

United States House of Representatives Committee on Energy and Commerce
Subcommittee on Health
Examining Legislation to Improve Public Health

Statement of the Alzheimer's Association on the Palliative Care and Hospice Education and Training Act

September 8, 2016

Thank you for holding today's hearing on legislation to improve public health. We applaud your leadership on issues important to Americans with Alzheimer's disease and other dementias and their caregivers. The Alzheimer's Association proudly supports the Palliative Care and Hospice Education and Training Act (H.R. 3119/S. 2748), which was introduced in the House of Representatives by Representative Eliot Engel (D-NY-16) and Representative Tom Reed (R-NY-23) in July 2015. This legislation, which currently has 200 bipartisan cosponsors in the House of Representatives, will ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research.

Alzheimer's disease is a progressive, neurodegenerative and fatal disease for which there is currently no treatment or cure. More than 5 million Americans are currently living with Alzheimer's disease and other dementias. In addition, 15.9 million friends and family of those with Alzheimer's disease are also acting as uncompensated caregivers. In 2015, these individuals provided 18.1 billion hours of care, valued at more than \$221 billion.¹ Alzheimer's disease was identified by the *New England Journal of Medicine* as the costliest disease in the United States.² As the baby boom generation continues to age, one in nine Americans above age 65 will develop Alzheimer's disease or another dementia. By 2050, the number of people in the United States with Alzheimer's disease may be as high as 16 million, representing an annual cost to the nation of nearly \$1.1 trillion (in today's dollars).³

Palliative and hospice care – with a focus on managing and easing symptoms, reducing pain and stress, and increasing comfort – can improve both the quality of care and quality of life for those with advanced dementia. Observational studies have shown that as many as half of nursing home residents with advanced dementia have documented pain in the last weeks of life – and about a third have difficulty breathing or swallowing, or suffer from agitation. Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30

¹ Alzheimer's Association. (2016). *2016 Alzheimer's Disease Facts and Figures*.

² Michael D. Hurd, Ph.D., Paco Martorell, Ph.D., Adeline Delavande, Ph.D., Kathleen J. Mullen, Ph.D., and Kenneth M. Langa, M.D., Ph.D. Monetary Costs of Dementia in the United States. *N Engl J Med* 2013; 368:1326-1334 April 4, 2013 DOI: 10.1056/NEJMsa1204629.

³ Alzheimer's Association. (2016). *2016 Alzheimer's Disease Facts and Figures*.

days of life, and better symptom management. Additionally, a recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are up to 15 times less likely to die in a hospital, nearly 2.5 times less likely to have a hospitalization in the last 30 days of life, and are up to 4.6 times less likely to have an emergency room visit in the last week of life.⁴ Families of individuals with dementia who are enrolled in hospice also have a greater satisfaction with patient care.

People with Alzheimer's and other dementias also rely heavily on hospice at the end of life. Of all people living with dementia, 18.6 percent are currently in hospice care – a higher percentage than other chronic conditions.⁵ Among seniors in hospice care, one in every six has a primary hospice diagnosis of Alzheimer's or other dementia. Nearly half of all people with dementia die in hospice care. The population of persons with dementia using hospice has grown dramatically in recent years⁶ – a trend that is likely to continue as the number of Americans with Alzheimer's disease and other dementias grows.⁷

Congress unanimously passed the bipartisan National Alzheimer's Project Act (P.L. 111-375) in 2010. The law instructs the Department of Health and Human Services (HHS) to develop a strategic plan to address the rapidly escalating Alzheimer's disease crisis. The annually updated *National Plan to Address Alzheimer's Disease* must be transmitted to Congress each year and is to include outcome-driven objectives, recommendations for priority actions and coordination of all federally funded programs in Alzheimer's disease research, care and services. The Alzheimer's Association recently convened an expert workgroup to develop milestones for the care and support goals under the *National Plan to Address Alzheimer's Disease*. Those milestones include actions that need to be taken by both the federal and state governments in order to create a high quality care and support system for individuals with the disease and their families. Specifically, the expert workgroup recommends action to outline comprehensive standards of dementia care for palliative and hospice care; to develop components of dementia-competent palliative care for persons with Alzheimer's disease and other dementias; to modify hospice criterion from end of life estimate to disability severity for persons with Alzheimer's disease and other dementias; and to define process components for clinicians to discuss end of life planning with individuals with Alzheimer's disease and key caregivers, which would include hospice care.⁸

The Palliative Care and Hospice Education and Training Act would ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research. Specifically, this legislation would establish palliative care and hospice workforce training programs for doctors, nurses, and other health professionals; create

⁴ Susan C. Miller et al. "The Effect Of Palliative Care Consults On Acute Care Use For Residents With Dementia In Nursing Homes". (November 2015).

⁵ Unpublished tabulations based on data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014. Prepared under contract by Avalere Health, January 2016.

⁶ National Hospice and Palliative Care Organization. (2014). *NHCPO's Facts and Figures: Hospice Care in America*.

⁷ Alzheimer's Association. (2016). *2016 Alzheimer's Disease Facts and Figures*.

⁸ Soo Borson et al., "Report on Milestones for Care and Support Under the U.S. National Plan to Address Alzheimer's Disease," *Alzheimer's & Dementia* 12, no. 3 (March 2016).

a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care and available services and supports; and enhance research on improving the delivery of palliative care. In addition, the legislation is consistent with findings and recommendations made by the Institute of Medicine expert panel on advanced dementia, as well recommendations made by the Advisory Council on Alzheimer's Care, Research, and Services.

Thank you for holding today's hearing and for your continued leadership on issues that are so important to individuals and families facing Alzheimer's disease. We look forward to working with you and your colleagues on efforts to improve care and support for individuals and families affected by this disease, including the Palliative Care and Hospice Education and Training Act.