2022 Alzheimer's Disease Facts and Figures

Special Report

More Than Normal Aging: Understanding Mild Cognitive Impairment

alzheimer's association®

About this report

2022 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, the dementia care workforce, and the use and costs of health care, long-term care and hospice. A Special Report examines consumers' and primary care physicians' perspectives on awareness, diagnosis and treatment of mild cognitive impairment (MCI), including MCI due to Alzheimer's disease.

The statistics, facts, figures, interpretations and statements made in this report are based on currently available data and information as cited in the report, all of which are subject to revision as new data and information become available.

Alzheimer's Association. *2022 Alzheimer's Disease Facts and Figures*. Alzheimers Dement 2022;18.

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

- Brain changes that occur with Alzheimer's disease (page 8).
- Risk factors for Alzheimer's dementia (page 13).
- Number of Americans living with Alzheimer's dementia nationally (page 19) and for each state (page 22).
- Lifetime risk for developing Alzheimer's dementia (page 24).
- Proportions of women and men with Alzheimer's and other dementias (page 24).
- Number of deaths due to Alzheimer's disease nationally (page 30) and for each state (page 33), and death rates by age (page 35).
- Number of family caregivers, hours of care provided, and economic value of unpaid care nationally (page 38) and for each state (page 42).
- The impact of caregiving on caregivers (page 43).
- The roles of the paid workforce in diagnosing, treating and caring for people with Alzheimer's or other dementias (page 53).
- 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 (page 61).
- Medicare payments for people with dementia compared with people without dementia (page 65).
- The public's awareness of mild cognitive impairment (page 85).
- Primary care physicians' perspectives on diagnosing mild cognitive impairment (MCI) and MCI due to Alzheimer's disease (page 89).

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."

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OVERVIEW

Alzheimer's disease is the most common cause of dementia.

Alzheimer's disease is a type of brain disease, just as coronary artery disease is a type of heart disease. It is caused by damage to nerve cells (neurons) in the brain.

The neurons damaged first are those in parts of the brain responsible for memory, language and thinking. As a result, the first symptoms of Alzheimer's disease tend to be memory, language and thinking problems. Although these symptoms are new to the individual affected, the brain changes that cause them are thought to begin 20 years or more before symptoms start.[1-8]

Individuals with mild symptoms often may continue to work, drive and participate in their favorite activities, with occasional help from family members and friends. However, Alzheimer's disease is a progressive disease, meaning it gets worse with time. How quickly it progresses and what abilities are affected vary from person to person. Medications can temporarily help neurons in the brain to communicate with each other and in that way help symptoms for varying lengths of time, but do not cure Alzheimer's.

As time passes, more neurons are damaged and more areas of the brain are affected. Increased help from family members, friends and professional caregivers is needed to carry out activities of daily living,[A1] such as dressing and bathing, and to keep the individual safe. People may develop changes in mood, behavior or personality as a result of the thinking and memory challenges they are experiencing. One area of special concern is preventing falls, which can cause head injury, fractures and hospitalization. Preventing wandering is another area of special concern. Wandering refers to individuals walking away from a particular location and being unable to retrace their steps. Individuals become lost, putting them at risk of significant injury and death.[9]

Eventually, the neuronal damage of Alzheimer's disease extends to parts of the brain that enable basic bodily functions such as walking and swallowing. Individuals become bed-bound and require around-the-clock care. Ultimately, Alzheimer's disease is fatal. 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.[10-18]

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. Dementia has several causes (see Table 1, page 6). These causes reflect specific changes in the brain.

Alzheimer's disease is one cause of dementia. The brain changes of Alzheimer's disease include the accumulation of the abnormal proteins beta-amyloid and phosphorylated tau, as well as the degeneration of nerve cells. The brain changes of Alzheimer's disease are the most common contributor to 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. It is used interchangeably with *dementia due to Alzheimer's disease*.

table **1**

Common Causes of Dementia and Associated Characteristics*

Cause	Characteristics
Alzheimer's disease	The hallmark pathologies of Alzheimer's disease are the accumulation of the protein beta-amyloid (plaques) outside neurons and twisted strands of the protein tau (tangles) inside neurons in the brain. 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. 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.[21-22] This is called mixed pathologies, and if recognized during life is called mixed dementia. Symptoms Difficulty remembering recent conversations, names or events is often an early 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.
Cerebrovascular disease	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. 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. Some cerebrovascular disease is commonly present in people with Alzheimer's, and may worsen symptoms. About 5% to 10% of individuals with dementia show evidence of vascular dementia alone.[21-22] 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.[21-22] Symptoms Slowed thoughts or impaired ability to make decisions, plan or organize may be the initial symptoms, 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 become less emotional and have difficulty with motor function, especially slow gait and poor balance.
Lewy body disease	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. About 5% of older individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer's disease pathology. Symptoms People with DLB have some of the symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and visuospatial impairment. These symptoms may differ dramatically hourly or from day to day. Problems with motor function (similar to Parkinson's disease) are also common. They may occur in the absence of significant memory impairment, but memory loss often occurs at some point in the disease, especially when the brain changes of other causes of dementia are present.

table **1** (cont.)

Common Causes of Dementia and Associated Characteristics*

Cause	Characteristics
Frontotemporal lobar degeneration (FTLD)	FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy. 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 abnormal protein is present (usually tau protein or the transactive response DNA-binding protein, TDP-43). 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.[23] Some scientists think that FTLD is the most common cause of dementia in people younger than 60.[23] 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.[24] Symptoms 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.
Parkinson's disease (PD)	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.[25] As PD progresses, alpha-synuclein can also accumulate in the cortex of the brain. Dementia may result. Symptoms Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. Cognitive symptoms develop later in the disease, years after movement symptoms.
Hippocampal sclerosis (HS)	HS is the shrinkage and hardening of tissue in the hippocampus of the brain. The hippocampus plays a key role in forming memories. HS brain changes are often accompanied by accumulation of the misfolded protein TDP-43. HS is a common cause of dementia in the "oldest-old," individuals age 85 or older. Symptoms The most pronounced symptom of HS is memory loss, and individuals are often misdiagnosed as having Alzheimer's disease.
Mixed pathologies	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 or mixed etiology dementia. Studies suggest that mixed dementia is more common than previously recognized, with more than 50% of people diagnosed with Alzheimer's dementia who were studied at Alzheimer's Disease Research Centers having pathologic evidence of more than one cause of dementia.[22] In community-based studies, the percentage of mixed dementia cases is considerably higher.[21] The likelihood of having mixed dementia increases with age and is highest in people age 85 or older.[26-27] Symptoms Symptoms vary depending on the combination of brain changes present.

*This table describes the most common causes of dementia. Emerging causes such as limbic-predominant age-related TDP-43 encephalopathy (LATE) are under active investigation.

Brain Changes of Alzheimer's Disease

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual 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 taken up by another neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain. These signals create 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. These changes are followed by the damage and destruction of neurons, called neurodegeneration, which along with tau and beta-amyloid accumulation are key features of Alzheimer's disease.

Plaques and smaller accumulations of beta-amyloid called oligomers may damage neurons 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 neurons' 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.[19-20]

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.

Great progress has been made in measuring these brain changes. For example, we can now identify abnormal levels of beta-amyloid and tau in cerebrospinal fluid (the fluid surrounding the brain), and a scanning technique known as positron emission tomography (PET) can produce images showing where beta-amyloid and tau have accumulated. Beta-amyloid and tau accumulation are 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. Biomarkers are commonly used in health care. 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. Biomarkers are not equivalent to a diagnosis but might be used to help determine underlying brain changes that are causing dementia.

Some individuals have a rare genetic mutation that causes Alzheimer's disease. This is called dominantly inherited Alzheimer's disease (DIAD). A study[7] of people with 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 study[1] 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 study[2] 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. More research is ongoing to understand how these biomarkers operate in individuals without the genetic mutations of DIAD.

Mixed Dementia

Many people with dementia have brain changes associated with more than one cause of dementia.[21,28-33] This is called mixed dementia. Some studies[21-22] 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 disease 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.[21] Studies suggest that mixed dementia is the norm, and the number of distinct combinations of mixed dementia is extensive.[34-35]

Mixed dementia is especially common at advanced ages.[28,36] For example, the oldest-old, those age 85 or older, are more likely than those younger than 85 to have evidence of two or more causes of dementia.[26-27] Having Alzheimer's brain changes plus brain changes of another type of dementia increases one's chances of having dementia symptoms in one's lifetime[21,28] 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.

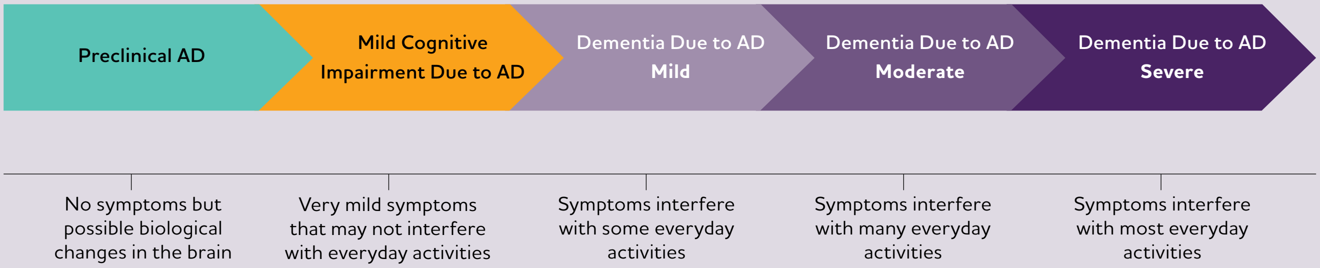
Alzheimer’s Disease Continuum

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, also called Alzheimer’s dementia (see Figure 1).[37-40] The Alzheimer’s dementia phase is further broken down into mild, moderate and severe dementia.

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.

While we know the Alzheimer’s disease continuum starts with preclinical Alzheimer’s disease (no symptoms) and ends with severe Alzheimer’s dementia (severe symptoms), how long individuals spend in each part of the continuum varies. The length of each part of the continuum is influenced by age, genetics, biological sex and other factors.[41]

Preclinical Alzheimer’s Disease

In this phase, individuals may 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) scans[42] and in analysis of cerebrospinal fluid (CSF),[43] changes in tau protein in CSF and plasma, and decreased metabolism of glucose as shown on PET scans.[44] When the early changes of Alzheimer’s disease occur, the brain compensates for them, enabling individuals to continue to function normally.

Although 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.[45-46] For example, some individuals have beta-amyloid plaques at death but did not have memory or thinking problems in life.[47]

MCI Due to Alzheimer’s Disease

People with MCI due to Alzheimer’s disease have biomarker evidence of Alzheimer’s brain changes plus new but subtle symptoms such as problems with memory, language and thinking. These cognitive problems may be noticeable to the individual, family members and friends, but not to others, and they may not interfere with individuals’ ability to carry out everyday activities. The subtle problems with memory, language and thinking abilities occur when the brain can no longer compensate for the damage and death of neurons caused by Alzheimer’s disease.

Alzheimer's Disease Continuum (cont.)

Among those with MCI, about 15% develop dementia after two years.[48] About one-third develop dementia due to Alzheimer's within five years.[49] However, 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.

Dementia Due to Alzheimer's Disease

Dementia due to Alzheimer's disease, or Alzheimer's dementia, is characterized by noticeable memory, language, 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 neurons 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. Handling money and paying bills may be especially challenging, and they may need more time to complete common daily tasks. They may still be able to drive, work and participate in their favorite activities.

Moderate Alzheimer's Dementia

In the moderate stage of Alzheimer's dementia, which is often the longest stage, individuals experience more problems with memory and language, are more likely to become confused, and find it harder to complete multistep tasks such as bathing and dressing. They may become incontinent at times, and they may start having personality and behavioral changes, including suspiciousness and agitation. They may also begin to have problems recognizing loved ones.

Severe Alzheimer's Dementia

In the severe stage of Alzheimer's dementia, individuals' ability to communicate verbally is greatly diminished, and they are likely to require around-the-clock care. Because of damage to areas of the brain involved in movement, individuals become bed-bound. Being bed-bound makes them vulnerable to physical complications 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, page 29).

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 dementia and other dementias, these conditions often may be reversed with treatment.

In addition, the differences between normal age-related cognitive changes (changes in memory, language and thinking) and the cognitive changes of Alzheimer's disease can be subtle (see Table 2, page 11). People experiencing cognitive changes should seek medical help to determine if the changes are normal for one's age, are reversible (for example, caused by a new medication or vitamin deficiency), or may be a symptom of Alzheimer's or another dementia.

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, especially in the early stage, is forgetting recently learned information. Others include asking the same questions 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 or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when managing finances or household bills.
Difficulty completing familiar tasks: People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people have trouble driving to a familiar location, organizing a grocery list or remembering the rules of a favorite game.	Occasionally needing help to use microwave settings or record a television show.
Confusion with time or place: People living 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 also have problems judging distance and determining color and contrast, causing issues with driving.	Vision changes related to cataracts.
New problems with words in speaking or writing: People living 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 trouble naming a familiar object or use 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 living with Alzheimer's may put things in unusual places. They may lose things and be unable to go back over their steps to find them. They may accuse others of stealing, especially as the disease progresses.	Misplacing things from time to time and retracing steps to find them.
Decreased or poor judgment: Individuals may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money or pay less attention to grooming or keeping themselves clean.	Making a bad decision or mistake once in a while, such as neglecting to schedule an oil change for a car.
Withdrawal from work or social activities: People living with Alzheimer's disease may experience changes in the ability to hold or follow a conversation. As a result, they may withdraw from hobbies, social activities or other engagements. They may have trouble keeping up with a favorite sports team or activity.	Sometimes feeling uninterested in family and social obligations.
Changes in mood, personality and behavior: The mood and personalities of people living 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 when 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.

Treatments

The U.S. Food and Drug Administration (FDA) has approved six drugs for the treatment of Alzheimer's disease. Five of these drugs — donepezil, rivastigmine, galantamine, memantine and memantine combined with donepezil — temporarily treat Alzheimer's symptoms but do not change the underlying brain changes of Alzheimer's or alter the course of the disease. With the exception of memantine, they improve symptoms by increasing the amount of chemicals called neurotransmitters in the brain. Memantine protects the brain from a neurotransmitter called glutamate that overstimulates neurons and can damage them. These five drugs may have relatively mild side effects, such as headache and nausea.

The sixth drug, aducanumab, was approved by the FDA in June 2021 and is the first FDA-approved drug to address the underlying biology of Alzheimer's disease rather than the symptoms. It does this by reducing beta-amyloid plaques in the brain. It is not a cure for Alzheimer's disease and is not appropriate for all individuals living with Alzheimer's disease. The drug was studied in people with early Alzheimer's disease — which includes people with MCI or mild dementia due to Alzheimer's disease — who also have evidence of a buildup of amyloid plaques in the brain. Treatment with aducanumab may be appropriate for people with MCI or mild dementia due to Alzheimer's disease. There is no safety or effectiveness data on initiating treatment at earlier or later stages of the disease than were studied. To help physicians determine if an individual is a candidate for aducanumab, appropriate use recommendations were published soon after FDA approval.[50] Information for clinicians and patients is also available online from the Alzheimer's Association. Unlike the other drugs approved to treat Alzheimer's disease, aducanumab is associated with an increased risk of a serious condition called amyloid-related imaging abnormalities (ARIA), which can be an indicator of brain swelling.[51] Individuals receiving aducanumab should be monitored closely so ARIA is quickly identified and safely managed should it arise.

It is important to note that aducanumab was approved through a process called the accelerated approval pathway. This approval pathway provides individuals with a serious disease earlier access to drugs when there is an expectation that the drug will have a clinical benefit.[52] The accelerated approval pathway requires the company that makes the drug to verify clinical benefit in a post-approval trial. If the sponsor cannot verify clinical benefit, the FDA may initiate proceedings to withdraw approval of the drug.

There are also non-drug treatments for Alzheimer's disease. Non-drug treatments do not change the underlying biology of the disease. They are often used with the goals of maintaining or improving cognitive function, overall quality of life and engagement, and the ability to perform activities of daily living. Non-drug treatments include cognitive stimulation, music-based therapies and psychological treatment (for example, cognitive behavioral therapy). Non-drug treatments may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. A 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] In practice, nonpharmacologic interventions are the primary tools used to address agitation and aggression, as they are typically more effective than pharmacologic interventions and pose minimal risk or harm.

If non-drug treatments are not successful and behavioral and psychiatric 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 severe hallucinations, aggression and agitation in people living with dementia. However, research has shown that antipsychotics are associated with an increased risk of stroke and death in individuals with dementia.[54-55] The decision to use antipsychotics to treat individuals living with dementia must be considered with extreme caution. The potential dangers of using antipsychotic drugs to treat behavioral and psychiatric symptoms of dementia are so severe that the FDA requires manufacturers to label the drugs with a "black box warning" explaining the drug's serious safety risks. Only one drug, suvorexant, has been specifically approved by the FDA to treat a behavioral or psychiatric symptom of Alzheimer's disease. This drug treats problems with falling asleep and staying asleep that can arise in Alzheimer's. It does this by blocking chemicals that cause wakefulness. Unlike the other drugs, suvorexant is prescribed for a wide range of individuals with sleeping problems, not just those with Alzheimer's.

The Lancet Commission 2020 report[56] on dementia prevention, intervention and care recommends care that addresses physical and mental health, social care, support, and management of neuropsychiatric symptoms, noting that multicomponent interventions are the treatments of choice to decrease neuropsychiatric symptoms.

Active Management of Dementia Due to Alzheimer's Disease

Studies have consistently shown that proactive management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers.[57-59] Proactive 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 their life.
- Maintaining a sense of self identity and relationships with others.
- 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.

Risk Factors for Alzheimer's

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.

Age, Genetics and Family History

The greatest risk factors for late-onset Alzheimer's are older age,[60-61] genetics[62-63] — especially the e4 form of the apolipoprotein E (APOE) gene — and having a family history of Alzheimer's.[64-67]

Age

Age is the greatest of these three risk factors. The percentage of people with Alzheimer's dementia increases dramatically with age: 5.0% of people age 65 to 74, 13.1% of people age 75 to 84 and 33.2% of people age 85 or older have Alzheimer's dementia (see Prevalence section, page 18). The aging of the baby-boom generation will significantly increase the number of people in the United States with Alzheimer's.[68] However, it is important to note that Alzheimer's dementia is not a normal part of aging,[69] and older age alone is not sufficient to cause Alzheimer's dementia.

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

*Percentages do not total 100 due to rounding.

Created from data from Rajan et al.[84]

Genetics

Researchers have found several genes that increase the risk of Alzheimer's. Of these, APOE-e4 has the strongest impact on risk of late-onset Alzheimer's. APOE 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.

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. The e3 allele is thought to have a neutral effect on Alzheimer's risk. 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.[70-72] In addition, those with the e4 form are more likely to have beta-amyloid accumulation and Alzheimer's dementia at a younger age than those with the e2 or e3 forms of the APOE gene.[73-74]

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.[75] 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.[76]

Most of the research to date associating APOE-e4 with increased risk of Alzheimer's has studied individuals of European ancestry. Studies of this association in Black and Latino populations have had inconsistent results. For example, some have found that having the e4 allele did not increase risk among Blacks,[77-79] while other studies have found that it significantly increased risk.[80-83] In addition, researchers have found differences in the frequency of APOE pairs in different racial and ethnic groups. For instance, data show that a higher percentage of African Americans than European Americans have at least one copy of the e4 allele (see Table 3).[77-78,84] Researchers have also found another genetic factor, the ATP-binding cassette transporter (ABCA7) protein, that doubles the risk of Alzheimer's disease in Blacks with ABCA7 compared with Blacks without ABCA7.[81]

To better understand inconsistencies in the effect of APOE-e4 in Hispanic/Latino groups, one research team[85] analyzed the effect of APOE-e4 in 4,183 individuals from six Latino backgrounds: Cuban, Central American, Dominican, Mexican, Puerto Rican and South American. They found that the effect of APOE-e4 on cognitive decline differed among groups, suggesting that factors related to geographic background and genetic ancestry may alter the extent to which APOE-e4 contributes to cognitive decline.

These inconsistencies point to the need for more research to better understand the genetic mechanisms involved in Alzheimer's risk among different racial and ethnic groups.

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 the amyloid precursor protein (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.[86] According to the National Down Syndrome Society, about 30% of people with Down syndrome who are in their 50s, and about 50% of those in their 60s, have Alzheimer's disease.[87] Studies suggest that the brain changes of Alzheimer's disease in people with Down syndrome are more common than these percentages indicate.[88-89]

As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. Life expectancy of people with Down syndrome has more than doubled in the last 70 years, which corresponds to a growing population of adults with both this condition and dementia. Dementia is the leading cause of death for adults with Down syndrome.[90] Care for people with Down syndrome and dementia is challenging due to the intellectual disability and cognitive and communication impairments associated with Down syndrome and structural inequities surrounding intellectual disabilities. Making advances in the care of people living with Down syndrome and dementia is stymied by the common exclusion of people with Down syndrome from research studies.

Genetic Mutations

A small percentage of Alzheimer's cases (an estimated 1% or less)[91] 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 APP gene 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.[92] Symptoms tend to develop before age 65, sometimes as young as age 30.

Family History

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, individuals who have or had 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.[64,70] Those who have more than one first-degree relative with Alzheimer's are at even higher risk.[67] A large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-e4.[93] 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.

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 care[56] 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,[56] the 2019 World Health Organization (WHO) recommendations[94] to reduce risk of cognitive decline and dementia, an Alzheimer's Association article[95] evaluating the effects of modifiable risk factors on cognitive decline and dementia, and a report from the National Academy of Medicine[96] 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 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.[79] For example, it is possible that smoking may contribute to cerebrovascular disease, which in turn increases the risk of dementia, but smoking 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.[97] 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, particularly dementia due to cerebrovascular disease (i.e., vascular dementia).[98] These factors include smoking[99-104] and diabetes.[105-108] The specific mechanisms linking diabetes and dementia are unclear but may be numerous, potentially involving aspects of insulin resistance.[109-110] The age at which some risk factors develop appears to affect dementia risk. For example, midlife obesity,[111-115] hypertension,[82,111,116-119] prehypertension (systolic blood pressure from 120 to 139 mm Hg or diastolic pressure from 80 to 89 mm Hg)[82] and high cholesterol[120] are associated with an increased risk of dementia. In contrast to midlife obesity, late-life obesity[121] and hypertension onset after age 80[122] 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 dementia. Physical activity[123-135] appears to be one of these factors. Although researchers have studied a wide variety of physical activities, they do not know which specific types, what frequency or what duration of physical 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.[136-143] A heart-healthy diet emphasizes fruits, vegetables, whole grains, fish, chicken, nuts, legumes and healthy fats such as olive oil while limiting saturated fats, red meat and sugar. Examples of heart-healthy diets are the Mediterranean, DASH (Dietary Approaches to Stop Hypertension) and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets.[144-146]

A systematic review[147] 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. While two multidomain studies did not find clear cognitive benefits,[148-149] the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER)[150] showed slower cognitive decline among high-risk individuals assigned to a multidomain lifestyle intervention The success of FINGER has led to the launch of multidomain intervention studies in other countries, including the Alzheimer's Association U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER).[151]

Education and Educational Opportunities

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.[77,152-156] The underlying reasons for the relationship between formal education and reduced Alzheimer's risk are unclear. 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.[157-158] 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.[159-162]

Other researchers emphasize the indirect effects of formal education, such as its effects on dementia risk through socioeconomic status. Having fewer years of formal education is associated with lower socioeconomic status.[163] 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 closely linked to brain health; decrease one's ability to engage in educational opportunities outside of formal schooling; 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,[164] lead[165] and pesticides.[166]

In addition, people with fewer years of education tend to have more cardiovascular risk factors that lead to cerebrovascular disease, including being less physically active,[167] having a higher risk of diabetes,[168-170] and being more likely to have hypertension[171] and to smoke.[172]

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.[124,173-185] 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.[186] 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 a head injury caused by an external force to the head or body resulting in disruption of normal brain function.[187] TBI is associated with an increased risk of dementia.[188-189]

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 this information is available.[187] In 2017, there were nearly 224,000 TBI-related hospitalizations. The leading causes were falls (49%) and motor vehicle crashes (24.5%).[187]

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia[190] and by the individual's initial score on the 15-point Glasgow Coma Scale.[191]

- *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.[192]
- *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.[188] Even those who experience mild TBI are at increased risk of dementia compared with those who have not had a TBI. A study found that mild TBI is associated with a two-fold increase in the risk of dementia diagnosis.[193] 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.[194-195] Whether TBI causes Alzheimer's disease, other conditions that lead to dementia, or both, is still being investigated.

The relationship between TBI and chronic traumatic encephalopathy (CTE) is a growing area of research. 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 odds of developing CTE, which is associated with dementia, increased 30% per year played.[196] Currently, there is no test to determine if someone has CTE-related brain changes during life. A review article indicated 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.[197] 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.[198-199] How the brain changes associated with CTE are linked to cognitive or behavioral changes is unclear. More research is needed to better understand the relationship between TBI, repeated blows to the head, CTE and Alzheimer's disease.

Other Risk Factors
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.[200-206] The emergence of novel coronavirus disease in 2019 (COVID-19) resulted in more than 1.3 million hospitalizations among U.S. adults age 65 and older between January 1, 2020, and July 24, 2021.[207] This has the potential to increase the number of cases of cognitive impairment following critical illness. Furthermore, a number of these individuals will receive or have received mechanical ventilation, which increases one's risk of delirium,[208] an acute state of short-term confusion that is a risk factor for dementia.[209-211]

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 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 are associated with worse cognitive decline.[164]

Researchers are also studying a variety of other risk factors. Among the many being studied are inadequate sleep or poor sleep quality,[212-214] excessive alcohol use,[215] depression[216] and hearing impairment.[217]

Looking to the Future

The relatively recent discovery that Alzheimer's begins 20 years or more before the onset of symptoms helps explain why it has been difficult to prevent and treat Alzheimer's disease effectively. However, it also implies that there is a substantial window of time in which we can intervene in the progression of the disease. Scientific advances are likely to help us identify effective methods to prevent and treat Alzheimer's disease. For example, 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 may 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. The lack of inclusion has several consequences. First, accurately measuring the current and future burden of Alzheimer's disease in the United States requires adequate data from Black, Hispanic, Asian American/Pacific Islander and Native American communities. The lack of representation is a concern because the populations of older adults from these groups make up nearly a quarter of the older adult population, and that share is projected to grow.[218] Second, current data indicate that, compared with non-Hispanic Whites, Blacks and Hispanics are at increased risk for Alzheimer's (see Prevalence section, page 18). Alzheimer's research that minimally involves Black and Hispanic participants largely ignores populations who bear the greatest risk. As a result, risk factors common in these populations but less common in non-Hispanic Whites are likely to be poorly understood.

Inclusion is more than a matter of enrolling more participants from underrepresented groups. Increasing diversity among researchers and engaging with and seeking input from communities are also important. Improving inclusion in all of these ways expands the range of lived experiences among participants and the extent to which those experiences are known and become topics of investigation.[219] Finally, lack of inclusion limits our ability to understand whether and how Alzheimer's risk factors and interventions work in populations that carry different baseline susceptibility to Alzheimer's disease. 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.

PREVALENCE

By 2050, the number of people age 65 and older with Alzheimer's dementia is projected to reach 12.7 million.

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 grow, so too will the number and proportion of Americans with Alzheimer's or other dementias.

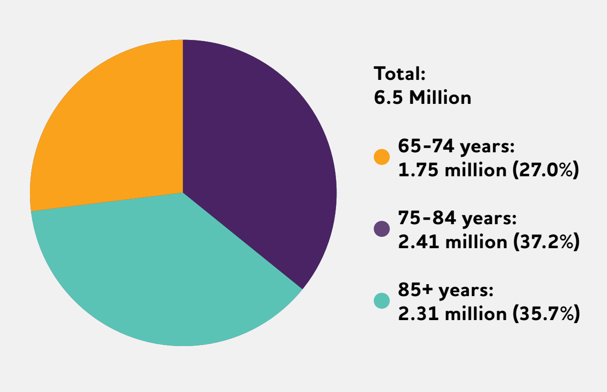
That is because the risk of dementia increases with advancing age. The population of Americans age 65 and older is projected to grow from 58 million in 2021 to 88 million by 2050.[220-221] The baby-boom generation (Americans born between 1946 and 1964) has already begun to reach age 65 and beyond,[222] the age range of greatest risk of Alzheimer's dementia;[223] in fact, the oldest members of the baby-boom generation turned aged 75 in 2021.

The incidence rate of Alzheimer's — the number of people per 100,000 who newly develop this condition per year — appears to be declining, which has been attributed to improvements over the 20th century in Alzheimer's risk factors, such as hypertension and low educational attainment. However, even with this potentially lower incidence rate, the number of people with Alzheimer's is expected to continue growing because of an increase in the number of adults age 65 and over, the age group that is at increased risk of Alzheimer's. It is unknown how COVID-19, including infection with SARS-CoV-2 (the virus that causes COVID-19), mortality from COVID-19, and changes in health care access resulting from the COVID-19 pandemic, will influence the number and proportion of people in the U.S. with Alzheimer's.

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 communities 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 several studies of the number and proportion of people with Alzheimer's or other dementias are used in this section. Those estimates vary depending on how each study was conducted.

figure **2**

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2022*



*Percentages do not total 100 due to rounding.
Created from data from Rajan et al.[A2,224]

Prevalence of Alzheimer's and Other Dementias in the United States

An estimated 6.5 million Americans age 65 and older are living with Alzheimer's dementia in 2022.[A2,224] Seventy-three percent are age 75 or older (Figure 2).[224]

Of the total U.S. population:

- About 1 in 9 people (10.7%) age 65 and older has Alzheimer's dementia.[A2,224]
- The percentage of people with Alzheimer's dementia increases with age: 5.0% of people age 65 to 74, 13.1% of people age 75 to 84, and 33.2% of people age 85 and older have Alzheimer's dementia.[A2,224] People younger than 65 can also develop Alzheimer's dementia. Although prevalence studies for younger-onset dementia in the United States are limited, researchers believe about 110 of every 100,000 people, about 200,000 Americans, have younger-onset dementia.[225]

Prevalence Estimates

The prevalence numbers included in this report are based on an estimate of how many people in the United States are living with dementia (prevalence) and the pace at which people newly develop the condition (incidence). The estimate of 6.5 million older adults who have Alzheimer's dementia comes from a single longitudinal study in which participants were systematically evaluated and then re-evaluated on a regular basis; those who exhibited the clinical symptoms of Alzheimer's were classified as having Alzheimer's dementia. A major advantage of this approach is that it attempts to capture all individuals living with the condition and does not rely on the diagnosis of people living with Alzheimer's by the health care system, a process that has resulted in a large underdiagnosis of the Alzheimer's population. The disadvantage is that the longitudinal study is located in a single, small geographic area and may not be nationally representative (although the modeling estimates attempt to account for the demographics of the entire U.S. population). Furthermore, it is still based on the identification of clinical symptoms to classify an individual as having Alzheimer's instead of relying on the brain changes responsible for Alzheimer's disease across the continuum of the disease. As data sources, methods and scientific knowledge improve, estimates of prevalence may change.

First, a prevalence estimate based on the brain changes involved with Alzheimer's, rather than clinical symptoms, is likely to be lower than the 6.5 million figure reported here. Evidence from biomarker-based studies[21,69,229-231] indicates that some individuals counted as having 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. Thus, these studies indicate that, compared with prevalence estimates based on the symptoms of Alzheimer's dementia, estimates based on the biomarkers of Alzheimer's disease could be up to 30% lower than current figures. 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 study.[A3,228]

Second, as measurements of the brain changes of Alzheimer's disease are more widely used, we will be able to estimate how many people have *Alzheimer's disease* (not just dementia due to Alzheimer's disease), which includes people in the earliest detectable stages of Alzheimer's who have the brain changes of Alzheimer's but not the overt symptoms of Alzheimer's that interfere with their ability to carry out everyday activities. 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 abnormal 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 younger than 65, there are likely far more than 5 million Americans — of any age — with MCI due to Alzheimer's disease.

Last, the National Institute on Aging – Alzheimer's Association (NIA-AA) Framework[232] hypothesizes that there is an incipient and silent stage of Alzheimer's disease before the emergence of cognitive symptoms of either MCI or dementia. While this is still the subject of additional research to better understand these early brain changes, estimates have begun to be made regarding the prevalence of "preclinical" Alzheimer's disease in the population.[233] More research is needed to validate preclinical Alzheimer's and determine how to measure it with biomarkers that conclusively represent Alzheimer's disease, as opposed to other dementia-causing diseases.

What does all this mean for future prevalence estimates? Future *Facts and Figures* reports will continue to include the estimated prevalence of individuals in the dementia stage, defined according to clinical symptoms only, currently estimated at 6.5 million Americans, in addition to the best available estimated prevalence of MCI due to Alzheimer's disease. *Facts and Figures* will not include prevalence estimates of the preclinical Alzheimer's disease stage until (1) there is convincing 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 in this stage. In addition, as the evidence and epidemiological data warrant, future reports may also include estimates of the prevalence of dementia from all causes.

Ultimately, future estimates of the prevalence of Alzheimer's dementia, as defined by the presence of pathologic biomarkers, will be lower than the estimated prevalence based on clinical symptoms (the currently reported 6.5 million). For example, if we were to assume that 30% fewer individuals with the clinical symptoms of Alzheimer's dementia lack the presence of defining biomarkers, in 2022, this would translate to roughly 4.5 million Americans age 65 and older being classified as having Alzheimer's dementia.

By contrast, the prevalence of Alzheimer's disease will be higher because it will include those with MCI due to Alzheimer's disease. Using 2022 again as an example, combining the roughly 4.5 million Americans age 65 and older with Alzheimer's dementia and the estimated 5 million Americans age 65 or older with MCI due to Alzheimer's disease, there would be 9.5 million Americans with Alzheimer's disease. It should be noted that both symptom-based prevalence estimates of Alzheimer's dementia and biomarker-based prevalence estimates of Alzheimer's disease will increase in the future due to growth in the proportion of Americans age 65 and over, the population most at risk.

When a conclusive connection is shown between biomarkers and the preclinical stage and when epidemiological studies include biomarker-based diagnoses, an Alzheimer's disease prevalence estimate that includes individuals throughout the continuum of Alzheimer's disease will be even higher, as it will incorporate those with biomarker-confirmed Alzheimer's dementia, those with biomarker-confirmed MCI due to Alzheimer's disease and those with preclinical Alzheimer's disease.

The estimated number of people age 65 and older with Alzheimer's dementia comes from an updated study using the latest data from the 2022 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.[224]

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.[A3,226-227] Based on estimates from ADAMS, 11% of people age 65 and older in the United States have dementia.[228]

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 this line of research is in its infancy. 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.[48] 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.[234-235] 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.

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.[236-241] 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.[242-246] 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 setting, see the Special Report from *2019 Alzheimer's Disease Facts and Figures*.[247]

table **4**

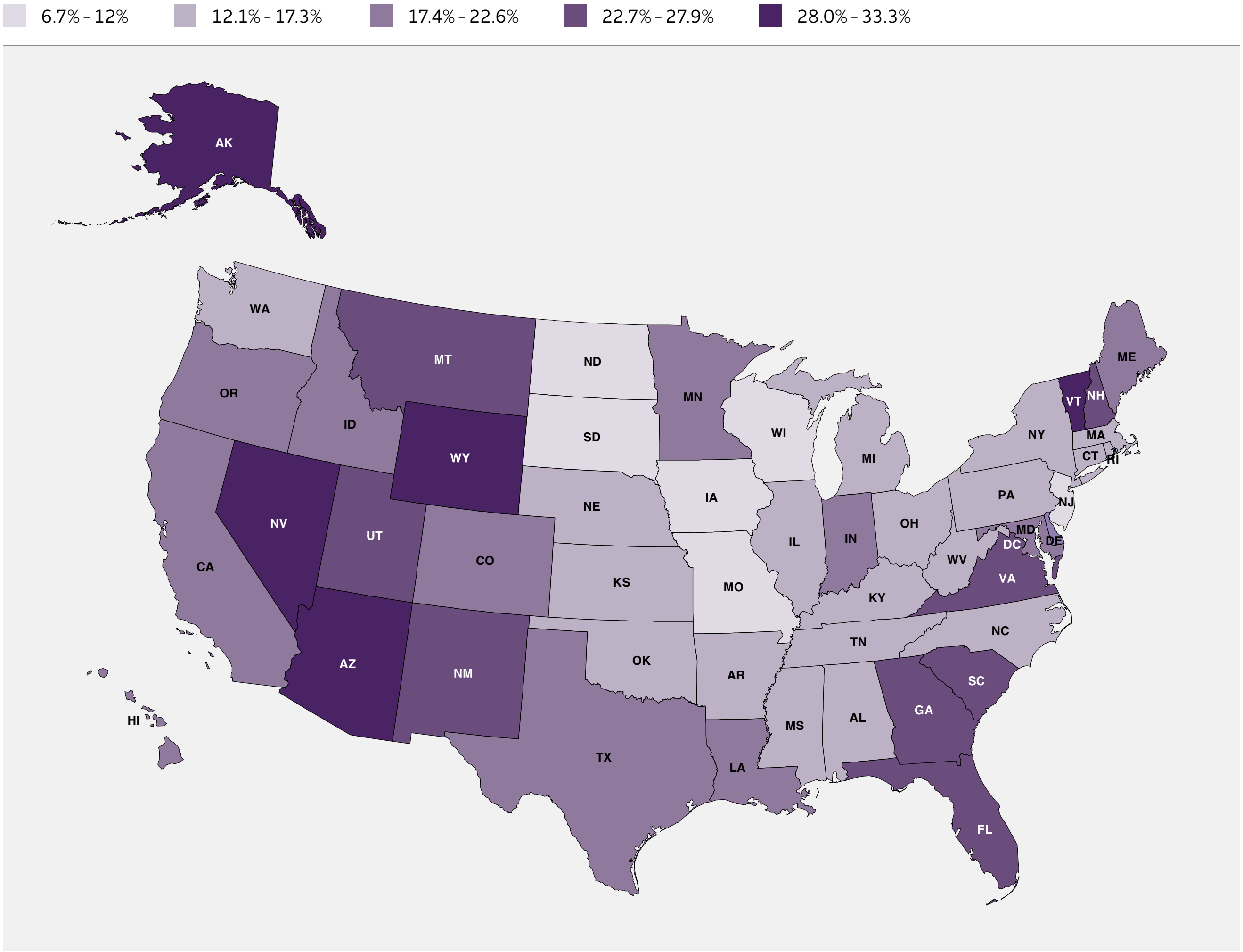
Projections of Total Numbers of Americans Age 65 and Older with Alzheimer's Dementia by State

	Projected Number with Alzheimer's (in thousands)		Percentage Increase
State	**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
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.[A4,259]

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.[A4,259]

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.[248-252] Subjective cognitive decline refers to self-perceived worsening of memory and other thinking abilities by an individual, separate from cognitive testing, a physician's diagnosis or anyone else noticing. Not all those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.[253-255] Subjective cognitive decline often prompts medical attention, and a proper diagnosis can help distinguish experiences that may relate to higher Alzheimer's disease risk versus those with other contributors, including other underlying health conditions.[256] 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.[257] The Behavioral Risk Factor Surveillance System survey, a large survey of people across the United States that includes questions on subjective cognitive decline, found that 10% of Americans age 45 and older reported subjective cognitive decline, but 54% of those who reported it had not consulted a health care professional.[258] Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

Estimates of the Number of People with Alzheimer's Dementia by State

Based on projections shown in Figure 3 (see page 23), between 2020 and 2025 every state across the country will have experienced an increase of at least 6.7% in the number of people with Alzheimer's. The prevalence estimates for 2020 and 2025, and changes between these two years, are shown in Table 4 (see page 22).[A4,259]

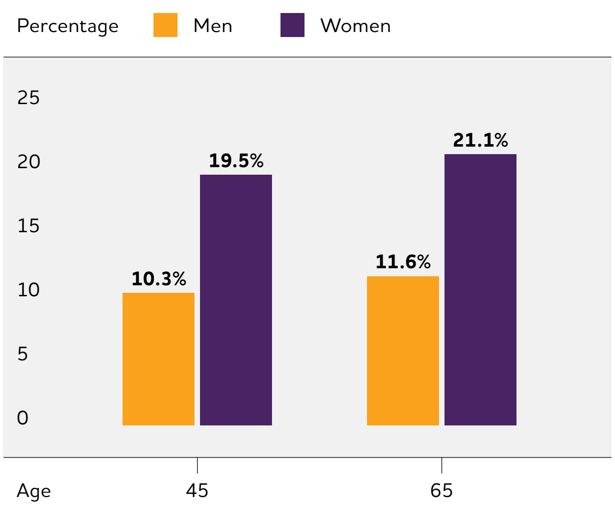
These projected increases in the number of people with Alzheimer's are based primarily on projected changes in the population age 65 and older in these states, specifically the numbers of persons at each specific age (e.g., 66, 67, etc.). Based on changes over time in the age composition of their populations, 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 nearly a quarter of Medicare beneficiaries with Alzheimer's or other dementias.[260] The regional patterns of current and future burden do not reflect potential future variation across regions and states in other risk factors for dementia such as midlife hypertension and diabetes.

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 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 Bureau, 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 2022 if CHAP estimates were available for that year.[261] 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 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).[261] A 2015 study using data from the Adult Changes in Thought Study, a cohort of members of a health care delivery system (Group Health Cooperative of Puget Sound (now Kaiser Permanente Northwest) in the Seattle area of Washington, reported similar incidence rates to the CHAP study.[10] 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.[262]

figure **4**

Estimated Lifetime Risk for Alzheimer's Dementia, by Sex, at Ages 45 and 65



Created from data from Chene et al.[263]

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 that person's remaining life span. Data from the Framingham Heart Study were used to estimate lifetime risks of Alzheimer's dementia by age and sex.[A5,263] 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.[263]

Differences Between Women and Men in the Prevalence and Risk of Alzheimer's and Other Dementias

Almost two-thirds of Americans with Alzheimer's are women.[224] Of the 6.5 million people age 65 and older with Alzheimer's in the United States, 4 million are women and 2.5 million are men.[224] This represents 12% of women and 9% of men age 65 and older in the United States.[221]

Women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.[263-265] This survival difference contributes to higher prevalence of Alzheimer's and other dementias in women compared with men. However, when it comes to differences in the 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.[10,77,265-267] Some European studies have reported a higher incidence among women at older ages,[268-269] and one study from the United Kingdom reported higher incidence for men.[270] Differences in the risk of dementia between men and women may therefore depend, in part, on age and/or geographic region.[271-272]

Other studies have provided evidence that any observed difference in dementia risk 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 to age 65 or beyond 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.[264] Recent studies have supported the notion that selection bias contributes to reports of sex and gender differences in Alzheimer's dementia.[273] More research is needed to support this interpretation.

Although differences in the rates at which men and women develop Alzheimer's or other dementias do not appear to be large or consistent, the reasons men and women develop dementia may vary. These differences may be based in biology such as chromosomal or hormonal differences related to reproductive history[274] (i.e., sex differences) or in how social and cultural factors are distributed among or are experienced by men and women (i.e., gender differences), or the combination of the two.[271,275] Gender differences may exist 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 may contribute to elevated risk in women, as limited formal education is a risk factor for dementia.[276] This possibility requires more research, but evidence supports that greater educational attainment over time in the United States — the gains in which have been more substantial for women than men — has led to decreased risk for dementia.[277] Interestingly, European studies have found that the relationship of lower education with dementia outcomes may be stronger in women than men.[278-279] 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.[280-282]

It is unclear whether genetic risk operates differently in women and men in the development of, or susceptibility to, Alzheimer's pathology.[283] A number of studies have shown that the APOE-e4 genotype, the best known common genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia[284-285] and neurodegeneration[286] in women than in men. A recent meta-analysis found no difference between men and women in the association between APOE-e4 and Alzheimer's dementia overall, although age played an interesting interactive role. That is, APOE-e4 was related to higher Alzheimer's risk in women than men between ages 55 to 70, when APOE-e4 is thought to exert its largest effects.[287] It is unclear whether the influence of APOE-e4 may depend on the sex hormone estrogen.[288-289]

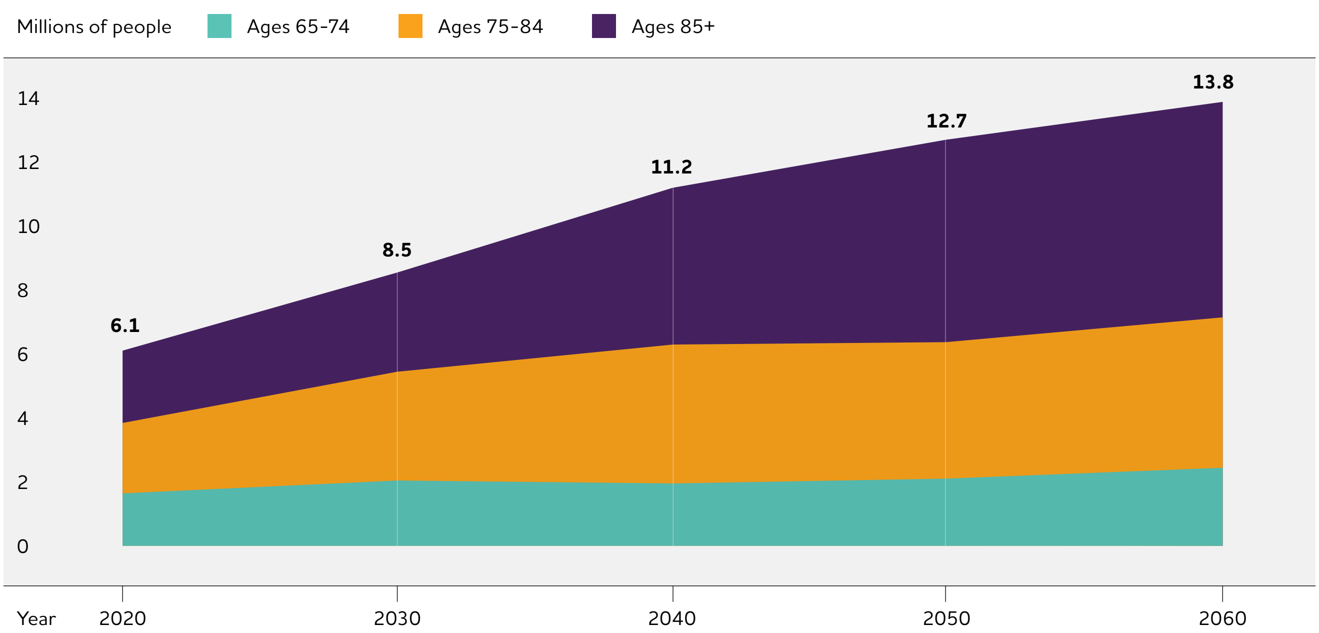
Racial and Ethnic Differences in the Prevalence of Alzheimer's and Other Dementias

Older non-Hispanic Blacks and Hispanic Americans are disproportionately more likely than older Whites to have Alzheimer's or other dementias.[290-296] Data from the CHAP study indicates 19% of Black and 14% of Hispanic adults age 65 and older have Alzheimer's dementia compared with 10% of White older adults.[224] Most other prevalence studies also indicate that older Blacks are about twice as likely to have Alzheimer's or other dementias as older Whites.[261,297-298] Some other studies indicate older Hispanic adults are about one and one-half times as likely to have Alzheimer's or other dementias as older White adults.[298-300] These disparities have remained constant over time.[292] However, the population of Hispanic persons comprises very diverse groups with different cultural histories 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).[301-302]

The higher prevalence of Alzheimer's dementia in Black and Hispanic populations compared with the White population appears to be due to a higher risk of developing dementia in these groups compared with the White population of the same age.[303] Race does not have a genetic basis, and genetic factors do not account for the large differences in prevalence and incidence among racial groups.[303-304] Some evidence does support that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race.[79-83,305]

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.[A6,224]

Instead, research suggests, the difference in risk for Alzheimer's and other dementias is explained by disparities produced by the historic and continued marginalization of Black and Hispanic people in the United States — disparities between older Black and Hispanic populations and older White populations in life experiences, socioeconomic indicators, and ultimately health conditions.[306] These health and socioeconomic disparities are rooted in the history of discrimination against Black individuals 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.[307-308] Structural racism pervades many aspects of life that may directly or indirectly alter dementia risk. Structural racism influences environmental factors such as where people can live, the quality of schools in their communities, and exposure to harmful toxins and pollutants. It also influences 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.[309-311]

Differences in the social and physical environment by race/ethnicity across the life course increase risk for chronic conditions that are associated with higher dementia risk, such as cardiovascular disease and diabetes. These health conditions, which disproportionately affect Black and Hispanic populations, may partially explain the elevated risk of dementia among Black and Hispanic populations.[79,306,312-313] Many studies suggest that racial and ethnic differences in dementia risk do not persist in rigorous analyses that account for health and socioeconomic factors.[153,226,303] The influence of structural racism may cascade and compound across the course of a person's life. 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.[309-311] This points to a need for health disparities research that employs life course perspectives and the insights of race equity scholars to account for the many environmental and sociopolitical factors that may put disproportionately affected populations at increased risk for Alzheimer's and other dementias.[306,313]

There is evidence that missed or delayed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among White older adults.[238,240,314-315] Based on data from Medicare beneficiaries age 65 and older, it has been estimated that Alzheimer's or another dementia has been diagnosed in 10.3% of White older adults, 12.2% of Hispanic older adults and 13.8% of Black older adults.[316] Although these percentages indicate that the dementia burden is greater among Black and Hispanic older adults than among White older adults, according to prevalence studies that detect all people who have dementia irrespective of their use of health care systems, the percentages should be even higher for Black and Hispanic older adults.

Population-based cohort studies regarding the national prevalence of Alzheimer's and other dementias in racial and ethnic groups other than White, Black and Hispanic populations 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 American older adults; intermediate for Latino older adults (the term used in the study for those who self-reported as Latino or Hispanic), American Indian and Native Alaskan older adults, Pacific Islander older adults, and White older adults; and lowest for Asian American older adults.[317] A follow-up study with the same cohort showed heterogeneity within Asian-American subgroups, but all subgroups studied had lower dementia incidence than the White population.[318] 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.[302] We have limited understanding of Alzheimer's disease as experienced by people of Middle Eastern and North African descent,[319] those who identify with more than one race/ethnicity, and subgroups of origin within racial/ethnic groups.[316] More studies, especially those involving community-based cohorts and those that focus on racial/ethnic groups historically not included in Alzheimer's research, are necessary to draw conclusions about the prevalence of Alzheimer's and other dementias in different racial groups and subgroups.

Trends in the Prevalence and Incidence of Alzheimer's Dementia Over Time

A growing number of studies indicate that the prevalence[223,267,315-322] and incidence[270,320-329] of Alzheimer's and other dementias in the United States and other higher income Western countries may have declined in the past 25 years,[270,277,320-328,330-333] though results are mixed.[60,261,334-335] 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.[336] Declines in dementia risk have been attributed to increasing levels of education and improved control of cardiovascular risk factors.[277,323,326,330,337-338] 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 increases in diabetes and obesity among persons under 65 years old — potential risk factors for Alzheimer's dementia — which may lead to a rebound in dementia risk in coming years.[113,321,339-342] It is also not clear that these positive trends pertain to all racial and ethnic groups.[261,292,337-338,343-344] 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 current evidence does not support a decline in the risk of Alzheimer's and other dementias.[345] It is not known how the prevalence of Alzheimer's dementia in low- and middle-income countries will be affected by the neurologic effects of COVID-19,[346] along with the pandemic's disruptions to general and brain-related health care.

Looking to the Future

Continued Population Aging

In 2011, the largest ever demographic generation of the American population — the baby boom generation — started reaching age 65, the age at which the risk for Alzheimer's and other dementias begins to increase. By 2030, the segment 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 18% in 2022).[221,347] 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.[A6,224]

- By 2025, the number of people age 65 and older with Alzheimer's dementia is projected to reach 7.2 million — an 11% increase from the 6.5 million age 65 and older affected in 2022.[224]
- 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.[A6,224]

The older adult population also will continue to increase relative to the population age 64 and younger — a shift is known as population aging. Population aging takes place primarily due to a decline in fertility, defined as the number of children born per woman, and secondarily due to mortality improvements at older ages. Even after members of the baby boom generation have died, population aging is expected to continue in the United States. The average number of children per woman in the United States was 3.7 in 1960 and has fluctuated between 1.7 and 2.1 from 1976 to 2019.[348] With fewer babies born each year, older adults will make up a larger proportion of the population.

As a result, a smaller share of the population will be of working age — the group of people who financially support older adults[349] and provide health care in the professional workforce[350] and informal caregiving.[351] In 2010 for every 100 working-age people 15-64, there were 49 people age 65 and older; in 2019 this value was 54.[352]

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.[347] This will lead to an increase in the number and percentage of Americans 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 12% in 2022 to 22% in 2050.[347] This will result in an additional 12 million oldest-old people — individuals at the highest risk for developing Alzheimer's dementia.[347]

- In 2022, about 2.3 million people who have Alzheimer's dementia are age 85 or older, accounting for 35% of all people with Alzheimer's dementia.[224]
- 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.[224]

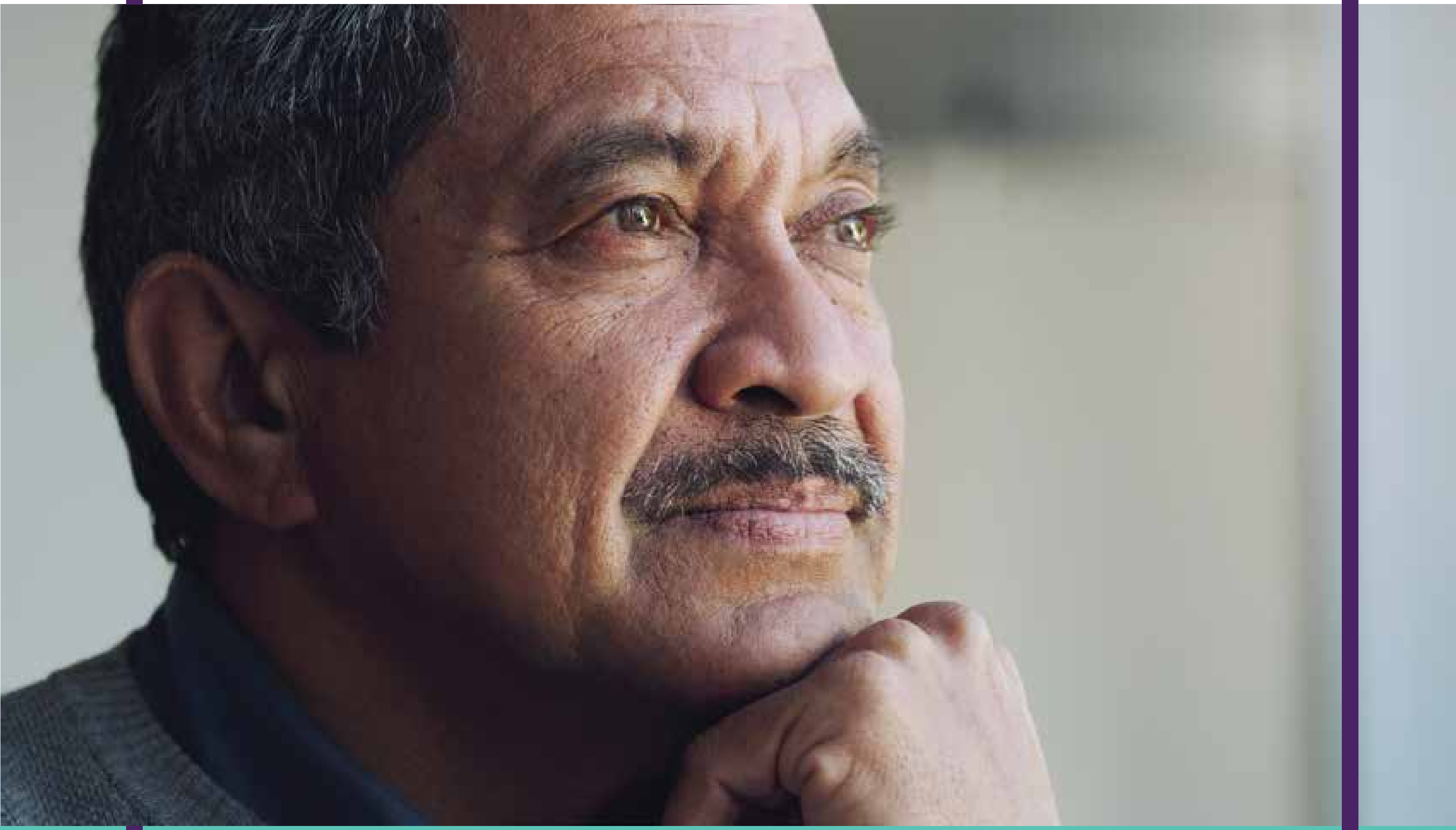
Diversification of Older Adults

The group of older adults who will be at risk for Alzheimer's in the coming years will be socially, culturally and economically different from previous groups of older U.S. adults. For example, between 2018 and 2040, the Black older adult population will increase by 88%, and the Hispanic older adult population will increase by 175%.[353]

In addition, in the coming decades women age 65 and older will be among the first generations of women to have widely worked outside the home, and they will have more years of formal education than previous generations of women.[354] In parallel these generations of women came of age during a decrease in the birth rate, resulting in smaller family size.[355] The role of these social and economic experiences in Alzheimer's risk and resilience for women will become clearer in the decades ahead.

Given the different life experiences of future older adult populations, it is unclear what the accompanying changes will be to dementia incidence and prevalence, both at the population level and within racial/ethnic, socioeconomic, and sex/gender groups. A birth cohort perspective, which considers how a certain group of people has passed through different stages of life in particular years, will be increasingly important for understanding factors of risk and resilience that may be unique to the groups of people at risk for dementia in the coming decades.[356-358]

MORTALITY AND MORBIDITY



1 in 3 seniors dies with Alzheimier's or another dementia.

Alzheimer's disease was officially listed as the sixth-leading cause of death in the United States in 2019[359] and the seventh-leading cause of death in 2020 and 2021,[360] when COVID-19 entered the ranks of the top 10 causes of death.

Alzheimer's disease remains the fifth-leading cause of death among individuals age 65 and older.[359-360] 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.[361] Before a person with Alzheimer's dies, they live through years of morbidity as the disease progresses.

Deaths from Alzheimer's Disease

The data presented in this section are through 2019. These data precede the COVID-19 pandemic and give an accurate representation of long-term trends in mortality and morbidity due to Alzheimer's and other dementias in the United States prior to the large increase in deaths due to COVID-19 in 2020 and 2021. See the box "The Effect of the COVID-19 Pandemic on Deaths from Alzheimer's Disease" for a discussion of the dramatic effect of the pandemic on Alzheimer's mortality.

In this section, "deaths from Alzheimer's disease" refers to what is officially reported on death certificates. 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.[360] 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 train of events leading directly to death."[362] Note that while death certificates use the term "Alzheimer's disease", the determination is made based on clinical symptoms in almost every case, and thus more closely aligns with "Alzheimer's dementia" as we have defined it in previous sections of this report; to remain consistent with the CDC terminology for causes of death, we use the terms "Alzheimer's disease" for this section.

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).[360,363] 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.[364-367] One pre-COVID-19 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.[365] Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[365-366] 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."[368]

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

The Effect of the COVID-19 Pandemic on Deaths from Alzheimer's Disease

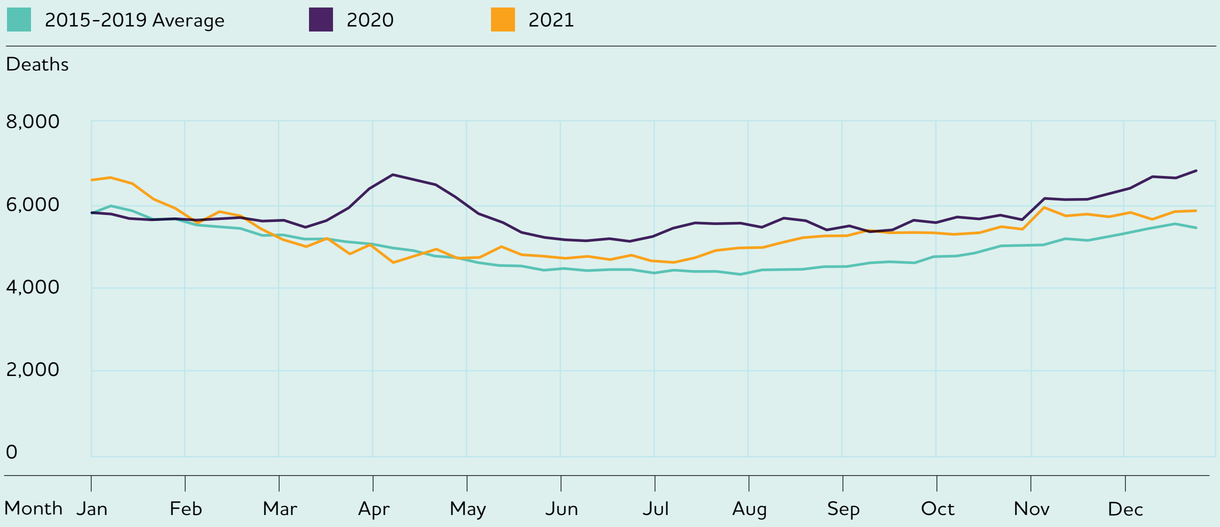
In 2020, COVID-19 was the third leading cause of death in the United States, pushing Alzheimer's disease from the sixth to the seventh leading cause of death, even though the total number of deaths from Alzheimer's disease recorded on death certificates increased 10.5% between 2019 and 2020 to 134,242.[360] COVID-19 was likely a significant contributor to the large increase in deaths from Alzheimer's. Data from the Centers for Disease Control and Prevention show that excess mortality (the difference between the observed number of deaths and the expected number of deaths during a given period) from any cause has been very high since the start of the pandemic, especially among older adults.[373] Many of these excess deaths were in vulnerable older adults with Alzheimer's disease and other dementias (Figure 6). Compared with the average of the five years before 2020, there were 15,925 more deaths from Alzheimer's disease and 44,729 more deaths from all dementias, including Alzheimer's, in 2020. This is, respectively, 13% and 17% more than expected.[360] Preliminary reports from 2021 show at least 11,000 more deaths from Alzheimer's and other dementias compared with the average of the five years before 2020.[374] While the number of people dying from Alzheimer's has been increasing over the last two decades, the number of excess deaths from Alzheimer's disease far exceeded what would be expected from the normal trend line. The lower number of excess deaths in 2021 compared with 2020 may, in part, be attributable to fewer deaths due to COVID-19 being incorrectly recorded as deaths due to dementia. It could also be the result of vaccinations. Older adults have the highest rate of COVID-19 vaccination in the United States, and based on preliminary data the percentage of deaths from COVID-19 that occurred among older adults decreased 15% from 2020 to 2021.[374]

The impact of COVID-19 can also be seen when examining the number of deaths from COVID-19 for which death certificates also listed Alzheimer's or another dementia as a cause of death (referred to as a "multiple cause of death"). In 2020 and 2021, 1 in every 10 death certificates listing COVID-19 as the primary cause of death also listed Alzheimer's disease or another dementia as a multiple cause of death. Among people age 85 or older who died of COVID-19, Alzheimer's disease or another dementia was listed as a multiple cause of death on 24% of death certificates.[374]

COVID-19 has clearly had a dramatic effect on mortality from Alzheimer's and other dementias. What remains unclear is whether and how this will affect the longer-term trend in deaths from Alzheimer's once the COVID-19 pandemic has subsided.

figure **6**

Deaths Due to Alzheimer's and Other Dementias in the United States in 2020 and 2021 Compared with Previous Years*

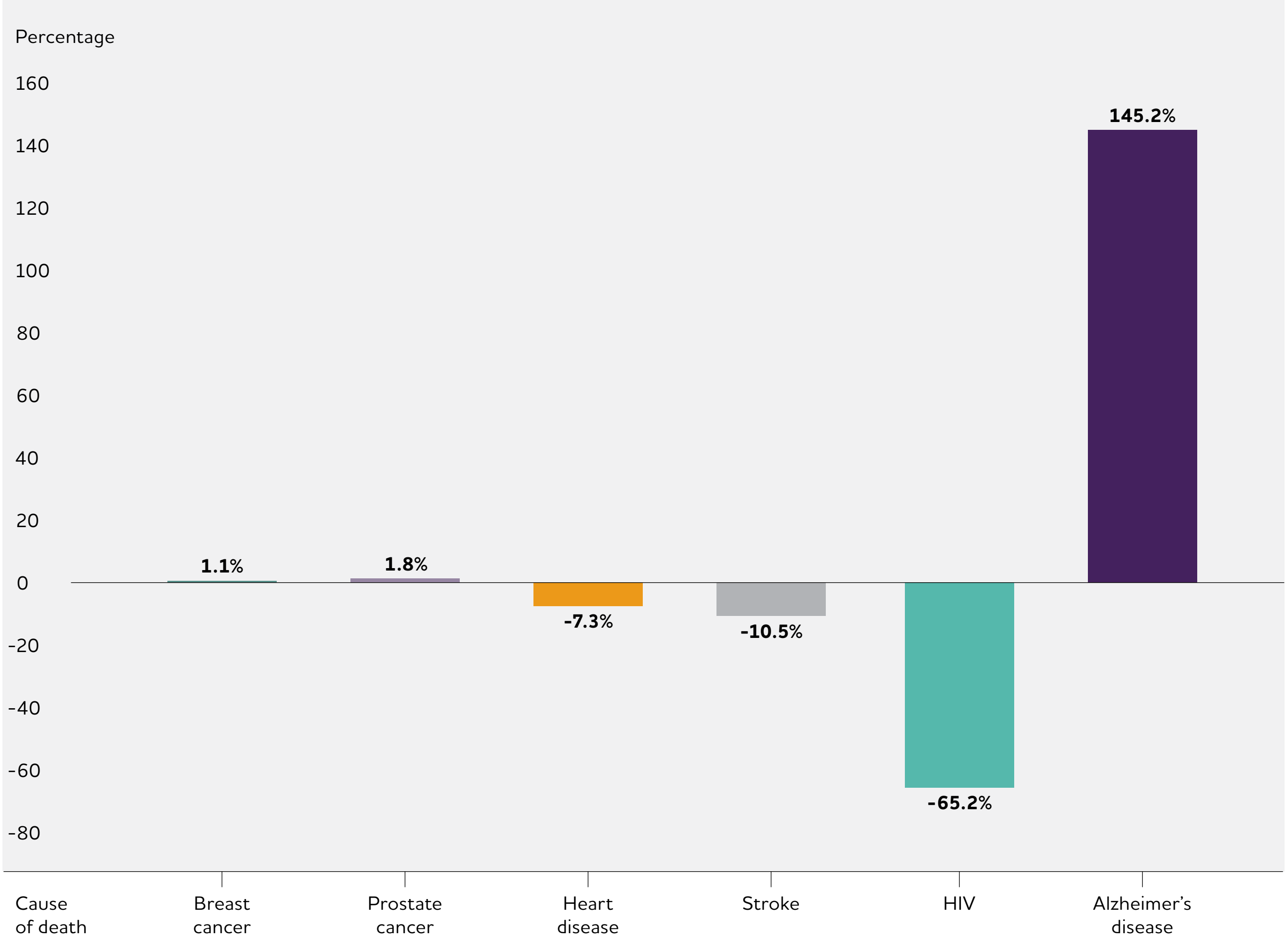


*Data for 2021 are as of February 7, 2022.

Created from data from the National Center for Health Statistics.[373]

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.[360,375]

age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if the individuals did not have Alzheimer's dementia.[364] A more recent study using data from the nationally representative Health and Retirement Study estimated that about 14% of deaths among 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.[369] 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.[370] 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 dementia at death.[371] Although some undoubtedly died from causes other than Alzheimer's, it is likely that many died from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia. Thus, taken together, the specific number of deaths caused by Alzheimer's is unknown.

To add further complexity, the vast majority of death certificates listing Alzheimer's disease as an underlying cause of death are not verified by autopsy, and research has shown that 15% to 30% of those diagnosed with Alzheimer's dementia during life do not have the brain changes of Alzheimer's disease but instead have the brain changes of another cause of dementia (see Table 1, page 6).[21,69,229-231] Therefore, an underlying cause of death listed as Alzheimer's disease may not be accurate. 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.[372]

table **5**

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

State	Number of Deaths	Mortality Rate
Alabama	2,659	54.2
Alaska	128	17.5
Arizona	3,047	41.9
Arkansas	1,507	49.9
California	16,859	42.7
Colorado	1,909	33.1
Connecticut	967	27.1
Delaware	339	34.8
District of Columbia	81	11.5
Florida	6,539	30.4
Georgia	4,221	39.8
Hawaii	471	33.3
Idaho	650	36.4
Illinois	3,954	31.2
Indiana	2,561	38.0
Iowa	1,344	42.6
Kansas	839	28.8
Kentucky	1,684	37.7
Louisiana	2,165	46.6
Maine	544	40.5
Maryland	1,012	16.7
Massachusetts	1,663	24.1
Michigan	4,467	44.7
Minnesota	2,552	45.3
Mississippi	1,662	55.8
Missouri	2,782	45.3
Montana	326	30.5
Nebraska	768	39.7
Nevada	678	22.0
New Hampshire	511	37.6
New Jersey	2,629	29.6
New Mexico	568	27.1
New York	3,753	19.3
North Carolina	4,508	43.0
North Dakota	403	52.9
Ohio	5,234	44.8
Oklahoma	1,775	44.9
Oregon	1,992	47.2
Pennsylvania	4,150	32.4
Rhode Island	456	43.0
South Carolina	2,323	45.1
South Dakota	495	56.0
Tennessee	3,252	47.6
Texas	10,101	34.8
Utah	980	30.6
Vermont	315	50.5
Virginia	2,631	30.8
Washington	3,585	47.1
West Virginia	832	46.4
Wisconsin	2,390	41.0
Wyoming	238	41.1
U.S. Total	**121,499**	**37.0**

Created from data from the National Center for Health Statistics.[A7,360]

Public Health Impact of Deaths from Alzheimer's Disease

In the two decades prior to the COVID-19 pandemic, although deaths from other major causes have *decreased* significantly or remained approximately the same, official records indicate that deaths from Alzheimer's disease *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).[360,375] 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.[376]

State-by-State Deaths from Alzheimer's

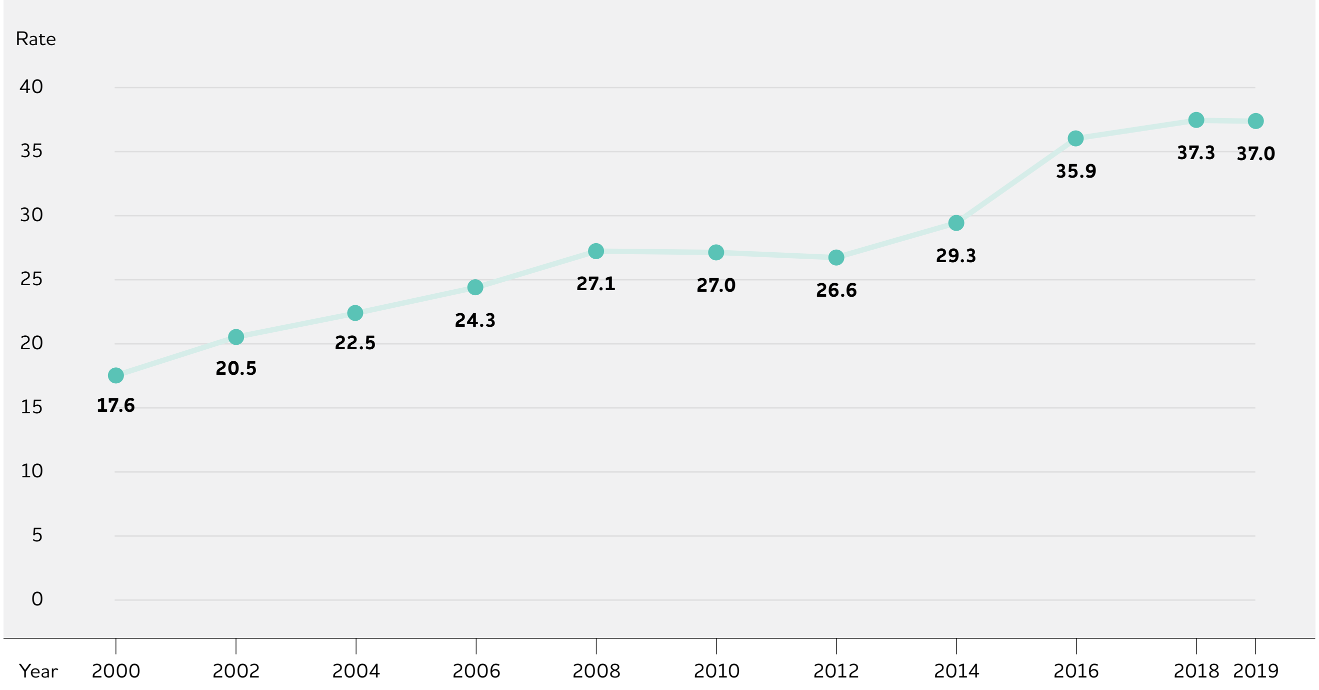
Table 5 provides information on the number of deaths due to Alzheimer's by state in 2019, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death. The 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 37.0 deaths per 100,000 people.[A7,360]

Alzheimer's Death Rates

As shown in Figure 8, the rate of deaths due to Alzheimer's — that is, the number of Alzheimer's deaths per number of persons in the population — has risen substantially since 2000.[360] Table 6 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65.[A7,360] The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old.[375] 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.[360] A report by the CDC determined that even after adjusting for changes over time in the specific ages of persons within these age groups, the annual Alzheimer's death rate in the United States increased substantially between 1999 and 2014.[376] Therefore, the advancing average age of the

figure **8**

U.S. Annual Alzheimer's Death Rate (per 100,000 People) by Year



Created from data from the National Center for Health Statistics.[360]

table 6

U.S. Annual Alzheimer's Death Rates (per 100,000 People) 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.[360]

older adult population in the U.S. 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 complete death certificates.[376]

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.[10-18] 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.[372] 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.[372] 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.[377]

The 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 severe disability and dependence. Scientists have developed methods to attempt 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. One 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.[361]

These estimates should be interpreted with consideration of challenges in the availability of data across time and place[378] and the incorporation of disability. These Alzheimer's burden estimates use different sources for each state in a given year, and a specific source of data may differ in data included across years. Models used to generate these estimates of Alzheimer's burden assume a year lived with disability counts as less than a year lived without disability.[379] Models do not account for the context in which disability is experienced, including social support and economic resources,[380] which may vary widely. These variations in data sources and consideration of disability may limit the value of these metrics and the comparability of Alzheimer's estimates across states and across years.

Looking to the Future

Taken together, these statistics indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, but also that the disease is contributing to more and more cases of poor health and disability in the United States. Most of the statistics in this section come from before the COVID-19 pandemic. We do not yet know how COVID-19 has influenced Alzheimer's mortality or increased the burden of living with Alzheimer's. Future reports will assess the influence of the COVID-19 pandemic on trends in mortality and morbidity from Alzheimer's disease. With population aging, the percentage of deaths related to Alzheimer's disease will likely continue to increase. A focus should be on ensuring the health and well-being of people with Alzheimer's disease in the years before death. Innovation in methods and data sources is required to understand the contribution of Alzheimer's disease to poor health, disability, and mortality.

CAREGIVING

Family members and friends provided more than $271 billion in unpaid care to people living with Alzheimer's and other dementias in 2021.

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.[381-382] 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).

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.[383] Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.[384] More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A8]

In 2021, caregivers of people with Alzheimer's or other dementias provided an estimated 16 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at $271.6 billion. This is approximately 49% of the net value of Walmart's total revenue in fiscal year 2020 ($559.2 billion)[385] and 14 times the total revenue of

table **7**

Dementia Caregiving Tasks

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: • 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.

McDonald's in 2020 ($19.2 billion).[386] The total lifetime cost of care for someone with dementia was estimated at $377,621 in 2021 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.[387-388] Current estimates of the lifetime costs of care may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity.[389]

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%).[A9] 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.[390]

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 do so.[391] 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.[391] Among 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.[392] 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.[393]

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:[A9,394-398]

- Approximately two-thirds of dementia caregivers are women.[A9,394-395]
- About 30% of caregivers are age 65 or older.[A9]
- Over 60% of caregivers are married, living with a partner or in a long-term relationship.[A9,395]
- Over half of caregivers are providing assistance to a parent or in-law with dementia.[398]
- Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.[398-399]
- Two-thirds of caregivers are White,[A9,395,398] 10% are Black, 8% are Hispanic and 5% are Asian American.[A9] The remaining 10% represent a variety of other racial/ethnic groups.
- Approximately 40% of dementia caregivers have a college degree or more of education.[A9,395,398]
- Forty-one percent of caregivers have a household income of $50,000 or less.[A9]
- 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.[397,400-401]
- Most caregivers (66%) live with the person with dementia in the community.[391]
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent but also for at least one child.[A9,398-399]
- Twenty-three percent of caregivers ages 18 to 49 help someone with dementia, which is an increase of 7% since 2015.[402]

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.[A9,394-395,400-401] Findings from the 2018 National Health and Wellness survey indicated that more dementia caregivers in the United States are women (61.5%) than in Japan (51.9%) or five European countries/regions (56.3%: France, Germany, the United Kingdom, Italy and Spain).[403] Over one-third of dementia caregivers are daughters caring for a parent.[383,391] It is more common for wives to provide informal care for a husband than vice versa.[404] On average, female caregivers spend more time caregiving than male caregivers.[391] 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.[405] 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.[399] Two and a half times as many women as men reported living with the person with dementia full time.[405] Of those providing care to someone with dementia for more than five years, 63% were women.[399] 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.[406-408]

Among dementia caregivers who indicated a need for individual counseling or respite care, the large majority were women (individual counseling, 85%, and respite care, 84%).[399]

Race/Ethnicity and Dementia Caregiving

Only recently have population-based studies examined racial disparities in caregiving for older people, and there is an ongoing need for culturally informed theories and research frameworks to guide future work in this critical area.[409] 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 than White caregivers to use respite services.[410] Hispanic, Black and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use and greater depression compared with White caregivers.[411-413] Mexican American older adults who live alone experience dual risks of both greater cognitive impairment and receiving less support from others compared with Mexican American older adults who live with others.[414] Cultural values may also influence gender disparities in perceptions of support among caregivers across diverse racial and ethnic contexts.[415] In a nationally representative study,[416] Black and Hispanic participants had poorer health prior to becoming a caregiver for a spouse with dementia than those of similar race/background who did not become caregivers; such differences were not apparent among White caregivers. The onset of dementia in a spouse was associated with a greater risk of depression across all race/ethnicities. Black caregivers are more likely than White caregivers to report positive aspects of caregiving.[417] 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.[418] 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. Among dementia caregivers of care recipients who have experienced severe psychiatric symptoms, those who live in low- or medium-income neighborhoods indicated higher distress than those caregivers living in high-income neighborhoods.[419] A more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among Black and White caregivers.[411]

Dementia caregiving is clearly common, regardless of race or ethnicity. The comparisons above suggest that the experience of caregiving often varies depending on racial and ethnic context. 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.[413] 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, and, by extension, if these individuals continue to lack representation in Alzheimer's research, they will not receive the benefits of prevention, treatment or care innovations.[413] Establishing stronger relationships with existing organizations and resources in Black communities, indigenous communities and communities of color offers the potential of research-based partnerships that not only enhance representation in Alzheimer's disease research but may also result in more culturally appropriate and effective services.[420-432] In addition, a greater understanding is needed of how multiple chronic diseases (multimorbidity) intersect with dementia among Black people, indigenous peoples and people of color.[433]

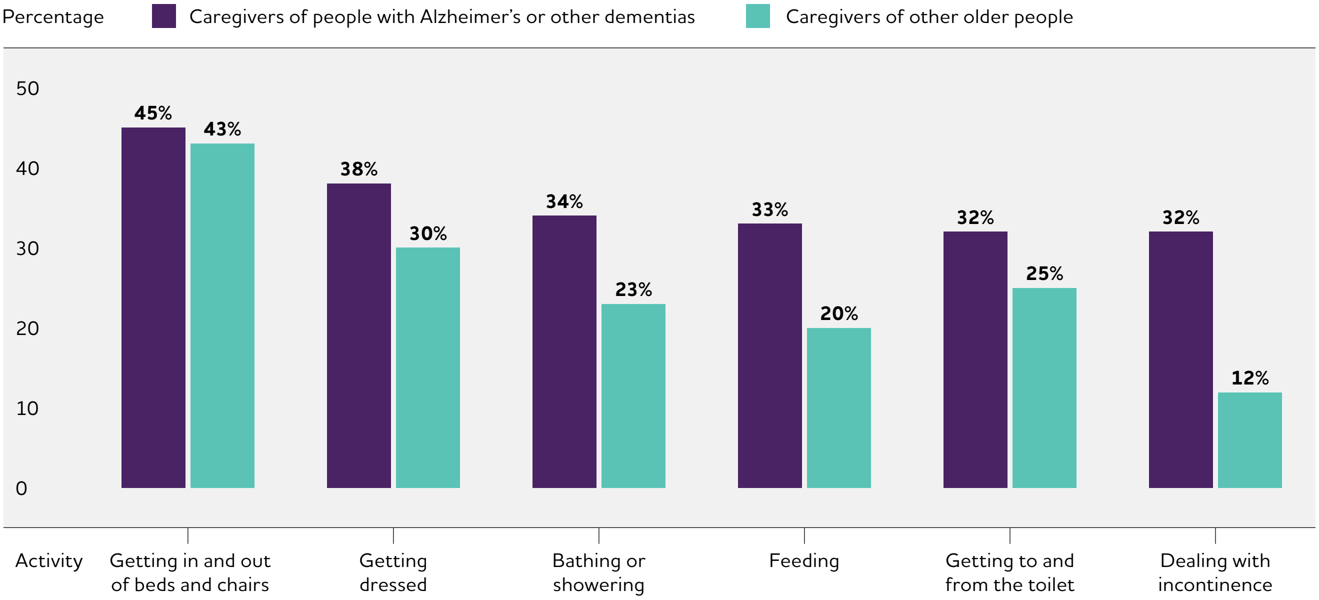
Caregiving Tasks

The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all-encompassing. Table 7 (see page 38) 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%).[434] 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%).[384,394] Figure 9 illustrates how caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.[398] The need for culturally responsive services and supports for people living with dementia and their caregivers is also pronounced.[420]

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 in Partnership with the Alzheimer's Association.[398]

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.[435]

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 (see page 38) 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.[436-437]

Duration of Caregiving

In 2014, 86% of dementia caregivers provided assistance for at least the past year.[A9] 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.[391]

Hours of Unpaid Care and Economic Value of Caregiving

In 2021, the 11.3 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 16 billion hours of unpaid help. This number represents an average of 27.1 hours of care per caregiver per week, or 1,413 hours of care per caregiver per year.[A10] With this care valued at the average of the state minimum wage and the median hourly cost of a home health aide,[A11] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was $271.6 billion in 2021. 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, Texas, Florida and New York — provided care valued at more than $16 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.[438-439] 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.

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, 2021*

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Alabama	211	230	$2,904
Alaska	12	21	409
Arizona	257	501	9,559
Arkansas	93	139	2,160
California	1,116	881	18,940
Colorado	159	184	3,711
Connecticut	143	158	2,994
Delaware	47	68	1,160
District of Columbia	14	15	302
Florida	806	1,267	20,596
Georgia	338	647	9,305
Hawaii	52	83	1,658
Idaho	42	49	749
Illinois	383	483	8,806
Indiana	216	276	4,313
Iowa	73	60	1,003
Kansas	86	96	1,406
Kentucky	150	266	3,861
Louisiana	203	316	3,829
Maine	46	69	1,409
Maryland	242	371	6,810
Massachusetts	284	411	8,865
Michigan	466	495	8,572
Minnesota	171	156	3,358
Mississippi	130	226	2,904
Missouri	194	292	4,868
Montana	17	24	$436
Nebraska	61	52	905
Nevada	48	79	1,346
New Hampshire	58	83	1,522
New Jersey	361	686	13,040
New Mexico	85	158	2,643
New York	563	835	16,082
North Carolina	356	514	7,262
North Dakota	19	29	526
Ohio	421	614	10,051
Oklahoma	129	244	3,811
Oregon	130	210	4,389
Pennsylvania	401	642	10,036
Rhode Island	39	50	1,063
South Carolina	197	296	4,326
South Dakota	19	18	341
Tennessee	361	489	6,901
Texas	1,085	1,769	25,874
Utah	97	119	1,985
Vermont	26	37	758
Virginia	351	524	8,515
Washington	297	429	9,716
West Virginia	72	135	1,841
Wisconsin	198	206	3,421
Wyoming	16	21	376
U.S. Total	**11,343**	**16,023**	**271,598**

*State totals may not add to the U.S. total due to rounding.

Created from data from the 2015-2020 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, National Alliance for Caregiving, AARP, U.S. Department of Labor and Genworth.[A8,A10,A11]

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.[394] 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.[440] 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.[441] 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.[442]

Health and Economic Impacts of Alzheimer's Caregiving

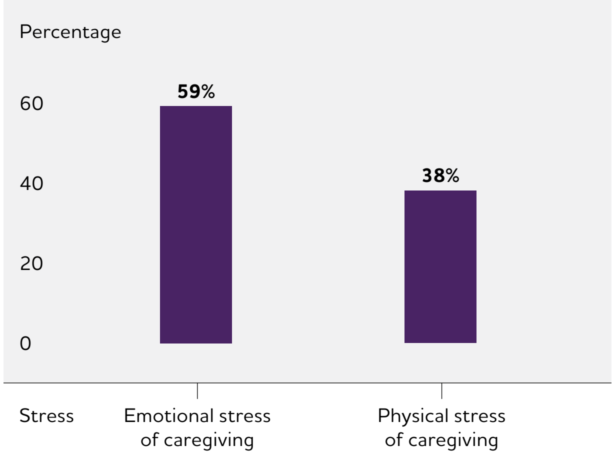
Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the moderate to severe stages of Alzheimer's dementia experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people 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.[443-445] Individuals with Alzheimer's also require increasing levels of supervision and personal care as the disease 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.[446-453]

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.[401] In a national study, greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends.[454] Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,[A9,455-461] they also frequently report higher levels of stress.

figure **10**

Percentage of Caregivers Who Report High to Very High Stress Due to Caregiving



Created from data from the Alzheimer's Association.[A9]

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.[394]
- 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).[A9]
- 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.[462]
- 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.[463]

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.[408] Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.[464]
- 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%).[465-467]
- Caring for a spouse with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.[468]
- 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.[465]
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).[465]
- Dementia caregivers in the United States were more likely to have experienced depression (32.5%) or anxiety (26%) when compared to dementia caregivers from Japan (16.8%, 12.9% respectively) or those from Germany, Italy, Spain, France and the United Kingdom combined (29.3%, 22.4%, respectively).[403]
- 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.[469-470]
- 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," as these caregivers are more likely to report clinically meaningful depression and burden (that is, negative emotional reactions to providing care).[471]

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.[434]
- Dementia caregivers often lack the information or resources necessary to manage complex medication regimens.[472-475]
- Compared with non-dementia caregivers, dementia caregivers indicate a greater decline in social network size.[476]
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.[A9]
- 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%).[A9]
- 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.[A9]
- 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.[477] Additional analyses of this sample found that number of self-care and behavior problems were most predictive of caregiver burden and depression, regardless of whether the care recipient lived with dementia or not.[478]

Stress of Care Transitions

- Admitting a relative to a care residence 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 care residence for some caregivers (such as spouses), but other studies have found that distress declines overall for dementia caregivers.[437,479-480]
- The demands of caregiving may intensify as people with dementia approach the end of life.[481] 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.[482] The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.[482]
- 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).[483] In addition, caregivers living with a family member with dementia pay for 64% of total care costs incurred during their family members' last seven years of life.[484]

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.[485] As shown in Figure 10 (see page 43), 38% of Alzheimer's and other dementia caregivers indicate that the physical stress of caregiving is high to very high.[A9] Dementia caregivers are 1.5 times more likely to indicate substantial physical difficulty providing assistance to their care recipients compared with non-dementia caregivers.[486] 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.[487-488] 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.[488] 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.[A9] A 2017 poll found that 27% of dementia caregivers delayed or did not do things they should to maintain their own health.[401] 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.[451,489-490] Data from the 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.[491] Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.[492]

Physiological Changes

The chronic stress of caregiving may be associated with an increased incidence of hypertension[493-500] and a number of physiological changes that could increase the risk of developing chronic conditions, including high levels of stress hormones,[470] impaired immune function,[494] slow wound healing[495] and coronary heart disease.[496] 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.[501] However, a study of physiological changes before and after the start of caregiving found no change on six biomarkers of inflammation among dementia caregivers.[502]

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 people with dementia alone.[503-504] 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.[504] Dementia caregivers also have twice the odds of experiencing an overnight hospitalization than non-caregivers.[505]

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.[506-507] 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).[508] 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.[509] 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.[506] 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.[510]

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.[398] These individuals worked an average of 35 hours per week while caregiving.[398] 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

table 9

Percentage of Dementia Caregivers Reporting Health Conditions by State

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

*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.

Created from data from the Behavioral Risk Factor Surveillance System survey.[399]

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

*Combination of coronary heart disease and stroke.

Table includes caregivers age 18 and older.

Created from data from the Behavioral Risk Factor Surveillance System survey.[399]

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.[398] In the 2018 National Health and Wellness Survey, close to 13% of dementia caregivers in the United States indicated absence from work in the past seven days due to a health problem compared with 6% of dementia caregivers in Japan and 10% of dementia caregivers in France, Germany, Italy, Spain and the United Kingdom combined.[403]

In 2021, it is estimated that dementia caregivers bore nearly twice the average out-of-pocket costs of non-dementia caregivers ($12,388 versus $6,667).[388,511] Examples include costs of medical care, personal care and household expenses for the person with dementia, and personal expenses and respite services for the caregiver. Caregivers of a spouse with dementia indicate higher home health care expenditures but lower outpatient expenditures than those who do not have a spouse with dementia, which suggests a possible “substitution” effect and greater referrals to home health care by providers for patients with dementia.[512-513] 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.[452] 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.[452]

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.[398]

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 someone with dementia being abused.[514] 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.[515] A synthesis of available qualitative studies found that "personhood," or the extent to which others value, support and establish meaningful relationships with someone with dementia, is enhanced through personal interactions with family, friends, other people with dementia and professional caregivers as well as through opportunities for ongoing engagement in social and occupational activities/roles.[516] See the Use and Costs of Health Care, Long-Term Care, and Hospice section (page 60) for additional information.

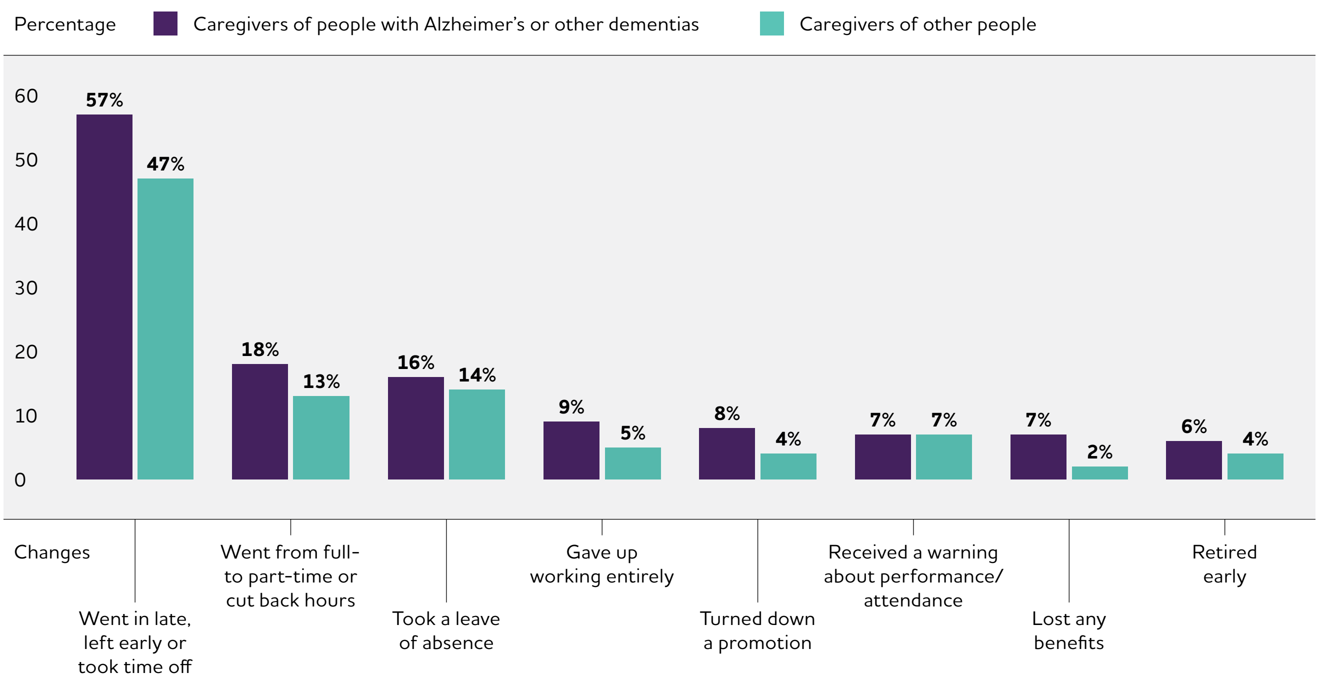
Interventions Designed to Assist Caregivers

For more than 35 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 (see page 49).[449,517]

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.

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 in Partnership with the Alzheimer's Association.[398]

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.[518] A prior 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.[519-524] 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.[525] Although several national reports have suggested few intervention types benefit dementia caregivers,[526] other recent meta-analyses report that specific intervention types (such as psychoeducation; see Table 11) may result in a small reduction in burden for caregivers, with other meta-analyses indicating broader effects of various interventions across multiple dementia caregiver outcomes.[527-531] 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.[532]

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.[533-535] 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 (this includes the Alzheimer's Association 24/7 Helpline).[536-537] 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 over a decade in an Indianapolis health care

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 preexisting 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 intervention, 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,[449] Gaugler et al[517] and Walter and Pinquart.[529]

system.[538] 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),[539-547] while others have integrated evidence-based dementia care interventions into community-based programs.[536,548]

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.[549-552] Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.[553-558] 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.[421,433,559-566] Additional research on interventions focused on disease stages is also required, as is research on specific intervention needs for LGBT caregivers.[393]

In 2019, the National Institute on Aging (NIA) awarded funding to create the NIA Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory. The Collaboratory includes experts from more than 30 research institutions and supports pilot trials and larger studies that 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.

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. Compared with dementia caregivers in 1999, dementia caregivers in 2015 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).[440] 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

COVID-19 and Dementia Caregiving

Although much of what is known about COVID-19 and dementia caregiving remains anecdotal, existing reports indicate that the COVID-19 pandemic has posed significant challenges to family members and friends who provide care for people with dementia.[574] Fatigue and burnout among dementia caregivers and their lack of access to services and supports for themselves and for the people for whom they provide care are common themes in research on the wide-ranging effects of the COVID-19 pandemic. For these reasons the pandemic has created a crisis for dementia caregivers.[575-577] In the earlier stages of the pandemic, caregivers were 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.[578] In addition, staff and directors of adult day service programs in the United States reported perceived declines in cognition, function and well-being among clients due to state closures during the pandemic. Together, this suggests the need for improved support of community-based long-term programs for people living with dementia and their caregivers at home.[579-580]

Studies have shown that family caregivers who were 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 to engage in communication resulted in lower perceived well-being among family caregivers and their relatives.[581] Telephone interviews with family caregivers in rural Virginia following the governor's stay-at-home order in 2020 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.[582] In a study of dementia caregivers of relatives living in nursing homes or similar residential settings, caregivers indicated a number of challenges during the COVID-19 pandemic, including severely limited contact with relatives due to visitation restrictions, a lack of transparent information and communication from care residences, fears of relatives dying alone and concerns about overburdened staff at care residences. In addition, caregivers highlighted a number of resources and practices that were helpful during COVID-19, including effective infection control measures adopted by care residences, robust communication with staff, and the need for creativity when remaining socially connected with relatives in nursing homes or similar residential settings.[583]

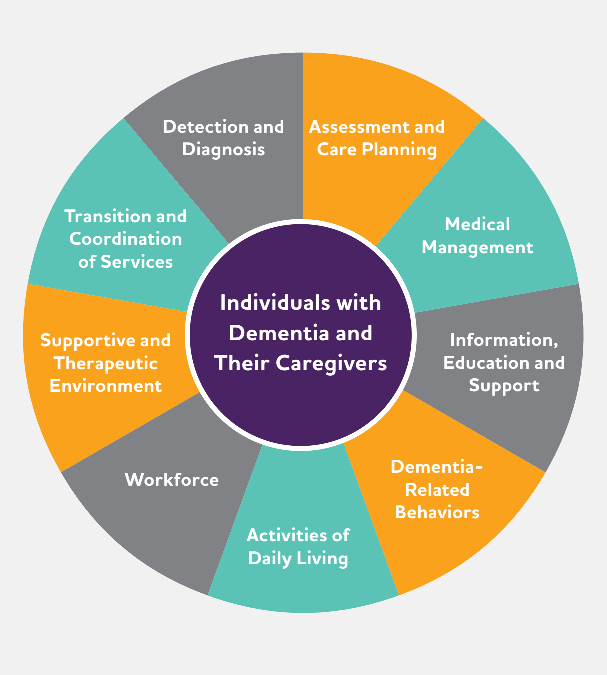
At the outset of the pandemic, the National Institutes of Health and other federal agencies issued multiple requests for rapid grant applications to study and design interventions to mitigate the effects of COVID-19 on people with dementia and their caregivers. The Alzheimer's Association also provides regularly updated guidance for dementia caregivers and professional care providers as the pandemic unfolds. In addition, the challenges of the pandemic have motivated some service providers to transition their support programs toward remote/virtual care delivery which has helped to extend the reach and accessibility of dementia care innovations,[584-585] although concerns remain about the "digital divide" facing caregivers who do not have reliable broadband access or do not regularly use the internet.

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.[567] In addition, there is some indication that the number of family members available to provide care to older relatives with health needs is likely to decrease due to a range of sociodemographic and health trends in the U.S. (e.g., the aging of the U.S. population, a lower birth rate and adult children's geographic mobility/dispersion over the prior several decades).[568] The need to bridge this impending "family care gap" through new policies, services and research is a growing public health concern.[569]

The Alzheimer's Association has undertaken several efforts to improve how dementia care is studied and delivered. Its recent dementia care practice recommendations[570] 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 care for people with dementia is measured and designed 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.[516,571] 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 possibilities of maintenance or even improvement of skills and abilities when living with dementia.[572-573] A core element of this and other 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.

figure **12**

Person-Centered Care Delivery



Created from data from the Alzheimer's Association.[570]

WORKFORCE

55% of primary care physicians caring for people living with Alzheimer's report there are not enough dementia care specialists in their communities to meet patient demands.

As the global prevalence of Alzheimer's disease increases, so does the need for members of the paid workforce who are involved in diagnosing, treating and caring for those living with the disease.

The paid workforce includes primary care physicians (PCPs) and specialists such as geriatricians and neurologists who diagnose Alzheimer's; members of the skilled care workforce such as registered nurses and physical therapists who help treat individuals during the course of their illness; and members of the direct care workforce such as home health aides and personal care aides who help with activities of daily living and some household tasks.

Diagnosis

The types of physicians involved in diagnosing Alzheimer's and other dementias include PCPs (family medicine, internal medicine and general practice physicians) and specialists such as geriatricians, neurologists, geriatric psychiatrists and neuropsychologists.

Studies show that PCPs frequently make the initial diagnosis of dementia.[586-587] One study found that 85% of people first diagnosed with dementia were diagnosed by a non-specialist physician, usually a PCP, and the remaining 15% by a specialist.[588] Of those diagnosed by a specialist, 44% were diagnosed by a neurologist, 34% by a psychiatrist and 22% by a geriatrician.[588]

Even though the vast majority of diagnoses are made by PCPs, in a survey conducted by the Alzheimer's Association in 2019,[589] nearly 40% of PCPs reported never or "only sometimes or never" being comfortable personally making a diagnosis of Alzheimer's or other dementias. In addition, 50% of PCPs reported that they do not feel adequately prepared to care for individuals with Alzheimer's and other dementias. More than 25% reported being only sometimes or never comfortable answering patient questions about Alzheimer's or other dementias. Given this discomfort and uncertainty, almost one-third of PCPs refer patients to a dementia specialist. However, most PCPs (55%) reported that there are not enough specialists in their area to meet patient demand.

According to the National Center for Health Workforce Analysis, there was already a shortage of geriatricians in 2013, with a projected increase in demand by 2025 that was not expected to be met.[590] Similarly, a study of the current and future U.S. neurology workforce projected a 19% shortage of neurologists by 2025,[591] and another found that only 1.2% of psychologists specialized in care for older people, which falls short of current and projected future demand.[592]

Table 12 (see page 54) shows state-by-state projections for the number of geriatricians needed in 2050. Looking to mid-century, the United States will have to nearly triple the number of geriatricians who were practicing in 2021 to effectively care for the approximately 10% of those 65 and older who are projected to have Alzheimer's dementia in 2050.[593-594] The number must increase nearly nine times to have enough geriatricians to care for the approximately 30% of the population age 65 and older who will need geriatrician care.

These shortages will affect states differently. For example, Hawaii and Washington, D.C., have more than enough or almost enough geriatricians to meet the approximately 10% of those age 65+ projected to have Alzheimer's dementia in 2050. In contrast, 12 states need to at least quintuple the number of practicing geriatricians by 2050 to care for those 65 and older projected to have Alzheimer's dementia, or increase the number by at least 13 times to care for the 30% of the population age 65 and older projected to need geriatrician care. Two states, Tennessee and Idaho, will need to increase the number of geriatricians by at least nine times just to meet the care needs of those projected to have Alzheimer's dementia in 2050, or by at least 29 times to meet the needs of all those projected to need geriatrician care in 2050.

table 12

Number of Geriatricians in 2021 and Projected Number of Geriatricians Needed in 2050 by State

State	Number of Geriatricians in 2021	Number of Geriatricians Needed in 2050 to Serve 10% of Those 65 and Older	Number of Geriatricians Needed in 2050 to Serve 30% of Those 65 and Older
Alabama	33	228	684
Alaska	8	31	92
Arizona	92	363	1,089
Arkansas	55	134	402
California	587	1,676	5,029
Colorado	96	289	867
Connecticut	91	166	497
Delaware	18	55	165
District of Columbia	36	28	83
Florida	362	1,365	4,096
Georgia	100	492	1,476
Hawaii	63	64	192
Idaho	8	87	261
Illinois	212	517	1,551
Indiana	66	299	897
Iowa	26	142	426
Kansas	20	121	364
Kentucky	39	207	622
Louisiana	31	198	595
Maine	36	71	213
Maryland	146	288	865
Massachusetts	214	347	1,042
Michigan	164	465	1,394
Minnesota	84	270	811
Mississippi	23	124	373
Missouri	91	283	849
Montana	9	59	177
Nebraska	23	84	253
Nevada	43	158	474
New Hampshire	33	72	217
New Jersey	206	398	1,193
New Mexico	27	93	279
New York	568	818	2,454
North Carolina	158	535	1,606
North Dakota	12	34	103
Ohio	163	537	1,611
Oklahoma	26	171	512
Oregon	69	232	695
Pennsylvania	273	601	1,803
Rhode Island	33	49	147
South Carolina	66	288	865
South Dakota	15	44	131
Tennessee	37	343	1,029
Texas	333	1,255	3,766
Utah	25	114	341
Vermont	9	32	95
Virginia	113	406	1,218
Washington	126	399	1,198
West Virginia	16	83	250
Wisconsin	83	273	820
Wyoming	3	26	79
U.S. Total	**5,170**	**15,417**	**46,252**

The 10% column is how many geriatricians will be needed to serve only those 65 and older projected to have Alzheimer's dementia in 2050, assuming that the percentage of people age 65 and older with Alzheimer's dementia remains at approximately 10%. The 30% column is how many geriatricians will be needed to serve the 30% of people age 65 and older who need geriatrician care, regardless of whether they have dementia. The number of practicing geriatricians in 2021 was provided by IQVIA and includes physicians with geriatrics as either their primary or secondary specialty. Calculations assume that each geriatrician can care for up to 700 patients.[596] The underlying state-by-state estimates of the 2050 population age 65 and older were provided by Claritas Pop-Facts 2020.

These data were obtained from IQVIA in December 2021. The data represent the number of practicing geriatricians at that time. The American Board of Medical Specialties (ABMS) is another source of statistics about geriatrician supply, but it provides the number of individuals who are board-certified in geriatrics. However, some of these board-certified geriatricians may not go on to practice in that specialty. Although IQVIA numbers are lower than ABMS numbers, the Alzheimer's Association chose to use the IQVIA numbers because they indicate how many practicing geriatricians people with dementia and their families could reach out to for help. The Alzheimer's Association will be working to standardize how the productivity of medical specialists such as neurologists, neuropsychologists and geriatric psychiatrists is determined to better understand how many will be needed in future years based on the growing U.S. population.

The shortage of specialists is a barrier to a timely and accurate diagnosis, and a lack of diagnosis means a delay in treatments, care delivery and supportive services. During this lost time, people living with dementia could be enrolled in potentially life-changing clinical trials of new treatments, receive emotional support by joining a support group of others living with Alzheimer's, or hire an eldercare attorney or other professional to begin planning for caregiving, housing and income changes as Alzheimer's progresses.

While there is a shortage of dementia specialists across the country, PCPs have reported a substantial difference in specialist availability between urban and rural settings. Forty-four percent of PCPs in a large city and 54% of those in a suburb near a large city reported that there were not enough specialists in their area.[589] In contrast, 63% of PCPs in a small city or town and 71% of PCPs in a rural area reported a lack of specialists.[588] Twenty U.S. states have been termed "dementia neurology deserts," meaning they are projected to have fewer than 10 neurologists per 10,000 people with dementia in 2025.[595]

Treatment

Professionals who may receive special training in treating older adults include nurse practitioners, registered nurses, social workers, pharmacists, physician assistants and case workers.[597] In 2021, there were 325,000 nurse practitioners in the United States, and 12% of them had special expertise in gerontological care.[598] Less than 1% of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.[597] Although 73% of social workers serve clients age 55 and older, only 4% have formal certification in geriatric social work.[597]

Among those providing treatment are members of the skilled care workforce — licensed health care professionals who provide medically necessary nursing or rehabilitation services ordered by a physician. This type of care can take place at home or in a skilled nursing residence and includes physical therapy, occupational therapy, wound care, intravenous injections and catheter care.

Involving a range of skilled care workers in a primary care setting to boost dementia workforce numbers may provide quality care in cost-effective ways. For example, one collaborative care model relying on a team composed of a PCP, registered nurse, social worker, medical assistant and technician who could administer neuropsychological tests found savings of up to $2,856 per patient annually.[599] Another dementia care program co-managed by nurse practitioners and physicians was cost-neutral or cost-saving, and fewer individuals in the program were placed into nursing homes compared with individuals who received standard care.[600] Finally, dementia care operating out of centralized hubs through telehealth services and involving teams consisting of a care navigator, advanced practice nurse, social worker and a pharmacist resulted in fewer emergency room visits, ambulance rides and hospitalizations compared with usual care.[601]

Although more research is needed, these findings suggest that investing in the wide range of professionals who make up the primary care dementia workforce and mobilizing it in collaborative care models may have health benefits for individuals living with dementia as well as save money.

Care

Direct care workers, such as nurse aides and nursing assistants (same job responsibilities, but job title varies by state), home health aides and personal care aides, provide most of the paid long-term care to older adults living at home or in settings such as assisted living residences and nursing homes.[602-603] In nursing homes, nurse aides and nursing assistants make up the majority of staff who work with cognitively impaired residents.[604-606] Direct care workers ensure individuals receive and take prescribed medications, help with activities of daily living, and play essential roles in providing nutrition, exercise and social engagement to those living with dementia.

On a broader scale, direct care workers play important roles in delaying nursing home placement and reducing repeated hospitalizations. Direct care workers who provide at-home care enable individuals to continue to live at home. They also provide care to individuals returning from a hospital stay and reduce their likelihood of returning to the hospital.[607-610]

As shown in Table 13 (see page 57), in all but two states (Maine and Mississippi), double-digit percentage increases in home health and personal care aides will be needed between 2018 and 2028 to meet demand. A 30% to 35% increase will be needed in 16 states, a 40% to 50% increase will be needed in seven states, and one state, New York, will require a greater than 50% increase (60.6%).

Direct care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.[597,605,611-613] Turnover rates are high among direct care workers — as high as 65% annually for certified nurse assistants[614] — and recruitment and retention are persistent challenges.[597,614]

One reason is low wages. According to the Bureau of Labor Statistics, the median income of home health aides and personal care aides was $27,080 in 2020, and the median hourly wage was $13.02.[615] Despite their critical role in the health and well-being of individuals living with dementia, their median wage is less than that of individuals such as janitors ($29,080; $13.98)[616] and retail sales clerks ($27,320; $13.13)[617] who do not have health care responsibilities.

Low wages lead to turnover and understaffing. Because of this, direct care workers who remain in their positions can be faced with taking care of more people in the same eight-hour shift. This may pose challenges to their ability to deliver quality care. In addition, understaffing can lead to direct care workers being mandated by their employers to work extra shifts, potentially compromising their own health as well as that of the people for whom they provide care.

Another potential reason for turnover is that being a direct care worker is a physically dangerous job with a high number of on-the-job injuries. According to the Paraprofessional Healthcare Institute's "Workplace Injuries and the Direct Care Workforce,"[618] in 2016 the number of injuries per 10,000 workers was 144 among personal care aides, 116 among home health aides and 337 among nursing assistants, compared with 100 per 10,000 workers across all occupations in the United States. The COVID-19 pandemic adds to the danger experienced by these essential workers, with some studies forecasting increased burnout, turnover and staff shortages as a result.[619-622]

According to "Making Care Work Pay,"[610] shortages of direct care workers often leave care recipients and families scrambling to fill the gaps. As a result, many care recipients may find themselves unable to live as independently as they had hoped, moving to residential care settings sooner than they had planned and facing worsening health outcomes.

About 4.5 million Americans make up the direct care workforce.[623] From 2016 to 2026, the demand for direct care workers is projected to grow by more than 40%, while their availability is expected to decline.[624-625] State governments are hoping to help bridge this gap through direct care workforce development programs, standardization of regulatory requirements for direct care work across states, and addressing wage issues to aid retention.[626]

Workforce Needs for New Therapies

As new therapies for Alzheimer's are developed, the demands on the dementia care workforce will change. For example, in 2021 the U.S. Food and Drug Administration approved the drug aducanumab, which is delivered through intravenous infusion and requires careful monitoring of patients for a serious potential side effect called amyloid-related imaging abnormalities (ARIA) (for more information about aducanumab, see the Overview, page 4). Ensuring the health of individuals while they receive aducanumab is crucial. This requires an expanded workforce including radiologists and radiology technicians with experience and special training in recognizing ARIA, as well as physician specialists skilled in managing ARIA should it occur. In addition, because aducanumab is delivered by intravenous infusion, infusion nurses are now key members of the dementia care workforce. Also essential are neuropsychologists and other health care professionals specializing in administering cognitive tests to determine if individuals with Alzheimer's are benefiting from aducanumab. Individuals who do not experience improvement in thinking skills and the ability to perform activities of daily living while receiving aducanumab may be advised by their physicians to discontinue use of the drug. Whether there are sufficient numbers of these members of the dementia care workforce to meet demand must also be explored.

The Rand Corporation's "Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment" projected that the existing shortage of dementia specialists will slow access to new disease-modifying therapies, with an average projected wait time of 18.6 months between diagnosis and treatment.[627] This highlights how the shortage of dementia specialists can directly impact patients' current and future health and points to the need for additional dementia specialists to prepare for future therapies.

Barriers to Developing Enough Well-Trained Members of the Alzheimer's and Dementia Care Workforce

Among PCPs, barriers to providing dementia care include not having the time, tools or expertise to diagnose Alzheimer's disease or other dementias. Visits with PCPs are typically brief, lasting an average of 17.4 minutes by one estimate.[628] This leaves little time to add cognitive assessments to their other services. PCPs are required to provide Medicare patients with a brief cognitive assessment as part of their annual wellness visit. However, PCPs are uncertain how to go about this, and fewer than one-third of Medicare beneficiaries reported receiving cognitive assessment at an annual wellness visit.[629]

table **13**

Projections of Total Home Health and Personal Care Aides Needed in 2028 by State*

	Number in 2018 and Projected Number Needed in 2028		Percentage Increase
State	**2018**	**2028**	**2018-2028**
Alabama	21,340	25,970	21.7%
Alaska	6,400	7,450	16.4%
Arizona	2,600	3,320	27.7%
Arkansas	23,860	31,610	32.5%
California	596,100	784,900	31.7%
Colorado	38,930	57,950	48.9%
Connecticut	36,690	48,730	32.8%
Delaware	6,970	9,380	34.6%
District of Columbia	11,490	14,800	28.8%
Florida	73,130	93,320	27.6%
Georgia	44,980	65,070	44.7%
Hawaii	10,090	13,620	35.0%
Idaho	15,930	19,260	20.9%
Illinois	90,120	108,040	19.9%
Indiana	43,640	59,990	37.5%
Iowa	19,490	26,070	33.8%
Kansas	24,860	32,760	31.8%
Kentucky	20,990	28,800	37.2%
Louisiana	42,910	53,370	24.4%
Maine	17,850	19,580	9.7%
Maryland	24,000	34,180	42.4%
Massachusetts	82,290	98,440	19.6%
Michigan	70,810	87,390	23.4%
Minnesota	101,110	131,170	29.7%
Mississippi	12,600	13,820	9.7%
Missouri	74,380	97,470	31.0%
Montana	7,250	9,170	26.5%
Nebraska	10,620	12,960	22.0%
Nevada	15,580	22,090	41.8%
New Hampshire	9,560	12,600	31.8%
New Jersey	58,930	82,250	39.6%
New Mexico	34,050	46,230	35.8%
New York	437,300	702,370	60.6%
North Carolina	63,400	78,080	23.2%
North Dakota	7,220	9,130	26.5%
Ohio	102,960	135,080	31.2%
Oklahoma	22,820	30,410	33.3%
Oregon	32,090	41,290	28.7%
Pennsylvania	165,900	210,460	26.9%
Rhode Island	7,390	8,900	20.4%
South Carolina	31,390	42,820	36.4%
South Dakota	4,010	4,980	24.2%
Tennessee	29,200	41,370	41.7%
Texas	293,400	388,230	32.3%
Utah	13,040	19,430	49.0%
Vermont	8,000	10,500	31.3%
Virginia	52,990	72,040	36.0%
Washington	63,800	77,170	21.0%
West Virginia	15,280	19,950	30.6%
Wisconsin	71,820	86,440	20.4%
Wyoming	3,170	4,390	38.5%
U.S. Total	**3,083,310**	**4,146,220**	**34.5%**

*Long-term occupational projections (2018-2028) are available via https://projectionscentral.org/Projections/LongTerm. State projections are developed in the labor market information sections of each State Employment Security Agency.

According to the American Public Health Association (APHA), bolstering the dementia care workforce has unique challenges, including recruitment, retention, career advancement, regulation and training.[624] Dementia care is also underrepresented in clinical training, both in curricula and in opportunities for clinical experience.[630] Dementia and geriatric education is needed across myriad professions, but dementia-specific training requirements across the nation are sparse and inconsistent. An analysis of training requirements across licensure and professional settings, including long-term care, showed that a minority of states require dementia training for various professionals such as long-term care community administrators, registered nurses, licensed practical nurses, licensed vocational nurses, home health aides, social workers and personal care assistants.[625,631]

Notes the APHA, "Continued failure to strengthen the dementia care workforce will increasingly limit the ability of people living with dementia to access quality services and supports, adding to health, social and economic burdens for individuals, families and society."[632]

Looking to the Future

More physicians who specialize in the health of older individuals are needed to meet the health care needs of the rapidly increasing numbers of Americans age 65 and older who are at the highest risk of developing Alzheimer's. This age group is projected to grow to from 6.5 million in 2022 to 7.2 million in 2025 (see Prevalence section, page 18).[633] It is also clear that more dementia training is needed among PCPs and across the non-physician dementia care workforce. In addition, increased wages should be considered for direct-care workers to reduce turnover and help ensure that they can provide high-quality care without concern for their own physical or financial health. Challenges remain in ensuring high-quality home care provided informally by family members and friends and formally by hired personal care aides.

On the hopeful side, now may be the time for health care systems to expand the job possibilities of the non-physician dementia care workforce and simultaneously give PCPs and specialists more time to do what they are best at. For example, the roles of physician assistants, nurse practitioners and non-clinical office staff could be expanded to include coordinating services with families, caregivers and community resources to enhance the patient experience both before and after diagnosis. Health care systems could also expand the range of health care professionals trained to notice symptoms, conduct structured cognitive assessments, refer and/or diagnose dementia, and communicate a care plan to patients and their families. Physician assistants, nurse practitioners, social workers and other care providers could play vital roles in specialized dementia care delivery, particularly for rural and underserved communities.[599-601]

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.[599] For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by $3,474 over a year for individuals with memory problems compared with others with memory problems whose care was overseen by a primary care provider only.[599] More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively inexpensive per person, with an average annual cost of $618 — a nearly 6-to-1 return on investment.

In addition, in its report "Gaps in the Dementia Care Workforce,"[634] the National Academies of Sciences, Engineering, and Medicine's Committee on Population notes that direct care workers are "well-positioned to implement non-pharmacologic interventions for behavioral and psychological symptoms, educate and support family members, and observe and record changes to clinical team members."

One example of reimagining the roles of the dementia care workforce is evident in the Gerontological Society of America KAER ("Kickstart, Assess, Evaluate, Refer") model. Among other things, this model suggests that non-clinical office staff also participate in the primary care team's efforts to detect cognitive impairment.[635] Receptionists or schedulers, for example, could make note of unkept appointments or patients showing up at the wrong time, patients deferring to family members while completing paperwork or answering questions, and patients having difficulty following care plans.[635] Another study of a collaborative care model involving health coaches as liaisons between a dementia care partner team and people with dementia and their caregivers found this model was feasible and provided satisfactory care.[636]

The Alliance to Improve Dementia Care recommends that primary care teams across settings — whether in private practice or as part of academic medical centers or health care networks — adapt existing procedures and staffing "to fit, and enhance, their clinical workflows to proactively detect and accurately diagnose dementia in its early stages."[637]

The dementia care workforce's time may also be optimized by turning to technology such as using computerized or digital screening tools for cognitive assessments before and between physician visits. Remote assessments through telephone or video could help reach those in rural areas and those with mobility challenges.[638] A randomized clinical trial of 1,560 individuals in both urban and rural areas in three states who participated in a telephone- and internet-based dementia care delivery system found that the system resulted in better quality of life for individuals with dementia, reduced emergency department visits and decreased caregiver depression and burden.[601] A systematic review of telehealth for dementia care,[639] including routine care, cognitive assessment and rehabilitation, found that telehealth delivered results similar to those of in-person cognitive assessment and diagnosis and was associated with improved rehabilitation outcomes. More research is needed to identify the strengths and weaknesses of telehealth and methods to optimize its use for individuals living with dementia and their care partners.

In the future, technology may also have a role in expanding biomarkers and in dementia screening and diagnosis. Studies of remote monitoring techniques, such as activity data from wrist-worn devices or game-like assessments on mobile phones, may produce digital biomarkers of MCI.[640-641] Similarly, technologies that identify speech patterns[642] and retinal blood vessel changes[643] may help flag the earliest stages of cognitive decline.

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

In 2022, the total national cost of caring for people living with Alzheimer's and other dementias is projected to reach $321 billion.*

*Does not include the $271.6 billion in unpaid caregiving by family and friends.

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.[644]

Total payments in 2022 (in 2022 dollars) for all individuals with Alzheimer's or other dementias are estimated at $321 billion (Figure 13), not including the value of informal caregiving that is described in the Caregiving section (see page 37). Medicare and Medicaid are expected to cover $206 billion, or 64%, 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 $81 billion, or 25% of total payments.[A12] For the remainder of this section, costs are reported in 2021 dollars unless otherwise indicated.[A13]

Total Cost of Health Care and Long-Term Care

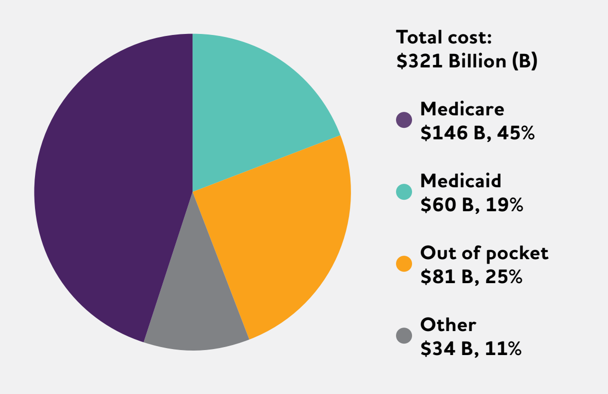
Table 14[A14] reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias. Total per-person health care and long-term care payments in 2021 from all sources for Medicare beneficiaries with Alzheimer's or other dementias were over three times as great as payments for other Medicare beneficiaries in the same age group ($41,757 per person for those with dementia compared with $14,026 per person for those without dementia).[A15,260]

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 $9,844 out of pocket annually for health care and long-term care services not covered by other sources (Table 14, see page 62).[260]

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).[387,644,646-647] In a 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.[648] 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

figure **13**

Distribution of Aggregate Costs of Care by Payment Source for Americans Age 65 and Older with Alzheimer's or Other Dementias, 2022*



*Data are in 2022 dollars.

Created from data from the Lewin Model.[A12] "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

table **14**

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 2021 Dollars*

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$21,024	$7,576
Medicaid	6,478	291
Uncompensated	184	229
Health maintenance organization	1,867	2,193
Private insurance	1,468	916
Other payer	893	401
Out of pocket	9,844	2,420
Total	**41,757**	**14,026**

*Payments for beneficiaries with Alzheimer's or other dementias include payments for community-dwelling beneficiaries and beneficiaries living in residential care settings.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[260]

dollars ($38,470 in 2021 dollars).[A16,644] Another research team found that the total incremental cost of dementia over five years, based on Medicare claims, was $15,704 in 2017 dollars ($17,322 in 2021 dollars), with the additional costs of care in the first year after diagnosis representing 46% of the five-year incremental costs.[649] 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.[650] 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 ($377,621 in 2021 dollars).[387] 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 in 2015 dollars ($216,518 in 2021 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 ($46,418 in 2021 dollars) more out-of-pocket between age 65 and death than individuals without dementia, due to nursing home care.[651] Another group of researchers found that community-dwelling individuals age 65 and older with Alzheimer's dementia had $1,101 in 2012 dollars ($1,391 in 2021 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.[652] 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.[649]

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 ($387,442 and $247,014, respectively, in 2021 dollars), a difference of 57%.[653] 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%). A recent systematic review of end-of-life costs for individuals with dementia reported a dramatic increase in the monthly cost of care when comparing monthly costs for the last 12 months of life compared to the last six months or last month of life.[654]

Use and Costs of Health Care Services

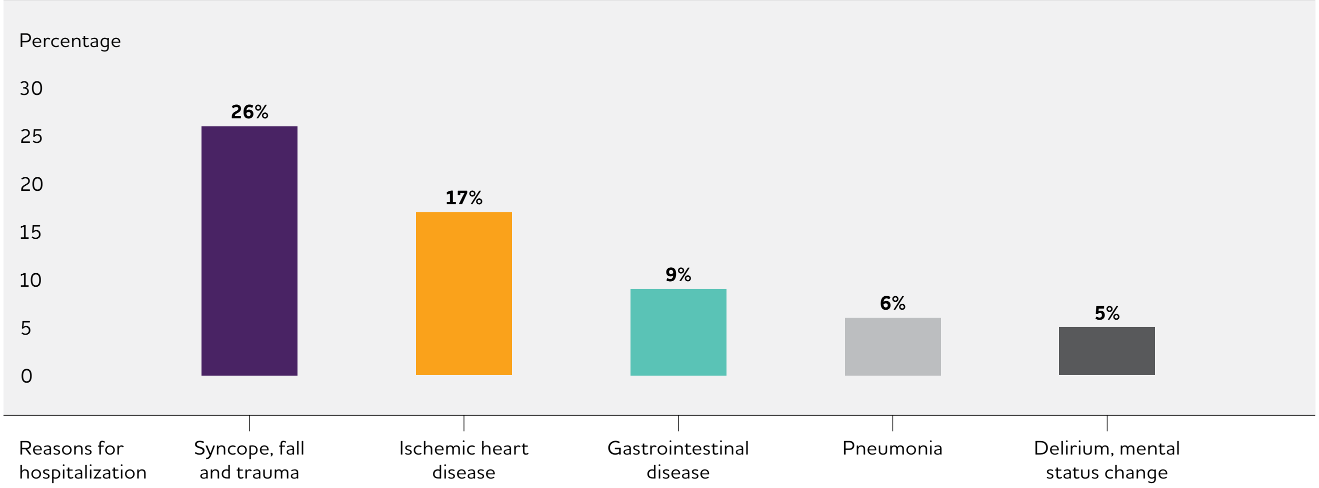
Use of Health Care Services

People with Alzheimer's or other dementias have more than twice as many hospital stays per year as other older people.[370] 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.

figure **14**

Reasons for Hospitalization of Individuals with Alzheimer's Dementia: Percentage of Hospitalized Individuals by Admitting Diagnosis*



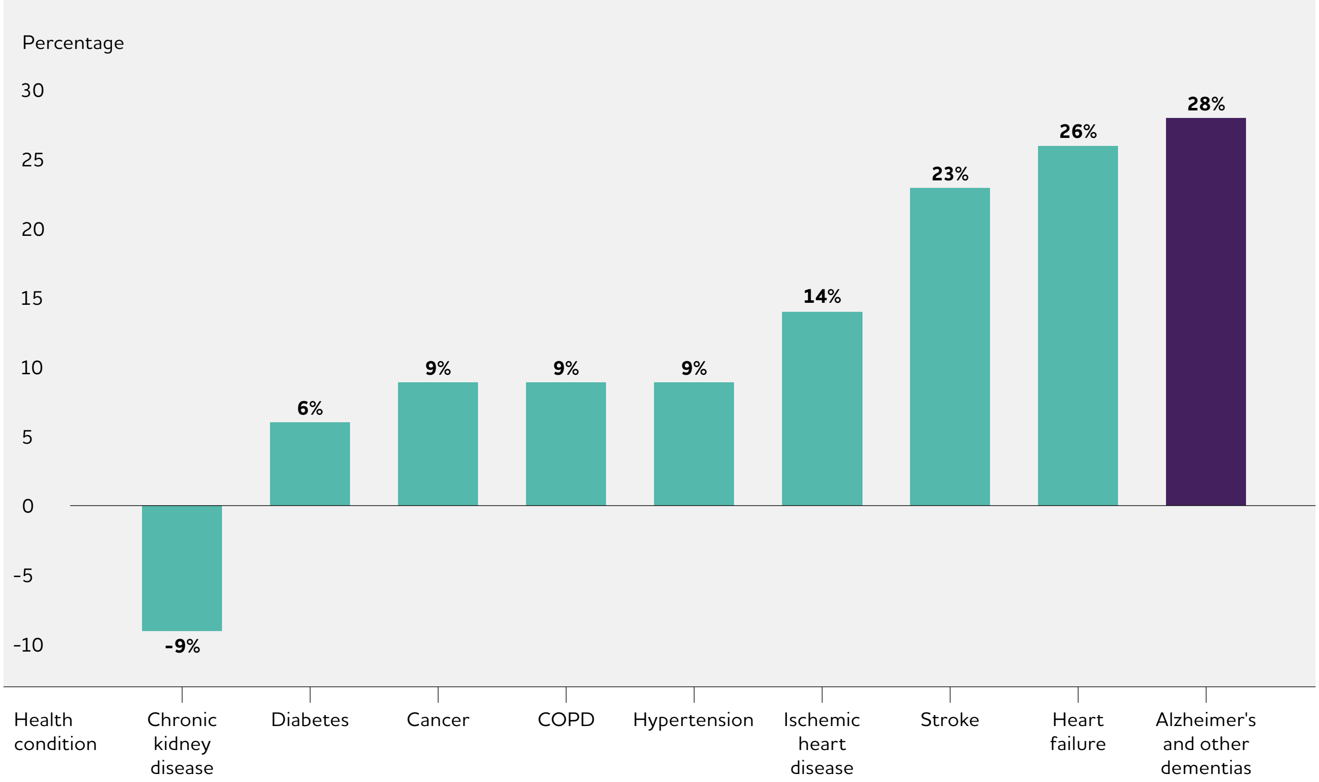
*All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's were used to calculate percentages. The remaining 37% of hospitalizations were due to other reasons.

Created from data from Rudolph et al.[655]

- Hospital. There are 518 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's or other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions.[370] Overall, 32% of Medicare beneficiaries with Alzheimer's or other dementias have at least one hospital discharge annually compared to 15% of beneficiaries without these conditions, with average hospital lengths of stay of 5.1 days versus 4.5 days respectively.[370] 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),[655] although the COVID-19 pandemic may have changed the most common reasons for hospitalization in 2020 and 2021. 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.[593] Among Medicare beneficiaries with Alzheimer's or other dementias, 22% of hospital stays are followed by a readmission within 30 days.[594] Although not directly comparable, one study of a portion of Medicare beneficiaries found an overall readmission rate of 18%.[656] 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).[657]
- Emergency department. Overall, 1.4% of all emergency department visits were for people with Alzheimer's or another dementia.[658] 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.[594] 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.[656] 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), exceeding the increases in emergency department visits for individuals with cancer, ischemic heart disease and heart failure (Figure 15, page 64).[594]
- 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.[659] There are 188 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's or other dementias per year compared with 40 stays per 1,000 beneficiaries without these conditions — a rate nearly five times as great.[370] Overall, 19% of Medicare beneficiaries with Alzheimer's or other dementias has at least one skilled nursing facility stay annually compared to 4% of Medicare beneficiaries without these conditions.

figure **15**

Percentage Changes in Emergency Department Visits per 1,000 Fee-for-Service Medicare Beneficiaries With 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 U.S. Centers for Medicare & Medicaid Services.[594]

- Home health care. Twenty-six 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 8% of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias.[370] Medicare covers home health services, such as part-time skilled nursing care; skilled therapy services; home health aide care, such as intermittent help with bathing, toileting and dressing if needed, with skilled nursing or therapy services; and medical social services in the home. Medicare does not cover homemaker services, such as meal preparation, or personal care services, such as help with bathing, toileting and dressing, if this is the only care that is needed. Home health agencies provide the majority of home care services.[660]

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 15, page 65).[A14,260]

Use and Costs of Health Care Services by State

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (see Table 16, page 66), similar to the geographic variation observed for Medicare beneficiaries with other medical conditions.[661] Emergency department visits, including visits that result in a hospital admission, range from 1,154 per 1,000 beneficiaries annually in Nebraska to 1,811 per 1,000 beneficiaries annually 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 $18,521 in North Dakota to $36,934 in Nevada (in 2021 dollars).[594]

table **15**

Average Annual Per-Person Payments by Type of Service for Health Care and Long-Term Care Services for Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2021 Dollars

Service	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	$7,074	$2,647
Outpatient events	2,679	3,784
Medical provider*	5,862	2,108
Skilled nursing facility	3,548	357
Nursing home	13,086	507
Hospice	2,232	131
Home health care	1,786	264
Prescription medications**	4,759	3,170
Dental care	485	699

*"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 residence.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[260]

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.[662] 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,[663-665] two years prior to diagnosis[666] and one year after diagnosis,[649,663-664] 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,[664] while in another study the differences in spending were primarily due to outpatient care, home care and medical day services.[665] In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment.[666] 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 ($8,012 in 2021 dollars)[649] based on individuals with fee-for-service Medicare coverage, to $17,852 in additional costs in 2014 dollars ($21,501 in 2021 dollars)[664] in the year after diagnosis, based on another group of individuals with Medicare fee-for-service coverage. One group of researchers, however, found no difference in health care spending in the two years after diagnosis.[666] 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 [$8,825 in 2021 dollars]).[664]

Another research team found that health care costs remained higher in the second through fourth years after a dementia diagnosis but were not significantly different in the fifth year after diagnosis.[649] Incremental costs decreased over time, from $4,241 in 2014 dollars ($4,678 in 2021 dollars) in year two to $1,302 ($1,436 in 2021 dollars) in year four. 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.[664] 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.[667] 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.

Impact of Alzheimer's and Other Dementias on the Use and Costs of Health Care in People with Coexisting Medical Conditions

Nearly 9 out of 10 Medicare beneficiaries with Alzheimer's disease or other dementias have at least one other chronic condition.[370] Additionally, they are more likely than those without dementia to have other chronic conditions.[370] Overall, 2.7 times more Medicare beneficiaries with Alzheimer's or other dementias have four or more chronic conditions (excluding Alzheimer's disease and other

table **16**

Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2021 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
Alabama	1,410.8	21.2	$24,396
Alaska	1,477.6	19.3	26,714
Arizona	1,436.2	20.2	26,499
Arkansas	1,530.4	21.5	23,982
California	1,496.3	23.0	35,752
Colorado	1,424.8	18.6	24,751
Connecticut	1,635.4	22.7	30,989
Delaware	1,577.6	21.5	29,193
District of Columbia	1,741.7	25.6	33,399
Florida	1,551.9	23.0	30,436
Georgia	1,573.2	22.5	26,475
Hawaii	1,248.2	16.0	21,630
Idaho	1,389.2	17.2	22,739
Illinois	1,624.1	23.4	30,672
Indiana	1,514.2	21.3	27,147
Iowa	1,310.7	18.0	20,069
Kansas	1,406.0	19.8	24,871
Kentucky	1,735.5	23.1	26,619
Louisiana	1,709.9	22.1	30,786
Maine	1,665.3	19.7	23,197
Maryland	1,524.1	24.4	32,017
Massachusetts	1,668.4	24.7	33,391
Michigan	1,691.4	24.0	29,519
Minnesota	1,467.1	21.6	24,831
Mississippi	1,714.8	22.1	28,655
Missouri	1,529.6	22.6	25,366
Montana	1,328.6	16.6	$20,215
Nebraska	1,153.6	18.7	22,821
Nevada	1,711.5	25.8	36,934
New Hampshire	1,493.8	20.4	26,996
New Jersey	1,456.3	22.9	33,285
New Mexico	1,563.7	20.6	24,316
New York	1,461.3	23.7	34,000
North Carolina	1,683.8	21.5	25,009
North Dakota	1,173.3	18.4	18,521
Ohio	1,618.7	22.5	28,297
Oklahoma	1,692.1	21.6	28,273
Oregon	1,628.4	18.7	23,054
Pennsylvania	1,470.5	22.0	28,381
Rhode Island	1,605.6	23.2	28,018
South Carolina	1,558.2	21.7	25,749
South Dakota	1,200.1	18.6	20,909
Tennessee	1,548.6	21.5	25,601
Texas	1,549.1	22.1	32,867
Utah	1,194.3	16.7	24,093
Vermont	1,528.4	19.6	24,091
Virginia	1,621.7	21.6	25,523
Washington	1,479.2	18.6	23,201
West Virginia	1,811.4	24.1	26,670
Wisconsin	1,519.9	19.9	23,572
Wyoming	1,445.9	17.4	23,404
U.S. Average	**1,544.8**	**22.3**	**29,092***

*The average per capita Medicare payment differs from the figure in Table 14 due to different underlying sources of data.

Created from data from the U.S. Centers for Medicare & Medicaid Services.[594]

table **17**

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	46
Chronic kidney disease	46
Diabetes	37
Congestive heart failure	34
Chronic obstructive pulmonary disease	20
Stroke	13
Cancer	10

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[370]

dementias) than Medicare beneficiaries without dementia.[370] Table 17 (see page 67) reports the percentage of people with Alzheimer's or other dementias who had certain coexisting medical conditions. In 2019, the latest year for which information is available, 46% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 46% had chronic kidney disease, 37% had diabetes, 34% had congestive heart failure and 20% had chronic obstructive pulmonary disease.[370]

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 18[A14] (see page 68) 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.[370] Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except physician payments for individuals with all of the chronic conditions, except coronary artery disease and diabetes. 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.[668] Additionally, larger proportions of individuals with dementia and behavioral disturbances used medications including antihypertensives, dementia treatments, antipsychotics, antidepressants, antiepileptics and hypnotics.

Use and Costs of Long-Term Care Services

An estimated 65% 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.[260] Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.[260] 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 residences 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.

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.[669]
- Adult day services. The third most common chronic condition in participants using adult day services is Alzheimer's disease or other dementias, and 28% of individuals using adult day services have Alzheimer's or other dementias.[670] Approximately 10% of adult day services centers in the United States specialize in caring for individuals with Alzheimer's disease or other dementias.[671] The percentage of participants with Alzheimer's or other dementias was higher in adult day services centers that provided either low- or moderate-level medical services than in centers that either provided no medical services or mainly provided health or medical services.[671]
- Residential care settings. Thirty-four percent of residents in residential care settings (that is, housing that includes services to assist with everyday activities, such as medication management and meals), including assisted living communities, have Alzheimer's or other dementias.[672] Sixty-one percent of residential care communities are small (four to 25 beds),[673] and these communities have a larger proportion of residents with Alzheimer's or other dementias than residential care settings with more beds (51% in settings with four to 25 beds compared with 44% in settings with 26 to 50 beds and 39% in settings with more than

table **18**

Average Annual Per-Person Payments by Type of Service and Coexisting Medical Condition for Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2021 Dollars

	Average Per-Person Medicare Payments					
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	**$27,190**	$7,896	$4,739	$3,978	$2,353	$3,655
Without A/D	**17,199**	5,710	4,643	1,234	902	405
Chronic kidney disease						
With A/D	**27,890**	8,211	4,715	4,152	2,377	3,710
Without A/D	**18,880**	6,271	4,840	1,483	1,041	452
Diabetes						
With A/D	**26,851**	7,911	4,758	4,029	2,264	3,138
Without A/D	**15,049**	4,865	4,158	1,119	796	279
Congestive heart failure						
With A/D	**30,074**	9,088	4,927	4,495	2,496	4,141
Without A/D	**24,316**	8,708	5,391	2,175	1,498	768
Chronic obstructive pulmonary disease						
With A/D	**30,598**	9,383	5,144	4,641	2,522	3,695
Without A/D	**21,800**	7,546	5,288	1,731	1,248	681
Stroke						
With A/D	**29,231**	8,542	4,989	4,427	2,486	3,610
Without A/D	**21,236**	6,821	5,144	2,129	1,489	627
Cancer						
With A/D	**27,127**	7,584	5,118	3,718	2,336	3,616
Without A/D	**17,537**	4,718	5,627	942	704	704

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[370]

50 beds).[674] Fifty-eight percent of residential care settings offer programs for residents with Alzheimer's or other dementias.[675] Average aide staff hours per resident day in residential care communities range from 2 hours and 11 minutes per day in settings with less than 25% of residents diagnosed with dementia to 2 hours and 44 minutes per day in settings with more than 75% of residents diagnosed with dementia.[673]

- Nursing home care. Overall, 48% of nursing home residents have Alzheimer's or other dementias,[669] 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.[676] Twenty-four percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with 1% of Medicare beneficiaries without these conditions.[260] 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.[372]
- Alzheimer's special care units and dementia-dedicated settings. An Alzheimer's special care unit is a dedicated unit, wing or floor in a nursing home or other residential care setting that has tailored services for individuals with Alzheimer's or other dementias. Fifteen percent of nursing homes and 14% of assisted living and other residential care communities have a dementia special care unit.[669] Less than 1% (0.4%) of nursing homes and 9% of residential care communities exclusively provide care to individuals with dementia.

Long-Term Care Services Provided at Home and in the Community

Overall, Medicaid represents 43% of long-term services and supports spending, followed by Medicare (21%) and out-of-pocket payments, including direct payments and deductibles and copayments for services covered by another payment source (15%). Private insurance covers only 9% of long-term services and supports.[677] 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 Medicaid, 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 care services and supports, with institutional care representing the remaining 43%.[678] Between 2008 and 2018, Medicaid spending on home and community-based services increased from 43% to 56% of total long-term services and supports expenditures.[679] Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias has increased dramatically between 2004 and 2018, although increases in spending may have been 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 for older adults.[680] In two 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.[681-682]

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%).[683] 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.[684] The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.[685]

Costs of Long-Term Care Services

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

- Home care. The median cost in 2020 for a non-medical home health aide was $24 per hour and $4,652 per month (in 2021 dollars).[686] Home care costs increased 3.7% annually on average between 2015 and 2020.
- Adult day centers. The median cost of adult day services was $75 per day in 2020 (in 2021 dollars).[686] The cost of adult day services increased 1.5% annually on average between 2015 and 2020.

- Assisted living residences. The median cost for care in an assisted living residence was $4,429 per month, or $53,148 per year in 2020 (in 2021 dollars).[686] The cost of assisted living increased 3.6% annually on average between 2015 and 2020.
- Nursing homes. The 2020 average cost for a private room in a nursing home was $299 per day, or $109,135 per year, and the average cost of a semi-private room was $263 per day, or $95,995 per year (in 2021 dollars).[686] The cost of nursing home care increased 3% annually on average between 2015 and 2020 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.[645]
- 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 ($88,316 in 2021 dollars) and 25% had savings of $9,650 or less in 2019 dollars ($10,164 in 2021 dollars). Median savings for White Medicare beneficiaries were 8.5 times higher than for Black beneficiaries and more than 15 times higher than for Hispanic beneficiaries.[687]

Long-Term Care Insurance

Long-term care insurance typically covers the cost of care provided in a nursing home, assisted living residence and Alzheimer's special care residence, 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.[695]

Based on data from the National Health Expenditure Account, it is estimated that private insurance represented only 9% ($38.5 billion) of long-term services and support spending in 2019.[677] While more recent data are not available, industry reports estimate that approximately 7.2 million Americans had long-term care insurance in 2014.[696] The median income for individuals purchasing long-term care insurance was $87,500 in 2010 dollars ($108,040 in 2021 dollars), with 77% having an annual income greater than $50,000 ($61,737 in 2021 dollars) and 82% having assets greater than $75,000 ($92,606 in 2021 dollars).[696] 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 ($28.7 billion of the $358 billion in 2021 dollars).[697] 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.[696]

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.[698] 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.

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-four percent of older individuals with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 10% of individuals without dementia.[260] 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 ($6,478) were 22 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($291) (see Table 14, page 62).[260] Much of the difference in payments for beneficiaries with Alzheimer's or other

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, it does not cover long-term care in a nursing home.[688]

The terms "nursing home," "skilled nursing home" and "long-term care hospital" are often confused, but as explained below, they are distinct from one another. 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.[452] 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.[659] 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.[689] 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.[690] 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.[691] 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.[692] 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).[693]

While Medicare is a federal program, Medicaid is a joint federal and state program, and benefits vary state-to-state.[694] 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 https://www.healthcare.gov/medicaid-chip/getting-medicaid-chip/.

table 19

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
Alabama	$925	$1,127	21.8
Alaska	76	110	44.6
Arizona	414	545	31.7
Arkansas	396	454	14.6
California	4,197	5,235	24.7
Colorado	635	789	24.1
Connecticut	1,022	1,187	16.1
Delaware	253	313	23.6
District of Columbia	126	135	6.8
Florida	2,689	3,453	28.4
Georgia	1,265	1,594	26.0
Hawaii	240	285	18.7
Idaho	149	196	31.2
Illinois	1,787	2,199	23.1
Indiana	1,054	1,233	17.1
Iowa	676	792	17.2
Kansas	473	543	14.6
Kentucky	803	949	18.2
Louisiana	765	934	22.1
Maine	212	274	29.5
Maryland	1,231	1,535	24.7
Massachusetts	1,753	2,031	15.9
Michigan	1,487	1,738	16.9
Minnesota	905	1,087	20.1
Mississippi	606	729	20.4
Missouri	973	1,137	16.8
Montana	$166	$203	22.2
Nebraska	372	411	10.3
Nevada	203	277	36.5
New Hampshire	254	335	31.9
New Jersey	2,186	2,614	19.6
New Mexico	227	279	22.9
New York	5,453	6,306	15.6
North Carolina	1,332	1,628	22.2
North Dakota	190	215	13.2
Ohio	2,534	2,940	16.0
Oklahoma	516	611	18.3
Oregon	253	317	25.4
Pennsylvania	3,658	4,029	10.2
Rhode Island	470	565	20.1
South Carolina	652	818	25.4
South Dakota	182	212	16.6
Tennessee	1,109	1,377	24.2
Texas	3,202	3,949	23.3
Utah	185	235	27.0
Vermont	116	146	26.4
Virginia	1,000	1,266	26.6
Washington	547	689	26.0
West Virginia	445	521	17.1
Wisconsin	777	924	18.9
Wyoming	86	111	28.8
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.[A12] dementias and other beneficiaries is due to the costs associated with long-term care (nursing homes and other residential care settings, such as assisted living residences) 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 $60 billion in 2022.[A12] Estimated state-by-state Medicaid spending for people with Alzheimer's or other dementias in 2020 (in 2020 dollars) is included in Table 19. Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias were 22 times as great as Medicaid payments for other Medicare beneficiaries.[260]

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 care residence 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.[699]

Twenty-one 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.[370] 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.[700] 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.[701] Additionally, 18% of Medicare beneficiaries who received hospice care had a primary diagnosis of dementia, including Alzheimer's dementia (Table 20, see page 74).[701] 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.[669] The average number of days of 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.[702] 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 individuals 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[702] 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.[703]

Per-person hospice payments among all individuals with Alzheimer's dementia averaged $2,232 compared with $131 for all other Medicare beneficiaries.[260] 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 last seven days of life. In fiscal year 2022, the routine home care rates are $203.40 per day for days 1 to 60 and $160.74 per day for days 61 and beyond.[704] 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.[705]

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.[706] Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life[707] and more likely to receive regular treatment for pain.[708] Nearly half of individuals with dementia die while receiving hospice care.[709] 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.[710]

table **20**

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

Created from data from the U.S. Centers for Medicare & Medicaid Services.[701]

Based on data from the National Hospice Survey for 2008 to 2011, nearly all (99%) hospices cared for individuals with dementia, and 67% of hospices had residents with a primary diagnosis of dementia.[702] 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 department visits in the last seven and 30 days of life, compared with those who did not receive palliative care.[711] Individuals 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.[711] Despite the introduction of advance care planning (i.e., a plan for future medical care that includes the patient's goals and preferences, if the patient is unable to make his or her own decisions), an essential component of palliative care, as a billable service in 2016, its use remains low, with only 2.9% of fee-for-service Medicare beneficiaries having at least one advanced care planning claim in 2017.[712] However, compared to individuals without any newly diagnosed conditions, Medicare beneficiaries with newly diagnosed Alzheimer's were 1.3 times as likely to have one or more claims for advance care planning.

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.[713] 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.[714-715] 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.[700] 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.[715]

Place of Death for Individuals with Alzheimer's or Other Dementias

Between 2000 and 2020, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 67% to 47%, and the proportion who died in a medical facility decreased from 14% to 4%.[716] During the same period, the proportion of individuals who died at home increased from 15% to 32% (Figure 16, see page 76).[716]

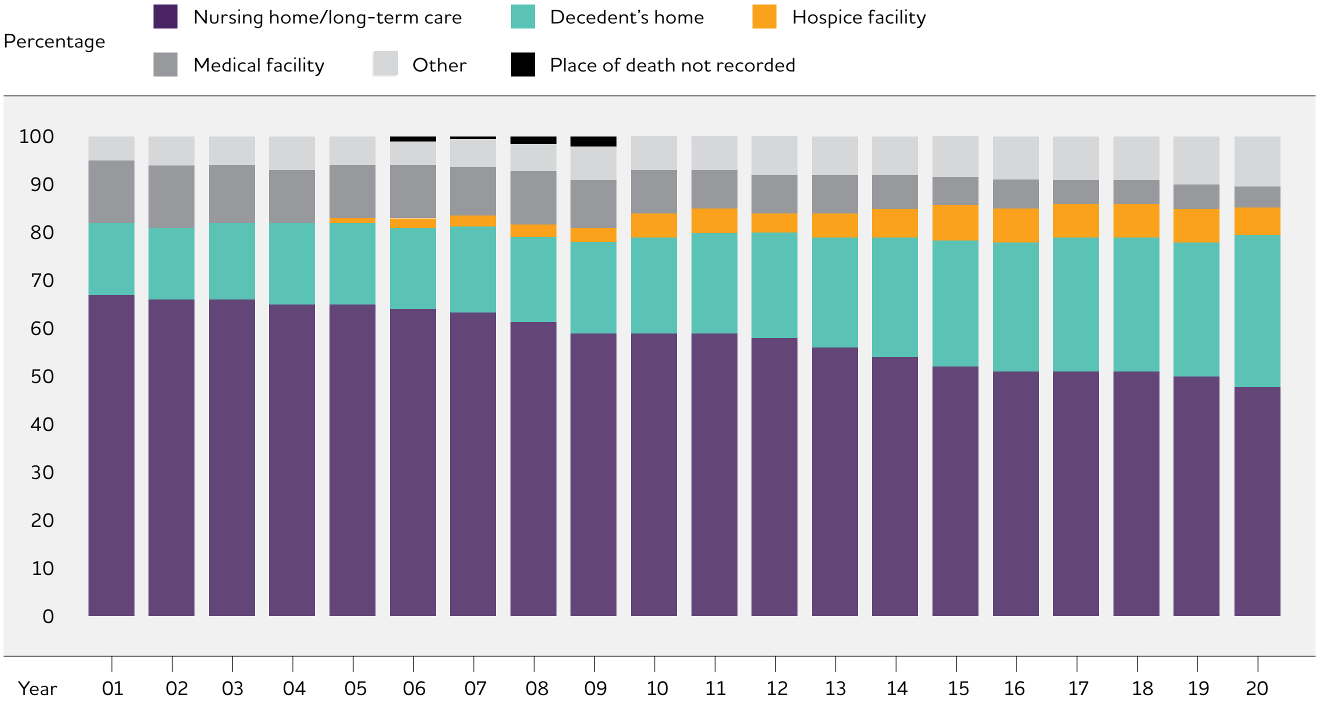
Use and Costs of Health Care and Long-Term Care Services by Race/Ethnicity

Among Medicare beneficiaries with Alzheimer's or other dementias, Black beneficiaries had the highest unadjusted Medicare payments per person per year, while White beneficiaries had the lowest payments ($26,611 versus $21,341, respectively) (Table 21, page 77). The largest difference in payments was for hospital care, with Black Medicare beneficiaries incurring 1.6 times as much in hospital care costs as White beneficiaries ($8,404 versus $5,404).[370] White beneficiaries had the highest hospice payments, however, of all racial and ethnic groups. A study of racial and ethnic differences in health care spending using the Medical Expenditure Panel Survey found similar patterns in unadjusted total spending.[717] However, after adjusting for socioeconomic characteristics and functional status, total health care spending did not significantly differ among groups.

In a study of Medicare-Medicaid dually eligible beneficiaries diagnosed with Alzheimer's dementia, researchers found significant differences in the costs of care by race/ethnicity.[718] 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.

figure **16**

Place of Death Due to Alzheimer's Disease, 2001 to 2020



Created from data from the National Center for Health Statistics.[716]

Avoidable Use of Health Care and Long-Term Care Services

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 these potentially preventable hospitalizations was $4.7 billion (in 2013 dollars; $5.8 billion in 2021 dollars).[719] 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, 23.5% of diagnosed individuals with Alzheimer's or other dementias had at least one preventable hospitalization.[720] 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 (e.g., chronic medical conditions, number of hospitalizations in the prior year) 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.[721] 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.[722]

table **21**

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 2021 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Care	Home Health Care	Hospice Care
White	$21,341	$5,404	$3,666	3,007	$1,839	$3,979
Black	26,611	8,404	4,457	3,957	1,895	2,799
Hispanic	24,617	7,312	4,230	3,432	2,281	3,286
Other	21,876	6,775	3,855	3,341	1,884	2,710

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[370]

The COVID-19 Pandemic and Health Care Utilization and Costs

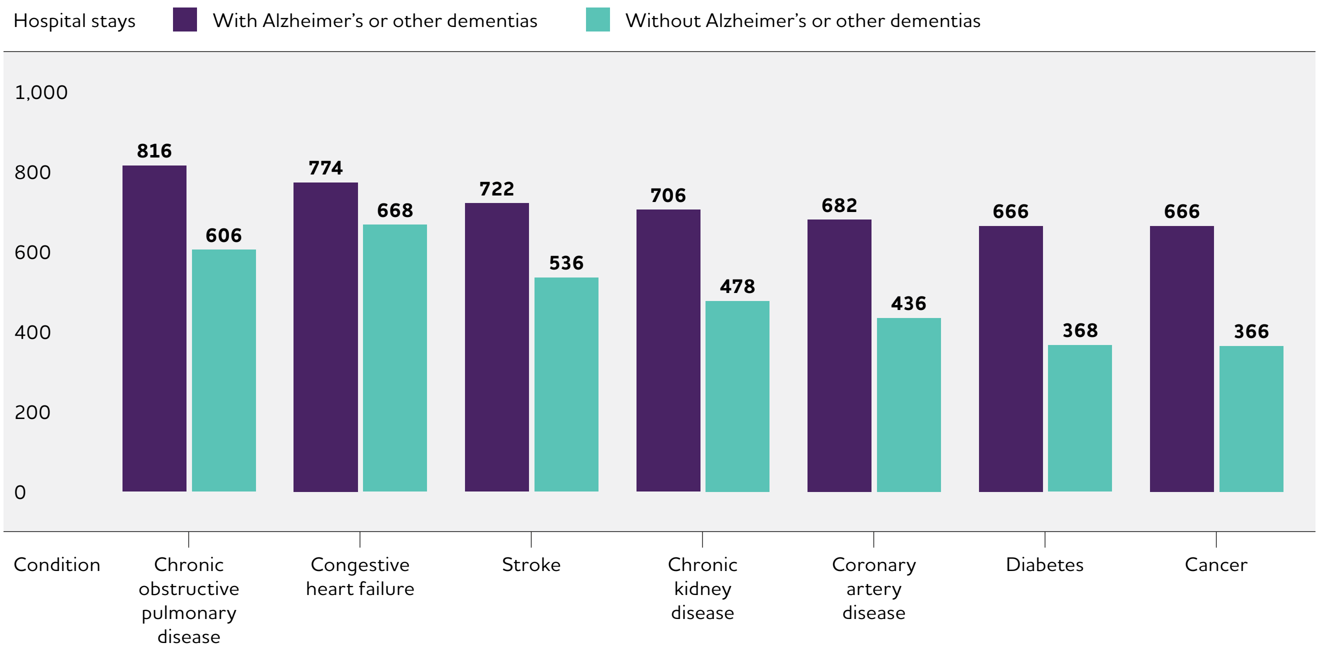
The COVID-19 pandemic has disproportionately affected Americans living with Alzheimer's and other dementias. As data continue to emerge on the toll of the pandemic, it is increasingly clear that these individuals are more susceptible both to contracting COVID-19 and severe illness due to COVID-19. Care communities are home to nearly 50% of nursing home residents who have Alzheimer's or other dementias.[669] Individuals living in care communities have been extremely vulnerable to COVID-19 due to the communal nature of these settings. More than 141,000 residents of long-term care communities had died of COVID-19 as of December 2021.[728]

Recent data and research have demonstrated that individuals living with Alzheimer's throughout the pandemic have been more likely to contract COVID-19, develop severe illness due to COVID-19 and die from COVID-19 than individuals without Alzheimer's. Through August 2021, of all people with Medicare fee-for-service (FFS) coverage who were hospitalized due to COVID-19, 32% had a diagnosis of dementia.[729] Even after adjusting for demographic characteristics and other COVID-19 risk factors (including living in long-term care or other care communities), individuals with Alzheimer's are at higher risk for contracting and dying from COVID-19.[730-731] One study using data from electronic health records and adjusting for COVID-19 risk factors found that individuals with Alzheimer's had twice the odds of being diagnosed with COVID-19 as individuals without Alzheimer's. The risk was even higher for Black adults with dementia, who had nearly three times the odds of COVID-19 compared with White adults.[731] Another study using Medicare claims data similarly found that beneficiaries with a diagnosis of dementia were 50% more likely to be diagnosed with COVID-19 and 60% more likely to die of COVID-19 than were beneficiaries without dementia, after adjusting for COVID-19 risk factors.[730]

Evidence is still emerging on how health care utilization changed during the pandemic for individuals with Alzheimer's and other dementias. For example, one area of interest is the effect of not receiving some types of health care because of service and other limitations related to COVID-19. However, we do know that individuals diagnosed with dementia had the highest rates of hospitalization for COVID-19 among all 21 chronic conditions analyzed (including chronic kidney disease, diabetes, hypertension, and obesity) in 2020.[732] This risk was not limited to congregant settings such as assisted living residences and nursing homes. Individuals with a diagnosis of Alzheimer's who were living in the community were more than 3.5 times as likely to be hospitalized for COVID-19 as individuals without Alzheimer's who were living in the community.

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, 2019



Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[370]

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).[370] 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.[723] 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.[724] 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.[725]

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.[726] For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

Health Care Delivery, Payment Models and Health Care Utilization

Changes in health care delivery and payment models may impact health care utilization for individuals with Alzheimer's disease or other dementias, such as the integration of care across different health care settings and the structure of health care payments. Research has shown modest differences in outcomes for skilled nursing facilities that share providers with at least one hospital versus those that have dedicated providers within the skilled nursing facilities. An analysis of Medicare claims data for 2008 to 2016 showed that individuals in skilled nursing facilities that shared providers with at least one hospital were more likely to have an Alzheimer unit, had fewer 30-day readmissions and had more patients successfully discharged to the community. The skilled nursing facilities that maintain these relationships have modestly better outcomes,[727] although there has been a decline in hospital-skilled nursing facility linkages in the past two decades due to a shift toward dedicated hospitalists and skilled nursing facility providers.

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 $321 billion in 2022 to just under $1 trillion in 2050 (in 2022 dollars). This dramatic rise includes three-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.[A12] Concurrent with this large projected increase, the Medicare Hospital Insurance Trust Fund, which covers spending for Medicare Part A (hospital care), is projected to go into a deficit, suggesting that broad changes to Medicare may be needed.[733]

Potential Impact of Changing the Trajectory of Alzheimer's Disease

While there are currently no FDA-approved treatments that prevent or cure Alzheimer's disease, a recently FDA accelerated approved anti-amyloid therapy reduces one of the defining brain changes of the disease — amyloid plaques. This reduction in amyloid plaques is reasonably likely to result in clinical benefit. This anti-amyloid treatment was tested in people living with MCI due to Alzheimer's disease and mild Alzheimer's dementia with confirmed amyloid in the brain. There are several other anti-amyloid drugs in late stage development.

Several groups of researchers have estimated the health and long-term care cost implications of hypothetical future interventions that either slow the onset of dementia or reduce the symptoms.[387,734-736] One analysis assumed a treatment that delayed onset of Alzheimer's by five years would be introduced in 2025. It estimated that such a treatment would reduce total health and long-term care spending for people with Alzheimer's by 33%, including a 44% reduction in out-of-pocket payments, in 2050.[734] A second study estimated how much would be saved with treatments that delayed the onset of Alzheimer's disease by one to five years.[735] For individuals age 70 and older, the study projected that in 2050, there would be a 14% reduction in total health care spending for people with Alzheimer's from a one-year delay, a 27% reduction from a three-year delay and a 39% reduction from a five-year delay.[735] Beyond the single-year costs, the study also found that a delay in onset may increase total lifetime per capita health care spending due to longer life associated with delaying the onset of dementia, although the additional health care costs may be offset by lower informal care costs. Finally, a third study estimated that a treatment slowing the rate of functional decline among people with dementia by 10% would reduce total average per-person lifetime costs by $3,880 in 2015 dollars ($4,553 in 2021 dollars), while a treatment that reduces the number of behavioral and psychological symptoms by 10% would reduce total average per-person lifetime costs by $680 ($798 in 2021 dollars).[387]

A therapy that changes the course of the disease may not be the only way to reduce health and long-term care costs. The Alzheimer's Association commissioned a study of the potential cost savings of early diagnosis,[736] 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 the result of (1) a smaller spike in costs immediately before and after diagnosis during the MCI phase compared with the higher-cost dementia phase, 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.

The potential savings from a treatment or an earlier diagnosis may depend on structural changes to the health care system. Capacity constraints — such as a limited number of qualified providers and facilities — could severely restrict access to new treatments.[627,737] For example, modeling by the RAND Corporation in 2017 showed that with an anti-amyloid therapy for people in the MCI and early dementia stages of the disease, 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 that the hypothetical treatment would require infusions at infusion centers and PET scans to confirm the presence of amyloid in the brain to support initiation of treatment with an anti-amyloid medication.

SPECIAL REPORT

MORE THAN NORMAL AGING: UNDERSTANDING MILD COGNITIVE IMPAIRMENT

Fewer than 1 in 5 Americans (18%) are familiar with mild cognitive impairment (MCI).

Subtle cognitive changes, such as those in memory and thinking, are often a feature of aging.

What does one do if these changes are not a result of normal aging, but caused by disease — offering a potential indicator of future cognitive decline and premature death? As the size of the United States' older population grows dramatically over the next 30 years, more individuals and their physicians will confront this question.

Confronting MCI and Why It Matters

Mild cognitive impairment (MCI) causes cognitive changes that are serious enough to be noticed by the person affected and by family members and friends, but may not affect the individual's ability to carry out everyday activities. Approximately 12% to 18% of people age 60 or older are living with MCI.[738] The population of Americans age 60 and older has grown more than 30% over the past decade,[739] and the number of older individuals in the United States is expected to increase significantly by 2050 (see Prevalence section, page 19).[218,220-221] These aging individuals are potentially at higher risk of developing MCI.[48]

> *"Mild cognitive impairment (MCI) is an early stage of memory loss or other cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living."*[738]

MCI is characterized by subtle changes in memory and thinking. MCI is sometimes confused with normal aging, but it is not part of the typical aging process. A variety of factors can cause MCI, so it is viewed as a broad set of symptoms; this can make the diagnosis of MCI challenging for affected individuals and physicians. When a person exhibits symptoms of MCI and has biomarker evidence of the brain changes characteristic of Alzheimer's disease, they are described as having MCI due to Alzheimer's disease — a subtype of MCI.[738]

For the purposes of this Special Report, the term *MCI* refers to "syndromic" MCI of unknown cause or due to causes other than the brain changes associated with Alzheimer's disease. The term *MCI due to Alzheimer's disease* is used to describe MCI with the presence of Alzheimer's disease-related biomarkers.

Individuals with MCI may have a higher risk of developing dementia. Studies estimate that 10% to 15% of individuals with MCI go on to develop dementia each year.[48,740-741] About one-third of people with MCI develop dementia due to Alzheimer's disease within five years.[49] However, some individuals with MCI revert to normal cognition or do not have additional cognitive decline.[738,740]

Identifying which individuals with MCI are more likely to develop dementia is a major goal of current research. Distinguishing between cognitive issues resulting from normal aging, those associated with the broad syndrome of MCI, and those related to MCI due to Alzheimer's disease is critical in helping individuals, their families and physicians prepare for future treatment and care.

MCI Diagnosis and Treatment

MCI is classified as one of two types based on a person's symptoms: *amnestic* (memory issues predominate) or *nonamnestic* (other cognitive issues, such as impaired language, visuospatial abilities, or executive function, predominate).[48,738] For example, a person with amnestic MCI could forget conversations or misplace items in their

table 22

Prevalence of Mild Cognitive Impairment in Older Adults by Age

Age	Prevalence
60-64	6.7%
65-69	8.4%
70-74	10.1%
75-79	14.8%
80-84	25.2%

Created from data from Petersen et al.[48]

home, whereas a person with nonamnestic MCI could have difficulty keeping their train of thought during a conversation, finding their way around a once familiar place, or finishing everyday tasks, such as paying a bill.[742]

The number of people living with MCI increases with age (Table 22).[48] One in four individuals age 80 to 84 experience symptoms of MCI (Table 22).[48]

MCI can be caused by a variety of factors, such as medication side effects, sleep deprivation or anxiety.[740] MCI may also develop as part of neurologic, neurodegenerative, systemic or psychiatric disorders, as well as stroke or other vascular disease and traumatic brain injury.[48,742] MCI can also arise from the brain changes that occur in Alzheimer's disease.

To diagnose MCI, physicians conduct a review of the patient's medical history and use patient questionnaires, clinical exams and brief assessments to evaluate thinking and memory function. Cognitive assessment tools evaluate cognitive impairment by testing memory (the ability to learn and recall new information) and measuring changes in reasoning, problem-solving, planning, naming, comprehension and other cognitive skills.[38]

Sometimes, diagnosis of MCI requires ruling out other systemic or brain diseases, such as Alzheimer's disease, Parkinson's disease, dementia with Lewy bodies (associated with rapid eye movement sleep abnormalities), cerebrovascular disease in the blood vessels that support the brain, or prion disease or cancer (characterized by more rapid cognitive decline).[38]

Although patient-reported symptoms and the results from screening tools and clinical exams provide clues about whether a person has MCI, there is no test that can give a definitive diagnosis.[738,740]

Strongest risk factors for MCI[740]

- Increasing age.
- Having a specific form of the Apolipoprotein E gene (APOE-e4) that has been linked to Alzheimer's disease.
- Some medical conditions and other factors, such as:
  - Diabetes
  - Smoking
  - High blood pressure
  - High cholesterol
  - Obesity
  - Depression
  - Sedentary lifestyle
  - Infrequent participation in mentally or socially stimulating activities

Currently there is no specific treatment for MCI.[48,743] In some cases, physicians may be able to identify reversible causes of cognitive impairment, such as depression, medication side effects or sleep apnea. They may also recommend exercise and healthy lifestyle interventions to help improve cognitive function and quality of life.[48]

Once someone is diagnosed with MCI, the outcome can vary depending on the underlying cause and other factors. For some individuals, MCI may be a transitional state between normal cognitive aging and dementia.[738,744] In some cases, however, MCI will revert to normal cognition or remain stable. For example, MCI that is linked to use of a medication may resolve when the medication is changed or discontinued. According to new research, nearly half of people diagnosed with MCI did not progress to dementia and were cognitively normal when they were evaluated 2.4 years after their MCI diagnosis.[745]

MCI Due to Alzheimer's Disease: A Distinct Condition

Although the symptoms of MCI due to Alzheimer's disease are no different than syndromic MCI, MCI due to Alzheimer's disease has a very specific underlying cause. MCI due to Alzheimer's disease is caused by distinct biological changes that lead to the damage and death of nerve cells in the brain.[38,738] MCI due to Alzheimer's disease is the symptomatic precursor to Alzheimer's dementia (see Alzheimer's Disease Continuum and Figure 1, page 9).

In fact, today, physicians can use biomarkers of Alzheimer's disease to diagnose MCI due to Alzheimer's disease. Biomarker tests measure beta-amyloid (Aβ) deposits, pathologic tau and other hallmarks of Alzheimer's disease-related neurodegeneration; these biomarkers can be detected in brain images or measured in cerebrospinal fluid (CSF).[746] Some biomarker tests, such as positron emission tomography (PET) imaging to look for beta-amyloid deposits or pathologic tau in the brain and measurement of a type of beta-amyloid called $A\beta_{42}$ in CSF are readily available to physicians, whereas others are currently limited to clinical research.[746-747]

Unfortunately, not all physicians and patients have access to biomarker testing methods, and not all patients are referred for a more thorough evaluation after MCI is diagnosed based on the symptoms. New blood tests are under development that provide simple, accurate, non-invasive detection of Alzheimer's disease biomarkers — sometimes even before symptoms appear. For now, these blood-based biomarker tests are for research use only and not available in everyday medical practice, but they hold promise for identifying patients at risk of MCI due to Alzheimer's disease earlier in the disease process.[747]

Estimates suggest that roughly 5 million Americans have MCI due to Alzheimer's disease (see Prevalence section, pages 20-21). Because MCI develops years before dementia and potentially affects individuals younger than 65, there are likely far more than 5 million Americans — of any age — with MCI due to Alzheimer's disease (see Prevalence section, pages 20 and 21). Blood-based biomarkers are expected to make it easier to identify individuals with MCI due to Alzheimer's disease as part of routine clinical practice. Until then, the true number of individuals living with MCI due to Alzheimer's disease remains unknown.

Progression to Alzheimer's Dementia Is Not Certain

Evidence suggests that over a 5- to 10-year period after a diagnosis of MCI due to Alzheimer's disease, 30% to 50% of people progress to Alzheimer's dementia.[49,586] Up to 3 in 20 (15%) people who have amnestic MCI are estimated to progress to Alzheimer's dementia in that period, and research indicates that progression to dementia may be more likely for people with this subtype of MCI due to Alzheimer's disease.[586,744]

> *Not everyone who has MCI due to Alzheimer's disease will go on to develop Alzheimer's dementia.*

MCI Due to Alzheimer's Disease Represents a Critical Turning Point in the Alzheimer's Disease Continuum

A key consideration for managing Alzheimer's disease is determining when to intervene. Researchers have long posited that pharmacologic treatments, or medications, aimed at slowing or stopping the progression of Alzheimer's disease to dementia and preserving brain function are most effective when administered early in the disease process.

Accurate diagnosis of MCI due to Alzheimer's disease, prior to the development of dementia, is thus crucial in identifying individuals who might benefit from early treatment. Initiation of treatment earlier in the disease process may also be associated with lower overall health care costs, as progression to dementia and the need for costly assisted living, nursing home and other types of residential care is postponed (see Use and Costs of Health Care, Long-Term Care and Hospice section, page 60).

Intervening earlier also offers significant benefits for diagnosed individuals, potentially allowing them more time to live independently while enjoying a higher quality of life.

The last 20 years has marked an acceleration in the development of a new class of treatments that target the underlying biology and aim to slow the progression of Alzheimer's disease. As of the writing of this report, 104 disease-modifying treatments are being evaluated in clinical trials or are at various stages of regulatory approval, including monoclonal antibodies, such as aducanumab, donanemab, lecanemab, gantenerumab and others.[748-749] The recent accelerated approval of aducanumab by the U.S. Food and Drug Administration is generating momentum and spurring progress for the development and approval of potential therapies aimed at slowing the progression of MCI due to Alzheimer's disease and mild Alzheimer's dementia.

Understanding MCI and MCI Due to Alzheimer's Disease Today: Adult and Primary Care Physician Surveys

To better understand real-world awareness, diagnosis and treatment of MCI and MCI due to Alzheimer's disease in the United States, the Alzheimer's Association commissioned Versta Research to conduct surveys of U.S. adults and primary care physicians (PCPs). Surveys across both groups explored wide-ranging issues related to MCI and MCI due to Alzheimer's disease, including concern and awareness of MCI, attitudes about diagnosis, challenges in diagnosis, clinical management and treatment of MCI, including MCI due to Alzheimer's disease, and views on future disease-related treatments. Attitudinal differences among racial and ethnic groups were also investigated.

Key Findings

The Alzheimer's Association surveys revealed:

Americans' awareness of MCI is low.

- Fewer than 1 in 5 Americans (18%) are familiar with MCI. Familiarity with MCI is low across all racial and ethnic groups surveyed: White Americans (18%), Asian Americans (18%), Native Americans (18%), Black Americans (18%) and Hispanic Americans (17%).
- More than 2 in 5 Americans (43%) report they have never heard of MCI.
- When prompted with a description of MCI more than half of all Americans (55%) say MCI sounds like "normal aging."

When MCI and MCI due to Alzheimer's disease are described, Americans express concern, but also reluctance to see their doctor.

- Nearly one-half of Americans (47%) say they worry about developing MCI in the future. More than 4 in 10 Americans (42%) say they worry about developing MCI due to Alzheimer's disease.
- A large majority of Americans (85%) say they would want to know if they had Alzheimer's disease early, including during the MCI stage (54%) and mild Alzheimer's disease stage (31%). Reasons cited most often for wanting to know early include planning for the future (70%), allowing for earlier treatment of symptoms (70%), taking steps to preserve existing cognitive function (67%) and to understand what is happening (66%).
- Yet only 4 in 10 Americans (40%) say they would talk to their doctor right away when experiencing symptoms of MCI. More than half of Americans (57%) say they would wait until they had symptoms for a while (33%), wait until symptoms worsened (12%) or wait until others expressed concern (12%).
- Overall, almost 8 in 10 Americans (78%) express concerns about seeing a doctor in the wake of MCI symptoms. Concerns cited most often include receiving an incorrect diagnosis (28%), learning of a serious health problem (27%), receiving unnecessary treatment (26%) and believing symptoms might go away (23%).

PCPs believe it is important to diagnose MCI, including MCI due to Alzheimer's disease, but challenges in diagnosis persist.

- An overwhelming majority of PCPs surveyed say it is important to diagnose MCI (98%) and MCI due to Alzheimer's disease (90%). One-third of PCPs (35%), however, are not fully comfortable diagnosing MCI and more than one-half of PCPs (51%) say they are not fully comfortable diagnosing MCI due to Alzheimer's disease.
- Nearly all PCPs (96%) say it is important to assess patients age 60 and older for cognitive impairment, but report that they conduct assessments for just half (48%) of their patients age 60 and older.
- When making an MCI diagnosis, the most frequently cited challenges by PCPs include difficulty in differentiating MCI from normal aging (72%) and difficulty in interpreting patient reports of daily functioning (51%).
- When diagnosing MCI due to Alzheimer's disease, top challenges cited by PCPs include lack of specialists/facilities to perform diagnostic testing (51%), patient reluctance to pursue follow-up testing (49%) and PCP reluctance to diagnose a condition that has limited treatment options (47%).
- Nine in 10 PCPs (90%) say it is hard to know where MCI ends and dementia begins.

PCPs say early intervention can slow progression of cognitive decline, but many are unfamiliar with clinical trials and research advances that may help diagnose and manage MCI and MCI due to Alzheimer's disease now and in the future.

- The vast majority of PCPs (86%) say that early intervention can slow progression of cognitive decline. When MCI is detected in patients, PCPs most often recommend lifestyle changes (73%), perform laboratory testing for reversible causes of MCI (70%) and/or refer patients to a specialist (53%).
- Only 4 in 10 PCPs (40%) say they are familiar (7% very familiar and 33% somewhat familiar) with current biomarker tests to aid in the diagnosis of Alzheimer's disease, and they refer fewer than 1 in 5 patients (18%) for biomarker testing for Alzheimer's disease when MCI is detected.
- One in 5 PCPs (20%) report being familiar with clinical trials available to their patients with MCI.
- Only 1 in 4 PCPs (23%) say they are familiar with new therapies in the pipeline to address MCI due to Alzheimer's disease.

Consumers and PCPs express optimism for future Alzheimer's disease treatments.

- More than 7 in 10 Americans (73%) expect new treatments to delay the progression of Alzheimer's disease to be available within the next decade. Six in 10 Americans (60%) anticipate new treatments to stop the progression of Alzheimer's disease. More than one-half of all Americans (53%) believe there will be new treatments to prevent Alzheimer's disease.
- PCPs also expressed optimism for future Alzheimer's disease treatments. More than 4 in 5 PCPs (82%) expect there will be new treatments to delay the progression of Alzheimer's disease during the next decade. More than half of PCPs (54%) anticipate there will soon be treatments to stop Alzheimer's disease progression. Less than half (42%) anticipate new treatments to prevent Alzheimer's disease.

Survey Results

Public Awareness of MCI

The Alzheimer's Association survey of U.S. adults found that fewer than 1 in 5 Americans (18%) are familiar with MCI (Figure 18 Left, page 86). Awareness and understanding of MCI is low across all racial and ethnic groups surveyed: White Americans (18%), Asian Americans (18%), Native Americans (18%), Black Americans (18%) and Hispanic Americans (17%). More than 2 in 5 Americans (43%) report they have never heard of MCI (Figure 18 Left, page 86). Americans aged 60 and older indicated no greater awareness of MCI despite being the most likely age group to develop the disease.

When prompted with a description of MCI, more than half of Americans (55%) say it sounds like normal aging (Figure 18 Right, page 86). Black and Asian Americans (58%) were most likely to associate symptoms of MCI with normal aging, followed by Hispanic (55%), White (53%) and Native Americans (47%).

The PCP survey echoes these findings, with only 1 in 8 PCPs (13%) saying they believe that patients with whom they have discussed MCI have a strong understanding of the disease, and 8 in 10 PCPs (81%) reporting that their patients believe MCI is a part of normal aging.

Patient Concern for MCI and MCI Due to Alzheimer's Disease

Even though awareness and understanding of MCI and MCI due to Alzheimer's disease among Americans is low, they express concern when prompted with a description of both conditions.

Nearly one-half of Americans (47%) say they worry about developing MCI in the future, with 13% indicating they worry "a lot." Asian (54%) and Hispanic (52%) Americans are more likely to worry about developing MCI compared with Native (47%), White (45%) and Black Americans (44%).

Survey Design and Research Methods

Survey of U.S. Adults

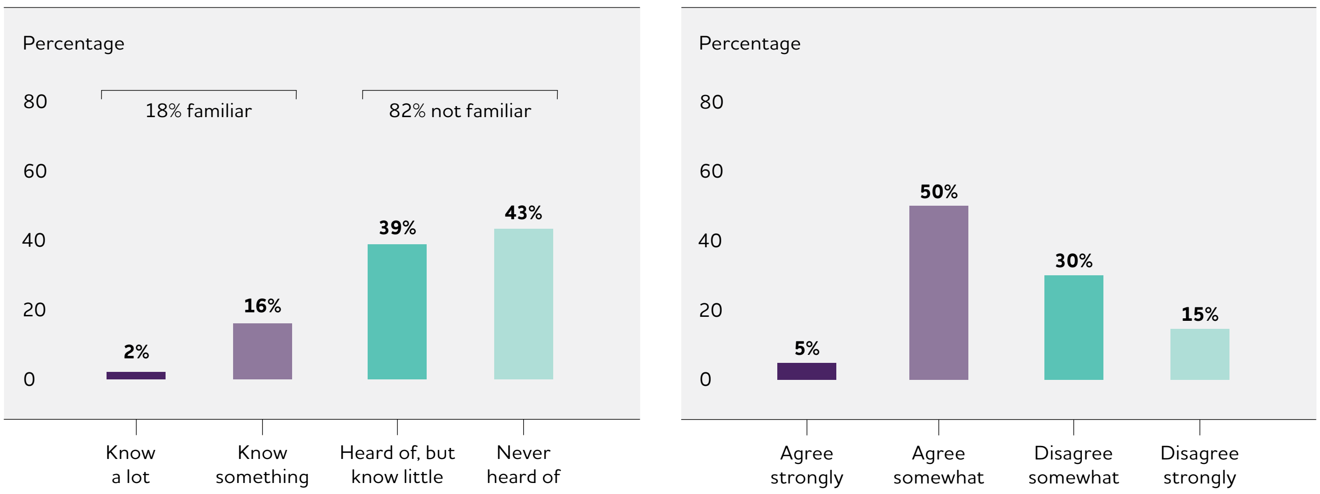
A survey of 2,434 U.S. adults age 18 and older was conducted from November 5, 2021, to December 5, 2021. Respondents included 662 who were age 60 or older, and 1,772 who were age 18 to 59. The survey included a probability sample of 2,099 Americans fielded by NORC at the University of Chicago via the AmeriSpeak® panel. It was offered online or as a phone survey in English or Spanish. Hispanic (n=328), Black (n=342), and Asian Americans (n=318) were oversampled and weighted back to their true population proportions for analysis and reporting. The probability sample of all Americans was additionally supplemented with an oversample of Native Americans (n=335) using non-probability online research methods. The Native American oversample was stratified and weighted by gender, age, income and education to match U.S. Census Bureau data.

Survey of U.S. Primary Care Physicians (PCPs)

A survey of 801 primary care physicians (M.D. or D.O.) was conducted from November 1, 2021, to November 22, 2021. Physicians were recruited via WebMD's Medscape physician network, which includes 70% of all practicing primary care physicians in the United States. Sampling was stratified and weighted by type of practice, specialty, years in practice and region using benchmarks from the American Medical Association Masterfile of all practicing physicians in the U.S. To be included in the survey, physicians had to have been in practice for at least two years and spend at least 50% of their time in direct patient care, with at least 10% of their patients being age 60 or older. Physicians included in the survey reported spending an average (mean) of 93% of their time in direct patient care, and reported that 45% of their patients were age 60 years or older. Years in practice ranged from 2 years to 54 years, with a mean of 20 years. Primary medical specialties represented were internal medicine (49%), family medicine (48%) and general practitioner (3%).

figure **18**

Familiarity and Perceptions of MCI Among U.S. Adults

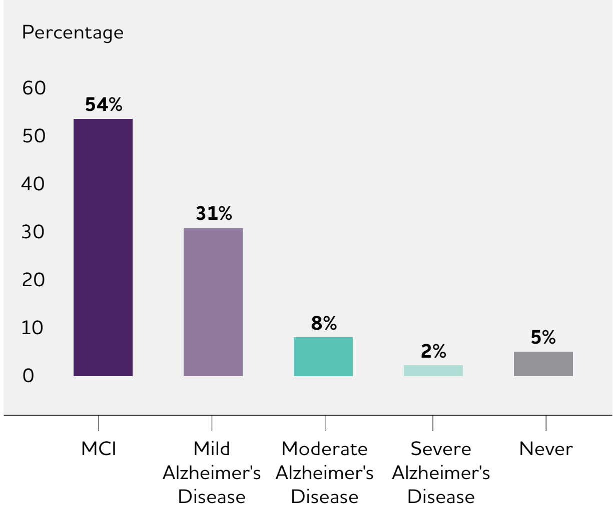


Familiarity of MCI Among U.S. Adults

Percentage of U.S. Adults Who Say MCI Sounds Likes Normal Aging

figure **19**

Stage at Which U.S. Adults Would Want to Know If They Have Alzheimer's Disease



Overall, 42% of Americans say they worry about developing MCI due to Alzheimer's disease, with 14% of individuals indicating they worry "a lot." Asian (50%), Hispanic (49%), and Black (47%) Americans are most likely to worry about developing MCI due to Alzheimer's disease, followed by Native (41%) and White Americans (39%).

Despite these concerns, a majority of Americans (85%) say they would want to know if they had Alzheimer's disease early, including during the MCI stage (54%) and mild Alzheimer's disease stage (31%) (Figure 19).

Reasons Americans cited most often for wanting to know early if they have Alzheimer's disease include planning for the future (70%), allowing for earlier treatment of symptoms (70%), taking steps to preserve existing cognitive function (67%) and being able to understand what is happening (66%) (Figure 20).

Overall, 43% of Americans cited clinical trial participation as a reason for early diagnosis of Alzheimer's disease (Figure 20). White Americans (50%) were twice as likely as Hispanic Americans (25%) to cite clinical trial participation as a reason for early diagnosis, followed by Asian (40%), Native (35%) and Black Americans (32%).

Hispanic (79%) and Black (80%) Americans are least likely to want to know if they had Alzheimer's during an earlier stage (MCI or mild Alzheimer's dementia), especially when compared with White Americans (88%). Among Asian and Native Americans, 84% say they would want to know if they had the disease during an earlier stage.

Only 15% of Americans say they would want to know if they had Alzheimer's disease during later stages of the disease (moderate/severe stage) or not at all (Figure 19). The most cited reasons for not wanting to know include: a diagnosis would be difficult to accept (34%), treatment options are limited (31%), there is no cure so it doesn't matter (28%) and people might treat me differently (26%) (Figure 21). Difficulty in accepting an Alzheimer's disease diagnosis was the most often cited reason across all racial and ethnic groups.

figure **20**

Reasons for Seeking an Early-Stage Alzheimer's Diagnosis Among U.S. Adults

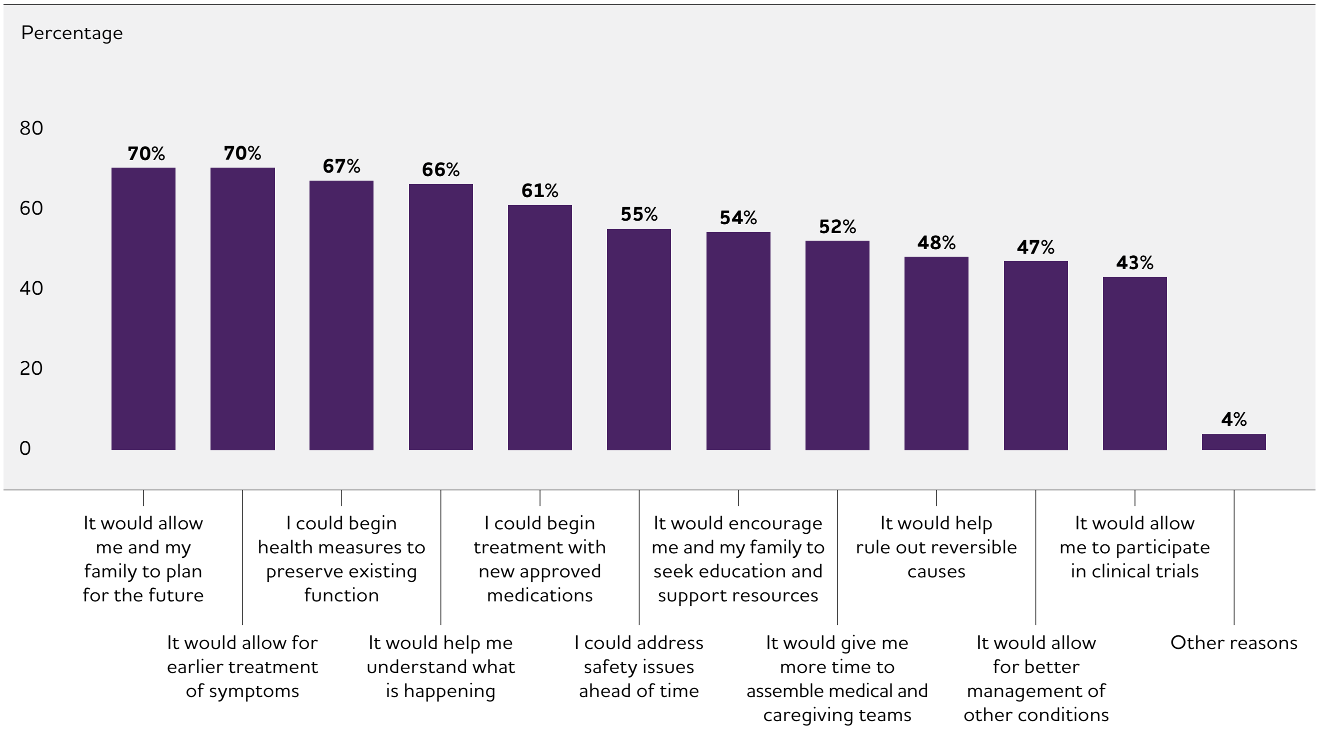


figure **21**

Reasons for Not Seeking an Early-Stage Alzheimer's Diagnosis Among U.S. Adults

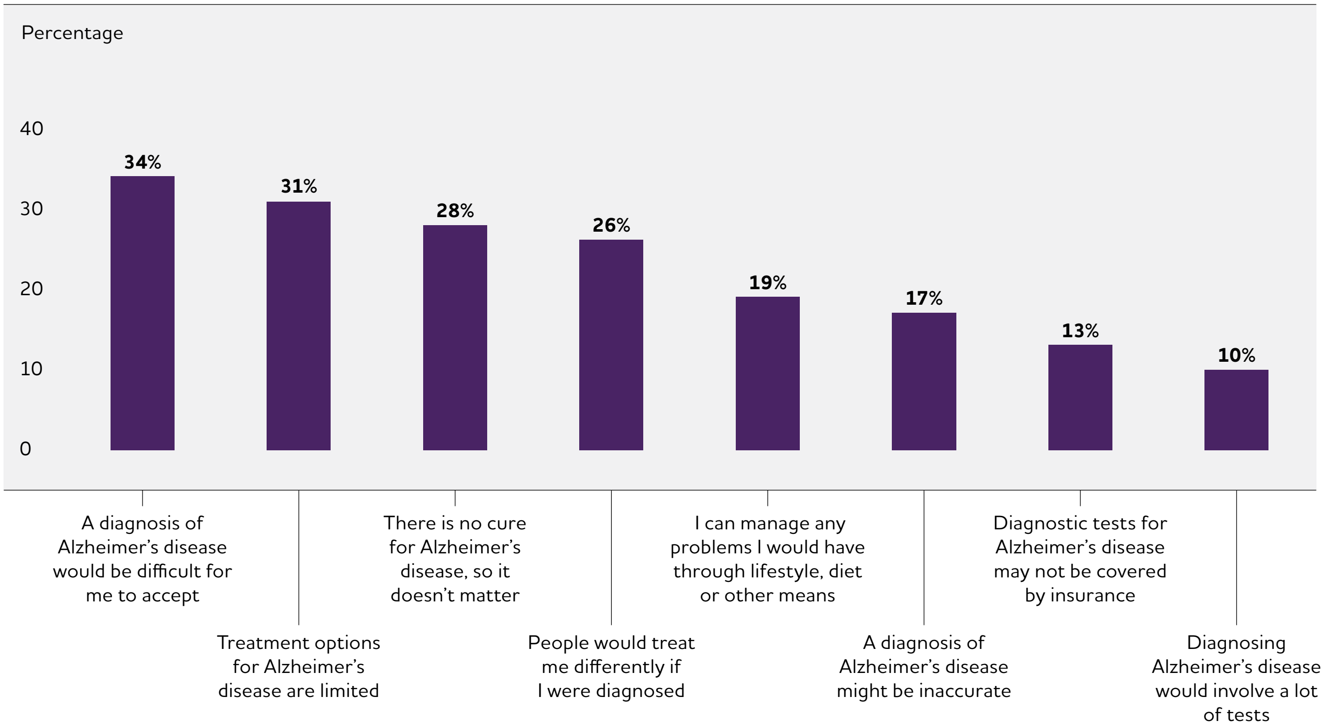
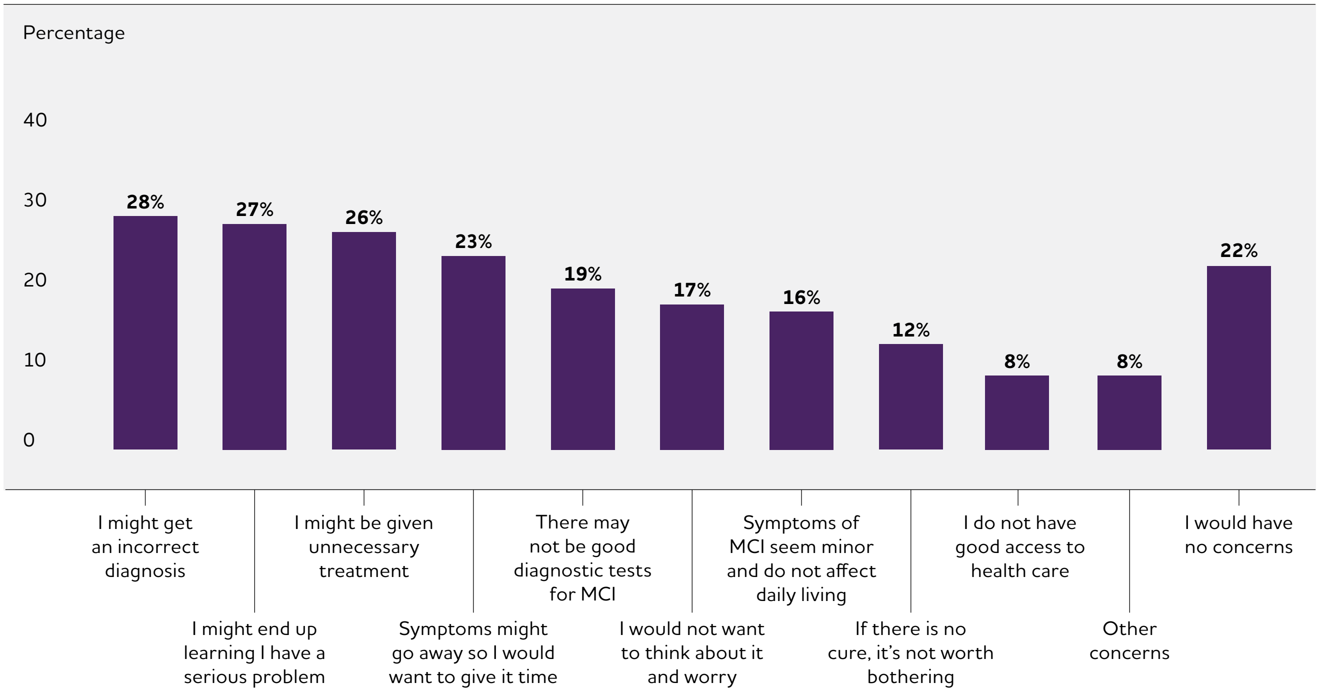


figure **22**

Concerns About Seeing a Doctor for MCI Symptoms Among U.S. Adults



Patient Reticence in Addressing Concerns About MCI and MCI Due to Alzheimer's

Most Americans (70%) say they would talk to someone if they started noticing symptoms of MCI but only 4 in 10 Americans (40%) report that they would talk to their doctor right away. More than half of Americans (57%) say they would wait until they had symptoms for a while (33%) or their symptoms worsened (12%), or wait until others expressed concern (12%). Just 2% of Americans say they would never talk to their doctor about MCI symptoms.

The Alzheimer's Association survey revealed that the decision to see a doctor when experiencing MCI symptoms is not a foregone conclusion for many individuals. In fact, almost 8 in 10 Americans (78%) say they would have concerns about seeing a doctor in the wake of MCI symptoms. Reasons for not seeing a doctor include concerns about receiving an incorrect diagnosis (28%), learning of a serious health problem (27%), receiving an unnecessary treatment (26%) and believing symptoms might go away (23%) (Figure 22).

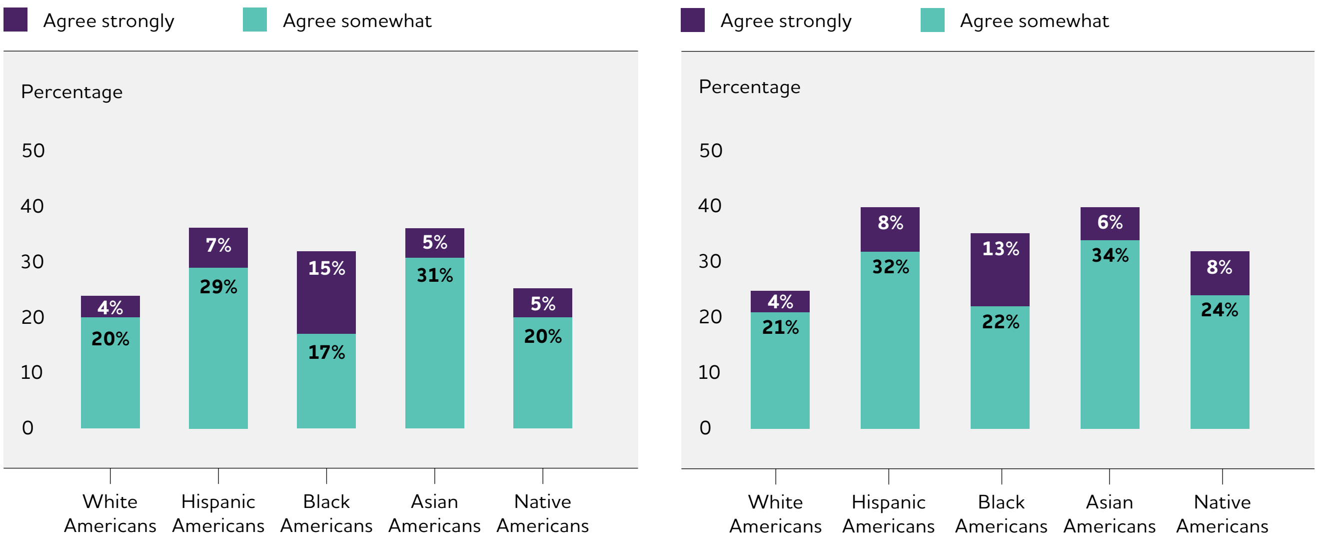
Receiving an incorrect diagnosis was the top concern for not seeing a doctor right away for MCI symptoms among Asian (38%), Black (31%) and White Americans (27%). The top reason cited by Hispanic (27%) and Native Americans (31%) was learning they might have a serious problem. Native Americans (16%) were three times as likely as White Americans (5%) to cite having good access to health care as a concern for seeing a doctor. Hispanic (12%), Asian (11%) and Black Americans (10%) were twice as likely to cite this concern as White Americans. Surveys reported by the Alzheimer's Association in 2021 found that affordability of care, lack of insurance coverage and lack of access to community health care services were significant barriers in accessing dementia care for Hispanic, Black, Asian and Native Americans.[750]

Despite their concerns and often with some delay, most Americans see value in having MCI (73%) and MCI due to Alzheimer's disease diagnosed (70%). Still, more than 1 in 4 Americans (27%) report seeing little value in having MCI formally diagnosed, while nearly 1 in 3 Americans (30%) say there is little value in having MCI due to Alzheimer's disease diagnosed. Hispanic, Black and Asian Americans expressed this view most often for both diagnoses (Figure 23).

Primary Care Physicians: On the Front Lines of Caring for Individuals With MCI

PCPs play an integral role in providing dementia care (see Workforce section, page 52). According to the Alzheimer's Association survey, 3 in 4 PCPs (75%) say they are on the front lines of providing care to patients with MCI, with two-thirds (62%) of PCPs reporting they receive questions figure 23

Percentage of U.S. Adults Who Question the Benefit of an MCI and MCI Due to Alzheimer's Disease Diagnosis


Percentage of U.S. Adults Who Question Benefit of Diagnosing MCI, by Race or Ethnicity

Percentage of U.S. Adults Who Question Benefit of Diagnosing MCI Due to Alzheimer's Disease, by Race or Ethnicity

at least weekly from their patients about symptoms consistent with MCI. These findings parallel those from a 2020 Alzheimer's Association report in which 82% of PCPs said they were on the front lines providing dementia care.[589]

Almost all PCPs (93%) surveyed are familiar with MCI and a majority of PCPs (65%) say they are "always comfortable" or "usually comfortable" answering patient questions about MCI. Nearly as many PCPs (85%) are familiar with MCI due to Alzheimer's disease, and the majority of them (60%) are comfortable discussing with their patients how MCI can be related to Alzheimer's disease.

More than 8 in 10 PCPs (82%) report having sought information on MCI due to Alzheimer's disease during the past year. Nearly 4 in 10 (39%) have done so during the past month, with almost 1 in 10 (9%) reporting they have done so within the past week.

Patients view PCPs as a trusted source for information on MCI, with 55% of Americans reporting they would discuss MCI symptoms with their PCP before others, including their spouse (42%) or physician specialists (29%).

Primary Care Physicians: Diagnosis of MCI and MCI Due to Alzheimer's disease

Almost all PCPs surveyed say it is important to diagnose MCI (98%) and MCI due to Alzheimer's disease (90%). Nearly two-thirds of PCPs (65%) say they are comfortable diagnosing MCI, while less than half (49%) report being comfortable diagnosing MCI due to Alzheimer's disease (Table 23).

Challenges cited most frequently when making an MCI diagnosis include difficulty differentiating MCI from normal aging (72%) and difficulty interpreting patient reports of daily functioning (51%) (Figure 24, page 91).

Top challenges in making an MCI due to Alzheimer's disease diagnosis include lack of specialists/facilities to perform diagnostic testing (51%), patient reluctance to pursue follow-up testing (49%) and PCP reluctance to diagnose a condition that has limited treatment options (47%) (Figure 25, page 91).

The Alzheimer's Association survey found that fewer than 1 in 10 PCPs (7%) are "very familiar" with current biomarker tests that aid in detecting Alzheimer's disease. This finding could partially explain why it is difficult for PCPs to diagnose MCI due to Alzheimer's disease.

table **23**

Primary Care Physicians' Perceptions on Diagnosing MCI and MCI Due to Alzheimer's Disease

PCP Perceptions	MCI	MCI Due to Alzheimer's Disease
It is important to diagnose	98%	90%
It is difficult to diagnose	57%	77%
PCP is comfortable diagnosing	65%	49%

table **24**

U.S. Adults and Primary Care Physicians' Expectations for New Alzheimer's Disease Treatments During the Next Decade

Treatment type that...	U.S. Adults	Primary Care Physicians
Delays progression of Alzheimer's Disease	73%	82%
Stops progression of Alzheimer's Disease	60%	54%
Prevents Alzheimer's Disease	53%	42%

One-third of PCPs (33%) report being "somewhat familiar" with biomarker testing. Not surprisingly, fewer than 1 in 5 patients (18%) are referred for biomarker testing when MCI is detected (Figure 26, page 92).

The Alzheimer's Association survey found that nearly all PCPs (96%) say it is important to assess patients 60 and older for cognitive impairment, but they report conducting assessments for just half their patients (48%). This finding is consistent with previous Alzheimer's Association reports published in 2019 and 2020 indicating PCPs provide cognitive assessments for less than half their patients age 65 and older.[247,589]

The current challenges PCPs face when diagnosing MCI and MCI due to Alzheimer's disease are underscored by the finding that 9 in 10 PCPs (90%) say "it is hard to know where MCI ends and dementia begins."

Primary Care Physicians: Management and Treatment of MCI

The vast majority of PCPs (86%) say early intervention can slow progression of cognitive decline. When MCI is detected in patients, PCPs most often recommend lifestyle changes (73%), perform laboratory testing for reversible causes of MCI (70%) and/or refer patients to a specialist (53%) (Figure 26, page 92).

As indicated in Figure 26 (page 92), PCPs infrequently recommend testing for Alzheimer's disease biomarkers (18%). In addition, fewer than 1 in 4 PCPs (20%) report being familiar with clinical trials in MCI due to Alzheimer's disease and recommend trial participation when MCI is detected just 8% of the time. PCP referral of patients to clinical trials is much lower than the 43% of Americans who cite the potential for clinical trial participation as a reason for early diagnosis (see Figure 20, page 87).

Finally, as referenced earlier in this report, there are more than 100 disease-modifying treatments for Alzheimer's disease, including those aimed at addressing MCI due to Alzheimer's disease, under investigation in clinical trials and at various stages of regulatory approval.[748-749] Yet fewer than 1 in 4 PCPs (23%) say they are familiar with these emerging treatments to address MCI due to Alzheimer's.

Optimism for Future Treatments

Despite the devastating toll Alzheimer's disease continues to have on individuals and families across the country, both patients and PCPs express optimism that new treatments to combat Alzheimer's disease are on the horizon.

More than 7 in 10 Americans (73%) expect new treatments to delay the progression of Alzheimer's disease to be available within the next decade (Table 24). Six in 10 Americans (60%) anticipate new treatments to stop the progression of Alzheimer's disease. More than one-half of all Americans (53%) believe there will be new treatments to prevent Alzheimer's disease.

PCPs also expressed optimism for future Alzheimer's disease treatments (Table 24). More than 4 in 5 PCPs (82%) expect there will be new treatments to delay the progression of Alzheimer's disease during the next decade. More than half of PCPs (54%) anticipate there will be treatments to stop Alzheimer's disease progression, and more than 4 in 10 (42%) anticipate new treatments to prevent Alzheimer's disease.

A Path Forward: Increasing Awareness and Diagnosis of MCI and MCI Due to Alzheimer's Disease

Taken together, the Alzheimer's Association surveys provide important insights and perspectives from the American public and primary care physicians on the current state of understanding, awareness, diagnosis, and management of MCI and MCI due to Alzheimer's disease. The findings indicate improvements are needed to increase public awareness of MCI, including MCI due to Alzheimer's, and that enhanced support is needed for primary care physicians on the front lines tasked with diagnosis,

figure **24**

Primary Care Physician Challenges in Diagnosing MCI

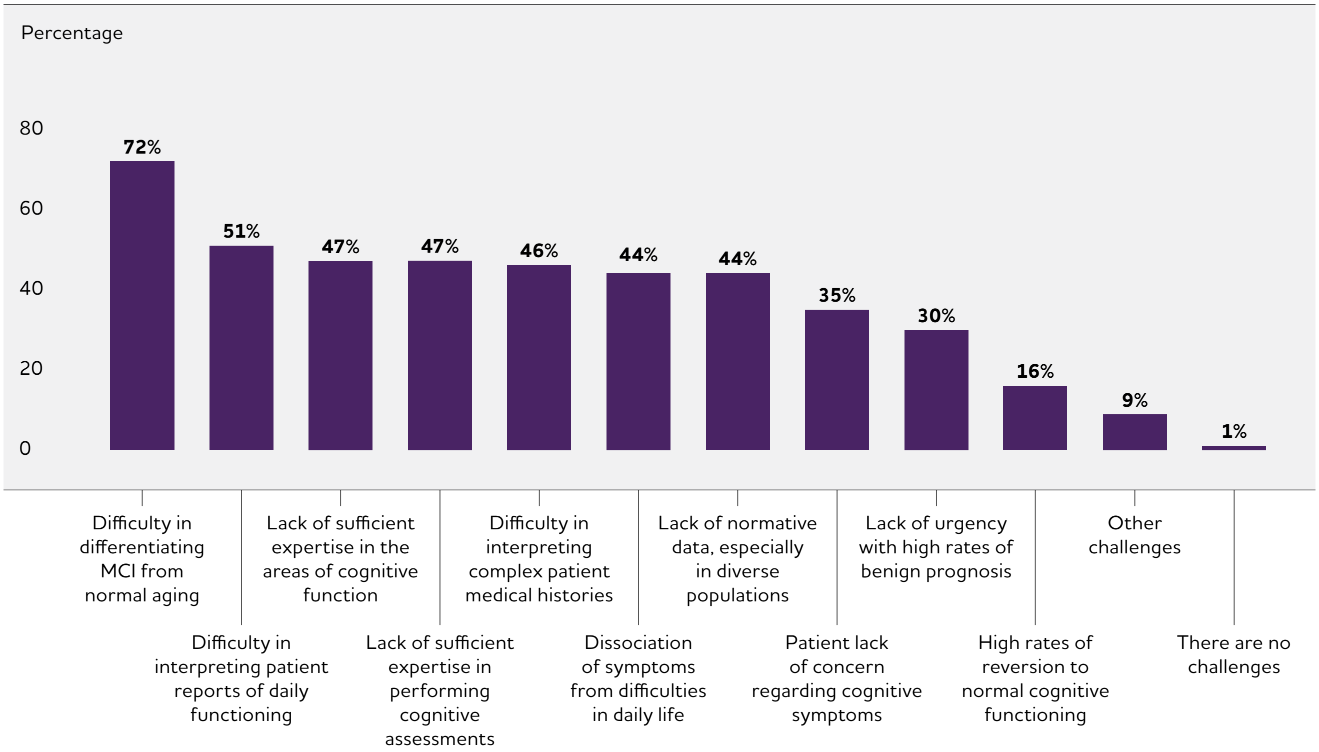


figure **25**

Primary Care Physician Challenges in Diagnosing MCI Due to Alzheimer's Disease

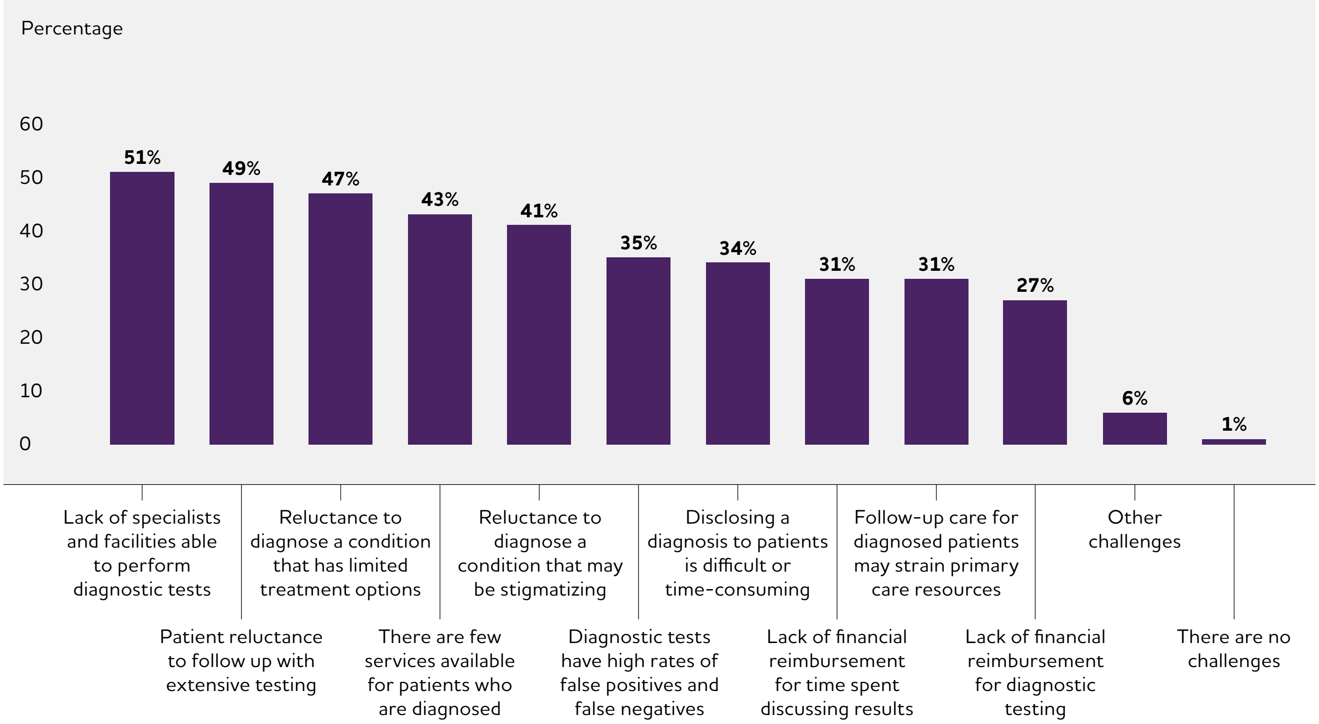
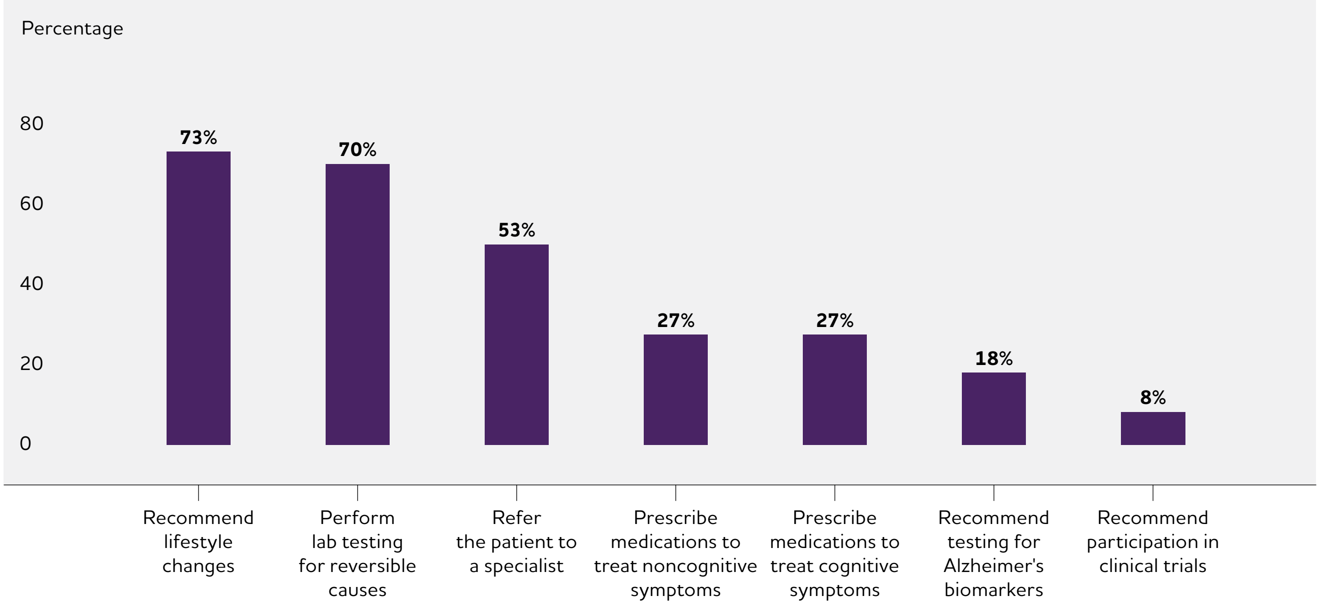


figure **26**

Steps Recommended by Primary Care Physicians When MCI Is Detected



management and treatment of MCI, including MCI due to Alzheimer's disease, and other dementias. The Alzheimer's Association proposes four broad efforts to improve the current situation:

- Promote greater public awareness by leveraging awareness campaigns and community-based disease education programs.
- Improve ease of use and uptake of cognitive assessments in the primary care setting.
- Expand primary care physicians' ability to diagnose cognitive impairment, including MCI and MCI due to Alzheimer's disease.
- Bolster public and primary care physician awareness of and patient participation in Alzheimer's disease-related clinical trials and research.

Leveraging Public Awareness Campaigns and Community-Based Disease Education Programs

Findings from the Alzheimer's Association surveys reveal that Americans have a concerning lack of awareness of MCI, MCI due to Alzheimer's disease, and the distinction between these conditions and normal aging. When Americans do have concerns about their cognitive functioning, they are often slow to act — potentially delaying or impeding diagnosis and potential intervention for MCI or MCI due to Alzheimer's disease.

Public awareness campaigns and community-based disease education programs offer two important avenues for building public awareness nationally and locally.[751] Given low consumer awareness of MCI, core messaging to public audiences within these efforts should be broad, encouraging more Americans to be proactive in recognizing early symptoms of cognitive impairment and addressing concerns with their physician.

These efforts should engage not only individuals at risk for cognitive decline, but family members as well. Close family members are typically the first to notice memory concerns or cognitive problems, yet many are reluctant to initiate a conversation with the affected individual or their physician. Touting the value and benefits of early diagnosis in messaging can help overcome reticence and rectify concerns identified in the current Alzheimer's Association survey.

Since 2019, the Alzheimer's Association has partnered with the Ad Council on a national communications campaign aimed at encouraging families to discuss cognitive concerns with each other and their doctor sooner to enable early diagnosis of Alzheimer's disease and related dementias.

The campaign features real stories of people who noticed cognitive changes in a close family member and took the first, difficult step to initiate a conversation about those changes. The campaign offers tools and resources to help families recognize early warning signs of Alzheimer's disease, provides tips for facilitating conversations about cognition, and explains benefits of early detection and diagnosis.[752] The campaign resources also include a collection of disease-related information and a discussion guide for use with doctors and health care professionals.[753]

Community-based disease education programs provide another important avenue to raise awareness about MCI, including MCI due to Alzheimer's, with the advantage that they can be tailored to reach diverse communities. As indicated in the current Alzheimer's Association survey, there are differences in how racial and ethnic groups view and respond to concerns about cognitive impairment. Creating disease-related materials and messaging that resonates with diverse communities is essential.

Improving Cognitive Assessment in Primary Care Practice

Studies indicate that detection and diagnosis of cognitive impairment or dementia can be increased two- to three-fold with routine use of brief cognitive assessments.[586] Yet findings from the current Alzheimer's Association survey indicate that primary care physicians are evaluating just under half of their patients for cognitive impairment. These findings parallel those from Alzheimer's Association surveys of primary care physicians published in 2019 and 2020.[247,589]

In recent years, the Centers for Medicare and Medicaid Services (CMS) has attempted to increase utilization of cognitive assessments in routine care by making it a requirement of the Medicare Annual Wellness Visit (AWV), reimbursing the cognitive assessment and care plan as a separate visit and at a higher dollar amount, and making the option of reimbursable telehealth evaluation permanent.[754] Three other approaches arising from this year's Alzheimer's Association survey findings that could complement these efforts to increase uptake of cognitive assessments in primary care are:

1. Implementing new assessment approaches that do not detract from the physician portion of a visit.
2. Supporting physicians with resources to equip them to more confidently perform and interpret cognitive assessments.
3. Developing and disseminating culturally appropriate assessment tools for use in diverse populations.

Rethinking Assessment Approaches

Currently, many physicians administer cognitive assessments themselves — asking patients questions, recording the answers, then interpreting the results and formulating next steps. This takes time, and not only do physicians have limited time with patients, but the cognitive assessment may also not be the priority during the visit. Time is a barrier to uptake without an easy solution. Using computerized or digital screening assessments outside of exam room time is one approach to overcome time constraints, as is using remote assessment through telehealth technology.[638] Other approaches include limiting the time it takes to conduct an assessment and involving other members of the care team to administer cognitive screenings (see Workforce section, page 52).[586,755]

Resources

Limited expertise is a frequently cited barrier to performing cognitive assessments in the literature and was raised by PCPs in the current Alzheimer's Association survey, with PCPs citing lack of expertise in areas of cognitive function (47%) and lack of sufficient expertise in performing cognitive assessments (47%) as significant challenges (Figure 24, page 91).[589,755]

Increasing PCP awareness of self-directed training resources is an important first step to help them gain confidence and comfort using cognitive assessments more regularly. Resources and information on performing cognitive assessments are available to primary care practices from numerous government and professional organizations, including:

- Centers for Medicare and Medicaid Services
- The National Institute on Aging
- The Alzheimer's Association Cognitive Assessment Toolkit
- The Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition
- The Gerontological Society of America Kickstart, Assess, Evaluate, Refer (KAER) Toolkit
- The American Academy of Family Physicians Cognitive Care Kit
- Minnesota's Act on Alzheimer's® Provider Practice Tools

The Alzheimer's Association and others, including a working group of international experts on MCI and Alzheimer's disease, have published recommendations and descriptions of operationalizing cognitive assessments, including the AWV, in primary care practice to guide this process.[586,755-757]

Culturally Appropriate Assessment

Clinicians need more cognitive assessment tools for diverse and underserved populations. Studies show sensitivity to differences in age, literacy levels and cultural variation are key limitations of many cognitive tests in use today.[755,758-761]

Evidence suggests that age, number of chronic conditions and socioeconomic status may influence screening rates with cognitive assessments, and that race, ethnicity, educational level and language barriers may negatively impact the utility of cognitive assessments in discriminating between normal aging and MCI or dementia.[755,758-759] Adapting existing cognitive assessments or developing new cognitive assessments for an increasingly diverse aging population is an avenue to explore to improve early diagnosis rates among groups that are disproportionately affected by Alzheimer's disease and related dementias (see Prevalence section, page 18).[762] An example of this is a best practices guide developed by CMS to help physicians adapt cognitive assessments based on cultural considerations for screening Native Americans.[763] Having cognitive assessments that are designed specifically for historically underrepresented groups may also improve uptake in primary care practices, as these assessments could generate the normative data in diverse populations that physicians surveyed as part of this year's Special Report say they are lacking to diagnose MCI.[755]

Expand Primary Care Physicians' Ability to Diagnose Cognitive Impairment Early

Ensuring that primary care physicians and care teams are equipped to diagnose and manage MCI and MCI due to Alzheimer's disease now and in a growing aging population is imperative, especially in light of a worsening shortage of other specialists, such as geriatricians (see Workforce section). Possible future directions informed specifically by the Alzheimer's Association survey findings are described below. They include adopting new diagnostic tools as they become available, continuing to enhance primary care capacity for dementia care, and ongoing efforts to deliver more culturally-competent care (for additional recommendations, see the Workforce section, page 52).

Simplify Adoption of Future Diagnostic Tools

Low diagnosis rates for MCI due to Alzheimer's disease can be partially explained by the challenges primary care physicians report in administering diagnostic tests. The Alzheimer's Association survey found that physicians report barriers in referring their patients to specialists for diagnostic tests, must overcome patient reluctance to pursue further testing and believe existing diagnostic tests can be inaccurate (Figure 25, page 91). Some of these barriers could be overcome with research advancements that bring new diagnostic tools, such as blood-based biomarker tests, to the primary care setting. Although not yet widely available in clinical practice, eventually blood-based biomarker tests could be ordered through the primary care practice and offer another way to help detect disease early so that a patient could be referred to a specialist or monitored more closely for cognitive decline by their primary care physician.

As reported in the 2017 Special Report, "*Alzheimer's Disease: The Next Frontier*," "Alzheimer's disease exists as a continuum beginning with a phase that may only be detectable through biomarkers, moving through the dementia stage."[764] Research funded by the Alzheimer's Association and other institutions is underway to discover new biomarkers and evaluate this approach.[747,765-768] Advances in biomarker science will also help PCPs perform a differential diagnosis to rule out modifiable causes of symptoms, and ascertain when it may be appropriate to refer patients to clinical trials of new treatment options.

The Alzheimer's Association survey found that very few PCPs are familiar with current biomarker tests that aid in detecting Alzheimer's disease. Therefore, when new blood-based biomarker tests are ready for adoption in routine primary care practice, it will be important to educate physicians about appropriate use. Education can be accomplished with implementation toolkits or stepwise diagnostic algorithms that clearly explain which patients to test and when, how biomarker tests complement other tools, such as cognitive assessments and clinical exams, and how to put the results into context with other clinical findings to create a care plan.[747,755]

Continue to Enhance Primary Care Capacity for Dementia Care

Although less frequently cited than other challenges in this year's Special Report, physicians did acknowledge that they have difficulty diagnosing MCI due to Alzheimer's disease because there are few services for patients who are diagnosed, and they believe that follow-up care may strain primary care resources (Figure 25, page 91).

The Alzheimer's Association is partnering with primary care clinicians and practices to increase equitable access to timely detection, accurate diagnosis, and quality, person-centered care. In 2018, the Association launched a Project ECHO® — a highly successful telementoring program — that has connected more than 50 primary care practices with dementia care experts to enhance dementia care in underserved areas. University of Washington and West Virginia University have also launched Project Dementia and Memory Health to support primary care practices.[769-770]

In addition to work through Project ECHO, the Alzheimer's Association is partnering directly with more than 300 health systems in the United States, from community health centers to large integrated delivery networks, and offers guidance and resources for them at: alz.org/professionals/health-systems-clinicians.

Another approach to enhancing primary care capacity for dementia care is through collaborative and coordinated care programs. The UCLA Alzheimer's and Dementia Care Program, for example, uses nurse practitioners and dementia care specialists to manage the care of people living with dementia. Since launching in 2011, the program has expanded to 18 sites across the country, reducing emergency department visits, days spent in the hospital, admissions to nursing homes for long-term care and overall Medicare costs.[771]

Dedicate Sustained Effort to Improve Diversity and Inclusion in Primary Care

This year's Special Report uncovered some distinctions between racial and ethnic groups in understanding, diagnosis and management of MCI and MCI due to Alzheimer's disease. As we move forward, it is critical to recognize racial and cultural differences in how underserved and disproportionately affected populations respond to health concerns and work to eliminate barriers that may delay or prevent timely access to care and treatment.

Recommendations outlined in the Alzheimer's Association *2021 Alzheimer's Disease Facts and Figures* Special Report still hold true this year. The Alzheimer's Association survey reported in 2021 found that individuals want health care providers who reflect their racial and ethnic backgrounds.[750] A diverse, representative, culturally-competent primary care workforce could strengthen trust with underserved populations, helping them to overcome some of their reticence to seek evaluation and diagnosis of cognitive impairment, potentially reducing future disparities in dementia care.[750]

Bolstering Public Awareness and Physician and Public Participation in Clinical Trials

Low public awareness, difficulty recruiting and retaining clinical trial participants, and a lack of diversity in clinical trials are ongoing challenges that impede progress toward advancing new disease-related treatments and therapies.

Registries established at the local and national levels aim to help in the recruitment process by offering people the chance to be matched to current and future Alzheimer's disease clinical trials.[772] Examples include the Alzheimer's Prevention Registry, which is trying to enlist large numbers of people for future disease prevention trials, The Alzheimer's Association's TrialMatch, the NIH-funded ResearchMatch and the Brain Health Registry. Rolling information about registries into public awareness campaigns and community outreach efforts could be a step towards educating the public.

Grassroots community outreach has also shown some success in recruiting Alzheimer's disease clinical trial participants from the community-at-large, and could be included as part of the public awareness campaigns described previously.[772-773] Online patient communities and support groups can also serve as an avenue to awareness and recruitment.[773]

The 2021 Alzheimer's Association Special report found that a majority of Americans feel that medical research is biased against Asian, Black, Hispanic and Native Americans, which leads these underrepresented groups to be less interested in participating in clinical trials.[745]

As outlined in the same report, building relationships with community-based organizations and trusted leaders from underrepresented groups can help facilitate education and the delivery of dementia-related information and resources to these communities, including the importance of these groups' participation in clinical trials and disease research.[774]

For PCPs, awareness may not be the only reason they are not recommending and referring patients for participation in clinical trials and disease research. Some studies have found that not all physicians see value in clinical trials.[772-773] Others are hesitant to refer due to potential risks to their patients, concerns from their patients and logistical obstacles that prevent easy referral if the physician is not affiliated with an academic research institution.[772-773]

The Alzheimer's Association survey of PCPs published in 2019 found that fewer than 4 in 10 believe participation in clinical trials or other research is an important benefit of early detection of Alzheimer's disease.[247] This finding appears to still hold true today, as PCPs recommend trial participation just 8% of the time when MCI is detected (Figure 26, page 92). Education that reinforces the value and benefits of clinical trial participation is warranted.

Finally, many clinical trials today seek to include patients with preclinical Alzheimer's disease or MCI due Alzheimer's disease, highlighting a heightened need for PCP referral. Findings from the current survey indicate many PCPs do not feel they have the diagnostic tools to accurately confirm MCI due to Alzheimer's disease without referral to a specialist and follow-up testing. As outlined previously, increasing use of cognitive assessments and the potential availability of blood-based biomarkers to aid in detection and diagnosis of MCI due to Alzheimer's disease may help overcome this particular challenge.

Conclusion

The Alzheimer's Association surveys of U.S. adults and primary care physicians underscore the need for robust efforts to raise the public's awareness of MCI, including MCI due to Alzheimer's disease, while also better preparing primary care physicians to identify, diagnose and manage their patients' cognitive impairment at its earliest stages. As we wait for widespread use of biomarkers to be common practice in the clinical setting, patients and physicians share responsibility in recognizing and addressing symptoms of MCI sooner and more proactively.

Early intervention offers the best opportunity for management and treatment, allowing individuals with MCI or MCI due to Alzheimer's disease more time to plan for the future, adopt lifestyle changes that may help slow disease progression, participate in clinical trials and to live more fully, with a higher quality of life, for as long as possible.

Appendices

End Notes

A1. Activities of daily living: Everyday activities a person typically performs without assistance, including getting into and out of a bed or chair, bathing, dressing, grooming, eating and using the toilet.

A2. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer's dementia for 2022: The estimated 6.5 million persons ages 65 years and older with Alzheimer's dementia and the estimated numbers of persons with Alzheimer's in each age group were reported from a study that used data from the Chicago Health and Aging Project (CHAP) in combination with population projections from the U.S. Census.[224] The number, 6.5 million, is higher than estimated from previous study that also combined CHAP and U.S. Census data. This is because the more recent study used updated Census projections and incorporated information from Hispanic/Latino American persons. The proportion of the population with Alzheimer's dementia (among all persons age 65 and older and by age group) is calculated using as the numerators the numbers of persons with Alzheimer's dementia, as reported by the recent study in CHAP.[224] The denominators were the U.S. Census population projections for the specific age groups of interest.

A3. 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).[224,228] 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.[227] 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,[32] 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.

A4. 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.[259] 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 2022.

A5. 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.[263] 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.

A6. Projected number of people with Alzheimer's dementia, 2020-2060: This figure comes from the CHAP study.[224] Other projections are somewhat lower (see, for example, Brookmeyer et al.[775]) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.[A3] 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.

A7. 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.

A8. 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 2020, 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." In the 2019 and 2020 BRFSS, an additional follow-up question was included, asking if the caregiving recipient also had dementia in addition to their main condition. Prior to 2019, the survey did not include caregivers of recipients for whom dementia was not their main condition, so these numbers were imputed using data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP survey. 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 six states without 2015-2020 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 2021, using U.S. Census Bureau data available at: https://www.census.gov/programs-surveys/popest/data/tables.html. This resulted in a total of 11.343 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.

A9. 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. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

A10. 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,[395] 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[A8] 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 16.023 billion hours.

A11. Value of unpaid caregiving: For each state, the hourly value of care was determined as the average of the state minimum hourly wage[776] and the most recently available state median hourly cost of a home health aide. (For Nevada, the minimum wage used was the average of the minimum wage for those who are not provided health insurance and the minimum wage for those who are provided health insurance.)[686] The average for each state was then multiplied by the total number of hours of unpaid care in that state[A10] 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 $271.598 billion for dementia caregiving in the United States in 2021.

A12. 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 2018 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 colleagues[224] and included in this report (6.5 million in 2022), 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. Because state-specific prevalence estimates do not exist for 2022, the state-specific Medicaid costs included in *Facts and Figures* are based on the 2020 prevalence estimates reported here.[A4]

A13. All cost estimates were inflated to year 2021 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.

A14. 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: Payments are unadjusted, and therefore, do not account for differences in patient characteristics, such as age or sex.

A15. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2018 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Health Care Cost Institute.[260] 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 setting, 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 *2022 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 setting 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 2018 and reported in 2021 dollars.

A16. Differences in Estimated costs reported by Hurd and colleagues: Hurd and colleagues[644] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2022 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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The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Our vision is a world without Alzheimer's and all other dementia.®

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