

United States House of Representatives
Energy and Commerce Subcommittee on Health

Testimony of Robert Egge
Vice President of Public Policy
Alzheimer's Association

June 21, 2010

"Dual-Eligibles: Understanding This Vulnerable Population and How to Improve Their Care."

Good afternoon Chairman Pitts, Ranking Member Pallone and distinguished members of the Subcommittee.

I am Robert Egge, Vice President of Public Policy at the Alzheimer's Association. Thank you for the opportunity to discuss the unique perspective of the millions of Americans living with Alzheimer's disease and other dementias who rely on both Medicare and Medicaid, as well as the Association's ongoing efforts to improve their care and quality of life.

I have two major points to make today. The first of these points is that it is important to examine those dual-eligible individuals with Alzheimer's and other dementias simply because they are such a large, vulnerable and costly portion of the overall dual-eligible population. Even if there were no broader benefit, better understanding and addressing the needs of this group are likely to yield much better care at lower cost, because there is such room for improvement.

The second major point is that improving care for dual-eligibles with Alzheimer's and other dementias will bring additional benefits for dual-eligibles in general, and almost certainly for those many more beneficiaries in Medicare and in Medicaid programs more broadly. Over the past decade, our growing awareness of the significance of manageable chronic conditions like diabetes led to an important emphasis on themes like prevention, self-management, and patient-centered care. Today, in a similar way, our growing awareness of the widespread impact of cognitive impairments due to Alzheimer's and other causes should introduce much needed attention to themes such as program simplification and supporting the unpaid caregiver.

Alzheimer's impact on America, and on the dual-eligible population specifically

Today, there are 5.4 million Americans living with Alzheimer's and almost 15 million unpaid caregivers. If left unchecked, by 2050 this devastating disease will affect as many as 16 million Americans. Alzheimer's disease is the sixth leading cause of death in the United States; the fifth leading cause of death for those over the age of 65; and the only one of the top ten causes of death in the United States without a means to prevent, cure or slow its progression. From 2000 to 2008, deaths from Alzheimer's disease increased by 66 percent, while deaths from heart disease, breast cancer, prostate cancer and stroke declined.

Turning specifically to the matter of today's hearing, we know Alzheimer's disease is highly prevalent among dual-eligible individuals. According to a Kaiser Family

Foundation analysis of the Medicare Current Beneficiary Survey Cost & Use File (2006), 61 percent of dual-eligible individuals are cognitively or mentally impaired. Nearly one in every six dual-eligibles in America today has Alzheimer's disease or other dementia. And 22 percent of older people with Alzheimer's disease and other dementias are dual-eligibles. Alzheimer's disease is also extremely prevalent among dual-eligibles in nursing homes, where 59 percent of residents live with the disease.

Alzheimer's beneficiaries are among the costliest of dual-eligibles. Medicare and Medicaid pay over 70 percent of the total cost of caring for people with the disease. Absent a cure or effective treatment options, total care costs for those with Alzheimer's and other dementias will rise from \$183 billion today to \$1.1 trillion in 2050, and Medicare and Medicaid's share of these costs will rise from \$130 billion to over \$800 billion in 2050 in today's dollars.

In addition, costs for individuals with Alzheimer's are significantly higher than their counterparts. In 2004, average per person Medicaid payments for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were more than nine times as great as average per person Medicaid payments for Medicare beneficiaries without Alzheimer's and other dementias.

The reasons for these increased costs become apparent when examined along different dimensions, such as care setting. For instance, hospital stays are a major component of

Medicare expenditures. As reported in the Alzheimer's Association's *2011 Alzheimer's Disease Facts and Figures*: "In 2004, there were 828 hospital stays per 1,000 Medicare beneficiaries aged 65 and older with Alzheimer's or other dementia compared with 266 hospital stays per 1,000 Medicare beneficiaries without these conditions. At any point in time, about one-quarter of all hospital patients aged 65 and older are people with Alzheimer's and other dementias."

Due to the sheer scale of the population of dual-eligibles with Alzheimer's and other dementias, and the disproportionate costs that they bring to the Medicare and Medicaid systems, they merit an in-depth investigation to determine innovative ways to deliver better care to these beneficiaries as effectively as possible. Even if cost saving is not the driving motivation for such efforts, unmanaged dementia is so inefficient in terms of poorly managed coexisting medical conditions, increased hospitalization and readmissions, earlier placement in institutional care and the like, that cost savings are almost sure to follow in tandem with better outcomes. We urge that the dual-eligible population with Alzheimer's and other dementias be a particular focus for innovation in pilots, demonstrations, and broader system reform efforts.

The challenges faced by dual-eligibles with Alzheimer's and other dementias

Who are these dual-eligible Americans with Alzheimer's and why is care for them so inefficient today? The Alzheimer's Association has a strong understanding of the

challenges faced by dual eligible individuals with Alzheimer's and other dementias. It is an understanding developed and refined by delivering programs and services through more than 300 points of care across the country, and through handling more than a quarter of million calls each year through our 24 hour a day, 365 day per year nationwide toll-free helpline. While every case is unique, the recent experiences of an individual I'll call John are typical, and illustrate how important it is to view the issues before us today through the perspective of this population.

John and his wife, Emma, are an elderly, low-income couple and are eligible for both Medicaid and Medicare. John has Alzheimer's disease and diabetes. John's physician is very attentive to his diabetes but not to his Alzheimer's. He has given John a good diabetes treatment plan, self-management guidelines and nutritional education. Yet, because of his impairments due to Alzheimer's disease, John cannot remember or fully comprehend his physician's instructions. So, despite his physician's efforts, John's diabetes is poorly managed and his blood glucose levels are out of control. Emma is ill-equipped to help him manage the demands of his dementia or his diabetes – let alone the interplay between the two – because of her own health issues and the lack of caregiver training and support provided to her.

Instead of effectively managing his health and avoiding unneeded expenses through proactive care, John and Emma take frequent trips to the hospital where John is perceived as a “non-compliant, difficult diabetic” by hospital staff. The staff does not recognize John's dementia and that his non-compliance with diabetes treatments is due

to his inability to self-manage his care. So, John continues to show up at the emergency room for diabetes-related conditions at ever more frequent intervals. Each time he is sent home with discharge orders – explained to him often without Emma present – that he has no hope of following. These ER episodes are disconnected from his physician’s care. John’s hospitalizations increase; his health deteriorates; claims to Medicare and Medicaid mount. Reluctantly, John and Emma decide he can no longer live in his home but must enter a Medicaid-funded nursing home instead much sooner than either of them had hoped or expected.

The Alzheimer’s Association can, unfortunately, attest that John's story is all too typical, and is but one of many that exemplify the need to plan and coordinate services to improve care – and to delay nursing home placement for as long as possible – for this vulnerable population.

Lessons from cases like John and Emma’s for dual-eligible programs in general

As I mentioned at the outset of this testimony, tracing the experiences of cognitively impaired, dual-eligible individuals like John highlights the challenges before us this afternoon – challenges that extend far beyond just this population, as large as it is. Specifically, this population casts into stark relief challenges – and opportunities – related to **access, coordination, innovation and alignment**.

Access: improving the beneficiary's experience by reducing complexity. Financial barriers to care have received considerable attention in recent years, as they should. But dual-eligibles with cognitive impairment illustrate that barriers are not only financial – they are often due to the complexity of and fragmentation of the systems these beneficiaries must contend with. As we know from calls we receive to our nationwide toll-free helpline each and every day, many Americans are at a loss for how to gain access to available services and are often overcome with frustration. From the vantage point of a cognitively impaired person, navigating through the Medicare and Medicaid systems is extremely daunting. The Medicaid application process can be cumbersome and laden with requirements that are particularly challenging for individuals with memory loss and impaired executive function. Separate applications are often required to access each of the services and benefits needed. For example, in John's case, though he has been deemed eligible for Medicaid services, he would need to apply separately for adult day care, or in-home care, or a respite program.

Peggy, from Montana, cares for her husband with Alzheimer's. Her challenges are also typical of what we hear regularly from families around the country: "When my husband was diagnosed with Alzheimer's in March 2005, I never dreamed that I wouldn't be the one to take care of him the rest of his life. I did meet his needs for several years, but at some point, I realized I couldn't do it alone. I learned about the PACE program, but I found out it would cost approximately \$3500 per month unless we chose to put Jim on Medicaid to pick up the cost. There was no way we would be able to pay for it without

this support. It was a very long process and a lot of paperwork of to apply for Medicaid that required the services of an attorney, delaying our access to support. All this has left me with a very insecure future, but I do not know how I could have possibly managed his illness without this help.”

As part of any dual-eligible system redesign, the Alzheimer’s Association encourages particular attention to what is all too often an afterthought – designing processes to be as simple as possible from the beneficiary’s perspective. For instance, a seamless Medicaid application process for Medicare beneficiaries, where the systems are fully integrated, service and benefit needs are assessed at the point of application, and eligibility for those services is determined at the outset, could alleviate administrative barriers to service access that many dual-eligibles experience. Further, the prevalence of Alzheimer’s and other cognitive impairments underscores how important it is for these processes to accommodate the assistance of the unpaid caregiver or surrogate representative as well.

Coordination: Improving the beneficiary’s experience through better diagnosis and documentation. John’s case illustrates that many dual-eligible beneficiaries, particularly those with Alzheimer’s disease and other dementias, face a fragmented system that often results in reduced quality of care and increased costs.

Many discussions of how to address these challenges understandably look to care coordination for improvement. However, it is essential to remember that care coordination in turn depends on having fundamental preconditions in place such as an accurate understanding of the individual's health challenges. In the case of Alzheimer's and other dementias, some of the largest challenges are related to detection and diagnosis, and then ensuring that these conditions are recognized and taken into account by the beneficiary's full care team across care settings and transitions.

Studies indicate that half of people with Alzheimer's and other dementias have never received a formal and documented diagnosis, and some studies suggest it could be as high as 80 percent. As we saw in the case of John, a documented diagnosis that follows him across care settings is critical to ensuring that care providers treating coexisting medical conditions, such as diabetes and heart disease, can devise appropriate courses of treatment.

The current system relies heavily on self-management, which can be challenging or inappropriate for the majority of dual-eligible individuals who, as previously noted, have a cognitive or mental impairment. Successful chronic disease management requires educating patients on how to self-manage their diseases. While this care model works well for some people living with certain chronic conditions, self-management is extremely difficult and requires special considerations when patients are cognitively impaired. Current self-management models fail to take into account the needs of the

cognitively impaired population, often resulting in repeat visits to their health care provider or the hospital. The Alzheimer's Association has been working with the nation's largest chronic disease self-management program to understand what happens when individuals with dementia are participants in such programs. Such programs may, when properly tailored, provide some benefit to some individuals with the disease and their caregivers. But, this much is clear: While we can treat people living with Alzheimer's and dementia for other diseases – we simply cannot do it in the same way as we do for a person who does not have cognitive impairment.

In keeping with the Alzheimer's Association's commitment to improving the quality of care that beneficiaries with Alzheimer's receive, we are pleased to support efforts, such as the Health Outcomes, Planning and Education (HOPE) for Alzheimer's Act, which will improve care and outcomes for Medicare beneficiaries with Alzheimer's disease, and we look forward to working with the Subcommittee on initiatives that will improve care for all individuals living with Alzheimer's.

Innovation: Improving the beneficiary experience through innovations such as caregiver assessments and counseling. Innovation is certainly needed to improve the experience of dual-eligible beneficiaries. Perhaps the leading areas ripe for innovation stem from widespread cognitive or mental impairment among this population. However, the Alzheimer's Association's experiences advocating on behalf of those with

dementia suggests that this reality was not front of mind when these programs were developed.

Among the leading areas of focus for innovation must be empowering unpaid caregivers in their often heroic and too often thankless role of caring for and advocating on behalf of individuals with cognitive impairment, and making additional accommodations through surrogates when such unpaid caregivers are not present. For instance, as suggested above in the discussion of the HOPE for Alzheimer's Act, when an individual is diagnosed with Alzheimer's or another dementia, this should trigger development of a care plan. This care plan should include an assessment of the needs and capabilities of the individuals and their caregivers – for example, does the individual have support from unpaid caregivers that can be integrated into the care process and what needs do the caregivers have to improve their effectiveness? Strong evidence indicates that well supported caregivers can lead to better outcomes for beneficiaries while reducing program costs through effects such as delayed nursing home placement.

If individuals do not have unpaid caregivers who can adequately advocate on their behalf, they should have the opportunity to work with a surrogate representative. As the disease progresses, individuals living with Alzheimer's have difficulty expressing their thoughts or wishes. Without a caregiver able to do so on their behalf, individuals are often unable to convey the difficulties they are experiencing or to comply with medication and other elements of care plans created for them.

Alignment: Improving the beneficiary’s experience through improved Medicare

and Medicaid alignment. The need for alignment between Medicare and Medicaid is most apparent for dual-eligibles with Alzheimer’s disease who are in a nursing home setting. Nursing home care is often required for individuals at some point during the progression of Alzheimer's. Once an individual has successfully qualified for Medicaid and is seeking nursing home care, they are likely to find a shortage of available Medicaid beds, resulting in placement on a waiting list and/or placement in a facility many miles away from their communities and families. They are also likely to find multiple points of fragmentation within the systems which affects their ability to access appropriate care. For example, some individuals are admitted to a nursing facility prematurely because their family could not access the needed home and community based services and supports to allow them to keep their loved one at home. Nursing home placement can present other difficult issues for dual-eligibles such as repeated hospitalization, a lack of high level nursing care, and a lack of communication and coordination between care settings.

According to a 2007 MedPAC report, almost 18 percent of Medicare beneficiaries who were discharged from the hospital were readmitted within 30 days. The report also found that Medicare spending on potentially preventable readmissions is substantial: \$12 billion for cases readmitted within 30 days. Hospital readmissions are particularly challenging for people with Alzheimer’s disease because they may experience

increases in cognitive impairment levels and have difficulty managing the transitions and changes in environment.

With 59 percent of dual-eligibles in nursing homes living with Alzheimer's or dementia, dementia training is critical. Our national training program, part of the Alzheimer's Association Campaign for Quality Residential Care, provides care professionals with specialized skills and hands-on practices based on the latest research and expert evidence in the dementia care field. Studies show that staff trained specifically in dementia care are able to provide a better quality of life for residents and have increased confidence, productivity and job satisfaction.

Another way to address these challenges is to encourage continuity during transitions between care settings. The MedPAC report suggest a variety of models that have seen success in hospitals around the nation. These models include employing a "transition coach," connecting patients and nurses after discharge to manage their discharge plan, and scheduled calls to report vital data. The Alzheimer's Association supports proposed new models of care that could be effective for dual-eligibles with Alzheimer's disease because of the need to decrease incidents of rehospitalization, monitor the effects of the transition between settings, and provide education and support about the disease progression and management of any other coexisting medical conditions. Such coordinated models advance the overarching goal of providing a seamless integration of benefits and coverage, allowing the focus to be on effective care for the beneficiary.

Mr. Chairman, without improved access, coordination, innovation and alignment, dual-eligible individuals, particularly those with Alzheimer's disease and other dementias, will continue to face inefficient health care leading to worse health outcomes and will cost Medicare and Medicaid unnecessary additional dollars. As we continue to make investments in research to find a therapy that will slow, stop, or prevent Alzheimer's, we must ensure that individuals have access to the available services that can improve their quality of life today. The Alzheimer's Association greatly appreciates the opportunity to address these issues and looks forward to working with the Subcommittee.