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Andy Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, Maryland 21244-1850

September 6, 2016

Re: Medicare Program: Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2017; Medicare Advantage Pricing Data Release; Medicare Advantage and Part D Medical Low Ratio Data Release; Medicare Advantage Provider Network Requirements; Expansion of Medicare Diabetes Prevention Program Model

Dear Acting Administrator Slavitt,

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. On behalf of the advocates of the Alzheimer's Association, I am pleased to offer the following comments on the Centers for Medicare & Medicaid Services' (CMS) assessment and care planning code for persons with cognitive impairment proposed in the Calendar Year 2017 Physician Fee Schedule.

Today, there are more than 5 million Americans living with Alzheimer's disease and more than 15 million individuals providing unpaid care for them. It is the only cause of death among the top 10 without a way to prevent, cure, or even slow its progression, and someone in the United States develops the disease every 66 seconds.¹ Caring for individuals with Alzheimer's disease will cost \$236 billion in 2016 with Medicare and Medicaid bearing \$160 billion--68 percent--of that figure.² Our advocates applaud CMS's proposal to pay physicians and other appropriate practitioners to assess and create care plans for beneficiaries with cognitive impairment.

Nearly 3,000 persons living with dementia, caregivers, and health care professionals shared with the Alzheimer's Association their recommendations regarding the proposed rule based on their first-hand experiences. The feedback is organized according to themes common to respondents, and pertinent personal remarks underscore those themes.

Theme #1: Comprehensive care planning that accounts for a wide range of needs and is tailored to an individual and his or her family can mean the difference between living with dementia and living well with dementia.

Alzheimer's disease and other forms of dementia are degenerative conditions that can last for years but symptoms and dementia-related behaviors can change from day to day. Dementia takes physical and emotional tolls on everyone around the individual, and its consequences are enduring. A comprehensive care plan is central to address all the variables, the daily unknowns, and a person's inevitable decline. As one person put it, "How important is an initial care plan and how helpful is it to patients and their families? It is everything. It grounds you. It takes a bit of the burden of this disease off your shoulders."

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

² Ibid.

Most advocates, however, reported that they or the persons for whom they provided care did not receive a care plan, information about the disease, or guidance on how to access needed resources. Many felt like it was their responsibility to ask all the right questions. Even of those respondents who received care planning, more than half did not feel they were prepared to address the types of care needed, legal and financial decisions, comorbid conditions, and planning for end-of-life.

In discussing their ideal care plans, many noted that plans must be individualized and need to be updated regularly. Citing the nature of dementia, one person summarized, “Care planning must be done periodically, as the disease progresses...The needs of the patient and the family change over time and the care plan requires constant reevaluation as things change.” Respondents reported that they needed information on the disease and its progression, treatment options, community resources, clinical trials, legal and financial issues, driving and safety issues, and palliative and end-of-life care. Many explained that even with a plan, they needed help implementing the various pieces. And as one stated, “Hearing it all just once does not work.”

Another summarized care planning this way: “Every care plan needs to include ongoing education, support, and care planning to match the needs of the individual with Alzheimer's disease as they change over time. At each step of the way, the needs of the caregiver also need attention...the care plan must address the physical, emotional, mental, social, spiritual, and life-planning needs of the individual, care partners, and family members.”

Theme #2: Caregivers are central to the daily lives of persons with dementia and need a variety of information and supports--for affected persons and for themselves.

The overwhelming majority of those who contributed to this letter are current or past caregivers of persons with dementia, so we note with gratitude CMS's inclusion of a caregiver-specific element. While caregiving often refers to attending to another individual's health needs, it also includes assistance with bathing, dressing, paying bills, shopping, and transportation. Beyond this, caregivers are responsible for seeking out resources and coordinating the care of persons with dementia. As one caregiver noted, “I *am* the care plan.” And although caregivers report positive feelings about caregiving, they also report substantial financial, emotional, and physical difficulties.³ Hundreds of caregivers echoed these challenges in their survey responses. To better support caregivers and the individuals for whom they care, we ask CMS to consider the following.

Caregivers must be a part of the discussions around beneficiaries' care, and their roles as caregivers should be documented in beneficiaries' medical records. According to caregiver respondents, 73 percent of providers included caregivers in discussions about diagnosis, treatment, or future care planning needs, and 78 percent of provider respondents indicated the presence of a caregiver most of the time, underscoring the fact that caregivers are fundamental to the daily lives of persons with dementia. One constituent stated that, “All family members and potential caregivers should be informed and involved as soon as possible,” and another said the primary care physician “requested that we as a family schedule an appointment so that she could educate us and provide information to us to help prepare our children and grandchildren for what lay ahead.”

Caregivers and providers agree that they must be able to communicate with each other, with or without the presence of the person with dementia. Due to the degenerative nature of the disease, an affected person will eventually be unable to participate in his or her care. Allowing providers to communicate directly with caregivers whether or not the beneficiary is present means more effective communication about the beneficiary's health as it declines. One respondent believes that the option for such

³ Ibid.

communication is needed to “ensure routine medical care is maintained,” and another noted the ongoing challenge of bringing her loved one to and from doctors’ appointments: “We need [to] allow caregivers to see their loved ones’ doctors on their behalf.”

Theme #3: CMS should ensure that health care professionals understand the disease, know about local resources, and are able to communicate information about this difficult topic to individuals with dementia and their caregivers.

While many advocates reported receiving high-quality, compassionate care from engaged, knowledgeable providers, 63 percent of respondents stated that they did not have enough information about Alzheimer’s disease or other form of dementia at the time of diagnosis. Many respondents noted considerable difficulty getting a diagnosis or having one confirmed, either because their physicians were unsure or because they seemed reluctant to provide one. Many of those who did receive diagnoses reported that they were simply given a prescription and were told to return to their doctors in six months. Several noted that they were too overwhelmed to know what questions to ask, and their physicians did not offer further guidance. One person stated that the provider suggested “types of information [she would need] but no information on where to find it.”

Beyond knowledge of disease progression or local resources, many respondents felt that their providers avoided a diagnosis or further discussion simply because it is a difficult topic. We fully appreciate how painful it can be to deliver a devastating diagnosis like Alzheimer’s disease, but it is all the more important for individuals who will slowly lose the ability to function and who will come to rely entirely on others. Many respondents noted that the sensitivity and honesty their providers showed eased the initial blow and helped them to feel supported. Some individuals, however, felt dismissed by their providers. A few felt stigmatized. One, for instance, reported that a physician refused to tell her mother, the patient, because there was “no point.” An inability or unwillingness to talk about the disease does not serve those affected. As it contemplates how to educate providers about this new code, we ask that CMS assist providers who need help communicating about dementia in a straightforward, sensitive manner.

Each of these points underscores the need for more provider education on dementia diagnoses, including what to expect and how to communicate all of this important information. As it finalizes and implements this code, CMS must ensure that physicians and other staff are trained in dementia and its impact and know about various resources in their communities. The Alzheimer’s Association remains a committed partner to CMS in this effort.

Theme #4: Delivering high-quality care and support requires a team of health care providers with different skill sets--and who are all knowledgeable about dementia and its impact.

Survey respondents reported a variety of practitioners have been involved in their care: physicians, nurse practitioners, nurses, pharmacists, social workers, psychologists, psychiatrists, skilled therapists, home health aides, and others. Providers who responded also noted referring persons with dementia to an equally wide range of other professionals.

The types of care they provided ranged from diagnosis and an explanation of treatment options to helping to develop a care plan to coordinating appointments to assessing homes for safety and beyond. Most of those who had a team--the composition of which varied greatly--reported a better experience than those who had a single practitioner, or, worse, no one at all.

The benefits of comprehensive support can go beyond day-to-day needs and logistics: one advocate reported that “having a consistent support team during the illness journey is crucial to building the trust necessary to make difficult decisions.” Others said that “So much is needed that no one doctor or source is going to be able to provide everything,” and “When a family receives a diagnosis of Alzheimer’s

disease, they should be advised that an interdisciplinary team approach along with family self-advocacy is the best and only way to keep your loved one safe and at home throughout the duration of this disease.”

Once more, thank you for taking the bold step you have proposed. We are confident that it will lead to better support for health care professionals and a better quality of life for persons living with the disease and the people who care for them. Please contact Laura Thornhill, Manager of Regulatory Affairs, at the Alzheimer’s Association at 202-638-7042 or lthornhill@alz.org with any questions or should you wish to learn more from those immediately affected by the disease.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Egge', with a stylized flourish extending to the right.

Robert Egge
Executive Vice President, Public Policy