



the compassion to care, the leadership to conquer

Committee on Aging
Public Hearing
Tuesday, February 25, 2014

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, on behalf of the Alzheimer's Association, CT Chapter, thank you for allowing me to submit testimony on several bills that are before you today.

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 submits comment on the following bills:

S.B. 179 An Act Concerning The Alzheimer's Disease and Dementia Task Force's Recommendations on Training

The Association thanks the committee for its leadership on the task force. The 23-member task force comprised of state agency representatives, long-term care facility and community-based providers and stakeholders overwhelmingly agreed after numerous meetings and deliberations that it was essential to address gaps in the quality of care by building a capable workforce through dementia specific training. The task force further found despite the large number of individuals cared for with the disease throughout the health care system, there are few Alzheimer's and dementia care training requirements for health professionals and facilities serving individuals with Alzheimer's disease or dementia in Connecticut. In particular, Connecticut only requires Alzheimer's special care units or programs to provide dementia-specific training. (See CGS Sections 19a-562 and 19a-562a).

The number of individuals with Alzheimer's and other dementias will increase as the number of elderly people increases. By 2050, the annual number of new cases of Alzheimer's is

projected to more than double.¹ Caring for an individual with cognitive limitations poses particular challenges requiring special skills. Many health care professionals and others that interface with patients are not equipped to deal with the unique needs of caring for an individual with Alzheimer's or dementia.

Although it was found that sixty-eight percent of nursing home residents in Connecticut have some form of dementia, seventy percent of individuals with Alzheimer's or related dementias reside in the community. Given Connecticut's aging population and re-balancing initiatives toward home and community-based care services, demand for direct care workers employed in community-based settings, such as home health aides, homemakers and companion and personal care assistants will increase. Currently, there are no dementia specific training requirements for home and community-based providers, and it is likely that workers will tend to serve consumers with more complex needs with less supervision.

The training requirements set forth in S.B. 179 are not burdensome when balanced against patient safety. As noted, the task force comprised of provider experts in the field which overwhelmingly agreed dementia specific training would be an asset and investment. Wandering occurs in sixty percent of patients with Alzheimer's. Learning basic dementia skills in understanding aggressive behaviors, interacting and communicating with aggressive behaviors, and pain management has made a significant difference in the quality of life for both patient and staff.

Dementia training is not only necessary to prepare workers for the tasks they face and ensure a dementia competent workforce, but has shown to reduce turnover and increase job satisfaction. Studies in nursing homes have shown that higher turnover is associated with poor quality of care as measured by use of restraints, pressure ulcers, psychoactive drug use, and certification survey quality of care deficiencies.² Recent nursing home fines and violations in Connecticut have shown to include a significant number with dementia.

This bill is in accord with several federal initiatives. Specifically, Section 6121 of the Affordable Care Act requires the Centers for Medicare and Medicaid Services "CMS" to ensure that nurse aides receive regular training on caring for residents with dementia and on preventing abuse. CMS, supported by a team of training developers and subject matter experts, created *Hand in Hand: A Training Series for Nursing Homes*, to address the need for nurse aides' annual in-service training on these important topics. CMS also has an initiative to reduce the use of anti-psychotic drugs administered in nursing facilities and incorporates dementia training through effective communication and use of patients' history.

Finally, the National Alzheimer's Project Act, passed in 2011 created the National Alzheimer's Council. Several of the Council's strategies include provisions to educate health care

¹ Alzheimer's Association 2013 Facts and Figures.

² Seavey & Marquand, 2011; Castel, N.G., Engberg, E., Anderson, R.A. & Meng, A., (2007). Job satisfaction of nursing aides in nursing homes: Intent to leave and turnover. *Gerontologist*, 47:193-204.

providers to develop a primary care Alzheimer's disease curriculum to build a workforce with the skills to provide high-quality care.

Thank you for your leadership in implementing the task force recommendations. For the reasons stated, The Association urges passage of S.B. 179.

S.B. 173 An Act Concerning an Income Deduction for Long-Term Care Insurance Premiums

The need for assistance with daily living increases with age. Alzheimer's patients and individuals with dementia are high users of health and long-term care and as the disease progresses 24/7 care is required. In fact, Alzheimer's disease is the most expensive malady. Dementia care costs are significant and are often a burden to families providing unpaid care. Caring for people with Alzheimer's disease also strains health care and long-term care systems. As the number grows, which is projected to escalate rapidly in the next two decades, the disease will place a major strain on these systems as well as on Medicare and Medicaid, major funders of this care.

Few individuals with Alzheimer's disease and other dementias have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services as long as the services are needed. One of the biggest challenges for people living with Alzheimer's disease and their caregivers is the financial burden of care. People living with Alzheimer's disease often rely heavily on government programs such as Medicare and Medicaid to mitigate these costs. Unfortunately, too often Medicare and Medicaid are inadequate, and the overwhelming costs of this disease exceed available personal funds, leaving families affected by Alzheimer's in the difficult position of struggling to balance care for their loved ones without impoverishing themselves.

Private health and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2009. The private long-term care insurance market has decreased substantially since 2010, with major insurance carriers exiting the market or substantially increasing premiums, making policies unaffordable for many individuals.

Allowing a tax deduction for premiums on a long-term care policy may provide an incentive to purchase long term care insurance which is often cost prohibitive and an unaffordable option. 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.

This is in accord with the recent Task Force on Alzheimer's disease and Dementia recommendation to amend the state tax code to provide a deduction or credit for tax filers for the premiums paid for a private long-term care insurance policy.

<http://www.cga.ct.gov/coa/pdfs/AlzheimersTF/AlzheimersTaskForceFINALREPORT.pdf>

S.B. 177 An Act Concerning a Community Spouse's Allowable Assets

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.

The community spouse must receive the maximum protected amount to avoid subjecting the community spouse to extreme financial hardship. Spousal impoverishment laws allow a healthy elderly spouse to maintain assets that generate income for his or her own living expenses and future long term care needs.

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 up to the maximum of the community spousal protected amount.

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.

Therefore, The Association supports SB 177 to allow the community spouse to keep the maximum community spouse protected amount.

S.B. 5223 An Act Concerning Funding for Elderly Nutrition

Adequate nutrition improves overall health and quality of life. 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.³ 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.⁴ For many of the elderly, meal delivery is the only source of daily check-up and contact.

³ Medicare Current Beneficiary Survey 2008.

⁴ Alzheimer's Facts and Figures 2012

S.B. 5225 An Act Increasing Eligibility for the Connecticut Home Care Program for the Elderly

According to the Home Care Program for Elders 2012 Annual Report, twenty-four percent of the recipients in the program have cognitive impairments. 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.

H.B. 5228 An Act Expanding Eligibility for the Alzheimer's Disease Respite Program

Alzheimer's disease is a progressive and degenerative disease. Community-based supports and services keep the individual with Alzheimer's and other dementia at home with their loved-ones where feasible often delaying costly institutional care.

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. Without respite, 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.

The Task Force Report on Alzheimer's Disease and Dementia recommends an increase in funding to expand the program to reflect the growing demand. However, raising the eligibility amount to \$50,000.00 may foreclose serving individuals that are in dire financial need.

Thank you for the opportunity to submit this testimony. Please feel free to contact me at Ljulian@alz.org, or (860) 828-2828.