

2021 Alzheimer's disease facts and figures

Abstract

This article describes the public health impact of Alzheimer's disease (AD), including incidence and prevalence, mortality and morbidity, use and costs of care, and the overall impact on caregivers and society. The Special Report discusses the challenges of providing equitable health care for people with dementia in the United States. An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia today. This number could grow to 13.8 million by 2060 barring the development of medical breakthroughs to prevent, slow or cure AD. Official death certificates recorded 121,499 deaths from AD in 2019, the latest year for which data are available, making Alzheimer's the sixth-leading cause of death in the United States and the fifth-leading cause of death among Americans age 65 and older. Between 2000 and 2019, deaths from stroke, heart disease and HIV decreased, whereas reported deaths from AD increased more than 145%. This trajectory of deaths from AD was likely exacerbated in 2020 by the COVID-19 pandemic. More than 11 million family members and other unpaid caregivers provided an estimated 15.3 billion hours of care to people with Alzheimer's or other dementias in 2020. These figures reflect a decline in the number of caregivers compared with a decade earlier, as well as an increase in the amount of care provided by each remaining caregiver. Unpaid dementia caregiving was valued at \$256.7 billion in 2020. Its costs, however, extend to family caregivers' increased risk for emotional distress and negative mental and physical health outcomes – costs that have been aggravated by COVID-19. Average per-person Medicare payments for services to beneficiaries age 65 and older with AD or other dementias are more than three times as great as payments for beneficiaries without these conditions, and Medicaid payments are more than 23 times as great. Total payments in 2021 for health care, long-term care and hospice services for people age 65 and older with dementia are estimated to be \$355 billion. Despite years of efforts to make health care more equitable in the United States, racial and ethnic disparities remain – both in terms of health disparities, which involve differences in the burden of illness, and health care disparities, which involve differences in the ability to use health care services. Blacks, Hispanics, Asian Americans and Native Americans continue to have a higher burden of illness and lower access to health care compared with Whites. Such disparities, which have become more apparent during COVID-19, extend to dementia care. Surveys commissioned by the Alzheimer's Association recently shed new light on the role of discrimination in dementia care, the varying levels of trust between racial and ethnic groups in medical research, and the differences between groups in their levels of concern about and awareness of Alzheimer's disease. These findings emphasize the

need to increase racial and ethnic diversity in both the dementia care workforce and in Alzheimer's clinical trials.

KEYWORDS

Alzheimer's dementia, Alzheimer's disease, Biomarkers, Caregivers, COVID-19, Dementia, Diagnostic criteria, Discrimination, Diversity, Equity, Ethnicity, Family caregiver, Health care costs, Health care disparities, Health care expenditures, Health care professional, Health disparities, Implicit bias, Incidence, Long-term care costs, Medicaid spending, Medicare spending, Morbidity, Mortality, Prevalence, Race, Risk factors, Spouse caregiver

1 | ABOUT THIS REPORT

2021 Alzheimer's Disease Facts and Figures is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia. Background and context for interpretation of the data are contained in the Overview. Additional sections address prevalence, mortality and morbidity, caregiving and use and costs of health care and services. A Special Report examines race, ethnicity and Alzheimer's in America.

1.1 | Specific information in this report

Specific information in this year's *Alzheimer's Disease Facts and Figures* includes:

- Brain changes that occur with Alzheimer's disease.
- Risk factors for Alzheimer's dementia.
- Number of Americans with Alzheimer's dementia nationally and for each state.
- Lifetime risk for developing Alzheimer's dementia.
- Proportion of women and men with Alzheimer's and other dementias.
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age.
- The effect of COVID-19 on deaths from Alzheimer's disease.
- Number of family caregivers, hours of care provided, and economic value of unpaid care nationally and for each state.
- The health and economic impact of caregiving on caregivers.
- The impact of COVID-19 on dementia caregiving.
- National cost of care for individuals with Alzheimer's or other dementias, including costs paid by Medicare and Medicaid and costs paid out of pocket.
- Medicare payments for people with dementia compared with people without dementia.
- Types of discrimination experienced by Alzheimer's and dementia caregivers.
- Racial and ethnic attitudes about medical research and clinical trial participation.

The Appendices detail sources and methods used to derive statistics in this report.

When possible, specific information about Alzheimer's disease is provided; in other cases, the reference may be a more general one of "Alzheimer's or other dementias."

2 | OVERVIEW OF ALZHEIMER'S DISEASE

Alzheimer's disease is a type of brain disease, just as coronary artery disease is a type of heart disease. It is also a progressive disease, meaning that it becomes worse with time. Alzheimer's disease is thought to begin 20 years or more before symptoms arise.¹⁻⁸ It starts with changes in the brain that are unnoticeable to the person affected. Only after years of brain changes do individuals experience noticeable symptoms such as memory loss and language problems. Symptoms occur because nerve cells (neurons) in parts of the brain involved in thinking, learning and memory (cognitive function) have been damaged or destroyed. As the disease progresses, neurons in other parts of the brain are damaged or destroyed as well. Eventually, neurons in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. Individuals become bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

2.1 | Alzheimer's disease or dementia?

Many people wonder what the difference is between Alzheimer's disease and dementia. *Dementia* is an overall term for a particular group of symptoms. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Dementia has many causes (see Table 1). *Alzheimer's disease* is the most common cause of dementia. In this report, *Alzheimer's dementia* refers to dementia that is caused by, or believed to be caused by, the brain changes of Alzheimer's disease.

2.2 | Brain changes of Alzheimer's disease

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual

TABLE 1 Common Causes of Dementia and Associated Characteristics

Cause	Characteristics
Alzheimer's disease	<p>Alzheimer's disease is the most common cause of dementia, accounting for an estimated 60% to 80% of cases. Recent large autopsy studies show that more than half of individuals with Alzheimer's dementia have Alzheimer's disease brain changes (pathology) as well as the brain changes of one or more other causes of dementia, such as cerebrovascular disease or Lewy body disease.¹¹⁻¹² This is called mixed pathologies, and if recognized during life is called mixed dementia.</p> <p>Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioral changes and, ultimately, difficulty speaking, swallowing and walking.</p> <p>The hallmark pathologies of Alzheimer's disease are the accumulation of the protein fragment beta-amyloid (plaques) <i>outside</i> neurons in the brain and twisted strands of the protein tau (tangles) <i>inside</i> neurons. These changes are accompanied by the death of neurons and damage to brain tissue. Alzheimer's is a slowly progressive brain disease that begins many years before symptoms emerge.</p>
Cerebrovascular disease	<p>Cerebrovascular disease refers to the process by which blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients. People with dementia whose brains show evidence of cerebrovascular disease are said to have vascular dementia. About 5% to 10% of individuals with dementia show evidence of vascular dementia alone.¹¹⁻¹² However, it is more common as a mixed pathology, with most people living with dementia showing the brain changes of cerebrovascular disease and Alzheimer's disease.¹¹⁻¹²</p> <p>Impaired judgment or impaired ability to make decisions, plan or organize may be the initial symptom, but memory may also be affected, especially when the brain changes of other causes of dementia are present. In addition to changes in cognitive function, people with vascular dementia commonly have difficulty with motor function, especially slow gait and poor balance.</p> <p>Vascular dementia occurs most commonly from blood vessel blockage, such as that which occurs with stroke, or damage leading to areas of dead tissue or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.</p>
Lewy body disease	<p>Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. This is called dementia with Lewy bodies or DLB. People with DLB have some of the symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbance, well-formed visual hallucinations and visuospatial impairment. These symptoms may occur in the absence of significant memory impairment but memory loss often occurs, especially when the brain changes of other causes of dementia are present.</p> <p>About 5% of individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer's disease pathology.</p>
Frontotemporal lobar degeneration (FTLD)	<p>FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.</p> <p>Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease.</p> <p>Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein, TDP-43).</p> <p>The symptoms of FTLD may occur in those age 65 years and older similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60% of people with FTLD are ages 45 to 60.¹³ Scientists think that FTLD is the most common cause of dementia in people younger than 60.¹³ In a systematic review, FTLD accounted for about 3% of dementia cases in studies that included people 65 and older and about 10% of dementia cases in studies restricted to those younger than 65.¹⁴</p>
Parkinson's disease (PD)	<p>Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. Cognitive symptoms develop either just before movement symptoms or later in the disease.</p> <p>In PD, clumps of the protein alpha-synuclein appear in an area deep in the brain called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.¹⁵</p> <p>As PD progresses, alpha-synuclein can also accumulate in the cortex of the brain (similar to dementia with Lewy bodies). Dementia may result.</p>
Hippocampal sclerosis (HS)	<p>HS is the hardening of tissue in the hippocampus of the brain. The hippocampus plays a key role in forming memories. The most pronounced symptom of HS is memory loss, and individuals may be misdiagnosed as having Alzheimer's disease.</p> <p>HS brain changes are often accompanied by accumulations of a misfolded form of a protein called TDP-43.</p> <p>HS is a common cause of dementia in the "oldest-old," individuals age 85 or older.</p>
Mixed pathologies	<p>When an individual shows the brain changes of more than one cause of dementia, mixed pathologies are considered the cause. When these pathologies result in dementia symptoms during life, the person is said to have mixed dementia.</p> <p>Studies suggest that mixed dementia is more common than previously recognized, with more than 50% of people with dementia who were studied at Alzheimer's Disease Research Centers having pathologic evidence of more than one cause of dementia.¹² In community-based studies, the percentage of mixed dementia cases is considerably higher.¹¹ The likelihood of having mixed dementia increases with age and is highest in people age 85 or older.¹⁶⁻¹⁷</p>

neurons to form connections with other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by another neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain, and the information they carry creates the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

The accumulation of the protein fragment beta-amyloid into clumps (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes associated with Alzheimer's.

Plaques and smaller accumulations of beta-amyloid called oligomers may contribute to the damage and death of neurons (neurodegeneration) by interfering with neuron-to-neuron communication at synapses. Inside neurons, tau tangles block the transport of nutrients and other molecules essential for normal function and neuron survival. Although the complete sequence of events is unclear, beta-amyloid may begin accumulating before abnormal tau, and increasing beta-amyloid accumulation is associated with subsequent increases in tau.^{9,10}

Other brain changes associated with Alzheimer's include inflammation and atrophy (decreased brain volume). The presence of toxic beta-amyloid and tau proteins are believed to activate immune system cells in the brain called microglia. Microglia try to clear the toxic proteins as well as widespread debris from dead and dying cells. Chronic inflammation may set in when the microglia can't keep up with all that needs to be cleared. Atrophy occurs because of cell loss. Normal brain function is further compromised in Alzheimer's disease by decreases in the brain's ability to metabolize glucose, its main fuel. These brain changes are considered biomarkers of Alzheimer's. Biomarkers are biological changes that can be measured to indicate the presence or absence of a disease or the risk of developing a disease. For example, the level of glucose in blood is a biomarker of diabetes, and cholesterol level is a biomarker of one's risk of cardiovascular disease.

A study⁷ of people with rare genetic mutations that cause Alzheimer's, called dominantly inherited Alzheimer's disease (DIAD), found that levels of beta-amyloid in the brain were significantly increased starting 22 years before symptoms were expected to develop (individuals with these genetic mutations usually develop symptoms at the same or nearly the same age as their parent with Alzheimer's). Glucose metabolism began to decrease 18 years before expected symptom onset, and brain atrophy began 13 years before expected symptom onset. Another study¹ of people with DIAD found abnormal levels of the neurofilament light chain protein, a biomarker of neurodegeneration, 22 years before symptoms were expected to develop. A third study² found that levels of two types of tau protein begin to increase when beta-amyloid starts clumping together as amyloid plaques. Levels of these types of tau increase as early as two decades before the characteristic tau tangles of Alzheimer's begin to appear.

2.3 | Mixed dementia

Many people with dementia have brain changes associated with more than one cause of dementia.^{11,18-23} This is called mixed dementia. Some studies^{11,12} report that the majority of people with the brain changes of Alzheimer's also have the brain changes of a second cause of dementia on autopsy. One autopsy study showed that of 447 older people who were believed to have Alzheimer's dementia when they died, only 3% had the brain changes of Alzheimer's disease alone, 15% had the brain changes of a different cause of dementia, and 82% had the brain changes of Alzheimer's plus at least one other cause of dementia.¹¹ Studies suggest that mixed dementia is the norm, and the number of distinct combinations of mixed dementia is extensive.²⁴⁻²⁵

Mixed dementia is common at advanced ages.^{18,26} For example, the oldest-old, those age 85 or older, are more likely to have evidence of two or more causes of dementia than those younger than 85.¹⁶⁻¹⁷ Having Alzheimer's brain changes plus another type of brain change makes it more likely that a person will show dementia symptoms in their lifetime^{11,18} compared with someone with Alzheimer's brain changes alone. It may also account for the wide variety of memory and thinking problems experienced by people living with dementia.

2.4 | Alzheimer's disease continuum

The progression of Alzheimer's disease from brain changes that are unnoticeable to the person affected to brain changes that cause problems with memory and eventually physical disability is called the Alzheimer's disease continuum.

On this continuum, there are three broad phases: preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease (see Figure 1).²⁷⁻³⁰ The Alzheimer's dementia phase is further broken down into the stages of mild, moderate and severe, which reflect the degree to which symptoms interfere with one's ability to carry out everyday activities.

While we know the continuum starts with preclinical Alzheimer's and ends with severe Alzheimer's dementia, how long individuals spend in each part of the continuum varies. The length of each phase of the continuum is influenced by age, genetics, biological sex and other factors.³¹

2.4.1 | Alzheimer's begins before dementia

In the past, *Alzheimer's disease* was often used to describe the dementia phase of the disease. Today we know that dementia is only one part of the disease. It is preceded by mild cognitive impairment (MCI), a period when individuals have subtle cognitive changes that do not interfere with everyday activities. When biomarker tests show that individuals with MCI have the brain changes of Alzheimer's disease, they are said

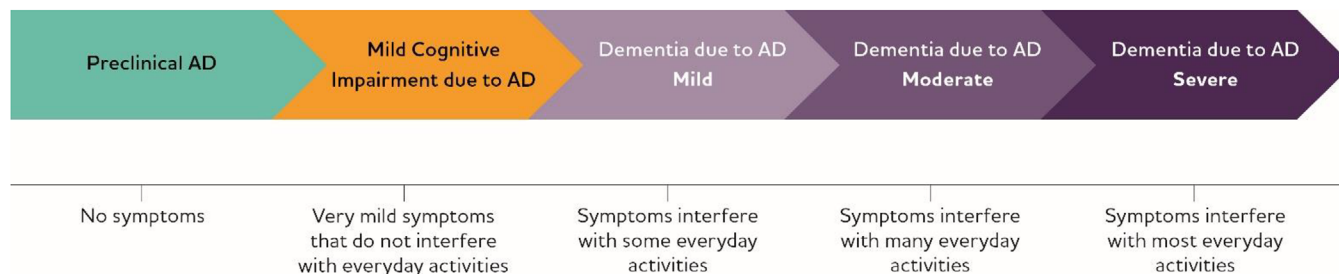


FIGURE 1 Alzheimer's disease (AD) continuum. Although these arrows are of equal size, the components of the AD continuum are not equal in duration

to have *MCI due to Alzheimer's disease*, another part of the Alzheimer's disease continuum.

MCI is a key area of interest to researchers involved in drug development. Because individuals with MCI are still able to function independently, a treatment that prevents MCI from progressing to dementia would have a significant impact on quality of life, caregiver burden, and use and cost of care.

2.4.2 | Preclinical Alzheimer's disease

In this phase, individuals have measurable brain changes that indicate the earliest signs of Alzheimer's disease (biomarkers), but they have not yet developed symptoms such as memory loss. Examples of Alzheimer's biomarkers include abnormal levels of beta-amyloid as shown on positron emission tomography (PET) scans³² and in analysis of cerebrospinal fluid (CSF), and decreased metabolism of glucose as shown on PET scans. When the early changes of Alzheimer's occur, the brain compensates for them, enabling individuals to continue to function normally.

While research settings have the tools and expertise to identify some of the early brain changes of Alzheimer's, additional research is needed to fine-tune the tools' accuracy before they become available for widespread use in hospitals, doctors' offices and other clinical settings. It is important to note that not all individuals with evidence of Alzheimer's-related brain changes go on to develop symptoms of MCI or dementia due to Alzheimer's.^{33,34} For example, some individuals have beta-amyloid plaques at death but did not have memory or thinking problems in life.

2.4.3 | MCI due to Alzheimer's disease

People with MCI due to Alzheimer's disease have biomarker evidence of Alzheimer's brain changes plus subtle problems with memory and thinking. These cognitive problems may be noticeable to the individual, family members and friends, but not to others, and they do not interfere with the individual's ability to carry out everyday activities.

The mild changes in thinking abilities occur when the brain can no longer compensate for the damage and death of nerve cells caused by Alzheimer's disease.

Among those with MCI, about 15% develop dementia after two years.³⁵ About one-third (32%) of individuals with MCI develop Alzheimer's dementia within five years' follow-up.³⁶ It's important to note that some individuals are diagnosed as having MCI several years after cognitive decline began, and these individuals are likely to develop dementia sooner than those whose cognitive decline is more recent. It's also important to note that some individuals with MCI revert to normal cognition or do not have additional cognitive decline. In other cases, such as when a medication inadvertently causes cognitive changes, MCI is mistakenly diagnosed and cognitive changes can be reversed. Identifying which individuals with MCI are more likely to develop dementia is a major goal of current research.

2.4.4 | Dementia due to Alzheimer's disease

Dementia due to Alzheimer's disease, or Alzheimer's dementia, is characterized by noticeable memory, thinking or behavioral symptoms that impair a person's ability to function in daily life, combined with biomarker evidence of Alzheimer's-related brain changes. As Alzheimer's progresses, individuals commonly experience multiple types of symptoms that change with time. These symptoms reflect the degree of damage to nerve cells in different parts of the brain. The pace at which symptoms of dementia advance from mild to moderate to severe differs from person to person.

Mild Alzheimer's Dementia

In the mild stage of Alzheimer's dementia, most people are able to function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe. They may still be able to drive, work and participate in favorite activities.

Moderate Alzheimer's Dementia

In the moderate stage of Alzheimer's dementia, which is often the longest stage, individuals may have difficulties communicating and performing routine tasks, including activities of daily living (such as bathing and dressing); become incontinent at times; and start

having personality and behavioral changes, including suspiciousness and agitation.

Severe Alzheimer's Dementia

In the severe stage of Alzheimer's dementia, individuals need help with activities of daily living and are likely to require around-the-clock care. The effects of Alzheimer's disease on individuals' physical health become especially apparent in this stage. Because of damage to areas of the brain involved in movement, individuals become bed-bound. Being bed-bound makes them vulnerable to conditions including blood clots, skin infections and sepsis, which triggers body-wide inflammation that can result in organ failure. Damage to areas of the brain that control swallowing makes it difficult to eat and drink. This can result in individuals swallowing food into the trachea (windpipe) instead of the esophagus (food pipe). Because of this, food particles may be deposited in the lungs and cause lung infection. This type of infection is called aspiration pneumonia, and it is a contributing cause of death among many individuals with Alzheimer's (see Mortality and Morbidity section).

2.4.5 | When dementia-like symptoms are not dementia

It is important to note that some individuals have dementia-like symptoms without the progressive brain changes of Alzheimer's or other degenerative brain diseases. Causes of dementia-like symptoms include depression, untreated sleep apnea, delirium, side effects of medications, Lyme disease, thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, these conditions often may be reversed with treatment. Consulting a medical professional to determine the cause of symptoms is critical to one's physical and emotional well-being.

2.4.6 | Normal age-related cognitive changes or symptoms of dementia?

The differences between normal age-related cognitive changes and the cognitive changes of Alzheimer's dementia can be subtle (see Table 2). People experiencing cognitive changes should seek medical help to determine if the changes are normal for one's age, reversible or a symptom of Alzheimer's or another dementia. The Medicare Annual Wellness Visit, available to all Medicare enrollees each year at no cost, includes a cognitive evaluation and is an opportune time for individuals age 65 or older to discuss cognitive changes with their physician.

2.5 | Diagnosis of dementia due to Alzheimer's disease

There is no single test for dementia due to Alzheimer's disease. Instead, physicians (often with the help of specialists such as neurologists, neu-

ropsychologists, geriatricians and geriatric psychiatrists) use a variety of approaches and tools to help make a diagnosis. They include the following:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member to provide input about changes in thinking skills and behavior.
- Conducting problem-solving, memory and other cognitive tests, as well as physical and neurologic examinations.
- Having the individual undergo blood tests and brain imaging to rule out other potential causes of dementia symptoms, such as a tumor or certain vitamin deficiencies.
- In some circumstances, using PET imaging of the brain to find out if the individual has high levels of beta-amyloid, a hallmark of Alzheimer's; normal levels would suggest Alzheimer's is not the cause of dementia.³⁷
- In some circumstances, using lumbar puncture to determine the levels of beta-amyloid and certain types of tau in CSF; normal levels would suggest Alzheimer's is not the cause of dementia.³⁸

Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause. Alzheimer's disease is the most common cause of dementia, but most people with the brain changes of Alzheimer's also have the brain changes of another cause of dementia.^{25,39-40} Many individuals who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed by a physician,⁴¹⁻⁴⁴ and fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records report (or their caregiver reports, if the beneficiary's cognitive impairment prevented him or her from responding) being told of the diagnosis.⁴⁵⁻⁴⁸ It is important that individuals who are living with dementia receive a diagnosis and are aware of the diagnosis. It is also important that individuals receive an accurate diagnosis to ensure treatment and follow-up care are appropriate for their specific cause of dementia.

2.6 | Treatment of Alzheimer's dementia

2.6.1 | Pharmacologic treatment

None of the pharmacologic treatments (drugs) available today for Alzheimer's dementia slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal. The U.S. Food and Drug Administration (FDA) has approved five drugs for the treatment of Alzheimer's — rivastigmine, galantamine, donepezil, memantine, and memantine combined with donepezil. A sixth drug, aducanumab, is under FDA review for potential approval at this writing. Of these drugs, aducanumab is the only one that may potentially slow the progression of Alzheimer's, and it has been tested only for individuals with MCI or early Alzheimer's dementia. With the exception of memantine, the remaining drugs temporarily

TABLE 2 Signs of Alzheimer's Dementia Compared with Typical Age-Related Changes*

Signs of Alzheimer's Dementia	Typical Age-Related Changes
Memory loss that disrupts daily life: One of the most common signs of Alzheimer's dementia is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events, asking for the same information over and over, and increasingly needing to rely on memory aids (for example, reminder notes or electronic devices) or family members for things that used to be handled on one's own.	Sometimes forgetting names or appointments, but remembering them later.
Challenges in planning or solving problems: Some people experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe, keeping track of monthly bills or counting change. They may have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when balancing a checkbook.
Difficulty completing familiar tasks at home, at work or at leisure: People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.	Occasionally needing help to use the settings on a microwave or record a television show.
Confusion with time or place: People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they forget where they are or how they got there.	Getting confused about the day of the week but figuring it out later.
Trouble understanding visual images and spatial relationships: For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.	Vision changes related to cataracts, glaucoma or age-related macular degeneration.
New problems with words in speaking or writing: People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock").	Sometimes having trouble finding the right word.
Misplacing things and losing the ability to retrace steps: People with Alzheimer's may put things in unusual places and lose things and be unable to go back over their steps to find them again. Sometimes, they accuse others of stealing. This may occur more frequently over time.	Misplacing things from time to time and retracing steps to find them.
Decreased or poor judgment: People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.	Making a bad decision once in a while.
Withdrawal from work or social activities: People with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.	Sometimes feeling weary of work, family and social obligations.
Changes in mood and personality: The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zones.	Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

*For more information about the symptoms of Alzheimer's, visit alz.org/alzheimers-dementia/10_signs.

improve cognitive symptoms by increasing the amount of chemicals called neurotransmitters in the brain. Memantine blocks certain receptors in the brain from excess stimulation that can damage nerve cells. The effectiveness of these drugs varies from person to person.

No drugs are specifically approved by the FDA to treat behavioral and psychiatric symptoms that may develop in the moderate and severe stages of Alzheimer's dementia. If nonpharmacologic therapy is

not successful and these symptoms have the potential to cause harm to the individual or others, physicians may prescribe drugs approved for similar symptoms in people with other conditions. A type of drug called antipsychotics may be prescribed to treat hallucinations, aggression and agitation. However, research has shown that some antipsychotics are associated with an increased risk of stroke and death in individuals with dementia.^{49,50} The decision to use antipsychotics must be considered with extreme caution. The FDA has ordered

manufacturers to label such drugs with a “black box warning” about their risks and a reminder that they are not approved to treat dementia symptoms.

Many factors contribute to the difficulty of developing effective treatments for Alzheimer's. These include the slow pace of recruiting sufficient numbers of participants and sufficiently diverse participants to clinical studies, gaps in knowledge about the precise molecular changes and biological processes in the brain that cause Alzheimer's disease, and the relatively long time needed to observe whether an investigational treatment affects disease progression. In addition, because mixed dementia is so common, even more brain changes than previously thought may be contributing to symptoms, further complicating decisions about which brain changes to target.

Researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function may be most effective when administered early in the disease continuum, either at the MCI due to Alzheimer's or preclinical Alzheimer's phase. Biomarker tests, such as PET brain imaging and analysis of proteins in blood and CSF, will be essential to identify which individuals are in these phases of the continuum and should receive treatments when they are available. Biomarkers also will be critical for monitoring the effects of treatment. Biomarker tests are already playing an important role in drug development because they enable researchers to recruit into clinical trials only those individuals with the Alzheimer's brain changes that a drug has been designed to affect.⁵¹ The most effective biomarker test or combination of tests may differ depending on where the individual is on the disease continuum and other factors.⁵²

2.6.2 | Nonpharmacologic therapy

Nonpharmacologic therapies are those that do not involve drugs. They are often used for people with Alzheimer's dementia with the goal of maintaining or improving cognitive function, overall quality of life or the ability to perform activities of daily living. They also may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. A recent review and analysis of nonpharmacologic treatments for agitation and aggression in people with dementia concluded that nonpharmacologic interventions seemed to be more effective than pharmacologic interventions for reducing aggression and agitation.⁵³ Examples of nonpharmacologic therapies include computerized memory training, listening to favorite music as a way to stir recall, and using special lighting to lessen sleep disorders. As with current pharmacologic therapies, nonpharmacologic therapies do not slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal.

Determining the effectiveness of nonpharmacologic therapies can be difficult because of the large number of unique therapies tested; the diversity of therapeutic aims (from improved overall quality of life

to improvements in specific symptoms); the range of dementia stages represented (from mild to moderate to severe); the multiple types of dementia that may be present among participants in a particular study given the pervasiveness of mixed dementia; and the lack of a standard method for carrying out any individual therapy. With these multiple factors to consider, it is challenging to group together and compare nonpharmacologic therapies.

Nevertheless, researchers have pooled data from multiple studies of nonpharmacologic therapies to provide insight into their potential effectiveness.

- A meta-analysis⁵⁴ found that aerobic exercise and a combination of aerobic and non-aerobic exercise had positive effects on cognitive function in people living with Alzheimer's dementia. A systematic review⁵⁵ found that exercise has a positive effect on overall cognitive function and may slow the rate of cognitive decline in people with Alzheimer's dementia.
- A systematic review⁵⁶ found that cognitive stimulation had beneficial effects on cognitive function and some aspects of well-being in people with Alzheimer's dementia. Another systematic review⁵⁷ reported that cognitive stimulation was associated with improved scores on tests of depression in people with mild-to-moderate Alzheimer's dementia. A summary of systematic reviews⁵⁸ reported that cognitive stimulation, music-based therapies and psychological treatment (for example, cognitive behavioral therapy) improved depression, anxiety and quality of life in people with dementia.
- A summary of systematic reviews⁵⁹ of cognitive training for people with mild-to-moderate dementia found cognitive training may show some benefits in overall cognition that may last for at least a few months.

The Lancet Commission 2020 report⁶⁰ on dementia prevention, intervention, and care recommends post-diagnostic care for people with dementia that includes physical and mental health, social care, and support; management of neuropsychiatric symptoms, noting that multicomponent interventions are the treatments of choice to decrease neuropsychiatric symptoms; and care for family caregivers, pointing out that specific interventions for family caregivers have long-lasting effects on depression and anxiety symptoms, increase quality of life, are cost-effective and might save money (see Caregiving section).

2.7 | Active management of Alzheimer's dementia

Studies have consistently shown that active management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers.⁶¹⁻⁶³ Active management includes:

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.

- Providing family caregivers with effective training in managing the day-to-day life of the care recipient.
- Coordination of care among physicians, other health care professionals and lay caregivers.
- Participation in activities that are meaningful to the individual with dementia and bring purpose to his or her life.
- Having opportunities to connect with others living with dementia; support groups and supportive services are examples of such opportunities.
- Becoming educated about the disease.
- Planning for the future.

To learn more about Alzheimer's disease, as well as practical information for living with Alzheimer's and being a caregiver, visit alz.org.

2.8 | Risk factors for Alzheimer's dementia

The vast majority of people who develop Alzheimer's dementia are age 65 or older. This is called late-onset Alzheimer's. Experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. Exceptions are cases of Alzheimer's related to uncommon genetic changes that greatly increase risk.

2.8.1 | Age, genetics and family history

The greatest risk factors for late-onset Alzheimer's are older age,^{64,65} genetics^{66,67} — especially the apolipoprotein e4 gene (APOE-e4) — and having a family history of Alzheimer's.⁶⁸⁻⁷¹

Age

Age is the greatest of these three risk factors. The percentage of people with Alzheimer's dementia increases dramatically with age: 5.3% of people age 65 to 74, 13.8% of people age 75 to 84 and 34.6% of people age 85 or older have Alzheimer's dementia (see Prevalence section). The aging of the baby-boom generation will significantly increase the number of people in the United States with Alzheimer's.⁷² However, it is important to note that Alzheimer's dementia is not a normal part of aging,⁷³ and older age alone is not sufficient to cause Alzheimer's dementia.

Genetics

Researchers have found several genes that increase the risk of Alzheimer's. The APOE-e4 gene is the gene with the strongest impact on risk of late-onset Alzheimer's. APOE-e4 provides the blueprint for a protein that transports cholesterol in the bloodstream. Everyone inherits one of three forms (alleles) of the APOE gene — e2, e3 or e4 — from each parent, resulting in six possible APOE pairs: e2/e2, e2/e3, e2/e4, e3/e3, e3/e4 and e4/e4. Researchers have found differences in the frequency of these pairs in different racial and ethnic groups. For example, data show that a higher percentage of African Americans

TABLE 3 Percentage of African Americans and European Americans with Specified APOE Pairs

APOE Pair	African Americans*	European Americans
e3/e3	45.2	63.4
e3/e4	28.6	21.4
e3/e2	15.1	10.2
e2/e4	5.7	2.4
e4/e4	4.5	2.4
e2/e2	0.7	0.2

Created from data from Rajan et al.⁷⁴

*Percentages do not total 100 due to rounding.

than European Americans have at least one copy of the e4 allele (see Table 3).⁷⁴⁻⁷⁶

Having the e4 form of APOE increases one's risk of developing Alzheimer's compared with having the e3 form, but does not guarantee that an individual will develop Alzheimer's. Having the e2 form may decrease one's risk compared with having the e3 form. Those who inherit one copy of the e4 form have about three times the risk of developing Alzheimer's compared with those with two copies of the e3 form, while those who inherit two copies of the e4 form have an eight- to 12-fold risk.⁷⁷⁻⁷⁹ In addition, those with the e4 form are more likely to have beta-amyloid accumulation⁸⁰ and Alzheimer's dementia at a younger age than those with the e2 or e3 forms of the APOE gene.⁸¹ A meta-analysis including 20 published articles describing the frequency of the e4 form among people in the United States who had been diagnosed with Alzheimer's found that 56% had one copy of the APOE-e4 gene, and 11% had two copies of the APOE-e4 gene.⁸² Another study found that among 1,770 diagnosed individuals from 26 Alzheimer's Disease Research Centers across the United States, 65% had at least one copy of the APOE-e4 gene.⁸³

However, a recent study⁸⁴ found that individuals with the APOE-e4 risk gene had a decreased risk of developing dementia if they had more years of early life education, had mentally challenging work in midlife, participated in leisure activities in late life, and/or had strong social networks in late life.

Studies of Alzheimer's risk based on APOE status among Blacks have had inconsistent results. For example, some have found that having the e4 allele did not increase risk among Blacks,^{75,76,85} while other studies have found that it significantly increased risk.^{86,87} More research is needed to better understand the genetic mechanisms involved in Alzheimer's risk among different racial and ethnic groups.

Family history

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, individuals who have a parent or sibling (first-degree relative) with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.^{68,77} Those who have more than one first-degree relative

with Alzheimer's are at even higher risk.⁷¹ A large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-ε4.⁸⁸ When diseases run in families, heredity (genetics) and shared non-genetic factors (for example, access to healthy foods and habits related to physical activity) may play a role.

2.8.2 | Modifiable risk factors

Although age, genetics and family history cannot be changed, other risk factors can be changed or modified to reduce the risk of cognitive decline and dementia. Examples of modifiable risk factors are physical activity, smoking, education, staying socially and mentally active, blood pressure, and diet. In fact, the 2020 recommendations of *The Lancet* Commission on dementia prevention, intervention and care⁶⁰ suggest that addressing modifiable risk factors might prevent or delay up to 40% of dementia cases. Modifiable risk factors have been the subject of much research. In addition to *The Lancet* Commission report,⁶⁰ the 2019 World Health Organization (WHO) recommendations⁸⁹ to reduce risk of cognitive decline and dementia, an Alzheimer's Association article⁹⁰ evaluating the effects of modifiable risk factors on cognitive decline and dementia, and a report from the National Academy of Medicine⁹¹ all point to the promising role of addressing these risk factors to reduce risk of dementia and cognitive decline. This section focuses on risk factors common to these reports.

It is important to note that "reducing risk" of cognitive decline and dementia is not synonymous with preventing cognitive decline and dementia altogether. Individuals who take measures to reduce risk may still develop dementia, but they may be less likely to develop it or they may develop it later in life than they would have if they had not taken steps to reduce their risk. It is also important to note that factors that increase or decrease the risk of cognitive decline and dementia may not necessarily do so by directly affecting the brain changes associated with Alzheimer's disease.⁸⁵ For example, it is possible that smoking may contribute to cerebrovascular disease, which in turn increases the risk of dementia, but it may not directly contribute to the development of the amyloid plaques and tau tangles that characterize Alzheimer's disease.

Cardiovascular disease risk factors, physical activity, and diet

Brain health is affected by the health of the heart and blood vessels. Although it makes up just 2% of body weight, the brain consumes 20% of the body's oxygen and energy supplies.⁹² A healthy heart ensures that enough blood is pumped to the brain, while healthy blood vessels enable the oxygen- and nutrient-rich blood to reach the brain so it can function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia.⁹³ These factors include smoking⁹⁴⁻⁹⁸ and diabetes.⁹⁹⁻¹⁰² Some studies propose that impaired glucose processing (a precursor to diabetes) may also increase risk for dementia.¹⁰³⁻¹⁰⁵ The age at which some risk fac-

tors develop appears to affect dementia risk. For example, midlife obesity,^{103,106-109} hypertension,^{103,110-114} prehypertension (systolic blood pressure from 120 to 139 mm Hg or diastolic pressure from 80 to 89 mm Hg)¹¹⁴ and high cholesterol^{115,116} are associated with an increased risk of dementia. Regarding hypertension, evidence from a large-scale clinical trial suggests that intensive medical treatment to reduce blood pressure may safely decrease the occurrence of MCI and dementia.¹¹⁷ In contrast to midlife, late-life obesity¹¹⁸ and hypertension onset after age 80¹¹⁹ are associated with decreased risk of dementia. It is possible that the disease causing dementia affects body mass and blood pressure rather than the reverse. More research is needed to understand why the effects of some modifiable risk factors may change with age.

Building on the connection between heart health and brain health, researchers have found that factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer's or other dementias. Physical activity¹²⁰⁻¹³⁰ appears to be one of these factors. Although researchers have studied a wide variety of exercises, they do not yet know which specific types of exercises, what frequency of exercise or what duration of activity may be most effective in reducing risk. In addition to physical activity, emerging evidence suggests that consuming a heart-healthy diet may be associated with reduced dementia risk.¹³¹⁻¹³⁵ A heart-healthy diet emphasizes fruits, vegetables, whole grains, fish, chicken, nuts and legumes while limiting saturated fats, red meat and sugar. A systematic review¹³⁶ of the use of supplements, including vitamins C, D and E, omega-3 fatty acids and ginkgo biloba, found little to no benefit in preventing cognitive decline, MCI or Alzheimer's dementia.

Researchers have begun studying combinations of health factors and health behaviors (for example, blood pressure as a health factor and physical activity as a health behavior) to learn whether combinations of risk factors better identify Alzheimer's and dementia risk than individual risk factors. They are also studying whether intervening on multiple risk factors simultaneously is more effective at reducing risk than addressing a single risk factor. Indeed, one such study,¹³⁷ the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), found that a multidomain intervention was associated with beneficial effects on cognitive function in older adults at high risk for cognitive decline and dementia. The success of FINGER has led to the launch of multidomain intervention studies in other countries, including the Alzheimer's Association's U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER).¹³⁸

Education

People with more years of formal education are at lower risk for Alzheimer's and other dementias than those with fewer years of formal education.^{75,139-143} Some researchers believe that having more years of education builds "cognitive reserve." Cognitive reserve refers to the brain's ability to make flexible and efficient use of cognitive networks (networks of neuron-to-neuron connections) to enable a person to continue to carry out cognitive tasks despite brain changes.^{144,145} The number of years of formal education is not the only determinant

of cognitive reserve. Having a mentally stimulating job and engaging in other mentally stimulating activities may also help build cognitive reserve.¹⁴⁶⁻¹⁴⁹

It is important to note that the underlying reason for the relationship between formal education and reduced Alzheimer's risk is unclear. It is possible that the generally higher socioeconomic status of individuals with more years of formal education is a protective factor. Having fewer years of formal education is associated with lower socioeconomic status.¹⁵⁰ This in turn may increase one's likelihood of experiencing poor nutrition; decrease one's ability to afford health care or medical treatments, such as treatments for cardiovascular disease risk factors that are so closely linked to brain health; and limit one's access to physically safe housing and employment. The latter could increase one's risk of being exposed to substances that are toxic to the nervous system such as air pollution,¹⁵¹ lead¹⁵² and pesticides.¹⁵³

In addition, people with fewer years of education tend to have more cardiovascular risk factors for Alzheimer's, including being less physically active,¹⁵⁴ having a higher risk of diabetes,¹⁵⁵⁻¹⁵⁷ and being more likely to have hypertension¹⁵⁸ and to smoke.¹⁵⁹

Social and cognitive engagement

Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.^{121,160-172} Socially and cognitively stimulating activity might help build cognitive reserve. However, it is also possible that undetected cognitive impairment decreases one's interest in and ability to participate in activities involving social and cognitive skills. In this case, the association may reflect the effect of cognitive impairment on social and cognitive engagement rather than the effect of engagement on dementia risk. More research is needed to better understand the biological processes that link social and cognitive engagement to dementia risk.

Traumatic brain injury (TBI)

TBI is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. TBI increases the risk of dementia.¹⁷³

According to the Centers for Disease Control and Prevention (CDC), nearly 3 million TBI-related emergency department visits, hospitalizations and deaths occurred in 2014, the latest year for which information is available.¹⁷⁴ The leading causes of TBI that resulted in emergency department visits were falls, being struck by an object and motor vehicle crashes.¹⁷⁴

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia¹⁷⁵ and by the individual's initial score on the 15-point Glasgow Coma Scale.¹⁷⁶

- *Mild TBI* (also known as a concussion) is characterized by loss of consciousness or post-traumatic amnesia lasting 30 minutes or less, or an initial Glasgow score of 13 to 15; about 75% of TBIs are mild.¹⁷⁷
- *Moderate TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting more than 30 minutes but less than 24 hours, or an initial Glasgow score of 9 to 12.

- *Severe TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting 24 hours or more, or an initial Glasgow score of 8 or less.

The risk of dementia increases with the number of TBIs sustained.¹⁷³ Even those who experience mild TBI are at increased risk of dementia compared with those who have not had a TBI. A recent study found that mild TBI is associated with a two-fold increase in the risk of dementia diagnosis.¹⁷⁸ Studies have also found that people with a history of TBI who develop Alzheimer's do so at a younger age than those without a history of TBI.^{179,180} Whether TBI causes Alzheimer's disease, other conditions that lead to dementia, or both, is still being investigated.

Chronic traumatic encephalopathy (CTE) is a neuropathologic diagnosis (meaning it is characterized by brain changes that can only be identified at autopsy) associated with repeated blows to the head, such as those that may occur while playing contact sports. Among former amateur and professional football players, the risk of developing CTE, which is associated with dementia, increased 30% per year played.¹⁸¹ Currently, there is no test to determine if someone has CTE-related brain changes during life. A review article indicates that the greatest risk factor for developing CTE-related brain changes is repetitive brain trauma — repeated, forceful blows to the head that do not, individually, result in symptoms.¹⁸² Like Alzheimer's disease, CTE is characterized by tangles of an abnormal form of the protein tau in the brain. Unlike Alzheimer's, beta-amyloid plaques are uncommon in CTE.^{183,184} How the brain changes associated with CTE are linked to cognitive or behavioral changes is unclear.

Other modifiable risk factors

Researchers are studying a variety of other potential modifiable risk factors. Among the many risk factors being studied are inadequate sleep or poor sleep quality,¹⁸⁵ excessive alcohol use,¹⁸⁶ depression¹⁸⁷ and hearing impairment.¹⁸⁸

In addition, a growing body of evidence indicates that critical illness and medical encounters such as hospitalization in older people increase their risk of long-term cognitive impairment.¹⁸⁹⁻¹⁹⁵ The emergence of novel coronavirus disease in 2019 (COVID-19) has resulted in tens of thousands of hospitalizations. This has the potential to increase the number of cases of cognitive impairment following critical illness. Furthermore, many of these individuals will receive or have received mechanical ventilation, which increases one's risk of delirium,¹⁹⁶ an acute state of short-term confusion that is a risk factor for dementia.¹⁹⁷⁻¹⁹⁹

There is also rapidly emerging evidence on how exposure to air pollution may be related to dementia risk. A number of different air pollutants have been studied in relation to cognition, cognitive decline, brain imaging and dementia itself. The most consistent and rigorous results concern fine particulate matter air pollution, which consists of tiny solid particles and liquid droplets generated by fuel combustion, fires, and processes that produce dust. Higher levels of long-term exposure to fine particulate matter air pollution is associated with worse cognitive function and cognitive decline.²⁰⁰⁻²⁰⁷

2.8.3 | Uncommon genetic changes that greatly increase risk

Certain genetic mutations and the extra copy of chromosome 21 that characterizes Down syndrome are uncommon genetic factors that greatly influence Alzheimer's risk.

Genetic mutations

A small percentage of Alzheimer's cases (an estimated 1% or less)²⁰⁸ develop as a result of mutations to any of three specific genes. A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes. These mutations involve the gene for the amyloid precursor protein (APP) and the genes for the presenilin 1 and presenilin 2 proteins. Those inheriting an Alzheimer's mutation to these genes are virtually guaranteed to develop the disease if they live a normal life span.²⁰⁹ Symptoms tend to develop before age 65, sometimes as young as age 30, while the vast majority of individuals with Alzheimer's have late-onset Alzheimer's.

Trisomy in Down syndrome

In Down syndrome, an individual is born with three copies of chromosome 21 (called trisomy 21) instead of two. People with Down syndrome have an increased risk of developing Alzheimer's, and this is believed to be related to trisomy 21. Chromosome 21 includes the gene that encodes for the production of APP, which in people with Alzheimer's is cut into beta-amyloid fragments that accumulate into plaques. Having an extra copy of chromosome 21 may increase the production of beta-amyloid fragments in the brain.

Overall, people with Down syndrome develop Alzheimer's at an earlier age than people without Down syndrome. By age 40, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brains.²¹⁰ As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. According to the National Down Syndrome Society, about 30% of people with Down syndrome who are in their 50s have Alzheimer's disease.²¹¹ About 50% of people with Down syndrome who are in their 60s have Alzheimer's disease.²¹¹

2.9 | Looking to the future

With the discovery that Alzheimer's may begin 20 years or more before the onset of symptoms, a substantial window of time has been opened to intervene in the progression of the disease. During this window of time, advances in the identification of biomarkers for Alzheimer's will enable earlier detection of the disease, giving those affected the opportunity to address modifiable risk factors that may delay cognitive decline and participate in clinical studies of potential new treatments. Biomarker advances will also accelerate the development of these new treatments by enabling clinical trials to specifically recruit individuals with the brain changes experimental therapies target. In addition, biomarker, basic science and other research advances offer

the potential to expand the field's understanding of which therapies may be most effective at which points in the Alzheimer's disease continuum.

However, a fuller understanding of Alzheimer's — from its causes to how to prevent it, how to manage it and how to treat it — depends on other crucial factors. Among these is the inclusion of participants from diverse racial and ethnic groups in all realms of Alzheimer's research. Most of the research to date has not included sufficient numbers of Blacks, Hispanics, Asian Americans/Pacific Islanders and Native Americans to be representative of the U.S. population. Moreover, because Blacks and Hispanics are at increased risk for Alzheimer's (see Prevalence section), their underrepresentation hampers the conduct of rigorous research to understand factors that may contribute to their increased risk. Improving inclusion also increases the diversity of lived experiences of participants (and investigators), which opens the door to discovering environmental and societal factors that may influence health behaviors and other factors that increase risk. It is important that researchers identify risk factors that can be addressed to alter the disparate burden of Alzheimer's. Only by improving representation in clinical trials, observational studies and other investigations will everyone have the potential to benefit from advances in Alzheimer's science.

3 | PREVALENCE

Millions of Americans are living with Alzheimer's or other dementias. As the size of the U.S. population age 65 and older continues to increase, the number of Americans with Alzheimer's or other dementias will grow. Both the number and proportion will escalate rapidly in coming years, as the population of Americans age 65 and older is projected to grow from 58 million in 2021 to 88 million by 2050.^{212,213} The baby-boom generation (Americans born between 1946 and 1964) has already begun to reach age 65 and beyond,²¹⁴ the age range of greatest risk of Alzheimer's dementia²¹⁵; in fact, the oldest members of the baby-boom generation turn age 75 in 2021.

This section reports on the number and proportion of people with Alzheimer's dementia to describe the magnitude of the burden of Alzheimer's on the community and health care systems. The prevalence of Alzheimer's dementia refers to the number and proportion of people in a population who have Alzheimer's dementia at a given point in time. Incidence refers to the number or rate of new cases per year. Estimates from selected studies on the number and proportion of people with Alzheimer's or other dementias vary depending on how each study was conducted. Data from several studies are used in this section.

3.1 | Prevalence of Alzheimer's and other dementias in the United States

Based on updated calculations, an estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia in 2021.^{A1,216} Seventy-two percent are age 75 or older (Figure 2).²¹⁶

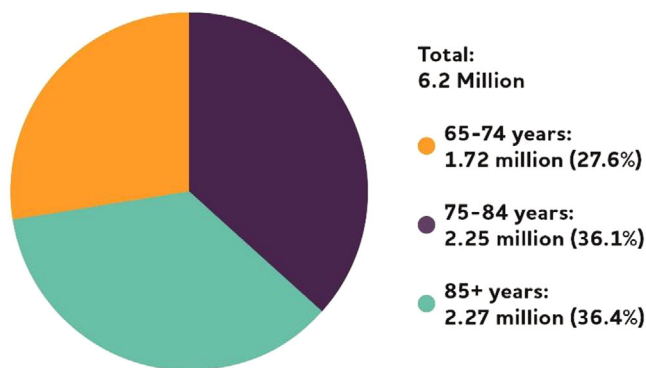


FIGURE 2 Number and ages of people 65 or older with Alzheimer's dementia, 2021. Created from data from Rajan et al.^{A1,216} Percentages do not total 100 due to rounding

Of the total U.S. population:

- More than 1 in 9 people (11.3%) age 65 and older has Alzheimer's dementia.²¹⁶
- The percentage of people with Alzheimer's dementia increases with age: 5.3% of people age 65 to 74, 13.8% of people age 75 to 84, and 34.6% of people age 85 and older have Alzheimer's dementia.²¹⁶ People younger than 65 can also develop Alzheimer's dementia, but it is much less common and prevalence is uncertain.

The estimated number of people age 65 and older with Alzheimer's dementia comes from an updated study using the latest data from the 2020 projections from the U.S. Census Bureau and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health conditions of older people.²¹⁶

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from other population-based studies including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.^{A2,217,218} Based on estimates from ADAMS, 11% of people age 65 and older in the United States have dementia.²¹⁹

3.1.1 | Prevalence estimates

The 6.2 million prevalence estimate included in this section refers to people age 65 and older who have Alzheimer's dementia based on symptoms such as memory loss and difficulty thinking. It is based on data from a single longitudinal study in which all individuals who exhibited the clinical symptoms of Alzheimer's were classified as having Alzheimer's dementia. Future prevalence estimates will be different.

First, the number of Americans with *Alzheimer's dementia* (the 6.2 million figure reported here) is likely to be lower. This is because future estimates of Alzheimer's dementia are more likely to be based on whether individuals have the actual brain changes of Alzheimer's in addition to whether they have clinical changes in memory, thinking and other cognitive skills. Evidence from biomarker-based studies^{11,73,220-222} indicates that some individuals counted as hav-

ing Alzheimer's dementia based on symptoms do not have the biological brain changes of Alzheimer's disease; that is, their dementia is caused by something other than Alzheimer's disease. Both autopsy studies and clinical trials have found that 15% to 30% of individuals who met the criteria for Alzheimer's dementia based on symptoms did not have Alzheimer's-related brain changes.^{11,73,220-222} Thus, these studies indicate that biomarker-based prevalence estimates – rather than symptom-based prevalence estimates – will likely result in up to a 30% decrease in prevalence estimates of Alzheimer's dementia. Another potential contributor to a decrease in prevalence estimates of Alzheimer's dementia is the use of multiple symptom-based longitudinal studies when determining prevalence rather than one.^{A2,219}

Second, the estimate of how many people have *Alzheimer's disease* (not just dementia due to Alzheimer's disease) will be higher. For decades it has been recognized that all individuals with dementia pass through a precursor stage frequently referred to as mild cognitive impairment (MCI). More recently, with the advent of biomarkers that detect elevated levels of the beta-amyloid and tau proteins that characterize Alzheimer's, it is now possible to determine which individuals diagnosed with MCI have MCI due to Alzheimer's disease. As biomarker-based diagnoses become more common, individuals with MCI due to Alzheimer's disease will be included in prevalence estimates of the number of Americans with Alzheimer's disease.

As reported in this section, the limited data available to date show that about half of individuals age 65 and older with MCI – roughly 5 million Americans – have MCI due to Alzheimer's disease. Because MCI develops years before dementia, and potentially affects individuals before age 65, there are likely far more than 5 million Americans with MCI due to Alzheimer's disease.

Lastly, the National Institute on Aging – Alzheimer's Association (NIA-AA) Framework²²³ hypothesizes that there is an incipient and silent stage of Alzheimer's disease in which the individual appears not to have the cognitive symptoms of either MCI or dementia. An estimate of the prevalence of "preclinical" Alzheimer's disease population has been previously published,²²⁴ but we clearly need more research to validate preclinical Alzheimer's and determine how to measure it with biomarkers that conclusively represent Alzheimer's disease.

What does all this mean for future prevalence estimates? Prevalence estimates of Alzheimer's disease reported in future *Facts and Figures* reports will continue to report clinically diagnosed individuals in the dementia stage, currently estimated to be 6.2 million Americans, in addition to the best-available estimates of MCI due to Alzheimer's disease. *Facts and Figures* will not include prevalence estimates for the preclinical Alzheimer's disease stage until (1) there is conclusive evidence of a connection between biomarkers in this silent stage and the development of MCI due to Alzheimer's disease and (2) prevalence studies have then attempted to calculate the number of individuals impacted.

Ultimately, with these refinements, future prevalence estimates of Alzheimer's disease will be higher, although estimates of Alzheimer's dementia (the currently reported 6.2 million) will be lower. For example, in 2021, biomarker-based estimates of Alzheimer's disease could result in up to 30% fewer individuals in the dementia stage of the

disease, leaving roughly 4 million Americans age 65 and older with Alzheimer's dementia, while also including an additional 50% of those over age 65 with MCI (those with MCI due to Alzheimer's disease). A conservative estimate of the number of people with MCI due to Alzheimer's disease is 5 million Americans. This would result in a very rough current estimate of 9 million Americans with Alzheimer's disease. It should be noted that both symptom-based and biomarker-based prevalence estimates will rapidly increase in the future due to growth in the proportion of Americans age 65 and over, the population most at risk.

When epidemiological studies include biomarker-based diagnoses and a conclusive connection is shown between biomarkers and the preclinical stage, an Alzheimer's disease prevalence estimate ought to include individuals throughout the continuum of Alzheimer's disease: those with biomarker-confirmed Alzheimer's dementia, those with biomarker-confirmed MCI due to Alzheimer's disease, and those with preclinical Alzheimer's disease — making the true prevalence of Alzheimer's disease even higher.

3.1.2 | Mild cognitive impairment due to Alzheimer's disease

The number and proportion of older adults who have MCI due to Alzheimer's disease is currently difficult to estimate because it requires population-based prevalence measures of MCI and Alzheimer's biomarkers, and these studies are in their infancies. Furthermore, there is variation across studies in both the threshold of cognitive impairment required for an MCI diagnosis and the level of biomarker burden that defines the presence of Alzheimer's disease. However, we can roughly estimate this prevalence indirectly using multiple data sources. A systematic review of more than 30 studies of MCI reported that 16.6% of people age 65 and older had MCI.³⁵ Meanwhile, studies assessing biomarkers for Alzheimer's disease with PET scans have reported that about half of people with MCI have Alzheimer's-related brain changes.^{225,226} Therefore, roughly 8% of people age 65 and older — or approximately 5 million older Americans — may have MCI due to Alzheimer's disease. This prevalence estimate needs to be confirmed with population-based studies involving biomarkers.

3.1.3 | Underdiagnosis of Alzheimer's and other dementias in the primary care setting

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study undergoes evaluation for dementia. But outside of research settings, a substantial portion of those who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed with dementia by a physician.⁴¹⁻⁴⁴ Furthermore, only about half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records report being told of the diagnosis.^{45-48,227} Because Alzheimer's dementia is often

underdiagnosed — and if it is diagnosed by a clinician, people are often unaware of their diagnosis — a large portion of Americans with Alzheimer's may not know they have it. For more detailed information about detection of Alzheimer's and other dementias in the primary care and clinical setting, see the Special Report from *2019 Alzheimer's Disease Facts and Figures*.²²⁸

Since 2011, the Medicare Annual Wellness Visit has included a required cognitive evaluation. A survey by the Alzheimer's Association found that only 1 in 3 older adults were aware that these visits should include a cognitive assessment.²²⁸ Furthermore, while 82% of older adults believe it is important to have their memory and thinking checked, only 16% report having their memory and thinking checked. Most (93%) older adults said they trust their doctor to recommend testing for memory and thinking problems; however, despite 94% of primary care physicians stating that it is important to assess all older patients for cognitive impairment, fewer than half (47%) say it is their standard protocol to do so. The primary reasons given by surveyed physicians for not assessing older patients for cognitive impairment are (1) the patient presents with no symptoms or complaints (68%) and (2) lack of time (58%).

3.1.4 | Prevalence of subjective cognitive decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's or other dementias as well as MCI.²²⁹⁻²³³ Subjective cognitive decline refers to self-perceived worsening of memory and other thinking abilities by an individual, separate from cognitive testing, clinical diagnosis or anyone else noticing. Not all those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.²³⁴⁻²³⁶ One study showed those who over time consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia.²³⁷ The Behavioral Risk Factor Surveillance System survey, which includes questions on subjective cognitive decline, found that 11% of Americans age 45 and older reported subjective cognitive decline, but 54% of those who reported it had not consulted a health care professional.²³⁸ Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

3.2 | Estimates of the number of people with Alzheimer's dementia by state

Table 4 lists the estimated number of people age 65 and older with Alzheimer's dementia by state for 2020 (the most recent year for which these numbers are available), the projected number for 2025, and the projected percentage change in the number of people with Alzheimer's between 2020 and 2025.^{A3,239}

TABLE 4 Projections of Total Numbers of Americans Age 65 and Older with Alzheimer's Dementia by State

State	Projected Number with Alzheimer's (in thousands)		Percentage Increase
	2020	2025	2020-2025
Alabama	96	110	14.6
Alaska	8.5	11	29.4
Arizona	150	200	33.3
Arkansas	58	67	15.5
California	690	840	21.7
Colorado	76	92	21.1
Connecticut	80	91	13.8
Delaware	19	23	21.1
District of Columbia	8.9	9	1.1
Florida	580	720	24.1
Georgia	150	190	26.7
Hawaii	29	35	20.7
Idaho	27	33	22.2
Illinois	230	260	13.0
Indiana	110	130	18.2
Iowa	66	73	10.6
Kansas	55	62	12.7
Kentucky	75	86	14.7
Louisiana	92	110	19.6
Maine	29	35	20.7
Maryland	110	130	18.2
Massachusetts	130	150	15.4
Michigan	190	220	15.8
Minnesota	99	120	21.2
Mississippi	57	65	14.0
Missouri	120	130	8.3
Montana	22	27	22.7
Nebraska	35	40	14.3
Nevada	49	64	30.6
New Hampshire	26	32	23.1
New Jersey	190	210	10.5
New Mexico	43	53	23.3
New York	410	460	12.2
North Carolina	180	210	16.7
North Dakota	15	16	6.7
Ohio	220	250	13.6
Oklahoma	67	76	13.4
Oregon	69	84	21.7
Pennsylvania	280	320	14.3
Rhode Island	24	27	12.5
South Carolina	95	120	26.3
South Dakota	18	20	11.1

(Continues)

TABLE 4 (Continued)

State	Projected Number with Alzheimer's (in thousands)		Percentage Increase
	2020	2025	2020-2025
Tennessee	120	140	16.7
Texas	400	490	22.5
Utah	34	42	23.5
Vermont	13	17	30.8
Virginia	150	190	26.7
Washington	120	140	16.7
West Virginia	39	44	12.8
Wisconsin	120	130	8.3
Wyoming	10	13	30.0

Created from data provided to the Alzheimer's Association by Weuve et al.^{A3,239}

As shown in Figure 3, between 2020 and 2025 every state across the country is expected to experience an increase of at least 6.7% in the number of people with Alzheimer's. These projected increases in the number of people with Alzheimer's are based on projected increases in the population age 65 and older in these states. Because risk factors for dementia such as midlife obesity and diabetes can vary dramatically by region and state, the regional patterns of future burden may be different than reported here. Based on these projections, the West and Southeast are expected to experience the largest percentage increases in people with Alzheimer's dementia between 2020 and 2025. These increases will have a marked impact on states' health care systems, as well as the Medicaid program, which covers the costs of long-term care and support for many older residents with dementia, including more than a quarter of Medicare beneficiaries with Alzheimer's or other dementias.²⁴⁰

3.3 | Incidence of Alzheimer's dementia

While prevalence refers to *existing* cases of a disease in a population at a given time, incidence refers to *new* cases of a disease that develop in a given period of time in a defined population – in this case, the U.S. population age 65 or older. Incidence provides a measure of risk for developing a disease. According to estimates using data from the CHAP study and the U.S. Census, approximately 910,000 people age 65 or older developed Alzheimer's dementia in the United States in 2011, a number that would be expected to be even higher in 2021 if CHAP estimates were available for that year.²⁴¹ A study using data from the Adult Changes in Thought Study, a cohort of members of Group Health Cooperative of Puget Sound (now Kaiser Permanente Northwest), a health care delivery system in the Seattle, Washington, area, reported similar incidence rates to the CHAP study.²⁴² The number of new cases of Alzheimer's increases dramatically with age: according to estimates from CHAP, in 2011 the average annual incidence in people age 65 to 74 was 0.4% (meaning four of every 1,000 people age 65 to 74

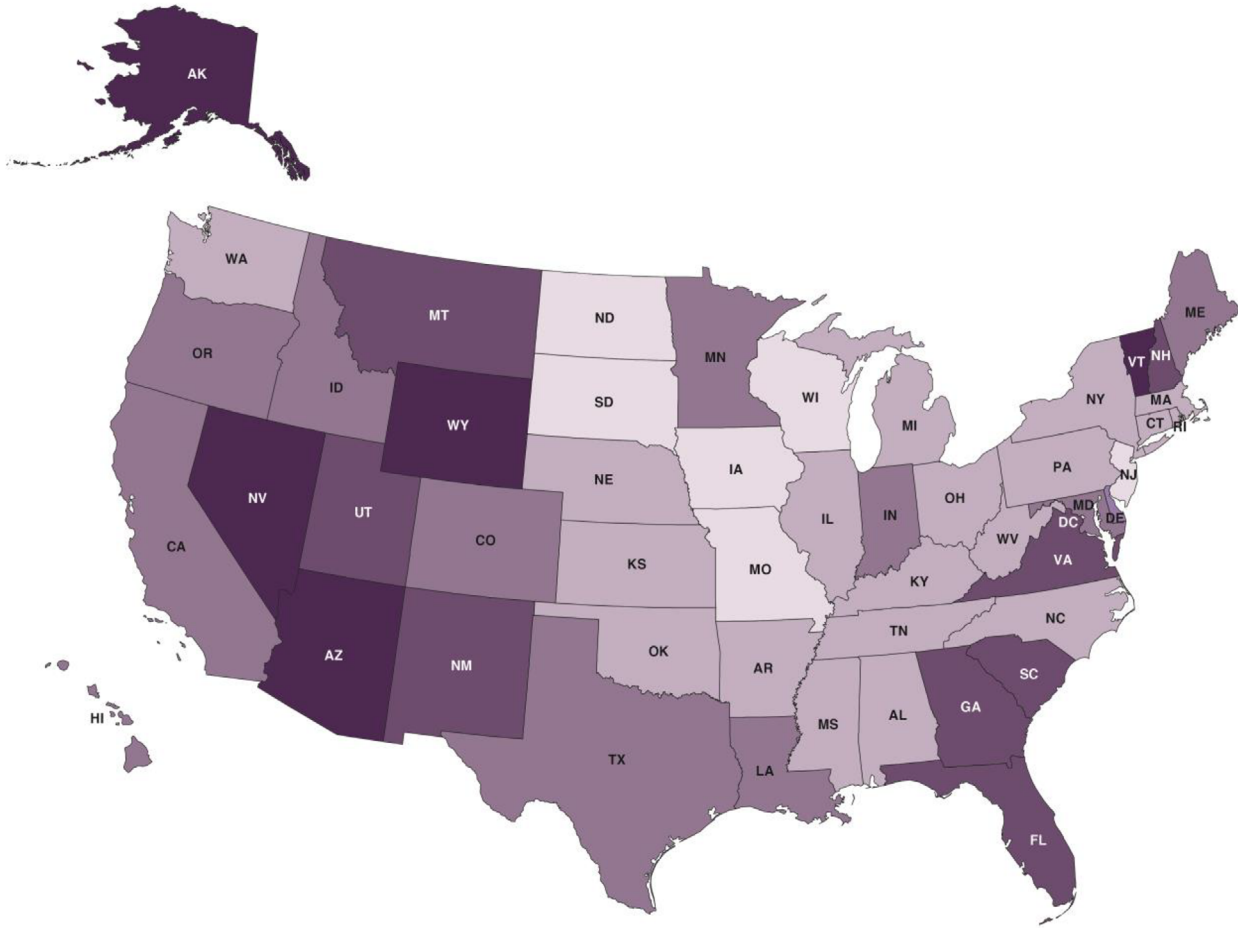
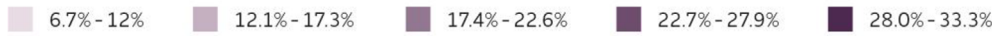


FIGURE 3 Projected increases between 2020 and 2025 in Alzheimer's dementia prevalence by state. Change from 2020 to 2025 for Washington, D.C.: 1.1%. Created from data provided to the Alzheimer's Association by Weuve et al.^{A3,239}

developed Alzheimer's dementia in 2011); in people age 75 to 84, the annual incidence was 3.2% (32 of every 1,000 people); and for age 85 and older (the "oldest-old"), the incidence was 7.6% (76 of every 1,000 people).²⁴¹ Because of the increasing number of people age 65 and older in the United States, particularly the oldest-old, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050.²⁴³

3.4 | Lifetime risk of Alzheimer's dementia

Lifetime risk is the probability that someone of a given age who does not have a particular condition will develop the condition during his or her remaining life span. Data from the Framingham Heart Study were used to estimate lifetime risks of Alzheimer's dementia by age and sex.^{A4,244} As shown in Figure 4, the study found that the estimated lifetime risk for Alzheimer's dementia at age 45 was approximately 1 in 5 (20%) for women and 1 in 10 (10%) for men. The risks for both sexes were slightly higher at age 65.²⁴⁴

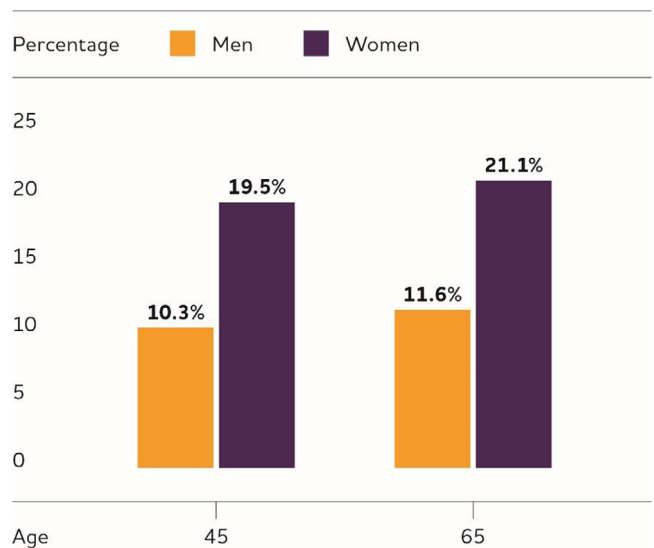


FIGURE 4 Estimated lifetime risk for Alzheimer's dementia, by sex, at ages 45 and 65. Created from data from Chene et al.²⁴⁴

3.5 | Differences between women and men in the prevalence and risk of Alzheimer's and other dementias

More women than men have Alzheimer's or other dementias. Almost two-thirds of Americans with Alzheimer's are women.²¹⁶ Of the 6.2 million people age 65 and older with Alzheimer's in the United States, 3.8 million are women and 2.4 million are men.²¹⁶ This represents 12% of women and 9% of men age 65 and older in the United States.²¹³

The prevailing reason that there are more women living with Alzheimer's or other dementias than men is most likely the fact that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.²⁴⁴⁻²⁴⁶ However, when it comes to differences in the actual risk of developing Alzheimer's or other dementias for men and women of the same age (i.e., *incidence*), findings have been mixed. Most studies of incidence in the United States have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age.^{75,242,246-248} Some European studies have reported a higher incidence among women at older ages,^{249,250} and one study from the United Kingdom reported higher incidence for men.²⁵¹ Differences in the risk of dementia between men and women may therefore depend on age and/or geographic region.^{252,253}

Although there do not appear to be large or consistent differences in the rate at which men and women develop Alzheimer's or other dementias, there may be differences in the reasons they develop dementia. These differences may be based in biology such as chromosomal or hormonal differences (i.e., sex differences) or differences in environmental, social and cultural influences on men and women (i.e., gender differences), or the combination of the two.^{252,254} There are many instances of gender difference in the distribution of or even the effect of known risk factors for dementia, such as education, occupation, and health behaviors. For example, lower educational attainment in women than in men born in the first half of the 20th century could account for elevated risk in women, as limited formal education is a risk factor for dementia.²⁵⁵ This explanation requires more research, but there is evidence that increases in educational attainment over time in the United States — which have been more substantial for women than men — have led to decreased risk for dementia.²⁵⁶ Interestingly, European studies have found that the relationship of lower education with dementia outcomes may actually be stronger in women than men.^{257,258}

Other societal gender differences may also be at play, such as differences in occupational attainment between men and women, with a recent study showing that women who participated in the paid workforce earlier in life had better cognitive outcomes after age 60.^{259,260} Other studies have provided evidence that any observed difference in risk for dementia between men and women may be an artifact of who is more or less likely to die of other health factors before developing dementia. A study using Framingham Heart Study data suggested that men in the study appear to have a lower risk for dementia due to "survival bias," in which the men who survived beyond age 65 and were

included in the study were the ones with a healthier cardiovascular risk profile (men have a higher rate of death from cardiovascular disease in middle age than women) and thus a lower risk for dementia.²⁴⁵ More research is needed to support this interpretation.

Research into biological sex differences has examined whether genetic risk operates differently in women and men or whether there are sex differences in the development of or susceptibility to Alzheimer's pathology.²⁶¹ A number of studies have shown that the APOE-e4 genotype, the best known genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia^{262,263} and neurodegeneration²⁶⁴ in women than in men. However, a recent meta-analysis found no difference between men and women in the association between APOE genotype and Alzheimer's dementia overall, though there was an elevated risk for women with the APOE-e4 genotype at certain age ranges.²⁶⁵ It is unknown why the APOE gene could convey different risk for women, but some evidence suggests that it may be due to an interaction between the APOE genotype and the sex hormone estrogen.^{266,267} Finally, there is some evidence that women show more rapid cognitive decline and neurodegeneration than men despite having similar levels of beta-amyloid and tau, meaning the hallmark proteins of Alzheimer's disease may have more negative effects for women than men.²⁶⁸⁻²⁷⁰

3.6 | Racial and ethnic differences in the prevalence of Alzheimer's and other dementias

Although there are more Whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States (because Whites are the largest racial/ethnic group in the country), older Black and Hispanic Americans are disproportionately more likely than older White Americans to have Alzheimer's or other dementias.²⁷¹⁻²⁷⁷ Data from the CHAP study indicates 18.6% of Blacks and 14% of Hispanics age 65 and older have Alzheimer's dementia compared with 10% of White older adults.²¹⁶ Most other prevalence studies also indicate that older Blacks are about twice as likely to have Alzheimer's or other dementias as older Whites.^{241,278,279} Some studies indicate older Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older Whites.²⁷⁹⁻²⁸¹ However, Hispanics comprise very diverse groups with different cultural histories, genetic ancestries and health profiles, and there is evidence that prevalence may differ from one specific Hispanic ethnic group to another (for example, Mexican Americans compared with Caribbean Americans).^{282,283}

The higher prevalence of Alzheimer's dementia in underrepresented racial and ethnic groups compared with Whites appears to be due to a higher risk of developing dementia in these groups compared with whites of the same age.²⁸⁴ This higher risk, or incidence, of Alzheimer's and other dementias appears to stem from variations in medical conditions, health-related behaviors and socioeconomic risk factors across racial groups.²⁷⁷ Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may

differ by race,^{85,87,285} genetic factors do not account for the large differences in prevalence or incidence among racial groups.^{284,286}

Instead, the difference in risk for Alzheimer's and other dementias is explained by disparities in health conditions, socioeconomic, and life experiences for older Black and Hispanic populations compared with older White populations. Many studies suggest that racial and ethnic differences in dementia risk do not persist in rigorous analyses that account for health and socioeconomic factors.^{140,217,284} Chronic health conditions that are associated with higher dementia risk, such as cardiovascular disease and diabetes, disproportionately affect Black and Hispanic populations.^{287,288} Social and environmental disparities including lower levels and quality of education, higher rates of poverty, and greater exposure to adversity and discrimination increase risk for these chronic conditions and risk for dementia in Black and Hispanic populations.^{85,287-289} These health and socioeconomic disparities are rooted in the history of discrimination against Black and other people of color in the United States, not only during interpersonal interactions, but also as enshrined in the rules, practices and policies of U.S. banks, laws, medical systems and other institutions — that is, structural racism.^{290,291}

Structural racism influences environmental factors such as where people can live, the quality of schools in their communities, and exposure to harmful toxicants and pollutants. It also influences sociocultural factors such as access to quality health care, employment prospects, occupational safety, the ability to pass wealth to subsequent generations, treatment by the legal system, and exposure to violence. Structural racism impacts many aspects of life that may directly or indirectly alter the ability to adhere to healthy behaviors or access resources that influence dementia risk. For example, some studies indicate that early life experiences with residential and school segregation can have detrimental effects on the cognitive health of Black Americans in later life.^{292,293} This points to a need for health disparities research that employs lifecourse perspectives to account for the many environmental and sociocultural factors that may put disproportionately affected populations at increased risk for Alzheimer's and other dementias.^{288,289}

There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among older Blacks and Hispanics than among older Whites.²⁹⁴⁻²⁹⁶ Based on data for Medicare beneficiaries age 65 and older, it has been estimated that Alzheimer's or another dementia has been diagnosed in 10.3% of Whites, 12.2% of Hispanics and 13.8% of Blacks.²⁹⁷ Although rates of diagnosis were higher among Blacks and Hispanics than among Whites, according to prevalence studies that detect all people who have dementia irrespective of their use of health care systems, the rates should be even higher for Blacks and Hispanics.

Data from population-based cohort studies regarding the national prevalence of Alzheimer's and other dementias in racial and ethnic groups other than Whites, Blacks and Hispanics are relatively sparse. However, a study examining electronic medical records of members of a large health plan in California indicated that dementia incidence — determined by the first presence of a dementia diagnosis in members' medical records — was highest for African Americans, intermediate for Latinos (the term used in the study for those who self-

reported as Latino or Hispanic) and Whites, and lowest for Asian Americans.²⁹⁸ A follow-up study with the same cohort showed heterogeneity within Asian American subgroups, but all subgroups studied had lower dementia incidence than Whites.²⁹⁹ A recent systematic review of the literature found that Japanese Americans were the only Asian American subgroup with reliable prevalence data, and that they had the lowest prevalence of dementia compared with all other ethnic groups.²⁸³ More studies, especially those involving population-based cohorts, are necessary to draw conclusions about the prevalence of Alzheimer's and other dementias in different racial groups and subgroups.

3.7 | Trends in the prevalence and incidence of Alzheimer's dementia over time

A growing number of studies indicate that the prevalence^{219,256,300-307} and incidence^{251,303,307-315} of Alzheimer's and other dementias in the United States and other higher income Western countries may have declined in the past 25 years,^{251,256,302-314} though results are mixed.^{64,241,316,317} One recent systematic review found that incidence of dementia has decreased over the last four decades while incidence of Alzheimer's dementia, specifically, has held steady, but more research on this distinction is needed, especially in non-Western countries.³¹⁸ Declines in dementia risk have been attributed to increasing levels of education and improved control of cardiovascular risk factors.^{256,302,309,312,319,320} Such findings are promising and suggest that identifying and reducing risk factors for dementia may be effective. Although these findings indicate that a person's risk of dementia at any given age may be decreasing slightly, the total number of people with Alzheimer's or other dementias in the United States and other high-income Western countries is expected to continue to increase dramatically because of the increase in the number of people at the oldest ages.

It is unclear whether these encouraging trends will continue into the future given worldwide trends showing increases in diabetes and obesity — potential risk factors for Alzheimer's dementia — which may lead to a rebound in dementia risk in coming years,^{107,301,303,321-323} or if these positive trends pertain to all racial and ethnic groups.^{241,273,300,319,320,324} Thus, while recent findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow. Moreover, 68% of the projected increase in the global prevalence and burden of dementia by 2050 will take place in low- and middle-income countries, where there is currently no evidence that the risk of Alzheimer's and other dementias has been declining.³²⁵

3.7.1 | Looking to the future: Aging of the baby-boom generation

A large segment of the American population — the baby-boom generation — has started reaching age 65 and older, when the risk for Alzheimer's and other dementias is elevated. By 2030, the segment

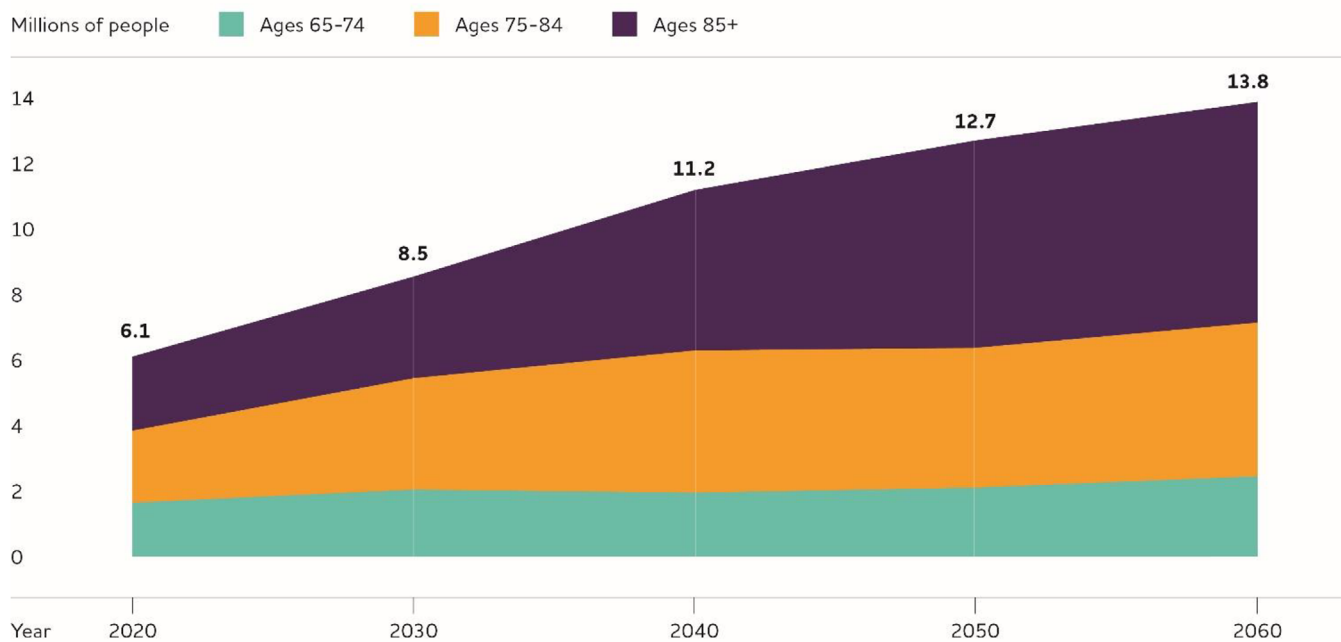


FIGURE 5 Projected number of people age 65 and older (total and by age) in the U.S. population with Alzheimer's dementia, 2020 to 2060. Created from data from Rajan et al.^{A5,216}

of the U.S. population age 65 and older will have grown substantially, and the projected 74 million older Americans will make up over 20% of the total population (up from 17% in 2021).^{213,326} As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's dementia, as shown in Figure 5.^{A5,72}

- By 2025, the number of people age 65 and older with Alzheimer's dementia is projected to reach 7.2 million — a 16% increase from the 6.2 million age 65 and older affected in 2021.²¹⁶
- By 2060, the number of people age 65 and older with Alzheimer's dementia is projected to reach 13.8 million, barring the development of medical breakthroughs to prevent, slow or cure Alzheimer's disease.^{A5,216}

3.7.2 | Growth of the oldest-old population

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to the aging of the large baby-boom cohort, as well as longer life expectancies due to medical advances and changes to social and environmental conditions.³²⁶ This will lead to an increase in the number and percentage of Americans who will be 85 and older, the oldest-old. Between now and 2050, the oldest-old are expected to comprise an increasing proportion of the U.S. population age 65 and older — from 17% in 2021 to 22% in 2050.³²⁶ This will result in an additional 12 million oldest-old people — individuals at the highest risk for developing Alzheimer's dementia.³²⁶

- In 2021, about 2.3 million people who have Alzheimer's dementia are age 85 or older, accounting for 36% of all people with Alzheimer's dementia.²¹⁶
- By 2060, 6.7 million people age 85 and older are expected to have Alzheimer's dementia, accounting for about half (48%) of all people 65 and older with Alzheimer's dementia.²¹⁶

4 | MORTALITY AND MORBIDITY

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States and is the fifth-leading cause of death for those age 65 and older.³²⁷ However, it may cause even more deaths than official sources recognize. Alzheimer's is also a leading cause of disability and poor health (morbidity) in older adults. Before a person with Alzheimer's dies, he or she lives through years of morbidity as the disease progresses.

4.1 | The effect of the COVID-19 pandemic on deaths from Alzheimer's disease

The data presented in the Mortality and Morbidity section comes from the most recent data sources available, all of which preceded the COVID-19 pandemic that emerged in the United States in 2020. Initial reports from the Centers for Disease Control and Prevention (CDC) show that excess mortality (the difference between the observed number of deaths and the expected number of deaths during a given time period) due to all causes was very high in 2020 compared with previous

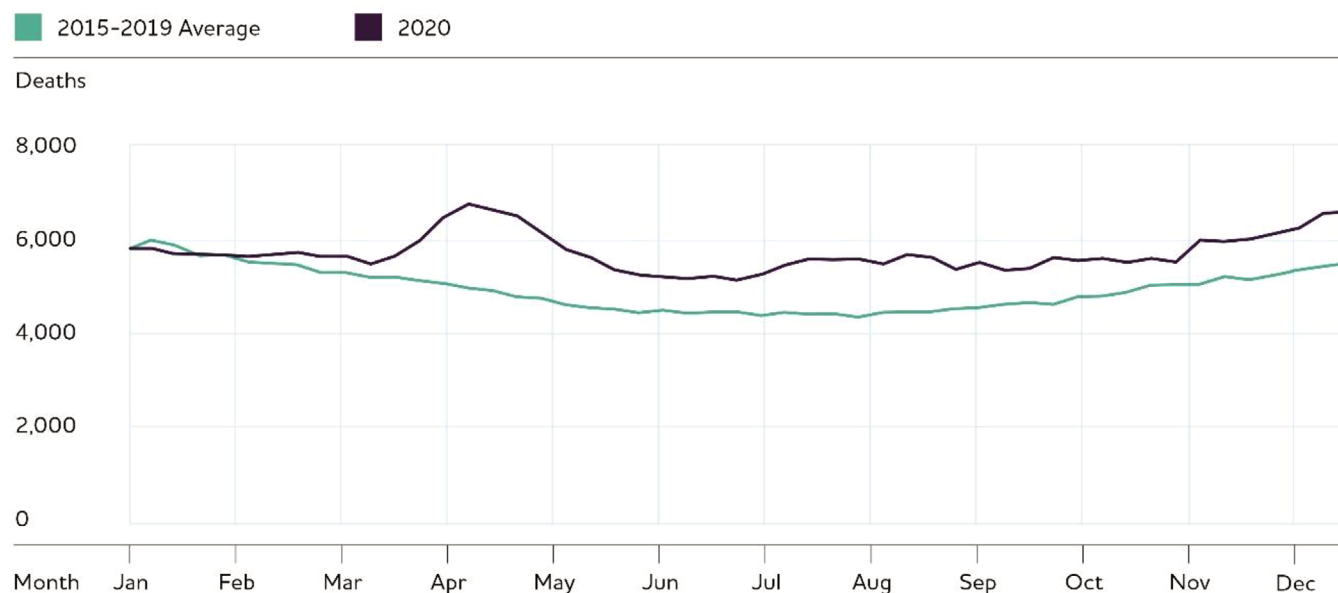


FIGURE 6 Deaths due to Alzheimer's and other dementias in the United States in 2020 compared with previous years. Data for 2020 are current as of February 3, 2021. Created from data from the National Center for Health Statistics.³²⁸

years, especially among older adults.³²⁸ Many of these excess deaths were in vulnerable older adults with Alzheimer's disease and other dementias (Figure 6). Preliminary reports from the CDC indicate that there were at least 42,000 more deaths from Alzheimer's disease and other dementias in 2020 compared with the average of the five years before 2020. This is approximately 16% more than expected. Additionally, the CDC reported the number of COVID-19 deaths for which death certificates listed additional conditions as a cause of death: in 4% of death certificates listing COVID-19 as the primary cause of death, Alzheimer's disease was also listed as one of multiple causes of death, and in 11% of death certificates listing COVID-19 as the primary cause of death, vascular or unspecified dementia was also listed. Among people over age 85 who died of COVID-19, Alzheimer's disease was listed as one of multiple causes of death for 8% and vascular or unspecified dementia was listed for 20%.³²⁹ Thus, we expect the dramatic effect of this pandemic on patterns of death from Alzheimer's to be apparent in coming years' *Facts and Figures* reports that incorporate data from 2020 and 2021.

4.2 | Deaths from Alzheimer's disease

It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to data from the CDC, 121,499 people died from Alzheimer's disease in 2019, the latest year for which data are available.³³⁰ The CDC considers a person to have died from Alzheimer's if the death certificate lists Alzheimer's as the underlying cause of death, defined as "the disease or injury which initiated the chain of events leading directly to death."³³¹

In the United States, Alzheimer's disease is counted as a cause of death that can be ranked against other leading causes of death such as cancer and heart disease, but deaths due to other types of dementia are not ranked in this manner. The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's deaths. In 2019, some form of dementia was the officially recorded underlying cause of death for 271,872 individuals (this includes the 121,499 from Alzheimer's disease).^{330,332} Therefore, the number of deaths from all causes of dementia, even as listed on death certificates, is more than twice as high as the number of reported Alzheimer's deaths alone.

Severe dementia frequently causes complications such as immobility, swallowing disorders and malnutrition that significantly increase the risk of serious acute conditions that can cause death. One such condition is pneumonia (infection of the lungs), which is the most commonly identified immediate cause of death among older adults with Alzheimer's or other dementias.³³³⁻³³⁶ One autopsy study found that respiratory system diseases were the immediate cause of death in more than half of people with Alzheimer's dementia, followed by circulatory system disease in about a quarter.³³⁴ Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.³³⁵⁻³³⁶ As a result, people with Alzheimer's dementia who die due to these acute conditions may not be counted among the number of people who die from Alzheimer's disease, even though Alzheimer's disease may well have caused the acute condition listed on the death certificate. This difficulty in using death certificates to determine the number of deaths from Alzheimer's and other dementias has been referred to as a "blurred distinction between death *with* dementia and death *from* dementia."³³⁷

Another way to determine the number of deaths from Alzheimer's dementia is through calculations that compare the estimated risk of

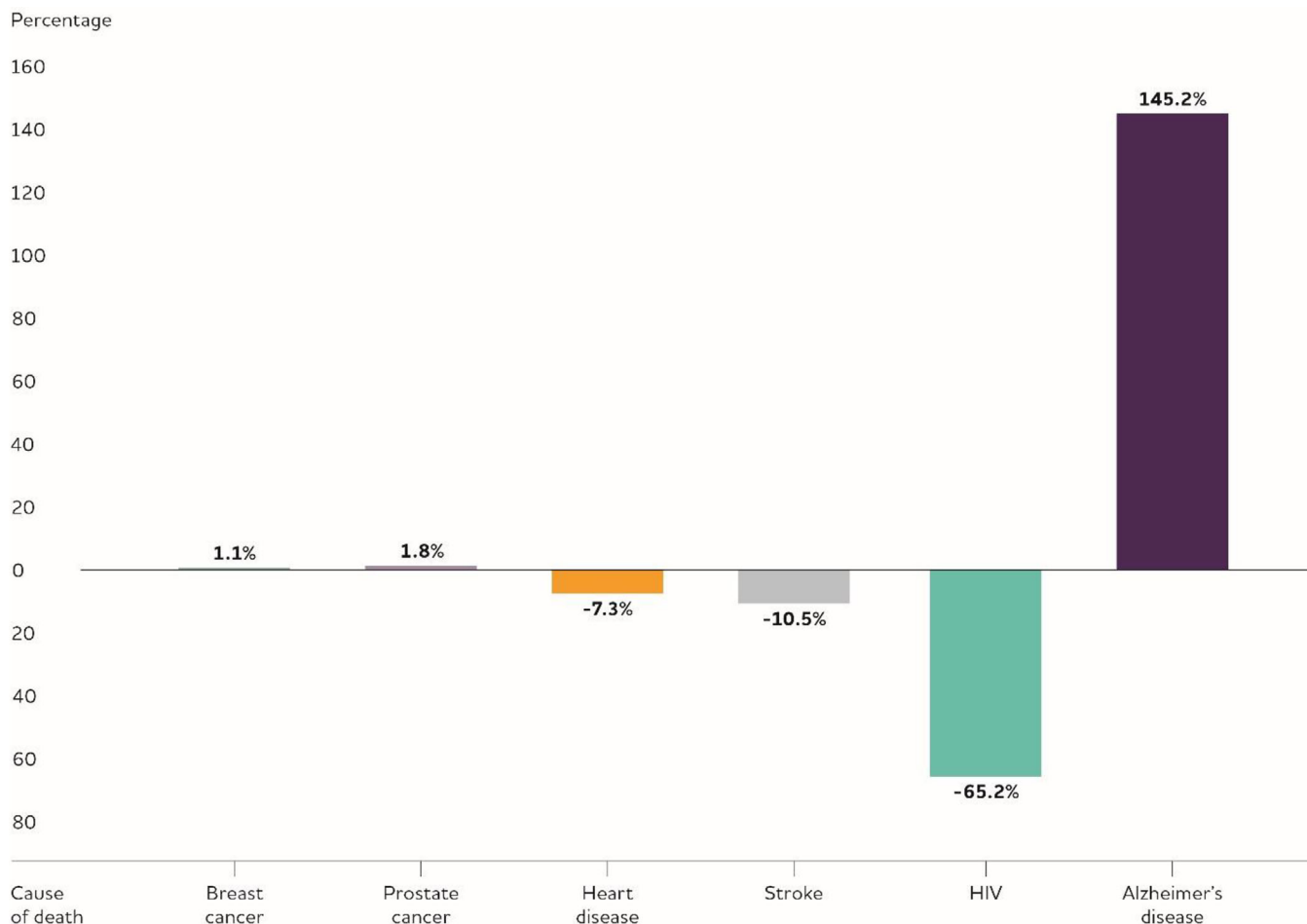


FIGURE 7 Percentage changes in selected causes of death (all ages) between 2000 and 2019. Created from data from the National Center for Health Statistics.^{330,343}

death in those who have Alzheimer's dementia with the estimated risk of death in those who do not have Alzheimer's dementia. A study using data from the Rush Memory and Aging Project and the Religious Orders Study estimated that 500,000 deaths among people age 75 and older in the United States in 2010 could be attributed to Alzheimer's dementia (estimates for people age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if those individuals did not have Alzheimer's dementia.³³⁸ A more recent study using data from the nationally representative Health and Retirement Study estimated that about 14% of deaths in Americans age 70 and older from 2000-2009 were attributable to dementia, while only 5% of death certificates listed dementia as the underlying cause of death for this age group in that time period, indicating underreporting on death certificates.³³⁹ According to 2014 Medicare claims data, about one-third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or another dementia.³⁴⁰ Based on data from the Chicago Health and Aging Project (CHAP) study, in 2020 an estimated 700,000 people age 65 and older in the United States had Alzheimer's at death.³⁴¹ The true number of deaths caused by Alzheimer's is somewhere between the number of deaths from Alzheimer's recorded on death certificates and the number of

people who have Alzheimer's disease when they die. Although some older adults who have Alzheimer's disease at the time of death die from causes that are unrelated to Alzheimer's, many die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia.

To add further complexity, the vast majority of death certificates listing Alzheimer's disease or dementia as an underlying cause of death are not verified by autopsy, and research has shown that about 15% to 30% of those diagnosed with Alzheimer's dementia during life do not in fact have dementia due to Alzheimer's disease, but have dementia due to another cause (see Table 1).^{11,73,220-222} Therefore, an underlying cause of death listed as Alzheimer's disease may not be accurate. In this section, "deaths from Alzheimer's disease" refers to what is officially reported on death certificates, with the understanding that the person filling out the report believed dementia due to Alzheimer's disease was the underlying cause of death, usually without pathologic confirmation.

Irrespective of the cause of death, among people age 70, 61% of those with Alzheimer's dementia are expected to die before age 80 compared with 30% of people without Alzheimer's dementia.³⁴²

TABLE 5 Number of Deaths and Annual Mortality Rate (per 100,000) Due to Alzheimer's Disease by State, 2019

State	Number of Deaths	Mortality Rate	State	Number of Deaths	Mortality Rate
Alabama	2,659	54.2	Montana	326	30.5
Alaska	128	17.5	Nebraska	768	39.7
Arizona	3,047	41.9	Nevada	678	22
Arkansas	1,507	49.9	New Hampshire	511	37.6
California	16,859	42.7	New Jersey	2,629	29.6
Colorado	1,909	33.1	New Mexico	568	27.1
Connecticut	967	27.1	New York	3,753	19.3
Delaware	339	34.8	North Carolina	4,508	43
District of Columbia	81	11.5	North Dakota	403	52.9
Florida	6,539	30.4	Ohio	5,234	44.8
Georgia	4,221	39.8	Oklahoma	1,775	44.9
Hawaii	471	33.3	Oregon	1,992	47.2
Idaho	650	36.4	Pennsylvania	4,150	32.4
Illinois	3,954	31.2	Rhode Island	456	43
Indiana	2,561	38	South Carolina	2,323	45.1
Iowa	1,344	42.6	South Dakota	495	56
Kansas	839	28.8	Tennessee	3,252	47.6
Kentucky	1,684	37.7	Texas	10,101	34.8
Louisiana	2,165	46.6	Utah	980	30.6
Maine	544	40.5	Vermont	315	50.5
Maryland	1,012	16.7	Virginia	2,631	30.8
Massachusetts	1,663	24.1	Washington	3,585	47.1
Michigan	4,467	44.7	West Virginia	832	46.4
Minnesota	2,552	45.3	Wisconsin	2,390	41
Mississippi	1,662	55.8	Wyoming	238	41.1
Missouri	2,782	45.3	U.S. Total	121,499	37

Created from data from the National Center for Health Statistics.^{A6,330}

4.3 | Public health impact of deaths from Alzheimer's disease

Although deaths from other major causes have *decreased* significantly or remained approximately the same, official records indicate that deaths from Alzheimer's disease have *increased* significantly. Between 2000 and 2019, the number of deaths from Alzheimer's disease as recorded on death certificates more than doubled, increasing 145.2%, while deaths from the number one cause of death (heart disease) decreased 7.3% (Figure 7).^{330,343} The increase in the number of death certificates listing Alzheimer's as the underlying cause of death probably reflects both a real increase in the actual number of deaths from Alzheimer's due in large part to Alzheimer's becoming a more common cause of death as the population ages, as well as increased reporting of Alzheimer's deaths on death certificates over time by physicians, coroners and others who assign causes of death.³⁴⁴

4.4 | State-by-state deaths from Alzheimer's

Table 5 provides information on the number of deaths due to Alzheimer's by state in 2019, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death. The table also provides annual mortality rates by state to compare the risk of death due to Alzheimer's disease across states with varying population sizes. For the United States as a whole, in 2019, the mortality rate for Alzheimer's disease was 37 deaths per 100,000 people.^{A6,330}

4.5 | Alzheimer's death rates

As shown in Figure 8, the rate of deaths due to Alzheimer's has risen substantially since 2000.³³⁰ Table 6 shows that the rate of death

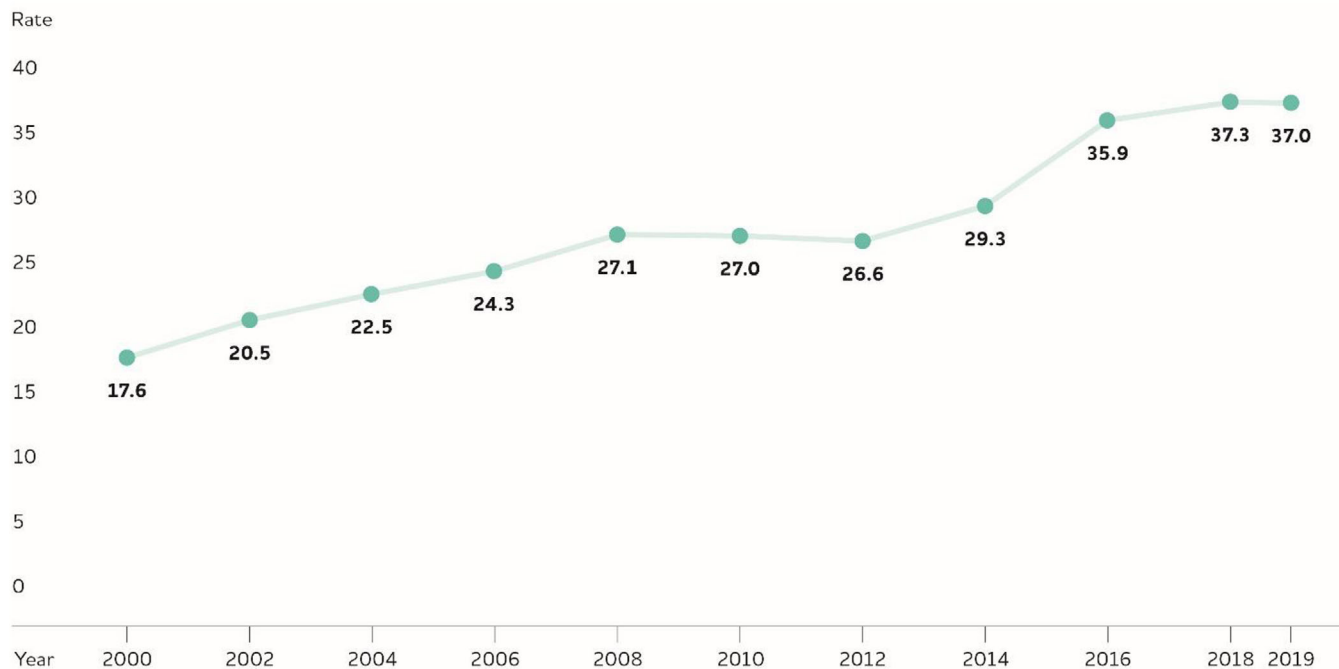


FIGURE 8 U.S. annual Alzheimer's death rate (per 100,000) by year. Created from data from the National Center for Health Statistics.³³⁰

from Alzheimer's increases dramatically with age, especially after age 65.^{A6,330} The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old.³⁴³ Between 2000 and 2019, the death rate from Alzheimer's increased 33% for people age 65 to 74, but increased 51% for people age 75 to 84 and 78% for people age 85 and older.³³⁰ A report by the CDC determined that even after adjusting for differences in age distributions over time, the annual Alzheimer's death rate in the United States increased substantially between 1999 and 2014.³⁴⁴ Therefore, the growing proportion of older adults in the country is not the only explanation for the increase in Alzheimer's death rates. Other possible reasons include fewer deaths from other common causes of death in old age such as heart disease and stroke; increased clinical recognition of and formal diagnosis of Alzheimer's dementia; and increased reporting of Alzheimer's as a cause of death by physicians and others who fill out death certificates.³⁴⁴

4.6 | Duration of illness from diagnosis to death

Studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's dementia, yet some live as long as 20 years with Alzheimer's dementia.^{242,345–352} This reflects the slow, insidious and uncertain progression of Alzheimer's. A person who lives from age 70 to age 80 with Alzheimer's dementia will spend an average of 40% of this time in the severe stage.³⁴² Much of this time will be spent in a nursing home. At age 80, approximately 75% of people with Alzheimer's dementia live in a nursing home compared with only 4% of the general population age 80.³⁴² In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared

with 20% of people with cancer and 28% of people dying from all other conditions.³⁵³

4.7 | Burden of Alzheimer's disease

The long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease because much of that time is spent in a state of disability and dependence. Scientists have developed methods to measure and compare the burden of different diseases on a population in a way that takes into account not only the number of people with the condition, but also the number of years of life lost due to that disease and the number of healthy years of life lost by virtue of being in a state of disability. The primary measure of disease burden is called disability-adjusted life years (DALYs), which is the sum of the number of years of life lost (YLLs) due to premature mortality and the number of years lived with disability (YLDs), totaled across all those with the disease or injury. These measures indicate that Alzheimer's is a very burdensome disease, not only to the individuals with the disease, but also to their families and informal caregivers, and that the burden of Alzheimer's has increased more dramatically in the United States than the burden of other diseases in recent years. According to the most recent Global Burden of Disease classification system, Alzheimer's disease rose from the 12th most burdensome disease or injury in the United States in 1990 to the sixth in 2016 in terms of DALYs. In 2016, Alzheimer's disease was the fourth highest disease or injury in terms of YLLs and the 19th in terms of YLDs.³⁵⁴

Taken together, these statistics indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, but

TABLE 6 U.S. Annual Alzheimer's Death Rates (per 100,000) by Age and Year

Age	2000	2002	2004	2006	2008	2010	2012	2014	2016	2018	2019
45-54	0.2	0.1	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.3	0.3
55-64	2.0	1.9	1.8	2.1	2.2	2.1	2.2	2.1	2.7	2.9	3.0
65-74	18.7	19.6	19.5	19.9	21.1	19.8	17.9	19.6	23.6	24.7	24.9
75-84	139.6	157.7	168.5	175.0	192.5	184.5	175.4	185.6	214.1	213.9	210.2
85+	667.7	790.9	875.3	923.4	1,002.2	987.1	936.1	1,006.8	1,216.9	1,225.3	1,191.3

Created from data from the National Center for Health Statistics.³³⁰

also that the disease is contributing to more and more cases of poor health and disability in the United States.

5 | CAREGIVING

Caregiving refers to attending to another person's health needs and well-being. Caregiving often includes assistance with one or more activities of daily living (ADLs), including bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation.^{355,356} Caregivers also provide emotional support to people with Alzheimer's as well as communicating and coordinating care with other family members and health care providers, ensuring safety at home and elsewhere, and managing health conditions (see Table 7). In addition to providing descriptive information about caregivers of people with Alzheimer's or other dementias, this section compares caregivers of people with dementia to either caregivers of people with other medical conditions or, if that comparison is not available, to people who are not caregivers (referred to here as non-caregivers).

5.1 | Unpaid caregivers

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers.³⁵⁹ Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.³⁶⁰ More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.^{A7}

In 2020, caregivers of people with Alzheimer's or other dementias provided an estimated 15.3 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at \$256.7 billion. This is approximately 49% of the net value of Walmart's total revenue in fiscal year 2020 (\$524 billion)³⁶¹ and 12 times the total revenue of McDonald's in 2019 (\$21.1 billion).³⁶² The total lifetime cost of care for someone with dementia was estimated at \$373,527 in 2020 dollars. Seventy percent of the lifetime cost of care is borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses for items ranging from medications to food for the person with dementia.^{363,364} Current estimates of the lifetime costs of care may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity.³⁶⁵

TABLE 7 Dementia Caregiving Tasks

Helping with instrumental activities of daily living (IADLs), such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.
Helping the person take medications correctly, either via reminders or direct administration of medications.
Helping the person adhere to treatment recommendations for dementia or other medical conditions.
Assisting with personal activities of daily living (ADLs), such as bathing, dressing, grooming and feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.
Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
Finding and using support services such as support groups and adult day service programs.
Making arrangements for paid in-home, nursing home or assisted living care.
Hiring and supervising others who provide care.
Assuming additional responsibilities that are not necessarily specific tasks, such as: <ul style="list-style-type: none"> • Providing overall management of getting through the day. • Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver. • Managing other health conditions (i.e., comorbidities), such as arthritis, diabetes or cancer. • Providing emotional support and a sense of security.

Three of the main reasons caregivers provide assistance to a person with Alzheimer's or another dementia are: (1) the desire to keep a family member or friend at home (65%), (2) proximity to the person with dementia (48%) and (3) the caregiver's perceived obligation to the person with dementia (38%).^{A8} Caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend living with dementia.³⁶⁶

Individuals with dementia living in the community are more likely than older adults without dementia to rely on multiple unpaid caregivers (often family members); 30% of older adults with dementia rely

on three or more unpaid caregivers, whereas 23% of older adults without dementia rely on three or more unpaid caregivers.³⁶⁷ Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8%). Of these individuals, nearly half live alone, perhaps making it more difficult to ask for and receive informal care.³⁶⁷ Of caregivers of spouses with dementia who are at the end of life, close to half provide care without the help of other family or friends.³⁶⁸ Living alone with dementia may be a particular challenge for certain subgroups, such as lesbian, gay, bisexual and transgender (LGBT) individuals, who may experience greater isolation for reasons ranging from social stigma to a diminished social network of available family or friend caregivers.³⁶⁹

5.1.1 | Calculating the number of caregivers

The estimated number of caregivers for people with Alzheimer's and other dementias in 2020 (11.2 million) is significantly lower than previous estimates of the number of caregivers. As noted in last year's *Alzheimer's Disease Facts and Figures* report, preliminary analysis of recently released data on caregivers indicated that the number of family caregivers for all older Americans had declined compared with a decade earlier. Because the previous version of the model used to estimate the number of dementia caregivers had incorporated data from 2009 (the most recent date for which some data were available), the model had not reflected these broader trends.

With the release of newer data over the last few years — including, most notably, more detailed state-specific data on dementia caregivers that allows for more precise estimates for each state (as opposed to applying national data to each state) — the Alzheimer's Association worked with caregiving and modeling experts to rebuild the caregiving model with entirely new methodology, inputs and assumptions. The result is that the number of unpaid dementia caregivers declined over the decade from 14.9 million in 2010, according to an earlier *Alzheimer's Disease Facts and Figures* report, to 11.2 million in 2020.

This comparison is consistent with the data showing fewer unpaid caregivers in total compared with a decade ago. The previous model, using the best available data at the time, did not reflect this broader trend, and in fact showed slight year-over-year increases. Thus, the current estimate should be compared with a decade ago, not with the number reported for 2019 in last year's report. For the future, the new model has been designed to allow for easier incorporation of newer data as it is released, including data from individual states, to increase the likelihood that trends in the prevalence and burden of dementia caregiving will be identified in a more timely fashion.

While the number of unpaid caregivers — both overall and for people living with dementia — has declined, this does not reflect a significant lessening in the amount of care provided. Data for both caregivers in general and for dementia caregivers as reflected in the new model show that as the number of unpaid caregivers decreased, the amount of care each remaining caregiver provided increased, placing an even greater burden on those providing care. In fact, a dementia caregiver today is providing, on average, 20.2% more hours of care each week

compared with a dementia caregiver a decade ago. In other words, the amount of care received by a person with dementia is about the same, but it is provided by fewer people.

Finally, while rebuilding the caregiving model, external experts advised that the Association was undervaluing the care provided by unpaid caregivers by being too conservative in the method used to assess the economic value of care. The experts noted that most other assessments of caregiver value used a less conservative methodology. In light of this advice, the new model incorporates an assessment method^{A10} that is more consistent with, but still more conservative than, the expert recommendations. This has resulted in an increase in the estimate of the economic value of unpaid care, even while the number of caregivers has declined.

5.1.2 | Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's or other dementias in the United States. They have found the following:^{A8,370-374}

- Approximately two-thirds of dementia caregivers are women.^{A8,370,371}
- About 30% of caregivers are age 65 or older.^{A8}
- Over 60% of caregivers are married, living with a partner or in a long-term relationship.^{A8,371}
- Over half of caregivers are providing assistance to a parent or in-law with dementia.³⁷⁴ Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.^{374,375}
- Two-thirds of caregivers are White,^{A8,371,374} 10% are Black, 8% are Hispanic and 5% are Asian American.^{A8} The remaining 10% represent a variety of other racial/ethnic groups.
- Approximately 40% of dementia caregivers have a college degree or more education.^{A8,371,374}
- Forty-one percent of caregivers have a household income of \$50,000 or less.^{A8}
- Among primary caregivers (individuals who indicate having the most responsibility for helping their relatives) of people with dementia, over half take care of their parents.^{373,376,377}
- Most caregivers (66%) live with the person with dementia in the community.³⁶⁷
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for a child.^{A8,374,375}
- Twenty-three percent of all caregivers ages 18 to 49 help someone with dementia, which is an increase of 7% since 2015.³⁷⁸

5.1.3 | Caregiving and women

The responsibilities of caring for someone with dementia often fall to women. As mentioned earlier, approximately two-thirds of dementia caregivers are women.^{A8,370,371,376,377} Over one-third of

dementia caregivers are daughters.^{359,367} It is more common for wives to provide informal care for a husband than vice versa.³⁷⁹ On average, female caregivers spend more time caregiving than male caregivers.³⁶⁷ According to the 2014 Alzheimer's Association Women and Alzheimer's Poll which surveyed both men and women, two-thirds of those providing care for 21 hours or more (67%) were women.³⁸⁰ Similarly, the 2015-2017 Behavioral Risk Factor Surveillance System (BRFSS) surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.³⁷⁵ Two and a half times as many women as men reported living with the person with dementia full time.³⁸⁰ Of those providing care to someone with dementia for more than five years, 63% were women.³⁷⁵ Similarly, caregivers who are women may experience slightly higher levels of burden, impaired mood, depression and impaired health than caregivers who are men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, assume more caregiving tasks, and care for someone with more cognitive, functional and/or behavioral problems.³⁸¹⁻³⁸³ Of dementia caregivers who indicated a need for individual counseling or respite care, the large majority were women (individual counseling, 85%, and respite care, 84%).³⁷⁵

5.1.4 | Race, ethnicity and dementia caregiving

Only recently have population-based studies examined racial disparities in caregiving for older people. When compared with White caregivers, Black caregivers are more likely to provide more than 40 hours of care per week (54.3% versus 38.6%) and are also more likely to care for someone with dementia (31.7% versus 11.9%). Black dementia caregivers were found to be 69% less likely to use respite services when compared with White caregivers.³⁸⁴ Hispanic, Black, and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use, and greater depression when compared with White caregivers.³⁸⁵⁻³⁸⁷ Mexican American older adults who live alone experience dual risks of both greater cognitive impairment and receiving low support from others when compared to Mexican American older adults who live with others.³⁸⁸ Cultural values may also influence gender disparities in perceptions of support among caregivers across diverse racial and ethnic contexts.³⁸⁹

Black caregivers are more likely than White caregivers to report positive aspects of caregiving.³⁹⁰ A meta-analysis found that Black dementia caregivers indicate slightly higher psychological well-being than White dementia caregivers. Hispanic dementia caregivers, however, reported slightly lower physical well-being than White dementia caregivers.³⁹¹ Other research has examined variations in self-rated health among dementia caregivers of diverse racial and ethnic backgrounds. Support from family and friends is associated with better self-rated health for Black dementia caregivers, but not for White or Hispanic caregivers. A more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among Black and White caregivers.³⁸⁵

Dementia caregiving is clearly common, regardless of race or ethnicity. The comparisons above suggest that the experience of caregiv-

ing may vary depending on racial and ethnic context, perhaps intersecting with research. Studies of caregivers often lack sufficient numbers of diverse participants to confirm these findings or delve deeper into them for important insights. Recent reviews and national summits have emphasized the need to revise recruitment strategies to capture the range of dementia care experiences among Black caregivers, indigenous caregivers and caregivers of color.³⁸⁷ If representation in dementia care research is not improved, our ability to generalize findings or determine whether findings vary by diverse subgroups is not possible. This hinders the progress of all Alzheimer's disease caregiving research. In addition, if these individuals continue to lack representation in Alzheimer's research, they will not receive the benefits of prevention, treatment or care innovations.³⁸⁷ Establishing stronger relationships with existing organizations and resources in Black communities, indigenous communities and communities of color offer the potential of research-based partnerships that enhance representation in Alzheimer's disease research.^{374,375} In addition, a greater understanding of how multiple chronic diseases (multimorbidity) intersect with dementia among Blacks, indigenous peoples, and people of color is needed.³⁹¹

5.1.5 | Caregiving tasks

The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all-encompassing. Table 7 summarizes some of the most common types of dementia care provided.

Though the care provided by family members of people with Alzheimer's or other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely to monitor the health of the care recipient than are caregivers of people without dementia (79% versus 66%).³⁹³ Data from the 2011 National Health and Aging Trends Study indicated that caregivers of people with dementia are more likely than caregivers of people without dementia to provide help with self-care and mobility (85% versus 71%) and health or medical care (63% versus 52%).^{360,370} Figure 9 illustrates how family caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.³⁷⁴

People with dementia tend to have larger networks of family and friends involved in their care compared with people without dementia. Family members and friends in dementia care networks tend to provide help for a larger number of tasks than do those in non-dementia care networks.³⁹⁴

When a person with Alzheimer's or another dementia moves to an assisted living residence or a nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 7 to providing emotional support, interacting with residential care staff and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing and other ADLs.^{394,395}

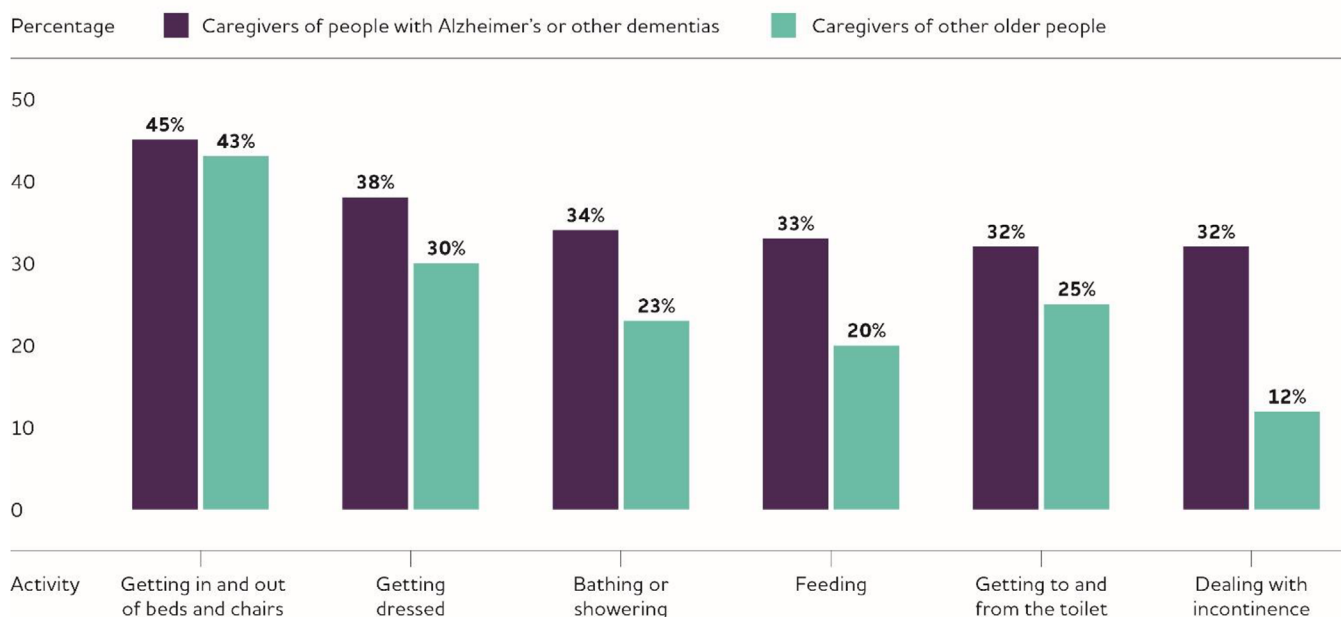


FIGURE 9 Proportion of caregivers of people with Alzheimer's or other dementias versus caregivers of other older people who provide help with specific activities of daily living, United States, 2015. Created from data from the National Alliance for Caregiving and AARP.³⁷⁴

5.1.6 | Duration of caregiving

In 2014, 86% of dementia caregivers provided assistance for at least the past year.^{A8} According to another study, well over half (57%) of family caregivers of people with Alzheimer's or other dementias living in the community had provided care for four or more years.³⁶⁷

5.1.7 | Hours of unpaid care and economic value of caregiving

In 2020, the 11.2 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 15.3 billion hours of unpaid help. This number represents an average of 26.3 hours of care per caregiver per week, or 1,369 hours of care per caregiver per year.^{A9} With this care valued at the average of the state minimum wage and the median hourly cost of a home health aide,^{A10} the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was more than \$256.7 billion in 2020. Table 8 shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's or other dementias provided care valued at more than \$4 billion in each of 21 states. Unpaid caregivers in each of the four most populous states — California, Florida, New York and Texas — provided care valued at more than \$10 billion. A longitudinal study of the monetary value of family caregiving for people with dementia found that the overall value of daily family care increased 18% with each additional year of providing care, and that the value of this care further increased as the care recipient's cognitive abilities declined.³⁹⁷ Additional research is needed to estimate the future value

of family care for people with Alzheimer's disease and other dementias as the U.S. population continues to age.

Apart from its long duration, caregiving involves immediate demands that are also time-intensive. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.³⁷⁰ An analysis of national caregiving trends from 1999 to 2015 found that the average hours of care per week increased from 45 in 1999 to 48 in 2015 for dementia caregivers; over the same time period, weekly hours of care decreased for non-dementia caregivers from 34 to 24.³⁹⁸ The amount of time required for caregiving increases as dementia progresses; one study showed that people with dementia required 151 hours of caregiving per month at the outset of dementia and increased to 283 hours per month eight years later.³⁹⁹ Each instance of a decrease in an ADL or IADL in someone with dementia results in close to five more hours of monthly caregiving compared with a similar functional decrease for someone without dementia.⁴⁰⁰

5.1.8 | Health and economic impacts of Alzheimer's caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the moderate-to-severe stages of Alzheimer's dementia experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are affected as well, and these changes are often among the most challenging for family caregivers.^{401–403} Individuals with Alzheimer's also require increasing levels of supervision and personal care as the disease

TABLE 8 Number of Caregivers of People with Alzheimer's or Other Dementias, Hours of Unpaid Care and Economic Value of Unpaid Care by State, 2020*

State	Number of Caregivers (in thousands)	Hours of Care (in millions)	Value of Care (in millions of dollars)
Alabama	206	225	\$2,842
Alaska	12	21	\$406
Arizona	262	511	\$9,711
Arkansas	93	140	\$2,098
California	1,120	884	\$18,126
Colorado	158	184	\$3,675
Connecticut	142	156	\$2,877
Delaware	46	67	\$1,141
District of Columbia	15	16	\$322
Florida	527	685	\$10,636
Georgia	334	640	\$9,198
Hawaii	51	81	\$1,621
Idaho	40	47	\$719
Illinois	381	480	\$8,514
Indiana	215	274	\$4,288
Iowa	73	60	\$995
Kansas	85	95	\$1,396
Kentucky	149	265	\$3,841
Louisiana	204	318	\$3,854
Maine	46	68	\$1,378
Maryland	238	364	\$6,560
Massachusetts	281	406	\$8,602
Michigan	463	491	\$8,509
Minnesota	170	155	\$3,326
Mississippi	131	227	\$2,925
Missouri	194	292	\$4,741
Montana	16	24	\$425
Nebraska	61	51	\$894
Nevada	48	78	\$1,334
New Hampshire	57	82	\$1,495
New Jersey	347	658	\$12,178
New Mexico	85	157	\$2,511
New York	586	774	\$14,620
North Carolina	358	517	\$7,302
North Dakota	19	29	\$521
Ohio	442	590	\$9,633
Oklahoma	129	244	\$3,814
Oregon	155	257	\$5,274
Pennsylvania	500	622	\$9,726
Rhode Island	38	48	\$1,026

(Continues)

TABLE 8 (Continued)

State	Number of Caregivers (in thousands)	Hours of Care (in millions)	Value of Care (in millions of dollars)
South Carolina	199	298	\$4,354
South Dakota	19	18	\$339
Tennessee	357	483	\$6,823
Texas	1,079	1,759	\$25,726
Utah	104	144	\$2,397
Vermont	25	36	\$717
Virginia	349	521	\$7,886
Washington	295	426	\$9,620
West Virginia	85	145	\$1,971
Wisconsin	196	204	\$3,386
Wyoming	16	21	\$379
National	11,199	15,338	\$256,650

*State totals may not add to the U.S. total due to rounding. Created from data from the 2015–2019 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, National Alliance for Caregiving, AARP, U.S. Department of Labor and Genworth.^{A7,A9,A10}

progresses. As the person with dementia's symptoms worsen, caregivers can experience increased emotional stress and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and people living with dementia.^{404–412}

Caregiver emotional and social well-being

The intimacy, shared experiences and memories that are often part of the relationship between a caregiver and person living with dementia may be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's. In a national poll, however, 45% of caregivers of people with dementia indicated that providing help to someone with cognitive impairment was very rewarding.³⁷⁷ In a national study, greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends.⁴¹³ Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,^{A8,414–420} they also frequently report higher levels of stress.

Burden and stress

- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.³⁷⁰
- Fifty-nine percent of family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high (Figure 10).^{A8}
- Spousal dementia caregivers are more likely than non-spousal dementia caregivers to experience increased burden over time. This increased burden also occurs when the person with dementia develops behavioral changes and decreased functional ability.⁴²¹

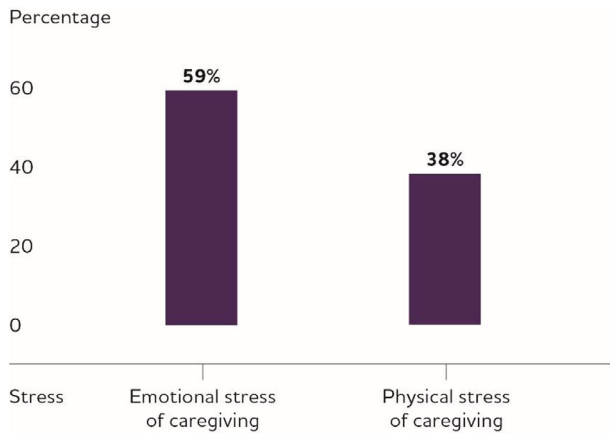


FIGURE 10 Percentage of caregivers who report high to very high stress due to caregiving. Created from data from the Alzheimer's Association.^{A8}

- Many people with dementia have co-occurring chronic conditions, such as hypertension or arthritis. A national study of caregivers of people with dementia living with additional chronic conditions found that caregivers of people with dementia who had a diagnosis of diabetes or osteoporosis were 2.6 and 2.3 times more likely, respectively, to report emotional difficulties with care compared with caregivers of people with dementia who did not have these co-occurring conditions.⁴²²

Depression and mental health

- A meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers.³⁸³ Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.⁴²³ Approximately 30% to 40% of family caregivers of people with dementia report depression, compared with 5% to 17% of non-caregivers of similar ages.⁴²⁴⁻⁴²⁹
- The prevalence of depression is higher among dementia caregivers (30% to 40%) than other caregivers, such as those who provide help to individuals with schizophrenia (20%) or stroke (19%).^{428,430,431}
- Among spousal caregivers, having a partner with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.⁴³²
- In a meta-analysis, the type of relationship was the strongest predictor of caregiver depression; caregivers of spouses with dementia had two-and-a-half times higher odds of having depression than caregivers of people with dementia who were not spouses.⁴²⁸
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).⁴²⁸
- Caregivers of individuals with Alzheimer's report more subjective cognitive problems (for example, problems with memory) and experience greater declines in cognition over time than non-caregivers matched on age and other characteristics.^{433,434}
- Caring for people with dementia who have four or more behavioral and psychological symptoms (for example, aggression, self-

harm and wandering) represents a "tipping point" for family caregivers, as they are more likely to report clinically meaningful depression and burden (that is, negative emotional reactions to providing care).⁴³⁵

Strain

- Caregivers of people with Alzheimer's or other dementias were twice as likely as caregivers of individuals without dementia (22% compared with 11%) to report that completing medical/nursing-related tasks (for example, injections, tube feedings and catheter/colostomy care) was difficult.³⁹³
- Dementia caregivers often lack the information or resources necessary to manage complex medication regimens.⁴³⁶⁻⁴³⁹
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.^{A8}
- The poll also found that more than half of women with children under age 18 felt that caregiving for someone with dementia was more challenging than caring for children (53%).^{A8}
- Many caregivers of people with Alzheimer's or other dementias provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.^{A8}
- A population-based sample of caregivers found that although dementia caregivers indicated greater strain than non-dementia caregivers, no substantial differences in strain between White and Black dementia caregivers were evident.⁴⁴⁰

Stress of care transitions

- Individuals who assume care responsibilities for someone with dementia are more likely to report a decline in social network size than those helping people without dementia.⁴⁴¹
- Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility for some caregivers (such as spouses), but other studies have found that distress declines following admission overall for dementia caregivers.^{396,442-443}
- The demands of caregiving may intensify as people with dementia approach the end of life.⁴⁴⁴ In the year before the death of the person living with dementia, 59% of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful.⁴⁴⁵ The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.⁴⁴⁵ In the last 12 months of life, people with dementia relied on more hours of family care (64.5 hours per week) than people with cancer (39.3 hours per week).⁴⁴⁶ In addition, caregivers living with a family member with dementia pay for 64% of total care costs incurred during their family member's last seven years of life.⁴⁴⁷

TABLE 9 Percentage of Dementia Caregivers Reporting Health Conditions by State

State	% of Caregivers Reporting at Least One Chronic Condition	% of Caregivers Reporting Depression	% of Caregivers Reporting Frequent Poor Physical Health	State	% of Caregivers Reporting at Least One Chronic Condition	% of Caregivers Reporting Depression	% of Caregivers Reporting Frequent Poor Physical Health
Alabama	59.8	28.3	12.9	Montana	56.9	22.8	10.0
Alaska	*	*	*	Nebraska	55.6	19.3	8.8
Arizona	53.5	15.4	9.9	Nevada	80.2	18.3	*
Arkansas	73.4	23.4	11.4	New Hampshire	†	†	†
California	*	*	*	New Jersey	68.1	27.4	13.0
Colorado	73.1	23.2	14.0	New Mexico	56.3	34.2	7.9
Connecticut	47.0	17.6	*	New York	52.2	28.4	17.0
Delaware	†	†	†	North Carolina	†	†	†
District of Columbia	65.1	20.5	*	North Dakota	62.0	14.4	14.0
Florida	47.8	16.3	*	Ohio	67.8	13.6	16.1
Georgia	54.0	21.6	13.7	Oklahoma	53.5	27.5	*
Hawaii	65.3	14.9	10.5	Oregon	53.7	19.9	16.7
Idaho	73.7	30.8	16.7	Pennsylvania	62.0	24.0	16.1
Illinois	53.5	21.4	16.7	Rhode Island	54.8	27.4	14.9
Indiana	64.0	26.8	6.9	South Carolina	54.2	21.9	11.8
Iowa	63.9	28.7	11.8	South Dakota	40.9	9.4	65.8
Kansas	62.9	23.5	13.5	Tennessee	66.7	29.8	17.0
Kentucky	69.6	27.1	20.2	Texas	56.4	10.7	*
Louisiana	54.7	20.8	16.7	Utah	69.0	22.3	10.7
Maine	69.8	25.4	11.1	Vermont	†	†	†
Maryland	68.8	27.7	13.6	Virginia	60.4	23.6	13.8
Massachusetts	†	†	†	Washington	†	†	†
Michigan	59.2	27.2	21.5	West Virginia	72.2	25.3	16.6
Minnesota	55.3	29.9	14.4	Wisconsin	57.0	17.8	10.7
Mississippi	60.2	14.9	11.0	Wyoming	46.4	17.1	15.0
Missouri	64.1	35.8	13.3	National	57.5%	24.4%	13.0%

Created from data from the Behavioral Risk Factor Surveillance System (BRFSS) survey.³⁷⁵

*Data not included because the sample size was less than 50 or the relative standard error was greater than 50%.

†State did not collect data between 2015–2017.

Caregiver physical health and health conditions

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications.⁴⁴⁸ As shown in Figure 10, 38% of Alzheimer's and other dementia caregivers indicate that the physical stress of caregiving is high to very high.^{A8} The distress associated with caring for a relative with Alzheimer's or another dementia has also been shown to negatively influence the quality of family caregivers' sleep.^{449,450} Compared with those of the same age who were not caregivers, caregivers of people with dementia are estimated to lose between 2.4 hours and 3.5 hours of sleep a week.⁴⁵⁰ In addition, many caregivers may contend with health challenges of their own. Tables 9 and 10 present data from 44 states and the District of Columbia on caregiver physical and

mental health. Table 9 presents state-by-state data on the health status of dementia caregivers and Table 10 compares the percentages of dementia caregivers, non-dementia caregivers, and non-caregivers who report having a specific chronic health condition.

General health

Seventy-four percent of caregivers of people with Alzheimer's or other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.^{A8} A 2017 poll found that 27% of dementia caregivers delayed or did not do things they should to maintain their own health.³⁷⁷ Dementia caregivers indicate lower health-related quality of life than non-caregivers and are more likely than non-caregivers or other caregivers to report that their health is fair or poor.^{410,451,452} Data from the

TABLE 10 Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2%	3.4%	3.2%
Coronary heart disease	8.3%	7.2%	6.6%
Cardiovascular disease*	11.8%	9.5%	8.6%
Diabetes	12.8%	11.1%	11.3%
Cancer	14.3%	13.3%	11.5%
Obesity	32.7%	34.6%	29.5%

Table includes caregivers age 18 and older.

*Combination of coronary heart disease and stroke.

Health and Retirement Study showed that dementia caregivers who provided care to spouses were much more likely (41% increased odds) than other spousal caregivers of similar age to become increasingly frail during the time between becoming a caregiver and their spouse's death.⁴⁵³ Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.⁴⁵⁴

Physiological changes

The chronic stress of caregiving may be associated with an increased incidence of hypertension^{404,455-462} and a number of physiological changes that could increase the risk of developing chronic conditions, including high levels of stress hormones,⁴³⁴ impaired immune function,^{404,456} slow wound healing⁴⁵⁷ and coronary heart disease.⁴⁵⁸ A recent meta-analysis of studies examining the associations between family caregiving, inflammation and immune function suggests that dementia caregivers had slight reductions in immune function and modestly elevated inflammation.⁴⁶³ However, a study of physiological changes before and after the start of caregiving found no change on six biomarkers of inflammation among dementia caregivers.⁴⁶⁴

Health care

When persons with dementia also have depression, behavioral disturbances or low functional status, their caregivers face a higher risk of emergency department visits and hospitalization compared with caregivers of persons with dementia alone.^{465,466} Increased depressive symptoms among caregivers over time are linked to more frequent doctor visits, increased outpatient tests and procedures, and greater use of over-the-counter and prescription medications.⁴⁶⁶

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.^{467,468} For example, caregivers of spouses who were hospitalized and had dementia were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia (after accounting for differences in caregiver age).⁴⁶⁹ In addition, caregivers who perceive higher strain due to care responsibilities were at higher risk for death than

caregivers who perceive little or no strain.⁴⁷⁰ In contrast, a longitudinal analysis of the Health and Retirement Study found that dementia caregivers were less likely to die than non-caregivers of similar age over a 12-year period. These results are consistent with a protective effect of dementia care, at least as it pertains to death.⁴⁶⁷ The findings are also consistent with the possibility that individuals who assume dementia care roles do so in part because their initial health allows them to do so. Eighteen percent of spousal caregivers die before their partners with dementia.⁴⁷¹

Caregiver employment and finances

Six in 10 caregivers of people with Alzheimer's or another dementia were employed or had been employed in the prior year while providing care.³⁷⁴ These individuals worked an average of 35 hours per week while caregiving.³⁷⁴ Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 57% reported sometimes needing to go in late or leave early compared with 47% of non-dementia caregivers. Eighteen percent of dementia caregivers reduced their work hours due to care responsibilities, compared with 13% of non-dementia caregivers. Other work-related changes among dementia and non-dementia caregivers who had been employed in the past year are summarized in Figure 11.³⁷⁴

In 2020, it is estimated that dementia caregivers bore nearly twice the average out-of-pocket costs of non-dementia caregivers (\$11,535 versus \$6,209).^{364,472} Examples of these costs include costs of medical care, personal care and household expenses for the person with dementia, and personal expenses and respite services for the caregiver. Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey indicated that among care contributors (a friend or relative who paid for dementia expenses and/or provided care for someone with dementia at least once a month in the prior year), 48% cut back on other spending and 43% cut back on savings due to the out-of-pocket costs of providing help to someone with dementia.⁴¹¹ Due to care responsibilities in the year prior to the survey, close to 4 in 10 care contributors indicated that the "food they bought just didn't last, and they didn't have money to get more," and 3 in 10 ate less because of care-related costs.⁴¹¹

One in 5 caregivers of people with Alzheimer's or other dementias (22%) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia, compared with 9% of caregivers of people without dementia.³⁷⁴

Effects of stress and other caregiving factors on people with dementia

Research has documented the effects of caregiver stress on people with dementia and their use of health care services. For example, distress on the part of family caregivers is associated with increased odds of institutionalization of the person with dementia, exacerbated behavioral and psychological challenges in the person with dementia, and increased likelihood of people with dementia being abused.⁴⁷³ Individuals with dementia are more likely to be hospitalized if their caregiver has less than one year of caregiving experience when compared with caregivers who have provided assistance for more than one year.⁴⁷⁴ See the Use and Costs of Health Care, Long-Term Care, and Hospice section for additional information.

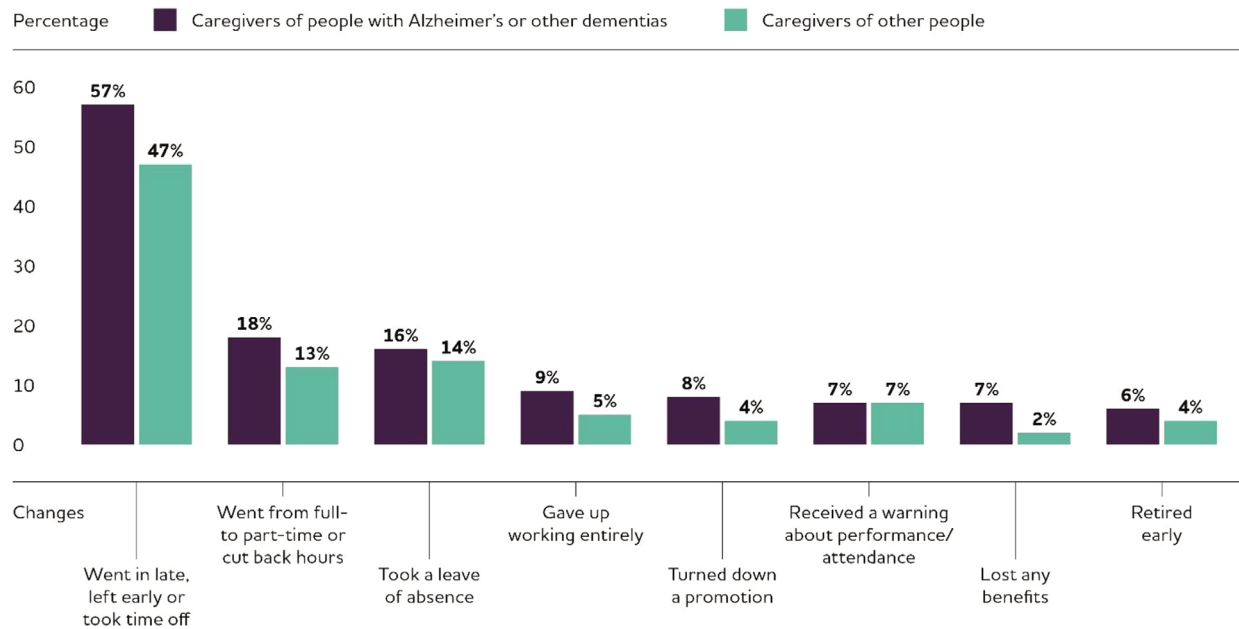


FIGURE 11 Work-related changes among caregivers of people with Alzheimer's or other dementias who had been employed at any time since they began caregiving. Created from data from the National Alliance for Caregiving and AARP.³⁷⁴

TABLE 11 Type and Focus of Caregiver Interventions

Type	Focus
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational approaches	Include structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite care for a certain number of weekly hours.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of isolation.
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of interventions, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

Created from data from Pinquart et al.⁴⁰⁸ and Gaugler et al.⁴⁷⁵

5.1.9 | Interventions designed to assist caregivers

For more than 30 years, strategies to support family caregivers of people with dementia have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 11.^{408,475}

In general, the goal of interventions is to improve the health and well-being of dementia caregivers by relieving the negative aspects of

caregiving. Some also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue helping their relatives or friends at home. Specific approaches used in various interventions include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers and providing caregivers with respite from caregiving duties.

According to a publication on dementia caregiver interventions that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers, but of people living with dementia as well.⁴⁷⁶ A 2012 report examined randomized, controlled studies of caregiver interventions and identified 44 interventions that benefited individuals with dementia as well as caregivers. More such interventions are emerging each year.⁴⁷⁷⁻⁴⁸² A meta-analysis examining the components of dementia caregiver interventions that are most beneficial found that interventions that initially enhance caregiving competency, gradually address the care needs of the person with dementia, and offer emotional support for loss and grief when needed appeared most effective.⁴⁸³ Recent meta-analyses suggest that specific intervention types (psychoeducation; see Table 11) may result in a small reduction in burden for caregivers, with other meta-analyses reporting broader effects of various interventions across multiple dementia caregiver outcomes.^{484,485} A meta-review of over 60 meta-analyses and systematic reviews of dementia caregiver interventions indicate that although various interventions may have positive effects on depression and other measures of caregiver well-being, challenges related to how interventions are reported and classified has made it difficult to ascertain what works and why for dementia caregivers.⁴⁸⁶

Interventions for dementia caregivers that have demonstrated efficacy in scientific evaluations have been gradually implemented in the community, but are still not widespread or available to all family caregivers.^{487,488} When interventions are implemented, they are generally successful at improving how caregiver services are delivered, and have the potential to reach a large number of families while also helping caregivers cope with their responsibilities.⁴⁸⁹ In one example, researchers utilized an "agile implementation" process to more rapidly select, localize, evaluate and replicate a collaborative care model for dementia care. This care model has successfully operated for nearly a decade in an Indianapolis health care system.⁴⁹⁰ Other efforts have attempted to broaden the reach and accessibility of interventions for dementia caregivers through the use of technologies (for instance, video-phone delivery and online training),⁴⁹¹⁻⁴⁹⁷ while others have integrated evidence-based dementia care interventions into community-based programs.⁴⁸⁹

Because caregivers and the settings in which they provide care are diverse, more studies are required to define which interventions are most effective for specific situations and how these interventions are successful.⁴⁹⁸⁻⁵⁰¹ Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.⁵⁰²⁻⁵⁰⁷ More studies are also needed to adapt proven interventions or develop new intervention approaches for families from different racial, ethnic and socioeconomic backgrounds and in different geographic settings (see the Special Report).⁵⁰⁸⁻⁵¹⁴ Additional research on interventions focused on disease stages is

also required, as is research on specific intervention needs for LGBT caregivers.³⁶⁹

In 2019, the National Institute on Aging (NIA) awarded funding to create the NIA Imbedded Pragmatic AD/DRD Clinical Trials (IMPACT) Collaboratory. The Collaboratory includes experts from more than 30 research institutions and will support pilot trials to test non-drug, care-based interventions for people living with dementia. The goal of IMPACT is to expedite the timeline of research implementation in real-world settings to improve care for people living with dementia and their caregivers. In 2020, the Centers for Disease Control and Prevention established three Public Health Centers of Excellence to disseminate best practices and tools to local, tribal and state public health organizations throughout the United States that support dementia caregivers, encourage early detection of Alzheimer's and reduce the risk of dementia, respectively.

5.2 | Paid caregivers

5.2.1 | Direct-care workers for people with Alzheimer's or other dementias

Direct-care workers, such as nurse aides, home health aides, and personal and home care aides provide most of the paid long-term care to older adults living at home or in residential settings.^{515,516} In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents.⁵¹⁷⁻⁵¹⁹ Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and geographic backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.^{518,520-523} Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.^{521,524} Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments.³⁵⁷ Studies have shown that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits.^{520,525-529} The National Academies of Sciences, Engineering, and Medicine have recommended changes to federal requirements for general direct-care worker training, including an increase in training hours from 75 to 120, and instructional content with a stronger focus on knowledge and skills related to caring for individuals with Alzheimer's and other dementias.^{521,522}

5.2.2 | Shortage of geriatric health care professionals

Professionals who may receive special training in caring for older adults include physicians, nurse practitioners, registered nurses, social workers, pharmacists, physician assistants and case workers.⁵²¹ As summarized in the 2020 *Alzheimer's Disease Facts and Figures Special Report*,

On the Front Lines: Primary Care Physicians and Alzheimer's Care in America, the United States would have to triple the number of geriatricians who were practicing in 2019 to effectively care for those 65 and older who are projected to have Alzheimer's dementia in 2050.^{530,531} There were 290,000 nurse practitioners in the United States in 2020. Thirteen percent of nurse practitioners had special expertise in gerontological care.⁵³² Less than 1% of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.⁵²¹ Although 73% of social workers serve clients age 55 and older, only 4% have formal certification in geriatric social work.⁵²¹ Furthermore, the overall aging of the long-term care workforce may affect the number of paid caregivers.³⁵⁷

5.2.3 | Enhancing health care for family caregivers

There is a growing consensus that professionals should acknowledge the role family caregivers play in facilitating the treatment of dementia, and that professionals should assess the well-being of family caregivers to improve overall disease management of the person with dementia.⁵³³⁻⁵³⁵ The complex care challenges of people with dementia also require interprofessional collaboration and education.⁵³⁶⁻⁵³⁹ Ongoing efforts have attempted to integrate innovative care management practices with traditional primary care for people with dementia. One example involves a skilled professional who serves as the care manager of the person with dementia. The care manager collaborates with primary care physicians and nurse practitioners to develop personalized care plans. These plans can provide support to family caregivers, help people with dementia manage care transitions (for example, a change in care provider or site of care) and ensure the person with dementia has access to appropriate community-based services. Other models include addressing the needs of family caregivers simultaneously with comprehensive disease management of people living with dementia to improve the quality of life of both.⁵⁴⁰ Several evaluations have suggested that such approaches have considerable potential for improving outcomes for people with dementia and their family caregivers (for example, delayed nursing home admission and reduction in caregiver distress).⁵⁴¹⁻⁵⁵¹ Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate.⁵⁵²⁻⁵⁵⁵ One approach to accelerate the adoption of dementia care innovations is to reform payment reimbursement strategies for providers, such as paying for services provided to caregivers and identifying metrics of success in dementia care.⁵⁵⁶

In 2016, the National Academies of Sciences, Engineering, and Medicine released *Families Caring for an Aging America*, a seminal report that includes a number of recommendations to refocus national health care reform efforts from models of care that center on the patient (person-centered care) to models of care that also explicitly engage and support the patient's family (family-centered care).⁵⁵⁷ These service models recognize the important role family members play in providing care and incorporate family caregivers during the delivery of health care to their relatives with dementia. Furthermore,

these models encourage health care providers to deliver evidence-based services and support to both caregivers and people living with dementia.⁵⁵⁷⁻⁵⁵⁹

In January 2017, Medicare began reimbursing physicians, physician assistants, nurse practitioners and clinical nurse specialists for health care visits that result in a comprehensive dementia care plan. Comprehensive care planning is a core element of effective dementia care management and can result in the delivery of services that potentially enhance quality of life for people with dementia and their caregivers. In the first year the care planning benefit was available, less than 1% of those with Alzheimer's disease or other dementias received a comprehensive dementia care plan. In seven states (Alaska, Montana, New Hampshire, North Dakota, Rhode Island, South Dakota and Vermont) and the District of Columbia, no fee-for-service Medicare beneficiaries received a comprehensive dementia care plan. Use of the Medicare care planning benefit did increase throughout the year (3.3 times greater in the fourth quarter of 2017 compared with the first quarter of 2017), although the rate of use remained low.⁵⁶⁰ The Alzheimer's Association has developed a care planning kit (alz.org/careplanning) to help guide providers to deliver effective care planning for people with dementia and their family caregivers.

5.3 | Trends in dementia caregiving

There is some indication that families are now better at managing the care they provide to relatives with dementia than in the past. From 1999 to 2015, dementia caregivers were significantly less likely to report physical difficulties (from 30% in 1999 to 17% in 2015) and financial difficulties (from 22% in 1999 to 9% in 2015) related to care provision. In addition, use of respite care by dementia caregivers increased substantially (from 13% in 1999 to 27% in 2015).³⁹⁸ However, as noted earlier, more work is needed to ensure that interventions for dementia caregivers are available and accessible to those who need them. A 2016 study of the Older Americans Act's National Family Caregiver Support Program found that over half (52%) of Area Agencies on Aging did not offer evidence-based family caregiver interventions.⁵⁶¹

The Alzheimer's Association has undertaken several efforts to improve how dementia care is studied and delivered. Its recent dementia care practice recommendations⁵⁶² place individuals with dementia and their caregivers at the center of how care should be delivered (see Figure 12). Essential to this model is the need to reconsider how we measure and design care for people with dementia by moving away from an approach that focuses on loss of abilities to an approach that emphasizes the individual's unique needs, personal experiences and strengths. This person-centered care philosophy not only values and respects the individual with dementia, but also promotes well-being and health.^{563,564} This framework is designed to shift how researchers and care providers think about dementia, and may point the way to a greater understanding of the resilience, adaptability, and the possibilities of maintenance or even improvement of skills and abilities when living with dementia.^{565,566} A core element of this and other



FIGURE 12 Person-centered care delivery. Created from data from the Alzheimer's Association.⁵⁶²

frameworks is ensuring that every experience and interaction is seen as an opportunity to have authentic and meaningful engagement, which in turn helps create a better quality of life for the person with dementia.

5.4 | COVID-19 and dementia caregiving

Although much of what is known about COVID-19 and dementia caregiving remains anecdotal, preliminary reports indicate that the COVID-19 pandemic has posed significant challenges to family members and friends who provide care for people with dementia.⁵⁶⁷ Caregivers have been limited in or completely barred from visiting and communicating with relatives who live in long-term care residences due to COVID-19 lockdown procedures. Adult day programs in many states have been interrupted or closed. These and other factors shaped by the COVID-19 pandemic have caused emotional distress and other negative outcomes among caregivers.⁵⁶⁸ Data are beginning to emerge from studies documenting the experience for dementia caregivers during COVID-19. For example, family caregivers who are able to engage in more direct phone and email contact with relatives in long-term care residences indicated greater emotional well-being for themselves and

their relatives, whereas relying on residential care staff rather than family members to engage in communication resulted in lower perceived well-being among family caregivers and their relatives.⁵⁶⁹ Telephone interviews with family caregivers in rural Virginia following the governor's stay-at-home order found that those who were more concerned about the COVID-19 pandemic and those who received less help from family and friends experienced greater feelings of emotional exhaustion and fatigue related to dementia care.⁵⁷⁰

Concerns about COVID-19 in long-term care settings arise from the devastating burden it has placed on residents and staff: about 40% of COVID-19 deaths in the United States are residents or staff of long-term care facilities.⁵⁷¹ The lack of preparation of many residential long-term care settings to effectively manage, contain and prevent the rapid spread of COVID-19 has had a detrimental effect on not only residents and their family caregivers in terms of their social well-being and health, but also on professional care staff. Media reports, observational evidence, and limited research to date have suggested that the lack of personal protective equipment (PPE), lack of transparent communication about the extent of COVID-19 outbreaks within and across facilities, work-related strain due to COVID-19 management protocols, and increases and abrupt changes in workload have all contributed

to a nearly untenable work situation for various types of staff in residential long-term care.^{572,573} Although direct care workers, administrators, and directors of residential long-term care settings have rightfully received praise for their often heroic efforts to continue to provide care in nursing homes or other residential long-term care settings, whether these staff are receiving meaningful support to successfully manage their feelings of emotional strain, bereavement (due to the high proportion of resident deaths concentrated in residential long-term care due to COVID-19) or other adverse consequences is unknown. Several clinical and policy experts have noted that COVID-19 has laid bare and exacerbated structural inequities in how residential long-term care is financed and regulated, and that short of payment reform, improved reporting, incentive restructuring, and significant environmental changes, residential long-term care settings such as nursing homes will again be susceptible to future pandemics or similar crises.⁵⁷⁴

At the outset of the pandemic, the National Institutes of Health and other federal agencies issued multiple requests for rapid grant applications to study and design interventions to mitigate the effects of COVID-19 on people with dementia and their caregivers. The Alzheimer's Association also provides regularly updated guidance for dementia caregivers and professional care providers as the pandemic unfolds.⁵⁷⁵

6 | USE AND COSTS OF HEALTH CARE, LONG-TERM CARE AND HOSPICE

The costs of health care and long-term care for individuals with Alzheimer's or other dementias are substantial, and dementia is one of the costliest conditions to society.⁵⁷⁶ Total payments in 2021 (in 2021 dollars) for all individuals with Alzheimer's or other dementias are estimated at \$355 billion (Figure 13), not including the value of informal caregiving that is described in the Caregiving section. Medicare and Medicaid are expected to cover \$239 billion, or 67%, of the total health care and long-term care payments for people with Alzheimer's or other dementias. Out-of-pocket spending is expected to be \$76 billion, or 22% of total payments.^{A11} Throughout the rest of this section, all costs are reported in 2020 dollars unless otherwise indicated.^{A12}

6.1 | Total cost of health care and long-term care

Table 12 reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias. Total per-person health care and long-term care payments in 2020 from all sources for Medicare beneficiaries with Alzheimer's or other dementias were over three times as great as payments for other Medicare beneficiaries in the same age group (\$52,481 per person for those with dementia compared with \$14,976 per person for those without dementia).^{A13,240}

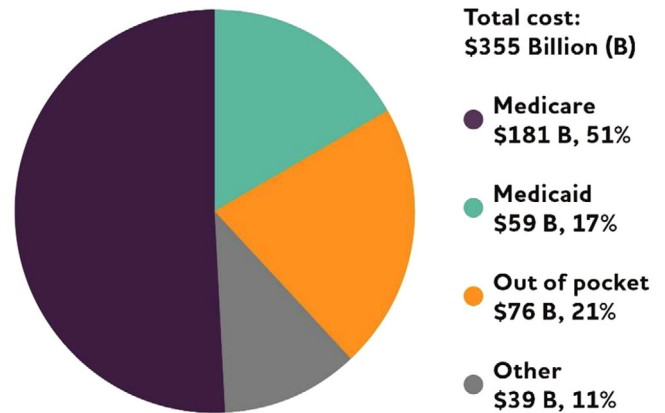


FIGURE 13 Distribution of aggregate costs of care by payment source for Americans age 65 and older with Alzheimer's or other dementias, 2021. Data are in 2021 dollars. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care. Created from data from the Lewin Model.^{A11}

TABLE 12 Average Annual Per-Person Payments by Payment Source for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2020 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	\$26,358	\$8,102
Medicaid	9,178	391
Uncompensated	408	409
Health maintenance organization	1,351	1,655
Private insurance	2,414	1,524
Other payer	1,004	259
Out of pocket	11,571	2,503
Total*	52,481	14,976

*Payments from sources do not equal total payments exactly due to the effects of population weighting. Payments for all beneficiaries with Alzheimer's or other dementias include payments for community-dwelling and facility-dwelling beneficiaries.

Created from unpublished data from the Current Medicare Beneficiary Survey for 2011.²⁴⁰

Despite these and other sources of financial assistance, individuals with Alzheimer's or other dementias still incur high out-of-pocket costs. These costs are for Medicare copayments and coinsurance, other health insurance premiums, deductibles, copayments, coinsurance and services not covered by Medicare, Medicaid or additional sources of support. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid \$11,571 out of pocket annually for health care and long-term care services not covered by other sources (Table 12).²⁴⁰

Researchers have evaluated the additional or “incremental” health care, residential long-term care and family caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics).^{363,576–578} In a recent systematic review of studies of older adults with Alzheimer's and other dementias enrolled in private Medicare managed care plans, researchers found a wide range of incremental costs attributable to Alzheimer's and other dementias.⁵⁷⁹ One group of researchers found that the incremental health care and nursing home costs for those with dementia were \$28,501 per person per year in 2010 dollars (\$38,053 in 2020 dollars).^{A14,576} Another research team found that the five-year incremental cost of dementia, based on Medicare claims, was \$15,704 (in 2017 dollars; \$17,134 in 2020 dollars), with the additional costs of care in the first year after diagnosis representing 46% of the five-year incremental costs.⁵⁸⁰ A third group of researchers found that the incremental lifetime cost of Alzheimer's dementia was substantially higher for women than men, due to women both having a longer duration of illness and spending more time in a nursing home.⁵⁸¹ Additionally, because women are more likely to be widowed and living in poverty, the incremental Medicaid costs associated with Alzheimer's dementia were 70% higher for women than men. A fourth group of researchers found that the lifetime cost of care, including out-of-pocket costs, Medicare and Medicaid expenditures, and the value of informal caregiving, was \$321,780 per person with Alzheimer's dementia in 2015 dollars (\$373,527 in 2020 dollars).³⁶³ The lifetime cost of care for individuals with Alzheimer's dementia was more than twice the amount incurred by individuals without Alzheimer's dementia, translating into an incremental lifetime cost of Alzheimer's dementia of \$184,500 (\$214,170 in 2020 dollars).

Several groups of researchers have examined the additional out-of-pocket costs borne by individuals with Alzheimer's or other dementias. In an analysis of the lifetime incremental cost of dementia, researchers found that individuals with dementia spent \$38,540 (in 2014 dollars; \$45,915 in 2020 dollars) more out of pocket between age 65 and death, due to nursing home care.⁵⁸² Another group of researchers found that community-dwelling individuals age 65 and older with Alzheimer's dementia had \$1,101 (in 2012 dollars; \$1,376 in 2020 dollars) higher annual out-of-pocket health care spending than individuals without Alzheimer's dementia, after controlling for differences in patient characteristics, with the largest portion of the difference being due to higher spending on home health care and prescription drugs.⁵⁸³ Furthermore, individuals with Alzheimer's dementia spend 12% of their income on out-of-pocket health care services compared with 7% for individuals without Alzheimer's dementia.⁵⁸⁰

Other researchers compared end-of-life costs for individuals with and without dementia and found that the total cost in the last five years of life was \$287,038 per person for individuals with dementia in 2010 dollars and \$183,001 per person for individuals without dementia (\$383,242 and \$244,336, respectively, in 2020 dollars), a difference of 57%.⁵⁸⁴ Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% versus 11%).

6.2 | Use and costs of health care services

6.2.1 | Use of health care services

People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people.³⁴⁰ Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

In addition to having more hospital stays, older people with Alzheimer's or other dementias have more skilled nursing facility stays and home health care visits per year than other older people.

- **Hospital.** There are 538 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's or other dementias compared with 266 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions.³⁴⁰ A person with dementia in 2012 had, on average, 23 inpatient days — defined as days in a hospital or skilled nursing facility — compared with five days for the Medicare population as a whole.⁵⁸⁵ The most common reasons for hospitalization of people with Alzheimer's dementia are syncope (fainting), fall and trauma (26%); ischemic heart disease (17%); and gastrointestinal disease (9%) (Figure 14),⁵⁸⁶ although the COVID-19 pandemic may have changed the most common reasons for hospitalization in 2020. A study of inpatient hospitalizations of adults age 60 and older found that those with Alzheimer's dementia were at 7% greater risk of dying during the hospital stay and stayed nearly a day longer than individuals without Alzheimer's dementia.⁵⁸⁷ Among Medicare beneficiaries with Alzheimer's or other dementias, 22% of hospital stays are followed by a readmission within 30 days.⁵⁸⁸ Although not directly comparable, one study of a portion of Medicare beneficiaries found an overall readmission rate of 18%.⁵⁸⁹ The proportion of hospital stays followed by a readmission within 30 days remained relatively constant between 2008 and 2018 (23% in 2007 versus 22% in 2018).
- **Emergency department.** Overall, 1.3% of all emergency department visits were for people with Alzheimer's or another dementia.⁵⁹⁰ There are 1,545 emergency department visits per 1,000 Medicare beneficiaries with Alzheimer's or other dementias per year, including emergency department visits that result in a hospital admission.⁵⁸⁸ Although not directly comparable, there were 640 emergency department visits per 1,000 Medicare beneficiaries per year based on a review of utilization patterns of a subset of Medicare beneficiaries.⁵⁸⁹ Emergency department visits for people with Alzheimer's or other dementias per 1,000 Medicare beneficiaries increased 28% between 2008 and 2018 (from 1,265 to 1,545), similar to the increases in emergency department visits for individuals with cancer, ischemic heart disease and heart failure (Figure 15).⁵⁸⁸

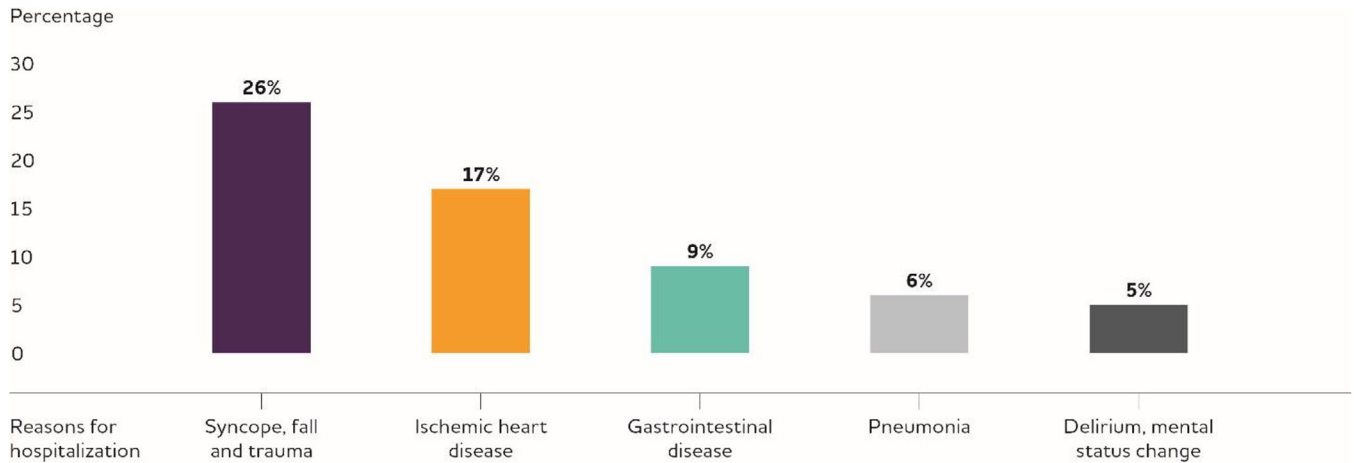


FIGURE 14 Reasons for hospitalization of individuals with Alzheimer's dementia: Percentage of hospitalized individuals by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's were used to calculate percentages. The remaining 37% of hospitalizations were due to other reasons. Created from data from Rudolph et al.⁵⁸⁶

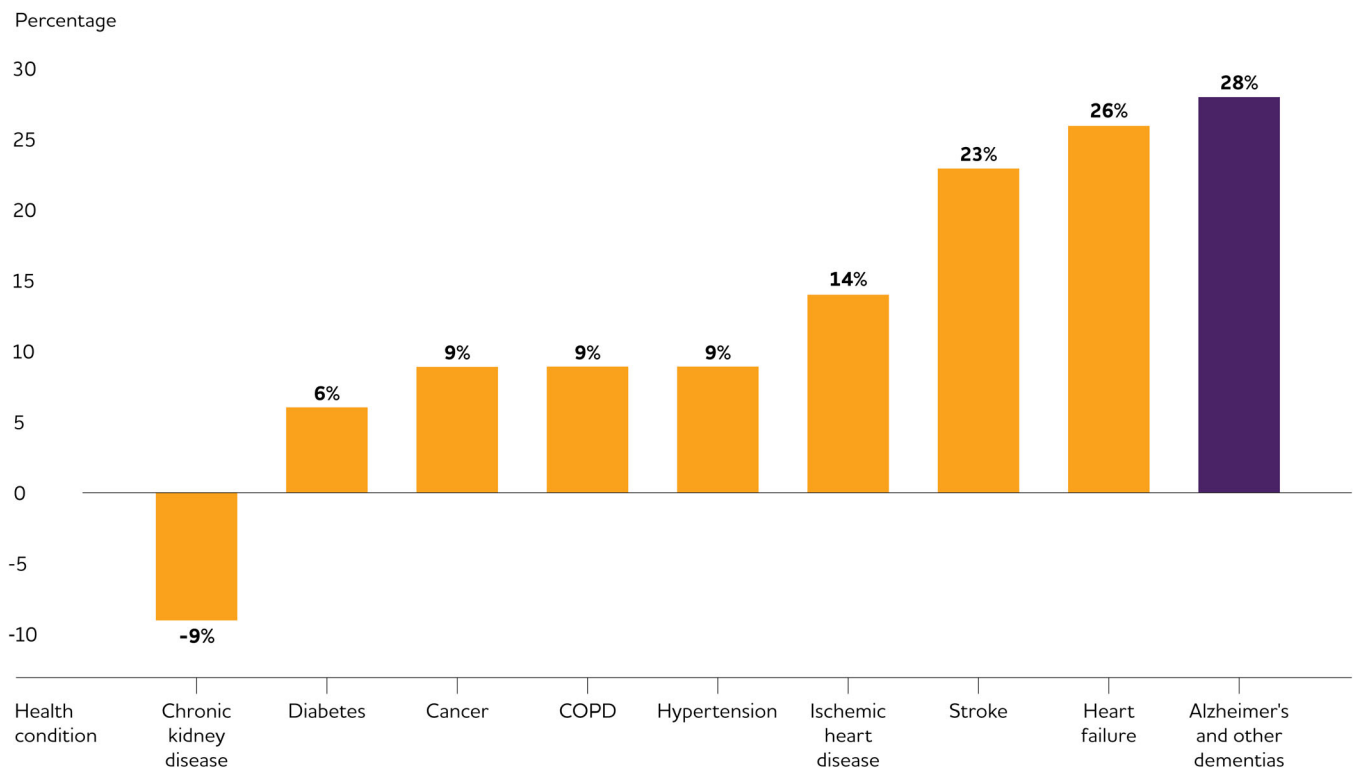


FIGURE 15 Percentage changes in emergency department visits per 1,000 fee-for-service Medicare beneficiaries for selected health conditions between 2008 and 2018. Includes Medicare beneficiaries with a claims-based diagnosis of each chronic condition. Beneficiaries may have more than one chronic condition. Created from data from the U.S. Centers for Medicare & Medicaid Services.⁵⁸⁸

- **Skilled nursing facility.** Skilled nursing facilities provide direct medical care that is performed or supervised by registered nurses, such as giving intravenous fluids, changing dressings and administering tube feedings.⁵⁹¹ There are 283 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's or other dementias per year compared with 73 stays per 1,000 beneficiaries without these conditions – a rate nearly four times as great.³⁴⁰
- **Home health care.** Twenty-five percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have at least one home health visit during the year, compared with 10% of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias.³⁴⁰ Medicare covers home health services, such as part-time skilled nursing care, home health aide (personal hands-on) care, therapies, and medical social services in

TABLE 13 Average Annual Per-Person Payments by Type of Service for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2020 Dollars

Services	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	\$11,933	\$3,855
Medical provider*	5,862	3,651
Skilled nursing facility	7,405	507
Nursing home	16,964	822
Hospice	2,240	170
Home health care	2,804	407
Prescription medications**	3,534	3,031

*"Medical provider" includes physician, other provider and laboratory services, and medical equipment and supplies.

**Information on payments for prescription medications is only available for people who were living in the community, that is, not in a nursing home or an assisted living facility.

Created from unpublished data from the Current Medicare Beneficiary Survey for 2011.²⁴⁰

the home, but does not include homemaker or personal care services.

6.2.2 | Costs of health care services

Average per-person payments for health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice and home health care) and prescription medications were higher for Medicare beneficiaries with Alzheimer's or other dementias than for other Medicare beneficiaries in the same age group (see Table 13).²⁴⁰

6.2.3 | Use and costs of health care service by state

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (see Table 14), similar to the geographic variation observed for Medicare beneficiaries with other medical conditions.⁵⁹² Emergency department visits, including visits that result in a hospital admission, range from 1,153 per 1,000 beneficiaries in Nebraska to 1,811 per 1,000 beneficiaries in West Virginia, and the percentage of hospital stays followed by hospital readmission within 30 days ranges from 16% in Hawaii to 25.8% in Nevada. Medicare spending per capita ranges from \$18,320 in North Dakota to \$36,533 in Nevada (in 2020 dollars).⁵⁸⁸

6.2.4 | Use and costs of health care services across the spectrum of cognitive impairment

Health care costs increase with the presence of dementia. In a population-based study of adults age 70 to 89, annual health care

costs were significantly higher for individuals with dementia than for those with either mild cognitive impairment (MCI) or without cognitive impairment.⁵⁹³ Annual health care costs for individuals with MCI were not significantly different, however, from costs for individuals without cognitive impairment.

Several groups of researchers have found that both health care and prescription drug spending are significantly higher in the year prior to diagnosis,⁵⁹⁴⁻⁵⁹⁶ two years prior to diagnosis,⁵⁹⁷ and one year after diagnosis,^{580,594,595} compared with otherwise similar individuals not diagnosed with Alzheimer's or another dementia, although there are differences in the sources of increased spending. In one study, the largest differences were in inpatient and post-acute care,⁵⁹⁵ while in another study the differences in spending were primarily due to outpatient care, home care and medical day services.⁵⁹⁶ In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment.⁵⁹⁷ Additionally, three groups of researchers have found that spending in the year after diagnosis was higher than for individuals not diagnosed with the disease, by amounts ranging from \$7,264 in 2017 dollars, based on individuals with fee-for-service Medicare coverage (\$7,925 in 2020 dollars)⁵⁸⁰ to \$17,852 in additional costs in 2014 dollars in the year after diagnosis, based on another group of individuals with Medicare fee-for-service coverage (\$21,268 in 2020 dollars).⁵⁹⁵ One group of researchers, however, found no difference in health care spending in the two years after diagnosis.⁵⁹⁷ In research that has examined health care costs after dementia diagnosis, one research team found that the incremental costs remained higher in the second year after diagnosis (\$7,327 in additional costs in 2014 dollars [\$8,729 in 2020 dollars]).⁵⁹⁵ Another research team found that health care costs remained higher in the second through fourth years after a dementia diagnosis, although the incremental costs decreased over time, from \$4,241 (\$4,627 in 2020 dollars) in year two to \$1,302 (\$1,421 in 2020 dollars) in year four, but were not significantly different in the fifth year after diagnosis.⁵⁸⁰ Researchers have also found a similar increase in health care costs in the two years after a diagnosis of MCI, although the additional costs were lower than for dementia.⁵⁹⁵ One possible explanation for the spike in health care costs in the year immediately before and the year immediately after diagnosis of Alzheimer's or another dementia relates to delays in timely diagnosis. One group of researchers found that individuals with cognitive decline who sought care from a specialist (that is, a neurologist, psychiatrist or geriatrician) had a shorter time to diagnosis of Alzheimer's disease.⁵⁹⁸ Additionally, individuals diagnosed with cognitive impairment by a specialist had lower Medicare costs in the year after receiving a diagnosis of Alzheimer's dementia than those diagnosed by a non-specialist.

6.2.5 | Impact of Alzheimer's and other dementias on the use and costs of health care in people with coexisting medical conditions

Overall, 96% of Medicare beneficiaries with Alzheimer's disease or other dementias have at least one other chronic condition.⁵⁹⁹ Additionally, they are more likely than those without dementia to have other

TABLE 14 Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2020 Dollars by Medicare Beneficiaries with Alzheimer's or Other Dementias by State, 2018

State	Number of ED Visits per 1,000 Beneficiaries	Percentage of Hospital Stays Followed by Readmission within 30 Days	Per Capita Medicare Payments	State	Number of ED Visits per 1,000 Beneficiaries	Percentage of Hospital Stays Followed by Readmission within 30 Days	Per Capita Medicare Payments
Alabama	1,410.8	21.2	\$24,132	Montana	1,328.6	16.6	\$19,995
Alaska	1,477.6	19.3	26,424	Nebraska	1,153.6	18.7	22,573
Arizona	1,436.2	20.2	26,211	Nevada	1,711.5	25.8	36,533
Arkansas	1,530.4	21.5	23,722	New Hampshire	1,493.8	20.4	26,703
California	1,496.3	23.0	35,364	New Jersey	1,456.3	22.9	32,924
Colorado	1,424.8	18.6	24,482	New Mexico	1,563.7	20.6	24,052
Connecticut	1,635.4	22.7	30,653	New York	1,461.3	23.7	33,631
Delaware	1,577.6	21.5	28,876	North Carolina	1,683.8	21.5	24,737
District of Columbia	1,741.7	25.6	33,037	North Dakota	1,173.3	18.4	18,320
Florida	1,551.9	23.0	30,106	Ohio	1,618.7	22.5	27,990
Georgia	1,573.2	22.5	26,188	Oklahoma	1,692.1	21.6	27,966
Hawaii	1,248.2	16.0	21,395	Oregon	1,628.4	18.7	22,804
Idaho	1,389.2	17.2	22,493	Pennsylvania	1,470.5	22.0	28,073
Illinois	1,624.1	23.4	30,339	Rhode Island	1,605.6	23.2	27,714
Indiana	1,514.2	21.3	26,852	South Carolina	1,558.2	21.7	25,470
Iowa	1,310.7	18.0	19,851	South Dakota	1,200.1	18.6	20,683
Kansas	1,406.0	19.8	24,601	Tennessee	1,548.6	21.5	25,323
Kentucky	1,735.5	23.1	26,331	Texas	1,549.1	22.1	32,510
Louisiana	1,709.9	22.1	30,452	Utah	1,194.3	16.7	23,832
Maine	1,665.3	19.7	22,946	Vermont	1,528.4	19.6	23,830
Maryland	1,524.1	24.4	31,669	Virginia	1,621.7	21.6	25,246
Massachusetts	1,668.4	24.7	33,029	Washington	1,479.2	18.6	22,949
Michigan	1,691.4	24.0	29,199	West Virginia	1,811.4	24.1	26,381
Minnesota	1,467.1	21.6	24,562	Wisconsin	1,519.9	19.9	23,317
Mississippi	1,714.8	22.1	28,344	Wyoming	1,445.9	17.4	23,151
Missouri	1,529.6	22.6	25,091	U.S. Average	1,544.8	22.3	28,777*

*The average per capita Medicare payment differs from the figure in Table 12 due to different underlying sources of data. Created from data from the U.S. Centers for Medicare & Medicaid Services.⁵⁸⁸

chronic conditions.³⁴⁰ Overall, 2.8 times more Medicare beneficiaries with Alzheimer's or other dementias have four or more chronic conditions (excluding Alzheimer's disease and other dementias) than Medicare beneficiaries without dementia.³⁴⁰ Table 15 reports the percentage of people with Alzheimer's or other dementias who had certain coexisting medical conditions. In 2014, the latest year for which information is available, 38% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 37% had diabetes, 29% had chronic kidney disease, 28% had congestive heart failure and 25% had chronic obstructive pulmonary disease.³⁴⁰

Medicare beneficiaries who have Alzheimer's or other dementias and a coexisting medical condition have higher average per-person

payments for most health care services than Medicare beneficiaries with the same medical condition but without dementia. Table 16 shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have Alzheimer's or other dementias and beneficiaries who do not have Alzheimer's or another dementia.³⁴⁰ Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except hospital care payments for individuals with congestive heart failure. One group of researchers found that individuals with dementia and behavioral disturbances, such as agitation, had more psychiatric comorbidities than individuals with dementia but without behavioral disturbances.⁶⁰⁰ Additionally, larger proportions of individuals with

TABLE 15 Percentage of Medicare Beneficiaries Age 65 and Older with Alzheimer's or Other Dementias Who Have Specified Coexisting Conditions

Coexisting Condition	Percentage
Coronary artery disease	38
Diabetes	37
Chronic kidney disease	29
Congestive heart failure	28
Chronic obstructive pulmonary disease	25
Stroke	22
Cancer	13

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.³⁴⁰

dementia and behavioral disturbances used medications including anti-hypertensives, dementia treatments, antipsychotics, antidepressants, antiepileptics and hypnotics.

6.3 | Use and costs of long-term care services

An estimated 70% of older adults with Alzheimer's or other dementias live in the community, compared with 98% of older adults without Alzheimer's or other dementias.²⁴⁰ Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.²⁴⁰ As their disease progresses, people with Alzheimer's or other dementias generally receive more care from family members and other unpaid caregivers. Many people with dementia also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times during the often long course of the disease. Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the severe stage of their illnesses.

6.3.1 | Use of long-term care services by setting

Most people with Alzheimer's or other dementias who live at home receive unpaid help from family members and friends, but some also receive paid home- and community-based services, such as personal care and adult day care. People with Alzheimer's or other dementias make up a large proportion of all older adults who receive adult day services and nursing home care.

- **Home health services.** Thirty-two percent of individuals using home health services have Alzheimer's or other dementias.⁶⁰¹
- **Adult day services.** Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias, and approximately 10% of adult day services centers in the United States specialize in caring for individuals with Alzheimer's disease or other dementias.⁶⁰² The percentage of participants with Alzheimer's or other dementias was higher in adult day services centers that pro-

vided either low- or moderate-level medical services than in centers that either provided no medical services or mainly provided health or medical services.⁶⁰²

- **Residential care facilities.** Forty-two percent of residents in residential care facilities (that is, housing that includes services to assist with everyday activities, such as medication management and meals), including assisted living facilities, have Alzheimer's or other dementias.⁶⁰¹ Sixty-one percent of residential care communities are small (four to 25 beds),⁶⁰³ and these facilities have a larger proportion of residents with Alzheimer's or other dementias than facilities with more beds (51% in facilities with four to 25 beds compared with 44% in facilities with 26 to 50 beds and 39% in facilities with more than 50 beds).⁶⁰⁴ Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's or other dementias.⁶⁰⁵ Average aide staff hours per resident day in residential care communities range from 2 hours and 11 minutes per day in facilities with less than 25% of residents diagnosed with dementia to 2 hours and 44 minutes per day in facilities with more than 75% of residents diagnosed with dementia.⁶⁰³
- **Nursing home care.** Overall, 48% of nursing home residents have Alzheimer's or other dementias,⁶⁰¹ while 37% of short-stay (less than 100 days) nursing home residents have Alzheimer's or other dementias, and 59% of long-stay (100 days or longer) residents have these conditions. In 2014, 61% of nursing home residents with Alzheimer's or other dementias had moderate or severe cognitive impairment.⁶⁰⁶ Ten percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with 1% of Medicare beneficiaries without the condition.²⁴⁰ One group of researchers has estimated that approximately 75% of surviving Alzheimer's disease patients diagnosed at age 70 will reside in a nursing home by age 80, compared with only 4% of the general population surviving to age 80.³⁴²
- **Alzheimer's special care units and dedicated facilities.** An Alzheimer's special care unit is a dedicated unit, wing or floor in a nursing home or other residential care facility that has tailored services for individuals with Alzheimer's or other dementias. Fifteen percent of nursing homes and 14% of other residential care facilities have a dementia special care unit,⁶⁰¹ even though 72% of Medicare beneficiaries with Alzheimer's dementia have a nursing home stay in the last 90 days of life.⁶⁰⁷ Additionally, 9% of residential care facilities exclusively provide care to individuals with dementia, while less than 1% (0.4%) of nursing homes exclusively provide care to individuals with dementia.

Long-term care services provided at home and in the community

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home- and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. The federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs. In 2016, home- and community-based services represented the majority (57%) of Medicaid spending on long-term

TABLE 16 Average Annual Per-Person Payments by Type of Services and Coexisting Medical Condition for Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2020 Dollars*

Medical Condition by Alzheimer's/Dementia (A/D) Status	Total Medicare Payments	Hospital Care	Physician Care	Skilled Nursing Home Care	Home Health Care	Hospice Care
Coronary artery disease						
With A/D	\$29,414	\$8,997	\$2,273	\$4,961	\$2,670	\$3,276
Without A/D	18,358	6,480	1,617	1,594	1,107	426
Diabetes						
With A/D	28,474	8,561	2,225	4,798	2,583	2,950
Without A/D	15,719	5,363	1,426	1,386	961	290
Congestive heart failure						
With A/D	32,275	10,111	2,387	5,423	2,796	3,933
Without A/D	27,382	10,265	2,144	2,936	1,985	919
Chronic kidney disease						
With A/D	31,410	9,689	2,330	5,278	2,642	3,503
Without A/D	22,520	8,008	1,838	2,130	1,368	539
Chronic obstructive pulmonary disease						
With A/D	31,179	9,717	2,359	5,230	2,733	3,633
Without A/D	21,270	7,782	1,783	1,978	1,368	686
Stroke						
With A/D	29,846	8,880	2,250	5,163	2,568	3,644
Without A/D	21,501	7,224	1,812	2,595	1,657	689
Cancer						
With A/D	28,275	8,423	2,179	4,450	2,362	3,260
Without A/D	17,933	5,537	1,495	1,188	788	552

*This table does not include payments for all kinds of Medicare services, and as a result the average per-person payments for specific Medicare services do not sum to the total per-person Medicare payments.

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.³⁴⁰

services and supports, with institutional care representing the remaining 43%.⁶⁰⁸ Between 2013 and 2016, Medicaid spending on home- and community-based services increased 26% overall, while spending on institutional care increased only 1.5%. Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias nearly doubled between 2004 and 2011, although increases in spending may be due to a variety of factors, including more people being diagnosed with Alzheimer's dementia, more people using home care, an increase in the number of coexisting medical conditions, more intensive use of home care services and an increase in Medicaid coverage by older adults.^{240,609} In two recent systematic reviews of the cost-effectiveness of home support interventions for individuals with dementia, researchers found some evidence to support occupational therapy, home-based exercise and some psychological and behavioral treatments as potentially cost-effective approaches, although the research that has evaluated both the costs and benefits of home support interventions is scant.^{610,611}

Transitions between care settings

Individuals with dementia often move between a nursing facility, hospital and home, rather than remaining solely in a nursing facility. In a longitudinal study of primary care patients with dementia, researchers

found that individuals discharged from a nursing facility were nearly equally as likely to be discharged home (39%) as discharged to a hospital (44%).⁶¹² Individuals with dementia may also transition between a nursing facility and hospital or between a nursing facility, home and hospital, creating challenges for caregivers and providers to ensure that care is coordinated across settings. Other researchers have shown that nursing home residents frequently have burdensome transitions at the end of life, including admission to an intensive care unit in the last month of life and late enrollment in hospice.⁶¹³ The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.⁶¹⁴

6.3.2 | Costs of long-term care services

Long-term care services include home- and community-based services, assisted living and nursing home care. The following estimates are for all users of these services.

- **Home care.** The median cost in 2020 for a paid non-medical home health aide is \$24 per hour and \$4,576 per month.⁶¹⁵ Home

care costs increased 3.7% annually on average over the past five years.

- **Adult day centers.** The median cost of adult day services is \$74 per day.⁶¹⁵ The cost of adult day services has increased 1.5% annually on average over the past five years.
- **Assisted living facilities.** The median cost for care in an assisted living facility is \$4,300 per month, or \$51,600 per year.⁶¹⁵ The cost of assisted living has increased 3.6% annually on average over the past five years.
- **Nursing homes.** The average cost for a private room in a nursing home is \$290 per day, or \$105,850 per year, and the average cost of a semi-private room is \$255 per day, or \$93,075 per year.⁶¹⁵ The cost of nursing home care has increased 3% annually on average over the past five years for both private and semi-private rooms.

Affordability of long-term care services

Few individuals with Alzheimer's or other dementias have sufficient long-term care insurance or can afford to pay out of pocket for long-term care services for as long as the services are needed.

- Medicare beneficiaries with a dementia diagnosis have lower household incomes on average than beneficiaries without a dementia diagnosis. In 2018, 23% of community-dwelling Medicare beneficiaries with a dementia diagnosis had household incomes below the federal poverty level and 53% had household incomes between 100% and 200% of the federal poverty level, while 15% of those without a dementia diagnosis lived below the federal poverty level and 40% had household incomes between 100% and 200% of the federal poverty level.⁶¹⁶
- Asset data are not available for people with Alzheimer's or other dementias specifically, but 50% of Medicare beneficiaries age 65 and older had total savings of \$83,850 or less in 2019 dollars (\$84,740 in 2020 dollars) and 25% had savings of \$9,650 or less in 2019 dollars (\$9,752 in 2020 dollars). Median savings for White Medicare beneficiaries were 8.5 times higher than for Blacks and more than 15 times higher than for Hispanics.⁶¹⁷

Long-term care insurance

Long-term care insurance typically covers the cost of care provided in a nursing home, assisted living facility and Alzheimer's special care facility, as well as community-based services such as adult day care and services provided in the home, including nursing care and help with personal care.⁶¹⁸

Industry reports estimate that approximately 7.2 million Americans had long-term care insurance in 2014.⁶¹⁹ The median income for individuals purchasing long-term care insurance was \$87,500 in 2010 dollars (\$103,665 in 2020 dollars), with 77% having an annual income greater than \$50,000 (\$59,237 in 2020 dollars) and 82% having assets greater than \$75,000 (\$88,856 in 2020 dollars).⁶¹⁹ Private health care and long-term care insurance policies funded only about 8% of total long-term care spending in 2013, representing \$24.8 billion of the \$310 billion total in 2013 dollars (\$27.5 billion of the \$344 billion in 2020 dollars).⁶²⁰ The private long-term care insurance market is highly

concentrated and has consolidated since 2000. In 2000, 41% of individuals with a long-term care policy were insured by one of the five largest insurers versus 56% in 2014.⁶¹⁹

To address the dearth of private long-term care insurance options and high out-of-pocket cost of long-term care services, Washington became the first state in the country to pass a law that will create a public state-operated long-term care insurance program.⁶²¹ The Long-Term Services and Supports Trust Program will be funded by a payroll tax on employees of 58 cents per \$100 earned that begins in 2022, and self-employed individuals will be able to opt into the program. The program is currently structured to pay up to \$36,500 in lifetime benefits, beginning in 2025.

Medicare does not cover long-term care in a nursing home

Although Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing home, and hospice care, long-term care in a nursing home is not covered by Medicare.⁶²²

The terms "nursing home," "skilled nursing facility," and "long-term care hospital" are often confused. Additionally, results from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey revealed that 28% of adults believed Medicare covered the cost of nursing home care for people with Alzheimer's, and 37% did not know whether it covered the cost of nursing home care.⁴¹¹ These findings suggest that Medicare beneficiaries and caregivers need more education and information about the types of services that Medicare covers.

Medicare does not cover custodial care, that is, care to assist with activities of daily living, such as dressing and bathing. Most nursing home care is custodial care, and therefore is not covered by Medicare.

Medicare does cover skilled nursing care, or nursing and therapy care that must be performed or supervised by medical professionals, such as registered or licensed nurses.⁵⁹¹ For Medicare to cover skilled nursing care, the Medicare beneficiary must have a qualifying hospital stay, a physician must decide that skilled care is needed, and the medical condition requiring skilled care must be related to the hospitalization.⁶²³ Fee-for-service Medicare (Part A) covers the first 20 days of skilled nursing care with \$0 coinsurance for each benefit period. For the next 80 days of skilled nursing care (days 21-100), the beneficiary pays \$185.50 per day in coinsurance.

A long-term care hospital is an acute care hospital that specializes in caring for people who stay more than 25 days, on average. A long-term care hospital provides specialized care, such as respiratory therapy, pain management and treatment for head trauma.⁶²⁴ Benefits work in the same way that Medicare covers other acute care hospitalizations.

The terms "Medicare" and "Medicaid" are also often confused. Most individuals who are age 65 or older, have a permanent disability or have end-stage renal disease qualify for Medicare Part A, which is also referred to as hospital insurance.⁶²⁵ Individuals are eligible to receive Medicare Part A at no cost if they have worked and paid Medicare taxes for at least 10 years (i.e., have a sufficient earnings history) or a spouse, parent or child has a sufficient earnings history. Medicare Part B (medical insurance) is a voluntary program that requires enrollees to pay a monthly premium. Medicare Advantage Plans, also referred to

as Medicare Part C, are becoming more common, with more than one-third of Medicare beneficiaries enrolled in this type of plan in 2020.⁶²⁶ Medicare Advantage Plans are privately offered Medicare plans that combine Medicare Parts A and B and often also include prescription drug coverage (Medicare Part D).⁶²⁷

While Medicare is a federal program, Medicaid is a joint federal and state program, and benefits vary state-to-state.⁶²⁸ Individuals with low incomes and/or low resources may qualify for coverage. Medicaid covers some services that Medicare either does not cover or only partially covers, such as nursing home care and home- and community-based care. Individuals who are enrolled in both Medicare and Medicaid are sometimes referred to as “dual eligibles.”

For more information about Medicare, visit medicare.gov. For more information about Medicaid, visit healthcare.gov/medicaid-chip/getting-medicaid-chip/.

Medicaid costs

Medicaid covers nursing home care and long-term care services in the community for individuals who meet program requirements for level of care, income and assets. To receive coverage, beneficiaries must have low incomes. Most nursing home residents who qualify for Medicaid must spend all of their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse. Although Medicaid covers the cost of nursing home care, its coverage of many long-term care and support services, such as assisted living care, home-based skilled nursing care and help with personal care, varies by state.

Twenty-seven percent of older individuals with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11% of individuals without dementia.²⁴⁰ Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias (\$9,178) were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias (\$391) (Table 12).²⁴⁰ Much of the difference in payments for beneficiaries with Alzheimer's or other dementias and other beneficiaries is due to the costs associated with long-term care (nursing homes and other residential care facilities, such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid.

Total Medicaid spending for people with Alzheimer's or other dementias is projected to be \$59 billion in 2021 (in 2021 dollars).^{A11} Estimated state-by-state Medicaid spending for people with Alzheimer's or other dementias in 2020 (in 2020 dollars) is included in Table 17. Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias were 23 times as great as Medicaid payments for other Medicare beneficiaries.²⁴⁰

6.3.3 | Use and costs of care at the end of life

Hospice care provides medical care, pain management, and emotional and spiritual support for people who are dying, including people with Alzheimer's or other dementias, either in a facility or at home. Hospice care also provides emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid and other sources also pay for hospice care. Medicare beneficiaries enrolled in Medicare Part A (i.e., Medicare's hospital insurance) can choose to enroll in Medicare's hospice benefit if a hospice physician certifies that the individual is terminally ill (i.e., expected to live six months or less), and the individual accepts palliative or comfort care and forgoes curative care for the terminal illness, so that hospice care replaces other Medicare-covered benefits for treating the terminal illness and related conditions.⁶²⁹

Nineteen percent of Medicare beneficiaries with Alzheimer's and other dementias have at least one hospice claim annually compared with 2% of Medicare beneficiaries without Alzheimer's or other dementias.³⁴⁰ Expansion of hospice care is associated with fewer individuals with dementia having more than two hospitalizations for any reason or more than one hospitalization for pneumonia, urinary tract infection, dehydration or sepsis in the last 90 days of life.⁶³⁰ In 2017, 4,254 U.S. companies provided hospice care in the home, assisted living communities, long-term care residences, inpatient hospitals, and inpatient hospice and other settings.⁶³¹ Additionally, 18% of Medicare beneficiaries who received hospice care had a primary diagnosis of dementia, including Alzheimer's dementia (Table 18).⁶³¹ Dementia was the second most common primary diagnosis for Medicare beneficiaries admitted to hospice overall, with cancer being the most common primary diagnosis. Forty-five percent of hospice users in 2015 had a diagnosis of Alzheimer's or other dementias, suggesting that a large proportion of hospice users have Alzheimer's as a comorbid condition.⁶⁰¹ The average number of days with hospice care for individuals with a primary diagnosis of dementia was more than 50% higher than for individuals with other primary diagnoses, based on data from the 2008 to 2011 National Hospice Survey.⁶³² Individuals with a primary diagnosis of dementia use an average of 112 days versus 74 days for individuals with other primary diagnoses. Researchers have found that patients with dementia are more likely to be disenrolled from hospice after a long hospice stay (more than 165 days in hospice) than patients with other primary diagnoses,⁶³² due to admission to an acute care hospital and loss of eligibility because the individual was no longer terminally ill or failed to recertify for hospice.⁶³³

Per-person hospice payments among all individuals with Alzheimer's dementia averaged \$2,240 compared with \$170 for all other Medicare beneficiaries.²⁴⁰ In 2016, Medicare reimbursement for home hospice services changed from a simple daily rate for each setting to a two-tiered approach that provides higher reimbursement for days 1 to 60 than for subsequent days and a service intensity add-on payment for home visits by a registered nurse or social worker in the

TABLE 17 Total Medicaid Payments for Americans Age 65 and Older Living with Alzheimer's or Other Dementias by State*

State	2020 (in millions of dollars)	2025 (in millions of dollars)	Percentage Increase	State	2020 (in millions of dollars)	2025 (in millions of dollars)	Percentage Increase
Alabama	\$925	\$1,127	21.8	Montana	\$166	\$203	22.2
Alaska	76	110	44.6	Nebraska	372	411	10.3
Arizona	414	545	31.7	Nevada	203	277	36.5
Arkansas	396	454	14.6	New Hampshire	254	335	31.9
California	4,197	5,235	24.7	New Jersey	2,186	2,614	19.6
Colorado	635	789	24.1	New Mexico	227	279	22.9
Connecticut	1,022	1,189	16.1	New York	5,453	6,306	15.6
Delaware	253	313	23.6	North Carolina	1,332	1,628	22.2
District of Columbia	126	135	6.8	North Dakota	190	215	13.2
Florida	2,689	3,453	28.4	Ohio	2,534	2,940	16.0
Georgia	1,256	1,594	26.0	Oklahoma	516	611	18.3
Hawaii	240	285	18.7	Oregon	253	317	25.4
Idaho	149	196	31.2	Pennsylvania	3,658	4,029	10.2
Illinois	1,787	2,199	23.1	Rhode Island	470	565	20.1
Indiana	1,054	1,233	17.1	South Carolina	652	818	25.4
Iowa	676	792	17.2	South Dakota	182	212	16.6
Kansas	473	543	14.6	Tennessee	1,109	1,377	24.2
Kentucky	803	949	18.2	Texas	3,202	3,949	23.3
Louisiana	765	934	22.1	Utah	185	235	27.0
Maine	212	274	29.5	Vermont	116	146	26.4
Maryland	1,231	1,535	24.7	Virginia	1,000	1,266	26.6
Massachusetts	1,753	2,031	15.9	Washington	547	689	26.0
Michigan	1,487	1,738	16.9	West Virginia	445	521	17.1
Minnesota	905	1,087	20.1	Wisconsin	777	924	18.9
Mississippi	606	729	20.4	Wyoming	86	111	28.8
Missouri	973	1,137	16.8	U.S. Average	51,226	61,581	20.2

*All cost figures are reported in 2020 dollars. State totals may not add to the U.S. total due to rounding. Created from data from the Lewin Model.⁴¹¹

last seven days of life. In fiscal year 2020, the routine home care rates were \$199.25 per day for days 1 to 60 and \$157.49 per day for days 61 and beyond.⁶³⁴ In a simulation to evaluate whether the reimbursement change will reduce costs for Medicare, a group of researchers found that the new reimbursement approach is anticipated to reduce costs for Medicare, although individuals with dementia who receive hospice care will have higher Medicare spending overall than individuals with dementia who do not receive hospice care.⁶³⁵

For Medicare beneficiaries with advanced dementia who receive skilled nursing home care in the last 90 days of life, those who are enrolled in hospice are less likely to die in the hospital.⁶³⁶ Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life⁶³⁷ and more likely to receive regular treatment for pain.⁶³⁸ Nearly half of individuals with dementia die while receiving hospice care.⁶⁰⁷ Satisfaction with medical care is higher for families of individuals with dementia who are enrolled in hospice care

than for families of individuals with dementia not enrolled in hospice care.⁶³⁹

Based on data from the National Hospice Survey for 2008 to 2011, nearly all (99%) hospices cared for individuals with dementia, although only 67% of hospices had residents with a primary diagnosis of dementia.⁶³² Fifty-two percent of individuals in for-profit hospices had either a primary or comorbid diagnosis of dementia, while 41% of individuals in nonprofit hospices had a diagnosis of dementia. More research is needed to understand the underlying reasons for the differences in the percentage of people with dementia in for-profit versus nonprofit hospices.

Researchers have found similar reductions in hospitalizations at the end of life for individuals receiving palliative care. For nursing home residents with moderate-to-severe dementia, those who received an initial palliative care consultation between one and six months before death had significantly fewer hospitalizations and emergency

TABLE 18 Number and Percentage of Medicare Beneficiaries Admitted to Hospice with a Primary Diagnosis of Dementia by State, 2017

State	Number of Beneficiaries	Percentage of Beneficiaries	State	Number of Beneficiaries	Percentage of Beneficiaries
Alabama	5,867	18	Montana	507	11
Alaska	95	14	Nebraska	1,648	18
Arizona	7,229	18	Nevada	2,167	17
Arkansas	3,133	18	New Hampshire	1,007	17
California	30,045	20	New Jersey	8,207	23
Colorado	3,254	15	New Mexico	1,523	15
Connecticut	2,380	15	New York	7,669	16
Delaware	716	12	North Carolina	8,486	17
District of Columbia	263	18	North Dakota	468	18
Florida	19,897	15	Ohio	12,656	17
Georgia	10,435	21	Oklahoma	4,102	18
Hawaii	943	16	Oregon	3,565	17
Idaho	1,566	17	Pennsylvania	12,384	17
Illinois	9,795	18	Rhode Island	1,657	25
Indiana	5,922	17	South Carolina	6,038	20
Iowa	3,278	17	South Dakota	421	13
Kansas	2,770	18	Tennessee	6,435	19
Kentucky	2,895	15	Texas	26,672	22
Louisiana	4,786	19	Utah	2,506	19
Maine	1,494	19	Vermont	543	17
Maryland	4,072	17	Virginia	6,440	19
Massachusetts	7,245	23	Washington	5,459	20
Michigan	9,001	16	West Virginia	1,552	15
Minnesota	5,399	21	Wisconsin	5,086	16
Mississippi	3,547	20	Wyoming	89	7
Missouri	5,991	17	U.S. Total	278,192	18

Created from data from the U.S. Centers for Medicare & Medicaid Services.⁶³¹

department visits in the last seven and 30 days of life, compared with those who did not receive palliative care.⁶⁴⁰ Patients with an initial palliative care consultation within one month of death also had significantly fewer hospitalizations in the last seven days of life compared with those who did not receive palliative care.⁶⁴⁰

Feeding tube use at the end of life

Individuals with frequent transitions between health care settings are more likely to have feeding tubes at the end of life, even though feeding tube placement does not prolong life or improve outcomes.⁵⁸⁵ The odds of having a feeding tube inserted at the end of life vary across the country and are not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. Researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. By contrast, feeding tube use was lower among people with dementia whose care was managed by a general practitioner.^{641,642} With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last

90 days of life has decreased for individuals with Alzheimer's or other dementias.⁶³⁰ Finally, with the increased focus on the lack of evidence supporting feeding tube use for people with advanced dementia, the proportion of nursing home residents receiving a feeding tube in the 12 months before death decreased from nearly 12% in 2000 to less than 6% in 2014.⁶⁴²

Place of death for individuals with Alzheimer's or other dementias

Between 1999 and 2018, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 68% to 51%, and the proportion who died in a medical facility decreased from 15% to 5%.⁶⁴³ During the same period, the proportion of individuals who died at home increased from 14% to 28% (Figure 16).⁶⁴³

6.4 | Use and costs of health care and long-term care services by race/ethnicity

Among Medicare beneficiaries with Alzheimer's or other dementias, Blacks had the highest Medicare payments per person per year, while

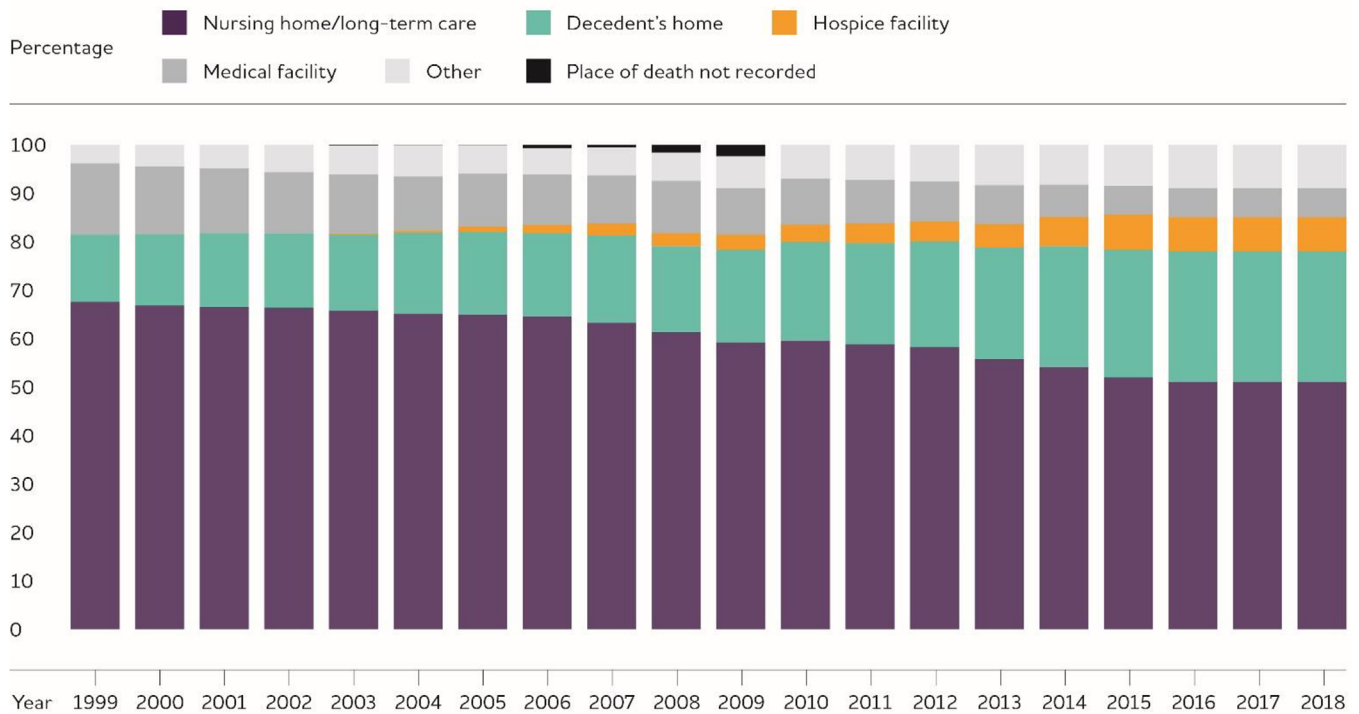


FIGURE 16 Place of death due to Alzheimer's disease, 1999 to 2018. Created from data from the National Center for Health Statistics.⁶⁴³

TABLE 19 Average Annual Per-Person Payments by Type of Service and Race/Ethnicity for Medicare Beneficiaries Age 65 and Older, with Alzheimer's or Other Dementias, in 2020 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Care	Home Health Care	Hospice Care
White	\$22,135	\$5,915	\$1,665	\$3,809	\$1,931	\$3,563
Black	29,934	9,957	2,258	4,721	2,360	2,638
Hispanic	23,725	8,004	1,963	3,629	2,035	1,964
Other	28,799	9,003	2,208	3,802	4,182	2,904

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.³⁴⁰

Whites had the lowest payments (\$29,934 versus \$22,135, respectively) (Table 19). The largest difference in payments was for hospital care, with Blacks incurring 1.7 times as much in hospital care costs as Whites (\$9,957 versus \$5,915).³⁴⁰

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's dementia that included both Medicaid and Medicare claims data, researchers found significant differences in the costs of care by race/ethnicity.⁶⁴⁴ These results demonstrated that Blacks had significantly higher costs of care than Whites or Hispanics, primarily due to more inpatient care and more comorbidities. These differences may be attributable to later-stage diagnosis, which may lead to higher levels of disability while receiving care; delays in accessing timely primary care; lack of care coordination; duplication of services across providers; or inequities in access to care. However, more research is needed to understand the reasons for this health care disparity.

6.5 | Avoidable use of health care and long-term care services

6.5.1 | Preventable hospitalizations

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to, or quality of, preventive and primary care. Unplanned hospital readmissions within 30 days are another type of hospitalization that potentially could have been avoided with appropriate post-discharge care. In 2013, 21% of hospitalizations for fee-for-service Medicare enrollees with Alzheimer's or other dementias were either for unplanned readmissions within 30 days or for an ambulatory care sensitive condition (a condition that was potentially avoidable with timely and effective ambulatory – that is, outpatient – care). The total cost to Medicare of

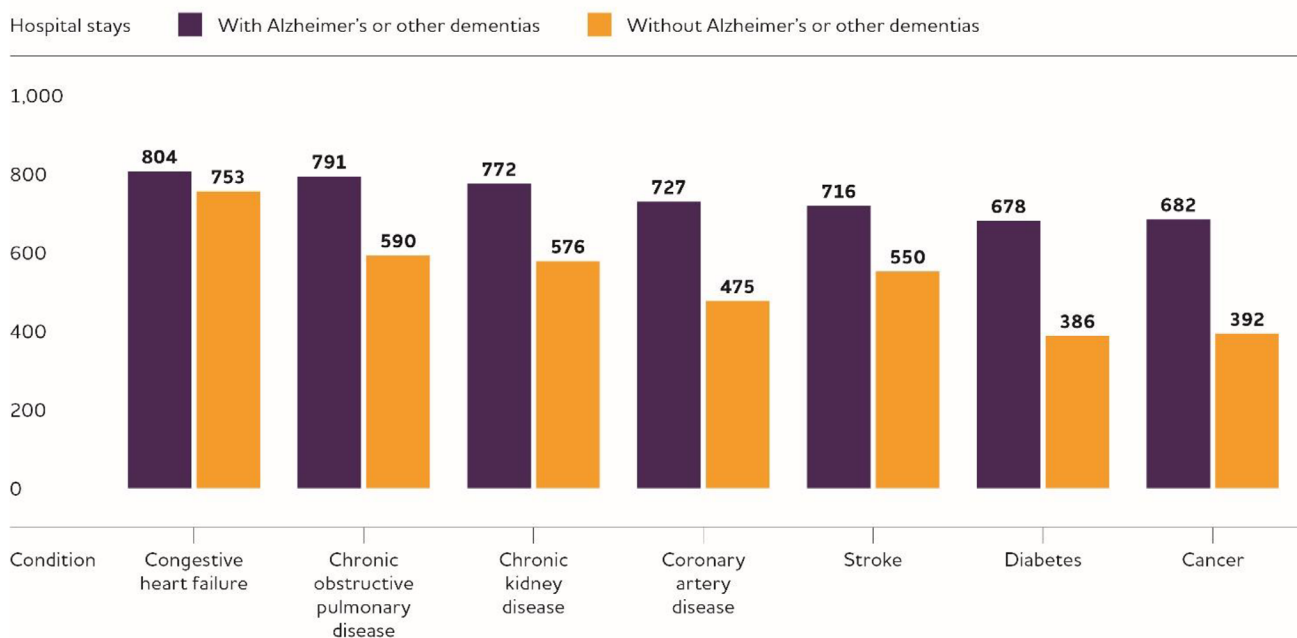


FIGURE 17 Hospital stays per 1,000 Medicare beneficiaries age 65 and older with specified coexisting medical conditions, with and without Alzheimer's or other dementias, 2014. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.³⁴⁰

these potentially preventable hospitalizations was \$4.7 billion (in 2013 dollars; \$5.7 billion in 2020 dollars).⁶⁴⁵ Of people with dementia who had at least one hospitalization, 18% were readmitted within 30 days, and of those who were readmitted within 30 days, 27% were readmitted two or more times. Ten percent of Medicare enrollees had at least one hospitalization for an ambulatory care sensitive condition, and 14% of total hospitalizations for Medicare enrollees with Alzheimer's or other dementias were for ambulatory care-sensitive conditions.

Based on Medicare administrative data from 2013 to 2015, preventable hospitalizations represented 23.5% of total hospitalizations for individuals with Alzheimer's or other dementias.⁶⁴⁶ Black older adults had a substantially higher proportion of preventable hospitalizations (31%) compared with Hispanic and White older adults (22% for each group).

Based on data from the Health and Retirement Study and from Medicare, after controlling for demographic, clinical and health risk factors, individuals with dementia had a 30% greater risk of having a preventable hospitalization than those without a neuropsychiatric disorder (that is, dementia, depression or cognitive impairment without dementia). Moreover, individuals with both dementia and depression had a 70% greater risk of preventable hospitalization than those without a neuropsychiatric disorder.⁶⁴⁷ Another group of researchers found that individuals with dementia and a caregiver with depression had 73% higher rates of emergency department use over six months than individuals with dementia and a caregiver who did not have depression.⁶⁴⁸

Medicare beneficiaries who have Alzheimer's or other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with

the same coexisting medical condition but without dementia (Figure 17).³⁴⁰ One research team found that individuals hospitalized with heart failure are more likely to be readmitted or die after hospital discharge if they also have cognitive impairment.⁶⁴⁹ Another research team found that Medicare beneficiaries with Alzheimer's or other dementias have more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting.⁶⁵⁰ A third research team found that having depression, rheumatoid arthritis or osteoarthritis was associated with higher emergency department use in Medicare beneficiaries with possible or probable dementia and two more chronic conditions.⁶⁵¹

Differences in health care use between individuals with and without dementia are most prominent for those residing in the community. Based on data from the Health and Retirement Study, community-residing individuals with dementia were more likely to have a potentially preventable hospitalization, an emergency department visit that was potentially avoidable, and/or an emergency department visit that resulted in a hospitalization.⁶⁵² For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

6.5.2 | Initiatives to reduce avoidable health care and nursing home use

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other

focusing on the care delivery team. The Caregiving section describes a number of interventions to support caregivers, and some of these also hold promise for reducing residential care admissions for individuals with Alzheimer's or other dementias. Additionally, collaborative care models — models that include not only geriatricians, but also social workers, nurses and medical assistants, for example — can improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits.⁵⁴⁵ For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by \$3,474 in 2012 dollars (\$4,342 in 2020 dollars) over a year for individuals with memory problems compared with others with memory problems whose care was overseen by a primary care provider only.⁵⁴⁵ More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of \$618 (\$695 in 2020 dollars) — a nearly 6-to-1 return on investment. Another group of researchers found that a telephone- and internet-based dementia care delivery system reduced emergency department visits over 12 months, although they found no effect on the number of hospitalizations or use of ambulance services.⁵⁴¹

Researchers of two recent systematic reviews, however, have found little evidence to support health services interventions successfully reducing acute hospitalizations or emergency department visits. One group of researchers who conducted a recent systematic review and meta-analysis of 17 randomized controlled trials from seven countries aimed at reducing avoidable acute hospital care by community-dwelling individuals with dementia found that none of the interventions reduced acute hospital use, such as emergency department visits, hospital admissions, or hospital days.⁶⁵³ In another systematic review and meta-analysis that included some of the same studies, researchers also found no evidence that non-pharmacological interventions reduced hospital admission for community-dwelling individuals with dementia.⁶⁵⁴ However, in an observational study of Medicare beneficiaries, a group of researchers found that individuals with dementia whose care was concentrated within a smaller number of clinicians had fewer hospitalizations and emergency department visits and lower health care spending overall compared with individuals whose care was dispersed across a larger number of clinicians.⁶⁵⁵ More research is needed to understand whether continuity of care is a strategy for decreasing unnecessary health care use for people with Alzheimer's or other dementias.

There is also some evidence that community care coordination reduces nursing home admission. In a systematic review and meta-analysis of non-pharmacologic interventions aimed at reducing hospital or nursing home admissions for community-dwelling individuals with dementia, researchers found that community care coordination reduced nursing home admission, based on the findings of two randomized trials.⁶⁵⁴ The researchers also found, however, that other types of single interventions, including exercise, psychosocial support and health professional training, and multifactorial assessment and treatment had no effect on nursing home admissions.⁶⁵⁴ In a retrospective case-controlled study of a dementia care program that used nurse practitioners and physicians to co-manage individuals with dementia,

individuals enrolled in the program had 9.4 fewer emergency department visits and 160.1 fewer hospital days per 1,000 participants per quarter,⁶⁵⁶ and were less likely to have a long-term care nursing home admission over three years,⁶⁵⁷ although there was no difference in hospital admissions.⁶⁵⁶ Additionally, the program saved \$284 per person per quarter in 2013 dollars (\$346 in 2020 dollars) after taking into account program costs that included clinician and staff time, payments to community-based organizations, supplies and other costs.⁶⁵⁷ More clinical trials and comparative studies are needed to identify promising interventions aimed at reducing hospital and nursing home admissions.

6.6 | Projections for the future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's or other dementias are projected to increase from \$355 billion in 2021 to more than \$1.1 trillion in 2050 (in 2021 dollars). This dramatic rise includes more than three-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.^{A11}

6.6.1 | Potential impact of changing the trajectory of Alzheimer's disease

While there are currently no FDA-approved pharmacologic treatments that prevent or cure Alzheimer's disease or slow its progression, several groups of researchers have estimated the cost savings of future interventions that either slow the onset of dementia or reduce the symptoms.^{363,658–660} One group of researchers estimated that a treatment introduced in 2025 that delays the onset of Alzheimer's by five years would reduce total health care payments by 33% and out-of-pocket payments by 44% in 2050.⁶⁵⁸ A second group of researchers estimated the cost savings of delaying the onset of Alzheimer's disease by one to five years. For individuals age 70 and older, they projected a one-year delay would reduce total health care payments by 14% in 2050, a three-year delay would reduce total health care payments by 27%, and a five-year delay would reduce health care payments by 39%.⁶⁵⁹ They also projected that a delay in onset may increase per capita health care payments through the end of life due to longer life, although the additional health care costs may be offset by lower informal care costs. A third group of researchers estimated that a treatment that slows the rate of functional decline by 10% would reduce average per-person lifetime costs by \$3,880 in 2015 dollars (\$4,504 in 2020 dollars), while a treatment that reduces the number of behavioral and psychological symptoms by 10% would reduce average per-person lifetime costs by \$680 (\$789 in 2020 dollars).³⁶³

The Alzheimer's Association commissioned a study of the potential cost savings of early diagnosis,⁶⁶⁰ assuming that 88% of individuals who will develop Alzheimer's disease would be diagnosed in the MCI phase rather than the dementia phase or not at all. Approximately \$7 trillion could be saved in medical and long-term care costs for individuals who were alive in 2018 and will develop Alzheimer's disease. Cost savings were due to a smaller spike in costs immediately

before and after diagnosis due to (1) the diagnosis being made during the MCI phase rather than the dementia phase, which has higher costs, and (2) lower medical and long-term care costs for individuals who have diagnosed and managed MCI and dementia compared with individuals with unmanaged MCI and dementia.

A treatment that prevents, cures or slows the progression of the disease could result in substantial savings to the U.S. health care system. Without changes to the structure of the health care system, however, access to new treatments for Alzheimer's may be severely restricted by capacity constraints. For example, one group of researchers developed a model of capacity constraints that estimated that individuals would wait an average of 19 months for treatment in 2020 if a new treatment had been introduced by then.⁶⁶¹ Under this model, approximately 2.1 million individuals with MCI due to Alzheimer's disease would develop Alzheimer's dementia between 2020 and 2040 while on waiting lists for treatment. This model assumed both that the hypothetical treatment would require infusions at infusion centers and that it would depend on people being evaluated with amyloid PET scans. While the introduction of new treatments that prevent, cure or slow the progress of Alzheimer's could have a dramatic effect on the incidence and severity of Alzheimer's, it is clear that their effectiveness could be limited by constraints on both health care system capacity and health insurance reimbursement.

7 | SPECIAL REPORT: RACE, ETHNICITY AND ALZHEIMER'S IN AMERICA

Despite decades of research and calls to action to ensure that health care is accessible and equal for all regardless of gender, race, ethnicity, geography, and socioeconomic status, this aim is still far from reality for too many Americans.

7.1 | Disparities still impacting health and health care

Reducing or eliminating disparity has been part of the national conversation as a key goal of the U.S. Department of Health and Human Services' Healthy People initiative for more than 20 years.^{662,663} Yet disparity is still evident in health and health care.

While *health disparities* and *health care disparities* are often used interchangeably, there are important distinctions between the two terms. A *health disparity* exists when there is a higher burden of illness, injury, disability, or mortality in one group relative to another, whereas a *health care disparity* is used to describe differences between groups in health insurance coverage, access to and use of health care, and quality of health care.⁶⁶⁴ For both these disparities, the differences are not explained by variations in health needs, patient preferences, or treatment recommendations and are closely linked with social, economic, and/or environmental disadvantage.⁶⁶⁴

The existence and adverse effects of health disparities are well documented. For example, Blacks and Native Americans are more likely

than Whites to report a range of health conditions, including asthma and diabetes. Native Americans also have higher rates of heart disease compared with Whites.⁶⁶⁵

The existence of health care disparities is similarly well documented. People of color and low-income individuals have historically faced greater barriers to accessing care. One reason for this is that they are more likely to be uninsured than Whites and people with higher incomes.⁶⁶⁶

Health and health care disparities are intertwined with social, economic and environmental factors that perpetuate disadvantage. Both health and health care disparities are influenced by socioeconomic status, age, geographic location, gender, disability status and sexual orientation.⁶⁶⁴ Race and ethnicity are also important factors contributing to health and health care disparities.⁶⁶⁴

Health care system factors that contribute to disparity should also be acknowledged. These include implicit bias on the part of health care providers, as well as cultural and language barriers that impede patient-provider relationships.⁶⁶⁴

Understanding how different racial and ethnic groups view, access and experience health care is critical to informing improvements to the health care system and helping health providers care for an increasingly diverse population. The need to do so is urgent. It is projected that people of color will account for over half (52%) of the population in 2050.⁶⁶⁴

7.2 | Pandemic sparks new discussions about disparity

In 2020, the COVID-19 pandemic and social justice movements sparked new conversations about endemic and long-standing health and health care disparities faced by people of color, especially when it comes to access, discrimination and trust in the health care system.^{667,668} People of color were disproportionately affected by the environmental, societal and economic impact of the pandemic – facing greater risk of losing a job or income, being more likely to be frontline workers with greater risk of exposure to the SARS-CoV-2 virus that causes COVID-19, and having a higher likelihood of housing uncertainty and food insecurity due to the pandemic.⁶⁶⁹⁻⁶⁷³ The effects of these social, economic and environmental factors, known as social determinants of health, can put a population's current and future health in jeopardy. For example, they have created stark contrasts in COVID-19 infection rates and outcomes. Black, Native American and Hispanic communities have seen COVID-19 cases, hospitalizations and deaths at rates greater than Whites, and these events far exceed their share of the U.S. population.⁶⁷⁴⁻⁶⁷⁷

In seeking care for COVID-19, Black Americans nationwide report on social media and in news stories that they experienced bias and discrimination.^{678,679} One study found that Hispanics were prevented from accessing testing and care for COVID-19 because they lacked insurance and there were shortages of interpreters in local health systems.⁶⁸⁰ Language barriers and low health literacy also contributed to misunderstanding of COVID-19-related health information and the

spread of misinformation in some Hispanic communities.⁶⁸⁰ A separate survey found that Asian and White individuals were more knowledgeable about COVID-19 than Hispanic and non-Hispanic Black individuals; this difference in awareness and understanding could exacerbate existing disparities in health care.⁶⁸¹

7.3 | Racial and ethnic disparities exist in Alzheimer's and dementia care

Racial and ethnic disparities in health and health care, such as those observed during the pandemic, extend to dementia care. Stigma, cultural differences, awareness and understanding, and the ability to obtain a diagnosis, manage the disease, and access care and support services for dementia vary widely depending on race, ethnicity and socioeconomic status. These disparities reach beyond clinical care to include uneven representation of Black, Hispanic, Asian, and Native Americans in Alzheimer's research in clinical trials.

As discussed in the Prevalence section, health and socioeconomic disparities and systemic racism contribute to increased Alzheimer's and dementia risk in communities of color.^{85,140,217,284,287-289,292,293} Older Black and Hispanic Americans are also disproportionately more likely to have Alzheimer's and other dementias, as well as more likely to have missed diagnoses, than older White Americans.^{271-277,294-296}

Caregiving for individuals with Alzheimer's or other dementias differs between racial and ethnic groups too. These differences include the time spent on caregiving, cultural perceptions of the burden of caregiving, whether social networks provide support, and the psychological well-being of the caregiver.^{384-388,390}

7.4 | The state of disparity in Alzheimer's and dementia health care: Adult and caregiver surveys

To better understand racial and ethnic attitudes and experiences regarding Alzheimer's and dementia care in the United States, the Alzheimer's Association commissioned Versta Research to conduct surveys of (1) U.S. adults and (2) current or recent caregivers of adults age 50 or older with cognitive issues. Respondents were asked about access to care and support services, trust in providers and the health care system, participation in clinical trials and research, and caregiver experiences. This is the first Alzheimer's Association survey to ask and report the views of Asian Americans and Native Americans on these issues. It is also one of the few reports to investigate the experiences of diverse caregivers.³⁸⁷

7.4.1 | Key findings

The Alzheimer's Association surveys revealed:

Discrimination is a barrier to Alzheimer's and dementia care

- More than one-third of Black Americans (36%), and nearly one-fifth of Hispanic Americans (18%) and Asian Americans (19%),

believe discrimination would be a barrier to receiving Alzheimer's care.

- Half of Black Americans (50%) report they've experienced health care discrimination; more than 2 in 5 Native Americans (42%) and one-third of Asian Americans (34%) and Hispanic Americans (33%) likewise report having experienced discrimination when seeking health care.
- Among non-White caregivers, half or more say they have faced discrimination when navigating health care settings for their care recipient, with the top concern being that providers or staff do not listen to what they are saying because of their race, color or ethnicity. This concern was especially high among Black caregivers (42%), followed by Native American (31%), Asian American (30%) and Hispanic (28%) caregivers. Fewer than 1 in 5 White caregivers (17%) expressed this view.
- Two in 5 caregivers (41%) who provide unpaid care to a Black person say that race makes it harder for them to get excellent health care. Nearly 1 in 3 caregivers of Hispanic people (32%) say the same.

People of color want health care providers who understand their unique experiences and backgrounds, but many doubt they would have access to culturally competent providers

- An overwhelming majority of non-White Americans say it is important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences, including Native Americans (92%), Blacks (89%), Hispanics (85%) and Asian Americans (84%).
- But fewer than half of Black (48%) and Native Americans (47%) feel confident there is access to providers who are culturally competent, and only about 3 in 5 Asian Americans (63%) and Hispanics (59%) likewise feel confident.

Black Americans lack trust in research clinical trials, and half doubt that advances in Alzheimer's treatments will be shared

- Nearly two-thirds of Black Americans (62%) believe medical research is biased against people of color, and Black Americans are less interested in participating in clinical trials for Alzheimer's than all other groups surveyed.
- Only half of Black Americans (53%) trust a future cure for Alzheimer's will be shared equally regardless of race, color or ethnicity.

Knowledge, concern and stigma about Alzheimer's varies widely across racial and ethnic groups

- Concern about developing Alzheimer's is lower among Native Americans (25%), Blacks (35%) and Hispanics (41%), especially when compared with Whites (48%).
- More than one-third of Native Americans (35%) and nearly 3 in 10 Hispanics (28%) do not believe they will live long enough to develop Alzheimer's or another dementia.

- More than half of non-White Americans believe significant loss of memory or cognitive abilities is “a normal part of aging.”
- Hispanic, Black and Native Americans are twice as likely as Whites to say they would not see a doctor if experiencing thinking or memory problems.
- One in 5 Black (21%) and Hispanic Americans (20%) say they would feel insulted if a doctor suggested a cognitive assessment.
- Hispanic and Black Americans worry less than other groups about being a burden on family if they develop Alzheimer's disease.
- Nearly 2 in 3 caregivers (64%) across all groups say that caregiving is stressful, but nearly all (92%) say caregiving is rewarding as well.

Overall, the results of the Alzheimer's Association surveys indicate that despite ongoing efforts to address health and health care disparities in Alzheimer's and other dementias, there is still much work to do. People of color face more challenges in accessing and receiving high quality dementia care and support services in the current environment. The data suggest that discrimination and lack of diversity in the health care profession are significant barriers that demand attention.

7.4.2 | Survey design and research methods

Surveys across both groups explored wide-ranging issues related to Alzheimer's and dementia care, including:

- Knowledge and understanding of the disease.
- Access to care and support services.
- Trust in health care, providers and disease research.
- Interest in clinical trials.
- Existence of discrimination and how that impacts care.

Survey of U.S. adults

A survey of 2,491 U.S. adults age 18 and older was conducted from October 26, 2020, to November 11, 2020. Data was collected by NORC at the University of Chicago via the AmeriSpeak® panel. AmeriSpeak is a probability-based panel of all U.S. households. The survey included 945 White respondents. Oversamples of Hispanic (n = 541), Black (n = 515), and Asian Americans (n = 412) were weighted back to their true population proportions for statistical analysis and reporting. For full inclusion of Native Americans, the same survey was administered to an additional sample of 406 Native Americans recruited through online (non-probability) panels with sampling stratified and data weighted on gender, age, income and education to match U.S. Census Bureau data. The survey was offered in both English and Spanish.

Survey of caregivers

A survey of 1,392 U.S. adults who were current or recent unpaid caregivers for an adult relative or friend age 50 or older experiencing problems with thinking, understanding, or remembering things was conducted from October 21, 2020, through November 22, 2020. The sample included White (n = 313), Hispanic (n = 309), Black (n = 305), Asian (n = 301) and Native American caregivers (n = 154), and care-

givers who identified as belonging to another ethnic or racial group (n = 10). Respondents were recruited via non-probability online panels used exclusively for research, with full population screening and respondent data weighted to match U.S. Census data on age, gender, income, education and race/ethnicity to ensure accurate representation of the caregiving population, and to correct for demographic oversamples. The survey was offered in both English and Spanish.

For both surveys, differences noted in the report between racial and ethnic groups were tested and found to be statistically significant at the $p < .05$ level.

7.4.3 | Survey results

Discrimination continues to be a barrier to dementia care

The Alzheimer's Association survey of U.S. adults found that more than one-third of Black Americans (36%) and one-fifth of Hispanic (18%) and Asian (19%) Americans see discrimination as a barrier to receiving Alzheimer's and dementia care (Figure 1). Specifically, they expect to be treated differently because of their race, color or ethnicity.

Other perceived barriers to care (Table 20) cited by survey respondents include affordability (especially among Asian Americans), followed by lack of good health insurance coverage, lack of good local health care (especially among Black Americans and Asian Americans), and lack of family and social support. Fewer respondents saw language as a barrier to receiving dementia care, but among current caregivers, almost 1 in 4 Asian Americans (23%) and nearly 1 in 5 Hispanic caregivers (17%) cited language as a barrier to care.

When asked more directly about the impact of race or ethnicity on the quality of care, two-thirds of Black Americans (66%) believe it is harder for Black Americans to get excellent care for Alzheimer's disease or other dementias. Likewise, 2 in 5 Native Americans (40%) and Hispanic Americans (39%) believe their own race or ethnicity makes it harder to get care, as do one-third of Asian Americans (34%).

Caregivers, too, see discrimination as a top barrier, with 1 in 4 Black caregivers (25%) citing discrimination as a barrier, followed by Native American (19%), Asian American (17%), and Hispanic (8%) caregivers. In fact, more than half of Native American (63%), Black (61%) and Hispanic (56%) caregivers report having *experienced* racial discrimination when navigating health care settings for their care recipient. The same is true for nearly half of those who are Asian American (47%). Two in 5 caregivers (41%) who provide unpaid care to a Black person say that race makes it harder for them to get excellent health care. Nearly 1 in 3 caregivers of Hispanic people (32%) say the same.

What specifically have caregivers experienced? The top problem cited was that providers or staff do not listen to them because of their race, color, or ethnicity (Table 21). This was especially high among Black caregivers (42%), followed by Native American (31%), Asian American (30%) and Hispanic (28%) caregivers. Fewer than 1 in 5 White caregivers (17%) expressed this same view. More than 1 in 4 caregivers of color report health care providers treating them as if they were “not smart” (Native American, 43%; Asian American, 28%; Black, 28%; and

TABLE 20 Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer's or Another Dementia Among U.S. Adults

Barrier	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Affordability of care	61%	55%	52%	70%	61%
Lack of good health care insurance coverage	31%	41%	31%	39%	36%
Lack of good health care services in my community	20%	24%	27%	27%	24%
Lack of family and social support to help me	20%	21%	20%	25%	20%
Being treated differently because of my race, color or ethnicity	1%	18%	36%	19%	12%
Not being able to communicate easily in English	4%	9%	9%	8%	5%
Other barriers	2%	1%	1%	1%	2%
There would be no barriers	21%	17%	20%	12%	14%

TABLE 21 Types of Discrimination Based on Race, Color, or Ethnicity Among Alzheimer's and Dementia Caregivers

Type of Discrimination	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Felt not listened to	17%	28%	42%	30%	31%
Provider acted like you were not smart	11%	26%	28%	28%	43%
Treated with less courtesy than others	11%	26%	26%	23%	22%
Treated with less respect than others	8%	24%	26%	20%	27%
Received poorer service than others	7%	21%	19%	10%	18%
Provider acted afraid of you	7%	11%	13%	7%	4%

Hispanic, 26%) compared with about 1 in 10 White (11%) caregivers. In addition, at least one-fifth of caregivers of color report being treated with less courtesy and/or less respect.

Not surprisingly, the belief among Americans of color (not just caregivers) that discrimination is a barrier to Alzheimer's and dementia care is rooted in their own experiences with the health care system. Half of Black Americans (50%), more than 2 in 5 Native Americans (42%), and a third of all Asian (34%) and Hispanic (33%) Americans report having experienced discrimination when seeking health care (Figure 18). In contrast, fewer than 1 in 10 White Americans (9%) report having experienced discrimination because of their race, color or ethnicity.

Desire for providers who understand ethnic or racial background

Given their own experiences with discrimination, it is not surprising that people of color feel it is important for Alzheimer's and dementia care providers to be more culturally competent. Responses from both surveys indicate a strong desire for dementia care providers who understand different racial and ethnic backgrounds, but many survey respondents say access to these providers is lacking.

Figure 19 shows responses to two questions that were tailored to a respondent's race or ethnicity. For example, Black respondents were asked: "How important do you feel it is for Black people with Alzheimer's or other dementias to have health care providers who understand their background and experiences as Black people?" And then: "How confident are you that Black people with Alzheimer's or other dementias have access to health care providers who understand their background and experiences as Black people?"

An overwhelming majority of non-White respondents said it was important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences, including Native Americans (92%), Black Americans (89%), Hispanic Americans (85%) and Asian Americans (84%). However, fewer than half of Black respondents (48%) and Native American respondents (47%) felt confident that people in their communities with Alzheimer's or other dementias currently have access to such providers, and fewer than two-thirds of Asian Americans (63%) and Hispanic Americans (59%) felt the same.

The survey of caregivers mirrored these results. Among those caring for a non-White person, most felt it was important for health care providers to understand the ethnic or racial background and experiences of the person they are caring for, including 96% of those caring for Native Americans, 94% of those caring for Asian Americans, 91% of those caring for Black Americans and 89% of those caring for Hispanic Americans.

Far fewer caregivers rated their current health care providers as being "excellent" or "good" when it comes to understanding the ethnic or racial background and experiences of the person they are caring for (Native Americans, 67%; Hispanic Americans, 65%; Black Americans, 61%; and Asian Americans, 53%).

Belief that research is biased is more common among non-whites; Blacks do not believe a cure will be shared equally

The experiences and views of discrimination expressed by respondents in both surveys are reflected in their views on clinical

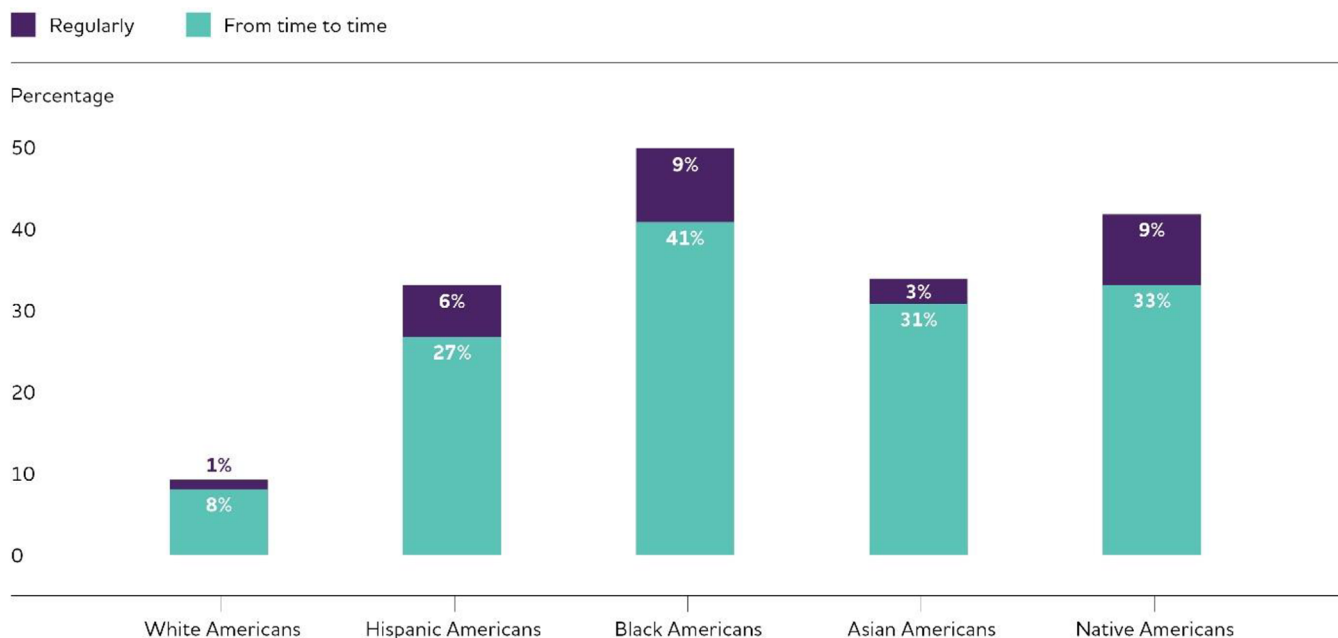


FIGURE 18 Percentage of U.S. adults who have experienced racial or ethnic discrimination when seeking health care

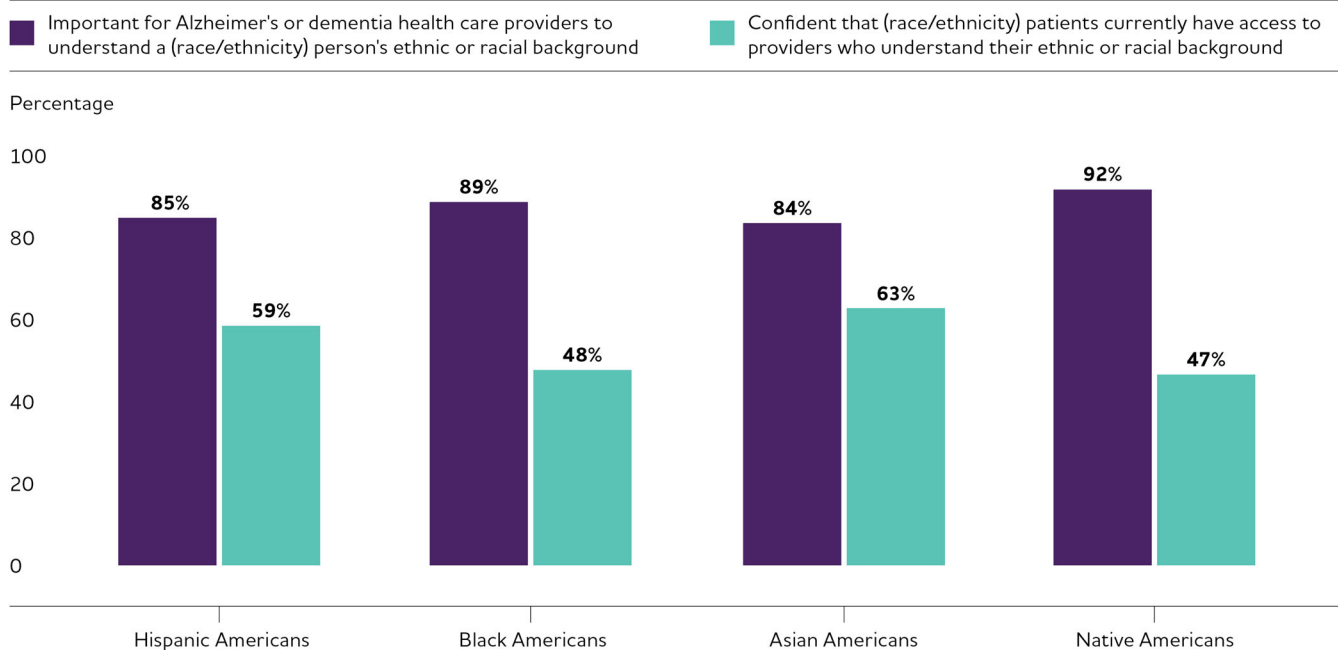


FIGURE 19 Access to health care providers who understand racial and ethnic backgrounds among U.S. adults

trials, research and potential treatment for Alzheimer's and other dementias.

A majority of Black Americans (62%) believe that medical research is biased against people of color – a view shared by substantial numbers of Asian Americans (45%), Native Americans (40%) and Hispanic Americans (36%) as well. Notably, even a third of White Americans (31%) see medical research as being biased against people of color (Figure 20).

It's not surprising, then, that among Americans as a whole, Blacks have less interest in clinical research trials to prevent or slow the progression of Alzheimer's disease. White Americans are most likely to express interest (82%), followed by Native Americans (81%), Hispanic Americans (78%), Asian Americans (73%) and lastly, Black Americans (67%).

Responses from caregivers present a somewhat different picture. Compared with other groups, Black caregivers and Hispanic caregivers

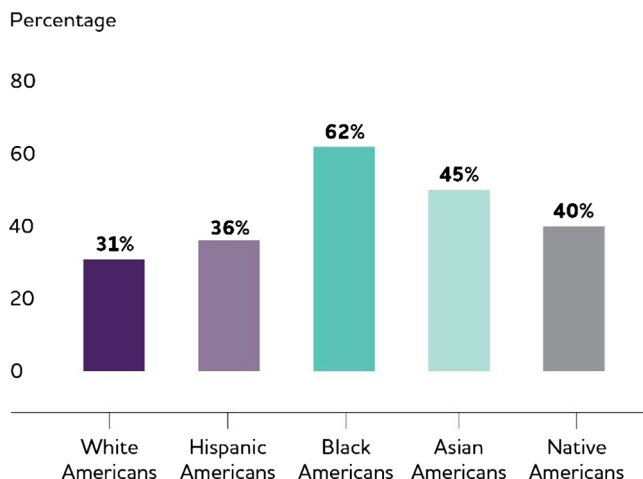


FIGURE 20 Percentage of U.S. adults who believe medical research is biased against people of color

are somewhat more interested in clinical trials for their care recipient (Black caregivers, 73%; Hispanic caregivers, 70%), while Asian American caregivers are least interested in having their care recipient be involved in clinical research (57%). Overall, interest in clinical trial participation was higher in both Alzheimer's Association surveys than is reflected in current trial participation, particularly for people of color.⁶⁸² Follow-up research is needed to better understand mitigating factors that may prevent interested individuals from actual trial participation.

Among all U.S. adults who are not interested in clinical trial participation, the most common reason cited regardless of race or ethnic group is not wanting to be a "guinea pig" (Table 22). This sentiment is especially strong among Black Americans (69%), for whom other differences stand out as well. For example, almost half of Black Americans (45%) worry that treatments might cause sickness. They are twice as likely as other groups to say they "don't trust medical research." And they are more than twice as likely than other racial or ethnic groups to say they "might not be treated fairly."

A noteworthy difference for Asian Americans is that the potential time and cost of clinical trials ranks second among their rea-

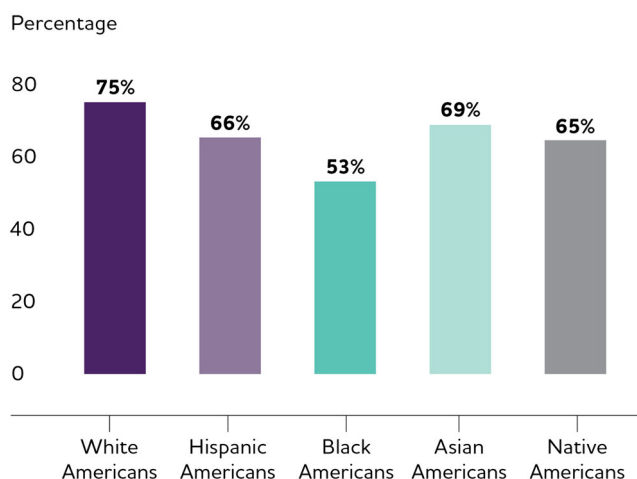


FIGURE 21 Percentage of U.S. adults who trust an Alzheimer's cure will be shared equally regardless of race, color or ethnicity

sons for not wanting to participate; this reason was cited by 43% of respondents.

For caregivers, reasons for lack of interest were more varied. Black caregivers were most focused on lack of perceived benefit (35%) and not wanting the person to be a guinea pig (32%). Hispanic caregivers were most focused on not wanting a placebo treatment (28%). Asian American caregivers were twice as likely as others to say the person might not be treated fairly (20%). Native American caregivers were more focused on not wanting the person to be a guinea pig (40%) and potential lack of support among family and community (39%).

The impact of discrimination and bias is also apparent in respondents' views on treatment access. Should clinical trials identify a treatment or "cure" for Alzheimer's disease, only half of Black Americans (53%) trust that this cure will be shared equally regardless of race, color or ethnicity (Figure 21). This is in sharp contrast to White Americans (75% of whom believe it will be shared) and lower than other racial and ethnic groups as well, including Asian Americans (69%), Hispanic Americans (66%), and Native Americans (65%).

TABLE 22 Reasons Cited By U.S. Adults for Not Being Interested in Clinical Trial Participation

Reason	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Don't want to be a guinea pig	49%	51%	69%	54%	51%
Treatment might cause sickness	37%	36%	45%	32%	18%
Time and cost might be too much	33%	26%	24%	43%	31%
Don't trust pharmaceutical companies	28%	22%	29%	19%	26%
Doubt there would be any benefit	26%	26%	21%	28%	36%
Might get placebo	17%	12%	14%	20%	9%
Don't trust medical research	10%	10%	24%	6%	16%
Unable to travel or get transportation	11%	11%	16%	19%	23%
Might not be treated fairly	3%	8%	22%	12%	10%

While the majority of both White and non-White Americans trust health care providers generally, trust is somewhat weaker among Hispanic, Black and Native Americans. Asian Americans are most likely to say they trust health care providers (93%), followed by White Americans (88%), with lower numbers for Black Americans (82%), Hispanic Americans (81%) and Native Americans (79%).

Perhaps related to this, Hispanic, Black and Native Americans are twice as likely as White Americans to say they would not see a doctor if they were experiencing thinking or memory problems. Almost 1 in 10 Hispanics (9%), Blacks (8%) and Native Americans (9%) say they would not see a health care provider, versus 1 in 25 White Americans (4%). Six percent of Asian Americans say they would not see a health care provider.

One in 5 Black Americans (21%) and Hispanic Americans (20%) say they would feel insulted if a doctor suggested an assessment for their thinking or memory, versus half as many White Americans who would feel insulted (10%). About 1 in 6 Asian Americans (16%) would feel insulted, as would 1 in 7 Native Americans (14%).

Hispanics are also least confident they would be able to access quality health care for Alzheimer's disease or other dementias if they needed it, especially compared with White Americans. In particular, fewer Hispanic Americans express confidence in being able to get excellent health care for specialist testing and diagnosis (69% vs 79% of White Americans) and health care and support to manage the disease (67% vs 74% of White Americans).

Knowledge and understanding of Alzheimer's disease varies

The Alzheimer's Association survey of US adults also revealed that fewer people of color report knowing someone with Alzheimer's. Four of 5 White Americans (80%) report having known somebody with Alzheimer's or another type of dementia. The numbers among all other groups are 15 to 20 percentage points lower (Hispanic Americans, 64%; Black Americans, 65%; Asian Americans, 59%; and Native Americans, 65%).

Native Americans are least worried about developing Alzheimer's disease, with 1 in 4 (25%) expressing concern, followed by 1 in 3 Black Americans (35%) and 2 in 5 Hispanic Americans (41%). In contrast, almost half of White Americans (48%) worry about it, as do nearly as many Asian Americans (46%). Hispanic and Native Americans are also more likely than other groups to believe they will not live long enough to get Alzheimer's or another dementia. More than a third of Native Americans (35%) and one-quarter of Hispanic Americans (28%) believe they will not live long enough, versus fewer than 1 in 4 Asian Americans (19%), Black Americans (20%), and White Americans (23%).

Additionally, more than half of non-White Americans believe that significant loss of memory or cognitive abilities is a "normal part of aging" rather than being an indicator of disease (Hispanic Americans, 57%; Asian Americans, 56%; Black Americans, 55%; and Native Americans, 53%). This is in contrast to White Americans, among whom fewer than half (48%) believe that memory loss or cognitive decline is normal.

Caregiving is stressful but rewarding

The Alzheimer's Association survey of caregivers provided additional insights, indicating that for many family and friends who provide care

for a loved one, the rewards of providing care may help balance the stress.

Over half of unpaid caregivers surveyed report providing assistance with personal care, such as bathing, eating or dressing. The percentage providing this form of care is highest among Black caregivers (71%) and Hispanic caregivers (68%), followed by Asian American caregivers (59%), Native American caregivers (56%) and White caregivers (53%).

Fewer Black Americans (78%) and Hispanic Americans (83%) worry about being a burden on family if they develop Alzheimer's disease compared with other groups (White Americans, 93%; Asian Americans, 90%; Native Americans, 84%).

And while nearly 2 in 3 caregivers (64%) say that caregiving is stressful, nearly all (92%) say that caregiving is rewarding, as well.

7.5 | Bridging racial and ethnic barriers in Alzheimer's and dementia care: A path forward

Findings from the Alzheimer's Association surveys indicate that despite ongoing efforts to address health and health care disparities in Alzheimer's and dementia care, there is still much work to do.

Current efforts to reduce health disparities, address social determinants of health, build diversity in the health care profession, and train health care providers to meet the needs of a growing population of older adults from different racial and ethnic groups must be accelerated. Amid broader calls for social justice, greater strides must be made to eliminate discrimination and other forms of bias to ensure all Americans have access to high quality dementia care and support services, as well as opportunities to participate in — and benefit from — Alzheimer's research.

Based on the surveys' findings, paths forward include:

- Preparing the workforce to care for a racially and ethnically diverse population of older adults.
- Increasing diversity in dementia care.
- Engaging, recruiting and retaining diverse populations in Alzheimer's research and clinical trials.

7.5.1 | Preparing the workforce to care for a racially and ethnically diverse population of older adults

As described in the Prevalence Section, older Black and Hispanic Americans are more likely to have Alzheimer's or other dementias than Whites, and this is likely due in part to health and health care disparities.^{85,87,271-277,284,285,287,288} Coinciding with increasing diversity in the general population, the number of older Americans, particularly the oldest-old (those age 85 or older), is also expected to grow — with more than twice as many cases of Alzheimer's and other dementias anticipated by 2050.²¹⁶ Up to 39% of this older adult population in 2050 will be minorities.^{683,684}

Current and future health care providers need to be prepared to screen, diagnose and treat Alzheimer's and dementia in this expanding

racially and ethnically diverse population of older adults so that disparities are not perpetuated.

Earlier reports on racial and ethnic differences in Alzheimer's health care have proposed cultural competence education as one solution to address disparities. Training providers to recognize and overcome implicit bias is another method that organizations are using to tackle disparities.

Cultural competence

At the organizational level, cultural competence helps build a diverse and inclusive workforce.⁶⁸⁵ At the provider level, cultural competence training equips professionals with the skills and resources needed to connect with dementia care recipients and caregivers across racial and ethnic groups in a way that is sensitive to culture and language.⁶⁸⁶

Elements of cultural competence⁶⁸⁶ are:

- A culturally diverse staff that reflects the population served.
- Ability to overcome language barriers, either with bilingual staff or interpreters.
- Training for providers on the cultures and languages represented in the population.
- Patient materials and practice signage that are translated and sensitive to cultural norms.

There have been several efforts to instill cultural competence into dementia care. Stanford Health Care's Memory Support Program (MSP) is one such example. The model's efforts encompass culturally competent care in inpatient and outpatient settings to ensure continuity for patients and caregivers.⁶⁸⁷ A case study showed that MSP is a valuable way to provide culturally competent care to African Americans and posits this model could be implemented in other settings.⁶⁸⁷ Cultural competence training has also been proposed as a component of Alzheimer's and dementia nursing and nursing assistant training curricula.⁶⁸⁸

Other organizations that engage health care providers who may screen and treat individuals with dementia are also committed to cultural competence. The U.S. Department of Health and Human Services' National Culturally and Linguistically Appropriate Services (CLAS) Standards offer information to improve communication with people from different ethnic groups in a way that is respectful and responsive to their culture.^{683,689} Recognizing the changing racial and ethnic demographics of Alzheimer's disease, the Alzheimer's Association began promoting cultural competence and cultural sensitivity in dementia care more than a decade ago and this effort remains a priority.⁶⁹⁰ In 2016, the American Geriatrics Society (AGS) formed an Ethnogeriatrics Committee that issued a guidance stressing the importance of cultural competence in geriatric care.⁶⁸³ An Ethnogeriatrics Special Interest Group now convenes at the annual AGS meeting to discuss ongoing projects and new developments in the field.⁶⁹¹

Implicit bias

Implicit bias, or when people act unintentionally on prejudices or stereotypes, is a key contributor to health care disparities.^{692,693} Implicit bias clouds decision-making such that race, gender, ethnicity

and other patient characteristics influence how physicians treat people. Medical schools are responding to the call to action to train future physicians to recognize and overcome implicit bias. Hospitals, clinics and health care systems are also working to address this issue among their employees.⁶⁹⁴

Although the Alzheimer's Association surveys did not explore how implicit bias is impacting dementia care, respondents did indicate that they faced discrimination. Discriminatory behaviors are often the result of implicit bias.⁶⁹⁵ A survey indicates that implicit bias held by the investigators and clinical trial recruiters in the field of cancer research may be a reason for the low recruitment and participation of racial and ethnic minorities in cancer clinical trials.⁶⁹⁶ Less has been reported on how implicit bias contributes to low participation rates in Alzheimer's and dementia research and suggests an area for future investigation.

There is little information about the implementation and outcomes of implicit bias training specifically in Alzheimer's and dementia care. However, specialties that play a role in dementia care, such as primary care/family medicine and geriatric medicine, do have materials to train providers. For example, the National Institute on Aging offers resources on implicit bias for those who care for older adults, and The EveryONE Project from the American Academy of Family Physicians recently introduced the comprehensive Implicit Bias Training Guide for primary care physicians.⁶⁹⁷⁻⁶⁹⁹

7.5.2 | Increasing diversity in dementia care

Trust in health care and perceptions of health care quality are eroded when individuals experience racial and ethnic discrimination in clinical settings. An analysis of data from the 2015 to 2016 Adult California Health Interview Survey found that discrimination in a clinical setting "make[s] a person less likely to have a future interaction with health care," such as by not receiving medical care when necessary or not filling prescriptions.⁷⁰⁰

The Alzheimer's Association surveys uncovered weaker trust in the health care system among Hispanics, Blacks and Native Americans. The same groups were also less likely to see a health care provider for diagnosis or treatment of Alzheimer's disease. This could exacerbate existing health disparities. People of color surveyed already face discrimination and anticipate encountering future discrimination when seeking Alzheimer's care, and as a result want to see their racial and ethnic backgrounds reflected in their Alzheimer's and dementia health care providers.

Currently, only 1 in 3 U.S. physicians are Black, American Indian or Alaska Native, Hispanic or Asian.⁷⁰¹ Primary care is more diverse, which is encouraging. Approximately 40% of primary care physicians are Black, Hispanic, American Indian or Alaska Native.⁷⁰² As discussed in the Alzheimer's Association 2020 *Alzheimer's Disease Facts and Figures* Special Report,⁵³⁰ primary care physicians play an important role in diagnosing and caring for people with Alzheimer's and other dementias. The survey results presented earlier indicate that Hispanic Americans may rely on their primary care providers more than other groups

to test for and diagnose Alzheimer's disease because they face barriers to accessing specialists. Ensuring diversity in these front-line providers may help reduce future disparities in dementia care. Diversity in other related specialties, such as neurology and geriatric medicine, however, remains low.^{703,704}

Shortages of physicians and other health care professionals in underserved areas contribute to health disparities. The racial and ethnic diversity of medical school applicants is not keeping pace with shifting demographics of the U.S. population. Half of applicants are White and almost one-quarter are Asian.⁷⁰⁵ Together, Blacks, Hispanics, individuals who are Latino or of Spanish origin, and American Indians or Alaska Natives make up only 15% of applicants.⁷⁰³ Since Blacks and American Indians or Alaska Natives enrolled in medical school are two to three times more likely than their White or Asian American counterparts to practice in an underserved area, it is important to support programs that recruit diverse students to medical schools in greater numbers.⁷⁰⁶

Developing a workforce that reflects the demographics of individuals with Alzheimer's or other dementias should begin during outreach and recruitment to training programs, continue with programming designed to support students of color during their training years, and extend to offering residency opportunities in health care settings that treat diverse populations. In addition, hiring practices should consider diversity and inclusion to meet the needs of local patient populations.

Future Alzheimer's and dementia research can be strengthened by increasing the diversity of investigators and professionals who conduct clinical trial and population health research. Doing so introduces varied perspectives, lived experiences and cultural nuances vital to culturally accountable research. For example, one study found that Black community liaisons were able to successfully recruit Black participants to a dementia clinical trial when they were the ones to explain and manage trial procedures.⁷⁰⁷

The innovative Institute on Methods and Protocols for Advancement of Clinical Trials in Alzheimer's disease and related dementias (IMPACT-AD) program launched in fall of 2020 is a step toward this goal.⁷⁰⁸ A major emphasis of this intensive training course is to enhance future Alzheimer's and dementia research. IMPACT-AD includes efforts to ensure program participants reflect diversity across the spectrum. Its inaugural class included physicians, nurses, public health professionals, scientists and study coordinators, as well as post-doctoral researchers and research fellows from universities and health care systems across the country. Participants included both early-career and established professionals. Seventy percent were women and 40% self-identified as people of color.

7.5.3 | Engaging, recruiting and retaining diverse populations in Alzheimer's research and clinical trials

There is a large body of evidence demonstrating low diversity in clinical trials and research, and in Alzheimer's research the participants are mostly older non-Hispanic Whites.⁷⁰⁹⁻⁷¹¹ Efforts to ensure

greater diversity in Alzheimer's disease research and clinical trials must be accelerated. Without appropriate participation by Black, Hispanic, Asian and Native Americans in Alzheimer's clinical trials and research, it is impossible to get a complete understanding of how racial and ethnic differences may affect the efficacy and safety of potential new treatments. Future clinical trials must do more to reflect the entire population so everyone benefits from advances in Alzheimer's research.

A critical first step to increasing diverse participation and representation in clinical research is building and restoring trust in underrepresented communities. One way to do so is through community-based organizations (CBOs) and other respected local partners.⁷⁰⁹ These efforts are gaining traction but should be expanded to more groups and more communities. The Healthy Brain Initiative *State and Local Public Health Partnerships to Address Dementia: 2018-2023 Road Map*, launched in partnership with the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC), is organized around a core principle of "eliminating disparities and collaborating across multiple sectors." In addition, the Alzheimer's Association and CDC collaborated to develop the first-ever *Healthy Brain Initiative Road Map for Indian Country*. The Association has used this guidebook to build relationships with American Indian/Alaska Native communities, raise awareness about Alzheimer's and collaborate with national partners on communications tailored to the unique tribal traditions present in American Indian/Alaska Native communities.^{712,713}

To succeed, relationships with CBOs must demonstrate that they are sustainable, transparent and integrated with other public health efforts. Strong community relationships can serve to address misconceptions and mistrust about research because the community has a sense of ownership in the research initiative.^{714,715} Participants are stakeholders rather than bystanders or subjects in the endeavor. This could make a difference in reinstating trust that Alzheimer's treatments or cures will be shared equitably. For example, a recent report suggests that strong commitment to earning the trust of the Black community is essential to encourage their participation in research.⁷¹⁶

The Alzheimer's Association is working with several CBOs and other groups to educate and engage diverse communities about Alzheimer's disease and care and support services the Association provides. National partnerships include those with the African Methodist Episcopal Church, the National Hispanic Council on Aging and SAGE (Advocacy & Services for LGBTQ Elders). In early 2021, the Association announced new partnerships with the Thurgood Marshall College Fund and Tzu Chi USA. Local Association chapters are also working with various nearby groups to engage diverse communities. In addition, several chapters are working with *promotoras de salud* (community health workers) to provide Alzheimer's education and resources to Spanish-speaking communities.

Other notable but relatively new efforts to increase recruitment and retention of diverse groups are also underway. In 2018, the National Institute on Aging released its National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Research. The strategy outlines practical, proactive approaches to help dementia study sites engage a wider, more diverse group of volunteers.⁷¹⁷

New guidance released in late 2020 by the U.S. Food and Drug Administration aimed at enabling greater diversity in clinical trials through changes to eligibility criteria, enrollment practices and trial designs is a welcome development. This guidance offers new approaches to help Alzheimer's and dementia researchers navigate current barriers that hinder clinical trial recruitment of racial and ethnic minorities. These barriers include strict eligibility requirements, participant burden, and lack of culturally appropriate communication and outreach to build trust with these diverse populations.⁷¹⁸

In December 2020, the Alzheimer's Association and the American College of Radiology announced the opening of recruitment for the New IDEAS study with particular focus on outreach in Black and Hispanic communities. New IDEAS will enroll 7,000 participants, including 2,000 Hispanics/Latinos and 2,000 Blacks/African Americans. New IDEAS will build upon the original IDEAS study, which provided the strongest phase 4 data to date supporting the clinical value of brain amyloid positron emission tomography (PET) scans. The goal of New IDEAS is to determine if using a brain amyloid PET scan can help inform an individual's memory care plan and improve their health outcomes.⁷¹⁹⁻⁷²¹

7.6 | Conclusion

The Alzheimer's Association surveys of U.S. adults and caregivers of individuals with cognitive issues are among the first to explore perspectives and experiences of different racial and ethnic groups as they relate to health care for Alzheimer's and other dementias. Collectively, the responses indicate that organizations must remain committed to rectifying health and health care disparities for older adults. Disparities in Alzheimer's and dementia care are the result of deeply rooted issues in the health care system. The NIA Health Disparities Research Framework⁷²² recommends responses that are multi-level and consider factors and risks over the lifecourse to address these disparities. Actions and solutions are needed to ensure the already devastating burden of Alzheimer's disease and other dementias on diverse racial and ethnic groups is not made worse by discrimination and health inequities in the current system.

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ENDNOTES

A1. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer's dementia for 2021: The number 6.2 million is from updated prevalence estimates based on data from the Chicago Health and Aging Project (CHAP) and population projections from the U.S. Census.²¹⁶ The number is higher than previous estimates from CHAP data and the US census because it used more recently updated Census

projections and incorporated information on the prevalence of Alzheimer's dementia for Hispanic/Latino Americans.

A2. Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence: The number of people in the U.S. living with Alzheimer's dementia is higher in CHAP than in the Aging, Demographics, and Memory Study (ADAMS).^{216,219} This discrepancy is mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's.²¹⁸ Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,²² the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's dementia in the United States.

A3. State-by-state prevalence of Alzheimer's dementia: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population for 2020 and 2025, with adjustments for state-specific age, gender, years of education, race and mortality.²³⁹ These projections come from a previous analysis of CHAP data that is not the same as the analysis providing the total number for the United States in 2021. State-by-state projections are not available for 2021.

A4. Criteria for identifying people with Alzheimer's or other dementias in the Framingham Heart Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.²⁴⁴ Diagnosis of dementia was made according to the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than six months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.

A5. Projected number of people with Alzheimer's dementia, 2020-2060: This figure comes from the CHAP study.²¹⁶ Other projections are somewhat lower (see, for example, Brookmeyer et al.⁷²³) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.^{A2} Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's dementia over the coming decades.

A6. Annual mortality rate due to Alzheimer's disease by state: Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to Alzheimer's — a burden that appears smaller relative to other states when the rates are adjusted for age.

A7. Number of family and other unpaid caregivers of people with Alzheimer's or other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS) survey. Between 2015 and 2019, 44 states and the District of Columbia utilized

the BRFSS caregiver module. This module identified respondents age 18 and over who had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. The module asks a series of follow-up questions, including asking the caregiver to identify what the main health problem, long-term illness, or disability that the person they care for has. One of the reported condition categories is Alzheimer's disease, dementia, or other cognitive impairment. This number does not include caregivers whose caregiving recipient has dementia, but is not their main condition. To calculate the total percentage of adults that are caregivers for individuals living with dementia, data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP was also utilized. The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care: 11% of respondents reported dementia as the main condition of their care recipient, while 26% of all respondents reported the presence of dementia. Using this ratio in combination with BRFSS data, the Alzheimer's Association was able to determine the percentage of adults in 44 states and the District of Columbia who are caregivers for individuals living with Alzheimer's or another dementia. For the 6 states without 2015-2019 BRFSS data, this percentage was estimated using state-specific BRFSS data from 2009 combined with the aggregated average of BRFSS data from 2015-2017. To determine the number of Alzheimer's and dementia caregivers in each state, the percentages were applied to the estimated number of people age 18 and older in each state in July 2020, using U.S. Census Bureau data available at: <https://www.census.gov/programs-surveys/popest/technical-documentation/research/evaluation-estimates.html>. This resulted in a total of 11.199 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.

A8. The 2014 Alzheimer's Association Women and Alzheimer's Poll: This poll questioned a nationally-representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics/Latinos, selected from U.S. Census tracts with higher than an 8% concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Question-

naire design and interviewing were conducted by Abt SRBI of New York.

- A9. Number of hours of unpaid care:** The BRFSS survey asks caregivers to identify, within five time frames, the number of hours they provide care in an average week. Using the method developed by Rabarison and colleagues,³⁷¹ the Alzheimer's Association assumed the midpoint of each time frame was the average number of hours for each caregiver within that time frame and then calculated the overall average number of hours of weekly care provided by dementia caregivers in each state. This number was then converted to a yearly average and multiplied by the number of caregivers in each state^{A7} to determine the total number of hours of care provided. For the 6 states without recent BRFSS data, their number of hours was calculated using the aggregated average of BRFSS data from 2015-2017. When added together, across all 50 states and the District of Columbia, the total number of hours provided by Alzheimer's and dementia caregivers is 15.338 billion hours.
- A10. Value of unpaid caregiving:** For each state, the hourly value of care was determined as the average of the state minimum hourly wage⁷²⁴ and the state median hourly cost of a home health aide.⁶¹⁵ The average for each state was then multiplied by the total number of hours of unpaid care in that state^{A9} to derive the total value of unpaid care. Adding the totals from all states and the District of Columbia resulted in an economic value of \$256,650 billion for dementia caregiving in the United States in 2020.
- A11. Lewin Model on Alzheimer's and dementia costs:** These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Rajan and colleagues²¹⁶ and included in this report (6.2 million in 2021), rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.
- A12. All cost estimates were inflated to year 2020 dollars using the Consumer Price Index (CPI):** All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.
- A13. Medicare Current Beneficiary Survey Report:** These data come from an analysis of findings from the 2011 Medicare Current

Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health.²⁴⁰ The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2021 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.

- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of Alzheimer's disease or dementia in their medical record.

- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's or other dementias in 2008. The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician, or other health care provider visit. The diagnostic codes used to identify survey participants with Alzheimer's or other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11.

Costs from the MCBS analysis are based on responses from 2011 and reported in 2020 dollars.

^{A14.} Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues⁵⁷⁶ estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2021 Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS) to be \$52,481. One reason that the per-person costs estimated by Hurd and colleagues are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that the Hurd et al. estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's and other dementias (those costs attributed only to dementia), while the per-person costs in *2021 Alzheimer's Disease Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

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