur on a spectrum: preclinical/presymptomatic Alzheimer's, mild cognitive impairment, and dementia due to Alzheimer's disease.[3] More information on the diagnostic guidelines can be viewed at: https://www.nia.nih.gov/health/alzheimers-disease-diagnostic-guidelines.

The Alzheimer's Association identifies three stages of dementia due to Alzheimer's disease: mild, moderate, and severe.[3] Alzheimer's disease 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]

Preclinical/Presymptomatic Alzheimer's Disease

Preclinical Alzheimer's disease 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 Alzheimer's disease begin to occur. Studies suggest the possibility of subtle cognitive changes that could be detectable years before meeting the criteria for mild cognitive impairment.[3]

Mild Cognitive Impairment

Mild cognitive impairment 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. Mild cognitive impairment causes cognitive changes that can affect memory, completion of tasks, reasoning, etc. "Amnestic mild cognitive impairment" affects memory, and "non-amnestic mild cognitive impairment" affects thinking skills outside of memory, such as judgment.[5] Individuals being evaluated for mild cognitive impairment should be screened and assessed for depression because this condition can exacerbate cognitive decline, or its symptoms may mirror cognitive impairment.
The symptoms of mild cognitive impairment 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] Mild cognitive impairment symptoms can be described as a range between the expected modest cognitive decline of normal aging and the more significant changes of Alzheimer's disease and related dementia.[6]

Mild cognitive impairment is significant to the risk assessment and early diagnosis of Alzheimer's disease, but some individuals with mild cognitive impairment never develop Alzheimer's disease. Studies indicate that as many as 15% to 20% of people over age 65 have mild cognitive impairment, and a review of 32 studies identified that a median of 31.5% of people with mild cognitive impairment progress to Alzheimer's disease over five years.[7] People with amnestic mild cognitive impairment are at greater risk of developing Alzheimer's disease. If an individual presents with both mild cognitive impairment and the biomarkers for Alzheimer's disease, there is a degree of certainty that he or she will develop Alzheimer's disease.[5] Limited information exists on the relationship between mild cognitive impairment and other dementias.

The causes of mild cognitive impairment are not fully understood, but there is significant evidence that mild cognitive impairment can be exacerbated by depression, certain medications, and/or co-occurring medical conditions, such as diabetes.[6] For those individuals with mild cognitive impairment caused by treatable conditions, managing these conditions can eliminate the presence of mild cognitive impairment-like symptoms. This is particularly true among older adults with acute depression.[8] Evidence indicates that people older than 70 years of age with mild cognitive impairment and untreated depression are at twice the risk of developing Alzheimer's disease than people with mild cognitive impairment without depression. While a correlation exists between depression, mild cognitive impairment, and Alzheimer's disease and related dementia, there is no definitive evidence that this is a causal relationship.[9]

Mild Alzheimer's Disease (Early-Stage)

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

- 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 an individual exhibits these warning signs, they 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]

Moderate Alzheimer's Disease (Middle-Stage)

Individuals in the middle stage of the Alzheimer's disease 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.

Severe Alzheimer's Disease (Late-Stage)

Individuals in the late stages of Alzheimer's disease experience extremely debilitating symptoms which can be devastating for their caregivers and families. The symptoms of Alzheimer's disease worsen over time. However, the rate of the disease's progression varies. A person with Alzheimer's disease will live on average, eight to ten years after diagnosis. However, in some cases, individuals with Alzheimer's disease can live as long as 20 years.[10, 11]

During the final stage of Alzheimer's disease'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). Schizophrenia is an under-recognized cause of dementia. In a recent study of 8,011,773 individuals (tracked from the national Medicare database), who were 66 years of age, 27.9% of the individuals living with schizophrenia also had a dementia diagnosis.[92]

Causes and symptoms of the various types of dementia vary, although some of the neurodegenerative processes have 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 Alzheimer's disease and related dementia).

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. Several studies report that a majority of people with Alzheimer's disease also had brain changes associated with another form of dementia upon autopsy.[93]. Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample.

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 Alzheimer's disease co-existing with blood vessel complications associated with vascular dementia. Alzheimer's disease symptoms can also have co-morbidity with Lewy bodies, the abnormal protein deposits characteristic of Lewy body dementia. In some cases, a person may have brain changes linked to all three conditions: Alzheimer's disease, vascular dementia, and Lewy body dementia. For more information on mixed dementia, see: https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia

Behaviors Associated with Dementia

Many individuals living with Alzheimer's disease and related dementia may never exhibit behaviors.[81] However, it is not uncommon for those living with the disease to experience behaviors at some point in their diagnosis. Behaviors may include but are not limited to:

Repetition

A person living with Alzheimer's disease and related dementia may have repetitive behaviors, such as asking the same question repeatedly or repeating words or activities.

Aggression

Aggression may be either physical or verbal. Aggressive behaviors may be caused by a frustrating event or may arise for no apparent reason.

Some common causes of aggressive behaviors are:

- Physical discomfort, including lack of sleep, hunger or thirst, or pain.
- Environmental factors - a noisy room, large groups of people, clutter, etc.
- Difficulty with communication - this can include difficulty understanding instructions, being asked too many questions, or given too many tasks at once. In addition,

presentation of aggressive behaviors may be due to the individual living with Alzheimer's disease and related dementia having difficulty communicating their own needs.

Agitation and Anxiety

Agitation and anxiety may be caused by several factors including:

- Change in environment, including hospital admissions, living environment, even new furniture or decor
- New or unfamiliar caregivers
- Uncertainty and fear
- Fatigue

Sundowning

Sundowning can occur from late afternoon/early evening and can last into the night. During this time of day, individuals living with Alzheimer's disease and related dementia may experience increased confusion and behavioral symptoms.

Wandering

Wandering occurs when an individual living with Alzheimer's disease and related dementia loses their way or becomes confused about their location. It is one of the most concerning behaviors associated with Alzheimer's disease and related dementia.[81] Signs of wandering include forgetting how to get to familiar places or talking about fulfilling former obligations (such as work or picking up their children). According to the Alzheimer's Association it is estimated that six in ten people living with Alzheimer's disease and related dementia will wander at least one time. Wandering can be dangerous and increases the risk of emotional strain, physical injury, or even death. Everyone living with Alzheimer's disease and related dementia is at risk for wandering.

More information can be found at: https://www.alz.org/help-support/caregiving/stages-behaviors

Prevalence and Mortality

National

An estimated 6.9 million Americans age 65 or older live with Alzheimer's disease, approximately 73% of these individuals are over age 75.[2] The number of Americans over the age of 65 living with Alzheimer's disease may grow to 12.7 million by 2050.[2] The rate of Alzheimer's disease increases with age, and approximately 35.4% of people over age 85 have Alzheimer's disease.[2] Although Alzheimer's disease is typically diagnosed in people over age 65, it is estimated that at least 200,000 Americans between the ages of 30 and 64 are diagnosed with "younger/early onset."[12] There is currently limited data addressing the prevalence and mortality of other forms of dementia. In 2021, the latest year that the data is available, Alzheimer's disease was the fifth leading cause of death in individuals ages 65 and older. [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 Alzheimer's disease 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. [13] According to data from the Centers for Disease Control and Prevention, 119,399 people died from Alzheimer's disease in 2021.[14] However, prevalence and mortality rates for Alzheimer's disease are not an accurate representation of actual figures due to underdiagnosis and underreporting of Alzheimer's disease on death certificates.[2]

Similarly, limited data related to other dementias could also contribute to their under-representation on death certificates. The Centers for Disease Control and Prevention 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. [15]

The Centers for Disease Control and Prevention, in collaboration with state health agencies, conducts the annual Behavioral Risk Factor Surveillance System (BRFSS) survey. The Behavioral Risk Factor Surveillance System has two modules related to Alzheimer's disease: the perceived cognitive impairment, and caregiver modules. National data from the perceived cognitive impairment module from the 2020 survey indicates that one in ten Americans over the age of 45 are experiencing confusion or memory loss. One in three of those who reported cognitive impairment also reported functional difficulties related to their confusion or memory loss. Less than half of those with cognitive decline have reported this condition to their health care providers.[16] Subjective Cognitive Decline Data from adults in 46 States, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older (cdc.gov)

New York State

The scope of Alzheimer's disease has been difficult to project for multiple reasons. These include the following: many people remain undiagnosed because they do not share their symptoms with their medical providers, medical providers are reluctant to give this diagnosis, and cultural barriers discourage individuals from seeking a diagnosis.

The Alzheimer's Association estimates over 426,000 individuals in New York State have Alzheimer's disease, and that number is expected to increase. An article published in the *Alzheimer's & Dementia: The Journal of Alzheimer's and Dementia*, reported that Bronx County is one of the top three counties in the United States with the highest prevalence of Alzheimer's Disease, with 16.6% of people over the age 65 living with Alzheimer's disease.[87] New York State has the second highest prevalence of Alzheimer's disease in the United States. Comparable data for other dementias is not available.[2]

The Centers for Disease Control and Prevention and the Alzheimer's Disease and Healthy Aging Program utilize the Behavioral Risk Factor Surveillance System (BRFSS) to obtain data on the disease. Similar to national figures, in New York State, one (1) in nine (9) individuals aged forty-five (45) and over reported confusion or memory loss in the 2021 Behavioral Risk Factor Surveillance System and less than half indicated that they reported the condition to their health care provider.[16] Additional New York State related *Behavioral Risk Factor Surveillance System* data is located at: https://www.cdc.gov/brfss/annual_data/annual_2021.html

The United States Department of Health and Human Services recognizes that Alzheimer's disease and related dementia disproportionately impacts racial and ethnic minorities, individuals with younger onset Alzheimer's disease and related dementia, and those with Down syndrome. Health and Human Services has created the Task Force on Specific Populations to address the

needs of these specific populations.[17] The Task Force issued an updated report with recommendations for these populations in 2018.

Early/Younger Onset Dementia

Early (also known as younger) onset dementia occurs when a person under the age of sixty-five (65) is diagnosed with Alzheimer's disease and related dementia. There is limited data available on the number of Americans in the neurotypical population who are currently living with early onset dementia. A systematic review and meta-analysis published by the National Institutes of Health in 2015 estimated that approximately five point five percent (5.5%) of individuals with dementia have an early onset form.[29] In 2006, the Alzheimer's Association calculated a tentative range of 200,000 to 640,000 individuals living with early onset Alzheimer's disease and related dementia in the United States; this wide range is due, in part, to limited information about the number of individuals with early onset of dementias other than Alzheimer's disease, and delayed diagnosis.[12] In addition, other types of dementias mimic early onset Alzheimer's disease including vascular dementia, Huntington's disease, Parkinson's disease, Frontotemporal Dementia, Lewy body dementia, Chronic Traumatic Encephalitis, and Human Immunodeficiency Virus associated neurocognitive disorder.

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 Alzheimer's disease result from inherited mutations on specific genes.[30] Individuals with Down syndrome are at a strikingly increased risk of developing early onset Alzheimer's disease.[31] Other early onset dementias, such as Huntington's disease, Frontotemporal Dementia, 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.[33, 34]

Individuals with early onset Alzheimer's disease and related dementia and their caregivers face unique challenges when planning and managing the disease progression. Since Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia programs are typically designed for older adults. Individuals with early onset Alzheimer's disease and related dementia frequently have dependent children living at home. These factors exacerbate the financial demands and stress on their caregivers.[12]

Down Syndrome

Individuals with Down syndrome, an intellectual and developmental disability, are at increased risk for developing Alzheimer's disease, particularly the early onset form of the disease. This is due to the accelerated aging process experienced by this population. Also, these individuals have a partial or full-third copy of chromosome 21. Chromosome 21 carries genes that are involved in the aging process and in producing the proteins that contribute to the development of Alzheimer's disease neuropathology. The properties of this chromosome set make Alzheimer's disease a more acute concern for this population.[35]

Despite the wide ranges reported for dementia prevalence in individuals with Down syndrome, a consistent feature of aging is the progressive accumulation of Alzheimer's disease brain pathologies. By the age of forty (40) years, virtually all have sufficient senile plaques and neurofibrillary tangles for a neuropathological diagnosis of Alzheimer's disease. Thus, there is dissociation between the age of onset of Alzheimer's disease neuropathology (40 years) and increasing signs of clinical dementia." Eur J Neurodegener Dis. 2012 Dec; 1(3): 353–364. PMCID: PMC4184282 Alzheimer's Disease in Down Syndrome Elizabeth Head,[1,5] David Powell,[2,5] Brian T. Gold,[3,5] and Frederick A. Schmitt.[4,5]

Given this early onset, it is important that families and caregivers of individuals with intellectual/developmental disabilities, Alzheimer's disease or Down syndrome who suspect memory problems and/or other symptoms communicate their concerns to the individual's healthcare provider and engage in early planning regarding Alzheimer's disease and related dementia.
Although most individuals with Down syndrome develop the pathology of Alzheimer's disease, not all exhibit the typical symptoms and cognitive decline associated with the disease. Researchers are focusing on individuals with Down syndrome who do not develop Alzheimer's disease in order to identify differences and protective qualities.[37] 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-morbid conditions such as sensory loss, hypothyroidism, obstructive sleep apnea, osteoarthritis, atlantoaxial instability, osteoporosis, and celiac disease. The presence of multiple co-morbidity conditions makes diagnosis of and treatment for this population difficult because many dementia symptoms are associated with other conditions.[37]

Due to the unique presentation of Alzheimer's disease in individuals with Down syndrome, this population requires specialized care from formal and informal caregivers.[39] 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.[38] More information on the connection of Down syndrome and Alzheimer's disease can be found at: https://www.ndss.org

Risk Factors

There currently is no exact known cause of Alzheimer's disease. Continued research to understand the biological origins of the disease is critically needed. However, researchers have discovered several factors directly associated with Alzheimer's disease: older age, family history and heredity, and lifestyle.

Age

The percentage of people living with Alzheimer's dementia increases with age. Five percent (5%) of individuals between the ages of sixty-five to seventy-four (65-74), thirteen-point two percent (13.2%) of individuals between the ages seventy-five to eighty-four (75-84), and thirty-three-point four percent (33.4%) of individuals aged eighty-five (85) or older have Alzheimer's disease.[2]

Genetics

Genetics research suggests that certain combinations of apolipoprotein enzyme (APOE ε2, ε3, or ε4) genes, inherited from both parents, increase an individual's risk of developing Alzheimer's disease.[2, 40] These gene(s) are responsible for providing the blueprint for a protein that transports cholesterol through the blood stream. Researchers estimate that as many as sixty-seven percent (67%) of individuals with Alzheimer's disease have at least one copy of APOE-ε4. Research also supports the conclusion that mutations of several specific genes cause Alzheimer's disease and related dementia.[40]

Modifiable Risk Factors

A report issued by the Lancet Commission in 2020 updated recommendations made by that group in 2017, highlighting twelve potentially modifiable risk and protective factors for dementia. These risk factors now include less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution.[78] The most recent Lancet Commission report released in 2024 added two additional risk factors; high LDL cholesterol and vision loss. The Commission proposes that up to forty-five percent (45%) of dementias worldwide could be impacted by addressing these fourteen factors.

Further research continues, exploring the influence of lifestyle choices and health conditions on Alzheimer's disease. For example:

- Research supports the importance of cardiovascular health, citing the high rates of Alzheimer's disease in individuals with cardiovascular disease. Risk factors for cardiovascular disease include high cholesterol, obesity, diabetes, lack of physical activity, poor diet, excessive alcohol use, and tobacco use.[2, 42] (Heart Disease Risk Factors | Heart Disease | CDC.)

- 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, Alzheimer's disease 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 are at an increased risk for developing Alzheimer's disease and related dementia.[2]

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring Alzheimer's disease and related dementia.[45] 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 ninety-five (95) than those born in 1905 did at age ninety-three (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 Alzheimer's disease and related dementia and will therefore be less likely to develop the disease. A similar study in England and Wales compared two generations of randomly selected individuals aged sixty-five (65) and older in the same geographic areas.[45] The rate of Alzheimer's disease and related dementia in this study dropped twenty-five percent (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 Alzheimer's disease and related dementia.

Further research regarding risk factors is essential to better understand causal relationships and to improve opportunities for the prevention of Alzheimer's disease and related dementia. Based on known risk factors, individuals can pursue many preventative lifestyle changes to potentially lower their risk of developing Alzheimer's disease and related dementia. These strategies include:

- Exercise/physical activity – Physical activity reduces inflammation, encourages generation of stem cells, helps maintain healthy weight, reduces stress, and risk of many chronic conditions.
- Sleep – The brain clears excess amyloid and other potentially harmful waste materials during deep sleep. Individuals should target seven to eight (7-8) hours of sleep per night.
- Diet – The 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 the risk of many chronic conditions.
- Intellectual Stimulation – 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 activities like exercise and meditation help reduce and control those chemicals.
- Social Stimulation and Reduction of Isolation – The subjective experience of social isolation can increase the risk of dementia by up to forty percent (40%). Feelings of social connectedness and fulfillment can help to reduce this risk.[46, 47]
- Studies have indicated a correlation between hearing loss and Alzheimer's disease and related dementia. A recent study conducted found that hearing intervention may have a significant effect on reducing cognitive decline.[86]

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 make up nearly two-thirds 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 (brain structure, disease progression, estrogen, and depression).[24] Studies have indicated a correlation between hypertensive disorders of pregnancy, including both gestational hypertension and preeclampsia, and vascular dementia. One study conducted found that women with a history of hypertensive disorders of pregnancy were more at risk for developing dementia than women who did not have hypertensive pregnancies. The study found that hypertensive disorders of pregnancy was associated with 1.64 times higher risk for vascular dementia.[80] Health behavior, including cognitive development, education, and physical activity throughout the lifespan might contribute to the difference in prevalence among men and women.[22, 23, 25]

Racial and Ethnic Minorities

Disparities are associated with the risk of developing of Alzheimer's disease and related dementia among certain racial, ethnic, and socioeconomic groups. Compared to older Caucasians, older African Americans are two times and Hispanics are one-and-a-half times more likely to have Alzheimer's disease.[2] More research is needed to estimate the prevalence of Alzheimer's disease and related dementia 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 Caucasians, and lowest among Asian Americans.[18]

Research has shown that higher prevalence rates of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.[2] These conditions include, but are not limited to, cardiovascular disease, diabetes, chronic kidney disease, and higher hemoglobin levels.[19, 20] Increased risk of cardiovascular disease due to diabetes and heart disease also increases the risk of vascular dementia.[2] Socioeconomic characteristics may also contribute to differences in prevalence or incidence among racial groups. These factors include lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination.[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 Alzheimer's disease in African Americans than in non-Hispanic Caucasians of European ancestry.[21] There is evidence that missed diagnoses of Alzheimer's disease and related dementia are more common among African-Americans and Hispanics than non-Hispanic Caucasicans.[2] Research has also found that upon initial diagnosis, African Americans and Hispanics had higher levels of cognitive impairment and dementia than non-Hispanic Caucasians, and suggested that more research is required to determine the reason (e.g., differing cultural views regarding medical care and cognitive decline).[2, 19]

Identification and Diagnosis

The National Institute of Aging's 2011 diagnostic guidelines encourage the early detection of Alzheimer's disease and related dementia by recognizing the preclinical/presymptomatic stage of the disease.[48] Biomarker tests have the potential to identify changes twenty (20) years before noticeable cognitive decline at the preclinical/presymptomatic stage, and these tests are a possible future method of detecting Alzheimer's disease and related dementia.[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 tau and certain other disease-related proteins in cerebrospinal fluid and blood and/or detection of mutations in blood tests).

Another form of biomarker analysis involves brain imaging technology. Magnetic resonance imaging and computed tomography scans enable brain structural abnormalities, including tumors and regional brain shrinkage, to be detected. Positron emission tomography 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 Alzheimer's disease from other forms of dementia with more precision. These new biomarker analyses may eventually enable definitive Alzheimer's disease and related dementia diagnoses to be made in the clinical setting.

Studies have indicated that blood biomarker tests are clinically equivalent to Food and Drug Administration approved cerebrospinal fluid (CSF) tests. These tests are significantly less invasive than cerebrospinal fluid tests. The use of biomarker testing may improve access to an accurate and early diagnosis of Alzheimer's disease.[90] Early and accurate diagnosis will improve access to treatment, including disease targeting therapies. Additionally, early diagnosis will allow the individual to plan for the future while they still have the capacity to do so.

Review and Report on Cognitive Screening Tools

Alzheimer's disease and related dementia cognitive screening tools are assessments that can determine a person's cognitive abilities, detect impairments, track functional/activities of daily living decline, and monitor progression of mild cognitive impairment and Alzheimer's disease and related dementia. 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.

Overall, there are more than forty (40) screening tools available to assess cognition and identify potential impairment.[49] The Alzheimer's Association, the National Institutes of Health, and Centers for Medicare and Medicaid Services have recommended validated tools that are applicable in a range of settings. Several of these tools are particularly suited to primary care offices and can be administered during annual physicals by physicians or other health and clinical professionals.[49] 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 cognitive assessment and the recommendations for clinical practice is located at: https://www.alz.org/professionals/healthcare-professionals/cognitive-assessment.

Additional information on assessing cognitive impairment is located at: https://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients.

Early Detection

New York State Department of Health, 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, 2023-2027 (*Public Health Road Map*)*, issued by the Centers for Disease Control and Prevention and the Alzheimer's Association, recommend early detection of Alzheimer's disease and related dementia National Healthy Brain Initiative State and Local Road Map | Alzheimer's Disease Program | CDC.[50]

Early detection is important for the individual living with Alzheimer's disease and related dementia 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]

The 2019 Alzheimer's Facts and Figures included a *Special Report: Alzheimer's Detection in The Primary Care Setting: Connecting Patients with Physicians*.[79] This report explored the state of cognitive assessment, termed "brief cognitive assessment," in the primary care setting and identified potential solutions for ongoing barriers to widespread adoption of assessment in primary care settings.

Support services, including support groups, care consultation, and educational programs help individuals living with Alzheimer's disease and related dementia connect with peers, and increase knowledge of the disease, caregiving options, and community resources. Individuals diagnosed with early-stage Alzheimer's disease and related dementia have the opportunity to engage in financial and advanced care planning and to determine and clearly express their wishes for the future.[79] 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.[52]

Early detection of Alzheimer's disease and related dementia 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 mild cognitive impairment.[33] In addition, other conditions mimic Alzheimer's disease and related dementia 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 brain imaging, biomarkers, and genetic testing during the preclinical stage before signs and symptoms appear.[53] Early detection provides individuals with the opportunity to participate in clinical trials that could be beneficial for treating or slowing Alzheimer's disease and related dementia in its early stages.

New Alzheimer's treatments, specifically recently approved disease targeting medications, are indicated for people with mild cognitive impairment, or mild dementia. Early diagnosis will ensure patients will have access to new treatments.

<u>Barriers</u>

Barriers to early detection include:

- The public's lack of understanding about the difference between normal aging and the early signs of mild cognitive impairment/dementia. The ten warning signs of Alzheimer's disease/dementia may not be recognized by individuals experiencing cognitive changes and their loved ones.

- Additionally, there is a lack of awareness/understanding among some primary care providers who dismiss the patient/family when they raise concerns about the warning signs of the disease(s).

- Social stigma associated with Alzheimer's disease and related dementia and denial of observed changes and symptoms.[53]

- Fear of being diagnosed with Alzheimer's disease or a related dementia.

- Lack of an affordable biomarker test for Alzheimer's/related dementia adds to the complexity of making an early and accurate diagnosis, especially in rural and under-served communities.

Another significant barrier to diagnosis is the shortage of healthcare providers, including but not limited to, neurologists, geriatric psychiatrists, geriatricians, geriatric nurse practitioners, and other providers who are trained in diagnosing Alzheimer's disease and related dementia. According to the report, "A Shortage of Neurologists – We Must Act Now: A Report from the AAN 2019 Transforming Leaders Program," there is a large disparity between the need for neurologists and the availability of providers. As the population ages, many with neurogenerative diseases, the gap will continue to widen. One of the most prominent effects of the disparity is longer wait times for an initial appointment with a neurologist.[88]

Strategies to overcome these barriers include educating the public and health care providers about the disease and its progression, the benefits of early detection, and the impact of cultural norms on its diagnosis and treatment. A new era of research, treatment, and available services may help mitigate fear of diagnosis. As such, this report addresses recommendations related to increased provider education in the diagnosis and treatment of the disease.

Research Update

Prevention and Risk Reduction

Research is a critical component of finding a method to prevent or cure Alzheimer's disease and related dementia and, given the growing number of individuals diagnosed with Alzheimer's disease and related dementia, time is of vital importance. The focus is on the prevention of Alzheimer's disease and related dementia 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. Aerobic exercise is presently the mainstay of delaying progression of the mild cognitive impairment stage of Alzheimer's disease. Currently, there are no clear prevention strategies for Alzheimer's disease and related dementia. However, there are steps that can be taken to recognize and mitigate risk factors.

The National Institutes of Health report titled *Sustaining Momentum: National Institutes of Health Takes Aim at Alzheimer's Disease & Relate*d *at National Institutes of Health Bypass Budget Proposal for Fiscal Year 2019* suggests that some of the most promising treatments under current investigation may be those focused on prevention by mitigating risk factors.[55] 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 Alzheimer's disease and related dementia.[53]

Several unique and promising prevention research trials are exploring gene therapies and the influence of the endocrine system on preventing Alzheimer's disease and related dementia. 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 Alzheimer's disease, although results of large trials thus far have been negative.

Clinical Trials

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.[55] Large scale clinical trials involving this approach in individuals with mild clinical symptoms of Alzheimer's disease have not shown therapeutic efficacy. The focus on amyloid targeting trials has 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 Alzheimer's disease due to genetic mutation or the presence of early amyloid deposits in the brain detected by neuroimaging.

Tau is a second protein implicated in Alzheimer's disease 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 Alzheimer's disease, these normal functions of tau become corrupted, leading to the aggregation of tau into forms that are considered toxic to neurons. Clinical trials using a tau antibody vaccine or other approaches to reduce tau levels in Alzheimer's disease or other tauopathies are ongoing.

Most recently, a widening range of therapeutic approaches are in pre-clinical and clinical development to target other brain abnormalities in Alzheimer's disease, inflammation and deficient "cell waste recycling" to name a few. Alzheimer's disease 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 Alzheimer's disease and related dementia, the advancements of biologics, particularly monoclonal antibodies, in drug development has led to significant optimism about potential disease targeting treatments. In addition, research has continued focus on non-pharmacological and other pharmacological interventions that can decrease or slow symptoms associated with Alzheimer's disease and related dementia. The Food and Drug Administration approval of disease targeting medications in recent years, and the fact that there are several additional medications under consideration with the Food and Drug Administration, hold hopes for new treatments that may serve as potential therapies for Alzheimer's disease.

Non-pharmacological

Behavioral and psychological symptoms exhibited by individuals with Alzheimer's disease and related dementia should be fully assessed, given that communication with the patient is often difficult. Careful history and assessment may reveal an underlying medical cause for behavioral symptoms which can be addressed and treated by a medical provider. Behavioral symptoms commonly observed with Alzheimer's disease and related dementia 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 must be understood, especially if symptoms are new onset. 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 underlying medical cause, behavioral changes should be approached using non-pharmacological interventions, including skilled communication strategies that are used by all medical and support personnel and formal or informal caregivers, and environmental management. Evidence shows that individuals living with Alzheimer's disease and related dementia are influenced significantly by fatigue, changes in routine, overwhelming sensory input, the need to integrate and respond to a demanding or busy environment and/or the misperceptions about their environment that are related to 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 several suggested interventions that should be considered to alleviate behavioral symptoms for individuals with Alzheimer's disease and related dementia. Person-centered approaches should be applied that demonstrate an understanding of who the person was before developing Alzheimer's disease and related dementia, acknowledge life experiences that were important to them, and support the social roles that the person valued throughout life. Effectively engaging a person in meaningful activities that simulate occupational tasks, such as childcare, past work experiences, and volunteerism, can enhance caregiving success while maintaining social connections and a sense of "self" for the person living with Alzheimer's disease and related dementia.

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 living with Alzheimer's disease and related dementias 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 living with Alzheimer's disease and related dementias 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 living with Alzheimer's disease and related dementia.

Additional non-pharmacological treatments of Alzheimer's disease and related dementia 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 activities of daily living, and/or enhance overall quality-of-life throughout the disease process. Best practices for Alzheimer's disease and related dementia care include care models that are team-based and coordinate care across settings, including medical.[59]

Pharmacological

Alzheimer's disease and related dementias have many co-pathologies; for this reason, development of medications to treat the disease is complex. Until recent years, the only available

medications addressed the symptoms of Alzheimer's disease and related dementia. These medications alter chemicals in the brain that are important to learning, mood, and memory, if only temporarily in the disease course. These pharmacological treatments do not stop the progression of the disease or offer a cure for Alzheimer's disease and related dementias. Future treatment for Alzheimer's disease and related dementias will likely be a combination of medication and risk reduction strategies.

These initial symptom managing medications, called cholinesterase inhibitors are often used to treat mild to moderate symptoms of Alzheimer's disease. The second type of medication available is used for moderate to severe Alzheimer's disease and is believed to mitigate glutamate levels in the brain that may lead to brain cell death.[2]

As previously noted, pharmaceutical companies are exploring new research aimed at the development of drugs that modify the disease by reducing accumulation of amyloid and the formulation/spread of abnormal Tau proteins in the brain.

The first of these disease targeting treatments was approved in June 2021 by the Food and Drug Administration as a treatment that may slow the progression of early-stage Alzheimer's disease by reducing amyloid. This medication was discontinued in 2024. This decision was not based on safety concerns or efficacy.[89]

In July 2023, the Food and Drug Administration granted full approval of a second disease targeting therapy to treat Alzheimer's disease in the early, mild stages. It is a monoclonal antibody medication. It is the first traditionally approved treatment that addresses the underlying course of Alzheimer's, treating the disease.

The Centers for Medicare and Medicaid Services has approved Medicare coverage for a portion of the cost of treatment for patients who have a diagnosis of mild cognitive impairment or mild Alzheimer's disease dementia. To qualify for coverage, the Centers for Medicare and Medicaid Services requires the medication be prescribed by a physician. The prescribing physician is required to enroll patients receiving the treatment in the Centers for Medicare and Medicaid Services National Patient Registry.

Another disease targeting treatment was approved by the Food and Drug Administration on July 3, 2024, furthering the advancements currently underway within Alzheimer's disease and related dementia clinical trials.

Research continues on existing treatments used to manage other diseases that have pharmacological properties, which may yield positive results for Alzheimer's disease and related dementia.[25] More information can be found at: http://www.nia.nih.gov/Alzheimers/publication/Alzheimers-disease-medications-fact-sheet.

Both treatments are covered by Medicare Part B. Individuals receiving treatment with traditional Medicare are responsible for the 20% coinsurance for the cost of the treatment. At this time, coverage for treatment by private insurance companies varies. Also in question is whether both Medicare and private insurance will cover the required ancillary testing, including magnetic resonance imaging and blood work. The Council advocates for universal coverage of the disease targeting therapy and all required testing.

As previously described, 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 Alzheimer's disease and related dementia, 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 Alzheimer's disease and related dementia.[2, 60]

Therefore, medications should be used judiciously for a short period of time. They are likely to be most effective at earlier stages of Alzheimer's disease and related dementia, and frequent assessment is important to ensure that the benefits of these medications outweigh the risks. The effectiveness and/or spectrum of adverse effects of a given psychotropic agent in treating behavioral/psychiatric symptoms may vary considerably. A variety of agents with novel mechanisms of action compared to current anti-psychotics are under development to treat behavioral symptoms of Alzheimer's disease and related dementia. In May 2023, the Food and Drug Administration approved a pharmacological treatment for agitation associated with dementia due to Alzheimer's disease. This is the first Food and Drug Administration-approved treatment option for this indication.

Individuals living with Alzheimer's disease and related dementia 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 the Alzheimer's disease and related dementia treatment approach.[53] It should be noted that the drugs used for Alzheimer's disease and other dementias are associated with significant interactions with other agents, particularly those that prolong the QT intervals (measurement made on an electrocardiogram used to assess some of the electrical properties of the heart). In addition, periodic evaluation of pharmacotherapy as the dementia process continues has also shown to reduce common geriatric syndromes (falls, weight loss, unsteady gait) and improve the general well-being for patients with Alzheimer's disease and related dementia.

Palliative Care

The National Institutes of Health indicates that palliative care should be initiated from the time of diagnosis and may have a substantial impact on improving the quality-of-life.[52] Palliative, or comfort care, aims to keep an individual comfortable and pain-free until life ends naturally.[60] 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 Alzheimer's disease and related dementia, and the disease results in death.[52] Most individuals with late-stage Alzheimer's disease and related dementia 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.[60] Palliative care is not limited to the advanced stages of illness or the end of life, although for people with even the most advanced dementia, comfort matters and is possible. Going forward, planning should include evaluating the efficacy of including palliative care interventions in the treatment of individuals with Alzheimer's disease and related dementia.

Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care, a guidance document developed by CaringKind, addresses the need for improving the quality-of-life and care for residents diagnosed with advanced dementia who live in nursing homes, through a program that generates the special adaptations needed to make palliative care more effective for persons living with advanced dementia and their families. More information on palliative care can be found at: https://caringkindnyc.org/palliativecare/.

Impacts of Caregiving

Informal Caregivers

Millions of Americans are informal caregivers defined as family members, friends and neighbors, who provide critically important unpaid care for individuals with Alzheimer's disease and related dementia. Nationally, informal caregivers for individuals with Alzheimer's disease and related dementia provide an estimated 18.4 billion hours of unpaid care.[2] The Alzheimer's Association reports that caregivers' unpaid care was valued at $346.6 billion in 2023.[2] In New York State, five hundred forty-thee thousand (543,000) caregivers provided eight hundred seventy-nine (879) million hours of unpaid care for individuals with Alzheimer's disease and related dementia, valued at almost $19 billion.[2] Studies have found that as many as twenty-five percent (25%) of individuals cared for by "sandwich generation caregivers" (caregivers who care for both an aging person and a dependent child) are persons living with Alzheimer's disease and related dementia.[2]

The role of an informal caregiver for a person with Alzheimer's disease and related dementia is intensely stressful. Caring for individuals with Alzheimer's disease, especially in the later stages of the disease, can be 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 activities of daily living, 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 living with Alzheimer's disease and related dementia.

Most of the contemporary research indicates that the impacts of caring for an individual living with Alzheimer's disease and related dementia disproportionately affects women and minorities.[62] Women provide more than sixty percent (60%) of all paid and unpaid caregiving for individuals with Alzheimer's disease and related dementia.[26] Of those who provide care for more than five years, sixty three percent (63%) of those caregivers are women. This means that much of the financial, emotional, and physical burden of caregiving falls on them.[2, 27] Women are more likely than men to reduce their work hours to part-time or stop working altogether to be able to provide care. Twenty percent (20%) of female care partners have gone from full-time to part-time, while only three percent (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.[22, 23, 28]

According to the *2023 Alzheimer's Disease Facts and Figures* and a study conducted by the American Association of Retired Persons, Hispanic and African American caregivers report more time caregiving and higher intensity of caregiving burden compared to non-Hispanic Caucasian caregivers.[2, 62, 63] Other research identifies non-Hispanic Caucasian caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.[64]

Research also demonstrates that providing caregivers with an array of support services alleviates caregiver burden, enhances the quality-of-life for both the individual living with Alzheimer's disease 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 Alzheimer's disease and related dementia.[65, 66, 67] The Alzheimer's Association recommends case management, psychoeducation, counseling, support groups, respite, psychotherapeutic approaches, multicomponent approaches, and training for caregivers of individuals with Alzheimer's disease and related dementia. Caregivers who receive support services can stave off negative impacts on their own health.[66]

Due to the substantial number of informal caregivers providing care to individuals living with Alzheimer's disease and related dementia in New York State, the Council has identified this issue as a vital priority.

Formal Caregivers

Formal caregivers are paid staff who provide in-home or residential care. This workforce includes direct care staff and supporting professionals. Additionally, there are care partners who work with paid/professional supports as a team to provide daily caregiving. These roles/duties may change as the person moves through the stages of Alzheimer's/dementia. The role of the care partner is not limited to spouses, partners, or close family members. They may serve as a primary, secondary, or remote support network. One of their greatest challenges is to know where, when, and how to provide assistance. As a result, these caregivers and professionals often experience high levels of stress, depression or anxiety, leading to high turnover rates for paid staff in this field and overwhelmed caregivers. A 2005 study, which examined attitudes of direct care workers serving people with Alzheimer's disease and related dementia, found that stress levels are particularly high in facilities with specialized Alzheimer's disease and related dementia units.[68] Stress levels were also higher among male workers, younger workers, and staff working for less than two years.

The growing number of individuals with Alzheimer's disease and related dementia has created an urgent need for additional training for *all* caregivers. It is important to develop effective strategies to attract and retain a more qualified workforce.[69] Workers, family members, and support providers who receive enhanced Alzheimer's disease and related dementia training are more likely to have a person-centered attitude and report more job satisfaction and work to maintain a family member in their home. This need is addressed in the goals of this report.

The Council recognizes increasing and supporting the direct care workforce in New York State as a vital priority:

Strategies include:

- Increasing compensation
- Providing specialized dementia training
- Incentivizing professional growth and development

Cost of Alzheimer's Disease and Other Dementia

Individuals living with Alzheimer's disease and related dementia use a disproportionate amount of healthcare resources. Until less invasive, more affordable biomarker tests are approved and available, even the cost of diagnosing Alzheimer's disease is disproportionately higher than other diagnoses. A study funded by National Institutes of Health found that health care costs for Alzheimer's disease and related dementia are greater than for any other disease. The National Institutes of Health reported that in the last five (5) years of life, total health care spending for an individual living with Alzheimer's disease and related dementia is more than $341,651, greater than costs associated with this period from any other diseases.[91]

The cost of health care, long-term care, and hospice services for individuals with Alzheimer's disease and related dementia makes dementia one of society's most costly chronic conditions.[70] The *2024 Alzheimer's Disease Facts and Figures* pinpoints the cost of care for Americans with Alzheimer's disease and related dementia is projected to reach $360 billion nationally. This includes an estimated $231 billion covered by Medicare and Medicaid, $91 billion in out-of-pocket expenses paid by individuals with Alzheimer's disease and related dementia and/or their caregivers, and $39 billion covered by other sources, including private insurance and health organizations.[2]

Nationally, almost four million individuals who have Alzheimer's disease and related dementia also have at least one other chronic condition. These individuals are five point five (5.5) times more likely to have six or more chronic conditions than a person without Alzheimer's disease and related dementia. According to the 2017 New York State Behavioral Risk Factor Surveillance System, eighty-three percent (83%) 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 Alzheimer's disease and related dementia are heart disease, stroke, and kidney disease. The combination of Alzheimer's disease and related dementia and chronic health conditions complicates treatment and increases the cost of care. In 2014, thirty-eight percent (38%) of Medicare beneficiaries aged sixty-five (65) and older with dementia also had coronary artery disease, thirty-seven percent (37%) also had diabetes, twenty-eight percent (28%) also had congestive heart failure, twenty-nine percent (29%) also had chronic kidney disease, and twenty-five percent (25%) also had chronic obstructive pulmonary disease.[2]

The average Medicare costs for seniors with Alzheimer's disease and related dementia and other chronic conditions are significantly higher than those individuals on Medicare who have a chronic condition without Alzheimer's disease and related dementia. According to a 2013 study, a senior with Alzheimer's disease and related dementia and diabetes costs Medicare eighty-one percent (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 Alzheimer's disease and related dementia. A senior with one chronic condition and Alzheimer's disease and related dementia costs Medicare an average of seventy-five percent (75%) more than a senior with one chronic condition but no Alzheimer's disease and related dementia. This equates to $16,775 as compared to $9,523. Seniors with three chronic conditions and Alzheimer's disease and related dementia cost Medicare, on average, twenty-five percent (25%) more than a senior with three chronic conditions but no Alzheimer's disease and related dementia ($27,097 compared to $21,581).[71]

Individuals living with Alzheimer's disease and related dementia 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, forty-two percent (42%) of individuals age sixty-five (65) and older with Alzheimer's disease and related dementia lived in long-term care facilities as compared with two percent (2%) of individuals age sixty-five (65) and older without Alzheimer's disease and related dementia.[71] A 2004 study estimated that individuals living with Alzheimer's disease and related dementia are hospitalized two to three times more frequently than individuals of the same age without Alzheimer's disease.[1, 72] However, a 2013 study showed a decrease in hospital discharges for individuals with Alzheimer's disease and related dementia between 1999 and 2009. This could be due to increasing mortality rates for individuals living with Alzheimer's disease and related dementia, as well as an increase in individuals living with Alzheimer's disease and related dementia who are cared for in residential facilities rather than hospitals.[72]

In addition to increased health care costs, the cost of Alzheimer's disease and related dementia 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.[74] 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 living with Alzheimer's disease and related dementia needs to exit the workforce prematurely due to symptoms of Alzheimer's disease and related dementia, particularly early onset.

Elder Justice for Individuals Living with Alzheimer's Disease and Other Dementia

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 Federal Elder Justice Act (42 U.S.C. § 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 New York State, elder abuse and exploitation cases are referred to Adult Protective Services and are tracked through the Adult Services Automation Program (ASAP.net) or Adult Protective Services (APS.net) in New York City. In addition, New York State has been participating with the federal government to provide statistical data to the National Adult Maltreatment Reporting System since 2016.

The number of individuals suffering from elder abuse is severely underreported. According to the 2011 New York State Elder Abuse Prevalence study titled *Under the Radar: New York State Elder Abuse Prevalence Study*, for each reported case of abuse, as many as twenty-four (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.[76] 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 living with Alzheimer's disease and related dementia 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 living with Alzheimer's disease and related dementia from abuse is for an advocate, friend, family member, or caregiver who recognizes the warning signs to intervene or contact New York State Adult Protective Services for assistance. More information about recognizing elder abuse can be found at: https://ocfs.ny.gov/main/psa/financial-exploitation.asp

Financial Exploitation

Financial exploitation is the most common form of elder abuse and is the most underreported. The 2011 *Under the Radar* study found that only one (1) in forty-four (44) cases of financial abuse is reported, compared to one (1) in twenty-four (24) cases overall.[76] 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 living with Alzheimer's disease and related dementia is more vulnerable to this exploitation. In general, financial exploitation is difficult to prove due to underreporting and, often, lack of proof.

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 New York State, Adult Protective Services has the authority to examine bank records when indicated. The New York State Office of Children and Family Services and Division of Financial Services have continued to conduct numerous trainings on these topics for state and local staff as well as representatives of financial institutions. A recording of one of these 2018 trainings is posted on the Office of Children and Family Services website.[78]

More information is available at:
http://www.nij.gov/topics/crime/elder-abuse/pages/financial-exploitation.aspx

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

https://acl.gov/programs/protecting-rights-and-preventing-abuse/elder-justice

Physical Abuse, Emotional Abuse, and Neglect

Individuals living with Alzheimer's disease and related dementia 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 more prevalent 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 Adult Protective Services. More information is available at: https://aging.ny.gov/programs/elder-abuse

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

National and New York State Public Policy Initiatives

National

The "Healthy Brain Initiative" Public Health Road Map
https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html?CDC_AAref_Val=https://www.cdc.gov/aging/healthybrain/roadmap.htm

The Healthy Brain Initiative's State and Local Public Health Partnerships to Address Dementia: the 2018-2023 Road Map (Healthy Brain Initiative Road Map) serves to advance cognitive health as an integral component of public health. It outlines how state and public health agencies, and their partners, can continue to promote brain health, address cognitive impairment for people living in the community, improve diagnosis and care of Alzheimer's disease and related dementia and help meet the needs of caregivers. This Healthy Brain Initiative Road Map forms the means by which policies, systems, and environments can further promote brain health. State Alzheimer's plans are increasingly being guided by the actions outlined in the Road Map.

The 2018-2022 Healthy Brain Initiative Road Map outlined 25 actions centered around four traditional domains of public health, including to Educate and Empower, Develop Policies and Mobilize Partnerships, Assure a Competent Workforce, and Monitor and Evaluate. Alignment of the Road Map actions with essential services of public health ensures that initiatives to address Alzheimer's disease can be incorporated easily and efficiently into existing public health initiatives.

A 2023-2027 version of the Healthy Brain Initiative Road Map was released in 2023. The updated Healthy Brain Initiative Roadmap outlines 24 actions centering around domains of public health. The domains were expanded from the previous report to: Strengthen Partnerships and Policies, Measure, Evaluate and Utilize Data, Build a Diverse and Skilled Workforce, and Engage

and Educate the Public. The Roadmap's continued goal is to fully integrate cognitive health and caregiving supports into public health practices.[50]

National Plan to Address Alzheimer's Disease

The National Alzheimer's Project Act was signed into law in early 2011 and requires the Secretary of Health and Human Services to create and maintain a national plan to address Alzheimer's disease. The *National Plan to Address Alzheimer's Disease* (National Plan) was released in May 2012, with the most recent update published in 2022. National Plan to Address Alzheimer's Disease: 2022 Update The National Plan coordinates federal research on Alzheimer's disease, works to improve prevention, diagnosis, treatment, and care for Alzheimer's disease, including health care services and long-term services and supports, and coordinates internationally on the fight against Alzheimer's disease.

The National Plan focuses on six goals: Prevent and Effectively Treat Alzheimer's disease and related dementia by 2025, Enhance Care Quality and Efficiency, Expand Supports for People with Alzheimer's Disease and Related Dementia and their Families, Enhance Public Awareness and Engagement, and Track Progress and Drive Improvements. In 2021, a new national goal was added specific to the promotion of healthy aging and the reduction of risk factors for Alzheimer's disease and related dementias. This new goal will guide research, public health, and clinical practice toward evidence-based lifestyle changes that may mitigate the development of disease.

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

The National Institutes of Health and other entities use large research Summits to engage with the research community and stakeholders and to solicit perspectives on research gaps and opportunities relevant to cognitive aging and Alzheimer's disease and Alzheimer's disease-related dementias. The third Summit on Care, Services and Supports for Persons with Dementia and their Caregivers was held in March 2023.

The goals of the Summits are 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 living with dementia, families, and other caregivers.

GUIDE Model

Guiding an Improved Dementia Experience

On July 1, 2024, the Guiding an Improved Dementia Experience (GUIDE) model was introduced by the Centers for Medicare and Medicaid Services (CMS) as an eight-year pilot program with the goal of supporting persons living with dementia and their caregivers through an interdisciplinary team. This model focuses on the importance care coordination including care management, caregiver education and support, and respite services.

Currently, to qualify for this model, potential participants must have Medicare Part A and B and a diagnosis of dementia, as confirmed by a physician, for the delivery of the comprehensive care model. Under the Guiding an Improved Dementia Experience (GUIDE) model, participants are

assigned a Care Navigator who will assist the person living with dementia and their caregivers to access both clinical and non-clinical support.

There are currently 390 healthcare organizations/systems enrolled in the Guiding an Improved Dementia Experience (GUIDE) model nationwide with 24 located in New York State.

The Guiding an Improved Dementia Experience (GUIDE) model delivers on the Biden Administration's Executive Order 14095 to increase access to high-quality care and supporting caregivers as well as supporting the goals of the National Plan to Address Alzheimer's Disease. Reference: https://www.cms.gov/priorities/innovation/innovation-models/guide

BOLD: Building Our Largest Dementia Infrastructure for Alzheimer's Act

The federal government advanced support for a public health approach to the prevention, treatment, and care of Alzheimer's disease and related dementia, under new legislation passed on December 31, 2018. The **Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act** authorized the Centers for Disease Control and Prevention to 1) Establish Public Health Centers of Excellence dedicated to promoting the best ways to effectively manage Alzheimer's disease and related dementia and support caregivers, 2) Work with state, local, and tribal public health departments to promote brain health, strategies to reduce cognitive decline and care for individuals with Alzheimer's disease and related dementia, and 3) Improve the analysis and timely reporting of data on Alzheimer's disease and related dementia, cognitive decline, caregiving and health disparities at both a state and national level. BOLD Infrastructure for Alzheimer's Act | Alzheimer's Disease Program | CDC Efforts under Building Our Largest Dementia Infrastructure have been directed at implementing the **Healthy Brain Initiative 2023-2027 Road map** Healthy Brain Initiative (HBI) Road Map | Alzheimer's Association.

Building Our Largest Dementia INITIATIVES UNDERWAY across the United States and in New York

Through competitive processes in 2020 and 2023, the Centers for Disease Control and Prevention successfully funded 43 state, local, and tribal health departments to implement or expand Alzheimer's disease and related dementia infrastructure. Several states and jurisdictions are at an early stage of developing an Alzheimer's disease and related dementia coalition and the partnerships needed to support Alzheimer's disease and related dementia services. States with more developed programs, such as New York, are expanding focus on early detection and diagnosis of Alzheimer's disease and related dementia and the promotion of brain health under Building Our Largest Dementia Infrastructure.

NEW YORK Building Our Largest Dementia INITIATIVES

The New York State Department of Health, Alzheimer's Disease Program (ADP), submitted an application (through Heath Research Inc.) in response to a January 2023 Notice of Funding Opportunity (NOFO). The Alzheimer's Disease Program project was awarded a 5-year cooperative agreement with the Centers for Disease Control and Prevention beginning on

9/30/2023 and ending on 9/29/2028. Project activities are specific to increasing awareness about brain health, risk reduction strategies, and the management of chronic disease comorbidities, as well as strengthening partnerships with primary care providers around early detection and diagnosis.

Building Our Largest Dementia Infrastructure project activities will specifically include:

1. Partnering with New York State Chronic Disease Programs to develop public awareness messaging about brain health and lifestyle changes that reduce the risk of developing dementia. These risk factors include smoking cessation, nutrition, physical activity, obesity management, and overall cardiovascular health.

2. Expanding knowledge about brain health and risk reduction strategies at a local level by engaging staff at county public health departments or offices on aging in efforts to promote important lifestyle change. Activities will be focused on underserved counties and regions of New York State.

3. Increasing access to early detection and diagnostic services for those individuals suspected of having Alzheimer's disease and related dementia. This project will train primary care providers using the clinical expertise of the New York State Centers of Excellence for Alzheimer's Disease and New York University Building Our Largest Dementia Infrastructure, Public Health Center of Excellence on Early Detection of Dementia (NYU BOLD PHCOE on EDD). This effort will build health provider capacity and the capability to manage Alzheimer's disease and related dementia in underserved regions of New York State.

Information about Building Our Largest Dementia Infrastructure can be found at: BOLD Infrastructure for Alzheimer's Act | Alzheimer's Disease Program | CDC

Related Public Policy Initiatives:

New York State Initiatives

On November 4, 2022, Governor Kathy Hochul directed an unprecedented new level of coordination, planning, and policymaking with Executive Order No. 23, creating the first Master Plan for Aging in New York State, heralding a new era of support for older adults and people of all ages to succeed.

Under the leadership of Governor Hochul, New York State has embarked on New York State's Master Plan for Aging. The Master Plan for Aging is designed to ensure that older adults and individuals of all ages can live healthy, fulfilling lives while aging with dignity and independence.

The New York State Department of Health and New York State Office for the Aging are coordinating the Master Plan for Aging, building on decades of work and partnerships with state agencies, local governments, and stakeholders. First announced in Governor Hochul's State of the State Address and Fiscal Year 2023 State Budget, the Master Plan for Aging process was further directed by Executive Order No. 23, which Governor Hochul signed on November 4, 2022.

In its structure and scope, the Master Plan for Aging is a new and unprecedented opportunity to support older adults and people of all ages. However, the Master Plan for Aging also builds on a

longstanding foundation of existing coordinated work in New York. This work has long recognized that the concerns of older adults – and the opportunities to support them – exist across traditional service, infrastructure, and program boundaries.

The Master Plan for Aging's origins extend from several preceding efforts and initiatives. These include Livable New York, in 2011, which helped municipalities better plan for the housing and community needs of older people, younger people with disabilities, families, and caregivers. In addition, the Downtown Revitalization Initiative – now in its sixth round of funding – has invigorated and enlivened smaller and rural downtowns to improve quality-of-life and foster age-friendly community spaces for people of all ages to thrive.

These and related efforts at the state and local levels led to a landmark distinction in 2017: New York became the first state in the nation enrolled into the World Health Organization Global Network of Age-Friendly Cities and the American Association of Retired People Network of Age-Friendly States. This Age-Friendly New York milestone was followed by Executive Order No. 190 (in 2018), which embeds age-friendly and livable principles into state policies, operation, and procurement based on a Health Across All Policies Approach in alignment with New York's Age-Friendly initiatives. New York State's Public Health and Planning Council lead the Prevention Agenda. The 2019-2024 Prevention Agenda furthers New York State's health improvement plan, which is the blueprint for state and local action to improve the health and well-being of all New Yorkers. Incorporated within the Prevention Agenda is the Health Across All Policies/Age Friendly New York initiative, whereby state agencies work together to identify and strengthen the ways that their policies and programs can have a positive impact on health.

New York State Department of Health is the first health department to be recognized by the Trust for America's Health as an Age-Friendly Public Health System. To achieve this designation, the New York State Department of Health completed all of the requirements of Trust for America's Health's Age-Friendly Public Health Systems, Public Health System Recognition Program.

Working caregivers is one of the areas of focus when planning and developing cross systems supports and services. In the United States today, one (1) in six (6) employees spends on average more than twenty (20) hours a week providing care for a loved one. https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/

New York State Department of Health

The 2023-2024 New York State budget dedicated $26.4 million for Alzheimer's disease and related dementia programs, representing the largest single-state investment of its kind. With these funds, the New York State Department of Health has continued to expand and strengthen existing Alzheimer's disease and related dementia programs and developed new initiatives using evidenced-based strategies to support caregivers of and individuals living with Alzheimer's disease and related dementia.

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

This initiative, one of many New York State Department of Health Medicaid Redesign Team 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.

The increased state appropriation funds three (3) major caregiver support initiatives. The goal of these initiatives is to expand the safety net for caregivers of individuals living with Alzheimer's disease and related dementia 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 living with Alzheimer's disease and related dementia and their caregivers, reduced hospitalizations, and increased ability to maintain individuals living with Alzheimer's disease and related dementia in the community. Programs which serve similar geographic regions collaborate with and reciprocally refer individuals living with Alzheimer's disease and related dementia 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 New York State map listing county-specific services can be found at:
https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/county/.

A description of each component of the initiative follows:

The Regional Alzheimer's Disease Caregiver Support Initiative

The Regional Alzheimer's Disease Caregiver Support Initiative provides $16.5 million annually to fund a network of ten (10) organizations across New York State which deliver programs that support caregivers who care for New Yorkers living with Alzheimer's disease and related dementia across New York State. Beginning in 2022, funds allocated for the former Alzheimer's Disease Caregiver Initiative for Underserved Communities were included in the Regional Caregiver Support Initiative. The Request for Applications for the Regional Alzheimer's Disease Caregiver Support Initiative included a program component to identify, engage, and provide targeted outreach and services to members of underserved communities. As these services are implemented, data is collected to assess their efficacy.

This statewide program provides*:*

- Caregiver Assessments
- Outreach to and Engagement with Underserved communities
- Caregiver Support and Engagement activities, such as
    - Support Groups,
    - Joint Enrichment Activities; and/or
    - Caregiver Wellness Programs
- Caregiver Education
- Respite

Centers of Excellence for Alzheimer's Disease

The Centers of Excellence for Alzheimer's Disease initiative provides $4.7 million annually to a network of ten (10) medical centers and teaching hospitals across New York State, recognized nationally and by New York State as experts in the diagnosis and care of individuals living with Alzheimer's disease and related dementia. The Centers of Excellence for Alzheimer's Disease

are leaders in the field of research and clinical trials seeking effective treatments and a cure for Alzheimer's disease and related dementia.

The Centers of Excellence for Alzheimer's Disease program provides:

- Interdisciplinary and comprehensive medical services for the diagnosis of Alzheimer's disease and related dementia.
- Coordinated treatment and care management for individuals living with Alzheimer's disease and related dementia.
- Linkages to community-based services for patients and caregivers.
- Expert training for physicians, health care professionals, and students on the detection, diagnosis, care management, and medications available for the treatment of Alzheimer's disease and related dementia.
- 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 Alzheimer's disease and related dementia 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 statewide and in every region of New York State. Through subcontracts with the seven (7) Alzheimer's Association Chapters, the Alzheimer's Association/Coalition delivers a comprehensive array of community-based services for individuals living with Alzheimer's disease and related dementia and their caregivers.

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 living with Alzheimer's disease and related dementia.
- Support groups for caregivers and individuals living with Alzheimer's disease and related dementia.
- A 24-hour Helpline available in more than two hundred (200) languages.
- Community education, awareness, and outreach.
- Training for professional caregivers, faith leaders, and gatekeepers, to create dementia-friendly and well-informed communities.

While not a direct replication, these initiatives reflect the evidence developed by Dr. Mary Mittelman at New York University (NYU) and others.[65, 66] Dr. Mittelman's research studies provide evidence that caregiver support and counseling can delay nursing home placement by a median of one point five (1.5) years.[65] 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."[66] Dr. Mittelman's newer research demonstrates that the New York University Caregiver Intervention can result in seventeen percent (17%) fewer Alzheimer's disease and related dementia deaths in nursing homes, and up to $178.9 million in Medicaid savings over a fifteen (15) year period.[77]

Researchers at the School of Public Health, University of Albany, State University of New York, have completed a comprehensive, statewide, multi-level evaluation of the Alzheimer's Disease Caregiver Support Initiative from 2016-2021. This evaluation examined process and outcomes with an emphasis on how New York State has changed as a result of this initiative.
The evaluation reports can be found at:
https://www.health.ny.gov/statistics/diseases/conditions/dementia/alzheimer/

In addition to documenting the effect of these expanded caregiver support services on a variety of patient, caregiver, and health system outcomes, the evaluation demonstrated significant contributions to the national evidence-base related to Alzheimer's disease support services. It generated important evidence for future programmatic and policy decisions at both the state and national levels.

The net estimated cost savings due to the delay in nursing home placement, using the most conservative estimates, was in excess of $1.9 billion over the course of the Initiative. Over the first 5-year period of the Initiative, contractors provided over 1.19 million units of service to caregivers, which averages to an approximate cost of $90 per unit of service. Based on this per-unit cost, the average cost of service per caregiver who said that services kept their loved one home longer was approximately $786.

As of December 2024, more than 323,000 unduplicated caregivers received services through the Alzheimer's Disease Community Assistance Program and the Regional Caregiver Support Initiatives from 2016-2024. Since its inception, the Caregiver Support Initiative has provided over 233,000 consultations/caregiver assessment services, over 27,200 support group sessions, and over 1,000,000 hours of respite care.

The Centers of Excellence for Alzheimer's Disease initiative has provided more than 66,000 new diagnostic assessments, over 205,000 referrals to community supports, and over 116,000 trainings to physicians, health care professionals, and students.

A survey of informal caregiver participants, conducted in the third year of the first Initiative, assessed outcomes such as the impacts on caregiving, benefits of services, positive aspects of caregiving, self-reported healthcare utilization, and reported nursing home delay. The survey reflects caregivers who participated in programs and services funded through the New York State Alzheimer's Disease Caregiver Support Initiative between January 2018 and July 2019. Caregivers reported a wide range of benefits from Alzheimer's Disease Caregiver Support Initiative services. These included improved knowledge and skills and increased quality-of-life for both the care recipient and caregiver. Caregivers reported that their overall health and well-being improved. Results also indicated that a greater number of benefits and stronger endorsement of benefits is associated with participation in a greater number of services provided through the Initiative. https://www.health.ny.gov/diseases/conditions/dementia/docs/eval_rpt_y1_rpt_2.pdf

Other New York State Department of Health Initiatives

Public Health Live!

Educational webcasts were produced on current evidenced-based information and interventions through a partnership between the New York State Department of Health and the University at

Albany School of Public Health known as ***Public Health Live*!** Continuing education credits for viewing webcasts were available for professionals, including physicians, nurses, and social workers. Webcasts related to Alzheimer's disease and related dementia for 2020 - 2021 were:

- *Caregiver and Patient Health in Alzheimer's Disease Policy and Systems Change* - David Hoffman, DPS, CCE

- *New York State's Public Health Approach to Alzheimer's Disease*
  Mary P. Gallant, PhD, MPH
  Meghan Fadel, Director of Evaluation, New York State Department of Health

- *Sex, Guns, and Driving: Considerations in Dementia Care* -
  Jessica Zwerling, MD, MS
  Andrea Sullivan, OT/L

The New York State Department of Health's participation with the Public Health Live! Webcasts was discontinued in 2021 but as noted, these programs remain available to the public. These can be found at https://www.albany.edu/cphce/phlchron.shtml.

Behavioral Health and Dementia Workgroup

The healthcare system in New York State has been lacking in its ability to support people with dementia who need behavioral health services. Although not all people diagnosed with Alzheimer's disease and related dementia experience behavioral symptoms, those who do often face difficulty accessing timely and appropriate acute care, episodic medical management, or long-term care services. Many are at a higher risk of hospitalization and placement outside of New York State.

The New York State Department of Health, Alzheimer's Disease Program, explored issues related to behavioral health services for those living with Alzheimer's disease and related dementia in 2019 with a plan to inform interagency policy, as well as the 2020 budget process. A workgroup was convened to identify barriers to accessing appropriate and timely behavior health services and to identify best practice approaches that address these barriers. Discussion participants represented the New York State Department of Health, New York State Office of Mental Health, National Alzheimer's Association, Center for Elder Law and Justice, and several behavioral health providers from St. Peter's Health Partners, University of Rochester, and State University of New York Downstate.

Three factors were identified that contribute to systematic gaps in behavioral health services: barriers to admission across all levels of care, a lack of specialized facilities within New York State, and a shortage of skilled workers equipped to care for this population. The use of technology such as telemedicine and the Alzheimer's and Dementia Care Project ECHO (Extension for Community Healthcare Outcomes) consultations were found to be useful in enhancing access to services and expertise in several regions of New York State. This initiative was in discussion in early 2020 but further action was delayed by the priorities of the COVID-19 pandemic.

Special Needs Assisted Living Residence

Adults with Alzheimer's disease and/or dementia who can no longer afford to pay privately for a Special Needs Assisted Living Residence generally have no other option than to enroll in the Medicaid Program. This enrollment often results in a transition from private pay residence in an assisted living facility to a skilled nursing facility. In order to explore options to prevent such transitions and to keep residents in the least restrictive setting possible when a higher level of care is not needed, the State of New York enacted the Special Needs Assisted Living Residence Voucher Program for Persons with Dementia.

The 2018-19 New York State Budget authorized the New York State Department of Health to establish a demonstration voucher program to subsidize the cost of a Special Needs Assisted Living Residence for eligible individuals with Alzheimer's disease and/or dementia living in a participating residence. This program became permanent in 2024. Through this program, the New York State Department of Health was authorized to issue up to two hundred (200) vouchers to individuals who are no longer able to pay for their assisted living care but remain appropriate for that level of care. The program can subsidize up to seventy-five percent (75%) of the regional average private pay rate for the monthly cost of a Special Needs Assisted Living Residence for an approved applicant. The Council advocates for continued funding of this program.

Dementia Friendly America

New York State has been designated as an active member of the Dementia Friendly America national network. Several counties in New York State have been designated as a Dementia Friendly America Community. More information can be found at: https://www.dfamerica.org

New York State Office for the Aging (NYSOFA)

The mission of the New York State Office for the Aging (NYSOFA) is to help older adults be independent for as long as possible, emphasizing hard-to-serve and diverse populations. This is achieved by advocacy, delivering person-centered, consumer-oriented, and cost-effective policies, programs, and services, and supporting and empowering older adults.

Services are delivered in partnership with a network of public and private state and community-based providers. A network of Area Agencies on Aging (AAA) located in every county are the primary providers of these services. New York State Office for the Aging partnerships help maintain older adults in their homes and engaged with their communities of choice – a goal of a majority of older adults, especially individuals living with Alzheimer's disease and related disorders and their caregivers.

New York State Office for the Aging's overall goal is to improve access to, and availability of, appropriate and cost-effective, non-medical support services for older individuals that can maximize their ability to age in a community of choice and avoid higher levels of care and publicly financed care. The following programs and services help achieve these goals for older adults with Alzheimer's disease and related disorders and their caregivers.

Social Adult Day Services (SADS) Programs

New York State Office for the Aging-Funded Social Adult Day Services and Data
Social Adult Day Services are structured, comprehensive programs that provide functionally impaired adults (those who need help with everyday tasks) with services in a protective setting

for any part of the day, but for less than a 24-hour period. Currently, there are 69 Social Adult Day Services programs in the state, of which 14 Social Adult Day Services are directly funded by New York State Office for the Aging and 55 Social Adult Day Services programs funded by the local Area Agencies on Aging.

New York State Office for the Aging-funded Social Adult Day Services programs served 1,082 adults in 2023 - 556 individuals and 509 caregivers. Of the 558 individuals served, 75% had Alzheimer's disease and related disorders. There is a tremendous need for the services and supports delivered by Social Adult Day Services programs, including socialization, monitoring and supervision, caregiver support, access to personal care, and nutrition.

Social Adult Day Care (SADC)/Social Adult Services (SADS) HCBS Final Rule Template
This is a care planning document implemented to ensure a person-centered planning process is followed. Sites had the option of using the new Person-Centered Service Plan template or updating their existing template to meet the person-centered requirements. This document can be access through the following link:
https://www.health.ny.gov/health_care/medicaid/redesign/mrt90/mltc_policy/sadc/docs/2023-12-14_release_sadc-sads_pcsp_template.pdf

Caregiver and Respite Supports and Services

The National Family Caregiver Support Program (NFCSP – Title IIIE)
The National Family Caregiver Support Program provides funding to assist family and informal caregivers to provide care to a loved one in their home. These services work in conjunction with other state and community-based services to provide a coordinated set of supports. Area Agencies on Aging that accept National Family Caregiver Support Program funds from New York State Office for the Aging must establish and operate a program that provides specific services including:

- Information to caregivers about available services.
- Assistance to caregivers in gaining access to services.
- Individual caregiver counseling.
- Caregiver support groups.
- Caregiver training.
- Respite care (in-home or out of home).
- Supplemental services, on a limited basis.

2023 Caregivers Served

- 2,775 caregivers received counseling.
- 780 caregivers received training.
- 1,750 caregivers received respite care.
- 1,843 caregivers received supplemental services.

Caregiver (Consumer) Directed Respite
There is an expanded caregiver-directed service delivery model offered by New York State Office for the Aging, which includes out-of-home respite care and a voucher allowance as a payment mechanism.

ARCHANGELS – Any Care Counts – New York
In partnership with AgingNY and ARCHANGELS, New York State Office for the Aging offers a technology-enabled program connecting caregivers to available supports and resources. This facilitates connections to available supports and resources through a Caregiver Intensity Index (CII) that provides each caregiver with a score, validates their experience, and helps navigate to resources. Additional information on the campaign and the Caregiver Intensity Index (CII) can be found at: https://www.archangels-cii.me/anycarecounts-ny/?utm_source=nov23-NYSOFA-pr&utm_medium=link&utm_campaign=accn

New York Caregiver Portal by Trualta: Web-Based Support Platform for Unpaid Caregivers
This partnership offers an evidence-based training and support platform free of charge to any caregiver in New York. The programming helps families build skills to manage care at home for individuals of any age and connects to local resources and support services by delivering personalized education, training, and informational links. Additional information on this partnership can be found at: https://www.newyork-caregivers.com/

Supporting Working Caregivers
New York State Office for the Aging supports working caregivers through the Working Caregiver Initiative, which was developed to respond to the tremendous impact that caregiving has on employees.

Employed Caregiver Survey
In partnership with the New York State Caregiving and Respite Coalition and the University of Wisconsin, New York State Office for the Aging issued the web-based Employed Caregiver Survey. Businesses were encouraged to share the survey with their employees and provided information on the many tools available to help caregivers self-identify. The Employed Caregiver Survey remains available on New York State Office for the Aging's website and was promoted on social media. The Employed Caregiver Survey can be found at: https://www.surveymonkey.com/r/WorkingCaregiverSurvey

Caregiver Guide for Businesses
In partnership with the Department of Labor, New York State Office for the Aging developed the Caregiver Guide for Businesses, which includes links to programs, supportive services, workplace data, and information on the State's Paid Family Leave policies, so employees know of job-protected, paid time off to care for a family member. The guide can be found on New York State Office for the Aging' website at https://aging.ny.gov/help-working-caregivers

Caregiver's Guide Video
This informational video helps individuals self-identify as caregivers and learn more about the resources available to support them. It is focused on tasks caregivers perform as well as information on resources the State has available. This video can be found at: https://www.youtube.com/watch?v=BazeE6Mtod0.

Caregiver Resource Centers
The Centers provide caregivers with information, assistance and counseling, support groups, and training, as well as initiatives including specialized training curricula for caregivers of adults with developmental disabilities, minority populations, and caregivers of grandchildren. Information about the Centers is located at https://aging.ny.gov/caregiver-resource-centers

Respite Services

Lifespan Respite Grant
Programs under this federal grant provide a coordinated system of accessible, community-based Respite care services for family caregivers of children and adults of all ages with disabilities. This helps reduce duplication of effort and assists in the development of Respite care infrastructure at state and local levels. These programs are administered at the local level in partnership with Lifespan of Greater Rochester, Inc. (Lifespan), the New York State Coalition on Caregiving and Respite, and local New York Connects.

Lifespan Respite: Project Period 2020-2023
This project period built on prior and current initiatives and engaged key stakeholders to strengthen the Lifespan Respite Care System through expanded services, new partnerships, and targeted outreach providing a sustainable, coordinated Respite care system that supports caregivers of individuals across the age and disability spectrum. There was an increased number and type of partnerships formed, expanded volunteer respite services, training, and oversight across the age and disability spectrum; expanded outreach strategies addressing underserved populations, increased emergency respite capacity and expanded engagement with businesses to support working caregivers.

Lifespan Respite Mini-Grants
Under the Lifespan Respite Grant, a Request for Applications awarded additional mini grants for development or expansion of Volunteer Respite Programs. Applicants had to expand on or develop innovative, local, or regional community Respite programs and demonstrate an ability to utilize volunteers. Applicants also had to commit to serving a minimum of 25 caregivers during the program period October 2022-August 2023. In total, seven mini grants were awarded, and their accomplishments included:

- Broome County Office for the Aging: Worked with college students to develop a drop-in Respite program and provided over 1,200 hours of Respite to 93 caregivers and trained 10 Respite volunteers.
- Colonie Senior Service Centers, Inc: Enhanced a Respite program by providing over 1,800 hours of Respite to 44 caregivers and trained 11 Respite volunteers.
- InterFaith Works: Trained 12 volunteers from a Retired Senior Volunteer Program to provide over 10,000 hours of Respite care.
- The Noyes Caregiver Resource Center: Used student volunteers in a Respite Program and provided over 1,600 hours of Respite care.
- Senior Citizens Center of Saratoga Springs: Recruited and trained 23 volunteers to provide 1,700 hours of Respite care to 105 caregivers.
- Tompkins County Office for the Aging: Expanded a student volunteer program by training 11 Respite volunteers who provided 183 hours of Respite care.
- West Falls Center for the Arts: Expanded a program by opening an additional site, trained 30 volunteers, and provided 4,800 hours of Respite care.

https://archrespite.org/wp-content/uploads/2022/09/New_York.pdf

New York State Caregiving and Respite Coalition Respite Voucher Program
This is caregiver-directed voucher model that helps to assist paying for Respite care. The voucher program serves kinship caregivers, as well as informal caregivers who are not eligible for Respite under Medicaid Managed Care programs and who are caring for someone with chronic conditions. Eligible caregivers can receive up to $600 in a voucher to pay for Respite

care and can apply twice a year. Applicants must live in New York and be the primary caregiver. The voucher can be found at https://www.nyscrc.org/help-paying-for-respite-care

Piloting a New York State Caregiving and Respite Coalition Satellite Regional Caregiver Wellness and Respite Center (CWRC)
The Caregiver Wellness and Respite Center is engaging, assessing, and providing services to rural family caregivers for better care coordination, Respite implementation, and improved social determinants of health for informal caregivers living in the targeted area (the Caregiver Wellness and Respite Center is being piloted in Clinton, Essex, Franklin, Hamilton, Warren, and Washington counties). This includes Respite vouchers, consultation and assessment services, and education and outreach to caregivers within the satellite's regional area.

Respite Care Provider Training (RCPT)
The Respite Care Provider Training curriculum developed by the New York State Office for the Aging (NYSOFA) in coordination with LifeSpan of Greater Rochester helps assist with training and availability of Respite care providers, by providing courses at the learner's pace and require a minimum final exam score of 75% to earn a certificate of completion. A searchable Respite registry will be developed with those completing the training having the option to be added. Information about the training offered by Lifespan can be found at - https://aging.ny.gov/respite

State Respite Program
The State Respite program provides relief to caregivers and allows them to tend to their own needs, maintain a normal routine, and deters need for long-term institutional placement of the person they are caring for - https://aging.ny.gov/respite

Elder Abuse Interventions and Enhanced Multi-Disciplinary Team Initiative

Enhanced Multi-Disciplinary Team (E-MDT) Initiative
The Enhanced Multi-Disciplinary Team is a statewide program operated regionally that recognizes collaboration is necessary to detect and address fraud and abuse. This work includes an Office of Victim Services partnership to establish and implement Elder Abuse Interventions. The Elder Abuse Interventions and Enhanced Multi-Disciplinary Team Initiative are coordinated by Lifespan through a network of 13 Regional Hub organizations that work in concert to provide technical assistance and training across the state, with New York State Office for the Aging providing strategic planning. The E-MDT Initiative provides access to specialty services and coordination and consultation services at the Hub organizations.

Restitution
Enhanced Multi-Disciplinary Team interventions have provided $4.8 million in restitution from cases of financial exploitation. Of this, $1.3 million was reported returned to the victims. Those who do pursue such cases do not always obtain the rulings they seek from the courts, nor is restitution always necessary to assist the victim in a financial exploitation case. Even without restitution, the interventions often stop further exploitation.

Enhanced Multi-Disciplinary Team Website and Video Series
Lifespan and New York City Elder Abuse Center partnered with Christopher Communications Inc. to develop, design, and launch a website devoted to the Elder Abuse Enhanced Multi-Disciplinary Team Initiative. This website is located at NYS E-MDT Lifespan and NYCEAC also partnered with Terra Nova films to produce a series of videos highlighting the Enhanced Multi-

Disciplinary Team approach to addressing elder abuse. The series includes twelve (12) videos, each with a different theme. These videos can be found at: https://www.nysemdt.org/allvideos

Diversity, Equity, and Inclusion
Lifespan, NYCEAC, and New York State Office for the Aging implemented steps to foster diversity, equity, and inclusion principles in the work of the Enhanced Multi-Disciplinary Team Initiative at all levels to increase access to services for underserved populations.

Elder Abuse Education and Outreach Program (EAEOP)
The Elder Abuse Education and Outreach Program provides education and outreach to the public to prevent elder abuse, neglect, and exploitation. The includes grants to local agencies to establish or expand on existing Elder Abuse Education and Outreach Programs and grants that have statewide focus designed to support efforts that increase awareness and prevention of elder abuse. Information about EAEOP can be found at https://aging.ny.gov/elder-abuse-education-and-outreach-program-eaeop

Elder Abuse Education and Training
Trainings were held, both virtually and in-person, to facilitate recognition and reporting of elder abuse, neglect, and financial exploitation. Trainings encouraged collaboration among professionals to facilitate appropriate intervention and prevention approaches that assist victims. The multidisciplinary, multi-county training programs covered issues related to elder mistreatment, with a focus on addressing challenges with the financial exploitation of older adults. These trainings supported by the New York State Office for the Aging (NYSOFA) are offered by LifeSpan of Greater Rochester. More information about these trainings can be found at https://www.lifespan-roch.org/education-and-training

Elder Abuse Outreach and Public Awareness Education
This program provides education and outreach to the public as well as grants to local agencies to establish or expand on existing local elder abuse education and outreach programs. Lifespan operates the Upstate Elder Abuse Center and Elder Abuse Education and Outreach Program funding has been used to expand critical services to benefit professionals and vulnerable older adults throughout New York State.

The New York State Coalition on Elder Abuse gathered information and prepared a report, from each region. The document was widely publicized and was the starting point for statewide recognition collaborations. The report is available at: https://aging.ny.gov/system/files/documents/2023/06/e-mdt-initiative-program-update-2017-to-2022.pdf

Lifespan Elder Abuse Interventions
The Lifespan Elder Abuse Interventions provide case management for older adults who experience suspected abuse, neglect, or financial exploitation. There were 460 cases, including ongoing cases from the previous year, which addressed all forms of elder abuse or mistreatment, financial exploitation, scams, fraud, and identity theft. Another 198 individuals received brief information and referral, or assistance related to issues outside the scope of the program. Additional information about this work can be found at - https://www.lifespan-roch.org/upstate-elder-abuse-center

HIV and Aging and the AIDS Institute
According to the NYS DOH/ Aids Institute in New York State, there are over 104,000 people living with diagnosed HIV and 57% of them are aged 50 years or older. The life expectancy of

people with HIV has increased significantly, meaning greater percentage of persons over age 50 with HIV are not only living longer but constitute a growing segment of the older adult population. Moreover, people over 50 represent a high proportion of new HIV infections. While the cognitive symptoms of aging are experienced by all, the neuropsychiatric symptoms, including depression, cognitive impairment, and substance abuse, are very common among persons over age 50 with HIV. Currently, there is little data available regarding this unique population and limited information for treatment of medical and psychiatric comorbidities for those of older age.

New York State Office for the Aging and the State's AIDS Institute are exploring opportunities to maximize HIV resources and enhance service delivery for older adults with HIV. New York State Office for the Aging has met with multiple providers in the People Aging with HIV (PAWH) pilot to discuss the New York Connects No-Wrong-Door system and the role of providers in information sharing, making referrals, and linking older adults diagnosed with HIV to services and other resources.

Technology and Innovation

Investing in technology has allowed the New York State Office for the Aging's (NYSOFA) to combat isolation, support caregivers, and create connections. Leveraging technology and making available digital tools supplements direct services and supports provided at the local level by Area Agencies on Aging. The New York State Office for the Aging (NYSOFA) pursues these partnerships to promote technological interventions that complement services and programs and can provide non-pharmaceutical intervention for older adults experiencing any stage of Alzheimer's, dementia, or memory loss.

Animatronic Pets – JoyForAll
These animatronic pets have been provided to older adults who experience social isolation, cognitive decline, Alzheimer's disease and other dementias, and more. The "pets" are designed to make realistic sounds and motions, providing comfort and companionship to individuals. In a pilot study, New York State Office for the Aging found that 70 percent of older adults receiving these pets reported a reduction/significant reduction in loneliness as well as a 75 percent decrease in pain. New York State Office for the Aging is working with local offices for the aging to identify older adults who would most benefit from the technology. More information can be found at: https://joyforall.com/

Memory Lane TV
This uses media sequences to stimulate memories through visual and audio cues that promote relaxation. This plotless content provides cues around the time of day, soothes anxiety, and stimulates positive memories. For professional and family caregivers looking for a meaningful way to connect with their patient, parent, spouse, or friend, manage their symptoms, or take a moment for themselves this solution has proven to improve the quality of life for all. New York State Office for the Aging is piloting this intervention in congregate and home settings.

Relish
This provides scientifically crafted products that improve the overall wellbeing of people with dementia by providing fun, meaningful activities that help build their relationships with their family, friends, and caregivers. Relish has developed clocks, jigsaw puzzles, arts and crafts, games, and brain teasers that foster satisfaction, achievement, and confidence for people with dementia. It was found that after using Relish products, 84% of respondents saw an

improvement across at least one pillar of well-being. More detailed information about Relish can be found at https://www.youtube.com/watch?v=EDPakJfH3xM

Map Habit
This platform uses scientifically proven step-by-step guides to empower individuals living with Alzheimer's disease and related dementias to master their daily routines. They offer a library of over one thousand maps, accessed through a tablet, covering everything from daily tasks to contacting caregivers and remaining physically active. This aids in increasing autonomy through the use of audio and visual prompts and works to ease caregiver strain. More detailed information about Map Habit can be found at https://www.youtube.com/watch?v=LpdGZIVeapc

ElliQ
This is a care companion that can assist with routine tasks and empower people and educate caregivers. ElliQ is the first-ever proactive and empathetic care companion that is designed to foster independence and provide support for older adults through daily check-ins, assistance with wellness goals and physical activities, connection to family and friends, and more using voice commands and/or on-screen instructions. New York State Office for the Aging is working with local offices for the aging to identify older adults who would most benefit from the technology. More detailed information on ElliQ can be found at: https://elliq.com/

Additional information about all of these innovations and others being deployed by the New York State Office for the Aging (NYSOFA) can be found at - https://aging.ny.gov/system/files/documents/2024/09/innovations-in-aging-report.pdf

Healthy Aging and Brain Health

New York State Office for the Aging works with partners across service spectrums to deliver programs and supportive services that keep older adults active and independent in their communities of choice. The World Health Organization defines healthy aging as "the process of developing and maintaining the functional ability that enables wellbeing in older age." Preserving the health of older adults through prevention education, assessment for services and creating impactful social connections allows all people to age healthier and reduce the need for costlier medical care or placement in a facility for care.

Age Friendly
New York State Office for the Aging fosters multi-sector partnerships to promote preventive health and services, help build community connections and improve the quality-of-life for older adults. The New York State Age-Friendly Action Community initiative helps participant health systems, and other service and support providers, accelerate the adoption of four evidence-based elements to organize the care of older adults, known as the "4Ms:" What Matters, Medication, Mentation and Mobility. This has allowed health systems across New York State to earn official recognition from the Institute for Healthcare Improvement as Age-Friendly Health Systems. Additional information can be found at: https://www.hanys.org/age-friendly/

The Healthy Brain Project
Embedding the Early Identification of Cognitive Impairment Among Older Adults into the New York State Aging Service System is a project in collaboration with State University of New York Upstate Medical University. This project pilots and evaluates the practicality and impact of a replicable service model embedding screening for early cognitive impairment into the workflow of case managers. Case managers in seven (7) pilot Area Agencies on Aging will be trained to

administer an evidence-based screening tool for early cognitive impairment and refer clients with scores suggesting impairment to the Center of Excellence for Alzheimer's Disease (CEAD) at SUNY Upstate Medical University's Department of Geriatrics for comprehensive geriatric assessments.

New York State Office of Children and Family Services

The New York State Office of Children and Family Services serves New York State by promoting the safety, permanency, and well-being of children, vulnerable and dependent adults, families, and communities.

On June 18, 2021, the Governor announced a $2.5 million expansion of the first-in-the-nation Enhanced Multidisciplinary Teams Initiative, which protects vulnerable adults who may have experienced financial exploitation and other co-occurring forms of abuse. Enhanced Multi-Disciplinary Teams assist adults sixty (60) years and older who are at risk due to physical limitations, cognitive impairment or dementia, and social isolation, and expands access to forensic accountants, geriatric psychiatrists/mental health professionals, and civil legal services. The initiative, developed by the New York State Office for the Aging and the New York State Office of Victim Services, was the first of its kind in the nation. In support of the efforts to identify and prevent financial exploitation, the *Office of Children and Family Services* Bureau of Adult Services, which oversees Adult Protective Services in all sixty-two (62) counties, worked with a forensic accountant in consultation with a multi-agency advisory board to develop new investigative tools and templates for Adult Protective Services workers referred to as the Financial Exploitation Investigative Suite of Tools.
The initial three-year investment that launched the Enhanced Multi-Disciplinary Teams Initiative in 2017 totaled $8.4 million. This investment consisted of federal Victims of Crime Act funds provided by the Office of Victim Services, combined with a state investment provided by New York State Office for the Aging. New York State Office for the Aging partnered with Lifespan of Greater Rochester and Weill Cornell Medicine's New York City Elder Abuse Center to manage, monitor, and distribute the funding. The Office of Victim Services is providing an additional $2 million in Victims of Crimes Act funding annually, and New York State Office for the Aging allocated an additional $500,000 annually for continued support of the Enhanced Multi-Disciplinary Teams Initiative.

Teams now cover the entire state. Services provided to abuse victims through Enhanced Multi-Disciplinary Teams interventions include information about and referral to other types of services, such as victim support programs or legal services and individual advocacy, such as return of personal property, or assistance with applying for public benefits. Enhanced Multi-Disciplinary Team Coordinators provide case consultation and access to consultation services, such as a forensic accountant, geriatric psychiatrist/mental health professionals and civil legal attorneys, as appropriate and available.

In April 2021, *Office of Children and Family Services* received $5,306,382 in federal funds under the Grants to Enhance Adult Protective Services to Respond to COVID-19. Additional federal funding ($14,059,718) was awarded to *Office of Children and Family Services* under the American Rescue Plan Act in 2022. These funds were allocated to Adult Protective Services units within the local departments of social services to enhance, improve, and expand the ability of Adult Protective Services to investigate allegations of abuse, neglect, and exploitation in the context of COVID-19. Counties have continued to use the funding, in part, to provide goods and services to Adult Protective Services clients, provide education and public awareness of scams

and frauds targeted toward vulnerable adult populations, and community awareness related to adult abuse reporting and prevention. Further, *Office of Children and Family Services* allocated almost $600,000 of the federal funds over a three-year period to partner with New York State Office for the Aging and Lifespan to provide Enhanced Multi-Disciplinary Teams-like services to vulnerable adults under the age of sixty (60). The pilot, Augmented Multidisciplinary Teams began reviewing cases in December 2022.

Office of Children and Family Services has continued to partner with the Alzheimer's Association of Northeastern New York, State Education and Outreach, and Office of Government Affairs with providing updated dementia-specific training designed specifically for Adult Protective Services workers. The training will provide guidance on the differences between aging and levels of cognitive impairment, identifying warning signs, ways to communicate, and understanding the impacts of dementia on the ability to live independently.

Office of Children and Family Services supports continuous training opportunities for agency professionals working with the aging population, law enforcement, attorneys, and Adult Protective Services workers at the annual Adult Abuse Training Institute conference. Several workshops focus on dementia related topics, including physiological aspects of aging, recognizing dementia, and preventing scams. The 2023 conference included representation from the Alzheimer's Association of Northeastern New York and workshops on cognitive impairments and aging as well as a presentation from Dementia Friends New York. The 2024 workshops will include Abuse and Exploitation in Individuals with Alzheimer's or Dementia: Effective Communication Strategies to Build Rapport, as well as other aging related topics.

Office of Children and Family Services also oversees the Family Type Home for Adults program. Family Type Home for Adults are a small adult care facility of one (1) to four (4) 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 activities of daily living. 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 residents with Alzheimer's and dementia in community-based settings, with individualized care. *Office of Children and Family Services*, through its local departments of social services, continues to facilitate trainings of Family Type Home for Adults operators by Alzheimer's Association staff to improve quality-of-care given to residents in Family Type Home for Adults.

At the end of 2023, the Administration for Community Living, issued first ever federal regulations for Adult Protective Services to be in place within four (4) years. The *Office of Children and Family Services* began the process to analyze current New York State statutes, regulations and policies for changes that will be needed to meet the new federal standards. Work groups including state and local Adult Protective Services have been formed to create recommendations in the areas of definitions, program administration, response protocols, conflict of interest, referral processes, interaction with other service providing entities, and annual state plans. The *Office of Children and Family Services* participated in the New York State Master Plan on Aging through workgroups on several topics that included level of care, guardianship, disaster preparedness, formal and informal caregiving, financial exploitation, adult abuse, respite, and housing. Recommendations were made and incorporated based on oversight of Adult Protective Services and Family Type Home for Adults program.

New York State Office of Mental Health

Aging and Dementia Research

The New York State Office of Mental Health provides support for two (2) psychiatric research institutes which study severely disabling mental disorders. The Nathan Kline Institute for Psychiatric Research and the New York State Psychiatric Institute both conduct research programs on the causes, early diagnosis, and treatment of Alzheimer's disease and related dementias. The major concentration of Alzheimer's disease research within New York State Office of Mental Health is conducted at the Center for Dementia Research. Center for Dementia Research programs have yielded over three hundred fifty (350) peer reviewed publications in the past ten (10) years, including reports in the most prestigious scientific journals (Proceedings of the National Academy of Sciences, Nature Medicine, Nature Neuroscience, Science, and others). Attesting to the influence of Center for Dementia Research in the research community, these publications have been cited by other investigators world-wide over seventy thousand (70,000) times.

Recognized internationally for influential advances toward innovative Alzheimer's disease therapies, Center for Dementia Research researchers have been awarded over $33 million in National Institutes of Health research funding during the last five (5) years. This sustained high level of funding has enabled them to continue pioneering investigations on the causes of Alzheimer's disease and additional related dementias. Their research has defined cellular abnormalities that arise decades before the earliest clinical symptoms and is yielding new biomarkers of Alzheimer's disease so that treatments can begin sooner. Notably, the neurological roles of Neurofilament Light, the recently discovered first reliable blood biomarker to track the progression of Alzheimer's disease, is a longstanding focus of Center for Dementia Research studies, which were pivotal in guiding the discovery of this biomarker. Understanding the biology underlying the earliest changes in Alzheimer's disease and related dementias has identified new drug targets, including a compound against an early disease target yielding promising therapeutic effects in a Phase 2 clinical trial in Lewy body dementia patients and will be the first therapy for this devastating common dementia if ongoing Phase 3 testing confirms Phase 2 results. Innovative lines of drug discovery, including approaches that address a novel molecular target in Alzheimer's disease which have recently been awarded patents, are being further validated in the Center for Dementia Research.

Additional ongoing programs include research to uncover mechanisms by which mutant genes or alternative gene forms like the APOE4 allele, the most influential risk factor for Alzheimer's disease, genetic basis, accelerate the onset of Alzheimer's disease. Major advances, for example, have been made in the Center for Dementia Research in understanding the biology, and possible treatment of Alzheimer's disease in individuals with Down syndrome, a population representing the most common form of early onset Alzheimer's disease. Additional patented technology is enabling an active program of genomic studies on individual neurons in the human brain with Alzheimer's disease, an area of research pioneered in the Center for Dementia Research.

Individuals with Alzheimer's disease decline faster if they also have vascular-related brain damage. Research in this area was catalyzed by the findings of the Nathan Kline Institute for Psychiatric Research scientist, who discovered the first gene known to cause a form of dementia related to Alzheimer's disease that affects primarily the blood vessels. Subsequently, Nathan Kline Institute for Psychiatric Research scientists have developed unique laboratory models of the disease for drug screening and understanding further this important interaction of blood

vessel disease with Alzheimer's disease, including characterizing new forms of communication in the brain via release from brain cells and spread of vesicles containing cell signals. Another major program is investigating the higher incidence of epilepsy in Alzheimer's disease and its contribution to initiation and progression of the disease.

Researchers in Nathan Kline Institute for Psychiatric Research's Center for Brain Imaging and Modulation are investigating abnormal brain function, possibly heralding the future onset of Alzheimer's disease, in clinically normal populations across the age spectrum and in symptom-free elderly individuals who are at higher risk genetic risk to develop the disease. Other new imaging techniques, initially perfected in Alzheimer's disease model systems, are now being applied in patient populations and in normal volunteers with the goal of widening the window of prevention opportunity even further. Recent acquisition of a 9.4 T magnetic resonance imager, one (1) of only three (3) in the world, and formation of a world class team of experts in high-field imaging promises to achieve previously impossible detail of human brain anatomy and disease pathology.

An important mission of New York State Office of Mental Health, Alzheimer's disease programs, is to optimize the management of both memory and behavioral symptoms of people with Alzheimer's disease and related dementia. 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 Nathan Kline Institute for Psychiatric Research's Geriatric Psychiatry Division and at the New York State Psychiatry Institute'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 living with Alzheimer's disease and related dementia, and the detection of loss of smell as a symptom emerging at the earliest stages of Alzheimer's disease. Additional clinical research is addressing the adverse effects of commonly used medicines when taken by individuals living with Alzheimer's disease and related dementia.

New York State Office of People with Developmental Disabilities

New York State Institute for Basic Research in Developmental Disabilities, the research arm of New York State Office of People with Developmental Disabilities, is in the eighth (8^{th}) year of a research program called, "Alzheimer Biomarker Consortium-Down Syndrome- ABC-DS." This project is a large multisite, multidisciplinary research initiative to find biomarkers to track Alzheimer's disease in people with Down syndrome and is funded by the National Institute on Aging, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and the National Institutes of Health and the New York State Office for People with Developmental Disabilities. Researchers collect demographic and health information, take blood samples and conduct brain scans of people with Down syndrome (and in some cases, their parents, and siblings).

Participants may undergo physical and neurological exams, brain scans, and assessments to measure cognition, memory, and movement. Additional information is obtained through personal and family health history, caregiver questionnaires, and genetic studies. Information gained from this initiative may help people with Alzheimer's disease and Down syndrome, as well as people with only Alzheimer's disease.

Adults with Down syndrome are more likely to develop Alzheimer's disease in middle age compared with most other people. This is an especially important and timely issue, given the

dramatic increase in their life expectancy. Researchers now need to discover the causes of this increased risk and how to prevent it. This knowledge will help us to anticipate the amounts and types of supports adults with Down syndrome and dementia will need as they age. In 2020, this grant was extended for another five (5) years, to continue this important research program. This work has been supported by funds from the New York State Office for People with Developmental Disabilities and National Institutes of Health grants U19 AG068054-01, P01 HD035897, U54 HD079123 and U01AG051412, among others.

The overall specific aims of the study are to:

- Establish an organizational infrastructure to follow and comprehensively characterize a clinical cohort of 600 individuals.
- Work within the community to increase the diversity of individuals in the cohort of adults with Down syndrome.
- Examine biomarkers of Alzheimer's disease in Down syndrome and determine if risk is modified by selected factors.
- Develop precision medicine ready biomarkers for future clinical trials.
- Disseminate data and biospecimens to qualified researchers outside of ABC-DS.
- Understand the pathways affected by the disease process and their implications for improved prevention and treatment.

The New York State Office for People with Developmental Disabilities continues to make progress on these aims with the specific hope that identifying the biomarkers of Alzheimer's disease progression will provide valuable insights into the sequence of pathogenesis of Alzheimer's disease, suggest targets for disease-targeting therapies, and improve the quality of life in people with Down syndrome specifically and possibly for the general population as well.

New York State Education Department

The New York State Education Department, under the authority and direction of the New York State Board of Regents, regulates more than fifty (50) professions licensed under Title VIII of the Education Law. The New York State Education Department oversees requirements for professional education, continuing education, and professional practice for each of these professions. The New York State Education Department serves a vital function in ensuring that New York State Education Department licensed professionals provide professional services safely and competently to the public, including individuals living with Alzheimer's disease and related dementia.

The New York State Education Department evaluates and registers (approves) professional education programs, which prepare students for safe, competent entry level practice in a specific profession. Successful completion of a professional education program is often a requirement licensure in a profession. Issues related to behavioral, emotional, and social needs and ethics are becoming a fundamental requirement of professional education programs through curricular mandates placed in regulation. 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 living with Alzheimer's disease and related dementia 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 professional education requirements for each profession differ, all licensed professionals who provide services to persons living with Alzheimer's disease and related dementia are required to ensure they are competent to provide the services before doing so. The New York State Education Department provides practice guidance for licensed health professionals through Practice Alerts, Practice Guidelines, webinars for professionals, and recommendations to programs during the approval of course content for the degrees. Some licensed professionals are required by law to complete continuing education. Many associations, employers, and schools offer mandatory continuing education courses through various means, including online offerings. In professions with no mandatory continuing education, such as medicine or nursing, non-mandated continuing education is offered to address professional competence that may specifically focus on the healthcare, social, and behavioral needs of persons living with Alzheimer's disease and related dementia. Regardless of whether it is legally required, many professionals complete continuing education that covers issues relevant to Alzheimer's disease and related dementia. This education helps to ensure that persons with Alzheimer's disease and related dementia receive relevant, competent professional services.

Within the broad services of the New York State Education Department, 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. Additionally, New York State Education Department and New York State Department of Health oversee training programs for personal care workers, such as home health aides and personal care aides, and certified nurse aides, in accordance with federal regulations. These personal care workers provide services to persons with Alzheimer's disease and related dementia, and most training program curriculums cover care for persons with memory issues.

Conclusion

In conclusion, members of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia wish to thank Governor Hochul and members of the NYS Legislature for their ongoing support for the work being done to address the needs of New Yorkers and their loved ones living with Alzheimer's disease and related dementia.

References/End Notes

1. U.S. Department of Health and Human Services (2018). National Plan to Address Alzheimer's disease: 2022 update. Retrieved from https://aspe.hhs.gov/sites/default/files/documents/59cefdd628581b48b2e389891a675af0/napa-national-plan-2022-update.pdf
2. Alzheimer's Association (2024). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2024.
3. Reisa A. Sperling,[a,*] Paul S. Aisen,[b] Laurel A. Beckett,[c] David A. Bennett,[d] Suzanne Craft,[e] Anne M. Fagan,[f] Takeshi Iwatsubo,[g] Clifford R. Jack, Jr.,[h] Jeffrey Kaye,[i] Thomas J. Montine,[j] Denise C. Park,[k] Eric M. Reiman,[l] Christopher C. Rowe,[m] Eric Siemers,[n] Yaakov Stern,[o] Kristine Yaffe,[p] Maria C. Carrillo,[q] Bill Thies,[q] Marcelle Morrison-Bogorad,[r] Molly V. Wagster,[r] and Creighton H. Phelps. Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimer's Dementia. 2011 May; 7(3): 280–292.
4. Schneider J.A., Arvanitakis Z, Bang W, & Bennett D.A. (2007). Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology 69*(24) 2197–2204.
5. Alzheimer's Association (2012) Mild Cognitive Impairment https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/mild-cognitive-impairment
6. Mayo Clinic (2015). Diseases and Conditions. Retrieved from: https://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/symptoms-causes/syc-20354578
7. Ward A, Tardiff S, Dye C, Arrighi HM (2013). Rate of Conversion from Prodromal Alzheimer's Disease to Alzheimer's Dementia: A Systematic Review of the Literature. Dementia and Geriatric Cognitive Disorders EXTRA. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3808216/
8. Lee, J. S., Potter, G. G., Wagner, H. R., Welsh-Bohmer, K. A., & Steffens, D.C., (2007), Persistent mild cognitive impairment in geriatric depression. *International Psychogeriatric 19*(1) 125-135.
9. Modrego P. J., Ferrández, J. (2004). Depression in patients with mild cognitive impairment increases the risk of developing dementia of Alzheimer's type: a prospective cohort study. *Archive of Neurology, 61*(8) 1290-1293.
10. Alzheimer's Association. Stages of Alzheimer's & Symptoms. https://www.alz.org/alzheimers-dementia/stages
11. Alzheimer's Association (2015c) Mixed Dementia; http://www.alz.org/dementia/mixed-dementia-symptoms.asp.
12. Alzheimer's Association. Early Onset Dementia: A National Challenge, a Future Crisis. Washington, D.C.: Alzheimer's Association; 2006.
13. Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft J. Morbidity and Mortality Weekly Report (MMWR). Centers for Disease Control and Prevention https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm Published July 21, 2017. Accessed September 14, 2017.
14. Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System, Mortality 2018-2021 https://wonder.cdc.gov/ucd-icd10-expanded.html
15. Weuve, J., Hebert, L. E., Scherr, P. A., Evans, D. A. Prevalence of Alzheimer's Disease in U.S. Epidemiology 2015; 26(1): e4-e6.

16. Alzheimer's Association (2015) Alzheimer's Caregiver: Data from the Behavioral Factors Surveillance System. Subjective Cognitive Decline Data from adults in 46 States, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older
17. U.S. Department of Health and Human Services (2013). Improving Care for Populations Disproportionately Affected by Alzheimer's Disease and Related Dementias: Report from the Task Force on Specific Populations. Retrieved from http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf.
18. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimer's & dementia: the journal of the Alzheimer's Association. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969071/.
19. Barnes, L. L., & Bennett, D. A. (2014). Alzheimer's Disease in African Americans: Risk Factors and Challenges for the Future. *Health Affairs*. *33*(4) 580-586.
20. Howard, G., Peace, F., Howard, V. J. The Contributions of Selected Diseases to Disparities in Death Rates and Years of Life Lost for Racial/Ethnic Minorities in the United States, 1999–2010. Prev Chronic Dis 2014;11:140138. DOI: http://dx.doi.org/10.5888/pcd11.140138.
21. Reitz, C.; Jun, G.; Naj, A.; Rajbhandary, R.; Vardarajan, B. N.; Wang, L. S.; Valladares, O.; Lin, C. F.; Larson, E. B.; Graff-Radford, N. R.; Evans, D.; DeJager, P. L.; Crane, P. K.; Buxbaum, J. D.; Murrell, J. R.; Raj, T.; Ertekin-Taner, N.; Logue, M.; Baldwin, C. T.; Green, R. C.; Barnes, L. L.; Cantwell, L. B.; Fallin, M. D.; Go, R. C.; Griffith, P.; Obisesan, T. O.; Manly, J. J.; Lunetta, K. L.; Kamboh, M. I.; Lopez, O. L.; Bennett , D. A.; Hendrie, H.; Hall, K. S.; Goate, A. M.; Byrd, G. S.; Kukull, W. A.; Foroud, T. M.; Haines, J. L.; Farrer, L. A.; Pericak-Vance, M. A.; Schellenberg, G. D.; Mayeux, R.; Alzheimer Disease Genetics Consortium. (2013). Variants in the ATP-Building Cassette Transporter (ABCA7) apolipoprotein E ϵ4, and the Risk of Late-Onset Alzheimer's Disease in African Americans. *The Journal of the American Medical Association. 309 (14); 1483-92.* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3667653/.
22. Alzheimer's Research UK (2015). Women and Dementia: A Marginalized Majority. http://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf.
23. Bamford S-M, Hayat SA, Luben R, et al. (2012). Women and Dementia - Not forgotten. https://www.researchgate.net/publication/230644343_
24. National Institute on Aging (2015). *Alzheimer's Disease Genetics (August, 2015)* NIS No. 15-6424.
25. Women's Health and Equality Consortium (2016). Women and Dementia. www.researchgate.net/publication/308985807_Women_and_Dementia_Women's_Health_Equality_Consortium_October_2016
26. Alzheimer's Association. Women and Alzheimer's. Retrieved from: https://www.alz.org/alzheimers-dementia/what-is-alzheimers/women-and-alzheimer-s
27. Alzheimer's Association (2017). Dementia and Caregiving in the U.S. https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-US_February-2017.pdf
28. University of York Social Policy Research Unit (2015). Women and Dementia: All But Forgotten? A Literature Review. https://www.york.ac.uk/inst/spru/research/pdf/womendementia_literature_review.pdf
29. Zhu X-C, Tan L, Wang H-F, et al. (2015). Rate of early onset Alzheimer's disease: a systematic review and meta-analysis. Annals of Translational Medicine. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4356853/
30. National Institute on Aging (2015). *Alzheimer's Disease Genetics (August, 2015)* NIS No. 15-6424

31. Lai, F. and Williams, R. S., (1989). A Prospective Study of Alzheimer's Disease in Down Syndrome. *Archive of Neurology 46,* 849-853.
32. Alzheimer's Association (2015) Types of Dementia. Retrieved from: http://www.alz.org/dementia/types-of-dementia.asp.
33. Kuruppu, D. K.; Mathews, B. R., (2013). Young-Onset Dementia. *Seminars in Neurology 33* (04), 365-885. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4033406/.
34. The Arc. *Introduction to Intellectual Disabilities*. Retrieved from https://thearc.org/wp-content/uploads/forchapters/Introduction%20to%20ID.pdf
35. National Down Syndrome Society (2012). Alzheimer's Disease & Down Syndrome. Alzheimer's Disease & Down Syndrome | National Down Syndrome Society (NDSS)
36. National Down Syndrome Society. Anesthesia and Down Syndrome. https://www.ndss.org/resources/anesthesia-down-syndrome/
37. National Down Syndrome Society (2013). Aging and Down Syndrome: A Health and Well-Being Guidebook. New York, NY: Moran, J.
38. National Task Group on Intellectual Disabilities and Dementia Practices (2013).
39. Loy, C. T.; Schofield, P. R.; Turner, A. M.; Kwok, J. B. J. Genetics of Dementia. Lancet 2014; 383:828–40.
40. Ridge, P. G., Ebbert, M. T., & Kauwe, J. S. (2013). Genetics of Alzheimer's disease. *BioMed research international*, *2013*, 254954. doi:10.1155/2013/254954
41. Fryar CD, Chen T, Li X. Prevalence of Uncontrolled Risk Factors for Cardiovascular Disease: United States, 1999–2010. NCHS Data Brief, No. 103. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention, US Dept of Health and Human Services; 2012. (Heart Disease Risk Factors | Heart Disease | CDC)
42. Stern, Yokov, Alzheimer Dis Assoc Disord. 2006 Jul-Sep; 20(3 Suppl 2):S69-74.
43. Alzheimer's Association, (2013a). 2013 Alzheimer's Disease Facts and Figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 9,* 208-245.
44. Span, P. (2013, July 17). In Europe, Dementia Rates May be Falling. New York Times. Retrieved from http://newoldage.blogs.nytimes.com/2013/07/17/in-europe-dementia-rates-may-be-falling/?_r=0.
45. Kolata, G. (2013). Dementia rate is found to drop sharply, as Forecast. *New York Times* Retrieved from http://www.nytimes.com/2013/07/17/health/study-finds-dip-in-dementia-rates.html.
46. Wilson RS, Krueger KR, Arnold SE, et al. Loneliness and Risk of Alzheimer Disease. *Arch Gen Psychiatry.* 2007;64(2):234–240. doi:10.1001/archpsyc.64.2.234
47. Sutin, Angelina R, et al. "Loneliness and Risk of Dementia." *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, U.S. National Library of Medicine, 26 Oct. 2018, https://www.ncbi.nlm.nih.gov/pubmed/30365023.
48. Cullen, B.; O'Neill, B.; Evans, J. J.; Coen, R. F.; & Lawlor, B. A. (2007). A Review of Screening Tests for Cognitive Impairment. *Journal of Neurology, Neurosurgery, & Psychiatry, 78*(8), 790-799.
49. Cordell, C. B.; Boroson, S.; Boustani, M.; Chodosh, J.; Reuben, D.; Verghese, J.; Thies, W.; & Fried, L. B. (2013) Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment During the Medicare Annual Wellness Visit in a Primary Care Setting, *Alzheimer's & Dementia* 9, 141-150.
50. Centers for Disease Control and Prevention (2023). The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships,2023-2027. Retrieved from National Healthy Brain Initiative | Alzheimer's Disease Program | CDC
51. Yeaman, P.A., Ford, J.L., & Kim, K.Y. (2012) Providing Quality Palliative Care in End-State Alzheimer Disease. *American Journal of Hospice & Palliative Medicine 30 (5),* 499-502.

52. National Institute on Aging (2015). 2014-2015 Alzheimer's Disease Progress Report Advancing Research Toward a Cure. Retrieved from http://www.questri.com/wp-content/uploads/2016/09/2014-2015_alzheimers-disease-progress-report.pdf.
53. Batsch, N. L., Mittelman, M. S. & Alzheimer's Disease International (2012). World Alzheimer's Report 2012: Overcoming the Stigma of Dementia. Retrieved from https://www.alzint.org/u/WorldAlzheimerReport2012.pdf
54. *SUSTAINING MOMENTUM: NIH Takes Aim at Alzheimer's Disease & Related Dementias*. National Institutes of Health, 28 July 2017, https://www.nia.nih.gov/sites/default/files/2017-07/FY19-bypass-budget-report-508_0.pdf
55. Kovach, C. R., Noonan, P. E., Schlidt, A.M. & Wells, T. (2005). A model of consequences of need-driven, dementia-compromised behavior. *Journal of Nursing Scholarship, 37*(2), 134-140.
56. Algase, D. L., Beck, C. Kolanowski, A., Whall, A., Berent, S., Richards, K. & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, 10-19.
57. World Health Organization & Alzheimer's Disease International (2015). http://www.who.int/mental_health/neurology/dementia/en/.
58. Iglehart, J.K. (2014). The elusive search for solutions to Alzheimer's. *Health Affairs, 33*(4) 526.
59. Taiple, H., Koponen, M., Tansknen, A., Tolppanen, A. M., Tiihonen, J., Hartikainen, S., (2014) Antipsychotic polypharmacy among a nationwide sample of community-dwelling persons with Alzheimer's Disease. *Journal of Alzheimer's Disease. 41* p. 1223-1228. U.S. Department of Health and Human Services (2014a). National plan to address Alzheimer's disease: 2014 update.
60. Alzheimer's Association (2015). End-of-life Decisions. https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf
61. Lynda A. Anderson, PhD; Valerie J. Edwards, PhD; William S. Pearson, PhD; Ronda C. Talley, PhD, MPH; Lisa C. McGuire, PhD; Elena M. Andersen, PhD. Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status http://www.cdc.gov/pcd/issues/2013/13_0090.htm.
62. National Alliance for Caregiving and AARP Research Report: Caregiving in the US 2020 https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf
63. Janevic, M.R. and Commell, C.M. Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience Recent Findings *The Gerontologist 41*(3) 334-347.
64. Mittelman, M,S., Haley, W.E., Clay, O.J. & Roth, D.L. (2006). Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease. *Neurology*, *67,* 1592-1599.
65. Mittelman, M,S., Haley, W.E., Clay, O.J. & Roth, D.L. (2006). *Mary S. Mittelman, Dr.P.H., David L. Roth, Ph.D., Olivio J. Clay, M.A., William E. Haley, Ph.D.* Preserving Health of Alzheimer Caregivers.
66. Mittelman, M. & Bartels, S. (2014). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs, 33*(4), 587-95.
67. Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E. & Sloane, P. D. (2005). Attitudes, Stress, and Satisfaction of Staff Who Care for Residents with Dementia. *The Gerontologist, 45*(1), 96-105.
68. Warshaw, G. A. & Bragg, E. J., (2014). Preparing the Health Care Workforce to Care for Adults with Alzheimer's Disease and Related Dementias. *Health Affairs 33*(4) 633-641.
69. Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J. & Lange, K. M. (2013). Monetary Costs of Dementia in the United States. *The New England Journal of Medicine, 368*(14), 1326-1334.

70. Bynum, J. (2011). Tabulations based on data from the Medicare current beneficiary survey for 2008. Unpublished manuscript. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School.
71. Bynum, J. P.; Rabins, P. V.; Weller, W.; Niefeld, M.; Anderson, G. F.; Wu, A. W.; (2004). The Relationship Between Dementia, Diagnosis, Chronic Illness, Medicare Expenditures, and Hospital Use. *Journal of American Geriatrics Society. 52 (2) p. 187-194.*
72. Pinette, A., Obisesan, T.O., Shetty, N., Tchiendji, C.S., Mehari. A. Trends in Hospitalization Associated with Alzheimer's Disease in the United States. Journal of the American Geriatrics Society. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3744116/.
73. Hemp, P. (2004). Presenteeism: at work – but out of it. *Harvard Business Review*. October 2014. Retrieved from https://hbr.org/2004/10/presenteeism-at-work-but-out-of-it/ar/1.
74. Kasper, J. D.; Freedman, V. A.; Spillman, B. C. (2014) Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. Available at http://aspe.hhs.gov/pdf-report/disability-and-care-needs-older-americans-analysis-2011-national-health-and-aging-trends-study.
75. Lachs, M., Berman, J. (2011). *Under the Radar: New York State Elder Abuse Prevalence Study.* Retrieved from: http://NYSOCFS.ny.gov/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf.
76. Lachs, M.S., & Berman, J. (2011). Under the Radar: New York State Elder Abuse Prevalence Study, Self-Reported Relevance and Documented Case Surveys https://ocfs.ny.gov/reports/aps/Under-the-Radar-2011May12.pdf
77. Foldes SS, Moriarty JP, Farseth PH, Mittelman MS, Long KH. Medicaid Savings From The New York University Caregiver Intervention for Families with Dementia | The Gerontologist | Oxford Academic. OUP Academic. https://academic.oup.com/gerontologist/article/doi/10.1093/geront/gnx077/3869333/Medicaid-Savings-From-The-New-York-University?rss=1. Published July 5, 2017
78. The Lancet Commission - Dementia, prevention, intervention and care: 2020 report of the Lancet Commission. https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext
79. Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. Special report: Alzheimer's detection in the primary care setting - connecting patients with physicians. Available at: https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf
80. Schliep, K. C., Shaaban, C. E., Meeks, H., Fraser, A., Smith, K. R., Majersik, J. J., Foster, N. L., Wactawski-Wende, J., Østbye, T., Tschanz, J., Padbury, J. F., Sharma, S., Zhang, Y., Facelli, J. C., Abdelrahman, C. S., Theilen, L., & Varner, M. W. (2023, May 21). *Hypertensive disorders of pregnancy and subsequent risk of Alzheimer's disease and other dementias*. Alzheimer's & dementia (Amsterdam, Netherlands). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10201212/
81. *Wandering*. Alzheimer's Disease and Dementia. (n.d.). https://www.alz.org/help-support/caregiving/stages-behaviors/wandering
82. Lancashire, L., Biggar, V., Comer, M., Frangiosa, T., Gage, A., Paulsen, R., Roniger, A., & Wolfe, J. (2023). Caring for Dementia Caregivers: Understanding Caregiver Stress During the COVID-19 Pandemic. *Gerontology & geriatric medicine*, *9*, 23337214231185664. https://doi.org/10.1177/23337214231185664
83. Borges-Machado F, Barros D, Ribeiro Ó, Carvalho J. The Effects of COVID-19 Home Confinement in Dementia Care: Physical and Cognitive Decline, Severe Neuropsychiatric Symptoms and Increased Caregiving Burden. *American Journal of Alzheimer's Disease & Other Dementias®*. 2020;35. doi:10.1177/1533317520976720
84. Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komuravelli, A., Shenton, J., Callaghan, S., Tetlow, H., Limbert, S., Whittington, R., Rogers, C., Rajagopal,

M., Ward, K., Shaw, L., Corcoran, R., Bennett, K., & Gabbay, M. (2021). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging & mental health*, *25*(7), 1281–1288. https://doi.org/10.1080/13607863.2020.1822292

85. Lin, F. R., Pike, J. R., Albert, M. S., Arnold, M., Burgard, S., Chisolm, T., Couper, D., Deal, J. A., Goman, A. M., Glynn, N. W., Gmelin, T., Gravens-Mueller, L., Hayden, K. M., Huang, A. R., Knopman, D., Mitchell, C. M., Mosley, T., Pankow, J. S., Reed, N. S., Sanchez, V., … ACHIEVE Collaborative Research Group (2023). Hearing intervention versus health education control to reduce cognitive decline in older adults with hearing loss in the USA (ACHIEVE): a multicenter, randomized controlled trial. *Lancet (London, England)*, *402*(10404), 786–797. https://doi.org/10.1016/S0140-6736(23)01406-X
86. O'Connor, M. K., Nicholson, R., Epstein, C., Donley, T., Salant, R., Nguyen, A. H., Shirk, S., Stevenson, E., & Mittelman, M. S. (2023). Telehealth Support for Dementia Caregivers During the COVID-19 Pandemic: Lessons Learned From the NYU Family Support Program. *The American journal of geriatric psychiatry: official journal of the American Association for Geriatric Psychiatry*, *31*(1), 14–21. https://doi.org/10.1016/j.jagp.2022.08.005
87. Dhana, K, Beck, T, Desai, P, Wilson, RS, Evans, DA, Rajan, KB. Prevalence of Alzheimer's disease dementia in the 50 US states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics. *Alzheimer's Dement*. 2023; 19: 4388–4395. https://doi.org/10.1002/alz.13081
88. Majersik, J. J., Ahmed, A., Chen, I. A., Shill, H., Hanes, G. P., Pelak, V. S., Hopp, J. L., Omuro, A., Kluger, B., & Leslie-Mazwi, T. (2021). A Shortage of Neurologists We Must Act Now: A Report From the AAN 2019 Transforming Leaders Program. *Neurology*, 10.1212/WNL.0000000000012111. Advance online publication. https://doi.org/10.1212/WNL.0000000000012111
89. NeurologyLive (2024). Biogen Walks Away From Aducanumab to Prioritize Lecanemab and Alzheimer Disease Pipeline. Retrieved from https://www.neurologylive.com/view/biogen-walks-away-from-aducanumab-prioritize-lecanemab-alzheimer-disease-pipeline
90. Palmqvist, S., Tideman, P., Mattsson-Carlgren, N., Schindler, S. E., Smith, R., Ossenkoppele, R., Calling, S., West, T., Monane, M., Verghese, P. B., Braunstein, J. B., Blennow, K., Janelidze, S., Stomrud, E., Salvadó, G., & Hansson, O. (2024). Blood Biomarkers to Detect Alzheimer Disease in Primary Care and Secondary Care. *JAMA*, *332*(15), 1245–1257. https://doi.org/10.1001/jama.2024.13855
91. Kelley, A. S., McGarry, K., Gorges, R., & Skinner, J. S. (2015). The burden of health care costs for patients with dementia in the last 5 years of life. *Annals of internal medicine*, *163*(10), 729–736. https://doi.org/10.7326/M15-0381
92. Stroup TS, Olfson M, Huang C, et al. Age-Specific Prevalence and Incidence of Dementia Diagnoses Among Older US Adults With Schizophrenia. JAMA Psychiatry. 2021;78(6):632–641. doi:10.1001/jamapsychiatry.2021.0042
93. Kapasi, A., DeCarli, C., & Schneider, J. A. (2017). Impact of multiple pathologies on the threshold for clinically overt dementia. *Acta neuropathologica*, *134*(2), 171–186. https://doi.org/10.1007/s00401-017-1717-7

<u>Attachment A -</u> Members of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia

Louis R. Belzie, MD, MPH, FAPA
Brookdale University

Denise Cavanaugh, Ed.D.
Caregiver

John Cochran
New York State Office for the Aging

Teresa A. Galbier, MPA
Vice President of Dementia Program Development
Episcopal Senior Life Communities

David E. Hart, MD
Stratton VA Medical Center

William Higgins, MD, MBA
New York Presbyterian/Hudson Valley Hospital

Michael Jabonaski, MPA
New York State Department of Health

Catherine J. James, BS
Has expertise in Alzheimer's disease, other dementia, or elder care issues

Julie Kelleher, MS, BS
New York State Office of Children and Family Services

Jed A. Levine, MA
CaringKind

David R. Okrent, Esq., CPA
Managing Attorney
The Law Offices of David R. Okrent

Carol Podgorski, PhD, MPH, LMFT
University of Rochester Department of Psychiatry

George Shaw, BSN, RN,
New York State Office for People with Developmental Disabilities

Maxine Smalling, MS, BS(N), RN
New York State Office of Mental Health

Elizabeth Smith-Boivin, MSHSA, BA
Alzheimer's Association, Northeastern New York Chapter

Suzanne Sullivan
New York State Education Department

James Taylor, MBA, BA
Caregiver, Voices of Alzheimer's

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Alzheimer's disease	**Characteristics:** Alzheimer's disease 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. Alzheimer's disease is the most common type of dementia, accounting for an estimated 60% to 80% of cases.
Alzheimer's disease *(continued)*	**Symptoms:** • Early-stage: o Difficulty remembering recent conversations, names, or events o Confusion with time and place o Word finding issues o Difficulty performing familiar tasks in home, social, or work settings o Misplacing valuable items o Losses in planning, problem solving, and organizational abilities o Changes in mood or behavior o Withdrawal from work or social activities o Impaired judgment • Middle-stage: o Forgetting events in one's personal history o Mood changes (apathy, depression, irritability) o Behavioral changes (agitation, wandering, aggression) o Increasing confusion related to date, time, and place o Difficulty maintaining continence o Disturbances in sleep, disruptions in sleep patterns o Increasing difficulties with activities of daily living, mobility, and functional independence • Late-stage: o Lack of awareness of recent experiences, surroundings, and physical functioning o Difficulty swallowing o At risk for infections, especially pneumonia o Further decline in physical ability and mobility o Significant dependence on caregivers for activities of daily living and personal care o Impaired verbal and receptive communication skills
	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.
	Diagnosing: An Alzheimer's disease diagnosis is based on a medical evaluation completed by a medical professional that includes a physical and neurological examination;

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	interviews of the patient and family member; mental status tests; functional assessments; and examinations to establish any differential diagnoses.
	Known risk factors: • Advancing age • Family history • Genetics, specifically the presence of the APOE-e4 gene or Down syndrome
Diagnosis	**Diagnostic Criteria**
Chronic Traumatic Encephalitis	**Characteristics:** Chronic Traumatic Encephalitis is a progressive degenerative brain disease associated with repetitive brain trauma and mild traumatic brain injury. Chronic Traumatic Encephalitis can occur as a result of concussions often received in contact sports or non-concussive hits to the head over time.
	Symptoms: • 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: Chronic Traumatic Encephalitis 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: • Repeated brain trauma • History of head injuries/traumatic brain injuries
Diagnosis	**Diagnostic Criteria**
<u>Creutzfeldt-Jakob disease</u>	**Characteristics:** Creutzfeldt-Jakob disease 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 Creutzfeldt-Jakob disease are uncharacteristically rapid and severe. There are three main types of Creutzfeldt-Jakob

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	disease: sporadic, familial, and transmitted/infectious. The most common form of Creutzfeldt-Jakob disease is sporadic.
	Symptoms: • Confusion and rapid decline in all areas of cognition • Involuntary muscle movements, twitches and/or stiffness • Difficulty walking • 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.
Creutzfeldt-Jakob disease *(continued)*	**Diagnosing:** Creutzfeldt-Jakob disease 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 magnetic resonance imaging. There is no known cause for sporadic Creutzfeldt-Jakob disease.
	Known Risk Factors: • Genetic variations • Exposure to external sources of abnormal prion protein (poorly sterilized medical equipment or infected meat)
Diagnosis	**Diagnostic Criteria**
Frontotemporal Dementia	**Characteristics:** Frontotemporal dementia 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 frontotemporal dementia, temporal/frontal frontotemporal dementia, progressive non-fluent aphasia, semantic dementia, primary progressive aphasia, Pick's disease, corticobasal syndrome, progressive supranuclear palsy, frontotemporal dementia with parkinsonism, and frontotemporal dementia with amyotrophic lateral sclerosis. Persons with frontotemporal dementia are typically diagnosed in their 40s to 60s.
Frontotemporal dementia *(continued)*	**Symptoms:** • 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 frontotemporal dementia. Frontotemporal dementia primarily affects the frontal

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	(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 frontotemporal dementia 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.
Frontotemporal dementia *(continued)*	**Diagnosing:** The diagnosis of frontotemporal dementia 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 magnetic resonance imaging and glucose positron emission tomography scans, are helpful in determining the diagnosis of frontotemporal dementia.
	Known Risk Factors: • Family history (accounts for 1/3 of the cases)
Diagnosis	**Diagnostic Criteria**
Human Immunodeficiency Virus associated neurocognitive disorder/Acquired immune deficiency syndrome Acquired Immune Deficiency Syndrome D Dementia Complex	**Characteristics:** Human Immunodeficiency Virus associated neurocognitive disorder is an umbrella term for Human Immunodeficiency Virus-related dementias that include: Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder and Human Immunodeficiency Virus-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.
	Symptoms: • 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
	Brain Changes: The Human Immunodeficiency Virus penetrates the blood-brain barrier and affects subcortical brain structures below the cerebral cortex. Human Immunodeficiency Virus 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 Human

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	Immunodeficiency Virus infections are likely to develop Acquired Immune Deficiency Syndrome dementia complex or Human Immunodeficiency Virus associated neurocognitive disorder, leading to behavioral changes and a gradual decline in cognitive function.
	Diagnosing: Human Immunodeficiency Virus associated neurocognitive disorder Acquired Immune Deficiency Syndrome dementia complex is diagnosed through a complete neurological examination, brain imaging, and potentially a lumbar puncture to assess cerebrospinal fluid. Cognitive testing is also recommended.
	Known Risk Factors: • Human Immunodeficiency Virus Infection
Diagnosis	**Diagnostic Criteria**
Huntington's disease	**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.
Huntington's disease *(continued)*	**Symptoms:** • 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 • 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 are strongly recommended.
	Known Risk Factors: • Heredity and family history
Diagnosis	**Diagnostic Criteria**
Lewy body dementia	**Characteristics:** Lewy body dementia presents with cognitive symptoms similar to Alzheimer's disease and movement symptoms typical of Parkinson's disease (muscle rigidity, shuffling gait, stooped posture, and difficulty initiating movement). Most experts estimate that Lewy body dementia

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Lewy body dementia *(continued)*	is the third most common cause of dementia after Alzheimer's disease and vascular dementia.
	Symptoms: • Cognitive difficulties similar to Alzheimer's disease, 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 Lewy body dementia.
	Diagnosis: A diagnosis of Lewy body dementia 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: • Advanced age • Male gender • Family member with history of Lewy body dementia Parkinson's disease diagnosis
Diagnosis	**Diagnostic Criteria**
Mild Cognitive Impairment	**Characteristics:** Mild cognitive impairment 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. Mild cognitive impairment is not cognitive decline related to normal aging. Individuals diagnosed with amnestic mild cognitive impairment are at a greater risk of developing Alzheimer's disease and related dementia but not all individuals with mild cognitive impairment progress to a dementia. The symptoms of other conditions, such as

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	depression or a Vitamin B12 deficiency, may mimic those of mild cognitive impairment.

	Symptoms:
	• Mild cognitive impairment primarily affecting memory ("Amnestic")
	  ○ Short-term memory and re-call problems
	  ○ Difficulty learning new information
	• Mild cognitive impairment primarily affecting thinking ("Non-amnestic")
	  ○ 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

	Brain Changes: Brain imaging has shown overall reductions in brain volume in persons with mild cognitive impairment, 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 Alzheimer's disease and related dementia.
	Diagnosing: Mild cognitive impairment is a clinical diagnosis based on a medical professional's best judgment after considering the individual's medical history, functional and activities of daily living assessment, input from family, and/or mental status testing. Diagnosis may be enhanced with the use of biomarker testing (cerebrospinal fluid examinations and imaging).
	Known Risk Factors: • Advancing age • Family history of Alzheimer's disease and related dementia • Conditions that increase a person's risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)
Diagnosis	**Diagnostic Criteria**
Mixed Dementia	**Characteristics:** Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of mixed dementia are Alzheimer's disease with vascular dementia, Alzheimer's disease with Lewy body dementia, or characteristics of Alzheimer's disease mixed with vascular and Lewy body dementia.

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	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 Alzheimer's disease 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 living with mixed dementia will have the pathology of the presenting combination of Alzheimer's disease and related dementia. For example, in an individual living with both Alzheimer's disease and vascular dementia, abnormal protein deposits associated with Alzheimer's disease 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.
Mixed Dementia *continued*	**Known Risk Factors:** • Risk factors are consistent with the types of dementia that comprise the mixed dementia diagnosis.
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 Lewy body dementia. 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.

Parkinson's disease	**Symptoms**
	• Memory impairment with disruptions in judgment and ability to concentrate
	• Parkinsonian motor changes, such as:
	  ○ Bradykinesia (slowed movements)
	  ○ Tremors, mostly at rest

Attachment B - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Parkinson's disease *(continued)*	○ Muscle rigidity ○ Gait disturbances (shuffling, forward propelling, difficulty initiating movement) ○ Mask-like fascial expression ○ Abnormal posture ○ Micrographia • Delusions and paranoid ideations • Sleep disturbances • Depression and anxiety • Overall fatigue • Low volume and muffled speech
	• **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.
Diagnosis	**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.
	Known Risk Factors: • Age 60 or older • Heredity • Male gender • Exposure to toxins (particularly herbicides and pesticides)
	Diagnostic Criteria
Vascular dementia	**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 Alzheimer's disease.
Vascular dementia	**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: • Decrease in ability to organize thoughts and actions • Confusion, disorientation, and poor attention span

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Vascular dementia *(continued)* **Diagnosis**	• 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 • Impairments in mobility and/or extremity weakness specific to the area of the brain affected.
	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: • A diagnosis of dementia or mild cognitive impairment • Evidence of a stroke or other blood vessel changes that affect cause damage in the brain • No evidence that factors other than vascular changes caused the decline
	• **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.
	Known Risk Factors: • History of heart disease and stroke • Smoking • Poorly managed diabetes • Obesity and lack of exercise • Hypertension and high cholesterol
	Diagnostic Criteria
Wernicke-Korsakoff syndrome	**Characteristics:** Wernicke-Korsakoff syndrome 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 Acquired Immune Deficiency Syndrome, chronic infections, malnutrition, or other medical conditions. Wernicke-Korsakoff syndrome is conceptually closely related to two syndromes: Wernicke encephalopathy,

<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	which is an acute phase of disease and potentially reversible, and Korsakoff dementia, which results from more chronic disease and is irreversible.
Wernicke-Korsakoff syndrome	**Symptoms:** • Memory problems, both recent recall and long-term, accompanying intact higher level cognitive and social skills • Difficulty learning new information • Tendance to confabulate and make-up information that can't be recalled
	• **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.
Wernicke-Korsakoff syndrome *(continued)*	**Diagnosing:** Wernicke-Korsakoff syndrome is a clinical diagnosis representing a doctor's best professional judgment about the reason for a 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.
	Known Risk Factors: • Alcohol misuse • Poor nutrition related to stringent dieting, fasting or anorexia • Presence of other diseases that lead to malnutrition such as Acquired Immune Deficiency Syndrome, 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
ADRD	Alzheimer's disease and related dementias
ADC	AIDS dementia complex
ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
AlzCAP	Coalition of Alzheimer's Association Chapters
APS	Adult Protective Services
BOLD	Building Our Largest Dementia Infrastructure
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	NAPA
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 Children 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
OAA	Older American's Act
PET	Positron Emission Tomography
PSA	Protective Services for Adults
Public Health Road Map	The Healthy Brain Initiative: The Public Health Road Map for State and National Partnership, 2013-2018
REST	Respite Education and Support Tools
SADS	Social Adult Day Service

SFY	State Fiscal Year
SNALR	Special Needs Assisted Living Residence
TBI	Traumatic Brain Injury
WHO	World Health Organization
WKS	Wernicke-Korsakoff syndrome