

Coalition of New York State Alzheimer's Association Chapters 2013 Legislative Agenda

The Coalition of New York State Alzheimer's Association Chapters, founded in 1980, advocates on behalf of the 320,000 Empire State residents living with Alzheimer's disease. It is New York's leader in meeting the needs of individuals with Alzheimer's disease and related dementias and those who care for them. Its member chapters provide care consultations, consumer education programs, a 24-hour Helpline, safety services and support groups at no charge and in all regions of New York with the goal of maintaining a high quality of life for individuals diagnosed with Alzheimer's or a related dementia and their family caregivers. These supports are proven methods of preventing premature institutional placement, therefore creating substantial savings for New York State taxpayers.

Dementia caregiving is a billion-dollar unpaid industry in New York State. Nearly one million New Yorkers provide daily unpaid care for someone with dementia totaling 1.13 billion hours of care annually. The market value of their unpaid care is more than \$13.7 billion.

PRIORITY:

Invest \$5 million in Alzheimer outreach services and care coordination

Services provided by Coalition member chapters are critical in addressing the public health crisis of Alzheimer's disease. While the Coalition is sensitive to economic conditions, evidence suggests that community-based services can delay nursing home placement and reduce the state's Medicaid burden. According to Dr. Mary Mittelman of New York University's Langone Medical Center, the use of community-based caregiver services creates a median delay of skilled nursing facility placement by 557 days. Based on data from MetLife's 2011 Market Survey of Long-Term Care Costs, the average potential savings per person is \$179,354. **The amount saved by delaying placement of only five individuals in skilled nursing care exceeds the amount currently spent on this program. Furthermore, the amount allocated by the State of New York through the Alzheimer's Community Assistance Program (AlzCAP) and Community Services Program (CSP) equals only \$1.84 per New Yorker with the disease.**

RESULTS

In 2011-12, the seven Alzheimer's Association chapters in New York state combined to deliver the following outreach services supported in part by AlzCAP:

- Fulfill more than 31,000 information and referral requests
- Provided nearly 8,200 care consultations
- Sponsored more than 5,800 support groups that attracted 37,600 attendees
- Educate more than 23,000 people at nearly 1,500 education programs

There is new evidence that, for a person with Alzheimer's disease, a stay in a hospital can lead to accelerated mental decline and increase the risk of going into a nursing home or dying. A recent study from Harvard researchers, Adverse Outcomes After Hospitalization and Delirium in Persons with Alzheimer Disease, demonstrated that 41 percent of the patients who were hospitalized with dementia experienced accelerated mental decline during the year following hospitalization. The Coalition believes that increased State funding to support appropriate community based services can help to keep more individuals with Alzheimer's disease at home for as long as possible.

THE ASK:

The Coalition respectfully requests \$5 million to support its initiatives under the Alzheimer's Community Assistance Program (AlzCAP). This investment will not only help individuals with Alzheimer's and their caregivers, but will also significantly reduce the State's Medicaid burden.

PRIORITY:

Invest \$1 million to prepare New York's caregivers for natural disasters

Hurricane Sandy impacted many New Yorkers, particularly its most vulnerable populations. A disaster situation significantly adds to the stress levels and confusion of individuals with Alzheimer's disease and can lead to wandering, agitation and separation from a caregiver.

As New York recovers and plans for future disasters, the Coalition urges the State to fund emergency preparedness trainings to assist Alzheimer's patients. The Coalition's chapters are uniquely positioned to facilitate trainings to help individuals and their caregivers prepare for emergency situations. Both Florida and

Louisiana fund this type of training to ensure that Alzheimer's patients are appropriately cared for in emergency situations. These trainings would be available to agencies responsible for disaster response and shelters, first responders, law enforcement, health care facilities, home health aides and informal caregivers.

THE ASK:

The Coalition asks that the State provide \$1 million dollars in funding for the Alzheimer's Association to deliver trainings on how to best prepare individuals with Alzheimer's and their caregivers for emergencies.

PRIORITY:

Enact Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (A.857/Weinstein and S.2534/Hannon)

Individuals with Alzheimer's disease or a related dementia may require assistance from a guardian, particularly when no advance directives exist. Differing systems of adult guardianship throughout the nation complicate matters as state courts attempt to determine jurisdiction.

states in adult guardianship cases. It also establishes a framework that allows state court judges in different states to communicate with each other about adult guardianship cases. This bill has broad-based support from agencies including the New York State Bar Association and the Long-Term Care Community Coalition.

The Coalition urges New York State to adopt the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (A.857/Weinstein and S.2534/Hannon). UAGPPJA, developed by the Uniform Law Commission and adopted by 33 states, establishes a uniform set of rules for determining jurisdiction, and thus simplifies the process for determining jurisdiction among multiple

THE ASK:

The Coalition urges the New York State legislature to pass the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (A.857/Weinstein and S.2534/Hannon).

PRIORITY:

Implement Priority Recommendations of the Alzheimer's Coordinating Council Plan

In 2007, New York State empaneled the Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias. This group of 21 dementia care experts was charged with providing a report to the Legislature and the Governor every two years. These reports include the Council's recommendations for policy relating to dementia and improved coordination between public and private agencies to meet the needs of individuals with Alzheimer's disease and other dementias. The Council's 2011 report was released in February of 2012 and includes a number of excellent recommendations that emphasize early diagnosis and education as critical components in the fight against Alzheimer's.

The Coalition believes that there are three recommendations in the 2011 Council report that should be prioritized for implementation:

- The Council's recommendation that individuals over age 65 should receive a cognitive assessment as part of their regular primary care visit. Early detection of Alzheimer's disease helps individuals receive treatment for symptoms and gain access to programs and support services. It also allows diagnosed individuals to take part in decisions about care, living arrangements and legal matters.
- The Council's recommendation to include key topics related to Alzheimer's disease in training programs for health professionals.

A crucial factor in delivering good care to a person with Alzheimer's disease in any care setting is the availability of properly trained care giving staff.

- The Council's recommendation that a public education campaign be conducted to raise awareness about Alzheimer's disease. State residents need to be educated about the warning signs of Alzheimer's disease, the opportunities for appropriate diagnosis and the healthcare and community based services available to them as they navigate the path of the disease.

THE ASK:

New York State must move swiftly to enact these priority recommendations of the Coordinating Council.

COALITION OF NEWYORK STATE ALZHEIMER'S ASSOCIATION CHAPTER, INC.

Co-Chairs: Catherine James, Central New York Chapter CEO
Elaine Sproat, Hudson Valley/Rockland/Westchester, NY Chapter CEO

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.

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