



the compassion to care, the leadership to conquer

Appropriations Committee
Public Hearing
Friday, February 14, 2014

Senator Bye and Rep. Walker and distinguished members of the committee, please accept this written testimony of Laurie Julian, Director of Public Policy, Alzheimer's Association, CT Chapter (The Association) in regards to ***H.B. 5030 An Act Making Adjustments to State Expenditures for the Fiscal Year Ending June 30, 2015.***

The Alzheimer's Association is a donor supported, non-profit organization serving the needs of families, health care professionals and those individuals who are affected with Alzheimer's disease and related dementias. The Association provides information and resources, support groups, education and training, and a 24 hour, 7 day a week Helpline.

We appreciate your support of the **Alzheimer's Statewide Respite program** and request that funding be maintained for this essential community-based program that provides much needed relief for exhausted and stressed caregivers. Family caregivers provide most of the care for individuals with dementia so they can remain at home for much longer than would otherwise be possible, delaying costly skilled nursing facility care and thereby potentially saving state Medicaid dollars.

In Connecticut, there are over 70,000 citizens with Alzheimer's or other related dementia.ⁱ This is projected to escalate rapidly in coming years as the baby boomer generation ages. There are more than 175,000 caregivers, usually family members who provide unpaid care for someone with the disease, often compromising their own health. Alzheimer's and Dementia caregivers provide over \$2.4 billion in uncompensated services and endure significant emotional, physical and mental stress, multiplying the overall cost of the disease.

ⁱⁱ Sixty-one percent of caregivers for people with Alzheimer's or other dementia rate the emotional stress of caregiving as high or very high, and are more than twice as likely as caregivers of people without these conditions to say the greatest difficulty associated with caregiving is that it creates or aggravates health problems.ⁱⁱⁱ

Alzheimer's also places significant financial burdens on families and businesses. Businesses lose billions a year in lost productivity and replacement expenses for employees who miss work or quit to care for a relative, according to the National Institute on Aging. The task of caring for a person with dementia is overwhelming. An occasional break allows an

exhausted caregiver to regroup, both physically and emotionally, and to find the strength to carry on.

Alzheimer patients are most at risk of nursing home transition. This has significant financial implications for state budgets. Average per person Medicaid payments for Medicare beneficiaries with Alzheimer's and other dementias are nineteen times as great as average Medicaid payments for Medicare beneficiaries without the disease.^{iv} In sum, individuals with Alzheimer's disease and other dementias are high users of health care, long-term care and hospice services.

The Task Force on Alzheimer's disease and Dementia recently recommended supporting and enhancing rebalancing initiatives that focus on diversion of individuals with dementia who are at risk for nursing home placement to community based settings. Specifically it recommended increasing funding to expand the CT Statewide Respite Care Program to reflect growing demand, and to expand and set aside slots for individuals with younger on set Alzheimer's disease in the **Connecticut Home Care Program for the Disabled**.

The Connecticut Statewide Alzheimer's Respite Program

Since its inception, the Statewide Respite Care Program has continued to be a success and provides the resources to a caregiver to establish an effective care plan developed for an individual with dementia, and allows the family caregiver much needed periods of respite to care for their loved-ones. Family and other unpaid caregivers often must reduce their hours of work or even quit their jobs, resulting in a loss of job-related income and benefits.

Eligible families may apply for daytime or overnight respite care services that may include: Adult day care, cognitive fitness training, home health aide, homemaker, companion, personal care assistants, skilled nursing care or short term nursing care.

Companions/Homemakers continues to be the most popular service requested in this program, and Adult Day Care is close behind representing the second most utilized service in the is program Home Health Aide ranks third.

Outcome measures demonstrate a high level of satisfaction from program participants, while the changing needs of families continue to demand interventions on the part of care managers to accommodate variable family dynamics and service needs. Statewide Respite Program services were beneficial in assisting the client in remaining at home during some portion of the program year in 85% of client cases. In 75% of the cases, the care recipient was able to remain at home for the entire program year, and the program was effective in improving the caregivers and client's quality of life and reducing caregiver stress in 93% of the cases.

In conclusion, Alzheimer's disease has profound implications for future state budgets. People with Alzheimer's disease and other dementias use state dollars to pay for their health care, especially long-term care. About half of all Medicaid beneficiaries with

Alzheimer's or another dementia are nursing home residents. Among nursing home residents with Alzheimer's disease and other dementias, just over half rely on Medicaid to help pay for their nursing home care.

The Connecticut Home Care Program for Disabled

This program provides home-based services to persons between the ages of 18 and 64, who have been diagnosed with a degenerative neurological condition and who are not eligible for other programs but need case management and other supportive services to remain in the community.

For more than 90 percent of people with Alzheimer's disease, the symptoms do not appear until after age 60, and the incidence of the disease increases with age. In rare cases, known as early or younger-onset, people develop symptoms in their 30s, 40s, or 50s. However, due to the age limit, the age eligibility for the The Connecticut Home Care for Elders is 65, the younger-onset individuals are unable to access services. At the same time, they are often supporting families and are no longer employed. It is our understanding that The Connecticut Home Care Program for Disabled, which currently has only 50 slots, has a waiting list of over three years.

We support expanding this program as outlined in the Governor's budget proposal and to implement the recommendations outlined in the Task Force on Alzheimer's Disease and Dementia.

Increase Rates for the Home Care Program for the Elderly

The Association supports increasing the rates as proposed in Governor Malloy's budget proposal. Increasing rates will give consumers a chance to reside in the community at the most cost-effective option. According to the Home Care Program for Elders 2012 Annual Report, twenty-three percent of the recipients in the program have dementia. The Home Care Program is an essential part of the long-term care safety-net. For many clients, the Home Care Program has allowed them to remain at home with its support services. This program is one of the most cost-effective diversionary programs.

Thank you for the opportunity to submit this testimony in support of maintaining funding for the Connecticut **Statewide Alzheimer's Respite Care program** and adopting the Governor's proposal to increase the number of slots in the **Home Care Program for Disabled**, and rate increase for the **Connecticut Home Care for the Elderly**. Please feel free to contact me at ljulian@alz.org, or (860) 828-2828.

ⁱ 2013 Alzheimer's Disease Facts and Figures report at alz.org/facts.

ⁱⁱ 2013 Alzheimer's Disease Facts and Figures report at alz.org/facts.

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- ⁱⁱⁱ The Council of State Governments, Alzheimer's Disease and Caregiving, Sept 2011.
- ^{iv} 2013 Alzheimer's Disease Facts and Figures report at alz.org/facts.