# Coalition of NYS Alzheimer's Association Chapters



#### **WHO WE ARE**

The Coalition of New York State Alzheimer's Association Chapters is the only statewide organization representing all New Yorkers affected by Alzheimer's disease and dementia.

The Coalition is comprised of seven NYS chapters (see map) and a main office in Albany.



#### WHAT WE DO

#### The Coalition

- ✓ promotes the concern and awareness of Alzheimer's disease and related dementia and caregiver health
- √ facilitates care and support
- ✓ advances public policy

on behalf of the 390,000 New Yorkers with Alzheimer's disease and their 1.1 million informal caregivers.

## alzheimer's No association

#### Chapters services include:

- a free 24/7 helpline –
- 1.800.272.3900
- information and referrals
- care consultations
- support groups
- safety services
- education for individuals, families, community members and healthcare professionals
- social enrichment programs

2016 | Alzheimer's Disease Facts and Figures



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THE BRAINS BEHIND SAVING YOURS:

# ADVOCATES FOR THOSE AFFECTED BY ALZHEIMER'S DISEASE

To ensure NYS policy reflects the concerns of those affected by Alzheimer's, we collaborate with:

- ✓ statewide organizations
- ✓ state agencies
- ✓ policy-minded individuals
- ✓ elected officials

We facilitate dementia capability while pursuing our vision - a world without Alzheimer's disease.

#### What is Dementia?

Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer's is the most common type of dementia.

### What is Alzheimer's Disease?

Characteristics: AD is a slowly progressive brain disease that begins well before symptoms emerge and is fatal. There is no known cure or vaccine for this disease. AD is the most common type of dementia, accounting for an estimated 60 to 80% of cases.

Early-stage:

- Difficulty remembering recent conversations, names, or events
- Confusion with time and place Word finding issues
- Difficulty performing familiar tasks in home, social, or work settings Misplacing valuable items
- Losses in planning, problem solving, and organizational abilities
- Changes in mood or behavior Withdrawal from work or social activities
- Impaired judgment

Middle-stage:

- Forgetting events in one's
- personal history Mood changes (apathy, depression, irritability)
- Behavioral changes (agitation, wandering, aggression)

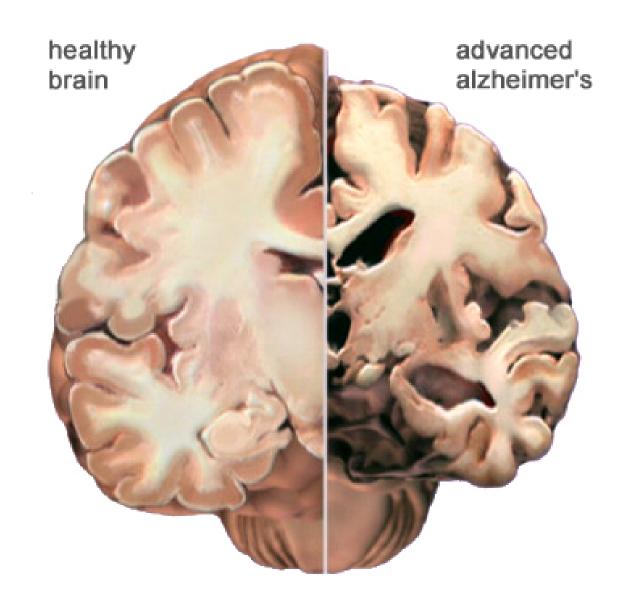
Increasing confusion related to date, time, and place

Difficulty maintaining continence

- Disturbánces in sleep, disruptions in sleep patterns
- Increasing difficulties with ADLs, mobility, and functional independence

Late-stage:

- Lack of awareness of recent experiences, surroundings, and physical functioning
- Difficulty swallowing
- At risk for infections, especially pneumonia
- Further decline in physical ability and mobility
- Significant dependence on caregivers for ADLs and personal care
- Impaired verbal and receptive communication skills



#### Why Alzheimer's Is Costly

780 hospital stays for every 1,000 seniors with Alzheimer's or dementia

243 hospital stays for every 1,000 seniors without these conditions

People with Alzheimer's or dementia have over 3 times as many hospital stays

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.

Source: 2015 Alzheimer's Association Facts & Figures

In April 2015, thanks to Governor Cuomo, the NYS legislature allocated \$25+ million/year for 5 years to Alzheimer's Disease Caregiver Initiatives.

This is the largest state award for Caregiver support ever in the US.

**AIZCAP** \$4,976,000

**CEAD** \$4,000,000

Caregiver Support and Respite \$15,000,000

**Underserved** \$1,500,000

### ALZHEIMER'S DISEASE CAREGIVER SUPPORT INITIATIVE

A five year initiative to provide a wide range of comprehensive and coordinated evidenced-based caregiver support and respite services within specified geographic regions.

#### STATEWIDE CAREGIVER PROJECT GOALS

- Develop and sustain of evidenced-based support services.
- Reduce avoidable ED visits and hospitalizations.
- Improve coordination and access to new and existing support services.
- Expand and enhance access to respite services.
- Improve health and well-being of caregivers and individuals with AD/D.
- Limit all unnecessary transitions.
- Continue community residence and reduce institutionalization of individuals diagnosed with AD/D.

### **CEAD Program Overview**

- Patient Management & Care
- Training and Education
- Community Collaborations
- Public Awareness
- Program Evaluation

**Albany Medical Center** 

**SUNY Downstate** 

**SUNY Upstate** 

Columbia University

NYU

University at Buffalo

**Burke Rehab Hospital** 

Glens Falls Hospital

SUNY at Stonybrook

University of Rochester

## Caregiver Support And Respite Services Grant

Ten regional contractors, reaching every county in the state... receive \$1.5 million each annually to provide support services to promote the mental and physical well-being of caregivers.

- Care Consultation
- FamilyConsultations
- Support Groups
- Respite
- Education & Training
- WellnessActivities
- Joint Enrichment

### Caregiver Support And Respite Services Grant cont'd

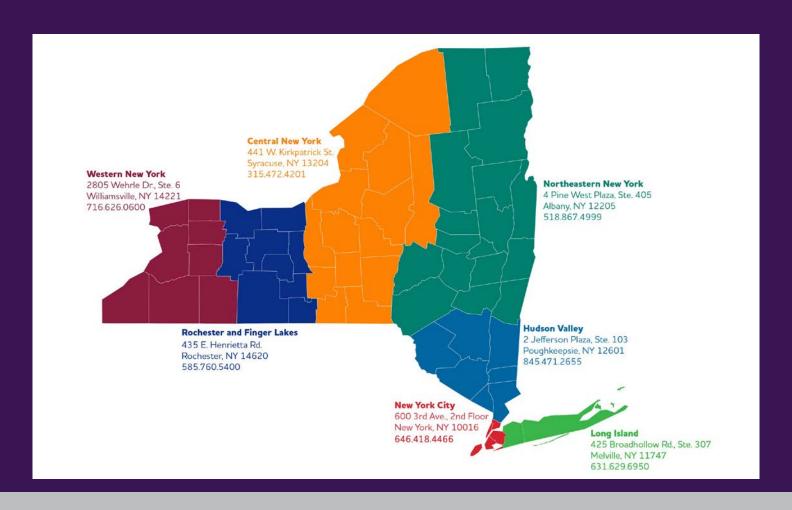
- Alzheimer's Association, Hudson Valley Chapter
- Alzheimer's Association, Central New York
- Research Foundation for SUNY Plattsburgh
- Northeast Health Foundation, Inc.
- Catholic Charities of Buffalo
- Lifespan of Greater Rochester, Inc.
- Parker Jewish Institute for Health Care and Rehabilitation
- Sunnyside Community Services, Inc.
- New York University School of Medicine
- Presbyterian Senior Services, Inc.

# Alzheimer's Disease Caregiver Support Initiative for Underserved Communities

- Outreach
- Education
- Support And
- Targeted Respite
  Opportunities for
  underserved ethnic or
  geographic populations

- Jamaica Service Program for Older Adults
- Jewish Community Ctr of Staten Island
- New York Memory Center
- Regional Aid for Interim Need
- Riverstone Senior Life Services
- Sunnyside Community
   Services
- Alzheimer's Association of the Hudson Valley
- Alzheimer's Association of Rochester and Finger Lakes
- Chautauqua Opportunities
- Family & Children's Association
- Lutheran Home of CNY
- Pride Center of WNY
- Caring Kind
- Resource Center for Independent Living
- Syracuse University

## Alzheimer's Community Assistance Program - AlzCAP



Through the generous support of DOH, the Coalition has expanded core services and outreach to important community partners. Through **AIZCAP**, and increased funds, we have increased the number of:

- support groups
- care consultations
- free 24-hour helpline response
- expanded community outreach and education caregiver education (professional and informal)
- safety services

#### We have grown AlzCAP and ...

- Partnered with providers, houses of worship, senior centers, first responders, pharmacies, cultural organizations, financial planners, lawyers, mail carriers, and so many others to bring public awareness to the Alzheimer's epidemic and empower them to be dementia-friendly and dementia-capable.
- Hired bilingual professionals, additional social workers and patient advocates to support family members of individuals with Alzheimer's.
- Created passionate ambassadors to increase concern and awareness, advance public policy and enhance the care and support so desperately needed through New York's 62 counties.

#### **Our Mandate**

As the statewide leader in Alzheimer's care and support, in collaboration with the NYS DOH, we partner with and convene other DOH contractors & subcontractors, community gatekeepers, healthcare and LTC providers - and others - who also support increased care and support for those facing Alzheimer's and related dementia.

## How can NYSADSA members work with the Coalition?

Train!

Offer Respite!

Partner!

### **Professional Training**

CARES online training, developed collaboratively by the Alzheimer's Association and HealthCare Interactive®, is a person-centered, easy-to-remember approach to caring for an individual with dementia at any stage of the disease.

The CARES training modules use a wide variety of interactive techniques, featuring demonstrations by real CNAs and staff members working with actual people living with dementia. CEUs are available for CARES Dementia Basics & Advanced Care online training.



http://www.hcinteractive.com/TestDriveCares

- The Alzheimer's Association and MedicAlert Foundation International have formed an alliance to improve the safety of individuals with Alzheimer's or a related dementia.
- MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency.
- If an individual with Alzheimer's or a related dementia wanders and becomes lost, caregivers can call the 24-hour emergency response line (1.800.625.3780) to report it.
- A community support network will be activated, including local Alzheimer's Association chapters and law enforcement agencies, to help reunite the family member or caregiver with the person who wandered.





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# Please be in touch. We want to work with you.

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24/7 Help Line **New York State Coalition** Central New York 315.472.4201 Western New York Northeastern New York 716.626.0600 518.867.4999 Rochester and Finger Lakes **Hudson Valley** 585.760.5400 845.471.2655 **New York City** 646.418.4466 Long Island 631.629.6950

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800.272.3900