

**Testimony of Robert Egge, Chief Public Policy Officer, Alzheimer's Association
House Committee on Ways and Means hearing on "Caring for Aging Americans"
November 14, 2019**

Chairman Neal, Ranking Member Brady, and members of the Committee, my name is Robert Egge and I serve as the Chief Public Policy Officer of the Alzheimer's Association. Thank you for holding this important hearing today and for the opportunity to testify on how America is caring for its aging population, including those living with Alzheimer's disease and related dementias and their caregivers.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Association is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association, working in strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of dementia.

Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other brain functions. Ultimately, Alzheimer's is fatal. We have yet to celebrate the first survivor of this devastating disease.

In addition to the suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the health care system, families, and federal and state budgets. According to a study funded by the National Institutes of Health and published in the *New England Journal of Medicine*, Alzheimer's is the most expensive disease in America, with costs set to skyrocket at unprecedented rates. While there are over 5 million Americans currently living with the disease, without significant action, as many as 14 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (in 2019 dollars). As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care. In fact, just this year alone Medicare and Medicaid will spend an estimated \$195 billion caring for people with Alzheimer's.

Caregiving

In addition to its economic impact, Alzheimer's takes a devastating toll on caregivers. Nearly half of all caregivers (48 percent) who provide help to older adults do so for someone with Alzheimer's or another dementia. In 2018, more than 16 million unpaid caregivers provided 18.5 billion hours of care valued at nearly \$234 billion. Caregivers of people living with Alzheimer's and other dementias report higher levels of stress, depression, and worse health outcomes when compared to others who are providing care to individuals without dementia. As a result,

Alzheimer's caregivers incurred \$11.8 billion in additional health costs last year. These dedicated caregivers need increased resources, training, and support to help them navigate the strain of caregiving and improve their health and quality of life.

Care Planning

Since January 1, 2017, Medicare has reimbursed physicians and other health care professionals for providing comprehensive care planning to individuals with cognitive impairment – a critical step in improving the quality of care and quality of life for those with Alzheimer's and their caregivers. A care planning visit includes an evaluation of cognition and function, measuring neuropsychiatric symptoms, a safety evaluation, identifying and assessing a primary caregiver, development of advance care directives, and referrals to community services.

The bottom line is that care planning helps ensure those with Alzheimer's get on the right care path--that's why it appears throughout the *National Plan to Address Alzheimer's Disease*. Analyses show dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management.¹ It allows diagnosed individuals and their caregivers to access medical and non-medical treatments, clinical trials, and support services available in the community. Alzheimer's and related dementias also complicate the management of other chronic conditions, so care planning is key to better care coordination and management of comorbid conditions. The availability of the care planning code, CPT® code 99483, is an important step in that direction.

The Alzheimer's Association and AIM contracted with the Health Care Cost Institute to analyze the use of the care planning benefit among Medicare fee-for-service (FFS) beneficiaries and among those in some Medicare Advantage (MA) plans. Unfortunately, the results illustrate that very few Medicare beneficiaries received care planning in 2017, the first year it was available.² Specifically:

- 18,669 FFS Medicare beneficiaries received care planning, a rate of 55.6 per 100,000 beneficiaries.
- 2,857 individuals in the Medicare Advantage plans that were analyzed received the services, a rate of 39.4 per 100,000 beneficiaries.³
- In seven states and Washington, D.C., not a single FFS Medicare beneficiary received care planning services.

In short, fewer than one percent of those living with Alzheimer's and other dementias received care planning in 2017.

¹ Healthsperien. (2015). *Analysis and estimate of the federal budget impact of the Health Outcomes, Planning and Education (HOPE) for Alzheimer's Act of 2015*.

² Health Care Cost Institute. (2019). *Examining the adoption of a new Medicare billing code for cognitive assessments: a slow but steady uptake*.

³ The Medicare Advantage plans analyzed represented 37 percent of total enrollment in Medicare Advantage plans.

For the benefits of care planning to reach more Americans affected by Alzheimer's, more clinicians must use the care planning benefit. The bipartisan *Improving HOPE for Alzheimer's Act* (H.R. 1873/S. 880), would help achieve that goal by requiring the Department of Health and Human Services to (1) educate clinicians on the existence and importance of Medicare's care planning benefit; and (2) report to Congress on the barriers to individuals receiving care planning services and how to increase their use. This bill has already garnered significant bipartisan support in both chambers and we urge the Committee on Ways and Means to hold a markup. We look forward to working with the bill's sponsors and Committee leadership to ensure its movement in the full House and Senate.

Robust care planning is the first step to learning about long-term care options and selecting the preferred, most appropriate services for persons with dementia, families, and caregivers. Because persons living with Alzheimer's and other dementias often use a variety of supports over the course of the disease and because many--if not most--people need help coordinating those services, a care plan can help these individuals sort through options and choose the long-term services and supports that can contribute the most to the quality of their life.

Long-Term Services and Supports (LTSS)

As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer's and other dementias will grow and every state across the country is expected to experience an increase of at least 12 percent in the number of people with Alzheimer's between 2019 and 2025. With that growth will come an increasing need for long-term services and supports. That's why one of the five goals of the *National Plan to Address Alzheimer's Disease* is devoted to expanding supports to persons living with dementia and their families and why the Alzheimer's Association developed our *Dementia Care Practices Recommendations*,⁴ designed for professional care providers who work with individuals living with dementia and their families in residential and community-based care settings.

Due to the length and complexity of the disease and the way it compounds the management of other health conditions, people need access to a wide variety of services such as adult day, home health, respite, skilled therapy, residential facilities, and nursing home care. Persons with Alzheimer's and other dementias make up a large proportion of the older adults who use long-term care services, but they often use them differently because they and their caregivers have unique needs. First, people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's, and some live as long as 20 years. During that period, individuals will spend an average of 40 percent of this time in dementia's most severe stage and much of it in a nursing home.

⁴ Alzheimer's Association. (2018). *Dementia Care Practice Recommendations*.

Second, most individuals experience dementia in stages—early, middle, and late. That means that they need different supports and services over the disease course. For example:

- In the early stages, individuals may still function independently. They may still drive, work, and be part of social activities. As some common difficulties develop—like trouble with planning or organizing—individuals (particularly those who live alone) may find it helpful to have access to occasional homemaker services.
- In the middle stage, which can last for many years, people with Alzheimer's will require greater levels of care. They may not be able to work, they may withdraw socially, and they experience increased confusion and behavioral changes, including an increased risk of wandering and becoming lost. These individuals often still need social engagement and assistance with daily activities, and caregivers need increasing support. An adult day program may meet some of these needs.
- In the late stage, individuals lose the ability to respond to their environment, to carry on conversations and, eventually, to control movement. Significant personality changes may take place and they need extensive help with daily activities and personal care. They also become increasingly physically vulnerable, eventually losing the ability to walk, sit, and swallow. These individuals are likely to need intensive nursing care, often provided in a facility.

Additionally, those affected by Alzheimer's often receive intensive support from a primary caregiver. Caring for a person with Alzheimer's or another dementia poses special challenges. For example, family caregivers help individuals with diagnoses manage difficulties communicating, changes in personality and behavior, and the increasing need for supervision and personal care. As symptoms worsen, family caregivers often experience increased emotional stress and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services. However, there are evidence-based, effective interventions to support caregivers. The most effective interventions can reduce depression among dementia caregivers, help them cope with their responsibilities, and can help to keep the person living with Alzheimer's in the home longer.

Finally, the needs of persons living with dementia and caregivers extend well beyond health care. Upon diagnosis, affected persons not only need help managing other chronic conditions, but they often need community-based supports like safety assessments, legal and financial services, and transportation.

Eventually, most persons living with a diagnosis will also experience behavioral and psychological symptoms of dementia, such as aggression, hallucinations, or wandering. These behaviors are frequently the impetus to placement in a long-term care facility when the family can no longer manage them in the home. Non-pharmacologic interventions such as reducing stimulation or redirecting an agitated person's attention should always be tried first. Sometimes, however, when behaviors have not responded to the non-drug approaches and are causing

physical or emotional harm to the person living with dementia or the caregivers, antipsychotic medications may need to be used in the short-term under the close supervision of a qualified physician. Long-term services and supports should integrate medical, psychological, and social needs and account for these behaviors.

As noted above, persons affected by dementia use a wide range of long-term supports and services:

Adult day services. Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias. Overall, 69 percent of adult day services offer specific programs for individuals with Alzheimer's or other dementias. The median cost of adult day services is \$72 per day, and the cost of adult day services has increased 2.1 percent annually over the past five years.

Residential care facilities. Forty-two percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias. Fifty-eight percent of residential care facilities offer programs for residents with dementia. The median cost for care in an assisted living facility is \$4,000 per month, or \$48,000 per year, and the cost of assisted living has increased three percent annually over the past five years.

Nursing home care. Fifty percent of nursing home residents in 2014 had Alzheimer's or other dementias. Nursing home admission by age 80 is expected for 75 percent of people with dementia compared with only four percent of the general population. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions. The average cost for a private room in a nursing home is \$275 per day (\$100,375 per year) and the average cost of a semi-private room is \$245 per day (\$89,297 per year). The cost of nursing home care has increased 3.6 percent and 3.4 percent annually over the past five years for a private and semi-private room, respectively.

Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias is 23 times as great as Medicaid payments for other Medicare beneficiaries due to their use of long-term residential care. Total Medicaid spending for people with Alzheimer's or other dementias is projected to be \$49 billion in 2019.

Home care. In-home care services, such as personal care services, companion services, or skilled care can allow a person living with dementia to stay in a familiar environment, delay institutionalization, and be of considerable assistance to caregivers. The median cost for a paid non-medical home health aide is \$22 per hour and \$132 per day. Home care costs have increased 2.5 percent annually over the past five years.

Respite. Given the demands on and responsibilities of caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer.

Use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. This is consistent with the growing demand the Alzheimer's Association hears from our constituents. Yet availability of respite programs in the community is limited. We applaud the House's recent passage of the *Lifespan Respite Care Reauthorization Act* (H.R. 2035/S. 995) to meet this demand, and are encouraged that the Senate Committee on Health, Education, Labor and Pensions passed it out of Committee earlier this month.

As we work to expand and improve long-term care options, we must ensure that populations who have been historically underserved have access to culturally-appropriate services. According to the *2019 Alzheimer's Disease Facts and Figures*, older black/African Americans are about twice as likely to have Alzheimer's or other dementias as older whites, and Hispanics are about one and one-half times as likely to be affected. Yet a study of Medicaid beneficiaries with a diagnosis of Alzheimer's indicated that black/African Americans had significantly higher costs of care than whites or Hispanics, primarily due to more inpatient care and more comorbidities. There may be a variety of reasons for this disparity--later-stage diagnosis, delays in timely access to primary care, and a lack of care coordination among them. Furthermore, of Alzheimer's family caregivers in the United States, 10 percent are black or African American, 8 percent are Hispanic, and 5 percent are Asian. These individuals need access to high-quality, culturally-appropriate services and supports, as stated in Strategy 3A of the *National Plan to Address Alzheimer's Disease*.

Home- and Community-Based Services

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community, and states are driving much of the development and better access to long-term care services in the community, also known as home- and community-based services (HCBS). State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

Several states are implementing innovative solutions to address Alzheimer's in the Medicaid and non-Medicaid space by developing critical, cost-effective dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and supports that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and to enjoy a greater quality of life.

CALIFORNIA

In 2012, California enacted legislation establishing the California Coordinated Care Initiative which increased supports for dual eligibles and moved the state from a fee-for-service model to Managed LTSS. Following receipt of a federal Alzheimer's Disease Supportive Services Program (ADSSP) grant in 2013, California worked to develop a dementia-capable system to effectively serve people with dementia and their caregivers. This resulted in a training program for health plan care managers (eight hours) and care managers with a dementia specialty (12

hours). The purpose of the training is to 1) increase care manager efficacy and referrals to HCBS; 2) reduce caregiver depression and improve self-efficacy; 3) increase health plan dementia capability, quality, and satisfaction; and 4) decrease health care utilization and cost.

ILLINOIS

In 2019, the Illinois Department of Healthcare and Family Services (HFS) announced that nearly 1,600 Medicaid members with dementia will have the opportunity to live in newly expanding settings that offer the services and safety they need. They are part of the Supportive Living Program (SLP), an HFS Medicaid alternative to nursing home care designed for older persons and persons with physical disabilities. SLP residents have their own apartments, decide which program services they will receive, and determine their own schedules. Residents in a dementia care setting receive increased oversight by staff and additional nursing assessments and are provided opportunities for more activities, all in a community setting. The SLP has 152 providers including five sites that are currently certified as dementia care settings and the program will expand to 40 dementia care sites by 2021. Without the program's dementia care settings, many residents with moderate dementia would have to transfer to a more costly and institutional higher level of care to receive the services and safety interventions they require.

MISSOURI

In 2019, Missouri enacted legislation to create Missouri's Structured Family Caregiver Program. The program, which is scheduled to take effect in 2020, pending approval by the Centers for Medicare & Medicaid Services (CMS), aims to improve access to home- and community-based services and support family caregivers of people living with dementia by providing reimbursement for daily caregiving tasks. If approved by CMS, 300 Missouri HealthNet (Medicaid) beneficiaries, including those living with Alzheimer's or another dementia, will be able to live in their choice of home setting and receive paid caregiving from the caregiver of their choice, including family caregivers.

VIRGINIA

Following an update to the State Alzheimer's Plan and an Administration for Community Living (ACL) grant to improve the state's dementia capability, Virginia added dementia-specific case management to its HCBS waivers. Dementia case management includes performing a cognitive assessment; conducting a structured needs assessment of the person with dementia and his or her caregivers; developing an individualized dementia care plan; and ensuring advocacy for the person with dementia and his or her family. State agency staff and managed care organizations (MCOs) recognized the value and improved quality that would come from such training and have already provided it to more than 300 case managers within the MCOs. Of note, Virginia utilized the dementia-specific case management training curriculum developed in California with support from a federal ACL grant.

WISCONSIN

In 2016, Wisconsin enacted legislation requiring the Department of Health Services to prepare a report describing where individuals who have dementia are currently placed in crisis situations,

established a pilot program for coalitions of two or more counties to create dementia crisis units, and appropriated two rounds of funding for dementia crisis innovation grants. These grants created a model for dementia-capable mobile crisis response that includes treating people in place when possible, clarifying roles and responsibilities for crisis response and stabilization, and addressing the need for appropriate placement options for people with dementia in crisis. Dementia-capable crisis response also requires a care system that is built around having trained staff and using care planning as a crisis prevention strategy to increase the success of stabilization efforts and reduce relocations of people during crisis, so grants were awarded to regions comprising multiple counties to obtain training on recognizing and providing services to people with dementia for their mobile crisis teams.

In 2013, the Wisconsin Dementia Care Specialist Program (DCS) began as a pilot program and was expanded throughout the state to provide dementia-specific information and assistance to individuals with dementia, their caregivers, and the community organizations that serve them. The program's goals are to ensure the highest quality of life for people with dementia that live at home; facilitate efforts to build dementia-friendly communities; support family caregivers; and to increase the dementia capabilities of local Alzheimer's Disease Resource Centers. In 2019, Wisconsin has 21 dementia care specialists, covering 34 of Wisconsin's 72 counties, and an additional three tribal-based DCSs. The most recent 2019-2021 state budget expanded the program with an additional 9 DCSs: 8 based in counties and one more tribal position, so that more counties across the state will have a dementia care specialist within the next year.

The Quality of Care in Residential Settings

As noted above, individuals with Alzheimer's often need to move into residential settings for more specialized care as the disease advances. In fact, among individuals with Alzheimer's, 75 percent will be admitted to a nursing home by the age of 80. Strong policies to ensure high-quality care in these settings are needed at both the federal and state levels. The Centers for Medicare & Medicaid Services and state governments must establish high standards to ensure that staff are properly trained, continue to reduce inappropriate antipsychotic use, and protect people with dementia from improper displacement from residential settings. State governments must also increase Medicaid reimbursement rates to reflect the higher cost of care for individuals living with Alzheimer's and other dementias and they should adopt a core set of dementia-specific home- and community-based services available through Medicaid.

Conclusion

The health care system, as it exists today, all too often fails both those living with dementia and their caregivers. In the absence of a treatment that would change the underlying course of the disease, we must do all we can to ensure the best quality of care and quality of life for those living with Alzheimer's and the people who care for them. We look forward to working with the Committee to advance bipartisan solutions that will have a meaningful impact on America's seniors, including passage of the *Improving HOPE for Alzheimer's Act*. This important bill will ensure that clinicians, Medicare beneficiaries with cognitive impairment, and their families are aware of the assessment and care planning services currently available to them. We also

appreciate the Committee's work to expand and improve affordable and quality long-term care options, such as ensuring access to respite care through the *Lifespan Respite Care Reauthorization Act*. Finally, we encourage the Committee to learn more about and consider the truly innovative home- and community-based services being developed and delivered in the states. Again, thank you for your continued leadership on improving care, supports, and services for America's aging population, including those living with Alzheimer's and their caregivers, and we appreciate the opportunity to be a resource to the Committee.