



The Honorable Max Baucus
Chairman
Senate Finance Committee

The Honorable Dave Camp
Chairman
House Committee on Ways and Means

The Honorable Orrin G. Hatch
Ranking Member
Senate Finance Committee

The Honorable Sander M. Levin
Ranking Member
House Committee on Ways and Means

August 19, 2013

Dear Senator Baucus, Senator Hatch, Representative Camp and Representative Levin,

On behalf of the millions of families affected by Alzheimer's disease, thank you for the opportunity to comment on ways to improve Medicare coverage of post-acute care (PAC). The Alzheimer's Association® is the world's leading voluntary health organization on Alzheimer's care, support and research. We would like to share the following responses to your questions on beneficiary protections as you consider potential reforms to Medicare coverage of PAC services.

Today, there are more than 5 million Americans in the United States living with Alzheimer's disease. Alzheimer's is the sixth-leading cause of death in the United States, and the only cause of death among the top 10 without a way to prevent, cure or even slow its progression. According to a study published in the *New England Journal of Medicine*, Alzheimer's is currently the most costly disease in the United States and is set to increase at an unprecedented rate due to our aging population. This year, Alzheimer's and other dementias will cost the United States an estimated \$203 billion, 70 percent of which will be borne by Medicare and Medicaid. By 2050, this number is expected to grow to more than \$1.2 trillion.

People with Alzheimer's disease experience three times as many hospital stays per year as other older individuals without dementia. High rates of hospitalization for individuals with dementia mean that they are also high users of PAC services. In 2008, the rate of skilled nursing facility (SNF) stays for individuals with Alzheimer's and other dementias was nearly nine times as high as it was for individuals without these conditions. In addition, nearly one-quarter of Medicare beneficiaries with Alzheimer's had at least one home health visit in 2008, compared with just 10 percent of beneficiaries without dementia. Cognitive impairment due to Alzheimer's disease and other dementias increases the complexity of post-acute care for these beneficiaries, increasing the risk for readmission to an acute-care facility.

Responses to Questions on Protection of Medicare Beneficiaries

We have prepared the following responses to questions posed in your letter regarding Medicare PAC reform and beneficiary protections that were of specific concern to the Alzheimer's Association. We hope that in developing any Medicare PAC reform proposal, you consider these concerns with regard to the Alzheimer's and dementia population.

the compassion to care, the leadership to conquer

1. If Congress alters incentives, what steps are needed to ensure that beneficiaries are protected and receive care in an appropriate setting?

The Alzheimer's Association is fully supportive of efforts to create a patient-centered care transition program that includes individualized care plans and appropriate assessments of abilities, needs and preferences. Any plan to reform Medicare PAC should ensure that the beneficiary's care plan is being followed in accordance with best medical practices and the instructions of their physician upon discharge from an acute-care facility.

Currently, dementia is an independent risk factor for placement in long-term care after hospitalization and skilled nursing services. Serious coexisting medical conditions are common in people with Alzheimer's disease and other dementias, often resulting in complex care plans. For example, people with Alzheimer's disease will often be afflicted with other serious medical conditions such as hypertension (66 percent), heart disease (30 percent) and diabetes (29 percent). Overall, at least 74 percent of individuals with Alzheimer's disease have another chronic condition. Hence, standard protocols governing transitions post-hospitalization must include specific provisions that address dementia-related needs. Any reforms of Medicare PAC must account for the progressive nature of Alzheimer's disease and the varying degree of symptoms that those persons with the disease experience. Maintaining full access to various levels of care, especially for those in the early to mid-stages of Alzheimer's, is especially important to reduce the likelihood of hospital readmission and premature placement in long-term care. An optimal transition of care for someone with Alzheimer's and other dementias would facilitate the return of that individual to a health status that would allow a return to the level of care they were receiving prior to the acute care episode (assuming that the pre-PAC care setting can accommodate the needed care plan). This would likely reduce beneficiary stress and may prevent exacerbations of dementia-related symptoms.

For some individuals with dementia, an appropriate setting for post-acute care may be a return to their home or another setting in the community, where family caregivers often assist in executing the medical discharge instructions from a practitioner or provider. Possible incentives for reducing the utilization of professional post-acute care providers could include providing family caregivers with training and financial assistance to ensure that an individual's needs are met round-the-clock without the cost of providing professional 24-hour care. The *National Plan to Address Alzheimer's Disease (National Plan)* highlights at Strategy 2.F, the need for people with Alzheimer's and their families to have support during care transitions to determine the best timing for transition and setting for care.¹ The *National Plan* also recommends that HHS implement and evaluate new care models to support effective transitions for people with Alzheimer's disease. Furthermore, in fulfillment of the *National Plan*, the Center for Medicare and Medicaid Innovation will be identifying practices that benefit people with complex needs, including those with Alzheimer's disease. Medicare PAC reforms should consider findings from these initiatives as well as draw upon successful government initiatives like the Partnership for Patients to identify best practices for reducing injuries, complications and improving care transitions from acute care settings.

The *National Plan to Address Alzheimer's Disease* was the result of a bipartisan effort by Congress to respond to the growing Alzheimer's crisis, which culminated in the unanimous passage of the National Alzheimer's Project Act (NAPA, P.L. 111-375) in 2010. Congress mandated through NAPA that the Secretary of Health and Human Services create a strong, accountable National Alzheimer's Plan, which was released in May 2012 and updated in June 2013. The National Plan is the result of unanimous

¹ Department of Health and Human Services. National Plan to Address Alzheimer's Disease: 2013 Update. 2013; 23

support by Congress to tackle the problems presented by Alzheimer's disease and any plan to reform Medicare PAC should consider the impact of those reforms on the Alzheimer's and dementia populations.

Training and support of family caregivers during transitions to post-acute care could potentially reduce the stay in skilled nursing facilities and delay the placement of beneficiaries into long-term nursing homes, which could reduce costs to individuals, families and the Medicare and Medicaid system. Aging and Disability Resource Centers are currently working to implement evidence-based care transition models at the state level that meaningfully engage older adults and their informal caregivers. In addition, the Centers for Medicare and Medicaid Services' (CMS) "Community-Based Care Transitions Program" demonstration project currently works to link hospitals with community-based organizations to improve care transitions and optimize community care. Evaluation of both of these programs will help in identifying ways to improve care transitions and protections for Medicare beneficiaries, including those with Alzheimer's disease.

Despite preferences to receive care in a home or community-based setting, most individuals living with Alzheimer's disease will need some level of facility-based care in their lifetime. Beneficiary protection with regards to PAC for individuals with dementia is synonymous with the ability to choose a facility where direct care workers are appropriately trained to care for individuals with Alzheimer's disease and other dementias. For example, The Alzheimer's Association's *Dementia Care Practice Recommendations for Assisted Living Facilities and Nursing Homes* contains guidelines on staff training for these facilities as well as for professionals delivering care in home settings. With regard to Medicare beneficiaries with Alzheimer's and other dementias, all of these settings are potential sites to receive PAC services and serve important functions on the continuum of care. Furthermore, quality measures that ensure appropriate training for all PAC staff who provide care for individuals with Alzheimer's disease should be incorporated into any reform of assessment tools for PAC facilities.

2. How should issues of beneficiary preference be accommodated (e.g. preference for a provider closer to home/family)?

Medicare beneficiaries with Alzheimer's and other dementias live in a variety of situations and settings. Some may live alone, with family or caregivers, or in residential facilities (e.g., assisted-living facilities, nursing homes, etc). For those experiencing transitions from acute care to PAC, beneficiary preferences should be accommodated whenever possible to ensure patient-centered care and adherence to established care plans developed in consultation with a beneficiary's primary care team. Medicare beneficiaries with Alzheimer's disease often need family or friends to communicate their needs or manage their affairs during times of transition between settings. As a result, the need for PAC providers who are closer to home or family is greater for people living with dementia than for those with normal cognition who are able to communicate their needs directly. Maintaining access to these providers is especially important for beneficiaries with Alzheimer's who are living in rural areas, where provider choice might already be limited. Restrictive payment policies could provide further disincentive for certain providers to operate in rural or otherwise underserved areas where provider choice is already limited. Although there is no one-size-fits-all approach to payment policies that will maintain options for all beneficiaries, any reforms should be flexible enough to preserve an adequate number of options for PAC services in a given area.

3. What steps need to be taken so that payment reform does not create incentives to avoid patients or inappropriately reduce care?

As we mentioned above, any reforms that inappropriately reduce payments to providers could create a negative incentive to care for all Medicare beneficiaries, especially those with Alzheimer's disease who

represent some of the most challenging and complex cases. PAC for the Alzheimer's population is typically a stop along a longer continuum of care that involves a number of different providers that span settings –inpatient, outpatient and in the community. Payments to providers must reflect the importance of maintaining continuity and coordination of care for beneficiaries with Alzheimer's disease as well as their families to reduce unnecessary complications and avoid costly hospital readmissions.

The Alzheimer's Association also strongly supports providing incentives for Medicare Advantage (MA) plans to create innovative care models for individuals with dementia and related conditions to advance care for the dementia population. For example in March 2013, the Alzheimer's Association responded to a CMS Call Letter regarding changes to the Risk Adjustment model used to reimburse MA and Program of All Inclusive Care for the Elderly (PACE) plans. These changes would result in significant decreases in risk-adjusted revenue for plans such as Special Needs Plans that serve the highest risk and most frail beneficiaries – many of whom are our constituents. These reductions will directly impact the ability of these plans to fulfill their mission to ensure that high-risk members with advanced disease are able to maintain or improve their health, rather than continue to deteriorate. In our comments, we specifically asked CMS to include dementia in the CMS-Hierarchical Condition Category (HCC) risk adjustment model for MA and PACE plans. An appropriate risk adjustment for dementia would allow MA plans to further develop supports targeting the unique needs of beneficiaries with Alzheimer's disease and other dementias during transitions to post-acute care. Therefore, PAC payment reforms that affect MA and PACE plans should include such a risk adjustment for dementia to preserve coverage of high-quality care for beneficiaries with Alzheimer's disease.

Enacting quality measures for PAC providers that measure patient/family satisfaction and standards of care for individuals with Alzheimer's and dementia is one step that CMS can take to prevent the inappropriate reduction in high-quality dementia care. The Advisory Council on Alzheimer's Research, Care, and Services recently made recommendations to HHS supporting the development and use of quality measures and indicators in the full array of medical settings, in addition to evaluating care coordination and transitions among settings. Finally, any reforms to Medicare PAC must acknowledge that providers will often seek to optimize financial return for their services. This could lead to a reduction in needed health care services for the most expensive beneficiaries, including those with Alzheimer's disease and other dementias.

4. Are there mechanisms other than cost sharing to encourage Medicare beneficiaries to more appropriately select PAC services?

Beneficiary decision making in selecting PAC services is primarily driven by the recommendations of their health care practitioners, most commonly their primary care physician or discharging provider from an acute care setting. Factors that play a role in a beneficiary's choice of PAC services include beneficiary knowledge of available options for PAC, out-of-pocket costs, location and proximity to home and/or family, personal comfort and preference as well as prior experiences with provider types/settings. Furthermore, these services are provided in a variety of settings (e.g. skilled nursing facilities, inpatient rehabilitation facilities, home health settings, etc.), each of which provides varying levels of care. Often, beneficiaries and families are ill-equipped with the knowledge to understand what PAC services are available, as well as the expected outcomes from receiving those services. Better education of beneficiaries and families may encourage more appropriate choices regarding utilization of PAC services.

In addition, providing beneficiaries and families dealing with Alzheimer's disease with supportive services such as caregiver training, respite care and caregiver counseling are examples of mechanisms that can

reduce the unnecessary utilization of more-expensive PAC services. Empowering caregivers allows individuals with Alzheimer's disease to remain at home or in community-based settings (e.g., assisted living facilities) for a longer period of time, ensuring beneficiary preferences are respected. Caregiver support services have also been shown to reduce caregiver stress, anxiety and depression, which helps improve the quality of care for beneficiaries with Alzheimer's disease in these settings. Improved caregiver support may also reduce the risk of beneficiary hospital readmission as well as avoid the unnecessary utilization of PAC services in more expensive settings.

We appreciate your leadership on this important issue. The Alzheimer's Association stands ready to assist the Committee in developing responsible reforms to Medicare coverage of PAC services. Please contact Rachel Conant, Director of Federal Affairs, at RConant@alz.org or 202-638-7121, if you have any questions or if we can be of assistance in the weeks ahead.

Sincerely,

A handwritten signature in black ink, appearing to read 'REgge', with a long horizontal flourish extending to the right.

Robert Egge
Vice President, Public Policy
Alzheimer's Association