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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

October 8, 2015

Re: Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities

Dear Acting Administrator Slavitt,

The Alzheimer's Association appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services' (CMS) proposed reforms for long-term care facilities.

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. Of all Medicare beneficiaries residing in nursing homes, 64 percent have Alzheimer's disease and other dementias.<sup>1</sup> Given the significant numbers of people with dementia living in these settings, the Alzheimer's Association deeply appreciates CMS's efforts to improve the care these individuals receive. We support many of the proposed changes but limit our specific comments to those that will impact persons with dementia and their caregivers in particular ways.

However, we note here an overarching concern regarding the tone and some of the language of this rule. In spite of the overwhelming prevalence of dementia among beneficiaries in nursing homes—indeed, CMS cites this very population as a reason to overhaul and update the rules—several provisions are written assuming residents have normal cognitive function. For example, CMS proposes that the post-discharge plan be developed with the participation of the resident and her representative. Her representative's participation, however, is contingent on the consent of the resident. Alzheimer's disease is more than difficulty completing activities of daily living (ADLs) and memory loss; it is impaired decision making and judgment. Thus, many of these individuals, especially those in the later stages of the disease, lack the capacity to consent or make sound decisions about who is involved in their care. We fully respect and support the rights and preferences of those individuals who will remain able to make decisions and direct their care. CMS's regulations must also reflect the health and safety needs of persons with dementia and recognize their dignity and that of their families.

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<sup>1</sup> Alzheimer's Association. (2015). *2015 Alzheimer's Disease Facts and Figures*.

Finally, we note the significant costs facilities will incur to comply with the important changes CMS proposes. To ensure that facilities can continue to serve these vulnerable beneficiaries with the high quality care CMS envisions, there must be adequate reimbursement.

### **Specific Comments**

#### *Resident Rights (§483.10)*

The Alzheimer's Association appreciates CMS's clarification and addition of several resident rights. However, we note the underlying assumption that a resident has the capacity to designate and revoke a representative and delegate rights. While we fully support these rights for persons with adequate decision-making capacity, CMS must account for and accommodate beneficiaries who cannot make such decisions, including the many people who enter facilities in the middle and later stages of a dementia.

Similarly, we appreciate CMS's emphasis on care planning in this rule and across its other programs and settings. Care planning is particularly important for persons with dementia and their families. It allows the affected person to participate in decision making while he is still able and can reduce stress and confusion for family and friends in the future. While we fully support every resident's right to be informed of medical conditions, participate in care planning, and identify other individuals to participate, we ask CMS to explicitly include family caregivers and/or representatives in these provisions. Even if a beneficiary enters a nursing facility able to participate in his care planning, the degenerative nature of dementia will cause his care needs to change and eventually render him unable to request a revision to his plan and involve other needed parties. CMS and facilities must consider the disease progression when supporting these residents. For example, a facility could create a standard practice of automatically convening a care team with a resident and his family if he has a dementia diagnosis.

#### *Facility Responsibilities (§483.11)*

The Alzheimer's Association appreciates CMS's clarification that individuals identified by a resident beyond legal representatives must be informed of any accidents, change in health status, the need for transfer/discharge, or the need to alter treatment. This is an important clarification, as multiple family members and friends are often involved in the care of a person with dementia.

We support CMS's clarifications and updates related to protecting residents' funds, including disclosures about the services and items for which facilities can and cannot charge residents. We further recommend that CMS require facilities to periodically review residents' accounts for suspicious activity and that the new training standards include training for administrators on protecting resident accounts.

Safety is a prominent concern for persons with dementia, especially for the six in 10 people with dementia who will wander. Many facilities, through their physical design, successfully balance personal safety with autonomy. We support the requirement that facilities ensure a safe environment and we encourage CMS to consider changing "...ensure that the physical layout of the facility maximizes independence *and does not pose a safety risk*" to "...maximizes independence *while ensuring safety*." This affirmative phrasing may spur facilities to be proactive in improving their properties to keep residents healthy, safe, and engaged.

*Comprehensive Person-Centered Care Planning (§483.21)*

The Association commends CMS's incorporation of resident assessments into the person-centered planning process. Persons with dementia have particular needs that will change daily for some people, so the proposed baseline interim care plan is an important part of their care. We echo CMS's expectation that the interim plan--as well as the comprehensive assessment and care plan--be revised and updated continuously.

We are encouraged to see a nursing assistant, food/nutrition staff, a social worker, the resident, and resident representatives added to the list of mandatory members of the interdisciplinary team (IDT). As CMS notes, broadening the skill sets of the IDT and the care planning process will better address the array of needs of this vulnerable population. We note with appreciation CMS's explicit inclusion of resident representatives.

Similarly, we applaud CMS for requiring that a facility consider the availability, capacity, and capability of caregivers with regard to discharge planning. Caregiving takes physical, financial, and emotional tolls, and assessing caregivers' capacity can help them to plan for the support and find the resources they will need. We also commend the inclusion of the representative in the discharge planning process but note above our concern that his participation is contingent on the consent of the resident.

*Quality of Care and Quality of Life (§483.25)*

We appreciate CMS's work to ensure the best possible quality of life and care for all nursing home residents. Because there is no treatment or cure for Alzheimer's disease, these efforts are particularly meaningful to affected persons and their caregivers.

CMS proposes to require that a facility provide the care needed for residents to maintain or improve their ability to perform ADLs and "ensure that those abilities do not diminish unless the diminution is unavoidable as a result of the individual's clinical condition." A form of dementia is, of course, one such clinical condition. Though we do not believe it to be CMS's intention, the language used here suggests that a facility may not owe a resident with a degenerative condition the same diligence or standard of care since she will not improve. We encourage CMS to clarify that all residents, regardless of condition, should receive the highest quality care possible.

We support the person-centered emphasis on activities programs for residents. A robust activities program can vastly improve the quality of life of persons with dementia, even if their abilities to interact with the community are limited. A variety of activities can keep them engaged and calm and can deter wandering.

The Alzheimer's Association fully supports the proposed requirements regarding tube feeding as consistent with the American Geriatrics Society's 2013 position statement. We also refer CMS and facilities to the Alzheimer's Association's position statement<sup>2</sup> on the matter.

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<sup>2</sup> Alzheimer's Association. (2011). *Assisted Oral Feeding and Tube Feeding*, available at [http://www.alz.org/documents\\_custom/statements/Assisted\\_Oral\\_Tube\\_Feeding.pdf](http://www.alz.org/documents_custom/statements/Assisted_Oral_Tube_Feeding.pdf).

#### *Pharmacy Services (§483.45)*

The Association supports CMS's ongoing efforts to reduce the inappropriate use of antipsychotic medications in persons with dementia. Within this rule, we also support the proposed extension of existing rules related to antipsychotics to psychotropic medications as well as their limited PRN use. Historically, antipsychotic medications have been used appropriately and inappropriately to address some of the behavioral and psychotic symptoms of dementia (BPSD), such as agitation, aggression, and hallucinations. The Association continues to support the appropriate use of medications in which BPSD pose a greater risk to individuals and families living with dementia than medications. For the more common occurrences of BPSD, non-pharmacologic interventions should be a first-line alternative to pharmacologic therapies. These interventions include routine activities, assessing for physical problems, and redirecting the person to an enjoyable activity. Non-pharmacologic interventions should be a part of all facilities' training programs and staff competency. We refer CMS and facilities to the Alzheimer's Association statement on BPSD.<sup>3</sup>

#### *Administration (§483.70)*

We commend the facility assessments and competency-based approach proposed in this section and throughout the rule. As discussed above, dementia can present special challenges, including behavioral and psychotic symptoms. What is actually an affected person's inability to express pain, for example, may be seen as aggressive behavior by caregivers, including staff. Thus, we support the proposed requirement that facilities assess their capability and capacity to serve their populations and employ a competency-based approach to ensure that residents' needs are met.

#### *Quality Assurance and Performance Improvement (§483.75)*

The Alzheimer's Association commends CMS's steps to implement quality assurance and performance improvement (QAPI) requirements for nursing and skilled nursing facilities. Many of the most commonly known and understood metrics of health care quality are based on the improvement of an individual's condition. Given the prevalence of persons with dementia in nursing facilities, it is important that their quality of care and life also be evaluated and improved. We strongly encourage facilities to make this population's care a part of their QAPI program, including collecting data on how many residents and caregivers are affected by dementia.

#### *Training Requirements (§483.95)*

The Alzheimer's Association commends the proposed dementia and abuse prevention training requirements. Studies show staff trained specifically in dementia care are able to provide better quality of life for residents and have increased confidence,<sup>4</sup> performance,<sup>5</sup> and job satisfaction.<sup>6</sup> We encourage CMS and facilities to consider the following:

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<sup>3</sup> Alzheimer's Association. (2011). *Challenging Behaviors*, available at [http://www.alz.org/documents\\_custom/statements/Challenging\\_Behaviors.pdf](http://www.alz.org/documents_custom/statements/Challenging_Behaviors.pdf).

<sup>4</sup> Hobday JV, Savik K, Smith S, Gaugler JE. Feasibility of Internet training for care staff of residents with dementia: the CARES program. *J Gerontol Nurs.* 2010;36(4):13-21. doi:10.3928/00989134-20100302-01.

<sup>5</sup> Burgio LD, Stevens A, Burgio KL, Roth DL, Paul P, Gerstle J. Teaching and maintaining behavior management skills in the nursing home. *Gerontologist.* 2002 Aug;42(4):487-96.

<sup>6</sup> Teri L, Huda P, Gibbons L, Young H, van Leynseele J. STAR: a dementia-specific training program for staff in assisted living residences. *Gerontologist.* 2005;45(5):686-693.

- At a minimum, curriculum used for the initial training should cover dementia and its progression and symptoms, strategies for providing person-centered care, communication, techniques for understanding and approaching behavioral symptoms, and aspects of care and safety (e.g. pain, food and fluid, wandering).
- Dementia training should be appropriate for the population served, include cultural competency, and provide ongoing learning opportunities, support, and mentoring.
- Indirect workers (e.g., maintenance, housekeeping, and administration employees) should receive, at a minimum, an overview of dementia and training on communication issues.

Given the complexity of dementia care, more than 12 hours will be required to fully inform staff, but an array of training curricula already exists and facilities should draw from them.

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](mailto: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

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