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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

December 29, 2015

Re: Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals (CAHs), and Home Health Agencies (HHAs)

Dear Acting Administrator Slavitt,

The Alzheimer's Association appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services' (CMS) proposed reforms for discharge planning.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Today, there are more than 5 million Americans 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.¹ In 2015, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$226 billion, including \$153 billion in costs to Medicare and Medicaid. Nearly one in every five dollars spent by Medicare is on people with Alzheimer's or another dementia. In 2050, it will be one in every three dollars. The number of Americans with Alzheimer's disease and other dementias will continue to grow each year as the size and proportion of the population age 65 and older continue to increase.²

Individuals with dementia often move between a nursing facility, hospital, and home.³ In fact, Callahan and colleagues found that persons with dementia not only transition frequently between settings, but also experience more transitions than those without dementia.⁴ Furthermore, persons with dementia have increasing difficulty processing new information and stimuli, and disruptive situations like transitions can cause anxiety and agitation. This creates additional challenges for caregivers, many of whom are already physically and emotionally overwhelmed. Given the growing number of beneficiaries with Alzheimer's disease and their unique circumstances, the Alzheimer's Association deeply appreciates CMS's efforts to improve their care and experience. Our comments below apply to hospitals, CAHs, and HHAs.

¹ Alzheimer's Association. (2015). *2015 Alzheimer's Disease Facts and Figures*.

² Ibid.

³ Callahan CM, Arling G, Tu W, Rosenman MB, Counsell SR, Stump TE, Hendrie HC. Transitions in care among older adults with and without dementia. *J Am Geriatr Soc* 2012;60(5):813-20).

⁴ Ibid.

Individualized, Written Plans

The Alzheimer's Association applauds CMS's continuing emphasis on care that is tailored to the needs and preferences of the individual and family. While we understand many of these changes are designed to reduce readmissions, we believe this approach benefits patients and caregivers well beyond this aim.

Dementia is a degenerative disease that will eventually rob a person of his or her ability to remember, communicate, or care for him- or herself. In the early and middle stages of the disease, however, the progressing damage to nerve cells in the brain can also cause changes in mood, behavior, and personality. This means that the needs of a person with dementia can change from day to day, not just over a period of months or years. Individualized, written evaluations and discharge plans that account for these changing needs are essential to these beneficiaries' care and quality of life. For these reasons, we also support the required regular re-evaluation and updating of discharge plans.

Caregiver Inclusion

The Alzheimer's Association commends CMS on its broad inclusion of active caregiver participation and consideration of caregiver needs and capacity. Eighty-five percent of unpaid help to older adults in the United States is from family members and more than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias.⁵ Persons with dementia rely on caregivers for assistance with a wide range of needs, from decisionmaking to bathing or dressing. While some caregivers report positive feelings about caring for loved ones, they also report high levels of stress: Compared to caregivers of people without dementia, twice as many caregivers of people with dementia indicate substantial financial, emotional, and physical difficulties.⁶

For these reasons, we are particularly appreciative of the proposed requirements that hospitals consider the availability and capability of caregivers to provide post-hospital care as well as patients' and caregivers' ability to provide self-care. We support patient and caregiver involvement in discharge plan development and that they both are informed of the final plan. We ask, however, that CMS require that hospitals, HHAs, and CAHs provide the patient and caregiver with a copy of the final plan since "informed of" is not defined. A verbal expression of the plan to a person with dementia or an overwhelmed caregiver is unlikely to be remembered. While CMS requires hospitals, HHAs, and CAHs to provide written instructions regarding follow-up care in discharges to the home, both patients and caregivers should have access to this written information regardless of the type of transition.

Plan Development

The Alzheimer's Association appreciates CMS's acknowledgement of the various professionals that can and should be involved in discharge planning. We encourage hospitals to include among the "other qualified personnel" in their policies those specialists a patient's condition requires. For persons with dementia, for example, this could include a geriatrician, psychiatrist or geriatric psychiatrist, or pharmacist.

⁵ Alzheimer's Association. (2015). *2015 Alzheimer's Disease Facts and Figures*.

⁶ Ibid.

The Association welcomes CMS's explicit inclusion of "ongoing" patient evaluation. As noted above, the needs of persons with dementia and their caregivers evolve daily and over the long-term. Thus, they are better served by evaluation and planning that tracks with those changing needs.

The Alzheimer's Association supports CMS's continued emphasis on the accessibility of community-based services. In this rule, we note with gratitude CMS's inclusion of any needed physical modifications to the home or post-acute environment. This becomes particularly important to beneficiaries and family caregivers when a person is diagnosed with cognitive impairment or it is first detected at the hospital. The Association, including its chapters across the country, is a community resource for individuals, hospitals, home health agencies, and CMS alike. Information and support are available 24 hours a day, seven days a week at www.alz.org and 800-272-3900.

While we appreciate that CMS continues to interpret and implement the IMPACT Act, the guidance on resource use measures in this rule is impracticable as it relates to beneficiaries with dementia. As noted above, nearly one in every five Medicare dollars is spent on people with dementia, and patients with dementia are at an increased risk for readmission.⁷ However, the Association is not aware of data on discharge to the community and data on preventable readmission rates for persons with dementia is limited. CMS could learn much more by collecting how many all-cause readmission beneficiaries have dementia since dementia is unlikely to be documented as the cause for readmission but is likely to be a contributing factor to it.

Hospitals should provide written instructions on home care to patients and caregivers as well as written information on warning signs and symptoms of a patient's condition, regardless of the setting to which patients are discharged. The information about the patient's conditions should include the condition for which he or she was admitted as well as conditions he or she may experience after discharge, such as potential side effects or consequences. Hospitals should also provide to older patients information on the signs and symptoms of delirium, which they may develop in the hospital but may not be the condition for which they were admitted. Delirium is associated with an increased risk of cognitive decline⁸ and can worsen symptoms of dementia, such as confusion. Hospital staff should be knowledgeable about cognitive impairment, delirium, and dementia, and understand their implications for discharge planning.

We commend CMS's proposed medication reconciliation as a required step in the discharge process. In addition to the elements in the rule, medication reconciliation should also account for the setting to which a patient is being discharged, who will administer the medications, and whether appropriate non-pharmacologic interventions are available. Specifically, we are concerned about inappropriate antipsychotic use in persons with dementia. While CMS and nursing homes are working to reduce the inappropriate use of antipsychotics, this may not be a priority for some hospitals. As a result, some patients may be put on antipsychotics once admitted to the hospital when safer, more effective alternative treatments may exist.

⁷ Daiello LA, Gardner R, Epstein-Lubow G, Butterfield K, Gravenstein S. Association of dementia with early rehospitalization among Medicare beneficiaries. *Archives of Gerontology and Geriatrics*, 2014; DOI: [10.1016/j.archger.2014.02.010](https://doi.org/10.1016/j.archger.2014.02.010).

⁸ ICU Delirium and Cognitive Impairment Study Group, available at <http://www.icudelirium.org/outcomes.html>.

The Association supports CMS's proposed minimum set of elements to be captured in written plans-- particularly caregiver contact information, applicable advanced directives, and psychosocial assessments including cognitive status. Since hospitals will consider caregiver capability and needs as part of the process, we recommend that CMS require this element in written plans.

Home Health Agency Discharge Planning

With specific regard to discharge planning by home health agencies, the Alzheimer's Association echoes our comments on the 2014 proposed Conditions of Participation. We applaud CMS's inclusion of one of those elements in this proposal, the patient's goals. We note, however, omission of any caregiver information. Given CMS's emphasis on caregivers throughout the rest of the rule, we request that CMS add caregiver name, contact information, and capacity to the HHA discharge summary. We also recommend CMS require HHAs to ensure that the patient and caregiver receive copies of the discharge summary.

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,

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

Robert Egge
Executive Vice President, Government Affairs