Re: Medicare and Medicaid Programs; Programs of All-Inclusive Care for the Elderly (PACE)

Dear Acting Administrator Slavitt,

The Alzheimer’s Association appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services’ (CMS) proposed updates and changes to the Programs of All-Inclusive Care for the Elderly (PACE) regulations.

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s disease care, support, and research. Today, there are more than 5 million Americans living with Alzheimer’s disease, and it is the only cause of death among the top 10 without a way to prevent, cure, or even slow its progression. As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer’s disease and other dementias will grow.\(^1\) 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.\(^2\) Because PACE organizations serve so many persons with dementia—nearly half of their enrollees—we appreciate CMS’s efforts to support PACE organizations (POs) and we encourage you to consider the following comments as you work to improve care for this growing population of beneficiaries.

The Alzheimer’s Association opposes CMS’s possible application of the Medicaid home- and community-based services (HCBS) settings rule to PACE service centers and entities with which POs contract. The underlying concept of PACE organizations is to enable the frail elderly, including those participants with dementia, to maximize function and independence in the community as an alternative to nursing home placement, which they have done successfully: 93 percent of enrollees remain in the community.\(^3\) Guidance published subsequent to the HCBS rule applying “heightened scrutiny” to settings that employ secured perimeters or means of delayed egress, including those settings serving persons with dementia, has created inconsistencies with individual service plan requirements, confusion for certain providers, and safety and access concerns for those caring for people with dementia.

Until CMS is able clarify how the heightened scrutiny process can be implemented in a manner consistent with


\(^2\) Ibid.

the rule’s individual service plan requirements and until it can ensure safety and access to preferred services for those with dementia, the rule should not be expanded to additional settings.

The Alzheimer’s Association supports CMS’s proposal to permit POs to furnish PACE program services in settings other than PACE centers. For example, some PACE participants with dementia and their families may prefer to receive at least some services in adult day centers. This increased flexibility is also consistent with the larger societal shift toward more choices in how and where care is received. In order to ensure the continuity of the fundamental PACE model, however, we encourage CMS to ensure that POs maintain PACE centers in addition to alternative settings and that a participant’s interdisciplinary team (IDT) will be available in the alternative care settings selected by or for that participant.

We support CMS’s proposed changes to the core IDT to increase flexibility, including allowing a nurse practitioner, physician assistant, or community-based physician to fulfill the IDT role of primary care practitioner. With so many participants living with a form of dementia, however, we strongly encourage POs to ensure that IDT members and any other provider actively involved in a participant’s care be educated about and trained in dementia, its progression, and the needs of persons with the disease and their families.

In its discussion of the clarification and additional elements of the plan of care, CMS makes reference to “care improvement strategies” and “actions to improve a participant’s health care outcome.” As it finalizes the language of this rule, we note for CMS’s consideration that the conditions of PACE participants with dementia will not improve. Care improvement strategies focused on quality of life for individuals with degenerative conditions must be reflected in plans of care just as any other treatment goal.

Finally, the Alzheimer’s Association supports CMS’s proposal to make available the results of a PO’s regular reviews by State Administering Agencies to any individual who may be making a decision about a PACE participant’s care. As CMS notes, some PACE participants may not be able to make informed decisions about their own care and rely on family members or caregivers. Access to such information allows for more informed decision making and can ease participant and caregiver stress. The Alzheimer’s Association encourages CMS to make the information contained in these reports easily understood and framed in plain language that is meaningful to the average consumer.

Thank you for the opportunity to comment. The Alzheimer’s Association would be pleased to serve as a resource to CMS as it considers these important issues and how they relate to individuals living with Alzheimer’s and related dementias. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202-638-7042 or lthornhill@alz.org if you have questions or if we can be of additional assistance.

Sincerely,

Robert Egge
Executive Vice President, Government Affairs