

alzheimer's association™

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Position Statement in support of Raised Bill No. 989, *AN ACT CONCERNING THE ALZHEIMER'S RESPITE CARE PROGRAM*

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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.

Eleven years ago I and three other family caregivers sat around a table with other representatives of the Alzheimer's Association and discussed the tremendous stress upon family care givers and what we might do lessen the caregiving burden. Each of us was personally familiar with those burdens and the toll that they had taken upon our lives and our ability to care for our loved ones. Although I wasn't my father's hands-on caregiver, my daily presence kept his anxiety under control without the need for psychotropic drugs and ensured that my father received the quality of care that he so deserved. For that to be possible, I, like so many other family caregivers, had to struggle with the often conflicting demands of my own needs and those of my family member. In my case, I did not take a vacation during the last five years of my father's life and made a series of career choices based solely upon the effect that they would have upon my caregiving responsibilities; another of us had learned that the only way that she could get a full night's sleep was by renting a room in a motel while a paid caregiver stayed with her husband; a third had been forced to leave this distinguished body when her caregiving responsibilities made it impossible for her to continue to serve as a legislator; the fourth

had simply put her own life and needs on hold while she struggled with the conflicting demands of caring for her husband and functioning as a de facto single parent for their college age children. Each of us knew first hand that without a break from care giving responsibilities, be it only for a few hours, even the most dedicated caregiver eventually reaches a breaking point. It was our shared awareness of the need for a safety net and the gaps in existing programs and services that gave birth to the legislation that created the Statewide Alzheimer's Respite Care program.

We recognized that there was a large segment of the caregiving population that lacked the resources to pay for needed respite care yet was too "affluent" to qualify for subsidized home care services. We were especially concerned about those individuals who were struggling to provide 24/7 care for a loved one with dementia while juggling the often competing and equally stressful demands of career and parenting responsibilities. Our objective was to create a program that would provide help for this underserved group of Connecticut citizens...commonly referred to as the "middle class". We investigated respite programs in other states and proposed what we thought at the time to be appropriate asset and income criteria. The criteria that we proposed in February of 1998 -- income of \$30,000 or less and no more than \$80,000 in liquid assets -- are still in effect today, more than eleven years later. Failure to adjust those figures has in effect slowly, but surely, eroded the effective reach of the Alzheimer's Respite Grant program and reduced the options available to the otherwise unserved Connecticut family caregivers that we sought to help.

Raised Bill No. 989 proposes a one-time corrective adjustment that translates the original financial criteria for the Alzheimer's Respite Grant program into their 2009 equivalents and provides for subsequent annual adjustments in order to avoid future erosion. While some might view this bill as an expansion of the statewide respite program, it is, in reality, simply a return to the original concept and objectives of this very important program. To that end, I urge you to support Raised Bill No. 989.