

June 22, 2015

The Honorable Johnny Isakson
United States Senate
131 Russell Senate Office Building
Washington, DC 20510

The Honorable Mark Warner
United States Senate
475 Russell Senate Office Building
Washington, DC 20510

Dear Senator Isakson and Senator Warner,

On behalf of the Alzheimer's Association®, thank you for your leadership on issues important to Americans with Alzheimer's disease and other dementias, as well as their families and caregivers. The Alzheimer's Association applauds your recent initiative aimed at improving care and lowering costs for Medicare beneficiaries with chronic diseases. We look forward to working with you in a bipartisan fashion to find solutions to these problems in order to improve care and outcomes for Americans living with Alzheimer's disease or other dementias.

People with Alzheimer's disease or other dementias are more likely to have additional chronic conditions and have significantly greater associated Medicare spending than other beneficiaries.

As you know, Alzheimer's disease is a neurodegenerative, progressive, fatal condition that cannot be prevented, cured, or even slowed. At least 74 percent of people with Alzheimer's disease or other dementias have one or more additional chronic conditions. These individuals are about 5.5 times more likely to have six or more additional chronic conditions than someone without Alzheimer's or another dementia. The onset of cognitive impairment and the deterioration of cognitive function undermine efforts to manage other chronic conditions unless those challenges are specifically addressed. For example, a senior who has diabetes and Alzheimer's will cost Medicare 81 percent more than a beneficiary with diabetes and no Alzheimer's. Similarly, a senior with Alzheimer's disease and heart disease costs Medicare 61 percent more than a senior with just heart disease. These complications result in three times as many hospitalizations and higher costs for Medicare beneficiaries with Alzheimer's disease and other dementias. This is especially alarming because these hospitalizations are not to treat the underlying Alzheimer's or dementia; instead, many of these admissions are the result of complications or exacerbations to other conditions caused by Alzheimer's disease or other dementias. Furthermore, according to the Centers for Disease Control and Prevention (CDC), one quarter of these hospitalizations are preventable. It is critically important for the public to see Alzheimer's disease as a severe chronic condition and to understand its impact on patient outcomes and on Medicare spending, especially in the context of a patient's other chronic conditions. We believe that Alzheimer's disease and other dementias should always be included in the list of examples of chronic conditions that policymakers raise when

addressing the policy options for chronic disease care, given the unique challenges this chronic disease poses to the Medicare program, both now and in the future.

In 2013, Alzheimer's disease was identified by the *New England Journal of Medicine* as the costliest disease in the United States. In 2014, per-beneficiary Medicare spending for those with Alzheimer's disease or other dementias was \$21,585. Medicare spending in the same year for beneficiaries without Alzheimer's or other dementias was just \$8,191. Furthermore, in 2015 Medicare will spend approximately \$113 billion to care for beneficiaries with Alzheimer's disease or other dementias, nearly 20 percent of total program spending. As the baby boom generation continues to age, spending will grow exponentially. Currently, there are more than 5 million Americans aged 65 or older living with Alzheimer's disease. 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 Medicare of nearly \$589 billion, without adjusting for future inflation.

Alzheimer's disease presents unique challenges to the country. Success in managing Alzheimer's depends on the recognition that this disease *is* different from other chronic conditions and, as a result, must be approached differently. Consequently, management of the patient's other chronic conditions must incorporate consideration of any cognitive impairment. Significant investments in biomedical research that leads to a treatment or cure will help reduce the long-term economic burden of Alzheimer's and dementia. However, we can begin to tackle high levels of current program spending on Alzheimer's disease and dementia by improving the quality of medical care for beneficiaries upon diagnosis – early in the care process – where gaps currently exist. Complicating already-low rates of disclosure for dementia diagnoses is the fact that when Medicare beneficiaries are informed of an Alzheimer's or dementia diagnosis, they are not given much, if any, information about the diagnosis. They are not being informed on how the disease will affect other conditions, or steps they might take to improve quality of life and maintain function for as long as possible. This gap in care at diagnosis often leaves families unable to properly cope with the disease, learn about options for supportive services in the community, or participate in clinical trials.

The Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act.

Following a diagnosis of Alzheimer's disease or another dementia, Medicare beneficiaries and families facing the disease must be adequately informed about the condition in order to plan appropriately for the future. The Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S. 857/H.R. 1559) would achieve the goals of the Senate Finance Committee Chronic Care Working Group's request for proposals to improve care for beneficiaries with multiple chronic conditions. The HOPE Act works by incentivizing health care practitioners to: (1) dedicate time and resources to fully inform a beneficiary as to his or her diagnosis; (2) have a meaningful discussion of treatment and support options; (3) develop a care plan specific to the beneficiary accounting for all of their conditions; and (4) document the diagnosis and care plan in the patient's medical record that is shared with all providers who treat the individual.

The HOPE for Alzheimer's Act would provide Medicare beneficiaries who are newly-diagnosed with Alzheimer's or another dementia with critical care planning services to provide them and their families with information about the disease as well as the availability and accessibility of medical and non-medical options for treatment, services, and support. Additionally, the HOPE benefit would provide for the development of an initial, comprehensive care plan that takes into account any other chronic conditions the beneficiary may have. The HOPE Act also requires documentation of the diagnosis as well as the care plan in the beneficiary's individual medical record, which will improve the ability of providers to coordinate care for a beneficiary with Alzheimer's disease or other dementia. Further, the HOPE Act provides flexibility for the care planning services to be furnished to

caregivers or personal representatives of the beneficiary to maximize communication between caregivers and providers in caring for a beneficiary who may be unable to effectively participate in their own care.

The HOPE Act would increase care coordination among individual providers across care settings who are treating patients living with chronic diseases.

Although Medicare requires documentation of a diagnosis for purposes of reimbursement, there is no requirement for diagnoses to be documented within an individual's medical record. For individuals with Alzheimer's and other dementias, the absence of a documented diagnosis can be catastrophic, since plans of care would not take into account that the beneficiary has an underlying cognitive disorder that affects his/her ability to understand, process and adhere to care instructions. By requiring documentation, the HOPE Act ensures that all treating providers are aware of the diagnosis, enabling them to better manage and coordinate care for beneficiaries with Alzheimer's or other dementias. The HOPE Act would ensure that beneficiaries and their families have the necessary information to appropriately engage with health care providers in the development and execution of a comprehensive and actionable care plan. Considering the goals of the Committee's bipartisan Working Group, this would also empower beneficiaries to take a greater role in planning and managing their own care and engaging with their health care providers, which would also lead to increased care coordination among providers.

The HOPE for Alzheimer's Act presents an opportunity to empower Medicare beneficiaries with Alzheimer's disease and other dementias to play a greater role in managing their care for as long as they are able, and provides caregivers with the knowledge and tools they need to properly execute the individual's desires and preferences if they are not. The HOPE Act also provides powerful disease management and care coordination guidance for the patient's health care providers.

The HOPE Act would incentivize the appropriate level of care for patients living with chronic diseases.

Providers are incentivized to coordinate the care of their most complex patients, including those with Alzheimer's disease, through the Medicare chronic disease management reimbursement to practices already engaged in care coordination. The HOPE Act seeks to enhance this by improving the management of all the beneficiary's conditions upon receiving a diagnosis of Alzheimer's or another dementia by reimbursing for the development of an initial, comprehensive care plan that takes into account the impact of cognitive impairment on the management of their other conditions. This care plan will be carried across providers and settings, providing for more-meaningful care management while setting the stage for proper care coordination. For beneficiaries with Alzheimer's disease and other dementias, this can help ensure that they receive the level of care most appropriately matched to their condition, including any functional abilities or limitations.

The HOPE Act facilitates the delivery of high-quality care to produce better patient outcomes, improves care transitions, increases program efficiency and contributes to an overall effort that will reduce the growth in Medicare spending.

Providing high-quality care for beneficiaries with Alzheimer's disease or other dementias begins with an appropriate diagnosis that is fully disclosed. Recent studies show that fewer than half of patients with Alzheimer's disease or their caregivers recall being informed of the diagnosis. Providers have cited insufficient time and resources as reasons why they are not disclosing the diagnosis to their patients or their families. By ensuring appropriate reimbursement for their time, the HOPE Act will facilitate the disclosure of more diagnoses which will lead to stronger patient outcomes for this

population, as their condition can only be accounted for once it is known. The HOPE Act will also facilitate high-quality care after diagnosis by empowering the beneficiary and his or her family with critical information that will enable them (as well as all treating providers of care) to properly plan for the future, which could lead to fewer complications and less utilization of expensive medical services.

Until an effective treatment or cure is found, Alzheimer's disease and other dementias will continue to drive the growth in Medicare spending, contributing to an environment that will jeopardize the Medicare program. Taking steps to improve care, manage other conditions and maintain function for beneficiaries with Alzheimer's disease and dementia will significantly contribute to the overall effort to reduce the growth in Medicare spending. Only by addressing current gaps in care for this population can we begin to tackle the massive spending associated with Alzheimer's disease and other dementias.

Meaningful risk adjustment for beneficiaries with Alzheimer's disease would improve Medicare Advantage for patients living with multiple chronic conditions.

The Alzheimer's Association strongly supports providing incentives for Medicare Advantage plans to create innovative care models for beneficiaries with dementia and related conditions to advance specialty care for this population. Additionally, other models, such as Program of All-Inclusive Plans for the Elderly (PACE) provide innovative opportunities for frail Medicare beneficiaries to receive nursing home-level of care while remaining in the community. Approximately 50 percent of PACE participants have a diagnosis of Alzheimer's or another dementia.

Currently, the Centers for Medicare & Medicaid Services Hierarchical Condition Categories (CMS-HCC) risk adjustment model provides for risk-adjusted reimbursements to Medicare Advantage and PACE plans to account for additional risk associated with beneficiaries with certain conditions. However, despite the high costs of providing care to Medicare beneficiaries with Alzheimer's or other dementias, there is inadequate risk adjustment currently for the majority of Medicare Advantage and PACE plans that serve the highest risk and most frail beneficiaries, other than Medicare Advantage Special Needs Plans. Failure to provide meaningful risk adjustment for beneficiaries with Alzheimer's disease or other dementias enrolled in Medicare Advantage and PACE plans ignores the issues related to the current unsustainable nature of costs associated with the Alzheimer's and dementia population. Congress should require CMS to account for the extremely high cost of medical care and care coordination for this population in the CMS-HCC risk model for future Medicare Advantage and PACE plan years.

The Alzheimer's Association appreciates your leadership on issues important to Americans affected by chronic disease, and we look forward to continuing to work with you and your colleagues to improve care and support for individuals and families affected by Alzheimer's disease and other dementias. If you have any questions, please contact Rachel Conant, Director of Federal Affairs, at rconant@alz.org or at 202-638-7121.

Sincerely,



Robert Egge
Executive Vice President, Government Affairs
Alzheimer's Association