ALZHEIMER'S DISEASE AND THE GROWING CONCERN

Rising Gaps in Diagnosis, Treatment and Access to Care

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EXECUTIVE SUMMARY

Alzheimer's disease and other forms of dementia are becoming increasingly prevalent in the United States and are placing a growing demand on families, communities, and the healthcare system. The number of Americans living with Alzheimer's disease is expected to double by the year 2050, and although progress has been made in diagnostic tools and treatments, there is still much work to be done to meet the growing demand for care. Scientific progress does not automatically translate to access.

Many patients across the United States still face delays in diagnosis, limited access to specialists which can result in long waiting lists for appointments and missing opportunities for clinical trials and available therapies. These challenges are particularly significant in rural settings which have been historically underrepresented in Alzheimer's and dementia studies.

The challenges faced within the healthcare setting add to the list of frustrations and concerns felt by families impacted by the disease. Navigating the complex, and often fragmented, healthcare landscape, while the demand for their time and attention grows as a loved one progresses through the disease has led to many caregivers experiencing emotional and mental health challenges of their own, as well as experiencing negative impacts on their own physical well-being.

As Alzheimer's disease and other dementias continue to affect a growing number of Americans, ensuring equitable access to timely diagnosis, specialized care, treatment options, and caregiver support has become an urgent priority. While scientific advances offer new opportunities to improve outcomes, significant gaps in access and care coordination remain, particularly in rural and underserved communities. Addressing these challenges will require a coordinated approach that strengthens healthcare infrastructure, expands access to resources and services, and better supports caregivers. Much work needs to be done to close the gap between innovation and implementation so quality of life for individuals living with dementia, as well as their families, can be improved while simultaneously preparing the healthcare system for the increasing demand ahead.

Alzheimer's Disease by the Numbers

Alzheimer's disease is a progressive, neurodegenerative disease that can require years of medical care, increasing hours of support and supervision, as well as assistance with activities of daily life. As symptoms advance, family members are often the ones to shoulder the additional demands and take on additional responsibilities in regard to daily activities including household chores, legal and financial decisions, meal preparation, appointments and medication management, as well as personal activities such as bathing, dressing, toileting and safe movement from one location to another.

Although there are many forms of dementia, Alzheimer's disease remains the most common form. In 2025, there were an estimated 7.4 million Americans age 65 and older living with Alzheimer's disease, representing roughly 11% of the U.S. population in that age bracket (Alzheimer's Association, 2025). It is believed that approximately 200,000 Americans between the ages of 30 and 64 are living with younger-onset dementia (Alzheimer's Association, 2025).

It is one of the most significant challenges facing the healthcare system today. Due to the increasing number of people in the U.S. who are age 65 and older, the number of Americans expected to be diagnosed with Alzheimer's disease is predicted to double by 2050.

There are over 12 million Americans providing care for a loved one with Alzheimer's disease or related dementias providing an estimated 19.6 billion hours of unpaid care equating to an economic value of $446 billion in 2025. Of those older adults living with dementia, 30% of them rely on three or more unpaid caregivers. Caregivers for those living with dementia have higher prevalences of depression and anxiety, with reports showing anywhere from 30% to 40% of caregivers, with 59% of caregivers reporting emotional stress related to caregiving and 38% indicating physical stress.

Of the 12.7 million dementia caregivers, 74% of them reported they were either "somewhat or very concerned" about maintaining their own health (Alzheimer's Association, 2025). These caregivers, when compared to same-aged peers who are not providing care for a loved one, also experience greater cognitive decline over time, accounting for nearly two-thirds of the association between cognitive decline and increasing depressive symptom (Alzheimer's Association, 2025). Looking at a more specific subset of caregivers, 18% of millennial caregivers between the ages of 18-34 years old reported worsening health while caring for a loved one with dementia, furthering the correlation between the strains of caregiving and personal health (UsAgainstAlzheimer's, n.d.).

Approximately two-thirds of dementia caregivers are women, and 23% of caregivers are between the ages of 18 and 49 (Alzheimer's Association, 2025) creating a "sandwich" generation of caregivers providing care for both young families and elders. Six out of every 10 caregivers for those living with Alzheimer's disease or another form of dementia work, but they experience significant impacts on their work-life. Approximately 18% of caregivers reduced their hours and another 31% percent either took a leave of absence, left the workforce entirely, or retired early to manage their caregiving responsibilities (Alzheimer's Association, 2025).

When looking at millennial caregivers between the ages of 18 and 34, the Caregiving in the U.S. 2015 study found that roughly 42% of millennial dementia caregivers are the sole caregiver for their loved one. They experience significant impact on their work, with roughly 50% stating that providing care interfered in some way, while 33%

reported severe interference resulting in a loss of hours, benefits, or their position (UsAgainstAlzheimer's, n.d.). Of millennial caregivers, the vast majority do not live in the same household of their loved one, and 16% had to travel more than one hour to reach their loved one to provide care or assist with an activity of daily living.

The economic impact across industries as well as among the family can be substantial. Flexible schedules and work arrangements could be very beneficial but might require significant work policy changes and it could lead to significant financial impacts on employers. For families, the economic and financial impact can be severe. It's estimated that dementia caregivers bear nearly twice the out-of-pocket costs of their peers providing care for someone without dementia (Alzheimer's Association, 2025).

The impact on rural caregivers isn't as widely known, but studies have shown that rates of loneliness and social isolation in rural settings are higher for family caregivers. More remote or rural areas generally see a lack in social and community services as well as access to specialists, leading to a population more vulnerable to anxiety (Griffith et al., 2022).

Millennial caregivers reported higher levels of emotional distress (79%) (UsAgainstAlzheimer's, n.d.) than the whole dementia caregiving population (59%) (Alzheimer's Association, 2025). Caregivers often report the need for additional support in managing the emotional and physical distress as well as accessing resources and outside care. Although there have been advances in recognizing that need, more work is needed around policies, making services more accessible, as well as more thorough research to better understand the impact and ways to improve long-term outcomes.

Changes in Diagnostics and Treatments

Until recently, much of Alzheimer's disease or dementia care focused primarily on managing symptoms. Advances in research are now beginning to change that approach.

Disease-modifying therapies Leqembi (FDA approved in 2023) and Kisunla (FDA Approved in 2024) represent significant advances in research, showing promise in slowing Alzheimer's disease progression. To qualify for these treatments, patients must be in early stages of the disease with only mild cognitive impairment or mild dementia. These huge wins in the field now place significant strain on both healthcare systems and families as the need for early detection and diagnosis increases.

These intravenous medications are administered at infusion centers under supervision either every two or four weeks with advanced imaging (like MRIs) needed frequently in the first 6 to 7 months of treatment. Hospital settings must be able to meet the demand and must have staff available to coordinate care and manage the increase in necessary appointments.

These treatments also represent a significant burden of care on caregivers who are already facing significant challenges as outlined before. The increase in appointments for treatment and imaging could prove to be difficult to manage, and the impact on rural or remote families could make it even more difficult if not impossible to participate in these new treatment options due to travel barriers.

These new therapies require a significant financial investment. List prices are reported to be over $25,000 per year, with insurance coverage varying. This does not include additional travel costs, hospitalizations for unforeseen side effects, or additional medications to manage any other symptoms of the disease.

In August 2026, the FDA approved a new subcutaneous injection of Leqembi that can be administered via self-injection at home with an autoinjector device (Medical Daily, 2026). This new form of delivery lowers the cost burden by approximately 60% (Biology Insights, 2026) and also addresses some of the highest barriers of participation like travel and geographical location. Although more frequent imaging is still needed to monitor risks, this is a significant advancement in addressing equitable access. This home injection option is still too new to know how it might affect those in rural or underserved communities.

Additional disease-modifying treatments for Alzheimer's disease and related dementias are moving through the research pipeline and may be approved by the FDA in the years ahead. These advances will further escalate the need for early detection and diagnosis, as anti-amyloid therapies and other disease-modifying therapies work to slow disease progression, not reverse damage, making early intervention crucial for effectiveness. Advances in diagnostic tools like the use of blood-based biomarkers for Alzheimer's disease have made earlier detection possible. This new method of testing is minimally invasive and much more cost-effective. However, a single standard for how to use and interpret the results does not yet exist (ScienceDirect, 2026). These tests are still primarily being administered in specialty clinics which again leads to an accessibility issue.

Patients in more rural parts of the United States face significant challenges. Some challenges, like navigating very complex care systems, are experienced by both urban and rural families. However, transportation remains a large constraint among rural settings. With most special services existing in urban areas, those living with dementia in rural settings must rely on caregivers to drive longer distances. Likewise, home care visits are often shortened or more spaced, leading to more negative consequences for those living with dementia. The lack of access leads to significant challenges not just in early intervention and treatment, but also on caregivers and loved ones during the progression of the disease (AgeUcate, 2026).

In order to access treatments and begin effective interventions earlier, the need for early education and awareness is significant. Research studies have shown that amyloid changes in the brain can begin 20 years before the onset of cognitive symptoms (Science Insights, n.d.). Although subtle changes in cognitive functioning might be present, the person functions relatively normally. With the ability to administer blood-biomarker testing and detect protein build-up in the brain prior to recognizable changes in cognitive functioning, trends in research are shifting to test the use of treatments before symptoms appear. However, it may take years to determine the effectiveness of this approach. If an amyloid-targeting treatment is approved by the FDA for use in pre-symptomatic individuals, the demand for care at memory clinics, most of which are already strained past their capacity, is likely to increase dramatically.

Even though it is not uncommon for amyloid to be present in the brain later in life and that presence doesn't guarantee a person will develop dementia, it's imperative that people know the warning signs and modifiable risk factors that can improve and/or preserve their cognitive functioning and even reduce their risk of developing some forms of dementia.

AARP lists 15 warning signs of dementia (AARP, n.d.):

1. Short-term memory loss
2. Word loss
3. Difficulty multi-tasking
4. Repetition
5. Personality changes
6. New sleep behaviors
7. Worsening sense of direction
8. Depression
9. Confusion about time and place
10. Difficult with visual or perceptual tasks
11. Financial missteps like inability to calculate a tip or understand a bank statement
12. Changes in judgement
13. Misplacing things
14. Misusing items
15. Hallucinations

People should not get overwhelmed or worried about every small change in cognitive behavior, but if they notice changes, they should consult their doctor. These changes could be a result of something else that is treatable like a

change in sleep habits, a medication side effect, or something else. If they are a result of dementia, early diagnosis is beneficial to determine eligibility for treatments.

The Lancet reports that nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors (Livingston et al., 2024). Eliminating the following risks throughout a person's lifetime could reduce new cases of dementia by approximately 45%:

- Less education early in life
- Untreated hearing loss
- High LDL (low-density lipoprotein) cholesterol
- Depression
- Traumatic brain injury
- Physical inactivity
- Diabetes
- Smoking
- Hypertension
- Obesity
- Excessive alcohol consumption
- Social isolation
- Air pollution
- Visual Loss

Outreach to populations with these risk factors as well as a greater awareness about the disease to all populations could significantly improve outcomes later in life. This education includes education for primary care physicians. In a 2020 report, nearly 39% of primary care physicians said they are "never" or "sometimes comfortable" making an Alzheimer's or dementia diagnosis, and 22% have no residency training in dementia diagnosis or care (Alzheimer's Association, 2020).

Ongoing efforts must be made to educate both the general public as well as primary care providers who serve on the frontlines for those at risk or are showing signs of dementia, especially providers within rural settings. Primary care providers are uniquely positioned to advocate for lifestyle changes and interventions early on while also connecting them to resources in their area. Better educating on the connectivity between lifestyle interventions and the impact on long-term brain health could prove beneficial. Likewise, understanding signs of mild-cognitive impairment early is crucial, as well as understanding other possible explanations for the impairment (i.e. change in medication or other health issue) could help with the diagnostic timeline. Better access to imaging and providers to interpret that data, as well as clearly defined protocols for using blood-based biomarkers in the primary care setting could lead to better outcomes not just in rural settings, but across the United States.

The Need for Specialists

In the 2020 special report by the Alzheimer's Association, more than half of primary care physicians said there are not enough dementia specialists in their area to meet patient demand. In rural areas, that number jumped to 71% (Alzheimer's Association, 2020).

The workforce needed to care for Alzheimer's disease and related dementias is made up of many fields with a large burden on behavioral neurologists, neuropsychologists, primary care physicians, advanced practice clinicians like nurse practitioners and physician assistants, as well as geriatricians.

Behavioral neurologists are specialized physicians that evaluate cognitive and behavioral changes. Neuropsychologists focus on how brain issues impact behavior and cognitive functions. Often, these two specialties work in tandem to diagnose Alzheimer's disease or other forms of dementia. Geriatricians are family physicians that are specially trained to manage adults aged 65 and older.

The American Academy of Neurology reported in 2024 that there are 452 neurologists in the United States with a subspeciality of behavioral neurology and neuropsychology with a median age of 54. The American Academy of Neurology also identified 813 general neurologists with an area of interest in behavioral neurology and neuropsychology. (American Academy of Neurology, n.d.). If each of the 7.4 million Americans living with Alzheimer's disease had access to a behavioral neurologist or general neurologists who worked within this area of interest, that would equate to a patient load of almost 6,000 patients per physician. That is almost the annual patient volume for just one specialty clinic. Additionally, in 2021, there was a reported 7,400 geriatricians but to meet the healthcare needs of the aging population, just shy of 24,000 are needed (Alzheimer's Association, 2025).

This shortage in providers has practical consequences. The process for diagnosing and then treating is often fragmented, with providers working in silos. With greater demand on specialty providers and clinics, even if timely referrals are made by physicians, wait times for an appointment at specialty clinics can often exceed nine to 12 months. For those in rural areas, access is even more pronounced due to an even greater shortage of providers.

A comprehensive national registry for Alzheimer's and dementia clinics does not currently exist, but the United States does have approximately 35 Alzheimer's Disease Research Centers (ADRC) funded by the National Institute on Aging (NIA). Often, these centers are based at major medical and academic institutions, and have a primary focus on research, dedicated to finding and testing new ways to detect, diagnose, treat and prevent Alzheimer's disease and related dementias (Alzheimer's.gov, n.d.). These centers contribute significantly to research; however, they represent a small portion of the nation's dementia-care infrastructure.

Increasing the dementia workforce is crucial but is proving to be challenging. In 2025, over half of the 382 geriatric medicine fellowships in the country went unfilled. For fellowships in behavioral neurology and neuropsychology, just 14 institutions are registered in the American Academy of Neurology as having a clinical fellowship program focusing on direct clinical care (American Academy of Neurology, n.d.). Many other behavior neurology and neuropsychology fellowships exist, often with an emphasis on research, and although that is

necessary to continue advancements for detection, diagnosis and effective treatment of the disease, there continues to be a gap in producing specialists to meet the growing demand for clinical care.

Greater recruitment to more rural areas is essential to address the well documented issue of “neurology deserts” or “dementia diagnostic deserts.” Americans that live in rural areas face a significantly higher burden of health risks associated with dementia. Compared with urban populations, they are 11% more likely to have hypertension, 22% more likely to be obese, and 29% more likely to have diabetes, all of which are known risk factors for Alzheimer’s disease and related dementias. In addition, nearly 60% of rural adults aged 65 and older live in communities with limited access to neurologists and memory care specialists, often resulting in delayed diagnoses and reduced access to treatment and support services (Information Technology and Innovation Foundation [ITIF], 2026).

Conclusion and Future Needs

Alzheimer's disease and other forms of dementia represent one of the most defining healthcare challenges of our time. Advances in diagnostics, biomarker testing, and disease-modifying therapies have created unprecedented opportunities to identify the disease earlier and slow progression for some patients, but too many individuals and families continue to face delays during the diagnostic process, lengthy wait times, geographic barriers, and significant financial and emotional burdens.

The growing prevalence of dementia demands a coordinated response that extends beyond research alone. Investments must be made to strengthen the dementia-care workforce, including expanding training opportunities for behavioral neurologists, neuropsychologists, geriatricians, advanced practice clinicians, and primary care physicians. Workforce development efforts need to address reaching rural and underserved communities where shortages are most severe.

Future progress will also depend on improving early detection and intervention. There is a need for public education aimed at increasing awareness of dementia warning signs and modifiable risk factors, as well as a need to provide physicians with the necessary tools and training to recognize cognitive changes sooner. As blood-based biomarkers and other emerging diagnostic tools become more widely available, clear clinical guidelines will be essential to ensure consistent and equitable adoption across settings.

At the same time, greater attention must be given to the needs of family caregivers who provide the majority of dementia care in the United States. Policies that expand access to respite services, caregiver education, mental health support, workplace flexibility, and financial assistance will be increasingly important as the number of individuals living with dementia grows. Without meaningful support, the physical, emotional, and economic impact felt by caregivers will continue to rise alongside disease prevalence.

Rural communities deserve particular attention in future planning efforts. Geographic isolation, transportation barriers, provider shortages, and limited access to specialty services threaten to widen disparities as new treatments become available. Future investments should prioritize expanding access to diagnostic testing, treatment facilities, monitoring services, clinical trials, and caregiver resources in these communities. A concerted effort to include rural populations in research efforts must be made so that innovations are developed and implemented with their unique needs in mind.

Ultimately, the future of dementia care will be determined not only by the discovery of new treatments, but by the ability to deliver those treatments effectively and equitably. Bridging the gap between innovation and implementation will require sustained collaboration among healthcare systems, policymakers, researchers, community organizations, employers, and caregivers.

The Pat Summitt Foundation

For nearly 15 years, the Pat Summitt Foundation has worked to advance research, support patients and caregivers, and educate the public about Alzheimer's disease and other forms of dementia.

The Foundation has invested over $3 million in the University of Tennessee Medical Center, helping establish the Pat Summitt Clinic in 2017. The multidisciplinary clinic provides diagnosis and treatment for Alzheimer's disease and other neurodegenerative diseases. Since opening its doors, the Clinic has cared for over 33,000 patients from 29 states, demonstrating its reach and need for specialized dementia care. With ongoing support pledged, the Foundation is committed not only to patients and families treated at the Clinic, but also to furthering outreach and impactful research as well.

PSF's impact also extends beyond clinic care. Since our founding, supporting families and caregivers have remained a central part of our focus. In 2024, the Foundation launched Pat's Gameplan, a guide for caregivers. This free tool provides crucial resources and information to help families navigate topics like legal and financial planning, safety, nutrition, and more. The Foundation committed over $1 million to getting these resources into the hands of families, and at the time of this publication, the website has been visited over 1 million times in less than two years with heavier use in the Southeastern United States as well as the Western Coast.

Additionally, since 2019, the Foundation has invested another $2 million in a number of organizations providing support to patients and caregivers throughout the Southeast with an estimated reach of over 85,000 individuals.

As the Foundation celebrates its 15th anniversary and makes plans for its future, we remain committed to advancing the fight against Alzheimer's disease.

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