

Alzheimer's and Other Dementias

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One in three older Americans dies with dementia, which is an umbrella term for a decline in mental ability severe enough to interfere with activities of daily living. Alzheimer's disease is the most common cause, accounting for 60–80% of cases of dementia. Other kinds of dementia include (but are not limited to) dementia with Lewy bodies, frontotemporal dementia, and vascular dementia. Many people have mixed dementia, in which brain changes associated with more than one cause of dementia occur simultaneously.

Understanding Alzheimer's Disease

Dementia is not a normal part of aging, although the biggest risk factor is increasing age. Damage to brain cells impairs their ability to communicate with one another, which is the cause of dementia. This can affect thinking, memory, feelings, and behavior.

Mild cognitive impairment (MCI), which typically precedes dementia, is characterized by cognitive changes that are significant enough for the affected person, their family members, and friends to notice but do not impair the person's ability to carry out daily tasks like dressing, eating, and using the restroom independently.

The presence of amyloid protein "plaques" and tau protein "tangles" in the brain distinguishes Alzheimer's from other causes of cognitive impairment. Because these hallmarks are detectable prior to the onset of dementia symptoms, researchers recognize a preclinical phase of the disease. This is akin to recognizing heart disease based on cholesterol buildup in the arteries before the onset of chest pain or heart attacks.

As dementia advances, symptoms get more severe and include disorientation, confusion, and behavior changes. Six in 10 people with dementia will wander and may get lost, even in familiar places. Over time, speaking, walking, and swallowing become difficult. Alzheimer's is progressive and ultimately fatal.



Modifiable Risk Factors

Experts believe there is not a single cause of Alzheimer's disease and that it likely results from multiple factors, such as genetics, lifestyle, and environment. People who have a parent, brother, or sister with Alzheimer's are more likely to develop the disease.

These include eating a healthy diet, staying socially active, avoiding tobacco and excess alcohol, exercising both the body and mind, managing other health conditions effectively, and protecting one's brain from head injury.

The Impact and Cost of Alzheimer's

Alzheimer's is a leading cause of death in the United States. (Alzheimer's disease was officially listed as the sixth-leading cause of death in the United States in 2019 and the seventh-leading cause of death in 2020 and 2021, when COVID-19 entered the ranks of the top 10 causes of death.) While there are some medications that may temporarily improve cognitive or behavioral symptoms, there is no cure and no known way to stop or slow the progression of the disease itself.

Alzheimer's is also the nation's most expensive disease. In 2022, total payments for caring for Americans age 65 and older with dementia are estimated at \$321 billion, not including the value of unpaid caregiving.

Recognizing the great and growing human and societal costs of Alzheimer's and other dementias, the U.S. created its [National Alzheimer's Plan](#) in 2011. The plan's first stated goal is to effectively treat and prevent Alzheimer's by 2025. Toward that end, federal funding for Alzheimer's research has increased more than sevenfold since 2011.

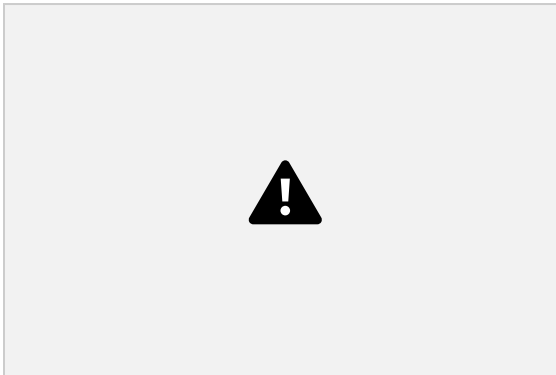
Incidence and Prevalence

An estimated 6.5 million Americans age 65 and older will live with Alzheimer's dementia in 2022. That number does not include untold others who have the brain changes of

Alzheimer's disease but who have not yet developed significant symptoms. In the absence of effective treatment and prevention, the number of Americans living with Alzheimer's dementia is projected to reach 12.7 million by 2050. This projection does not include the tens of millions of Boomers who will likely develop dementia but die before 2050.

Alzheimer's impact is disproportionately distributed. The fact that women live longer on average than men cannot fully explain why almost two-thirds of Americans with Alzheimer's are women.

Disparities



Studies show that blacks and

African-Americans are two times more likely, and Hispanics and Latinos are 1.5 times more likely, to develop Alzheimer's than whites. Although their rate of Alzheimer's and other dementias is high, blacks, Hispanics, and Latinos are also less likely than whites to receive a diagnosis.

When they are diagnosed, blacks and Hispanics are typically diagnosed in the later stages of the disease, when they are more cognitively and physically impaired. As a result, these groups typically use substantially more hospital, physician, and home health services and incur substantially higher costs for those services.

LGBT older people with dementia face a particularly challenging set of circumstances. They are less likely to have family members who can care for them and are more likely to experience social isolation and stigma, making it difficult to find support.

Trending Topics

Quality of life for individuals living with dementia and those who care for them depends greatly on the information and support available in three key domains: home and family, health systems, and long-term care.

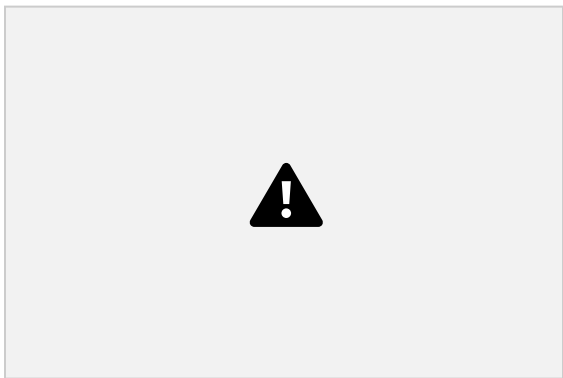
Burden on Family Caregivers

More than 80% of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. Nearly half of families caring for an older adult are caring for someone with dementia.

More than 11 million family and friends provide unpaid care for people with Alzheimer's or other dementias. In 2021, caregivers of people with Alzheimer's or other dementias provided an estimated 16 billion hours of informal, unpaid assistance, a contribution to the nation valued at \$271.6 billion. Women provide the majority of care to individuals living with dementia, and nearly one-third of caregivers are 65 or older.

Caring for someone with dementia can take a great emotional, physical, and financial toll. Family caregivers may not recognize the [early signs and symptoms](#) of dementia or know what to expect as the disease progresses. Many lack the knowledge, skills, and support they need to cope with the demands of caregiving that may stretch over a period of many years.

Nearly 80% of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming, or eating. About one-third of Alzheimer's caregivers deal with incontinence or diapers. Caregivers are often responsible for managing finances and planning for the future.



The heavy burden of caring for someone with Alzheimer's often harms caregivers' health and well-being. Dementia caregivers are twice as likely to report substantial emotional, financial, and physical difficulties as caregivers for people without dementia. Nearly 60% of dementia caregivers rate their emotional stress as high or very high; up to 40% suffer from depression.

Getting a break is difficult. State Medicaid programs cover some respite and other home and community-based services, but age and financial eligibility rules exclude many families. (Medicare covers many medical expenses but does not cover long-term care or respite care costs.) Those who do not qualify for assistance must shoulder these costs themselves or go without respite support. This forces many families to spend down their assets in order to qualify for Medicaid coverage of nursing home care.

Challenges for Health Systems

Early diagnosis and proper management of Alzheimer's and other dementias can [improve health outcomes](#) and [reduce costs](#). However, physicians are much less likely to diagnose dementia and/or disclose a diagnosis of dementia compared to a diagnosis of cancer, heart disease, or other serious disease.

Because few physicians specialize in geriatrics, most people who experience cognitive and functional decline receive care from primary care physicians (PCPs), 69% of whom say they learned little or nothing about the diagnosis and care for Alzheimer's and other dementias in medical school.

A 2019 [survey](#) of PCPs found nearly 90% expect to see more people living with dementia during the next five years, but 50% believe the medical profession is not prepared to meet the demand for care.

In 2017, the Centers for Medicare and Medicaid Services (CMS) began covering care planning services for Medicare beneficiaries living with cognitive impairment. Fewer than 1% of eligible older adults received the benefit in the first year, suggesting that most individuals, families, and providers aren't aware of its existence.

Care planning helps individuals living with Alzheimer's and their caregivers learn about medical and non-medical treatments, clinical trials, and support services available in their communities. It also helps health professionals coordinate and manage co-existing conditions. Nearly 9 out of 10 Medicare beneficiaries with Alzheimer's disease or other dementias have at least one other chronic condition. Additionally, they are more likely than those without dementia to have other chronic conditions.

People who receive dementia-specific care planning have fewer hospitalizations, fewer emergency room visits, and better medication management. Federal [legislation](#) now requires the U.S. Department of Health and Human Services to educate clinicians about these services.

Long-Term Care and Person-Centered Care



More than 2.1 million Americans currently live in long-term care communities and receive assistance with daily living activities such as eating, bathing, toileting, and getting dressed. People with Alzheimer's are more than three times as likely to require home health care and more than nearly four times as likely to need skilled nursing facility care. At age 80, approximately 75% of people living with Alzheimer's reside in nursing homes, while only 4% of the general population do.

Whether people receiving long-term care enjoy a good quality of life depends greatly on whether those caring for them understand their behaviors, special needs, and personal preferences. Over time, people with Alzheimer's will lose the ability to use words and may communicate their needs through behavior, which adds to the challenge.

Care workers often do not have sufficient dementia-specific knowledge and competencies to support those with Alzheimer's and other dementias. Certified nursing assistants and home health aides must receive at least 75 hours of training, but Alzheimer's and dementia care is only one of the 40 topics that must be covered.

Person-centered care has shown beneficial effects on well-being and behavior and helps reduce the use of psychotropic medication for individuals living with dementia.

Evidence-based practices also reduce stress and mitigate burnout and job dissatisfaction among professional care providers, a perennial challenge in the long-term care industry.

Conservative estimates of staff turnover across the long-term care sector range from 45 to at least 66 percent. This decreases the probability that caregivers will get to know residents and their personal preferences.

Philanthropic Support



Foundations and other funders have joined federal and local governments in supporting the research and implementation of many different types of dementia-related services. Here is a sampling of recent funding:

Supporting family caregivers

- [Alzheimer's Association® care consultation](#) is a free-of-charge care navigation service in which families receive a thorough assessment of their needs, discuss available resources and support, and learn about legal and financial plans, end-of-life decisions, and more. The **Stead Family Foundation** [funded](#) a study of the impact of telephone care consultation model.
- The [Innovations in Alzheimer's Caregiving Awards](#), funded by the **Rosalinde and Arthur Gilbert Foundation** and Bader **Philanthropies** and administered by the Family Caregiving Alliance, have provided annual grants since 2008 in three categories: creative expression, diverse and multicultural communities, and public policy. Review the full archive of winners [here](#). These 2021 winners received \$20,000 grants:
 - Elderly: Teaches, models, and promotes culture change among caregivers, family members, and healthcare professionals and provides arts-based activities, guided discussion, and movement with music.
 - ["Art Is... In"](#) is a technology-free, professionally curated art-at-home program that aims to engage and encourage meaningful creative expression for caregivers and individuals of diverse backgrounds living with dementia. Has distributed over 1,200 free art kits in partnership with the Memory Center at the University of Chicago Medicine.
 - [Care NYC](#): Sunnyside Community Services (based in Queens) serves one of the largest

Spanish-speaking Latin American groups in the US and matches caregivers to staff who provide and connect them to services (i.e., counseling, support groups, education workshops, respite, and supplemental/financial resources) and community-based organizations in their native language.

- **Neenah Public Library Memory Makers Kits** contain meaningful activities that a person with dementia or cognitive decline can successfully engage in, independently or with someone else. Funding from **Bader Philanthropies**.
- [Arts for ALL Wisconsin](#) will offer a pilot program of multidisciplinary art workshops for adults experiencing early-stage memory loss and their care partners. Funding from **Bader Philanthropies**.

Resources for Caregivers

- [Best Practice Caregiving](#) is a free online database of proven dementia programs for family caregivers. A program of the Benjamin Rose Institute on Aging and the Family Caregiver Alliance Funding comes from **the John A. Hartford Foundation, RRF Foundation for Aging,** and **Archstone Foundation**.

Respite care

- Respite services provide temporary, substitute care that gives caregivers a break. Services can be provided in settings including the individual's home, assisted living facilities, and nursing homes. Some respite services provide a safe environment for people living with dementia to participate in activities designed to match their needs and abilities.
- Respite care funders include [Hilarity for Charity](#) and [Alzheimer's Foundation's Milton & Phyllis Berg Family Respite Care Grants](#).

Creative Expression



- The [Alzheimer's Poetry Project](#) (APP) has used telephone- and video-based creative arts interventions for caregivers and their loved ones with dementia in Madison, Wisconsin, to facilitate communication and reduce isolation. [Funding](#) from **RRF Foundation for Aging**.
- Other APP work is funded by the **Bader Philanthropi Inc.**, the **Philanthropi Inc.**, the **Kolher Foundation**, the **McCune Foundation**, the **Mary Duke Biddle Foundation**, the **National Endowment for the Arts**, the **New York Community Foundation**, the **Pabst Charitable for the Arts**, and the **Poetry Foundation**.
- [Timeslips](#) is an interactive program that brings meaning and purpose into the lives of elders through creative engagement and infuses creativity into care relationships and systems. Funders include the **Greater Milwaukee Foundation**, **The Helen Daniels Bader Fund of the Bader Philanthropies**, **LeadingAge**, the **May and Stanley Smith Charitable Trust**, **The National Endowment for the Arts**, the **Ralph C. Wilson Jr. Foundation**, **RRF Foundation for Aging**, and the **Rosalinde and Arthur Gilbert Foundation**.

Training

- [The Alzheimer's and Dementia Care ECHO Program](#) connects dementia care experts with professional care providers for a free continuing education series of interactive, case-based video conferencing sessions. The original pilot was launched with [private family funding](#).
- [The Alzheimer's and Dementia Care Program](#), developed at UCLA, improves care for people living with dementia and their family caregivers, and will be disseminated nationally through health systems with continued education of clinicians, promotion of comprehensive payment models, and development of a dissemination center and a

National Dementia Care Learning Collaborative. Funding comes from **The John A. Hartford Foundation**.

- The [2018 Alzheimer's Association Dementia Care Practice Recommendations](#) outline 56 evidence-based recommendations for person-centered care. Funding from **MetLife Foundation**.
- [New Ways for Better Days/Tailored Activities Program](#) gives occupational therapists and other professionals a tested protocol to identify interests and abilities of people living with dementia, provide disease education, and instruct caregivers in using selected activities in daily care routines and in managing their own distress. Funding from the National Institute of Mental Health, the National Institute on Aging, and [the Scattergood Foundation](#).

Culturally appropriate outreach

- [Latino Alzheimer's and Memory Programs and Providers Alliance](#) works in five cities to educate and engage Latino caregivers by providing skill-building training and compassionate support programs. It also offers a curriculum for healthcare providers and an evidence-based practice program for caregivers that is sensitive to the Latino community. Funders [include](#) the **Chicago Community Trust**, **the Alzheimer's Foundation of America**, **Bright Focus Foundation**, and **RRF Foundation for Aging**.



Basic references

- [Alzheimer's Association 2022 Facts and Figures](#)
- [Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Roadmap](#)
- [National Alzheimer's Project Act/National Alzheimer's Plan](#)

Websites

- [Alzheimer's Association](#)
- [Centers for Disease Control and Prevention Alzheimer's Disease and Healthy Aging Program](#)
- [National Institute on Aging Alzheimer's Disease and Related Dementias](#)
- [Dementia Friendly America](#)
- [Institute for Healthcare Improvement Age Friendly Health Systems](#)

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