



OVERBURDENED BY ALZHEIMER'S:

THE NEED FOR CARE, INNOVATION AND ACCESS

TOPICS

Alzheimer's
and the Brain

Alzheimer's
and Aging

A Public
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Solutions

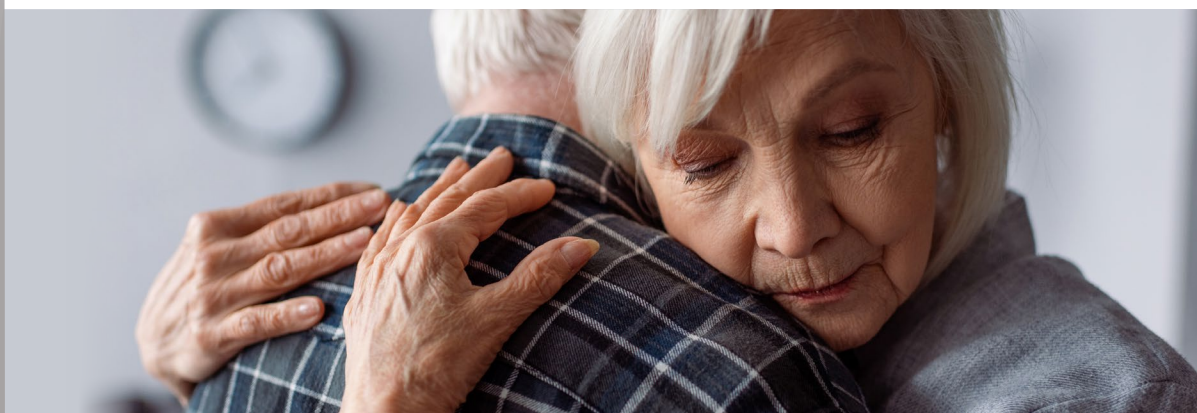
Affecting 6 million Americans, Alzheimer's disease permanently alters families and communities across the United States.

For patients and their loved ones, the most frightening aspect of an Alzheimer's diagnosis may not be the eventual fatal outcome. It's the mental and physical deterioration that is, in many cases, prolonged over the course of years. That process is emotionally and financially draining for patients and the families who often provide day-to-day care for them.

It also comes at a cost to society. Today, Alzheimer's disease costs Americans nearly \$300 billion a year, and annual costs are only expected to rise. To curb seen and unseen costs — for patients, families and society at-large — effective treatments and innovations in care are critical.

Intensive research continues on new options for preventing Alzheimer's, diagnosing it earlier, treating symptoms and delaying disease progression. In the meantime, the most effective strategy for lightening the burden of Alzheimer's to patients and their families is making diagnosis, treatment of symptoms and caregiving more accessible and affordable.

Given Alzheimer's growing impact on society, the time is now for bold public policy and treatment breakthroughs.





ALZHEIMER'S AND THE BRAIN

The human brain is an incredibly complex neural network. Intricate connections between cells form the infrastructure that make memory, thoughts and feelings possible.¹ But when Alzheimer's develops, it destroys brain cells — shrinking and toxifying the brain as neurons die off and plaque, called amyloid, builds up.

Early indications of Alzheimer's typically include symptoms like chronic forgetfulness. But over time disease progression impairs communications abilities, drives dramatic personality and behavior changes, and causes delusions and paranoia. Unfortunately, Alzheimer's is relentlessly progressive in every person affected.

The exact cause of Alzheimer's has not been discovered yet, but many scientists widely believe it is caused by a combination of genetics and environmental and lifestyle factors.²



ALZHEIMER'S AND AGING

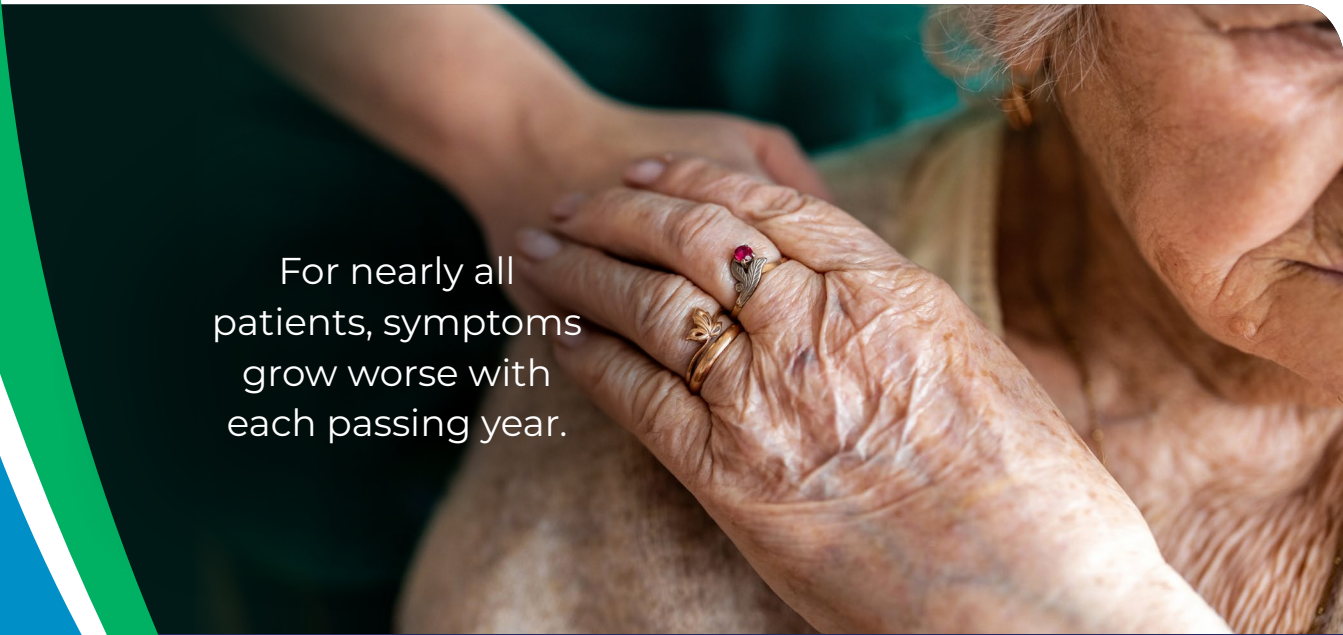
Alzheimer's is not an inevitable result of aging. Age, however, is a primary risk factor for Alzheimer's, as reflected in these findings from the CDC:³

- **One in 10** Americans age 65 or older has Alzheimer's.
- **One in three** Americans age 85 or older suffers from Alzheimer's.

As seniors make up a growing percentage of the American population, the prevalence of Alzheimer's cases is projected to continue.⁴

**Older people are not
the only ones impacted
by Alzheimer's disease.**

Approximately 200,000 Americans under age 65 are living with what's known as early-onset Alzheimer's.⁵



For nearly all
patients, symptoms
grow worse with
each passing year.



A PUBLIC HEALTH CRISIS

The Centers for Disease Control and Prevention has labeled Alzheimer's a public health crisis. Meanwhile, the Department of Health and Human Services has established a National Plan to Address Alzheimer's Disease, a recognition of the urgent need to meet the needs of the Alzheimer's and dementia community. The imperative is clear:

Alzheimer's is a growing health problem, particularly among traditionally underserved populations.

- Alzheimer's is projected to affect **12.7 million Americans** by 2050.⁷
- **Women** account for a disproportionate two-thirds of people with Alzheimer's.
- **Black Americans** are two times more likely to suffer from dementia than white Americans, and **Hispanics** are one-and-a-half times more likely.

- Alzheimer's is the **fifth leading cause of death** for Americans 65 and older and the sixth leading cause of death overall.
- Deaths from Alzheimer's **surged by 145%** between 2000 and 2019.

THE COVID CONNECTION

There is a concerning although not entirely understood correlation between Alzheimer's diagnoses and COVID-19, according to a nationwide study by Case Western University.

People with dementia, the study found, had a significantly higher risk of contracting COVID-19.

It also found that older people who were infected with COVID-19 were 50-80% more likely to be diagnosed with Alzheimer's within a year.⁶



FINANCIAL IMPACT

Alzheimer's is America's most expensive disease, even more so than cancer or heart disease.

The estimated national cost of caring for people living with Alzheimer's and other dementias in 2022 was \$321 billion, not including unpaid care given by family and friends, which is valued at \$271.6 billion.⁸

As cases continue to rise, the national cost of Alzheimer's disease is expected to exceed \$1.5 trillion by 2050.⁹



HUMAN IMPACT

Alzheimer's has a profound impact on many people beyond those with a clinical diagnosis. More than 11 million others — spouses, adult children, lifelong friends, neighbors — serve as primary and often full-time caregivers.

Caregivers are most commonly women and are often not compensated for their service. Many sacrifice personal time and potential income. And beyond the logistics, they shoulder the emotional burden of caring for a loved one who slowly loses the ability to even recognize them.

Caregivers make a personal sacrifice to care for their loved ones and often lack emotional and financial support.



Caregivers make a personal sacrifice to care for their loved ones.



Areas of Need and Policy Solutions



DIAGNOSIS

Alzheimer's disease can attack a brain for years before even mild symptoms appear. That reinforces the need for early diagnosis.

There is, however, hope for earlier and more accurate diagnoses and disease assessment. Clinical trials suggest that positive emission topography, or PET, scans enable doctors to discover diseases, including Alzheimer's, before they have progressed too far.

The arrival of blood biomarker tests may further strengthen diagnosis capabilities.

Access to PET scans historically has been tightly limited by the Centers for Medicare and Medicaid Services. The current policy covers only one PET scan during the life of a patient. Beyond its implications for diagnosis, this policy could also undermine research into disease-modifying treatments that require PET scans. The agency is currently revisiting its policy.

The arrival of blood biomarker tests may further strengthen diagnosis capabilities. Policies should be put in place now to allow for timely access to these tests once they become available.



TREATMENT

Much of current treatment research is focused on disease modification, especially on drugs that target amyloid. This innovation is badly needed, as Alzheimer's patients have historically had few treatment options and no cure. An emphasis on treatments that improve quality of life is also important.

Innovation, and access to the treatment advances that innovation produces, are paramount for patients and their families.

One innovative development is a class of treatments designed to target the buildup of amyloid plaques in the brain. The first in its class, aducanumab, was approved in 2021 through the FDA's accelerated approval pathway, which is designed to give patients faster access to urgently needed innovative drugs. Despite FDA's approval, the Centers for

Medicare & Medicaid Services decided not to provide full coverage for the medication or future medications in the class. Instead, it restricted coverage to only patients who are enrolled in a clinical trial.

CMS's decision is already impacting the accessibility of a newly-approved Alzheimer's drug, lecanemab, as the decision restricted access for future amyloid-targeting therapies in the same class. As a result, many Alzheimer's patients are left without access to either innovative, disease-modifying treatment.

Other treatments that target amyloid are forthcoming, with even more that target an abnormal form of tau, another protein found in brain cells. It is crucial that policymakers focus efforts on ensuring that patients can access Alzheimer's innovation as it is approved.



Intensive research
is underway to find
disease-modifying
treatments.



TREATMENT OF BEHAVIOR SYMPTOMS

Behavioral challenges are another area of treatment that needs innovative solutions and support from policymakers.

Patients commonly deal with agitation as the disease progresses. In middle- and late-stage Alzheimer's, patients can develop psychosis-driven behavior issues, exhibiting emotional and physical aggression. Others may experience wandering, becoming lost, or endangering themselves and their caregivers.¹⁰

Anti-psychotic drugs are often prescribed but should be used sparingly because they can create other health risks.

Innovative medications for Alzheimer's-related psychosis and agitation are currently in development. To maximize patients' and health care providers' ability to meet Alzheimer's disease head on, policymakers must swiftly review new treatment options and make them widely available.

Additional funding and research are needed for treatments, but so are policies that allow patients to access medications once they're available and approved by the FDA.



Supporting and expanding the community of caregivers is an urgent priority.



UNPAID CAREGIVING

The battle against Alzheimer's couldn't be waged without the 11 million people who provide daily care for Americans living with Alzheimer's.

Supporting and expanding this essential community of care partners is an urgent priority. It requires addressing the growing emotional, physical and financial challenges that caregivers face. Consider that:

- The prevalence of depression among dementia caregivers is **30-40% higher** than among other caregivers.
- **Almost half** of these caregivers do it alone.
- People caring for a family member with dementia report paying for **64% of the patient's health care costs** during the patient's last seven years of life.

A few policies currently exist that begin to address this complicated problem:

- **The Medicaid Self-Directed Care program** allows patients to hire family members as care partners in certain states.
- **The Veteran-Directed Home and Community Based Services program** offers veterans a budget to hire a family member or neighbor as a care partner.
- **Aid and Attendance benefits** for veterans work in conjunction with VA pensions and may allow for payments to a care partner.
- **Certain long-term care insurance policies** may pay family members as care partners.

While these programs help, more can be done. For example, long-term care insurance providers could revisit their policy of not paying family caregivers who live with a patient.



LONG-TERM CARE

The Department of Veterans Affairs, some state Medicaid programs and certain long-term care policies will sometimes pay family members for providing home health care. But these programs aren't a complete solution: Even the most dedicated caregivers sometimes get burnout, which necessitates that some Alzheimer's patients enroll in long-term care facilities.

Many Alzheimer's patients can't afford the out-of-pocket costs of residential long-term care or the high premiums that come with long-term care insurance.¹¹ Medicaid does offer some long-term care coverage for low-income people, though only after the patient's personal finances have been essentially exhausted. Medicare provides no coverage at all.

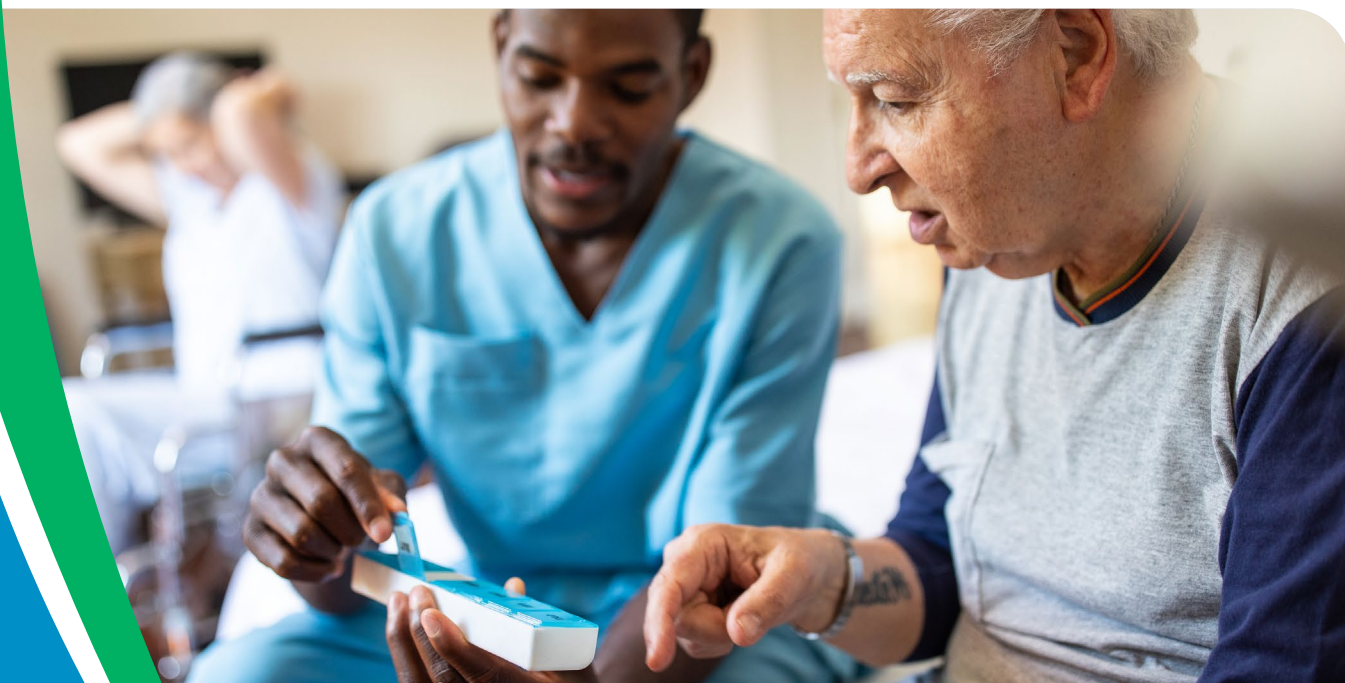
In addition to the financial burden, for many patients and their families,

entering a long-term care facility is an emotionally wrenching experience. Long-term care is not always pleasant for patients either. Gradual dose reduction requirements for some classes of medications may increase patients' behavioral or neuropsychiatric symptoms, heighten families' distress and place additional strains on facility staff.

Several bills now pending in Congress would address different aspects of the long-term care dilemma:

- **Long-Term Care Affordability Act**
- **PROTECT Long-Term Care Facilities Act**
- **Long-Term Care Hospital Access and Stability Act**

Timely policy action is important.





Conclusion

Hope for a cure for Alzheimer's disease certainly exists. But the nation can't afford to simply wait for a cure — not with Alzheimer's cases in the United States projected to double by 2050.

As research and medical innovations continue, more can and should be done to help patients, clinicians and families nationwide. Improving diagnosis and disease assessment, expanding access to treatments and addressing long-term care challenges are good places to start. Policy solutions are essential, as most Americans, one way or another, come to confront the reality and impact of Alzheimer's.

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