

# alzheimer's association

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## New York State Coalition

*Statement Prepared for January 29, 2020*

*Assembly Ways & Means Committee*

*&*

*Senate Finance Committee*

*on the*

*2020-2021 Joint Legislative Budget Hearing for*

*Health and Medicaid*

*Prepared by*

*Ian Magerkurth*

*Director of Government Affairs, New York State*

*Alzheimer's Association*

*60 East 42<sup>nd</sup> Street, Ste 2240*

*New York, NY 10165*

*646.793.4851*

*[imagerkurth@alz.org](mailto:imagerkurth@alz.org)*

*My name is Ian Magerkurth, Director of Government Affairs for the Alzheimer's Association in New York State. We appreciate the opportunity to testify today.*

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's advocacy, research and support. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Alzheimer's is a progressive and fatal disease, with no effective cure or way to prevent or slow the disease's progression. Approximately 400,000 New Yorkers over the age of 65 are living with Alzheimer's and that number is projected to increase by 15% by 2025. Based on our 2019 Alzheimer's Association Facts and Figures, over one million New York Alzheimer's Caregivers, are providing over 1 billion hours of unpaid care, valued at over \$14 billion dollars. Two thirds of all Alzheimer's caregivers are women.<sup>1</sup> Alzheimer's disease places an extreme burden on family caregivers and as New York's population continues to age, and more individuals are diagnosed with Alzheimer's disease and other dementias, the amount of time and money spent by family caregivers will only continue to grow. Additionally, caring for an individual with Alzheimer's can have a negative effect on employment, income and financial security. Among Alzheimer's and dementia caregivers who are employed full or part time, 57% said they had to go in late, leave early or take time off because of their caregiving responsibilities. More than 1 in 6 Alzheimer's and dementia caregivers had to quit work entirely either to become a caregiver or because their caregiving duties became too burdensome. We need crucial financial relief to these unpaid Alzheimer's and dementia family caregivers.

Almost two-thirds of individuals living with Alzheimer's are women. In addition to gender differences, Alzheimer's affects racial and ethnic groups disproportionately. Compared to older white adults, Black and African Americans are about twice as likely to have Alzheimer's or other dementias, and Latinx are approximately 1.5 times as likely. As New York's population ages, with more individuals aging over 65 each day, their risk of getting Alzheimer's and other dementias increase, more so than any other disease, with a staggering cost of \$4.8 billion in Medicaid dollars alone. Annual per-person Medicaid spending on seniors with Alzheimer's and other dementias is 19 times higher than average, annual per-person Medicaid spending across all seniors without dementia. Furthermore, at least 74 percent of people with dementia have multiple chronic conditions, which complicate their care and drive up costs. Seniors with Alzheimer's and other dementias have, on average, twice as many hospitalizations each year and four times as many skilled nursing facility stays as seniors without Alzheimer's.

For more than 30 years, through our New York State Coalition, made up of our seven Alzheimer's Association Chapters, has provided services to New Yorkers with Alzheimer's disease and all dementias, and their caregivers in all 62 counties in New York State. Thanks to generous statewide support from Governor Cuomo and the legislature through the monumental \$25 million Alzheimer's Disease Caregiver Support Initiative, which is the most progressive investment in Alzheimer's Care and Support by any state in the nation, the four

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<sup>1</sup> Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. Alzheimer's Dementia 2019;15(3):321-87

grants through this initiative provide the Alzheimer's Association and other partner contractors with an infrastructure to address the growing public health crisis precipitated by Alzheimer's disease. This Initiative provides evidence-based education and person-centered care and support to New Yorkers affected by Alzheimer's and other dementias through our free in-person and online programs for caregivers, professionals, and the public on a wide range of topics such as diagnosis, early warning signs, and the need for caregiver support and respite. We have a diverse and multilingual staff of specialists and master's-level clinicians that can work with New Yorkers in need, in person or over the phone and through our free 24/7 Helpline.

Based on a longitudinal study by Dr. Mary Mittelman of New York University, community-based caregiver services like those offered through the Alzheimer's Disease Caregiver Support Initiative, including robust caregiver education and support can help New Yorkers with Alzheimer's and all dementias delay premature placement into skilled nursing facilities by an average of 557 days<sup>2</sup>. By educating and empowering formal and informal caregivers, such as family and neighbors to recognize the nuances of care needed to support someone with dementia, such programs can help someone living with the disease to age in place without sacrificing their quality of life.

Additionally, through our Centers of Excellence for Alzheimer's Disease (CEADs) which are comprised of a network of ten medical centers and teaching hospitals, recognized nationally and by New York State as experts in the diagnosis and care of individuals living with Alzheimer's Disease and all dementias, New York continues to remain at the forefront of research and clinical trials seeking effective treatments and a cure.

We are thankful for these synergistic relationships and opportunities that we have to collaborate through this initiative. For example, through the Regional Caregiver Support Initiative grant of the Alzheimer's Disease Caregiver Support Initiative, several of our Chapters and grant partners directly contract with the Area Agencies on Aging (AAA's) to deliver respite services. This has worked very well as we build off the existing infrastructure that the AAA's have for administering respite dollars which has strengthened the collaboration between our agencies. We have found that many of the AAA's rely on us for a more in-depth understanding and knowledge of Alzheimer's which has provided us with opportunities to offer dementia-specific training for their staff, referrals both to and from the Association, delivery of education programs, support groups, and other dementia-specific support services. We have found that by creating partnerships and improving coordination with the AAA's, we can complement services that our respective agencies each specialize in and bridge any gaps to where barriers to services exist.

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<sup>2</sup> Mary S. Mittelman et al, Improving Caregiver Well-being Delays Nursing Home Placement of Patients with Alzheimer's Disease, 67 Neurology 1592, 1592-99 (November 14, 2006)

We work collaboratively with the New York State Department of Health, the New York State Office of the Aging and the Area Agencies on Aging to continue educating caregivers on how to effectively navigate the healthcare system and the importance of emergency preparedness to reduce avoidable emergency department visits, hospitalizations, and nursing home placements, all of which help New Yorkers, including those with Alzheimer's and all dementias, "Age in Place".

**Request:**

We are very thankful to Governor Cuomo and the legislature for their continued investment and support of the Alzheimer's Caregiver Support Initiative, the most progressive investment in Alzheimer's caregiver support by any state in the nation. As we move into the SFY20-21 budget cycle, we ask for your continued support in preserving and maintaining this initiative at its robust funding level of \$25 million per year in both the Assembly and Senate one-house budgets. However, with no effective treatment method or cure, Alzheimer's prevalence will only continue to rise in New York State. Greater capacity leads to greater demand and we know that the number of people served under this initiative still represents the tip of the iceberg in terms of the number of people with Alzheimer's disease and all dementias and their caregivers.

Additionally, the Alzheimer's Association supports a Family Caregiver Tax Credit as proposed by Senator Rachel May and Assembly Member Harry Bronson (S.5100/A.2709) to provide crucial financial relief to unpaid family caregivers through a tax credit on eligible goods and services including home health aides, adult day care, respite care, home modifications, and transportation – all of which helps those being cared for continue to "age in place".

We look forward to continuing to work with you to help New Yorkers with Alzheimer's Disease and all dementias continue to "age in place", support caregivers and achieve New York's Triple Aim – better care, better population health and lower health care costs – through collaborative community work to implement best practices and strategies to promote brain health and reduce healthcare disparities in underserved regions.

Our efforts to empower and enable caregivers to help those with dementia live at home longer greatly reduces the Medicaid burden now and into the future. The Alzheimer's Association, New York State Coalition is grateful for the support and looks forward to working together to grow resources and continue to improve the status quo for New Yorkers facing Alzheimer's disease and dementia.

Thank you again for this opportunity.



## Regional Caregiver Support Initiative

We are a network of ten organizations across New York State (NYS), which have developed programs that support family caregivers who care for New Yorkers living with Alzheimer’s disease and other dementias (AD/D).

We strive to provide a safety net for caregivers of individuals with AD/D by recognizing and addressing the need for supports and stress reduction.

We offer evidence-based or evidence-informed strategies and initiatives to develop a robust and innovative array of caregiver support services within every county of NYS. Each regional initiative offers:

- Care and Family Consultations
- Support Groups
- Education and Training Programs
- Respite
- At least one additional Caregiver Support Service, such as:
  - Access Services
  - Caregiver Companions
  - Care Support Teams
  - Caregiver Wellness Programs
  - Joint Enrichment Opportunities

“You came into our lives at just the right time. You made such a difference for dad and his final months were happy and he felt useful, valued and loved by everyone. I am sure there are many more lives for you to touch, families who need you.”

New York State Caregiver, Capital Region



### Regional Caregiver Support Initiative Contractors

- Northeast Health Foundation, Inc.  
Capital Region
- Alzheimer’s Association  
Central New York
- Lifespan of Greater Rochester, Inc.  
Finger Lakes
- Alzheimer’s Association  
Hudson Valley
- Parker Jewish Institute for Health Care and Rehabilitation  
Long Island
- New York University  
New York City
- Presbyterian Senior Services  
New York City
- Sunnyside Community Services, Inc  
New York City
- Alzheimer’s Association  
Western New York
- The State University of New York at Plattsburgh  
Northeastern New York

# The Impact of Alzheimer's Disease and Other Dementias

## New York State by the Numbers

**400,000**

New Yorkers are living with Alzheimer's disease (AD)

**\$5 billion**

Medicaid dollars spent caring for people with AD/D

**1 million**

Unpaid family caregivers

**\$895 million**

In higher health care costs for family caregivers

"Alzheimer's disease and other dementias are a public health crisis nationwide and here in New York State... We are committed to implementing this initiative in the most impactful way to benefit people in every corner of our state."

Dr. Howard Zucker  
New York State Health Commissioner

### The Impact of AD/D in the United States:

- AD is the sixth leading cause of death in the United States.
- In 2019, 5.8 million Americans age 65 and older are living with AD. By 2050, a projected 13.8 million Americans age 65 and older will be living with AD.
- In 2019, total payments for health care, long-term care and hospice care for people with AD/D in the United States is estimated at \$290 billion. By 2050, the projected cost of AD/D will be \$1.1 trillion.
- More than 16 million Americans provide over 18.5 billion hours of unpaid care annually for people with AD/D. This care is valued at around \$234 billion.
- 18% of caregivers went from full-time to part-time work or cut back hours, and 9% gave up working entirely due to caregiving responsibilities.

### The impact of AD/D in New York State:

- By 2025, NYS is projected to experience a 15% increase in people living with AD, meaning a projected 460,000 New Yorkers will be living with AD.
- New York's family caregivers provide approximately 1.2 billion hours of unpaid care annually for people with AD/D. This care is valued at an estimated \$14.6 billion.

## New York State Department of Health Alzheimer's Disease Program

**10**

Regional Caregiver Support Initiative Programs

**15**

Caregiver Support Initiative Programs for Underserved Communities

**10**

Centers of Excellence for Alzheimer's Disease

**1**

Statewide Alzheimer's Community Assistance Program

### The Alzheimer's Disease Caregiver Support Initiative

- All 62 counties across New York State served
- 95,623 consultation services
- 11,705 support group sessions
- 7,276 education sessions
- 337,841 hours of respite care
- 24,553 AD/D diagnostic assessments
- 75,283 physician referrals to community providers
- 55,312 students, physicians and healthcare professionals trained
- 72,280 Helpline calls



## Alzheimer's Disease Community Assistance Program

We are a statewide program providing a comprehensive array of community-based services for individuals with Alzheimer's disease and other dementias (AD/D) and their caregivers. The Alzheimer's Association, New York State Coalition is a not-for-profit organization that coordinates the Alzheimer's Disease Community Assistance Program (AlzCAP) in every region of New York State.

We provide critical services such as:

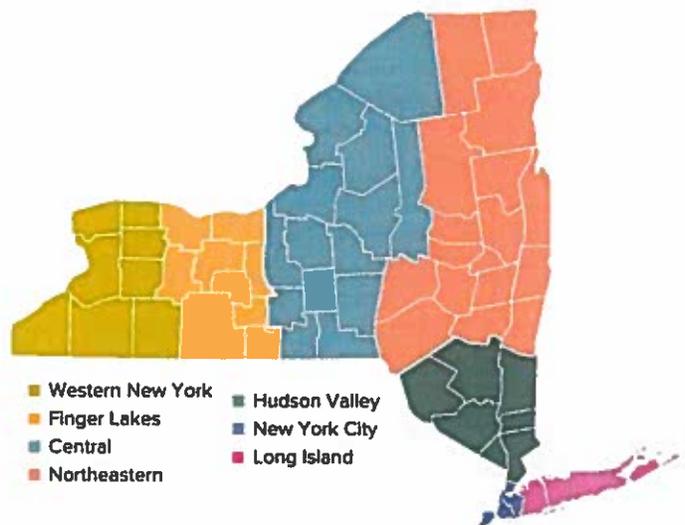
- Professional care consultations conducted in-person, by phone or virtually depending on the person's needs
- Training and education for both caregivers and individuals with AD/D
- In-person and virtual support groups for caregivers and individuals with AD/D
- A 24-hour Helpline available in more than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

We strive to provide services that are designed to postpone or prevent nursing home placements on a statewide basis. Services are offered to individuals with AD/D, caregivers and professionals.

"I was afraid to call but I am glad I did. Now I know what to do and there is hope."

"We have picked up and learned new ways to cope with situations and have learned that we are not alone in this."

AlzCAP Caregivers, New York State



### Alzheimer's Disease Community Assistance Program Alzheimer's Association, New York State Coalition Subcontractors

- Alzheimer's Association, Western NY Chapter
- Alzheimer's Association, Rochester and Finger Lakes Chapter
- Alzheimer's Association, Central NY Chapter
- Alzheimer's Association, Northeastern NY Chapter
- Alzheimer's Association, Hudson Valley Chapter
- Alzheimer's Association, New York City Chapter
- Alzheimer's Association, Long Island Chapter

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## Centers of Excellence for Alzheimer's Disease

### We are...

A network of ten medical centers and teaching hospitals, recognized nationally and by New York State as experts in the diagnosis and care of individuals living with Alzheimer's Disease or other dementias (AD/D). Our *Centers of Excellence for Alzheimer's Disease (CEAD)* are at the forefront of research and clinical trials seeking effective treatments and a cure.

### We offer...

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

### We strive to...

Enhance the availability of early screening and diagnosis of dementia; support research into its causes and potential treatments; expand the expertise of the health care workforce; and provide access to community-based services for patients and their caregivers

"I couldn't be more thankful for having the CEAD resources available so my husband obtained an accurate diagnosis and the right care. The social worker saved my life when I was suddenly responsible for everything."

Family Caregiver from the New York City Region



### Centers of Excellence for Alzheimer's Disease Serving New York State

- Albany Medical College  
Capital Region
- Upstate Medical University - SUNY  
Central New York
- University of Rochester  
Finger Lakes
- Montefiore Health System  
Hudson Valley
- University of Buffalo - SUNY  
Western New York
- New York University Langone Medical Center  
New York City
- Columbia University Irving Medical Center  
New York City
- Downstate Medical Center - SUNY  
New York City
- Glens Falls Hospital  
Northeastern New York
- Stony Brook University - SUNY  
Long Island

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## Caregiver Support Initiative for Underserved Communities

We are an initiative to reach caregivers of individuals with Alzheimer’s Disease and other dementias (AD/D), either or both of whom are members of underserved communities. These programs recognize and address the need for culturally competent support strategies.

We offer evidence-based or evidence-informed services including:

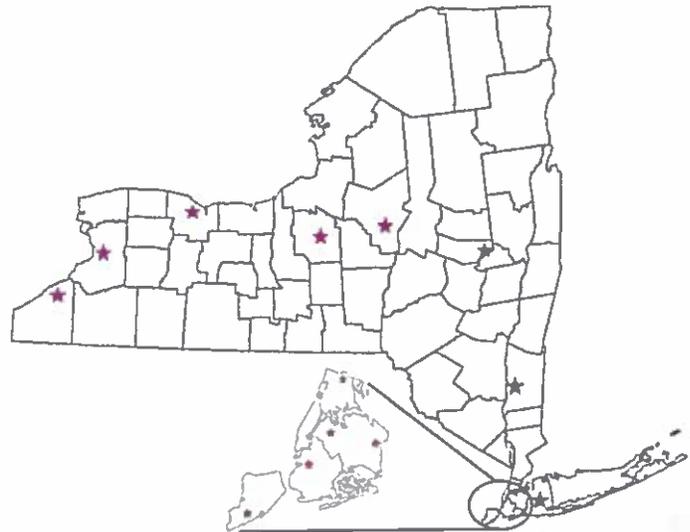
- Extensive Outreach to target communities
- Caregiver Assessment and Referrals
- Support Groups
- Education and Training
- Caregiver Wellness
- Joint Enrichment
- Respite

Our program models are designed to serve individuals that may experience challenges related to:

- Geographic isolation
- English as a second language
- Minority or ethnic group membership
- Sexual orientation & gender identity
- Low socioeconomic status
- Cultural isolation

*“I learned to see mom. The disease is not who she is. Be patient and enjoy her.”*

New York State Caregiver,  
Rochester/Finger Lakes Region



### Caregiver Support Initiative for Underserved Communities Contractors

- Chautauqua Opportunities - Dunkirk, NY
- Pride Center of Western New York - Buffalo, NY
- Syracuse University - Syracuse, NY
- Lutheran Home of Central New York - Clinton, NY
- Regional Aid for Interim Needs - Bronx, NY
- CaringKind - Queens, New York
- Jewish Community Center - Staten Island, NY
- Family and Children’s Association – Mineola, NY
- New York Memory Center - Brooklyn, NY
- Riverstone Senior Life Services - New York, NY
- Sunnyside Community Services - Sunnyside, NY
- Alzheimer’s Association, Hudson Valley Chapter - Poughkeepsie, NY
- Alzheimer’s Association, Rochester & Finger Lakes Chapter - Rochester, NY
- Jamaica Service Program for Older Adults - Jamaica, NY
- Resource Center for Independent Living - Amsterdam, NY

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