



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

United States Senate Special Committee on Aging Hearing on "Caught in the Middle: Supporting Families in the Sandwich Generation"

May 13, 2026

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) thank the Committee for its continued leadership on issues crucial to individuals living with Alzheimer's and other dementias. We appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing on **"Caught in the Middle: Supporting Families in the Sandwich Generation."** This statement highlights the growing demands facing individuals living with Alzheimer's and other dementias, and the family caregivers — particularly those in the sandwich generation — who are supporting them.

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 disease and other dementias 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.

The burden of Alzheimer's on individuals and families continues to grow, with over 7 million Americans aged 65 and older living with Alzheimer's dementia. Total payments for all individuals with Alzheimer's or another dementia are estimated at \$409 billion (not including unpaid caregiving) in 2026. Medicare and Medicaid are expected to cover \$263 billion — or 64 percent — of the total health care and long-term care payments for Alzheimer's or another dementia,

which are projected to increase to more than \$1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and the nation's health care system.

Families at the Center of Dementia Care

Nearly 13 million Americans provide unpaid care for a family member or friend with dementia. This care is valued at \$446.3 billion — more than 17 times the total revenue of McDonald's. In addition, unpaid caregivers provided care valued at more than \$30 billion in each of the four most populous states — California, Texas, Florida and New York.

While 83 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of all caregivers who help older adults do so for someone with Alzheimer's or another dementia. This underscores the central role of family caregivers in dementia care across the country.

Approximately one-quarter of Alzheimer's and dementia caregivers are "sandwich generation" caregivers, balancing care for someone living with the disease alongside responsibilities for children or grandchildren. For these individuals, caregiving is woven into already full lives, alongside work and family responsibilities that often require constant attention.

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 fact, the financial toll of Alzheimer's on individuals exceeds the toll on the Medicaid program. Most caregivers (66%) live with the person with dementia in the community, and dementia caregivers provide an average of 27 hours of care per week, reflecting the extraordinary dedication and responsibility carried by family caregivers on a sustained, ongoing basis.

Caregiving at this scale is deeply demanding and often sustained over many years. Fifty-nine percent of dementia caregivers report feeling high to very high emotional stress, and more than one-third experience significant emotional, financial, and physical difficulty compared with caregivers of older adults without dementia. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. This prolonged duration of care contributes to caregiver strain, particularly when combined with limited access to formal supports and increasing care

complexity over time. As families take on increasing responsibility for dementia care, earlier and more accurate diagnosis can help give them answers sooner, so they can better plan, prepare, and make informed decisions.

Enabling Earlier Detection to Support Families and Care Planning

Great progress has been made in advancing Alzheimer's and dementia research, and the approval of treatments that can slow disease progression in early stages has further increased hope for individuals and families.

Early and accurate diagnosis is critical, particularly as new therapies are limited to individuals in earlier stages of disease. For caregivers, especially those in the sandwich generation, earlier answers can also help bring clarity during periods of uncertainty and support more informed decision-making.

At the same time, diagnosing Alzheimer's disease and other dementias has historically required a combination of clinical assessments, cognitive evaluations, and imaging or cerebrospinal fluid testing — tools that, while effective, are not always accessible to every patient or primary care provider. Today, that landscape is changing rapidly. The FDA's recent clearance of blood-based biomarker tests marks a transformative advance in detection and diagnosis, opening new opportunities to identify Alzheimer's earlier, connect patients to treatment and care planning sooner, and ease bottlenecks in our health care system. Sustained NIH investment has been foundational to these breakthroughs — deepening our understanding of disease mechanisms and strengthening the broader therapeutic and diagnostic pipeline. Building on this progress, we strongly support the bipartisan Alzheimer's Screening and Prevention (ASAP) Act (S. 3267), led by Senators Susan Collins (R-ME), Catherine Cortez Masto (D-NV), Shelley Moore Capito (R-WV), and Mark Warner (D-VA), which would create a pathway for FDA-approved blood biomarker tests, ensuring that the seniors who need these innovations most can actually access them.

Without this legislation, Medicare coverage of new dementia screening tools could be delayed for years, even after FDA approval. The ASAP Act would not mandate coverage, but it would empower the HHS Secretary to determine whether FDA-approved dementia screening tests should be covered, translating scientific progress into meaningful, timely care that allows individuals and families to swiftly act on early detection, access interventions, and plan for the

future. We look forward to continuing to work with our bipartisan champions in Congress and on this Committee to ensure that advances in Alzheimer's diagnostics are translated into swift, meaningful care and improved outcomes for individuals living with Alzheimer's disease as well as their caregivers.

Supporting Caregivers Through HCBS and Respite

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as possible, and home- and community-based services (HCBS) allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services are essential to sustaining home-based care by helping caregivers manage increasingly complex needs while maintaining their own health and well-being. They also help reduce caregiver isolation — an often-overlooked challenge that affects emotional well-being and the sustainability of care.

Given the growing demands and responsibilities placed on caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. The use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. Yet the availability of respite programs in the community is limited, leaving many families without meaningful relief. We are proud to support the bipartisan Lifespan Respite Care Reauthorization Act of 2025 (S. 830), led by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI), to meet this growing demand.

One way the Alzheimer's Association is helping caregivers of individuals with Alzheimer's is by providing a 24/7 Helpline (800.272.3900) available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with dementia, caregivers, families, and the public. The Full-Year Continuing Appropriations and Extensions Act (P.L. 119-4) allocated \$2 million for the Alzheimer's Call Center, and we look forward to working with the Committee to continue funding this vital resource for individuals living with the disease as well as their caregivers.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of families affected by

Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to address the challenges facing the dementia community.