

New York State Coalition

**BUDGET PRIORITY**

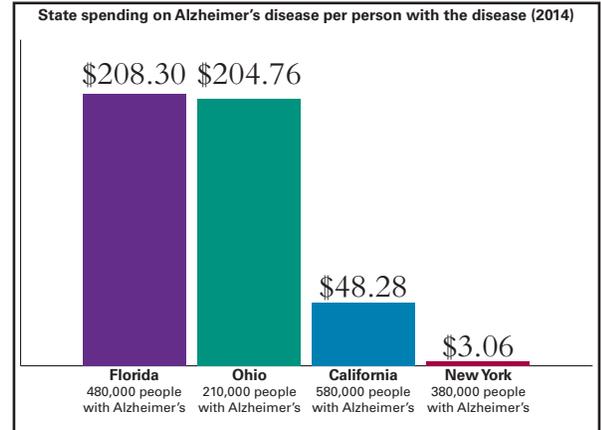
**Support proposed \$25 million increase to Alzheimer's Disease Caregiver Support Services**

The Coalition respectfully requests support of Governor Cuomo's proposed increase of \$25 million to Alzheimer's Disease Caregiver Support Services in New York State, including \$4 million for the Coalition's Alzheimer's Disease Community Assistance Program (AlzCAP).

Currently, New York State allocates a mere \$3.06 per person with Alzheimer's disease (see graph at right). The increased allocation would direct an additional \$65.79 per person to provide more statewide resources for those with or caring for someone with Alzheimer's disease and related dementias.

Community-based caregiver support services have been shown to delay nursing home placement. While caregivers often take on the task of caregiving willingly, the physical, emotional and financial demands can take a toll on their health, as well as their ability to care for themselves and their family members, and create an increased fiscal burden.

With the increased funding, the Coalition will be able to significantly expand evidence-based training, education, support programs, one-on-one care consultations and improved access to community based services statewide to help prevent caregiver fatigue and premature institutionalization.



**LEGISLATIVE PRIORITY**

**Make Advance Directives Easier to Declare**

New York State's population aged 65 and older will grow nearly 20 percent by 2025, according to Cornell University's Program on Applied Demographics. Research shows that 1/4 of seniors have given little or no thought to end of life plans, and have not expressed their wishes in writing. Advance care planning can reduce confusion and guilt among family members forced to make decisions about care, and ultimately, may help stabilize total healthcare and societal costs over time.

For those with Alzheimer's disease, due to the inability of the person with dementia to participate in medical decisions, potential crises are increased when there are no advance directives in place. However, with the addition of a declaration of advance directives on a driver's license or identification card, wishes can be communicated to the treating physician or first responder to avoid unwanted treatment.

These recommendations are consistent with those in the plan developed by the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Sections C and I), and *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* (Sections E-07).

**THE ASK**

**Pass A.449 (Rosenthal)/S.2581 (Valesky), to allow notification of advance care directives on driver's licenses and/or identification cards.**

**LEGISLATIVE PRIORITY**

**Identify Caregivers for Hospitalized Individuals**

The CARE Act supports implementing a system to identify caregivers for hospital patients. The bill mandates that caregivers are educated on the kind of detailed medical care and attention required following discharge, and it encourages open communication lines to best address future medical needs. Expanded and improved caregiver education is critical for the well-being of all patients, particularly those with dementia, throughout New York State.

**THE ASK**

**Pass S.676 (Hannon)/A.1323 (Rosenthal), also known as the CARE Act.**

**LEGISLATIVE PRIORITY**

**Create a Dementia Capable New York State**

Ensuring our community members understand what dementia is, and what the needs and limitations are of a person with dementia, is imperative. The Coalition seeks to introduce two pieces of legislation to:

1. Require direct-care staff in adult care facilities to complete a training curriculum to better educate them on the needs of the dementia population and authorize the Department of Health to establish a workgroup to develop a uniform curriculum and best practices.
2. Include a dementia education component for uniform emergency preparedness training for first responders and local officials. The NYS Emergency Management Certification and Training Program (NYS-EMC) would be able to certify participants for disaster response capabilities in counties across the state.

These recommendations are consistent with those in the plan developed by the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Sections C and I), and *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* (Sections E-07).

**THE ASK**

**Once the Coalition has appropriate legislation drafted, please consider co-sponsorship and advocate for its passage in the Senate and Assembly.**

## New York State Coalition

### COALITION OF NEW YORK STATE ALZHEIMER'S ASSOCIATION CHAPTERS

#### Our Mission

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.

#### Our Vision

The Coalition of New York State Alzheimer's Association Chapters is a recognized leader to effect systems change through ensuring that every political door is open, every voice is heard, and every legislative initiative contains the Association's voice to benefit people with Alzheimer's disease, their families and caregivers.

**In New York State, there are... 380,000 people with Alzheimer's disease  
1,001,000 caregivers for people with Alzheimer's or other dementia**

#### COALITION OFFICERS

##### Co-Chairs

Catherine James  
Elaine Sproat

##### Vice Chair

Elizabeth Smith-Boivin

##### Secretary

Leilani Pelletier

##### Treasurer

Teresa Galbier

#### POLICY TEAM

##### Coalition Representative

Jennifer Muthig  
Malkin & Ross  
518.449.3359 [jmuthig@malkinross.com](mailto:jmuthig@malkinross.com)

##### Director of Statewide Initiatives

Jane Ginsburg  
518.867.4999 x208 [jginsburg@alz.org](mailto:jginsburg@alz.org)

##### State Government Affairs Lead

Jared Paventi  
315.472.4201 x101 [jpaventi@alz.org](mailto:jpaventi@alz.org)

#### MEMBER CHAPTERS

##### Western New York

2805 Wehrle Dr.  
Ste. 6  
Williamsville, NY 14221  
716.626.0600  
Leilani Pelletier *Executive Director*

##### Rochester and Finger Lakes

435 E. Henrietta Rd.  
Rochester, NY 14620  
585.760.5400  
Teresa Galbier *President/CEO*

##### Central New York

441 W. Kirkpatrick St.  
Syracuse, NY 13204  
315.472.4201  
Catherine James *CEO*

##### Northeastern New York

4 Pine West Plaza  
Ste. 405  
Albany, NY 12205  
518.867.4999  
Elizabeth Smith-Boivin *Executive Director/CEO*

##### Hudson Valley/Rockland/ Westchester, NY

2 Jefferson Plaza  
Ste. 103  
Poughkeepsie, NY 12601  
845.471.2655  
Elaine Sproat *President/CEO*

##### New York City

360 Lexington Ave., 4th Fl.  
New York, NY 10017  
646.744.2900  
Lou-Ellen Barkan *President/CEO*

##### Long Island

425 Broadhollow Rd.  
Ste. 307  
Melville, NY 11747  
631.629.6950  
Douglas Davidson *Executive Director*