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Director
Regulation Policy and Management
Department of Veterans Affairs
810 Vermont Avenue NW, Room 1068
Washington, DC 20420

January 8, 2016

Re: Department of Veterans Affairs; Ensuring a Safe Environment for Community Residential Care Residents

To Whom It May Concern,

The Alzheimer's Association appreciates the opportunity to comment on the Department of Veterans Affairs' (VA) proposed rule on Ensuring a Safe Environment for Community Residential Care Residents.

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 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 In addition to aging, people who have experienced traumatic brain injury, including combat veterans, are at higher risk of dementia, cognitive impairment, and neurodegenerative disease.³ In 2017 alone, approximately 218,000 veterans will be diagnosed with dementia.⁴

The Alzheimer's Association is deeply grateful for the VA's comprehensive approach to dementia and the people it affects: its extensive research, its care and support services within the Geriatrics and Extended Care program, and its participation on the Advisory Council on Alzheimer's Research, Care, and Services. We are particularly appreciative of our joint pursuits, including the Alzheimer's Disease Neuroimaging Initiative (ADNI) and the Partners in Dementia Care program. While we support the spirit of the proposed rule and several specific provisions, we note the potential burden on smaller Community Residential Care facilities (CRCs), and we request additional information from the VA on how the rule will be enforced. The Alzheimer's Association is glad to serve as a resource to the VA as it continues to balance the protection of its aging veterans while encouraging the availability of high quality care.

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

² Ibid.

³ Ibid.

⁴ U.S. Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development (2015). Alzheimer's Disease Fact Sheet, retrieved from <http://www.research.va.gov/topics/alzheimers.cfm>.

Specific Comments

Persons with dementia are particularly vulnerable to abuse, neglect, and exploitation because the disease may prevent them from reporting the abuse or recognizing it. Thus, the Alzheimer's Association supports the proposed provision that would require CRCs to investigate staff with direct access to residents and/or residents' personal property. We also believe it is important that CRCs develop and implement written policies and procedures that prohibit and describe how to report mistreatment, neglect, and abuse of residents and misappropriation of property. In addition to the sample policies the VA will provide, it should also provide explicit guidance on how abuse is detected and reported in smaller CRCs, such as Medical Foster Homes (MFHs). In larger facilities with more personnel, such behavior can be easier to observe and report, and typically, would be reported to the service provider/facility operator. In smaller CRCs, however, it is possible that homeowners/service providers may be abusers, or that veterans may rely on a single caregiver who may be able to hide the abuse. For these reasons, the VA should develop guidance for small CRCs. Once developed, the VA should also incorporate this guidance into its other programs that may have limited staff, like home-based primary care and adult day programs.

The Alzheimer's Association supports the proposed timeline for reporting and investigating alleged violations, as well as the removal of accused employees from their duties pending investigation. Again, however, we request that the VA provide guidance as to the application of this provision to smaller CRCs. For example, if the live-in owner of a MFH is suspected, does he or she have to leave the home, or are resident veterans removed during the investigation? The VA should address scenarios unique to smaller CRCs.

In addition to the minimum elements the VA proposes to include in its sample policies and boilerplate language for CRC use, the Alzheimer's Association suggests including: the alleged victim's name and a contact person (such as a family member) for him or her; that any identified caregiver or legal representative be notified of alleged abuse; and that the record reflects resolution of the investigation. The VA should also require that CRCs provide written copies of the finalized policies and procedures to residents and caregivers or representatives.

The rule provides that CRCs must maintain records on each resident in a secure place and that these records may only be disclosed with the resident's permission. While we fully support a resident's right to privacy and control over his or her records, we note the underlying assumption that a resident has the capacity to make an informed disclosure (or denial of such a disclosure). Even if a veteran with dementia enters a CRC able to decide who may and may not access his records, the degenerative nature of the disease will eventually render him unable to grant access to his records, even to designated caregivers or legal representatives. We request that the VA include appropriate accommodation for caregivers/representatives in the final rule.

Finally, the VA should provide guidance for CRCs as to how and when non-VA authorities, such as police or adult protective services, are brought into an investigation. Because the CRC employees under this rule are not VA employees, we assume that criminal investigations, for example, cannot be managed entirely through the VA. The VA should clarify under what circumstances, how, and when external authorities are engaged.

Thank you for the opportunity to comment. 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 'RE', with a long horizontal stroke extending to the right.

Robert Egge
Executive Vice President, Government Affairs