



the compassion to care, the leadership to conquer

**Committee on Aging
Public Hearing
Tuesday, February 5, 2013**

Written Testimony of **Laurie Julian, Director of Public Policy, Alzheimer's Association**, CT Chapter (The Association).

Senator Ayala, Representative Serra and distinguished members of the Committee on Aging, thank you for allowing me to submit testimony on several bills that are before you today on behalf of the Alzheimer's Association, CT Chapter.

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.

The Chapter is in **support** of the following bills:

HB 5765 An Act Expanding Eligibility for the Alzheimer's Respite Program

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 174,000 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

The Alzheimer's Statewide Respite Program

The Statewide Respite Care Program continues to be a critical resource and offers assistance and support to caregivers in caring for their loved one. It also provides an effective plan of care for the individual with Alzheimer's Disease and allows the family caregiver much needed periods of respite to continue 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.

For the state fiscal year ending June 30, 2012, Statewide Respite Program services were beneficial in assisting the client in remaining at home during some portion of the program year in 93% of client cases. In 84% 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 89% of the cases.

Since Governor Malloy has yet to release his proposed biennial state budget for the next two fiscal years beginning July 1, 2013, it is impossible to comment other than to note that prior rescissions and proposals for cuts to the statewide respite program are counter to the Governor's long-term care re-balancing initiatives. Future cuts will impact over a hundred individuals and their families who rely on critical supports and services to care for their loved ones. Limiting a community-based support that provides caregivers with an option to keep individuals with Alzheimer's at home threatens to hasten transition to more expensive alternatives, such as assisted living or skilled nursing care.

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.

H.B. 5757 An Act Increasing Eligibility for the Connecticut-Home Care Program for the Elderly

The Association supports the intent of this bill to give consumers a chance to reside in the community at the most cost-effective option. According to the Home Care Program for Elders 2011 Annual Report, 24.3% percent of the recipients in the program have Alzheimer's or other dementia. The Home Care Program is an essential part of the long-term care safety-net. For many individuals with dementia, the Home Care Program has allowed them to remain in the community with its support services. It is one of the most cost-effective nursing home diversion programs and saves the State of Connecticut millions by avoiding more expensive nursing home care. In fact, DSS

reports that \$109,165,181 in savings were generated as a result of the reduced utilization of nursing facility beds due to the CT Home Care Program's Medicaid Waiver.

H.B. 5758 An Act Concerning An Income Tax Deduction for Long-Term Care Insurance Premiums

At some point in time the need for assistance with daily living is necessary, and increases with age. Alzheimer's patients and individuals with dementia are high users of health care. Since the repeal of the CLASS provision of the Affordable Care Act, which would have provided a voluntary incentive for the purchase of long-term care insurance, other options should be available to encourage saving for assistance with daily living supports to remain in the community and diminish the reliance on state funding of long-term care.

SB 520 An Act Concerning Medicaid Long-Term Care Coverage for Married Couples

Recognizing the high costs of long-term care, Federal Medicaid law provides certain financial protections for married couples, where one spouse is seeking Medicaid coverage of long-term care in a nursing facility or through home and community-based waiver services. These spousal impoverishment provisions, prescribe the amount of assets that the "community spouse" is entitled to retain when his or her spouse enters a nursing home and applies for Medicaid.

It is our understanding that Connecticut has adopted the most restrictive option, and only permits the community spouse to keep the lesser of one half of the couple's assets or \$113,641.00 and no less than \$22,728.00.

Alzheimer's disease or other dementias take a deep financial toll on spouses of individuals with the disease as most people survive an average of four to eight years after a diagnosis, but some live as long as 20 years. Only 4 percent of the general population will be admitted to a nursing home by age 80; but for people with Alzheimer's, 75 percent will end up in a nursing home by age 80. ^v

Therefore, The Association supports SB 520 to allow the community spouse to keep the maximum community spouse protected amount.

S.B. 522 An Act Increasing Funding for Elderly Nutrition

Although many people with dementia are able to perform basic aspects of self-care, several studies have found that people with dementia who live alone are at increased risk of inadequate self-care, including malnutrition. ^{vi} Inadequate self care has been cited as a cause of increased need for emergency medical services among people with dementia who live alone.

The available sources of information consistently indicate that at least 15 percent of Americans (or one out of seven) who have Alzheimer's disease and other dementias live alone in the community. ^{vii} For many of the elderly, meal delivery is the only source daily check-up and contact.

SB. 523 An Act Concerning the Return of a Gift to A Person in Need of Long-Term Care Services

The Association supports the intent of this bill to reduce the penalty period for the transfer of an asset if part of a gift has been returned. P.A. 11-44, Section 104, amending Conn. Gen. Stat. Section 17b-261a, states that only a full return of transferred assets will affect the penalty period. In other words, an institutionalized individual shall not be penalized for the transfer of an asset if the entire amount of the transferred asset is returned to the institutionalized individual. Conversely, the partial return of a transferred asset shall not result in a reduced penalty period.

The full return rule in the transfer of asset penalty replaces the long-standing partial return rule and eliminates the reduction in the waiting period caused by transfer of assets even though some of the gifts are returned. The result is that the waiting period is only modified when there is a full return of all the gifts, from each person who received them. The Association believes this will actually have the effect of reducing private funds available to pay for long term care services. In other words, it appears to be a disincentive to return part of a gift if the length of the penalty is not shortened.

Furthermore, certain provisions of the "full return" rule are inconsistent with federal law and guidance from Centers for Medicare and Medicaid Services in eliminating private funds from meeting part of the cost of long term services. We understand the full return concept on return of assets was reviewed by the Regulations Review Committee of the Legislature on June 9, 2009, and referenced an internal LCO memo that DSS did not have apparent authority under federal law for the regulation and was out of compliance with the Centers for Medicare and Medicaid Services.

The Alzheimer's Association, Connecticut Chapter, believes the unintentional transfer of gifts can occur, and partial return lessens the harshness of the rule.

HB 5762 An Act Concerning a Study of Funding and Support for Home and Community-Based Care for the Elderly and Alzheimer's Patients

We thank the committee for recognizing the Alzheimer's crisis. An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias. ^{viii} Most people with Alzheimer's disease and other dementias that live at home receive unpaid help from family members and friends, but some also receive paid home and community-based services, such as personal care and adult day center care.

Older people with Alzheimer's disease and other dementias have more hospital stays, skilled nursing facility stays and home health care visits than other older people. Given the high average costs of these services (e.g. adult day center services, \$70 per day, assisted living, \$41,724 per year, and nursing home care, \$79,110 to \$87,235 per year, individuals often spend down their assets and eventually qualify for Medicaid.

The Association also recommends that an Alzheimer's disease task force be created to gather stakeholders to draft a plan to respond to the impending crisis. Twenty-four states have published a state Alzheimer's plan to create the infrastructure to build dementia-capable programs for the growing number of people with the disease. To date, fifteen task forces have been established to develop a state Alzheimer's plan and two states have legislation filed. (See attached map).

Community-based supports provide caregivers with an option to keep individuals with Alzheimer's at home and delay transition to more expensive alternatives, such as assisted living or skilled nursing facility care. As noted previously, Alzheimer patients are most at risk of nursing home transition. Due to the progressive nature of the disease, the state has an interest in diverting costly care and avoiding skilled facility care in the beginning stages of the disease where appropriate.

Three established programs: the Connecticut Home Care Program for Elders, Alzheimer's Statewide Respite and Adult Day, have allowed Alzheimer's individuals to remain in the community with its support services. These are cost-effective diversion programs and save the State of Connecticut millions by avoiding more expensive skilled nursing facility care. To put this in perspective, in Connecticut, the average cost of nursing facility care (Medicaid) is \$94,000.00 vs. \$18,000.00 average home-care waiver services.

In conclusion, Alzheimer's disease has profound implications for future state budgets, and states must prepare now to address the multiple and complex challenges that Alzheimer's poses to individuals, families and state governments, the long-term and payment systems, particularly Medicaid. While only 7% of the Medicaid population receives long-term services and supports, 61% (\$2.863 billion) of the FY '12 state budget Medicaid expenditures of \$4.714 billion, were made on the behalf of long-term care beneficiaries.

Thank you for the opportunity to submit this testimony in support of studying long term care options for older adults and persons with Alzheimer's disease in need of assistance and care to stay in the community.

Please feel free to contact me at Ljulian@alz.org, or (860) 828-2828.

ⁱ 2012 Alzheimer's Disease Facts and Figures report at alz.org/facts.

ⁱⁱ 2012 Alzheimer's Disease Facts and Figures report at alz.org/facts.

ⁱⁱⁱ The Council of State Governments, Alzheimer's Disease and Caregiving, Sept 2011.

^{iv} 2012 Alzheimer's Disease Facts and Figures report at alz.org/facts.

^v Arrighi, HM; Newmann, PJ; Lieberburg, RJ. "Lethality of Alzheimer's disease and its impact on nursing home placement." *Alzheimer disease & Associated Disorders* 2010; 24 (1): 90-95.

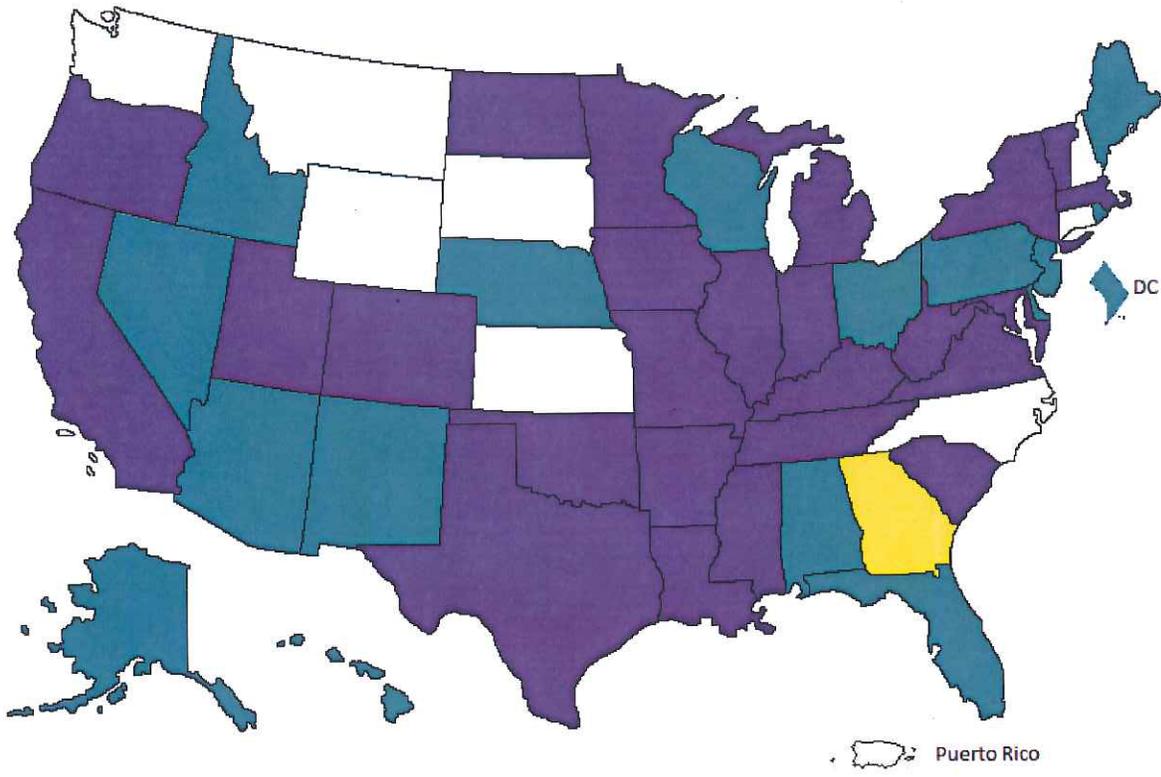
^{vi} Nourhashemi F, Moual-BarkateK, Gillette-Guyonnet S, Cantet C, Vellas B. Living alone with Alzheimer's disease: Cross-sectional and longitudinal analysis in the REAL FR Study. *Journal of Nutrition, Health & Aging* 2005; 9 (2):117-20.

^{vii} Medicare Current Beneficiary Survey 2008.

^{viii} MetLife Mature Market Institute. *Market Survey of Long-Term Care Costs: The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs*. New York, N.Y.: Metropolitan Life Insurance Company, 2011.

State Government Alzheimer's Disease Plans

Updated January 14, 2013



- Published a State Alzheimer's Plan. (25)
- Task Force established to develop a State Alzheimer's Plan (16 including DC)
- Legislation filed.
- No Legislation filed or Executive Branch activity pending. (9 including PR)

