



Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States House Committee on Veterans Affairs, Subcommittee on Health Hearing: "The Continuity of Care: Assessing the Structure of VA's Healthcare Network"

June 26, 2024

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the United States House Committee on Veterans Affairs Subcommittee on Health hearing on "The Continuity of Care: Assessing the Structure of VA's Healthcare Network." The Association and AIM thank the Subcommittee for its continued leadership on issues, such as the Department of Veterans Affairs (VA) health care network, that are important to our nation's veterans living with Alzheimer's and other dementia and their caregivers. This statement highlights the importance of dementia care and support programs at the VA and discusses how our nation's veterans living with dementia are benefiting from such programs.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. AIM is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

Nearly half a million American veterans have Alzheimer's — and as the population ages, that number is expected to grow. In 2015, an estimated 486,000 veterans were living with Alzheimer's. The annual number of veterans newly diagnosed with dementia has increased by more than 22 percent since 2008. For veterans, the prevalence may grow even faster in future years because they have a higher risk of developing dementia. The significant increase in the number of veterans with Alzheimer's and other dementias will place a heavy burden on the VA health care system and, in particular, rural health practices.

Home- and Community-Based Services (HCBS): The Impact on Family Caregivers and Needs of the Alzheimer's and Dementia Community

We are grateful for the VA's continuing commitment to supporting veterans living with Alzheimer's and other dementia by offering an array of long-term care and support services, such as assisted living, residential, adult day, and home health care.

HCBS allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while allowing them to manage and improve their own health.

While 83 percent of care provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of these caregivers do so for

individuals with Alzheimer's or other dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. In 2023, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of informal — that is, unpaid — assistance, a contribution valued at \$350 billion.

Several states are implementing innovative solutions to address Alzheimer's by developing critical, cost-effective, dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and support that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and enjoy a greater quality of life. Building off of innovative solutions by several states, the VA, through the Veterans Health Administration (VHA), should consider adopting a core set of home- and community-based services that are specifically designed for people with dementia. A core set of HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible.

Supporting Veterans' Access to High Quality Long-Term Care Services

While people living with Alzheimer's and other dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable, they make up a significant portion of all long-term care residents. More than 60 percent of the VA's costs of caring for those with Alzheimer's is for nursing home care. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance.

While much of the training for long-term care staff is regulated at the state level, we encourage the Subcommittee to consider proposals that support state VHA Medical Centers in implementing and improving dementia training for direct care workers, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on a thorough knowledge of the care recipient and their needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

We also urge the Subcommittee to support VHA Medical Centers in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that has hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

VA's Continued Role in Addressing Alzheimer's Disease in Rural Areas

We are grateful for the VA's participation in the Department of Health and Human Services (HHS) Advisory Council on Alzheimer's Research, Care, and Services, which plays a key role in developing and annually updating the *National Plan to Address Alzheimer's Disease* as set forth by the National Alzheimer's Project Act (P.L. 111-375). The National Plan is a roadmap of strategies and actions of how HHS and its partners can accelerate research, expand treatments, improve care, support people living with dementia and their caregivers, and encourage action to reduce risk factors. The most recent update to the Plan was released in December 2023, and includes a number of highlights on VA's continued work to better serve our nation's veterans living with dementia.

The VA continues to collaborate with federal agencies on a number of the key goals of the National Plan detailing rural health care, including Action 2.A.1, which is to educate health care providers on Alzheimer's disease. The VA's Geriatric Scholars Program is a workforce development program to infuse geriatrics into VA primary care settings by conducting intensive training in geriatrics, including rural interdisciplinary team training. The program includes an intensive workshop on quality improvement, and each participating Scholar initiates a local quality improvement project to demonstrate learning and improve care or clinic efficiency. The program also includes a wide variety of training activities focused on dementia, including training sessions on dementia caregiver coordinator education and rural caregiver education. Finally, the program provides participants with hands-on experience and practical skills in geriatric care necessary for adequately treating the aging population.

We also ask that the Subcommittee continue to support the Veterans Health Administration's 20 Geriatric Research, Education, and Clinical Centers (GRECCs), which are geriatric centers of excellence focused on aging. GRECCs reported in the 2023 National Plan Update that their work included 78 research grants in dementia covering basic science to clinical care and health services research and 25 clinical innovation projects that directly served veterans with dementia and their families. GRECC faculty have developed numerous clinical programs to aid family members and care providers, including e-Consults for Behaviors in Dementia, Health Care Directives for Veterans with Dementia, Reaching Out to Rural Caregivers and Veterans with Dementia Utilizing Clinical Video-Telehealth and Virtual Dementia Caregiver Support Programs. The GRECC Program produced 56 educational programs for staff and trainees on best practices in dementia care, including the use of simulation technology to demonstrate techniques for communication and facilitating ADLs for veterans with dementia. Finally, GRECC authors published 259 manuscripts in peer-reviewed journals in Fiscal Year 2022 on their research and clinical work in dementia. The VA must continue supporting the GRECCs in disseminating findings from this research to integrate scientifically-proven dementia interventions into local and rural communities.

Additionally, the VA also continues to collaborate with the Indian Health Service (IHS) and Centers for Disease Control and Prevention on the National Plan Action 2.A.6 to strengthen the ability of primary care teams in Indian country to meet the needs of people with Alzheimer's and related dementias and their caregivers. For example, in 2022, the IHS launched the Indian Health GeriScholars Pilot, developed with the support and collaboration of the VA Office of Rural Health. Modeled after the VA Geriatric Scholars Program, the Indian Health GeriScholars pilot provides primary care clinicians at IHS, Tribal, and Urban Indian Organization health programs with an individual intensive learning track for professional continuing education.

These are only a few examples of ways in which the VA remains involved in working to ensure a high-quality, well-trained dementia care workforce and continue bridging the gap in cognitive services in rural areas. The National Alzheimer's Project Act as a whole has led to great achievements in the treatment and research of Alzheimer's disease; however, this important law expires soon. The bipartisan NAPA Reauthorization Act (H.R. 619/S. 133) and Alzheimer's Accountability and Investment Act (H.R. 620/S. 134) would extend the National Plan, and ensure researchers at NIH continue to receive the funding necessary to sustain vital Alzheimer's and dementia research. These bills will ensure the nation continues addressing Alzheimer's as a national priority, providing continuity for the community.

Program for Advancing Cognitive Disorders Education for Rural Staff (PACERS)

The VA Employee Education System and South Central Mental Illness Research Education and Clinical Center administer the Program for Advancing Cognitive Disorders Education for Rural Staff, also known as PACERS. The PACERS program at the VA is designed to enhance dementia care through a specialized training program for clinicians who care for veterans with cognitive disorders. It aims to improve outcomes for veterans and their caregivers, especially those living in rural communities. The program includes six e-learning courses and five videos that focus on normal cognitive aging and dementia caregiving, addressing decision-making and safety in dementia, and reviewing case studies in treating dementia. In rural settings with limited resources, the PACERS program is a crucial tool for health care professionals to better provide patients with high-quality care within the constraints of rural health care infrastructure. The VA may consider adopting similar online programs to further enhance dementia care training for rural physicians at the Veterans Health Administration.

Conclusion

The Alzheimer's Association and AIM appreciate the Subcommittee's steadfast support for veterans and their caregivers and the continued commitment to advancing issues important to the millions of military families affected by Alzheimer's and other dementia. We look forward to working with the Subcommittee and other members of Congress in a bipartisan way to advance policies that will ensure access to high-quality dementia care and support in rural areas, especially as the population of veterans living with dementia continues to grow.