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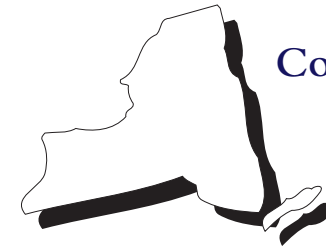
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Coalition of New York State Alzheimer's Association Chapters
and
Alzheimer's Disease Assistance Centers

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 for New York State

The Coalition of New York State Alzheimer's Association Chapters is the recognized leader to affect 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 caregivers and families.

Our Goals

- *Advancing research*
- *Mobilizing public support*
- *Providing and enhancing care and support*
- *Building unity and capacity*

2006 Legislative Agenda Highlights

Medicaid Reforms

- Spousal Refusal
- Transfer of Assets
- Homecare Eligibility

Safe Staffing

Single Point of Entry

Prescription Drug Reform

NYS Income Tax Check-Off Match

Family Health Care Decisions Act

Long Term Care Insurance Reform

Hospital Discharge Planning/Assessment

Enhanced Funding for Alzheimer's Community Services



There are almost half a million people with Alzheimer's disease and related disorders residing in New York State – helping to care for them are more than two million family caregivers. Studies have shown that some 70–75% of all consumers with Alzheimer's disease are being cared for in the home by families at little or no cost to New York State. However, the very high cost of private care over the long duration of dementia-related illness results in a deep dependence on publicly funded (primarily Medicaid) programs and services in the home and community and in residential facilities.

The Coalition of New York State Alzheimer's Association Chapters and the Alzheimer's Disease Assistance Centers (ADACs) are cognizant of the constraints placed on the state by rising Medicaid costs and the increasing service needs of an aging population, particularly those over 85 years of age. Nevertheless, the long term care needs of the growing number of persons with dementia cannot and must not be ignored. New studies predict that the prevalence of Alzheimer's will increase 27% by 2020, 44% by 2025, an astonishing 70% by 2030, and nearly 300% by 2050 (approximately 1.5 million New Yorkers) unless research scientists find a way to slow the progression of the disease or prevent it (Evans, Alzheimer's Disease in the U.S. Population; Archives of Neurology; August 2004). As such, people with Alzheimer's and their family members and other caregivers must not

bear the brunt of any state attempts to contain Medicaid costs.

The Coalition members play a significant role in the education and support of caregivers, both family and professional. Therefore, the financial support of the Alzheimer's Association Chapters and Alzheimer's Disease Assistance Centers is clearly a critical investment in cost avoidance to state taxpayers. Our work to empower and support the caregivers allows them to further provide care to loved ones, as well as providing for the necessary continuation of these invaluable and necessary care plans.

Priority Issues

To assure consumer protections, quality of life, and quality of care across the continuum of home and community based services and residential care, the Coalition is committed to the following priority legislative issues:

Medicaid Reforms

The Coalition supports maintaining Medicaid funding for long term care services in the home and community and residential settings. In addition, the Coalition supports initiatives designed to encourage the development of Medicaid financed respite care models designed to help caregivers remain in their role for as long as possible.

Specifically, the following New York State Medicaid proposals are of deep concern to individuals with Alzheimer's and their families:

Spousal Refusal: To afford oneself financial protection, currently the well spouse can refuse to contribute to the support of the ill spouse eligible for Medicaid long term care. The Coalition opposes any attempt by New York State to restrict or eliminate the right of spousal refusal.

Transfer of Assets: To become eligible for Medicaid, currently there is a three year look back period for transfer of assets. The Coalition opposes any attempt by New York State to extend the look back period.

Home Care Eligibility: At the present time, there is no transfer of assets penalty with regard to eligibility for Medicaid home care. Any attempt by New York State to initiate a penalty period for Medicaid home care would result in delaying access to care and potentially force frail individuals into more costly institutional settings. The Coalition opposes any attempt to initiate a transfer penalty period.

NYS Income Tax Check-Off Match

The funding collected through the Tax Check-Off helps Alzheimer's service organizations meet the increasing demand for their programs and services. Last year was the first time the New York State budget contained an appropriation to match contributions by tax payers for this purpose. The Coalition supports continued funding for the match of dollars collected through the New York State Income Tax Check-Off for Alzheimer's services

Enhanced Funding for Alzheimer's Community Services

The Coalition is requesting that \$4 million be included in the SFY 2006-07 budget to expand the capacity of the Alzheimer's Community Services Program (CSP), Alzheimer's Community Assistance Program (AlzCap) and the Alzheimer's Disease Assistance Centers (ADACs) to provide caregiver support services. These initiatives help families postpone the need for institutionalization of their loved one. This premise is based on sound academic research that demonstrated the cost effectiveness of the services provided by the Coalition members. A 1996 article appearing in the Journal of the American Medical Association (JAMA) indicated that the combination of the protocols/services offered by the Coalition and the ADACs, used by a treatment group, were able to achieve a median length of stay at home of 329 days longer than a control group. The findings of this study indicate that an outlay of \$4 million could generate

Medicaid savings for the State and local governments of **\$8,569,088** (NYU Medical Center, Vol. 276, No. 21).

Long Term Care Insurance Reform

As a means of helping ensure the future of Medicaid financing of long term care, the Coalition is supportive of efforts to encourage the use of private/public Long Term Care Insurance models. The Coalition supports legislative initiatives designed to provide incentives to purchase long term care insurance policies, along with strong consumer protections to ensure individuals are purchasing the coverage they expect and may need. In addition, the Coalition supports initiatives that are designed to encourage individuals to self finance a portion of their care with government support — as long as such initiatives contain provisions designed to protect against impoverishment.

Prescription Drug Reforms

The arrival in January 2006 of the new Medicare Part D drug benefit presents New York's elected leaders with both a challenge and an opportunity to use the Elderly Pharmaceutical Insurance Coverage (EPIC) to protect qualified low and moderate income New Yorkers from the unacceptably high cost of prescription drugs. The Coalition supports legislation and budget initiatives designed to ensure that New York's financial commitment to EPIC is maintained and a plan is developed to ensure the coordination between EPIC and Medicare Part D.

In addition, EPIC should be expanded by NYS to ensure a reduction in costs of prescription drugs for all seniors.

Safe Staffing

The Coalition supports initiatives designed to enhance healthcare workforce training, recruitment and retention initiatives that will help assure that the needs of the expanding dementia population residing in residential facilities can be safely met. Such

proposals are critical to ensuring that facilities can maintain the adequate and safe staffing levels that are needed to provide high quality of care.

Family Health Care Decisions Act

The legislature must address the need for family health care decision legislation. New York is one of a few states without a law that would enable families to make medical decisions for patients who lack decision-making capabilities and do not have a health care proxy in place. There is a need for legislative action to pass a Family Health Care Decision Act to enable families to make medical decisions foregoing life-sustaining treatment in medically and ethically appropriate circumstances. A mechanism for making health care decisions for incapacitated patients who are without family or friends should be included in this legislation.

Hospital Discharge Planning/Assessment

As many as one-third of older hospital patients have dementia, many of whom have never been formally diagnosed. Older hospital patients with dementia are at much higher risk than other older patients when it comes to such conditions as delirium, falls, dehydration, inadequate nutrition, untreated pain, and medication related problems. Research completed by the Center for Medicare Studies indicates that failure to recognize the extensive care needs of persons with dementia is likely to cause re-hospitalization or placement directly into a nursing home. The Coalition is supportive of legislative initiatives that ensure older hospital patients who have Alzheimer's disease receive an assessment/evaluation and, if necessary, services are designed to most effectively manage their care needs.

Single Point of Entry

While the Coalition supports advances to streamline processes and assist elderly individuals and their families with accessing

long-term care services, the proposed single point of entry system for New York State would fail people with Alzheimer's disease unless the following issues are sufficiently addressed:

- Necessary care options required by people with Alzheimer's disease must be in place to enable access to long-term care;
- Significant expansion of home and community based services;
- Widening of third-party payment streams for home and community based services, and;
- Targeted growth of service options in both urban and rural communities of our state.

