Alliance for Patient Access

NOVEMBER 2026

The Evolving Outlook of Alzheimer's Disease Care

A white paper from the Alzheimer's Initiative of the Neurological Disease Working Group





Introduction

As the U.S. median age continues to rise, Alzheimer's disease is quickly becoming one of the nation's fastest-growing public health challenges. More than 7 million Americans live with Alzheimer's today, a number that is expected to rise sharply in coming years.[1]

For patients and families, Alzheimer's disease can mean changes in personality, loss of independence and the need for around-the-clock care. Caregivers also face emotional, financial and time burdens as a loved one's needs evolve.

The societal impact is significant. One 2026 estimate places the total cost of dementia at $818 billion, including $222 billion in medical and long-term care spending.[2] Yet Alzheimer's remains a leading cause of death without a cure, and clinicians have historically had few options beyond managing symptoms.

Recent advances are changing Alzheimer's care. Blood-based biomarker testing is improving diagnosis and treatment planning, while disease-targeting therapies offer new possibilities for slowing progression in some patients.[3]

Access, however, has not kept pace with innovation. Insurance coverage, reimbursement challenges and utilization management practices can delay timely diagnosis and treatment, while patients and caregivers navigate a fragmented system and clinicians face administrative burdens.

Members of the Alliance for Patient Access' Alzheimer's Initiative emphasize that policy must keep pace with scientific progress.[4] Innovation can only improve care if patients can access it.



The Importance of Earlier Detection

Earlier diagnosis can make a meaningful difference for patients and families living with Alzheimer's disease. In the past, many people delayed seeking help until symptoms became severe enough to disrupt everyday life. Families frequently describe noticing subtle memory changes, confusion or shifts in behavior long before they receive a clear diagnosis. Today, advances in diagnostic technology are beginning to change that reality.[5]

Identifying potential disease earlier gives patients and caregivers time to plan, access support services and make informed decisions about treatment and care. It may also allow patients to access disease-targeting therapies earlier in the disease course, when interventions may be most effective. Perhaps most importantly, earlier diagnosis can help families better understand what they are experiencing in real-time.

Earlier identification can also give patients and families an opportunity to discuss risk reduction and make informed choices about care and lifestyle. The Alzheimer's Association's U.S. POINTER study found that structured and self-guided multidomain lifestyle interventions were associated with improvements in cognition among adults at risk of cognitive decline.[6]

The Promise of Blood-Based Biomarkers

Among the most promising developments in Alzheimer's care are blood-based biomarker tests. Biomarker testing has long been used in fields such as oncology and is now becoming an important tool in neurological care. As emphasized by the American Academy of Neurology, these tests may help clinicians detect biological signs associated with the disease without relying exclusively on more invasive or difficult-to-access tools.

Traditionally, identifying Alzheimer's disease pathology has required PET scans, spinal taps or specialty evaluations, all of which can be expensive, require travel or involve long wait times. Blood-based testing has the potential to lower the barrier to evaluation for patients, particularly those who live far from specialty centers or face long waits for neurology appointments.

Blood-based biomarkers may help primary care clinicians identify biological changes associated with Alzheimer's, determine which symptomatic patients need further evaluation and referral and, in some cases, inform treatment plans. They are not a stand-alone answer, however. Implementation must be thoughtful and paired with clinician education, clear patient communication and data-based guidance.

Current guidance supports the use of blood-based biomarkers in patients with cognitive concerns. These tests are not currently indicated as routine screening for people without symptoms, although their role may evolve as the evidence develops. Clear parameters for appropriate use are important so testing is directed to patients who are most likely to benefit.



> **Blood-based testing** has the potential to lower the barrier to evaluation for patients.

Barriers to Earlier Detection

Although opportunities for earlier diagnosis are improving, patients still face significant barriers. Earlier detection can give patients and families more time to understand the disease, consider treatment options and plan for future care.

Primary care clinicians are often the first to hear concerns about memory, missed medications or behavioral changes. Yet limited appointment time, administrative demands and insufficient training in cognitive assessments and biomarker testing can make early identification difficult. Greater investment in clinician education will be needed as diagnostic tools continue to evolve.[7]

Workforce shortages add to these challenges. Patients may wait months to see neurologists, geriatricians or memory specialists, with access particularly limited in rural and underserved communities.



Diagnostic and insurance barriers can cause further delays. Alzheimer's disease and cognitive decline can be evaluated through cognitive screening, MRI, PET scans, blood-based biomarkers, cerebrospinal fluid testing and, when appropriate, genetic testing. While MRI is generally more accessible and affordable than PET imaging, coverage for PET scans can vary and may require prior authorization. Commercial insurance requirements can also delay diagnostic testing and treatment while adding administrative burden for clinicians.

Stigma presents another barrier. Memory loss may be dismissed as a normal part of aging, delaying conversations about cognitive changes and adding stress for patients and families already navigating a complex health care system. Continued public education and outreach are therefore essential to encouraging earlier recognition and diagnosis.

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Expanding Access to New Treatments

Recent advances in disease-targeting therapies represent an important turning point in Alzheimer's care. New therapies that target disease processes associated with amyloid plaques and tau tangles—hallmark features linked to Alzheimer's disease—have introduced the possibility of addressing underlying biology rather than focusing solely on symptom management.[8]

For patients and families confronting a progressive disease, these therapies offer something that has often been in short supply: hope. Yet patients can benefit from innovation only if they can access it.

Clinicians participating in AfPA's Alzheimer's Initiative described a system where insurance-related barriers frequently delay or complicate access to care. Coverage requirements, prior authorization, workforce shortages and administrative burden can make accessing treatment frustrating for both patients and clinicians.



Coverage Barriers and Utilization Management

Insurance coverage for Alzheimer's care remains inconsistent. Patients may face barriers before treatment begins, including varying coverage and prior authorization requirements for PET imaging that can delay diagnosis.

Additional barriers can arise once treatment is prescribed. Patients earlier in disease progression may be better candidates for disease-targeting therapies but can still face utilization management requirements. Prior authorization and step therapy, which requires patients to try a health plan's preferred medication before receiving the prescribed treatment, can delay access. Commercial insurers may also lack the infrastructure needed to support evolving approaches to Alzheimer's diagnosis and treatment.

These requirements also burden clinicians, who may spend significant time completing paperwork, appealing denials and documenting medical necessity instead of caring for patients.

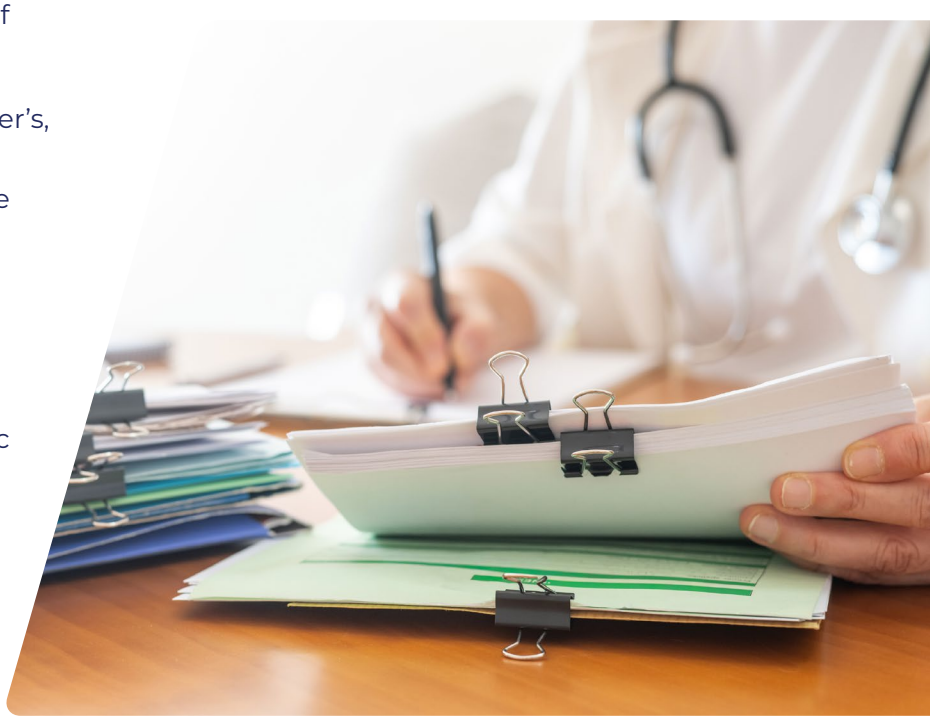
For a progressive disease such as Alzheimer's, delays in testing, specialist evaluation or prescribed treatment can affect care while adding uncertainty and stress for families. Patients should have timely access to FDA-approved therapies prescribed by their clinicians. As innovation continues, policymakers and payers must ensure coverage policies keep pace with scientific progress rather than create unnecessary barriers to care.



The Challenge of Specialist Access

Specialist shortages can limit access to Alzheimer's care even when insurance coverage exists. Nearly 60% of older Americans live in areas with too few dementia specialists to meet demand, with patients in rural and underserved communities facing the greatest burden through long waitlists, extensive travel and limited access to specialty care; their caregivers often shoulder additional financial and logistical costs.[9] As demand for newer treatments grows, improving access will require stronger clinical infrastructure and greater support for the health care workforce.

> **Clinicians may spend significant time completing paperwork,** rather than caring for patients.





Coordination of Care

Alzheimer's care is changing quickly. New biomarker testing, disease-targeting therapies and evolving diagnostic guidance require clinicians to navigate an increasingly complex landscape. Many primary care practices face time constraints and limited resources, making comprehensive cognitive evaluations difficult.

With the projected increase of the aging population and people living with Alzheimer's, there should be more attention given to equip front line clinicians. Primary care clinicians are often the first professionals to recognize signs of Alzheimer's disease.

A patient may mention memory concerns during a routine visit. A spouse may notice missed appointments, confusion or changes in behavior. Sometimes subtle warning signs emerge during conversations about medications or chronic disease management.

> **Primary care clinicians** are uniquely positioned to identify early cognitive changes.

Because primary care clinicians already have long-standing relationships with patients, they are uniquely positioned to identify early cognitive changes and initiate referrals.

Yet many clinicians feel underprepared for this role, emphasizing the need to invest in clinician education and training, including greater exposure to geriatric care. Primary care visits are often too short to fully address the complexities of dementia evaluation, educate patients and caregivers, and determine the appropriate next steps. Current reimbursement challenges may fail to incentivize primary care clinicians to prioritize cognitive evaluations. Without additional support, primary care practices may struggle to keep pace with advances in cognitive decline care. At the same time, relying on specialists alone is not sustainable.

It is critical to coordinate care and connect patients to clinicians who are well-versed in treatment of early Alzheimer's disease. Health systems should support structured, validated evaluation when a patient or caregiver reports cognitive concerns and consistently implement cognitive assessment requirements already included in annual wellness visits. Additional research can also help clarify when broader screening is appropriate. There should be increased support for standardized risk assessments for adults over 65 or those with risk factors, such as family history or related diseases.

Fostering stronger collaboration between primary care and specialists should be a priority, yet there is often a delay when patients are referred to specialists. Health systems should alleviate the bottleneck and make it easier for patients with mild cognitive impairment to see specialists and seamlessly transition from primary care. That also means instituting reimbursement policies that recognize the time required to evaluate cognitive concerns, educate families and coordinate care. Clinicians should not have to choose between providing thoughtful Alzheimer's care and maintaining an efficient practice workflow. Investing in primary care capacity can help ensure that innovation reaches patients earlier and more equitably.

Additionally, the Center for Medicare and Medicaid Services created the GUIDE Model to support people with dementia and their caregivers. GUIDE provides coordinated wraparound care for people with dementia and alleviates burden from care partners through resources, education and training, and respite services.



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Conclusion

Supporting Patients and Caregivers

An Alzheimer's diagnosis affects more than just the patient. Family members and caregivers often take on new responsibilities, including medication management, transportation, financial planning and day-to-day supervision. Many experience emotional strain as they watch a loved one change over time.

Clinicians participating in AfPA's Alzheimer's Initiative stressed that caregivers need greater support throughout the care process. Many families struggle to navigate complicated systems, identify community resources or understand treatment options. Patients and caregivers benefit from coordinated, team-based care models that reduce fragmentation and improve communication across providers.

Better care coordination can help families access support services, understand treatment decisions and navigate transitions in care more effectively. As Alzheimer's care evolves, supporting caregivers must remain part of the conversation.

Looking Forward

Alzheimer's disease care is changing rapidly. Advances in biomarker testing, imaging and disease-targeting therapies are reshaping what may be possible for patients and families. Clinicians are increasingly able to identify Alzheimer's disease earlier and intervene in ways that were not possible even a few years ago. This progress should be celebrated. But innovation alone cannot improve outcomes if patients face barriers to accessing care.

Patients need timely diagnosis, access to treatment and stronger support throughout the care journey. Policymakers have an important role to play in ensuring that scientific advances translate into real-world patient benefit. Support for bills like the ASAP Act, which would modernize Medicare coverage authority for blood-based Alzheimer's detection tools is crucial. Creating that authority does not mandate coverage of a specific test and allows coverage parameters to reflect the evidence as it continues to develop.

Efforts to improve Alzheimer's care should include:



Expanding access to earlier diagnosis, including the use of blood-based biomarkers with demonstrated performance and timely referral.



Reducing coverage barriers that delay access to disease-targeting therapies prescribed by clinicians.



Supporting the health care workforce, particularly primary care clinicians who serve as the front line for identifying cognitive concerns.



Improving reimbursement and care coordination so clinicians have adequate time to evaluate cognitive concerns, educate patients, support caregivers and navigate complex needs.



Strengthening support for caregivers, whose well-being is deeply connected to patient outcomes.

As the burden of Alzheimer's disease continues to grow, patients and families cannot continue to afford unnecessary delays in accessing care. In the near term, biomarker testing should become more available to support earlier testing and diagnosis, with clear parameters for appropriate use. Over time, these tools will also need to be thoughtfully integrated into the larger health care system, alongside stronger clinician education and access to specialty consultation. Scientific progress has created new opportunities to improve lives. Policy must now keep pace so that patients can benefit from the promise of innovation.

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