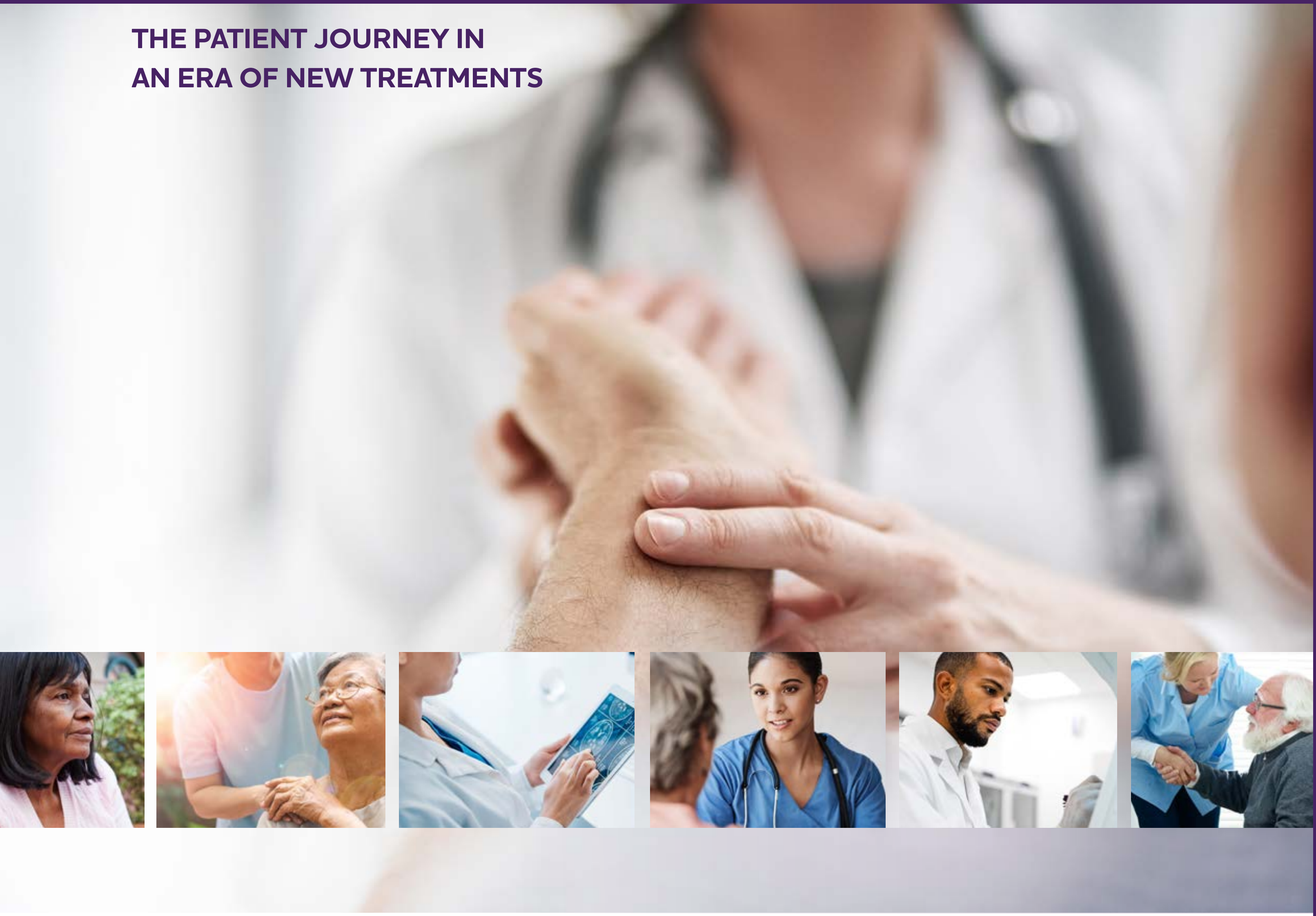
2023
ALZHEIMER'S DISEASE FACTS AND FIGURES

SPECIAL REPORT

THE PATIENT JOURNEY IN AN ERA OF NEW TREATMENTS



ALZHEIMER'S ASSOCIATION®

About this report

2023 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 and services. Better Alzheimer's disease care requires conversations about memory at the earliest point of concern and a knowledgeable, accessible care team that includes physician specialists to diagnose, monitor disease progression and treat when appropriate. The Special Report examines obstacles and opportunities for achieving better care in an era of new treatments for Alzheimer's.

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.

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

Brain changes that occur with Alzheimer's disease (page 8).

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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 66).

Medicare payments for people with dementia compared with people without dementia (page 67).

Mean number of unique patients dementia specialists report seeing per year (page 95).

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." This report keeps the racial and ethnic terms used in source documents when describing study findings. When not referring to data from specific studies, the adjectives "Black," "Hispanic" and "White" are used.

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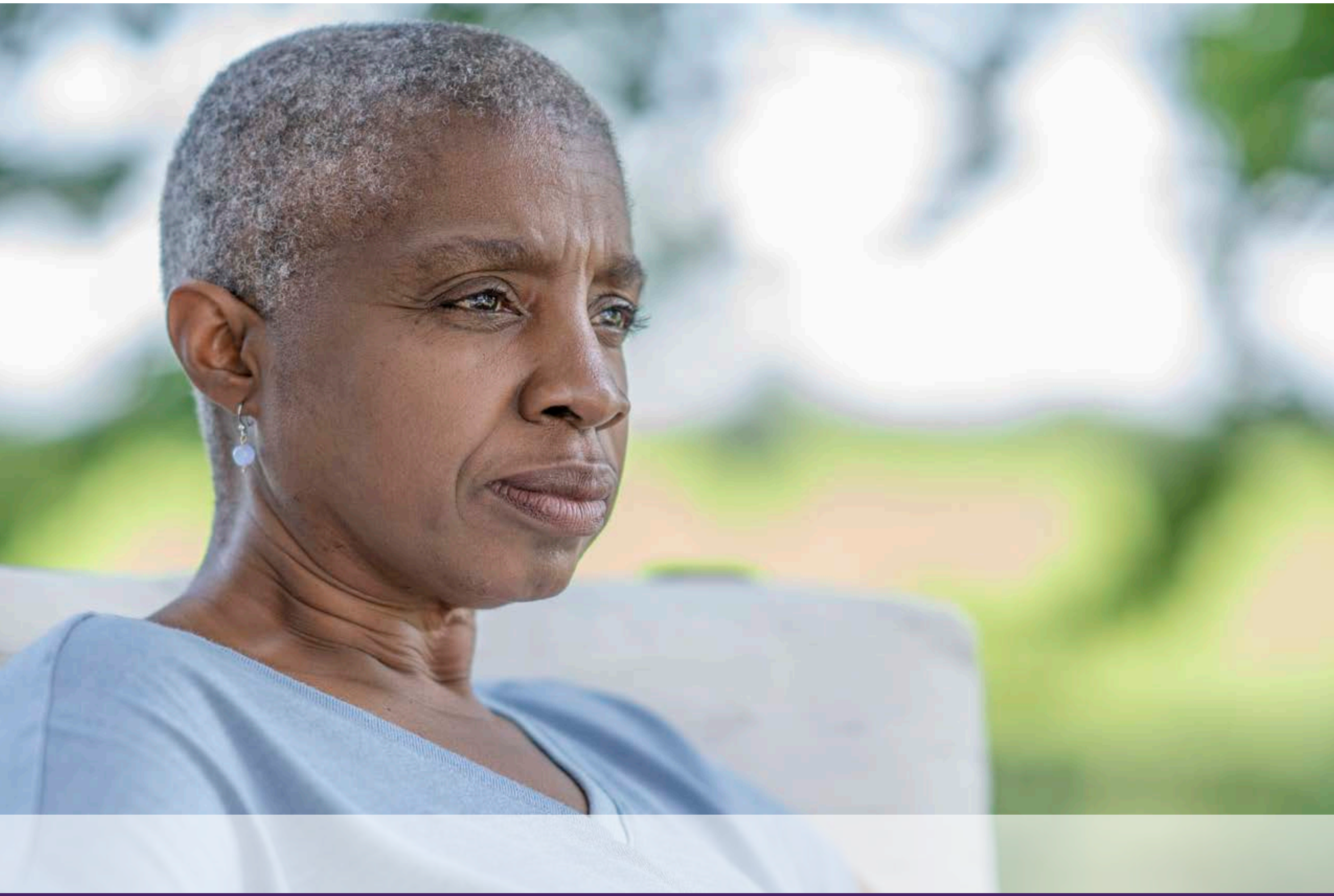
OVERVIEW

ALZHEIMER'S BEGINS 20 YEARS OR MORE BEFORE MEMORY LOSS AND OTHER SYMPTOMS DEVELOP.



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 brain's neurons are essential to thinking, walking, talking and all human activity.

In Alzheimer's, the neurons damaged first are those in parts of the brain responsible for memory, language and thinking. As a result, the first symptoms 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. 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. Individuals with Alzheimer's may develop changes in mood, personality or behavior. One behavior that is of special concern is wandering, which refers to individuals walking away from a particular location and not being able to retrace their steps. Individuals who wander may become lost, putting them at risk of significant injury and death.[9]

Eventually, the neuronal damage of Alzheimer's 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 neurons. 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*

Cause	Brain changes
Alzheimer's disease	Accumulation of the protein beta-amyloid outside neurons and twisted strands of the protein tau inside neurons are hallmarks. They are accompanied by the death of neurons and damage to brain tissue. Inflammation and atrophy of brain tissue are other changes.
Cerebrovascular disease	Blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients. People with these changes who develop dementia symptoms are said to have vascular dementia.
Frontotemporal degeneration (FTD)	Nerve cells in the front and temporal (side) lobes of the brain die and the lobes shrink. Upper layers of the cortex soften. Abnormal amounts or forms of tau or transactive response DNA-binding protein (TDP-43) are present.
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.
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.
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.
Parkinson's disease (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 the chemical dopamine.[29] As PD progresses, alpha-synculein can also accumulate in the cortex.

*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.

Percentage of dementia cases	Symptoms
Alzheimer's is the most common cause of dementia, accounting for an estimated 60% to 80% of cases. Most individuals also have the brain changes of one or more other causes of dementia.[21,22] This is called mixed pathologies, and if recognized during life is called mixed dementia.	Difficulty remembering recent conversations, names or events; apathy; and depression are often early symptoms. Communication problems, confusion, poor judgment and behavioral changes may occur next. Difficulty walking, speaking and swallowing are common in the late stages of the disease.
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]	Slowed thoughts or impaired ability to make decisions, plan or organize may be the initial symptoms, but memory may also be affected. People with vascular dementia may become less emotional and have difficulty with motor function, especially slow gait and poor balance.
About 60% of people with FTD are ages 45 to 60.[23] In a systematic review, FTD 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]	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.
HS is present in about 3% to 13% of people with dementia.[25] It often occurs with the brain changes of other causes of dementia. An estimated 0.4% to 2% of dementia cases are due to HS alone.[25]	The most pronounced symptom of HS is memory loss, and individuals are often misdiagnosed as having Alzheimer's disease. HS is a common cause of dementia in individuals age 85 or older.
About 5% of older individuals with dementia show evidence of DLB alone, but most people with DLB also have the brain changes of Alzheimer's disease.[26]	Early symptoms include sleep disturbances, well-formed visual hallucinations and visuospatial impairment. These symptoms may change dramatically throughout the day or from day to day. Problems with motor function (similar to Parkinson's disease) are common. Memory loss may occur at some point in the disease.
More than 50% of people diagnosed with Alzheimer's dementia who were studied at Alzheimer's Disease Research Centers had mixed dementia.[22] In community-based studies, the percentage is considerably higher.[21] Mixed dementia is most common in people age 85 or older.[27,28]	Symptoms vary depending on the combination of brain changes present.
A systematic review found that 3.6% of dementia cases were due to PD and 24.5% of people with PD developed dementia.[30]	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. Cognitive symptoms may develop later in the disease, typically years after movement symptoms.

Brain Changes of Alzheimer's Disease

A healthy adult brain has billions of 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 trillions of 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 damage to and destruction of neurons, called neurodegeneration (N), which along with beta-amyloid (A) and tau (T) accumulation is a key feature of Alzheimer's disease. Together, these changes are known as the AT(N) framework for Alzheimer's.

Beta-amyloid and tau have different roles in Alzheimer's. Plaques and smaller accumulations of beta-amyloid may damage neurons by interfering with neuron-to-neuron communication at synapses. Inside neurons, tau tangles block the transportation of nutrients and other molecules essential for the normal function and survival of neurons. Although the complete sequence of events is unclear, beta-amyloid may begin accumulating before abnormal tau, and increased 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 is 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 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 (CSF; 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 cardiovascular disease risk.

Some individuals have a rare genetic mutation that causes Alzheimer's disease. This is called dominantly inherited Alzheimer's disease (DIAD). A study 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).[5] Glucose metabolism began to decrease 18 years before expected symptom onset, and brain atrophy began 13 years before expected symptom onset. Another study[7] 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[8] 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.[21,31-36] 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, not just for those diagnosed with Alzheimer's but also for those diagnosed with other types of dementia.[37,38]

Mixed dementia is especially common at advanced ages.[31,39] For example, those age 85 or older are more likely than those younger than 85 to have evidence of two or more causes of dementia.[27,28] 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 compared with someone with Alzheimer's brain changes alone.[21,31] It may also account for the wide variety of memory and thinking problems experienced by people living with dementia. It is currently not possible to determine with certainty which symptoms are due to which 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.

Alzheimer’s Disease Continuum

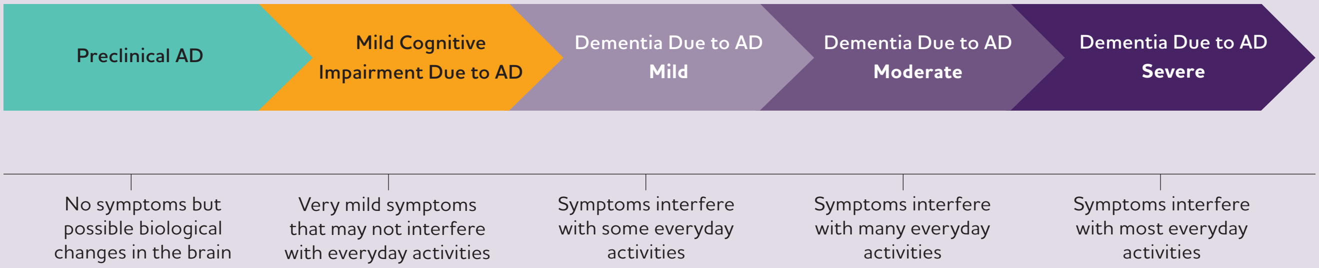
The progression of Alzheimer’s disease from brain changes that are unnoticeable by the person affected to brain changes that cause memory problems and eventually physical disability is called the Alzheimer’s disease continuum.

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).[40-43] The Alzheimer’s dementia phase is further broken down into mild, moderate and severe dementia.

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.[44]

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.

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 and in analysis of cerebrospinal fluid (CSF), changes in tau protein in CSF and plasma, and decreased metabolism of glucose as shown on PET scans.[45-47] 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.[48,49] For example, some individuals have beta-amyloid plaques at death but did not have memory or thinking problems in life.[50]

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.

Everyone who develops Alzheimer's dementia first experiences MCI. Among those with MCI, about 15% develop dementia after two years.[51] About one-third develop dementia due to Alzheimer's within five years.[52] However, some individuals with MCI do not have additional cognitive decline or revert to normal cognition. Among population-based studies, a systematic review and meta-analysis reported a reversion rate of 26%.[53] 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 finances 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.

When Dementia-Like Symptoms Are Not Dementia

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

In addition, the differences between normal age-related cognitive changes and the cognitive changes of Alzheimer's disease can be subtle (see Table 2, page 9). People experiencing cognitive changes should seek medical help to determine if the changes are normal for their age, are reversible, or may be a symptom of Alzheimer's or another dementia.

Treatments

Drug Treatments

At this writing, the U.S. Food and Drug Administration (FDA) has approved seven drugs for the treatment of Alzheimer's disease. Five of these drugs — donepezil, rivastigmine, galantamine, memantine and memantine combined with donepezil — are aimed at improving symptoms. They do not affect the underlying brain changes that cause symptoms, nor do they 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 excessive levels of a neurotransmitter called glutamate, which overstimulates neurons and can damage them. These five drugs may have side effects such as headache and nausea.

Two of the FDA-approved drugs — aducanumab and lecanemab — are aimed at changing the underlying biology of the disease. They remove beta-amyloid from the brain and slow cognitive and functional decline in people living with early Alzheimer's. They are not cures for Alzheimer's disease and not appropriate for all individuals living with Alzheimer's disease. They were studied in and approved for use by 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 beta-amyloid in the brain based on brain imaging or CSF analysis. There is no safety or efficacy data on initiating treatment in individuals without MCI or individuals living with moderate or severe Alzheimer's dementia.

As with any treatments, aducanumab and lecanemab may have side effects. Among the common potential side effects are headaches and reactions to having the drug infused (both drugs are administered through intravenous infusion, similar to some treatments for other chronic diseases, such as Crohn's disease and multiple sclerosis).

Some individuals may experience another common side effect called amyloid-related imaging abnormalities (ARIA). ARIA is typically, although not in all cases, a temporary, localized swelling of the brain that does not cause symptoms and resolves over time. It may be accompanied by small spots of bleeding in or on the surface of the brain. Individuals should be monitored closely and receive regular brain imaging assessments so ARIA is quickly identified and safely managed should it arise. Individuals should speak with their doctors to learn whether they are candidates to receive these medications and whether the potential benefits of treatment outweigh the potential risks.

A variety of other treatments targeting the underlying biology of Alzheimer's are in the research pipeline.[54] They address many of the brain changes associated with Alzheimer's, including but not limited to tau accumulation, altered cell metabolism and inflammation. Treatments that address the full scope of Alzheimer's biology, not only beta-amyloid, are critical.

Non-drug Treatments

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 physical activity, memory and orientation exercises, and music- and art-based therapies. Non-drug treatments may be used with a more specific goal of reducing behavioral and psychological 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.[55] 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 class of drugs called antipsychotics may be prescribed to treat severe hallucinations, aggression and agitation in people living with dementia. However, the decision to use antipsychotics to treat individuals living with dementia must be considered with extreme caution. Research has shown that antipsychotics are associated with an increased risk of stroke and death in individuals with dementia.[56,57] 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 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.[58]

Proactive 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.[59-61] 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 his or her 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 rare cases of Alzheimer's related to specific genetic mutations.

Age, Genetics and Family History

The greatest risk factors for late-onset Alzheimer's are older age,[62,63] genetics[64,65] — especially the e4 form of the apolipoprotein E (APOE) gene — and having a family history of Alzheimer's.[66-69]

Age

Age is the greatest of these three risk factors. The percentage of people with Alzheimer's dementia increases dramatically with age. Five percent of people age 65 to 74, 13.1% of people age 75 to 84, and 33.3% of people age 85 or older have Alzheimer's dementia (see Prevalence section, page 19). The aging of the baby-boom generation will significantly increase the number of people in the United States with Alzheimer's.[70] However, it is important to note that Alzheimer's dementia is not a normal part of aging, and older age alone is not sufficient to cause Alzheimer's dementia.[71]

Genetics

Researchers have found many genes that increase the risk of Alzheimer's. In fact, in 2022 researchers identified 31 new genes that appear to affect biological processes known to be at play in Alzheimer's disease.[72] Of the many genes that increase risk, 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 estimated eight- to 12-fold risk.[73-75] 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.[76,77]

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.[78] 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.[79]

Most of the research to date associating APOE-e4 with increased risk of Alzheimer's has studied White individuals. Studies of this association in Black and Hispanic populations have had inconsistent results. For example, some have found that having the e4 allele did not increase risk among Blacks,[80-82] while other studies have found that it significantly increased risk.[83-86] 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 have at least one copy of the e4 allele (see Table 3) than European Americans and American Indians.[80,81,87,88] 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.[84]

To better understand inconsistencies in the effect of APOE-e4 in Hispanic/Latino groups, one research team analyzed the effect of APOE-e4 in 4,183 individuals from six Latino backgrounds: Central American, Cuban, Dominican, Mexican, Puerto Rican and South American.[89] 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.[90] 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.[91] Studies suggest that the brain changes of Alzheimer's disease in people with Down syndrome are more common than these percentages indicate.[92,93]

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.[94] 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

Table **3**

Percentage of African Americans, European Americans and American Indians with Specified APOE Pairs*

APOE Pair	African Americans	European Americans	American Indians†
e3/e3	45.2	63.4	71.6 - 73.2
e3/e4	28.6	21.4	22.7 - 23.9
e3/e2	15.1	10.2	2.6 - 3.0
e2/e4	5.7	2.4	0.5
e4/e4	4.5	2.4	1.0 - 1.2
e2/e2	0.7	0.2	0.0 - 0.1

*Percentages do not total 100 due to rounding.

† Study provided a percentage for women and a percentage for men. Percentages represent the range for the two.

Created from data from Rajan et al[87] and Kataoka et al.[88]

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
Individuals with DIAD represent the estimated 1% or less of people with Alzheimer's who develop the disease as a result of mutations to any of three specific genes.[95] 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.[96] 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.[66, 73] Those who have more than one first-degree relative with Alzheimer's are at even higher risk.[69] A large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-e4.[97] 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, some 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 suggest that addressing modifiable risk factors might prevent or delay up to 40% of dementia cases.[58] A 2022 study found that nearly 37% of cases of Alzheimer's and other dementias in the United States were associated with eight modifiable risk factors, the top being midlife obesity, followed by physical inactivity and low educational attainment.[98]

In addition to *The Lancet* Commission report, the 2019 World Health Organization (WHO) recommendations to reduce risk of cognitive decline and dementia, an Alzheimer's Association article evaluating the effects of modifiable risk factors on cognitive decline and dementia, and a report from the National Academy of Medicine all point to the promising role of addressing these risk factors to reduce risk of dementia and cognitive decline.[99-101] These risk factors span the life course, and many risk factors that emerge later in life are affected, to some degree, by risk factors in middle age and earlier in life. Some may be modified by individual actions, others by policies, and many by both. This section focuses on risk factors common to the WHO recommendations, Alzheimer's Association article and National Academy of Medicine report.

Cardiovascular Health
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.[102] 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. One of the clearest examples of this relationship is how stroke — a cerebrovascular event that occurs when a blood vessel is blocked or bursts — markedly increases dementia risk.[103]

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia.[104] These factors include hypertension[85,105-107] and diabetes.[108-110] The age at which some risk factors develop appears to affect dementia risk. For example, midlife obesity,[105,111,112] hypertension,[85,105-107] prehypertension (systolic blood pressure from 120 to 139 mm Hg or diastolic pressure from 80 to 89 mm Hg)[85] and high cholesterol[113] are associated with an increased risk of dementia in later life. In contrast, late-life obesity[114] and hypertension onset after age 80[115] are associated with decreased risk of dementia.

Supporting the importance of modifiable risk factors, a recent study of more than 22,000 individuals age 18-89 found that the cognitive performance of individuals age 40-79 with none of eight modifiable risk factors was similar to that of people 10-20 years younger who had multiple risk factors.[116] Furthermore, another group of researchers found that addressing modifiable risk factors in midlife was associated with decreased risk of dementia even among groups of individuals with a higher genetic risk of dementia.[117] And so, while you cannot change the genes you've inherited, you may be able to influence their effect on cognition by addressing factors you can change.

Smoking, Physical Activity and Diet
Building on the connection between heart health and brain health, researchers have found that behaviors that influence the heart's health may also affect the brain and, in turn, the risk of developing dementia. Smoking is a behavior that increases risk of dementia.[118] In contrast, physical activity appears to decrease risk.[119-128] 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.[129-134] 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.[135-137]

A systematic review 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.[138]

Combinations of Health Factors and Health Behaviors

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 they better identify Alzheimer's and dementia risk than individual risk factors. Investigators 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,[139,140] the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER)[141] 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).[142]

Other studies are examining the effect of multiple daily activities that lower risk compared with the effect of a single daily activity that lowers risk. A recent study using data from the National Institute on Aging's longitudinal Health and Retirement Study found that the effect of multiple daily activities on memory decline was stronger than the effect of any individual activity.[143] The study considered 17 activities ranging from playing cards or doing word games to walking 20 minutes and speaking with or sending emails to family and friends. The researchers report that the effect of multiple daily activities increased with age, while the importance of historical factors such as education and baseline memory decreased.

Education

Researchers have long reported that 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.[80,144-149] Much of the research linking formal education to decreased risk of Alzheimer's was conducted without the benefit of technological advances such as PET imaging of the brain that might shed light on whether education affects Alzheimer's biomarkers such as beta-amyloid and tau accumulation that lead to dementia symptoms. More recent research incorporating these technological advances suggests that rather than reducing the risk of developing Alzheimer's brain changes, formal education may help sustain cognitive function in mid- and late life and delay the development of symptoms.[150,151]

To that point, 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.[152,153] 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.[154-157]

Other researchers emphasize the indirect effects of the number of years of formal education, such as its effects on dementia risk through socioeconomic status (SES). SES typically is defined as one's income, education and occupation but also includes factors such as financial security and perceived social standing. Having fewer years of formal education is associated with lower SES.[158] SES has many effects on one's health that are relevant to dementia risk. Researchers report that lower SES is associated with being less physically active,[159] having a higher risk of diabetes,[160-162] and being more likely to have hypertension[163] and to smoke[164] — all of which are risk factors for dementia. In fact, in 2022 researchers reported that SES is associated with changes in brain anatomy, including gray matter volume, that may affect overall cognitive ability.[165]

In addition, lower SES may decrease one's access to and ability to afford heart-healthy foods that support brain health; decrease one's ability to afford health care or medical treatments, such as treatments for cardiovascular risk factors that are closely linked to brain health; and limit one's access to physically safe housing and employment. The latter could increase one's risk of being exposed to substances that are toxic to the nervous system such as air pollution,[166] lead[167] and pesticides.[168]

It's important to realize that SES is not a biological entity, but rather a social construct reflecting inequities in how individuals and populations are treated and have been treated over time. It also reflects inequities in the perceived social standing of individuals and populations based on factors largely outside of their control.

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.[119,169-176] 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.[175] More research is needed to better understand the mechanisms that link social and cognitive engagement to dementia risk, along with types of activities that provide benefit.

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.[177] TBI is associated with an increased risk of dementia.[178-180]

According to the Centers for Disease Control and Prevention (CDC), people age 75 and older had the highest numbers and rates of TBI-related hospitalizations and deaths, accounting for about 32% of TBI-related hospitalizations and 28% of TBI-related deaths.[181] In 2018 and 2019, falls were the leading cause of TBI-related deaths among those 75 and older.[177]

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia[182] and by the individual's initial score on the 15-point Glasgow Coma Scale.[183]

- *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.[184]
- *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.[178,180] 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.[185] 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.[186,187] 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 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 increased 30% per year played.[188] Currently, there is no test to determine if someone has CTE-related brain changes during life. 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.[189] A recent review of published articles examining CTE suggests that the relationship between these repeated impacts and CTE is probably causal.[190] 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.[191,192] CTE is a neuropathologic diagnosis, meaning it is characterized by brain changes that can only be identified at autopsy.

Other Risk Factors

Researchers are studying a variety of other potentially modifiable factors that increase risk of Alzheimer's and other dementias. While the strength of the evidence for these risk factors has not yet met that of the previously described risk factors, the body of evidence is growing.

Among the many factors being studied is inadequate sleep or poor sleep quality.[193-195] Researchers have found that an important function of sleep is the removal of beta-amyloid and other toxins from the brain.[196,197] Poor sleep quality such as that caused by obstructive sleep apnea may increase risk by interfering with blood flow to the brain and normal patterns of brain activity that promote memory and attention.[198,199]

There is also rapidly emerging evidence on how exposure to toxicants in the environment, especially 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.[166,200] A systematic review and meta-analysis reported that the evidence suggested a significant association between exposure to fine particulate matter and incidence of dementia.[201]

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.[202-208] The emergence of the novel coronavirus disease in 2019 (COVID-19) resulted in more than 1.6 million hospitalizations among Medicare beneficiaries between January 1, 2020, and November 20, 2021.[209] These hospitalizations, which numbered more than what would have been expected in the absence of COVID-19, may potentially increase the number of people who develop cognitive impairment. Furthermore, a proportion of those patients hospitalized with COVID-19 will have received mechanical ventilation, which by itself increases one's risk of delirium,[210] an acute state of short-term confusion that is a risk factor for dementia.[211-213]

Additional research is needed to build the evidence for these and other risk factors being investigated and, importantly, to determine how these risk factors may vary across the lifecourse and among different racial and ethnic groups.

Looking to the Future

The relatively recent discovery that Alzheimer's disease begins 20 years or more before the onset of symptoms suggests that there is a substantial window of time in which we may be able to intervene in the progression of the disease. Scientific advances are already helping the field to make progress in these presymptomatic years. For example, advances in the identification of biomarkers for Alzheimer's make it possible to identify individuals who have beta-amyloid accumulation in the brain and who may qualify for clinical trials of experimental treatments that aim to reduce the accumulated beta-amyloid and in so doing prevent or delay the onset of symptoms. Biomarkers also enable earlier detection of Alzheimer's, giving those affected the opportunity to address modifiable risk factors that may slow or delay cognitive decline. Biomarkers are already accelerating the development of new treatments by making it possible for clinical trials to specifically recruit individuals with the brain changes that experimental therapies target. In addition, biomarker, basic science and other research advances offer the potential to expand the field's understanding of which therapies or combination of 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, manage it and 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 Asian, Black, Hispanic, Native American, Alaska Native, and Native Hawaiian and other Pacific Islander communities.[214] The lack of representation is a concern because the population of older adults from these groups make up nearly a quarter or more of the older adult population, and that share is projected to grow.[215] Second, current data indicate that, compared with non-Hispanic White older adults, Black and Hispanic older adults are at increased risk for Alzheimer's (see Prevalence section, page 19). 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 White older adults are likely to be poorly understood. In addition, 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.

Inclusion is more than a matter of enrolling more participants from underrepresented groups. Increasing diversity among researchers and engaging with and seeking input from marginalized 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.[216] Only by improving representation in the participation and leadership of clinical trials, observational studies and other investigations will everyone have the potential to benefit from advances in Alzheimer's science.

PREVALENCE

AN ESTIMATED 6.7 MILLION AMERICANS ARE LIVING WITH ALZHEIMER'S DEMENTIA.

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.

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, health care systems and social safety nets. 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.

The number and proportion of Americans with Alzheimer's or other dementias is expected to continue to grow in coming years 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.[217,218] The baby-boom generation (Americans born between 1946 and 1964) has already begun to reach age 65 and beyond,[219] the age range of greatest risk of Alzheimer's dementia;[220] in fact, the oldest members of the baby-boom generation turned aged 75 in 2021. A number of recent studies have reported the positive observation that the incidence rate of Alzheimer's — the number of people per 100,000 who newly develop this condition per year — appears to have declined in the last decade or so (see "Trends in the Prevalence and Incidence of Alzheimer's Dementia Over Time," page 29). This decline in incidence has been attributed to improvements over the 20th century in Alzheimer's risk factors, such as increased prevention and treatment of hypertension and greater educational attainment.[221] However, even with this potentially lower incidence rate, the absolute number of people with Alzheimer's is still expected to continue growing because of the large 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 in years to come.

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

An estimated 6.7 million Americans age 65 and older are living with Alzheimer's dementia in 2023.[A2,222] Seventy-three percent are age 75 or older (see Figure 2, page 21).[222]

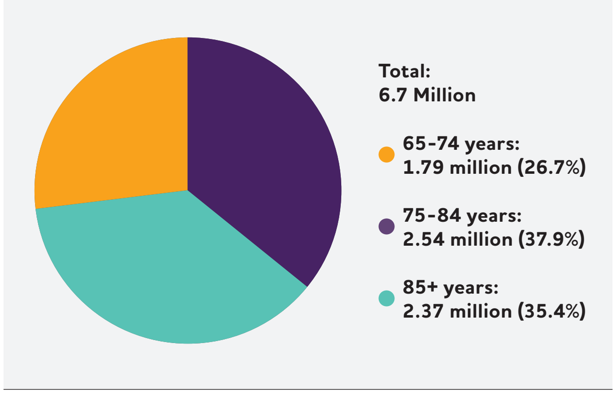
Of the total U.S. population:

- About 1 in 9 people (10.8%) age 65 and older has Alzheimer's dementia.[A2,222]
- 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 33.3% of people age 85 and older have Alzheimer's dementia.[A2,222] People younger than 65 can also develop Alzheimer's dementia. Although prevalence studies of younger-onset dementia in the United States are limited, researchers believe about 110 of every 100,000 people ages 30-64 years, or about 200,000 Americans in total, have younger-onset dementia.[223]

The estimated number of people age 65 and older with Alzheimer's dementia comes from an updated study using the latest data from the 2023 population 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.[222]

Figure **2**

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2023*



*Percentages do not total 100 due to rounding.

Created from data from Rajan et al.[A2, 222]

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from other population-based studies including the Health and Retirement Study (HRS), a nationally representative sample of older adults. Based on newly available estimates from HRS's Harmonized Cognitive Assessment Protocol (HCAP), 10% of people age 65 and older in the United States had dementia in 2016.[A3,149]

Mild Cognitive Impairment (MCI) 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 they require 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 about 17% of people age 65 and older had MCI.[51] The HRS HCAP study more recently estimated the prevalence of MCI in people age 65 and older to be 22%.[149] 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.[230,231] Therefore, roughly 8 to 11% of the 62 million Americans who are age 65 and older in 2023 — or approximately 5 to 7 million older Americans — may have MCI due to Alzheimer's disease. This rough prevalence estimate needs to be confirmed with population-based studies involving biomarkers and more discrete age-specific estimates.

Underdiagnosis of Alzheimer's and Other Dementias in the Primary Care Setting

Prevalence studies such as CHAP and the Aging, Demographics and Memory Study (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.[232-239] 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.[240-244] Because Alzheimer's dementia is often underdiagnosed — and if it is diagnosed by a clinician, people appear to often be 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*.[245]

Prevalence of Subjective Cognitive Decline

The experience of worsening or more frequent difficulties with thinking or memory (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.[246-250] Subjective cognitive decline refers to an individual's perception that their memory or other thinking abilities are worsening, independent of 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.[251-253] 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.[254] 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.[255] 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.[256] Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

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 Alzheimer's dementia (prevalence) and the pace at which people newly develop the condition (incidence).

The estimate of 6.7 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). In the future, this report could use data from multiple longitudinal studies using different symptom-based diagnostic criteria; these differences in criteria could result in different prevalence estimates from what we report here.[A3,149]

Almost all existing Alzheimer's dementia prevalence studies are based on the identification of clinical symptoms to classify an individual as having Alzheimer's dementia; they do not rely on the brain changes believed to be responsible for Alzheimer's disease across the continuum of the disease. As data sources, methods and scientific knowledge improve, estimates of prevalence may incorporate these brain changes. This addition could lead to very different prevalence estimates for a number of reasons, which are discussed below.

Prevalence Estimates of Dementia Due to Alzheimer's Disease Based on Biomarkers and Dementia Symptoms

First, a prevalence estimate of *dementia due to Alzheimer's disease* based on Alzheimer's brain changes, as well as overt clinical dementia symptoms, is likely to be lower than the 6.7 million figure reported here. This is because biomarker-based studies[21,71,224-226] indicate 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 meet the criteria for clinical Alzheimer's dementia based on symptoms did not have Alzheimer's-related brain changes. Thus, these studies indicate that, compared with prevalence estimates based only on symptoms, estimates using biomarkers of Alzheimer's disease could be up to 30% lower than current figures. This would translate to roughly 4.7 million Americans age 65 and older being classified as having dementia due to Alzheimer's disease in 2023.[A3,149]

Prevalence Estimates of Alzheimer's Disease Based on Biomarkers and any Cognitive Symptoms (Mild to Severe)

Second, as measurements of the brain changes of Alzheimer's disease become more widely available in studies, we will be able to estimate how many people have *Alzheimer's disease* (not just dementia due to Alzheimer's disease). This estimate would include people with the earliest detectable stages of cognitive impairment who have the brain changes of Alzheimer's but not the overt symptoms of dementia 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; see Overview, page 4). More recently, with the advent of biomarkers that detect the brain changes believed to characterize Alzheimer's disease, 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, which will result in a larger number than the number of Americans with Alzheimer's dementia. As reported in this section, using the best data available, an estimated 5 to 7 million Americans age 65 and older have MCI due to Alzheimer's disease. Combined with the roughly 4.7 million Americans age 65 and older with dementia due to Alzheimer's disease based on Alzheimer's brain changes, this would translate to approximately 10 to 12 million older Americans with Alzheimer's disease and some form of cognitive symptoms in 2023. Because MCI develops years before dementia onset and can affect individuals younger than 65, there are likely more than 5 to 7 million people of any age with MCI due to Alzheimer's disease, and thus this number could be even higher for all ages.

Prevalence of Alzheimer's Disease Across the Entire Cognitive Spectrum

Finally, the National Institute on Aging — Alzheimer's Association (NIA-AA) Framework[227] hypothesizes that there is an incipient and silent (i.e., "preclinical") stage of Alzheimer's disease before the emergence of cognitive symptoms of either MCI or dementia (see Overview, page 4). While this is still the subject of additional research, estimates are emerging of the prevalence of preclinical Alzheimer's disease in the population.[228,229] 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. We also need to further understand if this preclinical stage is a valid representation of people who may go on to develop dementia due to Alzheimer's disease. When a conclusive connection is shown between biomarkers and the preclinical stage, and when epidemiological studies include biomarker-based diagnoses, a prevalence estimate of Alzheimer's disease that includes individuals throughout the entire continuum of Alzheimer's disease (i.e., those with biomarker-confirmed Alzheimer's dementia, those with biomarker-confirmed MCI due to Alzheimer's disease and those with biomarker-confirmed preclinical Alzheimer's disease) will be even higher than any estimates presented in the current report.

Future *Facts and Figures* Prevalence Estimates

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 Alzheimer's dementia stage, defined according to clinical symptoms only, currently estimated at 6.7 million Americans, in addition to the best available estimated prevalence of MCI due to Alzheimer's disease. When biomarker-based prevalence estimates become available, *Facts and Figures* will report the estimated prevalence of individuals with Alzheimer's disease to reflect both those in the dementia phase and those in the MCI phase of Alzheimer's. *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 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. It should be noted that both symptom-based prevalence estimates of Alzheimer's dementia and biomarker-based prevalence estimates of Alzheimer's disease are expected to increase in the future due to growth in the proportion of Americans age 65 and over, the population most at risk for developing both cognitive symptoms and the underlying disease.

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

Based on projections shown in Figure 3, page 25, between 2020 and 2025 every state across the country (excluding the District of Columbia) 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, page 24.[A4,257]

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 people 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.[258] 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 — for example, the number of people who develop Alzheimer's dementia during 2023 among U.S. adults who are 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 2023 if CHAP estimates were available for that year.[259] The rate at which new cases of Alzheimer's develop 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 in people age 85 and older, the incidence was 7.6% (76 of every 1,000 people).[259] A 2015 study using data from the Adult Changes in Thought Study, a cohort of members of the health care delivery system Group Health Cooperative of Puget Sound,

Table **4**

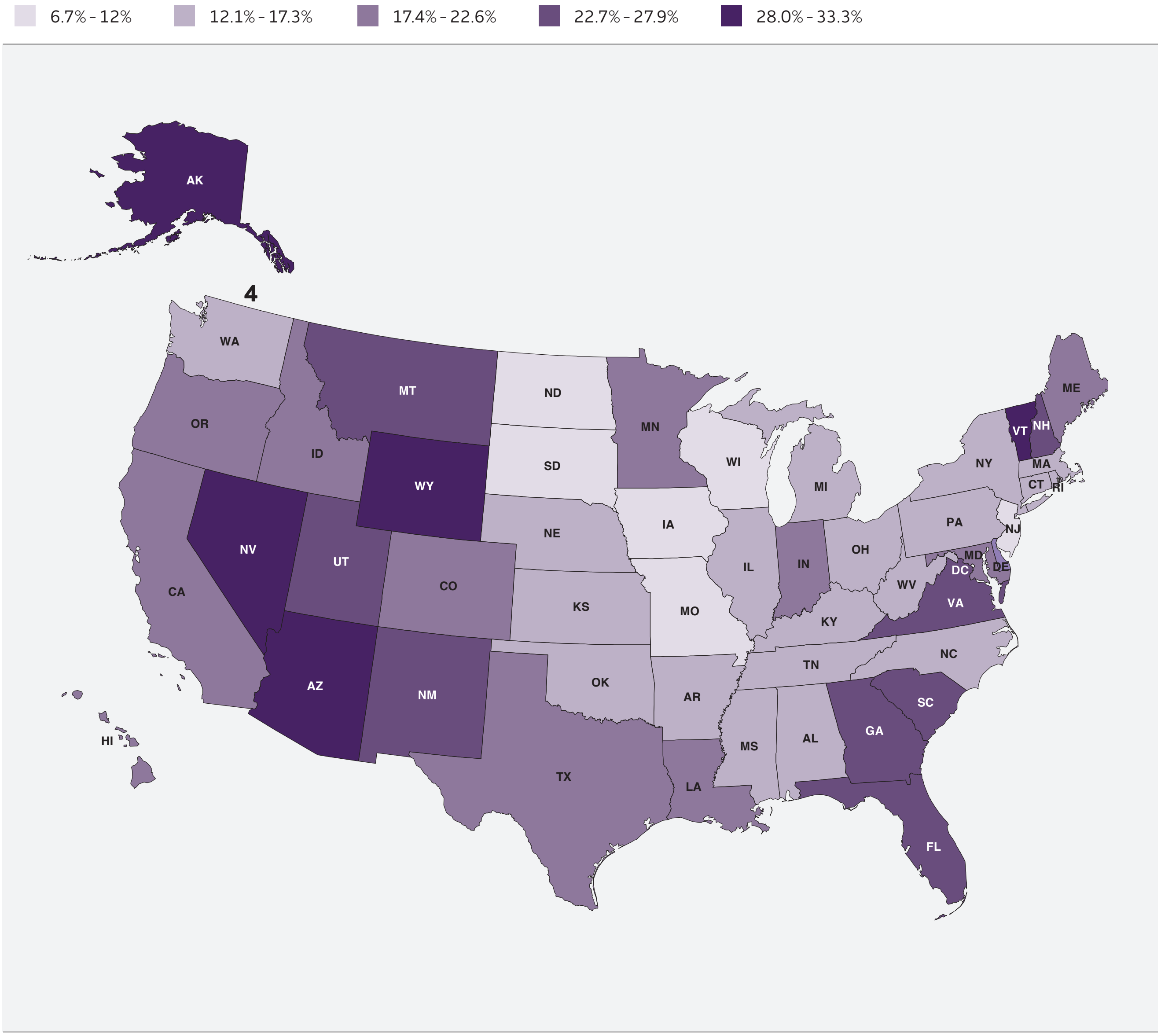
Projections of Total Numbers of Americans Age 65 and Older with Alzheimer's Dementia by State

	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. [A4,257]

Figure 3

Projected Increases Between 2020 and 2025 in Alzheimer's Dementia Prevalence by State

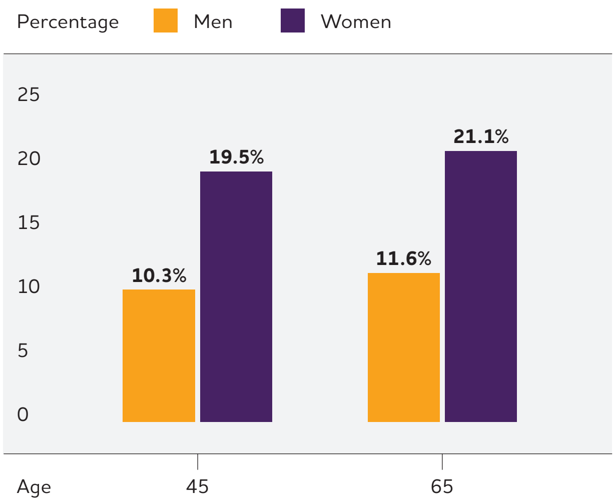


Change from 2020 to 2025 for Washington, D.C.: 1.1%.

Created from data provided to the Alzheimer's Association by Weuve et al.[A4,257]

Figure 4

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



Created from data from Chene et al.[261]

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 those age 85 and older, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050.[260]

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 risk of Alzheimer's dementia by age and sex.[A5,261] 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.[261]

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

Almost two-thirds of Americans with Alzheimer's dementia are women.[222] Of the 6.7 million people age 65 and older with Alzheimer's dementia in the United States, 4.1 million are women and 2.6 million are men.[222] This represents 12% of women and 9% of men age 65 and older in the United States.[218]

Women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.[261-263] This survival difference contributes to the 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 meaningful difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age.[10,80,263-265] Some European studies have reported a higher incidence among women at older ages,[266,267] and one study from the United Kingdom reported higher incidence among men.[268] Differences in the risk of dementia between men and women may therefore depend, in part, on age and/or geographic region.[269,270]

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.[262] Recent studies have supported the notion that selection bias contributes to reports of sex and gender differences in Alzheimer's dementia risk.[271] 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[272] (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 a combination of the two.[269,273,274] 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.[275] 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.[276] Interestingly, European studies have found that the relationship of lower educational attainment with dementia outcomes may be stronger in women than men.[277,278] 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 than women who were not part of the paid workforce.[271,279,280] Gender differences during the lockdown phase in the early part of the COVID-19 pandemic included increased child care and job loss in sectors where women were more likely to be employed.[281-283] It is unclear how these differential impacts on women may affect their brain health in the future. Researchers have begun exploring how mental health challenges, lost job opportunities and decreased employment earnings experienced during the pandemic may affect women's ability to maintain brain health.[282]

It is unclear whether genetic risk operates differently in women and men in the development of, or susceptibility to, Alzheimer's pathology.[284] A number of studies have indicated 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[285,286] and neurodegeneration[287] 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 is thought to exert its largest effects.[288] It is unclear whether the influence of APOE-e4 may depend on the sex hormone estrogen.[289,290]

It should be recognized that not all sex and gender identities can be reduced to binary categories. Individuals who identify with nonbinary sex or gender identities may have different risks for Alzheimer's disease (see "Risk for Alzheimer's and Other Dementias in Sexual and Gender Minority Groups," in this section).

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

In the U.S., non-Hispanic Black and Hispanic older adults are disproportionately more likely than White older adults to have Alzheimer's or other dementias.[291-297] 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.[222] Most other prevalence studies also indicate that Black older adults are about twice as likely to have Alzheimer's or other dementias as White older adults.[149,259,298,299] Some other studies indicate Hispanic older adults are about one and one-half times as likely to have Alzheimer's or other dementias as White older adults,[299-301] though others have shown similar prevalences among Hispanic older adults and White older adults.[149] The population of Hispanic people 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).[302,303]

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.[304,305] Race does not have a genetic basis, and genetic factors do not account for the large differences in prevalence and incidence among racial groups.[304,306] While there is some research into how the influence of genetic risk factors on Alzheimer's and other dementias may differ by race — for example, the influence of the APOE-e4 allele on Alzheimer's risk may be stronger for White Americans than Black Americans[82-86,307] — these small differences in genetic influence do not account for the large differences in dementia risk across racial groups. Race is a social construct with little to no genetic or other biological support. Instead, race is an idea created and used throughout history by groups in power to justify their control and dominance over other groups.

The difference in risk for Alzheimer's and other dementias among racial and ethnic groups is most likely 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.[308] 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.[309,310] 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 toxicants 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.[311-313]

The cumulative stress imparted by the effects of structural racism and the resulting differences in social and physical environment may directly influence dementia risk among historically marginalized and socially disadvantaged racial and ethnic groups. Further, structural racism leads to disparities by race and ethnicity in a wide range of health outcomes including increased risk for chronic conditions that are themselves associated with higher dementia risk for historically marginalized racial and ethnic groups, such as cardiovascular disease and diabetes. These health conditions, which disproportionately affect Black and Hispanic populations, are believed to explain much of the elevated risk of dementia among Black and Hispanic populations.[82,308,314,315] Many studies suggest that racial and ethnic differences in dementia risk do not persist in rigorous analyses that account for health and socioeconomic factors.[145,304,316]

The influence of structural racism on health and dementia risk 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.[311-313] 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.[308,315]

Many of the social processes that influence disparities in the development of Alzheimer's could also influence whether and when a diagnosis of dementia occurs. 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.[234,236,239,317,318] 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.[319] Although these percentages indicate that the dementia burden is greater among Black and Hispanic older adults than among White older adults, the percentages should be even higher according to prevalence studies that detect all people who have dementia irrespective of their use of health care systems.

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.[305] 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 (the term used in the study for those who self-reported as Black or African American); 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.[320] 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.[321] 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,[322] those who identify with more than one race or ethnicity, and subgroups of origin within racial or ethnic groups.[319] 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 and ethnic groups and subgroups.

Risk for Alzheimer's and Other Dementias in Sexual and Gender Minority Groups

There are other groups with shared social identities and characteristics that may experience different risks of Alzheimer's and other dementias. This includes members of sexual and gender minority (SGM) groups. SGM refers to individuals who identify as lesbian, gay, bisexual (sexual minorities), and/or transgender or gender non-binary, as well as people with a gender identity, gender expression or reproductive development that varies from traditional, societal, cultural or physiological norms (gender minorities).

SGM older adults may face an increased dementia risk, at least indirectly, through pervasive exposure to systematic discrimination, marginalization, disadvantage and/or exclusion from social institutions and enterprises. Those enterprises include Alzheimer's research, and, until recently, little has been known about the dementia risks of people who self-identify as SGM, including whether SGM older adults are at greater risk for dementia than non-SGM older adults. Although studies designed to investigate this question have been few, a growing body of preliminary evidence suggests that this may be the case. In a study of adults living in any of 25 U.S. states, SGM older adults reported experiencing more cognitive problems than non-SGM older adults.[323] Two population-based studies found higher rates of cognitive impairment among SGM older adults than among non-SGM older adults,[324,325] yet a third study reported that the risk for dementia and risk for MCI were similar for people in same-sex relationships and people in another-sex relationships.[326] Two studies found indications of potentially elevated dementia risk among transgender adults. One study of Medicare beneficiaries estimated that dementia was present among 18% of transgender adults age 65 years and older, compared with 12% among cisgender (not transgender) adults.[327] A second study of adults in Florida reported that transgender adults were more likely than cisgender adults to have a diagnosis of Alzheimer's and other dementias in their electronic medical records.[328]

More research is necessary to establish whether there are disparities in dementia risk for SGM older adults and to understand reasons for any potential disparity. Researchers have hypothesized that stressors experienced by SGM older adults, such as discrimination and marginalization, may elevate their risk for Alzheimer's and other dementias.[274] These stressors could take a toll on the physical and mental health of SGM older adults.[329] One study showed that SGM older adults who were experiencing depression were more likely to have dementia than their non-SGM peers.[330] SGM older adults experience disparities in other health-related factors that themselves elevate the risk of Alzheimer's and other dementias. These include higher alcohol and tobacco use, and obesity and other cardiovascular risk factors compared with non-SGM older adults. Further, SGM older adults have lower rates of accessing health care and having preventive health screenings, in part due to experiencing barriers such as discrimination and heterosexist attitudes in health care settings.[331] Finally, the history of HIV/AIDS and its burden of illness, mortality and social stigma has been tied to the SGM population, particularly gay and bisexual men and transgender people, since HIV/AIDS was first recognized. HIV/AIDS is now a chronic condition that can be managed successfully with medication, and many people with HIV/AIDS survive into older ages. In addition to any effects of this history on aforementioned social stressors and health care access, HIV/AIDS itself is a risk factor for dementia.[332] The elevated prevalence of HIV/AIDS in gay and bisexual men and transgender people puts them at higher risk for dementia due to HIV/AIDS than non-SGM older adults.

There is increasing recognition that historically marginalized groups — whether defined by gender, sexual orientation, race/ethnicity or other traits — are rarely monolithic when it comes to their identities and experiences. These identities and experiences intersect, and belonging to more than one of these groups may be particularly consequential for health, including dementia risk. This "intersectionality" framework is important for developing more informative dementia research and more effective and compassionate dementia care in these communities. It is important that research and care efforts consider how gender, race, ethnicity, class, sexual orientation and HIV status may intersect and influence dementia.[333, 334]

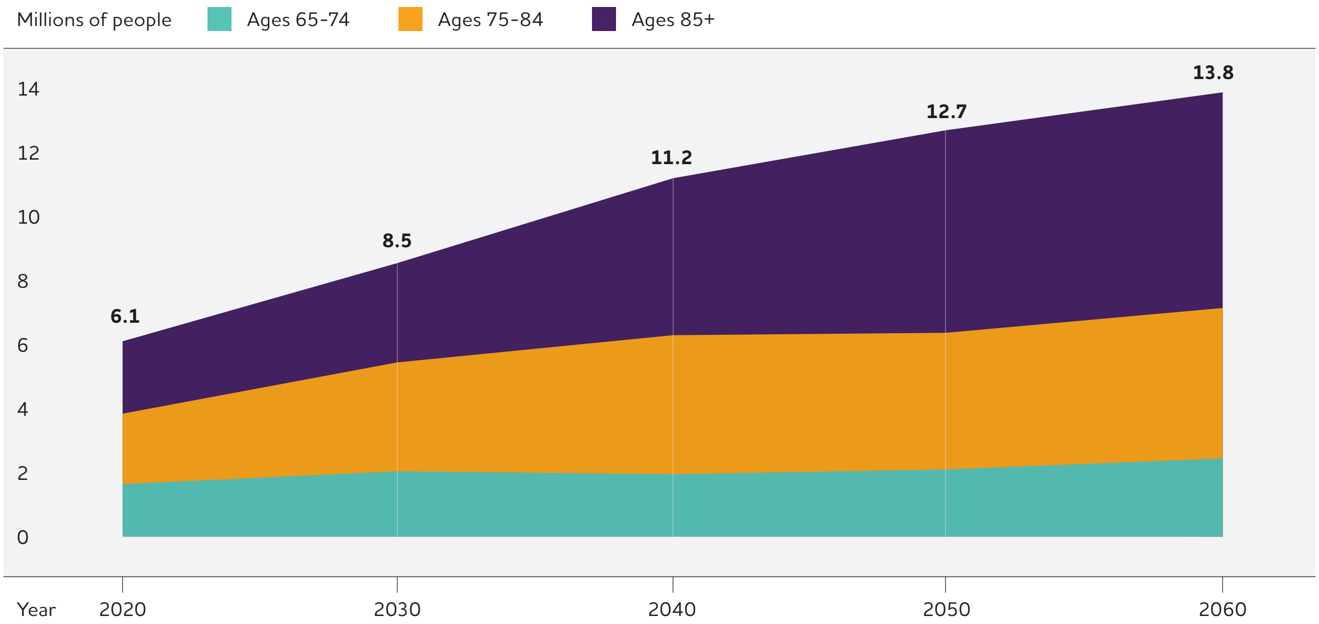
Trends in the Prevalence and Incidence of Alzheimer's Dementia Over Time

A growing number of studies indicate that the prevalence[220,239,264,318-322,335-337] and incidence[268, 335-344] of Alzheimer's and other dementias in the United States and other high-income countries may have declined in the past 25 years,[268,276,335-343,345-348] though results are mixed.[62,259,349,350] 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 low-income and middle-income countries.[351] Declines in dementia risk have been attributed to increasing levels of education and improved control of cardiovascular risk factors.[276,338,341,345,352,353] Such findings are promising and suggest that identifying and reducing risk factors for dementia may be effective — whether interventions occur person by person (such as obtaining treatment for one's blood pressure) or are integrated into the fabric of communities (such as changes in education policies). 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 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 declines in incidence will continue given worldwide increases in diabetes and obesity among people younger than 65 years old. Diabetes and obesity are risk factors for Alzheimer's dementia, and these increases may lead to a rebound in dementia risk in coming years.[336,354-357] It is also not clear that these encouraging trends pertain to all racial and ethnic groups.[259,297,352,353,358,359] Thus, while

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.[A6,222]

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.[360] Finally, it is not known how COVID-19 will influence the prevalence and incidence of Alzheimer's dementia. For example, the neurologic effects of COVID-19[361] and the pandemic's disruptions to general and brain-related health care may increase the incidence of Alzheimer's and other dementias. Some researchers have surmised that factors such as social isolation from lockdowns, no-visitor policies in long-term care facilities, and increased intensive hospitalizations may increase dementia risk at the population level, but research in coming years will be necessary to confirm this. On the other hand, increased mortality due to COVID-19 and other causes of death during the pandemic in 2020-2022 may result in death prior to the onset of Alzheimer's dementia, or death with fewer years lived with Alzheimer's dementia.[362]

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. 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 2023).[218,363,222] Additionally, the older adult population is expected to continue to increase relative to the population age 64 and younger — a shift known as population aging — due to a projected decline in fertility, as well as to mortality improvements at older ages. Fertility, the average number of children per woman in the United States, has decreased since 1960.[364] With fewer babies born each year, older adults will make up a larger proportion of the population. Because increasing age is the predominant risk factor for Alzheimer's dementia, as the number and proportion of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's dementia, as shown in Figure 5.[A6,222]

- By 2025, the number of people age 65 and older with Alzheimer's dementia is projected to reach 7.2 million — an 7% increase from the 6.7 million age 65 and older affected in 2023.[222]
- 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.[A6,222]

Growth of the Age 85 and Older Population

The number of Americans in their 80s, 90s and beyond is expected to grow dramatically due to the aging of the large baby-boom cohort.[363] This will lead to an increase in the number and percentage of Americans 85 and older. Between now and 2050, this age group is expected to comprise an increasing proportion of the U.S. population age 65 and older — from 11% in 2023 to 22% in 2050.[363] This will result in an additional 12 million people age 85 and older— individuals at the highest risk for developing Alzheimer's dementia.[363]

- In 2023, about 2.4 million people who have Alzheimer's dementia are age 85 or older, accounting for 33% of all people with Alzheimer's dementia.[222]
- 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.[222]

Increased Diversity of Older Adults

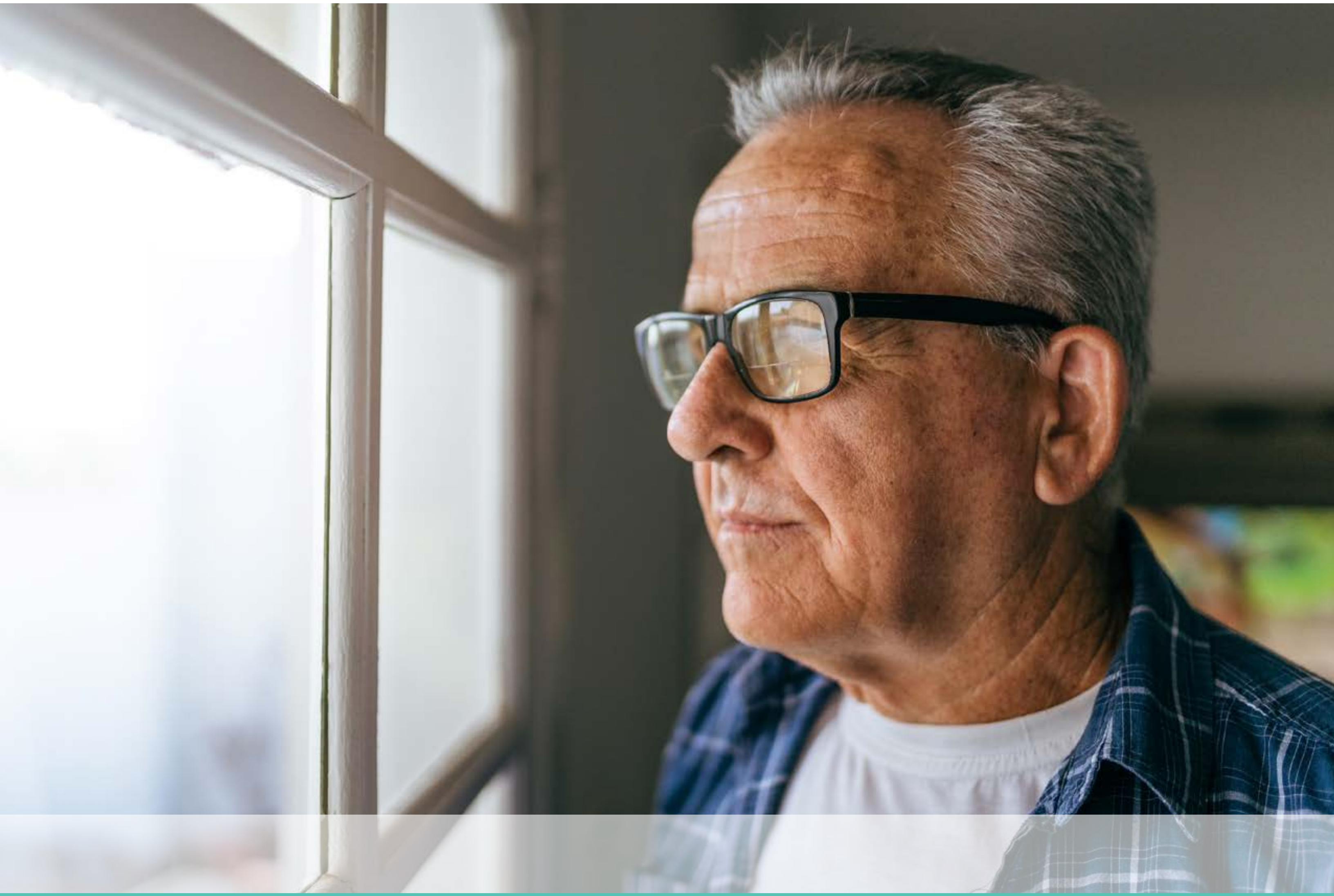
The group of older adults who will be at risk for Alzheimer's in the coming years will be socially, culturally and economically different from previous groups of older U.S. adults. For example, between 2018 and 2040, projections for older adults show increases in the American Indian population of 75%, in the Black population of 88%, in the Asian population of 113% and in the Hispanic population of 175%.[365]

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.[366] In parallel, these generations of women came of age during a decrease in the birth rate, resulting in smaller family size.[367] 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.[368-370]

MORTALITY AND MORBIDITY

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.



Alzheimer's disease was officially listed as the sixth-leading cause of death in the United States in 2019.[371] In 2020 and 2021, when COVID-19 became the third-leading cause of death, Alzheimer's disease was the seventh-leading cause of death; official counts for 2022 are still being compiled.[372]

Alzheimer's disease was the fifth-leading cause of death among individuals age 65 and older in 2019.[371] Alzheimer's disease may cause even more deaths than official sources recognize. It is also a leading cause of disability and poor health (morbidity) in older adults.[373] Before a person with Alzheimer's dies, they are likely to 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 Effect of the COVID-19 Pandemic on Deaths from Alzheimer's Disease," opposite, 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.[371] 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."[374] 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 term "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).[371,375] 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.[376-379] 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.[377] Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[377,378] 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."[380]

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

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

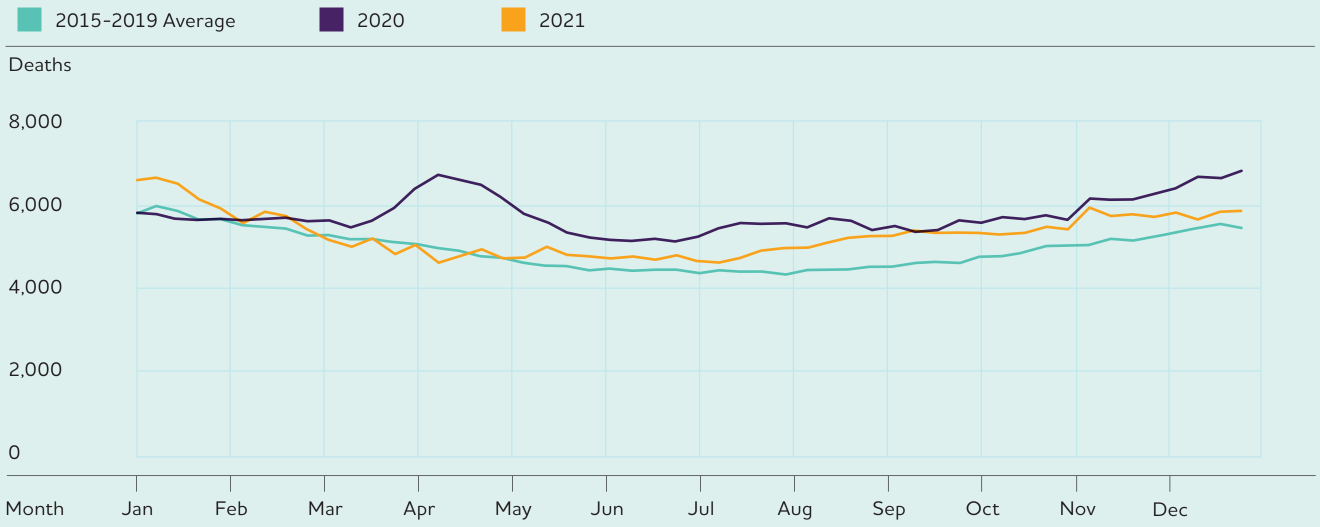
In 2020 and 2021, COVID-19 was the third-leading cause of death in the United States, pushing Alzheimer's disease from the sixth to the seventh-leading cause of death.[372] Data for 2022 were still being compiled as of the time this report was written. Despite the change in rankings on the list of causes of death, the total number of deaths from Alzheimer's disease recorded on death certificates increased 10.5% between 2019 and 2020 to 134,242.[371] 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 (CDC) 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.[385] Many of these excess deaths were in vulnerable older adults with Alzheimer's disease and other dementias. Among Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias, overall mortality increased 26% between 2019 and 2020, which is twice as high as the increase for beneficiaries without Alzheimer's disease and other dementias.[386] Further, increased mortality between 2019-2020 among Medicare beneficiaries with Alzheimer's disease and related dementia was greater among Black, Hispanic, and Asian beneficiaries than among White beneficiaries and the nursing home population.[386] As shown in Figure 6, compared with the average annual number of deaths in 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.[371] In 2021, there were about 20,000 more deaths from Alzheimer's and other dementias compared with the average of the five years before 2020.[372] 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 in 2020 and 2021 far exceeded what would have been expected from the normal trend line.

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 in 2020 or 2021, Alzheimer's disease or another dementia was listed as a multiple cause of death on almost a quarter of death certificates.[372]

COVID-19 has clearly had a dramatic effect on mortality from Alzheimer's and other dementias. Nursing homes and other long-term care facilities were the site of major outbreaks in the early stages of the pandemic and residents with Alzheimer's and other dementias were particularly vulnerable. What remains unclear is whether and how this will affect the longer-term trend in deaths from Alzheimer's as the COVID-19 pandemic starts to subside. As the pandemic has progressed and COVID-19 is no longer as fatal for most people, the question of "dying with" or "dying from" COVID-19 is getting harder to parse. In many ways this echoes the discussion about dying with or from Alzheimer's disease discussed in this section (see page 33). What is clear is that for at least the first years of the pandemic, having Alzheimer's or another dementia makes older adults more vulnerable to COVID-19 and increases the likelihood of dying from COVID-19.

Figure **6**

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

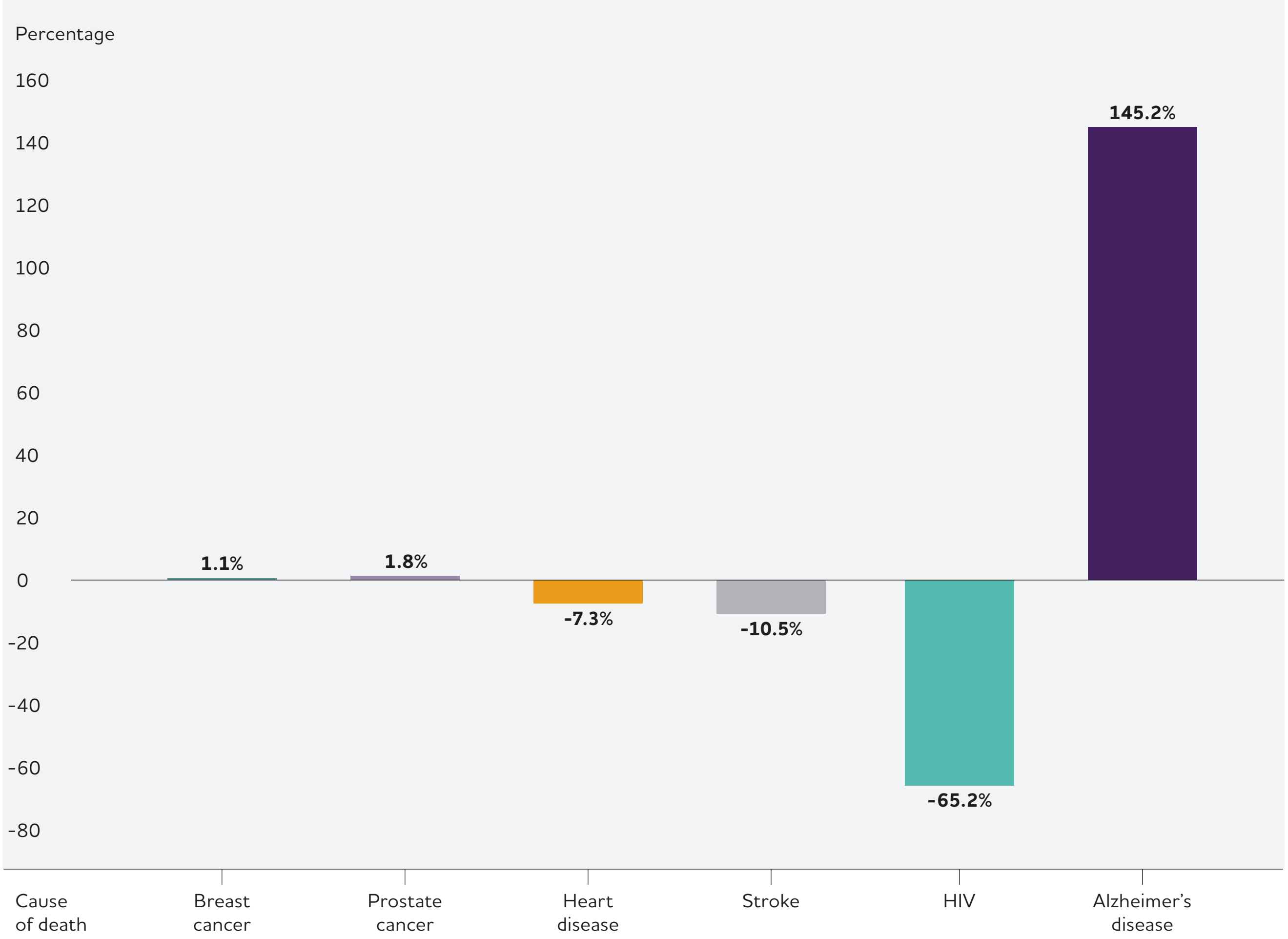


*Data for 2021 are as of February 7, 2022.

Created from data from the National Center for Health Statistics.[385]

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.[371,387]

attributed to Alzheimer's dementia (estimates for people age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if the individuals did not have Alzheimer's dementia.[376] A more recent study using data from the nationally representative Health and Retirement Study (HRS) 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.[381] According to 2019 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.[382] 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.[383] Although some undoubtedly died from causes other than Alzheimer's, it is likely that many died from Alzheimer's disease itself or from conditions for 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).[21,71,224-226] 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.[384]

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.[A7,371]

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 *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%, while deaths from the number-one cause of death (heart disease) decreased 7.3% (Figure 7, page 35).[371,387] The increase in the number of death certificates listing Alzheimer's as the underlying cause of death probably reflects two trends: first, Alzheimer's has become a more common cause of death as the population ages, and second, over time, physicians, coroners and others who assign causes of death may be increasingly likely to report Alzheimer's on death certificates.[388]

State-by-State Deaths from Alzheimer's

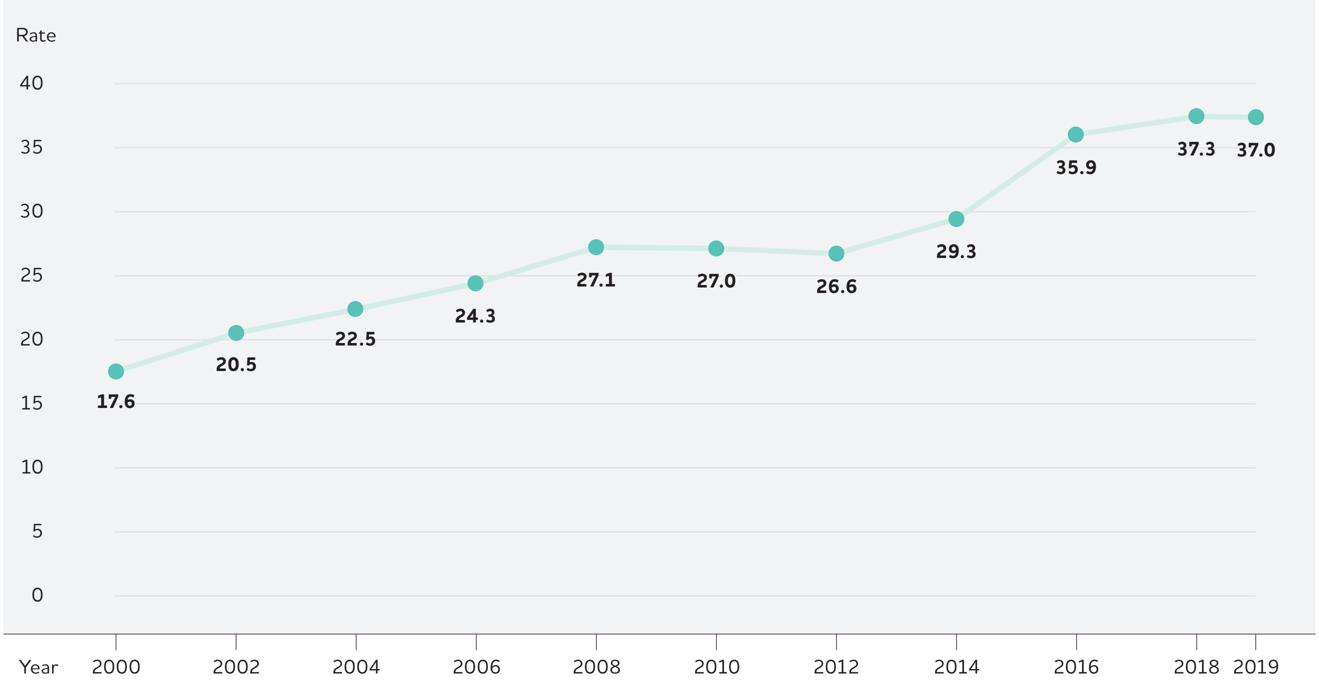
Table 5 provides information on the number of deaths due to Alzheimer's by state in 2019, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician or other medical personnel who filled out the death certificate as the underlying cause of death. The table also provides annual mortality rates by state, computed with the death certificate data, to compare the risk of death due to Alzheimer's disease across states with varying population sizes. For the United States as a whole, in 2019, the mortality rate for Alzheimer's disease was 37 deaths per 100,000 people.[A7,371]

Alzheimer's Death Rates

As shown in Figure 8, the annual 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.[371] Table 6, page 38, shows that the annual rate of death from Alzheimer's increases dramatically with age, especially after age 65.[A7,371] The increase in the Alzheimer's death rate over time has disproportionately affected people age 85 and older.[387] 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.[371] A report by the CDC determined that even after adjusting for changes over time in the specific ages of people within these age groups, the annual Alzheimer's death rate in the United States increased substantially between 1999 and 2014.[388] Therefore, the advancing average age of the 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

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.[371]

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.[371]

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.[388]

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.[384] 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.[384] 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.[389]

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 measures that 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, in recent years, the burden of Alzheimer's has increased more dramatically in the United States than the burden of other diseases. 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.[374]

These estimates should be interpreted with consideration of the comparability of data across time and place[390] and how disability is incorporated. These Alzheimer's burden estimates use different sources for each state in a given year, and data sources for states may differ over the years. Models do not account for the context in which disability is experienced, including social support and economic resources,[391] which may vary widely. Models may not fully account for variation in disability levels between individuals and along the Alzheimer's trajectory. 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 placed on ensuring the health and well-being of people with Alzheimer's disease in the years before death. Innovation in methods to more fully capture the lived experience of disability and inclusion of people with dementia and their families and caregivers in research studies are required to understand the contribution of Alzheimer's disease to poor health, disability and mortality.

CAREGIVING

MORE THAN 11 MILLION AMERICANS PROVIDE UNPAID CARE FOR A FAMILY MEMBER OR FRIEND WITH DEMENTIA, A CONTRIBUTION TO THE NATION VALUED AT NEARLY $340 BILLION.

Caregiving refers to attending to another person's health needs and well-being.

When supporting persons with Alzheimer's, 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.[392, 393] Caregivers also provide emotional support to people with Alzheimer's, help them manage health conditions, and communicate and coordinate care with other family members and health care providers to ensure safety at home and elsewhere (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.[394] Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.[395] More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A8]

In 2022, caregivers of people with Alzheimer's or other dementias provided an estimated 18 billion hours[A9] of informal (that is, unpaid) assistance, a contribution valued at $339.5 billion.[A10] This is approximately 59% of the net value of Walmart's total revenue in fiscal year 2022 ($572.8 billion)[396] and more than 14 times the total revenue of McDonald's in 2022 ($23.3 billion).[397] The total lifetime cost of care for someone with dementia was estimated at $392,874 in 2022 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. Remaining costs encompass Medicare and Medicaid expenditures.[398,399] Current estimates of the lifetime costs of care may underestimate the financial impact of a relative's dementia on family caregivers' health and workplace productivity, as other potential costs such as home modifications, respite service use and health/work productivity challenges are not considered in cost estimates.[400]

Table **7**

Dementia Caregiving Tasks

Helping with instrumental activities of daily living (IADLs), such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.
Helping the person take medications correctly, either via reminders or direct administration of medications.
Helping the person adhere to treatment recommendations for dementia or other medical conditions.
Assisting with personal activities of daily living (ADLs), such as bathing, dressing, grooming and feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.
Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
Finding and using support services such as support groups and adult day service programs.
Making arrangements for paid in-home, nursing home or assisted living care.
Hiring and supervising others who provide care.
Assuming additional responsibilities that are not necessarily specific tasks, such as: • 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.

Table 8

Who Are the Caregivers?

Sex/gender	• Approximately two-thirds of dementia caregivers are women.[A11,406,407]
Race/ethnicity	• Two-thirds of caregivers are White,[A11,407,408] 10% are Black, 8% are Hispanic, and 5% are Asian American.[A11] The remaining 10% represent a variety of other racial/ethnic groups.
Living status	• Most caregivers (66%) live with the person with dementia in the community.[402] • Over 60% of caregivers are married, living with a partner or in a long-term relationship.[A11,407] • 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.[A11,408,409]
Caring for parents	• Over half of caregivers are providing assistance to a parent or in-law with dementia.[408] • 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.[410-412]
Income	• Forty-one percent of caregivers have a household income of $50,000 or less.[A11]
Education	• Approximately 40% of dementia caregivers have a college degree or more of education.[A11,407,408]
Age	• About 30% of caregivers are age 65 or older.[A11] • Twenty-three percent of caregivers ages 18 to 49 help someone with dementia, which is an increase of 7% since 2015.[413]
Caring for spouse	• Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.[408]

According to the 2014 Alzheimer's Association Women and Alzheimer's Poll which surveyed both men and women, among the reasons shared by caregivers for providing assistance to a person with Alzheimer's or another dementia are the desire to keep a family member or friend at home (65%), close proximity to the person with dementia (48%), and the caregiver's perceived obligation to the person with dementia (38%).[A11] In addition, caregivers often indicate love and a sense of duty when describing what motivates them to assume care responsibilities for a relative or friend living with dementia.[401]

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.[402] 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.[402] 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.[403]

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 due to potential social stigma and a diminished social network of available family or friend caregivers.[404,405]

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.[A11,406,407,412] 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).[414] Over one-third of dementia caregivers are daughters caring for a parent.[394,402] It is more common for wives to provide informal care for a husband than vice versa.[415] On average, female caregivers spend more time caregiving than male caregivers.[402] The 2015-2017 BRFSS surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.[409] Two and a half times as many women as men reported living with the person with dementia full time.[416] Of those providing care to someone with dementia for more than five years, 63% were women.[409] 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.[417-419] 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%).[409]

Race, Ethnicity and Dementia Caregiving

Only recently have population-based studies examined racial disparities in dementia caregiving. 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 care for someone with dementia (31.7% versus 11.9%). Black dementia caregivers are also more likely to provide help with ADLs than White dementia, White non-dementia and Black non-dementia caregivers.[420,421] Black male dementia caregivers are 3.3 times more likely to experience financial burdens when compared with Black female and White male and female dementia caregivers, whereas Black and White male dementia caregivers are 37%-71% less likely than White female dementia caregivers to indicate emotional burden.[422] Black dementia caregivers were found to be 69% less likely than White caregivers to use respite services, although the need for dementia care relief is considerable among Black families.[423,424] Hispanic, Black and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use and greater depression compared with White caregivers.[425-427] In a nationally representative study,[428] 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. Discrimination is also linked with depressive symptoms among African American dementia caregivers.[429]

Existing research also suggests nuanced findings related to racial and ethnic differences in dementia caregiving. For example, Black caregivers are more likely than White caregivers to report positive aspects of caregiving.[420] 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.[430] 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.[425] Having a more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among Black and White caregivers.[425]

The need for culturally informed theories, research frameworks, and services and supports for people living with dementia and their caregivers is pronounced.[431,432] Cultural values (e.g., *familismo*: the Latino cultural value of placing family needs and loyalty to one's family above one's own needs) may influence disparities in perceptions and use of support among caregivers across diverse racial and ethnic contexts.[433] Underutilization of needed services on the part of Latino dementia caregivers may be due to culturally incongruent expectations on the part of health care systems and providers that assume that families are the predominant/only support network for Latino individuals with dementia.[434] Black/African-American dementia caregivers' needs include greater education about dementia treatment, diagnosis and care strategies; navigating what is often perceived as a "broken" health care system; improved access to affordable transportation and health care services; greater education about navigation of family conflict; increased availability of respite support; better communication about dementia within the Black/African-American community; and increased availability of financial/legal planning.[424,435-437]

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, however. 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 other caregivers of color.[427] 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. Furthermore, if individuals continue to lack representation in Alzheimer's research, they will not receive the benefits of racially and ethnically sensitive prevention, treatment or care innovations.[425,427] Establishing stronger relationships with existing organizations and resources in Black communities, indigenous communities and other communities of color offers the potential for research-based partnerships to enhance representation in Alzheimer's disease research and result in more culturally appropriate and effective services.[432,434,438-449]

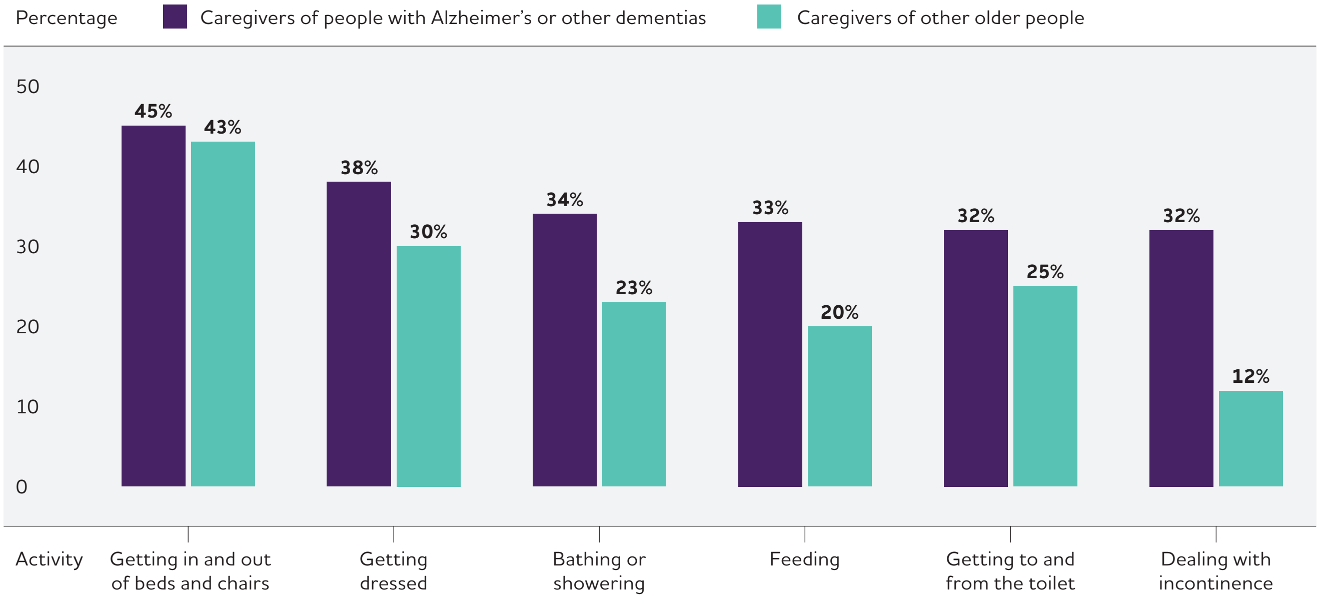
Caregiving Tasks

The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all-encompassing. Table 7, page 41 summarizes some of the most common types of dementia care provided.

Although the care provided by family members of people with Alzheimer's or other dementias is somewhat similar to that provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance.[450] Family caregivers of people with dementia are more likely to monitor the health of the care

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.[408]

recipient than are caregivers of people without dementia (79% versus 66%).[451] 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%).[395,406] Figure 9 illustrates how caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.[408]

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.[452]

When a person with Alzheimer's or another dementia moves to an assisted living residence or a nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 7 to providing emotional support, interacting with residential care staff and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing and other ADLs.[453,454]

Duration of Caregiving

A 2014 study found that 86% of dementia caregivers provided assistance for at least the past year.[A11] 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.[402]

Hours of Unpaid Care and Economic Value of Caregiving

In 2022, the 11.5 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 18 billion hours of unpaid help. This number represents an average of 30 hours of care per caregiver per week, or 1,565 hours of care per caregiver per year.[A9] With this care valued at the average of the state minimum wage and the median hourly cost of a home health aide (a conservative estimate),[A10] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was $339.5 billion in 2022. Table 9, page 45, 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 $5 billion in each of 23 states.

Table **9**

Number of Caregivers of People with Alzheimer's or Other Dementias, Hours of Unpaid Care and Economic Value of Unpaid Care by State, 2022*

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Alabama	216	385	$5,290
Alaska	25	39	795
Arizona	261	511	10,814
Arkansas	154	268	4,423
California	1,374	1,864	44,277
Colorado	160	186	4,393
Connecticut	128	201	4,231
Delaware	31	45	885
District of Columbia	14	15	333
Florida	827	1,301	23,409
Georgia	343	657	9,941
Hawaii	60	91	1,909
Idaho	65	103	1,848
Illinois	312	481	9,858
Indiana	216	321	5,174
Iowa	98	125	2,284
Kansas	89	125	1,989
Kentucky	157	302	4,867
Louisiana	200	363	4,850
Maine	51	87	1,896
Maryland	247	405	8,144
Massachusetts	213	308	7,075
Michigan	380	872	17,042
Minnesota	163	225	5,259
Mississippi	115	202	2,757
Missouri	223	350	6,466
Montana	17	25	$474
Nebraska	40	61	1,183
Nevada	84	141	2,642
New Hampshire	58	84	1,671
New Jersey	272	493	10,862
New Mexico	66	117	2,131
New York	546	884	19,089
North Carolina	369	533	8,067
North Dakota	19	25	463
Ohio	493	736	13,463
Oklahoma	135	164	2,679
Oregon	168	317	7,212
Pennsylvania	404	646	10,737
Rhode Island	36	51	1,129
South Carolina	216	355	5,465
South Dakota	26	34	709
Tennessee	367	496	7,744
Texas	1,000	1,507	23,552
Utah	99	122	2,278
Vermont	19	28	590
Virginia	354	529	10,350
Washington	300	434	10,907
West Virginia	65	116	1,591
Wisconsin	191	213	3,970
Wyoming	16	21	382
U.S. Total	**11,479**	**17,962**	**339,548**

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

Created from data from the 2016, 2020 and 2021 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, National Alliance for Caregiving, AARP, U.S. Department of Labor and Genworth. [A8,A9,A10]

Unpaid caregivers provided care valued at more than $19 billion in each of the four most populous states — California, Texas, Florida and New York. 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. In contrast, family care costs are reduced up to 24% in situations where caregivers indicated they were emotionally close to the person with dementia.[455,456] More research is needed to estimate the future value of family care for people with Alzheimer's disease and other dementias as the U.S. population continues to age.

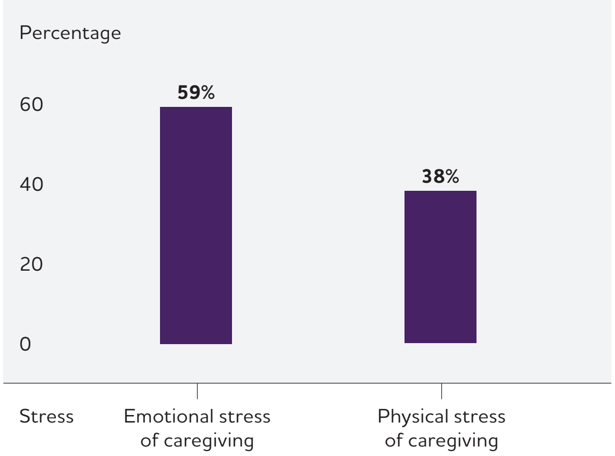
Apart from its long duration, caregiving involves demands that are time-intensive. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.[406] An analysis of national caregiving trends from 1999 to 2015 found that among dementia caregivers the average hours of care per week *increased* from 45 in 1999 to 48 in 2015; among non-dementia caregivers, weekly hours of care *decreased* from 34 to 24.[457] 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.[458] Each instance of a decrease in ADL or IADL function in someone with dementia results in nearly five more hours of monthly caregiving compared with a similar functional decrease for someone without dementia.[459]

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.[460-462] 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 both themselves and the person living with dementia.[463-470]

Figure **10**

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



Created from data from the Alzheimer's Association.[A11]

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 the 2017 National Poll on Healthy Aging, however, 45% of caregivers of people with dementia indicated that providing help to someone with cognitive impairment was very rewarding.[412] In the 2011 National Study of Caregiving, greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends.[471] Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,[A11,472-478] they also frequently report higher levels of stress.

Burden and Stress

- Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial and physical difficulties.[406,450]
- 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).[A11]
- 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.[479]

- 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.[480]

Depression and Mental Health (see also Table 10, page 49)

- A meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers.[419] Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.[481]
- The prevalence of depression is higher among dementia caregivers (30% to 40% as reported in multiple studies) than other caregivers, such as those who provide help to individuals with schizophrenia (20%) or stroke (19%).[482,483]
- Caring for a spouse with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.[484]
- 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.[482]
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).[482]
- Dementia caregivers in the United States were more likely to have experienced depression (32.5%) or anxiety (26%) when compared with dementia caregivers from Japan (16.8% and 12.9%, respectively) or those from across Germany, Italy, Spain, France and the United Kingdom (29.3% for depression and 22.4% for anxiety).[414]
- 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.[485,486]
- 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.[487]
- A systematic review found the prevalence of suicide ideation (thinking about or making plans for suicide) in dementia caregivers with a mean age of 64 was 32% compared with 2.7% in U.S. adults age 56 and older.[488,489]
- Sexual gender minority dementia caregivers are significantly younger and more likely to be employed than heterosexual dementia caregivers and indicate greater difficulty when paying for necessities while also reporting higher family quality of life than their heterosexual peers.[490]
- Providing physical and medical care is associated with worse mental health among dementia caregivers than non-dementia caregivers.[450]

Strain

- Caregivers of people with Alzheimer's or other dementias are 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.[451]
- Dementia caregivers often lack the information or resources necessary to manage complex medication regimens.[491-494]
- Compared with non-dementia caregivers, dementia caregivers indicate a greater decrease in their social networks.[495]
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.[A11]
- 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%).[A11]
- Many caregivers of people with Alzheimer's or other dementias provide help alone and are at risk of social isolation.[496] Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.[A11]
- 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.[497] Additional analyses of this sample found that the number of self-care and behavior problems was most predictive of caregiver burden and depression, regardless of whether the care recipient lived with dementia.[481]
- Among dementia caregivers of care recipients who have experienced severe psychiatric symptoms, those who live in low- or medium-income neighborhoods indicate higher distress than those caregivers living in high-income neighborhoods.[498]

Stress of Care Transitions

- Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases for some caregivers (such as spouses), but other studies have found that distress decreases.[454,499-501]
- The demands of caregiving may intensify as people with dementia approach the end of life.[502] 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.[503] The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.[503]
- 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).[504]

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.[505] As shown in Figure 10, page 46, 38% of Alzheimer's and other dementia caregivers indicate that the physical stress of caregiving is high to very high.[A11] Dementia caregivers are 1.5 times more likely to indicate substantial physical difficulty providing assistance to their care recipients compared with non-dementia caregivers.[506] 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.[507,508] 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.[508] In addition, many caregivers may contend with health challenges of their own. Tables 10 and 11 present data from 44 states and the District of Columbia on caregiver physical and mental health. Tables 10 and 11 present data on caregiver physical and mental health. Table 10 presents state-by-state data on the health status of dementia caregivers. Table 11, page 50, 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.[A11] A 2017 poll found that 27% of dementia caregivers delayed or did not do things they should to maintain their own health.[412,509,510] Data from the HRS 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.[511-514]

Physiological Changes

The chronic stress of caregiving may be associated with an increased incidence of hypertension and a number of physiological changes that could increase the risk of developing chronic conditions, including high levels of stress hormones, impaired immune function, slow wound healing and coronary heart disease.[515-522] 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.[523] However, a study of physiological changes before and after the start of caregiving found no change on six biomarkers of inflammation among dementia caregivers.[524]

Health Care

When people 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.[525,526] 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.[526] Dementia caregivers also have twice the odds of experiencing an overnight hospitalization than non-caregivers.[527]

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.[528,529] For example, spouses of those 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).[530] In addition, caregivers who perceived higher strain due to care responsibilities were at higher risk for death than caregivers who perceive

Table **10**

Percentage of Dementia Caregivers Reporting Health Conditions by State, 2015-2021

State	Percentage of Caregivers Reporting at Least One Chronic Condition	Percentage of Caregivers Reporting Depression	Percentage of Caregivers Reporting Frequent Poor Physical Health
Alabama	57.5	30.9	15.0
Alaska	53.7	27.7	15.2
Arizona*	53.5	†	†
Arkansas	72.8	38.0	25.0
California	61.0	18.6	13.1
Colorado	73.1	23.2	†
Connecticut*	64.0	27.9	9.4
Delaware	61.8	23.3	†
District of Columbia*	65.1	†	†
Florida	66.4	28.6	13.6
Georgia	51.6	25.1	11.7
Hawaii	49.6	16.5	8.1
Idaho	57.5	31.1	13.4
Illinois	64.2	29.0	†
Indiana	57.3	34.1	18.2
Iowa	60.5	27.4	13.8
Kansas	60.6	33.8	18.7
Kentucky	65.5	39.8	21.4
Louisiana	55.8	32.8	15.9
Maine	60.8	38.0	12.8
Maryland	55.7	24.8	8.4
Massachusetts	54.2	20.2	†
Michigan	66.0	30.6	22.1
Minnesota	53.1	29.8	8.4
Mississippi	69.3	32.2	13.2
Missouri	59.5	28.1	20.2
Montana*	56.9	22.8	†
Nebraska	57.6	25.4	13.2
Nevada	54.2	31.1	†
New Hampshire	‡	‡	‡
New Jersey	62.3	27.9	12.8
New Mexico	64.8	31.3	12.6
New York	59.0	24.7	12.0
North Carolina	58.8	41.0	18.1
North Dakota	60.1	30.4	8.6
Ohio	60.4	26.7	13.5
Oklahoma	59.1	24.4	17.2
Oregon	60.3	28.9	14.9
Pennsylvania	55.7	21.8	12.5
Rhode Island	54.2	41.0	11.5
South Carolina	60.6	31.0	15.2
South Dakota	61.0	22.2	†
Tennessee*	66.7	29.8	†
Texas	59.0	26.7	11.2
Utah	53.0	28.3	9.6
Vermont	61.5	35.4	10.7
Virginia*	60.4	23.6	13.8
Washington	‡	‡	‡
West Virginia	63.5	32.2	12.0
Wisconsin	53.4	22.4	10.5
Wyoming	59.8	22.8	†

*Data are for caregivers of individuals whose main reason for needing care is Alzheimer's or other dementia, which is not necessarily all caregivers of people with dementia.

†Data not included because the sample size was less than 50 or the relative standard error was greater than 30%.

‡State did not collect data between 2015-2021.

Created from data from the Behavioral Risk Factor Surveillance System Survey.[409]

Table **11**

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.[409]

little or no strain.[531] In contrast, a longitudinal analysis of the HRS 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.[528] 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.[532]

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.[408] These individuals worked an average of 35 hours per week while caregiving.[408] Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 57% reported sometimes needing to go in late or leave early compared with 47% of non-dementia caregivers. Eighteen percent of dementia caregivers reduced their work hours due to care responsibilities, compared with 13% of non-dementia caregivers. Other work-related changes among dementia and non-dementia caregivers who had been employed in the past year are summarized in Figure 11.[408] 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 across France, Germany, Italy, Spain and the United Kingdom.[414] 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.[533]

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).[399,534] 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.[535,536] Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey indicated that among care contributors (in this survey, 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.[469] 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.[469]

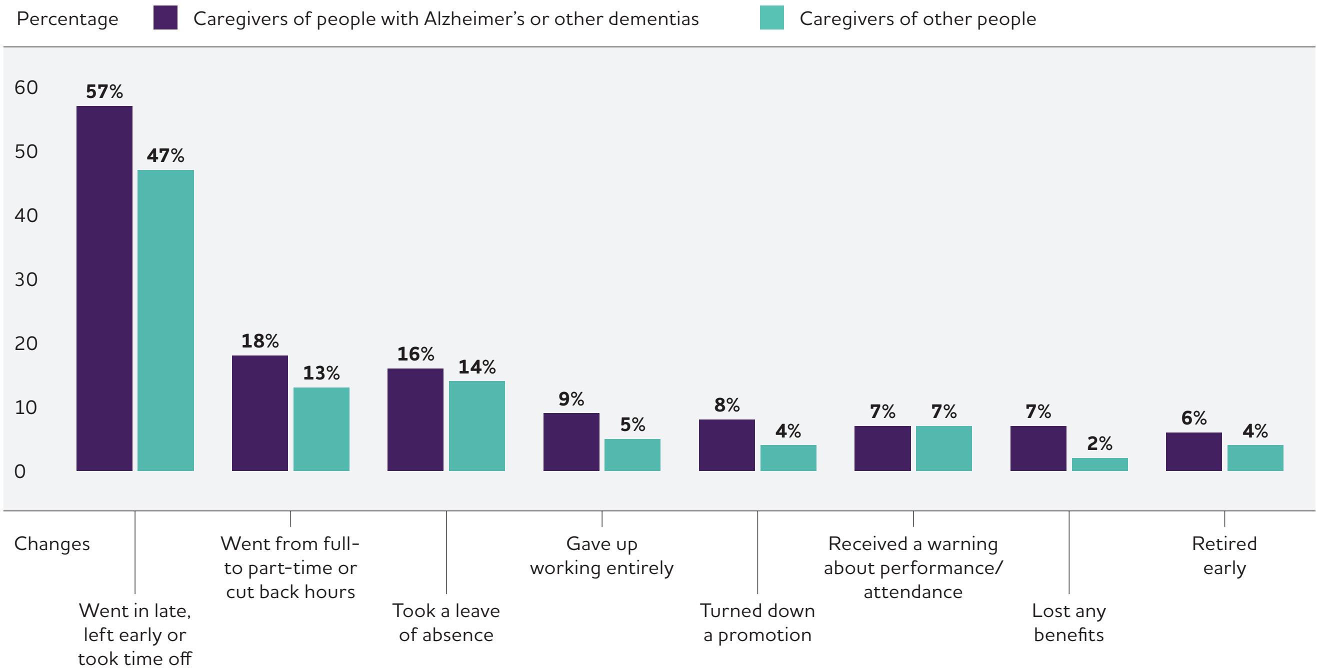
One in five caregivers of people with Alzheimer's or other dementias (22%) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia, compared with 9% of caregivers of people without dementia.[408]

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 residential care for the person with dementia, exacerbated behavioral and psychological challenges in the person with dementia, and increased likelihood of someone with dementia being abused.[537] 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.[538] 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

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.[408]

with family, friends, other people with dementia and professional caregivers as well as through opportunities for ongoing engagement in social and occupational activities/roles.[539] Some meta-analyses suggest that care coordination/case management and psychoeducational and multi-component programs delivered to dementia caregivers may benefit important care recipient outcomes, including improvements in behavior and mood, quality of life, and delayed institutionalization. However, effects sizes are small.[540]

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 12, page 50.[467,541]

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

According to a publication on dementia caregiver interventions that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers but of people living with dementia as well.[542] 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.[543-548] 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.[549]

Table **12**

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 Sörensen et al.,[467] Gaugler et al.[541] and Walter and Pinquart.[553]

Although several national reports have suggested that the available scientific evidence does not provide clear suggestions as to which intervention types benefit dementia caregivers consistently,[550] other recent meta-analyses report that specific intervention types (such as psychoeducation; see Table 12) 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.[540,551-555] 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.[556]

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.[557-559] 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).[560-562] 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 system.[563] 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),[564-572] while others have disseminated evidence-based dementia care interventions into community-based programs and health care systems.[560,573,574]

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 or care transitions and how these interventions are successful.[575-579] Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.[580-585] 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.[427,586-594] Additional research on interventions focused on disease stages is also required, as is research

COVID-19 and Dementia Caregiving

Existing reports indicate that the COVID-19 pandemic has posed significant social, psychological, emotional and physical challenges to family members and friends who provide care for people with dementia.[604-609] 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.[604,610,611]

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.[612] In the earlier stages of the pandemic, caregivers were limited in or completely barred from visiting and communicating with relatives who lived in long-term care residences due to COVID-19 lockdown procedures. The inability to visit or engage with relatives resulted in distress as well as significant concerns about the health of relatives living in residential long-term care during the pandemic.[613,614] Studies of end-of-life care during the pandemic indicated that dementia caregivers felt that enforced social isolation was prevalent and adversely influenced the death and dying experience of relatives during the pandemic.[615] Adult day programs in many states were interrupted or closed. These and other factors shaped by the COVID-19 pandemic have caused emotional distress and other negative outcomes among caregivers.[572,616] 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 long-term programs that serve community-residing people with dementia and their caregivers as well as strategies/policies to maintain links between family caregivers and residents of congregate care settings (assisted living, nursing homes) during future public health emergencies.[617,618]

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 during the COVID-19 lockdowns 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.[619] Other studies suggested that some dementia family caregivers adjusted during the pandemic by relying more heavily on other sources of family/unpaid help as well as technologies to maintain social connection with relatives.[620,621] 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.[614] 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.[614] There is also evidence of racial differences in dementia care provision during the pandemic. Compared with White dementia and non-dementia caregivers as well as Black non-dementia caregivers, Black dementia caregivers provided greater ADL care to relatives with dementia.[421] Providing telehealth support to dementia caregivers that was culturally appropriate, delivering COVID-19 safety education, and offering compassionate listening appeared to benefit social connections and reduced distress.[622]

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,[623,624] although concerns remain about the "digital divide" facing caregivers who do not have reliable broadband access or do not regularly use the internet.

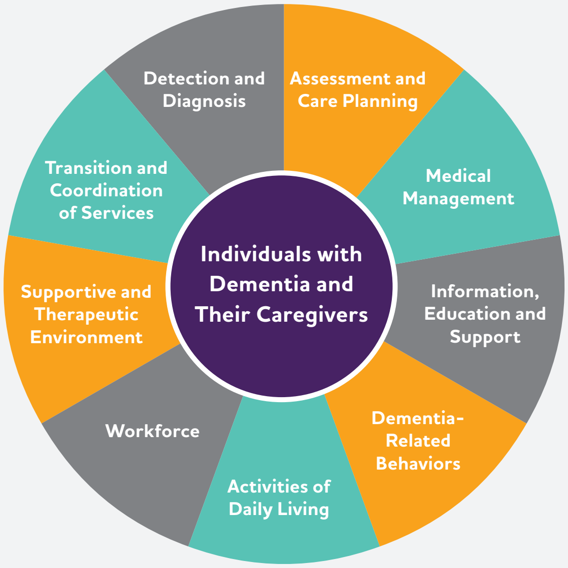
on specific intervention needs for LGBT caregivers for whom a lack of inclusive practices on the part of health care professionals, stigma, and a reluctance to seek support may result in greater unmet needs compared with non-LGBT dementia caregivers.[595,596]

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 CDC 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.

The Alzheimer's Association has also undertaken several efforts to improve dementia care interventions and services. Its dementia care practice recommendations[597] 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 one 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.[539,598] Frameworks such as the Alzheimer's Association dementia care practice recommendations are 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.[599,600] A core element of these 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.[597]

Trends in Dementia Caregiving

There is some indication that families have greater capacity to manage 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).[457] However, as noted earlier, more work is needed to ensure that interventions for dementia caregivers are available and accessible to those who need them. A 2016 study of the Older Americans Act's National Family Caregiver Support Program found that over half (52%) of Area Agencies on Aging did not offer evidence-based family caregiver interventions.[601] 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).[602] The need to bridge this impending "family care gap" through new policies, services and research is a growing public health concern.[603]

A National Strategy to Support Family Caregivers

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, which was signed into law in January 2018, authorized the Secretary of Health and Human Services to develop the first national strategy to support family caregivers. To advance the development of this strategy, a 30-member Family Caregiving Advisory Council was established to provide key recommendations, guidance and best practices that support family caregivers. In September 2022, the Advisory Council delivered its National Strategy to Support Family Caregivers to Congress, which features nearly 350 actions that 15 federal agencies will adopt and 150 actions that states, communities and others can take. The four core principles that drive these many supportive actions include: 1) placing the family and person at the center of all interactions; 2) addressing trauma and its impact on families; 3) advancing equity, accessibility and inclusion for family caregivers in underserved communities; and 4) elevating direct care workers as family caregiving partners.[625]

WORKFORCE

AN ESTIMATED 1.2 MILLION ADDITIONAL DIRECT CARE WORKERS WILL BE NEEDED BETWEEN 2020 AND 2030 — MORE NEW WORKERS THAN IN ANY OTHER SINGLE OCCUPATION IN THE UNITED STATES.

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

This workforce includes but is not limited to primary care physicians (PCPs) and advanced practice clinicians; specialists such as geriatricians, neurologists and psychiatrists; other licensed providers such as registered nurses, psychologists, therapists and social workers; and members of the direct care workforce, including personal care aides, home health aides and nursing assistants.

Screening and Diagnosing Workforce

The types of health care professionals involved in screening for and diagnosing Alzheimer's and other dementias include PCPs (e.g., family medicine and internal medicine physicians), advanced practice clinicians (such as nurse practitioners and physician assistants) and specialists such as geriatricians (who specialize in caring for older adults), neurologists (especially geriatric and cognitive neurologists), neuropsychologists, geropsychologists and geriatric psychiatrists.

Studies show that PCPs frequently make the initial diagnosis of dementia.[626,627] One study of Medicare beneficiaries found that 85% of those diagnosed with dementia were initially diagnosed by a clinician other than a dementia specialist (e.g., a PCP, emergency medicine physician or nurse practitioner), and the remaining 15% by a specialist.[628] Of those diagnosed by a specialist, 44% were diagnosed by a neurologist, 34% by a psychiatrist and 22% by a geriatrician.

Even though the vast majority of initial diagnoses are made by PCPs, nearly 40% of PCPs surveyed by the Alzheimer's Association in 2019 reported that they were "never" or "only sometimes" comfortable making a diagnosis of Alzheimer's or another dementia.[629] More than 25% of PCPs reported being "never" or "only sometimes" comfortable answering patient questions about Alzheimer's or other dementias, and 50% did not feel adequately prepared to care for individuals who had been diagnosed. Given this discomfort and uncertainty, almost one-third of PCPs in the survey reported referring patients to specialist providers.[629] However, most PCPs (55%) reported that there were not enough specialists in their area to meet demand.

Indeed, according to the National Center for Health Workforce Analysis (NCHWA), there was already a shortage of geriatricians a decade ago, with a projected increase in demand by 2025 that is expected to far exceed supply in every region of the United States.[630] Similarly, the NCHWA projects that there will be a shortfall of neurologists by 2025, but indicates that the growing number of physician assistants in neurology could help address this workforce gap.[631] Meanwhile, 20 U.S. states have already been identified as "dementia neurology deserts," meaning they are projected to have fewer than 10 neurologists per 10,000 people with dementia in 2025.[632]

Table 13 (see page 58) shows state-by-state projections for the number of geriatricians needed in 2050, using December 2021 data from IQVIA. 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.[633] 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 almost enough or more than enough geriatricians (respectively) to match 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 **13**

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.[633] The underlying state-by-state estimates of the 2050 population age 65 and older were provided by Claritas Pop-Facts 2020.

While the shortage of geriatricians and other specialists extends nationwide, it appears to be most acute in rural settings — with many rural counties facing a shortage of health care providers overall.[634,635] According to the 2019 Alzheimer's Association survey, 44% of PCPs in large cities and 54% in suburban areas near large cities reported that there were not enough specialists in their area, while 63% of PCPs in small cities or towns and 71% of PCPs in rural areas reported the same.[629]

The shortage of geriatricians and other relevant specialists has been attributed to a combination of factors, including growth in demand due to population aging; substantively lower pay for geriatricians and neurologists compared with many other specialist physicians; an inadequate number of clinician educators with relevant specialties on the faculties of health professional schools; limited availability of incentives to choose these specialties, such as loan forgiveness programs; and the insufficient respect and recognition accorded to geriatricians and related specialists.[636,637]

Limited confidence[629] and time[638] among PCPs and the widespread shortage of geriatricians and other specialists can result in delayed diagnosis of Alzheimer's disease and other dementias. During these delays, people living with dementia could otherwise have been enrolled in potentially life-changing clinical trials of new treatments, begun receiving emotional support through a support group of others living with dementia, and started planning for financial, accommodation and caregiving changes they may experience as their condition progresses.

Medical Treatment and Care Team

As well as screening for and diagnosing dementia, PCPs are responsible for managing treatment for people living with dementia.[639] Even so, dementia care is inadequately covered in health care training programs, both in curricula and in opportunities for clinical practice.[640]

Nurse practitioners and physician assistants also play key roles in treatment for people living with dementia. However, there is limited specialization in caring for older adults among these advanced practice roles, likely for many of the same reasons cited for the shortages of geriatricians and neurologists. In 2022, there were 355,000 nurse practitioners in the United States, up from 91,000 in 2010, but only 7% held a primary certification in gerontological primary care.[641,642] As of 2018, less than 1% of physician assistants were certified in geriatric medical care. Although this figure represents a nearly 400% increase in the absolute number of physician assistants specializing in geriatric care since 2013 (indicating a positive trend),[643] significant gaps remain in the capacity of this workforce to support older adults living with dementia and other chronic health concerns.

Registered nurses, licensed practical nurses, licensed psychologists and licensed therapists comprise other critical segments of the dementia care workforce, providing a range of nursing, rehabilitation and supportive services in community settings, skilled nursing homes and other settings. These services include medication administration, intravenous injections, wound care, catheter care, physical therapy, occupational therapy, behavioral consultation and much more. In addition, social workers assist with care navigation and management, and licensed clinical social workers and psychologists may also provide therapeutic services to people living with dementia and their caregivers. However, specialization in caring for older adults remains limited across all of these occupational groups as well. The last large national survey of licensed social workers, conducted in 2004, found that 9% identified aging as their specialty area,[644] while a more recent survey of Masters of Social Work students graduating in 2017 to 2019 found that only 4.2% were specializing in aging or gerontology.[645] Other reports indicate that less than 1% of registered nurses are certified in geriatrics (2020),[646,647] only 1.2% of psychologists specialize in geropsychology (2015),[648] and over half of geriatric psychiatrists certified by the American Board of Psychiatry and Neurology are concentrated in just seven states (2015).[649]

Several decades of research supports the value of collaborative primary care models that bring these different health professionals together to care for people living with dementia.[650,651] These models have been associated with a range of benefits including reduced behavioral symptoms, improved function and quality of life, decreased caregiver burden, and lower health care costs related to hospitalizations, emergency department visits and other outpatient visits.[651,652] One dementia care program co-managed by nurse practitioners and physicians was found to reduce nursing home admissions for participating Medicare beneficiaries and was cost-neutral after accounting for implementation costs.[653] As a second example, a team-based dementia care program utilizing telehealth that involved care navigators, advanced practice nurses, social workers and pharmacists resulted in fewer ambulance rides, emergency department visits and hospitalizations compared with usual care.[654]

With regard to cost savings, 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 those whose care was overseen by a PCP only.[652] More than half of the cost savings were attributed to lower inpatient hospital costs. The average annual cost of the program was $618 per person — indicating a nearly 6-to-1 return on investment.

As new therapies for Alzheimer's and other dementias are developed, the composition of the dementia care workforce is continuing to evolve. For example, the U.S. Food and Drug Administration recently approved two drugs (aducanumab and lecanemab) for the treatment of Alzheimer's that are delivered through intravenous infusion and require careful monitoring of patients for a serious potential side effect called ARIA (for more information see the Overview, page 12). Ensuring the health of individuals while they receive these drugs requires an expanded workforce including infusion nurses, radiologists and radiology technicians with special training in recognizing ARIA, and specialists with expertise in managing ARIA if it occurs. Neuropsychologists and other health professionals are also needed to evaluate whether individuals are benefiting from the drugs, as those who do not experience improvements in cognitive skills and the ability to perform activities of daily living (ADLs) may be advised to discontinue treatment.

Anticipating the development and approval of aducanumab (or a similar therapy), a 2017 simulation by RAND Corporation researchers found that "the U.S. health care system is ill-prepared to handle the potentially high volume of patients who would be eligible for treatment."[655] The researchers projected an average wait time of 18.6 months between diagnosis and treatment once the new drug was approved. As with the earlier discussion on barriers to diagnosis, this simulation highlights how workforce shortages can directly impact individuals' health outcomes and underscores the need to expand the workforce to meet existing and future demand.

Direct Care Workforce

The largest segment of the workforce that supports people living with dementia is the direct care workforce. Direct care workers — who are formally classified as personal care aides, home health aides and nursing assistants but known by a wide range of job titles in the field — assist older adults and people with disabilities in private homes, community-based settings such as adult day services and residential care, skilled nursing homes and other settings such as hospitals.[656] Across these settings, direct care workers deliver the majority of day-to-day care to patients, clients or residents living with Alzheimer's disease and other forms of dementia.

Direct care workers provide assistance with ADLs such as bathing, eating, toilet care and mobility. In home care settings, they also support individuals with household chores, meal preparation, attending appointments and other instrumental activities of daily living (IADLs). Under the supervision of licensed nurses or other health care professionals, home health aides and nursing assistants also perform certain clinical tasks, such as wound care, measuring vital signs and medication administration (depending on the setting and regulatory context).[657,658]

Beyond these distinct tasks, direct care workers play a broader role in promoting nutrition, exercise, functional ability, social engagement and emotional wellbeing for those living with dementia. With training in active listening and empathic response, direct care workers can provide emotional support and, with additional training, can help administer nonpharmacological treatments — such as hand massage, aromatherapy, music and pet therapy — to prevent or reduce distress associated with dementia.[659]

Direct care workers also support quality outcomes and cost savings. Direct care workers providing in-home care enable individuals to continue living at home and help prevent or delay nursing home placement.[660] They also provide care to individuals returning from a hospital stay and help reduce their risk of readmission.[661-663] Thanks to their daily caregiving role, direct care workers are well-placed to observe and report changes of status to clinical care partners, thereby helping to reduce the risk of emergency department visits, avoidable hospitalizations and other adverse outcomes that are disproportionately high among people living with dementia.[664,665]

Between 2011 and 2021, the number of direct care workers increased by 1.5 million from 3.2 million to 4.7 million due to growing demand for long-term care.[656] Looking ahead, an estimated 1.2 million additional direct care workers will be needed between 2020 and 2030 — more new workers than in any other single occupation in the United States.[656] This job growth is occurring primarily among personal care aides and home health aides, reflecting the overwhelming preference for "aging in place" and public policies that have expanded access to home and community-based services.[666]

This projected growth in the direct care workforce is being seen across the country. As shown in Table 14, page 61, double-digit percentage increases in the number of home health and personal care aides will be needed between 2020 and 2030 to meet demand in every state except Maine. Twenty-one states are expected to see a 30% to 40% increase in the size of this workforce, while in two states (Arizona and Nevada) the workforce is expected to increase more than 50%.

Although more direct care workers will be needed in the years ahead, the long-term care field is already struggling to fill existing direct care positions. Turnover rates are high in this workforce — estimated at 64% annually for direct care workers providing home care[667] and 99% for nursing assistants in nursing homes[668] — and recruitment and retention are long-standing challenges.[669-671] In turn, instability in the workforce and understaffing across care settings can lead to stress, injury and burnout among direct care workers while also compromising care access and quality.[672]

Table **14**

Expected Home Health and Personal Care Aide Job Growth, 2020-2030

	Number in 2020 and Projected Number Needed in 2030		Percentage Increase
State	**2020**	**2030**	**2020-2030**
Alabama	21,700	25,910	19.4%
Alaska	6,270	7,130	13.7%
Arizona	72,920	117,740	61.5%
Arkansas	21,900	28,350	29.5%
California	766,000	985,800	28.7%
Colorado	36,890	49,220	33.4%
Connecticut	44,180	53,250	20.5%
Delaware	8,430	11,780	39.7%
District of Columbia	12,120	15,180	25.2%
Florida	76,140	93,270	22.5%
Georgia	44,060	60,350	37.0%
Hawaii	9,290	12,270	32.1%
Idaho	17,400	20,640	18.6%
Illinois	99,460	118,600	19.2%
Indiana	42,200	55,720	32.0%
Iowa	23,880	31,580	32.2%
Kansas	25,710	30,110	17.1%
Kentucky	22,230	30,130	35.5%
Louisiana	37,900	44,160	16.5%
Maine	17,380	18,710	7.7%
Maryland	42,560	56,790	33.4%
Massachusetts	109,430	139,560	27.5%
Michigan	71,750	89,820	25.2%
Minnesota	107,500	133,420	24.1%
Mississippi	19,130	25,200	31.7%
Missouri	75,960	86,160	13.4%
Montana	7,190	9,670	34.5%
Nebraska	12,500	15,210	21.7%
Nevada	15,830	23,860	50.7%
New Hampshire	8,410	10,970	30.4%
New Jersey	59,610	76,930	29.1%
New Mexico	32,360	40,750	25.9%
New York	510,870	710,570	39.1%
North Carolina	65,150	82,070	26.0%
North Dakota	6,790	8,540	25.8%
Ohio	95,560	118,540	24.0%
Oklahoma	20,460	26,210	28.1%
Oregon	32,330	39,960	23.6%
Pennsylvania	175,140	214,740	22.6%
Rhode Island	7,410	9,450	27.5%
South Carolina	31,750	41,850	31.8%
South Dakota	3,830	4,570	19.3%
Tennessee	31,470	44,740	42.2%
Texas	320,780	418,500	30.5%
Utah	17,080	22,440	31.4%
Vermont	7,770	10,310	32.7%
Virginia	56,390	73,160	29.7%
Washington	63,300	80,760	27.6%
West Virginia	16,470	21,370	29.8%
Wisconsin	77,810	92,320	18.6%
Wyoming	3,750	5,020	33.9%
U.S. Total	**3,470,700**	**4,600,600**	**32.6%**

Created from data from Projections Managing Partnership.

Projections Managing Partnership. Projections Central: Long-Term Occupational Projections (2020-2030). Available at: https://www.projectionscentral.org/Projections/LongTerm. Accessed September 18, 2022.

Workforce challenges are driven by persistently low compensation and poor job conditions for direct care workers, which are in turn underpinned by structural racial and gender inequities (marginalizing this workforce of predominantly women and people of color[656]), as well as ageism and disablism (facing the individuals receiving care and, by extension, those providing it).[673] According to the most recent national data available, the median wage for direct care workers is just $14.27 per hour and, due to low wages and the high prevalence of part-time positions, median annual earnings are less than $22,000. Research shows that, despite their complex and critical role in supporting the health and wellbeing of older adults and people with disabilities, direct care workers earn a lower median wage than workers in other "entry-level" occupations with similar education and training requirements, such as janitors, retail salespersons and customer service representatives.[674]

Direct care workers also receive limited training and professional development opportunities, another indicator of poor job conditions. Nursing assistants in nursing homes and home health aides employed by Medicare-certified home health agencies are required by federal regulations to complete at least 75 hours of entry-level training and 12 hours of annual continuing education. Care for residents with cognitive impairment is among the requisite training topics for nursing assistants, but not for home health aides. In contrast, training requirements for other direct care workers vary by state and setting. A 2015 review found that 44 states and the District of Columbia set dementia care training standards for assisted living staff, but those regulations only pertained to special dementia care facilities or units in 14 of those states.[675] The same review found that only 13 states have established dementia care training requirements for direct care workers who provide in-home care. Inadequate training for direct care workers perpetuates their mischaracterization as "low-skill" workers, fails to prepare them for the complexity and challenges of their role, undermines job satisfaction and retention, and directly impacts the provision of dementia care.

Direct care is also physically and emotionally demanding work, which is not well-reflected in the training standards or compensation for this workforce. As one indicator, occupational injury data from the Bureau of Labor Statistics show that nursing assistants in nursing homes were nearly eight times more likely than U.S. workers overall to experience workplace injuries in 2020.[656] These data reflect the impact of the COVID-19 pandemic on this workforce — COVID-19 is classified as a "workplace injury"[676] — as well as long-standing occupational risks.[677] Comparable occupational injury data are not available for direct care workers in home and community-based settings due to reporting limitations, but these workers are also exposed to a range of occupational risks, including unsafe physical environments, infection hazards, interpersonal violence and more.[678]

Impact of COVID-19 on the Workforce

The COVID-19 pandemic had a significant impact on the health care workforce and especially on the dementia care workforce, given the disproportionately high infection and death rates due to COVID-19 among people with Alzheimer's and other dementias.[679]

At the onset of the pandemic, in April 2020, the number of people employed in health care overall dropped more than 8%, an unprecedented decrease.[680] Although health care employment rebounded fairly quickly, it was still 0.5% lower in July 2022 than it had been in February 2020.[680] Employment levels in nursing homes and community care settings — where a significant proportion of dementia care takes place — are still far below pre-pandemic levels,[680] and direct care workforce shortages remain acute.

Some of the initial job loss in health care was caused by changes in service delivery and utilization. Elective procedures were canceled, routine and preventive care visits were postponed, and admissions into congregate care settings such as nursing homes were avoided if possible. Health care workers also had to leave their jobs to safeguard their own or their families' health, because of illness, or for caregiving or other reasons. As one startling example of how COVID-19 directly impacted health care workers, nearly 1.5 million nursing home staff had contracted COVID-19 as of mid-December 2022 and 2,874 had died from the disease.[681]

Working during the COVID-19 pandemic has taken a significant emotional and psychological as well as physical toll on the health care workforce.[682-684] As stated by the U.S. Surgeon General, "COVID-19 has been a fully and uniquely traumatic experience for the health workforce, and for their families."[685] One survey conducted in 2020 found that, of more than 1,100 surveyed health care workers, 93% reported stress, 86% anxiety, 76% exhaustion and burnout, and 41% loneliness.[686] Another 2020 survey of nearly 21,000 health care workers found that stress related to workload and mental health was highest among nursing assistants, medical assistants and social workers versus other occupational groups, workers in inpatient versus outpatient settings, women versus men, and Black and Latinx workers versus White workers.[687]

For the dementia care workforce, the trauma of caring for those most vulnerable to COVID-19 (and related challenges, such as social isolation) has likely been particularly acute.[688] Given the preexisting shortages among different segments of this workforce, the longer-term impact of this crisis on workforce recruitment and retention must be closely monitored.

Looking to the Future

In 2020, the American Public Health Association (APHA) identified "strengthening the dementia care workforce" as a public health priority.[689] "Continued failure to strengthen the dementia care workforce," according to the APHA, "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." This section outlines five strategies for strengthening the dementia care workforce into the future.

Expand the Health Care Workforce Serving Older Adults

First and foremost, the health care workforce must expand to meet the needs of the rapidly growing population of older adults, who are at the highest risk of developing Alzheimer's disease and other dementias (see Prevalence section, page 19).[690] More PCPs, specialists, nurse practitioners and physician assistants, nurses, psychologists, therapists, social workers, direct care workers and other health care workers will be critically needed in the years ahead.

One notable effort to build the workforce is the Geriatrics Workforce Enhancement Program (GWEP) funded by the Health Resources and Services Administration, which comprises a network of 48 GWEPs across most U.S. states and two territories.[691] The goals of this program are to educate and train the health care workforce to care for older adults in integrated geriatrics and primary care models, and to partner with community-based organizations to address gaps in health care for older adults, promote age-friendly health systems and dementia-friendly communities, and address social determinants of health. In particular, the GWEPs are required to provide training to primary care and other health care providers on the 4Ms (What Matters, Medication, Mentation and Mobility). Central to this framework with regard to "mentation" is screening for cognitive impairment annually and at changes in status, with referral to appropriate intervention as needed.

Additionally, recognizing the need for expanded training for professionals who serve older adults, the Substance Abuse and Mental Health Services Administration (SAMHSA) has funded a Center of Excellence for Behavioral Health Disparities in Aging and a Center of Excellence for Building Capacity in Nursing Facilities to Care for Residents with Behavioral Health Conditions.

Strengthen Dementia Training and Specialization

Targeted dementia training and specialization is also needed among PCPs and across the health care workforce,[692,693] as well as training in cultural and linguistic competency to help overcome the misunderstandings, biases, misdiagnoses and related disparities experienced by people of color living with dementia and their families.[694-696] One successful training model is the Alzheimer's and Dementia Care ECHO® Program, which pairs PCPs with multidisciplinary specialist teams through telementoring to develop their knowledge and confidence in dementia care. According to an evaluation of the program, which was launched in 2018 by the Alzheimer's Association, 94% of surveyed participants reported making changes in their delivery of dementia care due to the program and 87% reported higher job satisfaction.[697]

Looking ahead, health care systems must continue to expand the range of health care professionals who are trained to notice symptoms, conduct structured cognitive screening, refer individuals to other health care professionals for dementia assessment and/or diagnosis, communicate a care plan to patients and their families, and coordinate services with families, caregivers and community resources. Nurse practitioners, physician assistants and other care providers can play a greater role in dementia care delivery, particularly for rural and underserved communities.[643,698] With training, support and recognition, direct care workers can also provide more tailored care for people living with dementia, for example by implementing non-pharmacological interventions to mitigate distress; observing and reporting changes to clinical team members; and educating and supporting family members.[699]

The Gerontological Society of America's Kickstart, Assess, Evaluate, Refer (KAER) model provides an example of how to expand the workforce to better detect and manage dementia.[700] Among other strategies, this model suggests that non-clinical office staff participate in the primary care team's efforts to detect cognitive impairment. Receptionists or schedulers, for example, can make note when patients miss their appointments or show up at the wrong time, defer to family members while completing paperwork or answering questions, or have difficulty following care plans.

Create New Dementia Care Roles

Innovative new roles are also needed to support dementia care. One notable example is the Dementia Care Specialist (DCS) program in California.[701] In this program, care managers (who are registered nurses or licensed social workers) are trained to enhance services and care coordination for people living with dementia and their families. An evaluation of the program concluded that "there is a growing demand for DCSs as a key component of effective dementia care management."[701] A related example is the non-clinical Care Team Navigator (CTN) role that has been utilized in a range of health care settings and more recently tested in dementia care.[702] The results of a clinical trial suggest that CTNs can support quality of life for people living with dementia and family caregivers in a range of ways, including by providing emotional support, resources and education, by making connections to other social services, and by assisting with medication management and advance care planning.

Develop Payment Models to Support the Dementia Care Workforce

Alternative payment models may be needed to scale up the delivery of collaborative, comprehensive and innovative dementia care.[703-705] One development in this area is that, as of 2017, Medicare will reimburse physicians, nurse practitioners, physician assistants and nurse specialists for health care visits that result in a comprehensive dementia care plan. Reimbursement requires cognition-focused evaluation, identification of caregiver needs, and development, revision or review of an advance care plan. Early uptake of this benefit has been limited; a study using a 20% nationwide random sample of eligible fee-for-service Medicare beneficiaries' claims data found that only 0.65% had received this benefit in the first two years.[706] The authors of this study concluded that providers may be insufficiently aware of these billing codes, especially in smaller practices and rural areas, and/or may be billing for similar services under different codes. In the future, providers could be better informed about these codes, and the codes could be revised to include social workers and psychologists as billing entities.

To promote more coordinated dementia care, the Alzheimer's Association and the Alzheimer's Impact Movement, a separately incorporated advocacy affiliate, have proposed a "dementia care management alternative payment model."[707] A key feature of this model is the requirement that a participating primary care practice has at least one interdisciplinary team member who meets the criteria for being a "dementia specialist." This payment model could incentivize both the development of dementia specialists and investments in dementia capability across the full care team.

Financing and other public policy reforms are also needed to strengthen and stabilize the direct care workforce. On a hopeful note, the federal government and states are taking unprecedented action to improve job quality and bolster this workforce, particularly through Medicaid, including by overhauling training and credentialing systems, designing new career development opportunities, implementing reimbursement rate increases tied to increased compensation, developing new recruitment campaigns and pipeline programs and more.[708,709] The challenge will be to sustain these investments into the future, as the need for direct care services continues to escalate.

Leverage Technology to Augment Dementia Care Delivery

Major advances in technology should also be leveraged to optimize the time and effectiveness of the dementia care workforce. As one example, e-learning programs can greatly increase access to dementia care training, although evidence suggests that the effectiveness of such programs relies on the relevance of the content and the inclusion of interactive learning strategies.[710]

Technology can also help improve access to care for people living with dementia, especially for those in rural areas and those with mobility challenges.[711] A randomized clinical trial of more than 1,500 individuals across 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, reduced emergency department visits, and decreased caregiver depression and burden.[654] A systematic review of telehealth for dementia care, including routine care, cognitive assessment and rehabilitation, found that telehealth delivered results similar to those of in-person services.[712] More research is needed to identify the strengths and weaknesses of telehealth and how it can be utilized appropriately in the diagnosis and treatment of individuals living with dementia as well as in supporting their caregivers.

Assistive, therapeutic and remote monitoring technologies, which range from smart home devices to automated medication prompts to robotic animals and devices that support personalized activities and much more, can be used to augment the role of the dementia care workforce.[713] As with telehealth, more research is needed to understand the efficacy of these myriad different technologies and to address concerns and unintended consequences related to privacy, autonomy and interpersonal interactions. As *The Lancet* Commission on dementia prevention, intervention, and care concludes, "technology is not a replacement for human contact."[58]

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

IN 2023, HEALTH AND LONG-TERM COSTS FOR PEOPLE LIVING WITH ALZHEIMER'S AND OTHER DEMENTIAS ARE PROJECTED TO REACH $345 BILLION.

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.[714]

Total payments in 2023 (in 2023 dollars) for all individuals with Alzheimer's or other dementias are estimated at $345 billion (Figure 13), not including the value of informal caregiving that is described in the Caregiving section (see page 40). Medicare and Medicaid are expected to cover $222 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 $87 billion, or 25% of total payments.[A12] For the remainder of this section, costs are reported in 2022 dollars unless otherwise indicated.[A13] With the exception of the section, "The COVID-19 Pandemic and Health Care Utilization and Costs," data reported in this section reflect patterns of use before the pandemic. It is unclear at this point what long-term effect, if any, the pandemic will have on these patterns.

Total Cost of Health Care and Long-Term Care

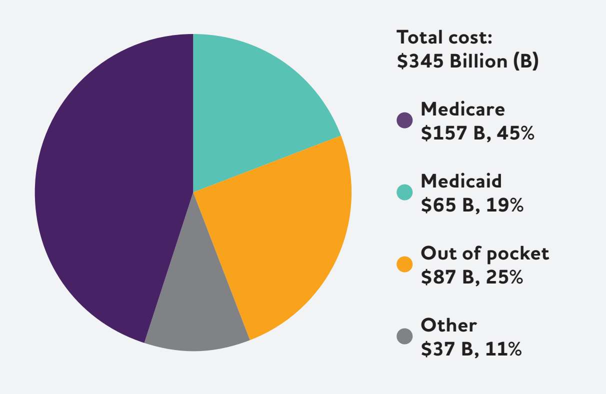
Table 15 (page 67) reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias based on data from the 2018 Medicare Current Beneficiary Survey.[A14] Total per-person health care and long-term care payments in 2022 dollars from all sources for Medicare beneficiaries with Alzheimer's or other dementias were nearly three times as great as payments for other Medicare beneficiaries in the same age group ($43,444 per person for those with dementia compared with $14,593 per person for those without dementia).[A15,258]

Despite Medicare and other sources of financial assistance, individuals with Alzheimer's or other dementias and their family members still incur high out-of-pocket costs. These costs are for Medicare deductibles, copayments and coinsurance; other health insurance premiums, deductibles, copayments and 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 $10,241 out of pocket annually for health care and long-term care services not covered by other sources (Table 15).[258] One group of researchers found that out-of-pocket and informal caregiving costs for a family member with dementia total $203,117 in 2016 dollars ($238,946 in 2022 dollars) in the last seven years of life, compared with $102,955 in 2016 dollars ($121,116 in 2022 dollars) for those without dementia.[533] However, out-of-pocket and informal caregiving costs were considerably higher for households with a family member with dementia living in the community compared with households with a family member with dementia living in a nursing home ($231,730 versus $165,910 in 2016 dollars [$272,606 versus $195,176 in 2022 dollars]).[533]

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

Figure **13**

Distribution of Aggregate Costs of Care by Payment Source for Americans Age 65 and Older with Alzheimer's or Other Dementias, 2023*



*Data are in 2023 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.

The sum of individual dollar amounts does not equal the total cost due to rounding.

Table 15

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 2022 Dollars*

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$21,873	$7,882
Medicaid	6,739	303
Uncompensated	192	239
Health maintenance organization	1,943	2,282
Private insurance	1,527	953
Other payer	929	417
Out of pocket	10,241	2,518
All Sources	43,444	14,593

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[258]

people with and without dementia who have the same coexisting medical conditions and demographic characteristics).[399,714–716] These studies have used different time horizons, ranging from lifetime costs (i.e., costs between the time of diagnosis and death) to annual costs. The lifetime total cost of care, including out-of-pocket costs, Medicare and Medicaid expenditures, and informal caregiving is estimated at $321,780 per person with Alzheimer's dementia in 2015 dollars ($392,874 in 2022 dollars).[398] Additionally, researchers found 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 ($225,263 in 2022 dollars). Another group of researchers found that lifetime total costs were three times higher for women compared with men with Alzheimer's dementia, due to women both having a longer duration of illness and spending more time in a nursing home.[717] Annual incremental health care and nursing home costs for individuals with dementia are estimated at $28,501 per person per year in 2010 dollars ($40,023 in 2022 dollars).[A16,714] The majority of incremental costs have been attributed to informal care and out-of-pocket costs, rather than medical care and nursing home costs paid by Medicare or Medicaid.[398,717,718] In fact, the incremental five-year cost of care for dementia paid by Medicare has been estimated at $15,704 per person in 2017 dollars ($18,022 in 2022 dollars), with nearly half of these costs incurred in the year after diagnosis.[718]

Several groups of researchers have specifically examined out-of-pocket costs and found that individuals with Alzheimer's or other dementias and their families incur substantially higher out-of-pocket costs compared with individuals without Alzheimer's. Higher out-of-pocket costs for Alzheimer's and other dementias have been attributed to nursing home care, home health care and prescription drug payments.[719,720] Furthermore, individuals with Alzheimer's dementia spend 12% of their annual income on out-of-pocket health care services, excluding nursing home and informal care, compared with 7% for individuals without Alzheimer's dementia.[720]

Another perspective to examine incremental costs for individuals with Alzheimer's and other dementias is through end-of-life costs. A recent systematic review of end-of-life costs for individuals with dementia reported that costs were especially high during the last month of life, even compared with monthly costs over the last year of life.[721] Researchers comparing end-of-life costs in the last five years of life for individuals with and without dementia found that the total cost was $287,038 per person for individuals with dementia in 2010 dollars and $183,001 per person for individuals without dementia ($403,092 and $256,991, respectively, in 2022 dollars), a difference of 57%.[722] Out-of-pocket costs represent a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% versus 11%).

Use and Costs of Health Care Services

Use of Health Care Services

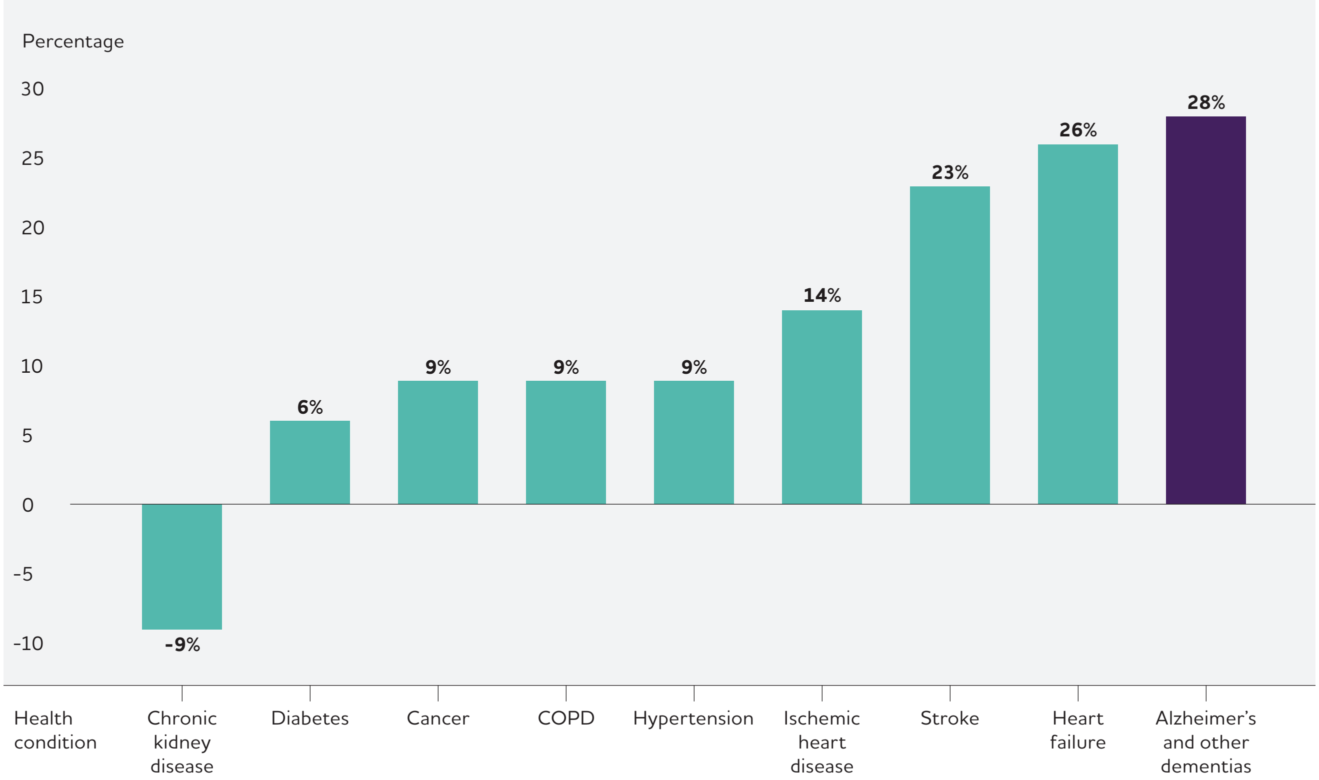
Unadjusted data (that is, data that don't account for differences in the characteristics of people with versus without Alzheimer's or other dementias) show that people with Alzheimer's or other dementias have more than twice as many hospital stays per year as other older people.[382] Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

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

- Hospital. In 2019, there were 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.[382] Overall, 32% of Medicare beneficiaries with Alzheimer's or other dementias have at least one hospital discharge annually compared with 15% of beneficiaries without these conditions, with average hospital lengths of stay of 5.1 days versus 4.5 days, respectively.[382] The most common reasons that people with Alzheimer's dementia are hospitalized are not due to the disease itself, but for other reasons, including syncope (fainting), fall and trauma (26%); ischemic heart disease (17%); and gastrointestinal disease (9%),[723] although the COVID-19 pandemic may have changed the most common reasons for hospitalization starting in 2020. A study of inpatient hospitalizations of adults age 60 and older found that those with Alzheimer's dementia were at 7% greater risk of dying during the hospital stay and stayed nearly a day longer than individuals without Alzheimer's dementia.[724] Among Medicare beneficiaries with Alzheimer's or other dementias, 22% of hospital stays are followed by a readmission within 30 days.[706] Although not directly comparable, one study of a random sample of Medicare beneficiaries from 50 U.S. hospital referral regions found an overall readmission rate of 18%.[725] The proportion of hospital stays followed by a readmission within 30 days remained relatively constant between 2008 and 2018 (23% in 2008 versus 22% in 2018).[726]
- Emergency department. Overall, 1.3% of all emergency department visits are for people with Alzheimer's or another dementia.[727] 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.[726] 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.[725] 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 among others (Figure 14).[726] One group of researchers found that individuals with Alzheimer's or other dementias seen in the emergency department are more likely to be admitted to the hospital or nursing home from the emergency department than Medicare beneficiaries without Alzheimer's or other dementias.[728] Additionally, individuals with Alzheimer's or other dementias are more likely to have at least one hospitalization, have at least one subsequent ED visit, and be admitted to hospice in the 12 months following the initial emergency department visit.
- 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, administering tube feedings and providing round-the-clock personal care services.[729] 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.[382] Overall, 19% of Medicare beneficiaries with Alzheimer's or other dementias have at least one skilled nursing facility stay annually compared with 4% of Medicare beneficiaries without these conditions.[382]
- 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 paid by Medicare during the year, compared with 8% of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias.[382] 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 health care services.[730] One group of researchers found that individuals age 65 and older with Alzheimer's or other dementias use an average of 110 days of home care per year (including homemaker services and other services not covered by Medicare) compared with 64 days per year for individuals age 65 and older without the disease.[730] Another group of researchers found that individuals with dementia who received home health services after discharge from the hospital were more likely to remain in the community for at least 30 days after hospital discharge, and the likelihood of remaining in the community increased with longer durations of home health care.[731]

Figure **14**

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.[726]

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 Medicare beneficiaries without dementia in the same age group (see Table 16, page 70).[A14,258]

Use and Costs of Health Care Service by State

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (see Table 17, page 72). 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 $19,269 in North Dakota to $38,426 in Nevada (in 2022 dollars).[726]

Use and Costs of Health Care Services Across the Alzheimer's Disease Continuum

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.[732] 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,[733-735] two years prior to diagnosis[736] and one year after diagnosis,[718,733,734] compared with otherwise similar individuals not diagnosed with Alzheimer's or another dementia, although the sources of increased spending differ across these studies. In one study, the largest differences were in inpatient and post-acute care,[734] while in another study the differences in spending were primarily due to outpatient care, home care and medical day services.[735]

In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment.[736] 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 ($8,336 in 2022 dollars)[718] based on individuals with fee-for-service (i.e., traditional) Medicare coverage, to $17,852 in additional costs in 2014 dollars ($22,370 in 2022 dollars)[734] in the year after diagnosis, based on another group of individuals with fee-for-service Medicare. One group of researchers, however, found no difference in health care spending in the two years after diagnosis.[736] 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 [$9,181 in 2022 dollars]).[734]

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.[718] Incremental costs decreased over time, from $4,241 in 2014 dollars ($4,867 in 2022 dollars) in year two to $1,302 ($1,494 in 2022 dollars) in year four, although costs increase dramatically in the last year and last month of life.[706] 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.[734] 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.[737] 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.[382] Additionally, they are more likely than those without dementia to have other chronic conditions.[382] 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 dementias) than Medicare beneficiaries without dementia.[382] Table 18, page 73, 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.[382]

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 19 (see page 74) 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.[382,A14] Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except physician care. Additionally, one group of

Table **16**

Average Annual per-Person Payments by Type of Service for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2022 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	$7,316	$2,738
Outpatient events	2,876	2,263
Medical provider*	5,936	3,832
Skilled nursing facility	3,694	372
Nursing home	13,623	527
Hospice	2,328	136
Home health care	1,863	275
Prescription medications**	4,811	3,245

*"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.[258]

researchers found that individuals with dementia and behavioral disturbances, such as agitation, had more psychiatric comorbidities than individuals with dementia but without behavioral disturbances.[738] This group of researchers also found that larger proportions of individuals with dementia and behavioral disturbances used medications including antihypertensives, dementia treatments, antipsychotics, antidepressants, antiepileptics and hypnotics compared with individuals with dementia but without behavioral disturbances.

Use and 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. 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.[258] Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.[258] 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 long-term care 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-six percent of individuals using home health agency services have Alzheimer's or other dementias.[739]
- 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.[739] Ten percent of adult day service centers in the United States specialize in caring for individuals with Alzheimer's disease or other dementias.[740] The percentage of participants with Alzheimer's or other dementias was higher in adult day service 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.[740]
- Residential care facilities. Thirty-four percent of residents in residential care facilities (that is, housing that includes services to assist with everyday activities, such as personal care, medication management and meals), including assisted living facilities, have Alzheimer's or other dementias.[741] Sixty-one percent of residential care communities are small (four to 25 beds),[741] and these facilities have a higher percentage of residents with Alzheimer's or other dementias than larger facilities (51% in facilities with four to 25 beds compared with 44% in facilities with 26 to 50 beds and 39% in facilities with more than 50 beds).[742] Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's or other dementias.[743] Average aide staff hours per resident day in residential care communities range from 2.2 hours per day in facilities with less than 25% of residents diagnosed with dementia to 2.7 hours per day in facilities with more than 75% of residents diagnosed with dementia.[741]
- Nursing home care. Overall, 49% of nursing home residents have Alzheimer's or other dementias,[739] although the prevalence differs by duration of nursing home stay. While 36% of short-stay (less than 100 days) nursing home residents have Alzheimer's or other dementias, 58% of long-stay (100 days or longer) residents have these conditions. 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.[258]
- Alzheimer's special care units and dedicated facilities. An Alzheimer's special care unit is a dedicated unit, wing or floor in a nursing home or other residential care facility that has tailored services for individuals with Alzheimer's or other dementias. Fourteen percent of nursing homes and 19% of assisted living and other residential care communities have a dementia special care unit.[739] Less than 1% (0.3%) of nursing homes and 6% of other care residences exclusively provide care to individuals with dementia.

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

Overall, Medicaid pays for 43% of long-term care services and supports, 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 care services and supports.[744]

Table 17

Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2022 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	$25,382
Alaska	1,477.6	19.3	27,793
Arizona	1,436.2	20.2	27,569
Arkansas	1,530.4	21.5	24,951
California	1,496.3	23.0	37,196
Colorado	1,424.8	18.6	25,750
Connecticut	1,635.4	22.7	32,241
Delaware	1,577.6	21.5	30,372
District of Columbia	1,741.7	25.6	34,748
Florida	1,551.9	23.0	31,665
Georgia	1,573.2	22.5	27,545
Hawaii	1,248.2	16.0	22,504
Idaho	1,389.2	17.2	23,658
Illinois	1,624.1	23.4	31,911
Indiana	1,514.2	21.3	28,243
Iowa	1,310.7	18.0	20,880
Kansas	1,406.0	19.8	25,875
Kentucky	1,735.5	23.1	27,695
Louisiana	1,709.9	22.1	32,029
Maine	1,665.3	19.7	24,134
Maryland	1,524.1	24.4	33,310
Massachusetts	1,668.4	24.7	34,740
Michigan	1,691.4	24.0	30,712
Minnesota	1,467.1	21.6	25,834
Mississippi	1,714.8	22.1	29,812
Missouri	1,529.6	22.6	26,390
Montana	1,328.6	16.6	$21,031
Nebraska	1,153.6	18.7	23,743
Nevada	1,711.5	25.8	38,426
New Hampshire	1,493.8	20.4	28,086
New Jersey	1,456.3	22.9	34,629
New Mexico	1,563.7	20.6	25,298
New York	1,461.3	23.7	35,374
North Carolina	1,683.8	21.5	26,019
North Dakota	1,173.3	18.4	19,269
Ohio	1,618.7	22.5	29,440
Oklahoma	1,692.1	21.6	29,415
Oregon	1,628.4	18.7	23,985
Pennsylvania	1,470.5	22.0	29,527
Rhode Island	1,605.6	23.2	29,150
South Carolina	1,558.2	21.7	26,789
South Dakota	1,200.1	18.6	21,754
Tennessee	1,548.6	21.5	26,635
Texas	1,549.1	22.1	34,195
Utah	1,194.3	16.7	25,066
Vermont	1,528.4	19.6	25,064
Virginia	1,621.7	21.6	26,554
Washington	1,479.2	18.6	24,138
West Virginia	1,811.4	24.1	27,748
Wisconsin	1,519.9	19.9	24,524
Wyoming	1,445.9	17.4	24,350
U.S. Average	**1,544.8**	**22.3**	**30,267***

*The average per capita Medicare payment differs from the figure in Table 15 due to different underlying sources of data.

Created from data from the U.S. Centers for Medicare & Medicaid Services.[726]

Table **18**

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.[382]

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 2019, home- and community-based services represented the majority (59%) of the $162.1 billion spent by Medicaid on long-term care services and supports, with institutional care representing the remaining 41%.[745] Thirty-four percent of Medicaid's total expenditures are related to long-term care services and supports.

Between 2008 and 2018, Medicaid spending on home-and community-based services increased from 43% to 56% of total long-term care services and supports expenditures.[746] Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias increased dramatically between 2004 and 2018. 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.[747] In two systematic reviews of the cost-effectiveness of enhanced 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 enhanced home support interventions is scant.[748,749]

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%).[750] 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,[751] although the number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.[752]

Costs of Long-Term Care Services

- Home care. The median cost in 2021 for a nonmedical home health aide was $27 per hour and $5,148 per month ($28 and $5,358 in 2022 dollars).[753] Nonmedical home care costs increased 5.9% annually on average between 2017 and 2021. The cost of homemaker services was $26 per hour and $4,957 per month ($27 and $5,159 in 2022 dollars) and increased 5.4% annually on average between 2017 and 2021.
- Adult day centers. The median cost of adult day care services was $78 per day in 2021 ($81 in 2022 dollars).[753] The cost of adult day care services increased 2.8% annually on average between 2017 and 2021.
- Assisted living residences. The median cost for care in an assisted living residence was $4,500 per month, or $54,000 per year in 2021 ($4,672 and $56,068 in 2022 dollars).[753] The cost of assisted living increased 4.4% annually on average between 2017 and 2021.
- Nursing homes. The 2021 average cost for a private room in a nursing home was $297 per day, or $108,405 per year ($308 and $112,556 in 2022 dollars), and the average cost of a semi-private room was $260 per day, or $94,900 per year ($270 and $98,534 in 2022 dollars).[753] The cost of nursing home care increased 3.3% annually on average for a private room and 2.9% annually on average for a semi-private room between 2017 and 2021.

Table 19

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 2022 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	**$28,288**	8,167	4,799	4,142	2,454	3,812
Without A/D	**17,893**	5,906	4,702	1,284	941	423
Diabetes						
With A/D	**27,936**	8,182	4,818	4,194	2,361	3,273
Without A/D	**15,656**	5,031	4,211	1,165	830	291
Congestive heart failure						
With A/D	**31,289**	9,399	4,990	4,679	2,603	4,319
Without A/D	**25,298**	9,006	5,460	2,265	1,562	801
Chronic kidney disease						
With A/D	**29,017**	8,492	4,775	4,322	2,479	3,869
Without A/D	**19,642**	6,486	4,902	1,544	1,086	472
Chronic obstructive pulmonary disease						
With A/D	**31,834**	9,705	5,209	4,831	2,630	3,854
Without A/D	**22,680**	7,804	5,355	1,802	1,302	710
Stroke						
With A/D	**30,411**	8,835	5,052	4,609	2,592	3,765
Without A/D	**22,094**	7,055	5,209	2,216	1,553	654
Cancer						
With A/D	**28,222**	7,844	5,183	3,871	2,437	3,772
Without A/D	**18,246**	4,880	5,698	980	734	734

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[382]

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.[754]
- 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 ($95,610 in 2022 dollars) and 25% had savings of $9,650 or less in 2019 dollars ($11,003 in 2022 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.[755]

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.[764]

Based on data from the National Health Expenditure Account, it is estimated that private insurance covered only 9% ($38.5 billion) of the cost of long-term services and supports in 2019.[744] While more recent data are not available, industry reports estimate that approximately 7.2 million Americans had long-term care insurance in 2014.[757] The median income for individuals purchasing long-term care insurance was $87,500 in 2010 dollars ($116,960 in 2022 dollars), with 77% having an annual income greater than $50,000 ($66,834 in 2022 dollars) and 82% having assets greater than $75,000 ($100,252 in 2022 dollars). 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.[757]

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.[765] 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 July 2023, and self-employed individuals can choose to participate in the program. The program is currently structured to pay up to $36,500 in lifetime benefits beginning in July 2026.[766]

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 other 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.[258] Because Medicaid pays for nursing home and other long-term care services, 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 ($6,739) were 22 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($303) (see Table 15, page 67).[258] Much of the difference in payments for beneficiaries with Alzheimer's or other dementias compared with other beneficiaries is due to the costs associated with nursing home care.

Total Medicaid spending for people with Alzheimer's or other dementias is projected to be $65 billion in 2023 and $186 billion in 2050.[A12] Actual and estimated state-by-state Medicaid spending for people with Alzheimer's or other dementias in 2020 and 2025 (in 2020 dollars) is shown in Table 20 (page 78).

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. In this way, hospice care replaces other Medicare-covered benefits for treating the terminal illness and related conditions.[767] Based on data from the National Hospice Survey for 2008 to 2011, nearly all hospices (99%) cared for individuals with dementia, and 67% of hospices had residents with a primary diagnosis of dementia.[768] 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.[769]

Nearly two-thirds (63%) of Medicare decedents (i.e., people who have died) with Alzheimer's or other dementias used hospice in their last 6 months of life in 2017 compared with 36% of Medicare decedents without Alzheimer's or other dementias using hospice in their last 6 months of life in 2004.[770] In 2017, dementia, including Alzheimer's dementia, was the second most common primary diagnosis for Medicare beneficiaries using hospice care, representing 18% of Medicare beneficiaries receiving hospice care (Table 21, page 80).[769] Alzheimer's and other dementias are even more common in individuals receiving hospice care when taking into account the disease as a coexisting or secondary condition. Forty-six percent of hospice users in 2017-2018 had an active diagnosis of Alzheimer's or other dementias, with only hypertension being more common.[739]

Patterns of hospice use for individuals with dementia differ from patterns for individuals without dementia in at least two notable ways. The average number of days of hospice care for individuals with a primary diagnosis of dementia was 50% higher than for individuals with other primary diagnoses, based on data from the 2008 to 2011 National Hospice Survey.[768] Individuals with a primary diagnosis of dementia use an average of 112 days of hospice care versus 74 days for individuals with other primary diagnoses. Recently, researchers found that individuals with dementias as either the primary hospice diagnosis or as a secondary condition were more likely than other hospice users to be enrolled in hospice for more than 6 months.[771] However, long hospice stays place individuals with dementia at risk for disenrollment, and researchers have found that individuals with dementia are more likely to be disenrolled after more than 6 months in hospice than patients with other diagnoses.[768,771] Reasons for disenrollment include admission to an acute care hospital, loss of eligibility because the individual was no longer terminally ill, and failure to recertify for hospice.[772] For hospice enrollments of at least 6 months, hospice providers are required to assess individuals every 60 days, beginning at 6 months, to ensure they continue to meet eligibility requirements, and these assessments coupled with Medicare payment rates that are roughly 20% lower after the first 60 days, may contribute to disenrollment, although more research is needed to understand the implications of these policies for individuals with dementia in hospice.[773,774]

Per-person hospice payments among all individuals with Alzheimer's dementia averaged $2,328 compared with $136 for all other Medicare beneficiaries.[258] 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 visits by a registered nurse or social worker in the last seven days of life. In fiscal year 2023, the routine home care rates are $211.34 per day for days 1 to 60 and $167 per day for days 61 and beyond.[773]

Intensity of care at the end of life has decreased over the past two decades as hospice enrollment has increased. One group of researchers found that the number of inpatient hospital days in the last 6 months of life decreased from 15.3 to 11.8 days between 2004 and 2017, although intensive care unit stays and number of days in a skilled nursing facility increased modestly over the same time period.[770] 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.[775] 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.[776] Additionally, those enrolled in hospice care are less likely to be hospitalized

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.[756]

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 such care.[469] These findings suggest that Medicare beneficiaries and caregivers need more education and information about the types of services that Medicare covers. In particular, 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 post-acute skilled nursing care, or nursing and therapy care that must be performed or supervised by medical professionals, such as registered or licensed nurses.[757] 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.[758] 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.[759] 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 kidney disease qualify for Medicare Part A, which is also referred to as hospital insurance.[760] 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 nearly one-half (48%) of Medicare beneficiaries enrolled this type of plan in 2022.[761] 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).[762]

While Medicare is a federal program, Medicaid is a joint federal and state program, and benefits vary state-to-state.[763] 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 being "dually eligible."

For more information about Medicare, visit medicare.gov. For more information about Medicaid, visit https://www.medicaid.gov/.

Table **20**

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

*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] in the last 30 days of life[777] and more likely to receive regular treatment for pain.[778] 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.[779]

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 1 and 6 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.[780] 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.[780] Despite the introduction of advance care planning (i.e., a plan for future medical care that includes the patient's goals and preferences should the patient become 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 advance care planning claim in 2017.[781] However, compared with individuals without 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.[782] 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 alone.[783,784] With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last 3 to 6 months of life has decreased for individuals with Alzheimer's or other dementias.[770,775] 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.[784]

Place of Death for Individuals with Alzheimer's Disease
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%.[785] During the same period, the proportion of individuals who died at home increased from 15% to 32% (Figure 15, page 81).[785]

Use and Costs of Health Care and Long-Term Care Services by Race and 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 ($27,686 versus $22,203, respectively) (Table 22, page 83). 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 ($8,765 versus $5,636).[382] 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.[786] 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 and ethnicity.[787] 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.

Table **21**

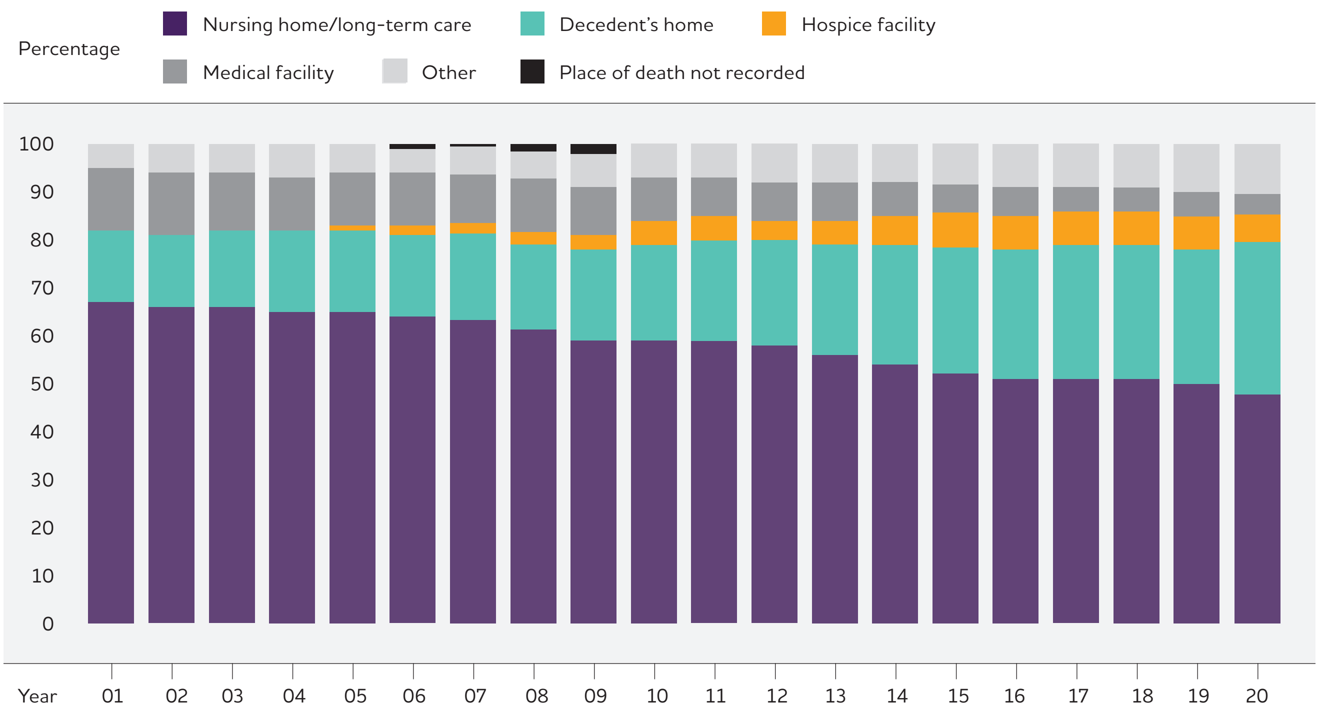
Number and Percentage of Medicare Beneficiaries Admitted to Hospice with a Primary Diagnosis of Dementia by State, 2017

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.[769]

Figure **15**

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



Created from data from the National Center for Health Statistics.[785]

Avoidable Use of Health Care and Long-Term Care Services

Preventable Hospitalizations and Emergency Department Care

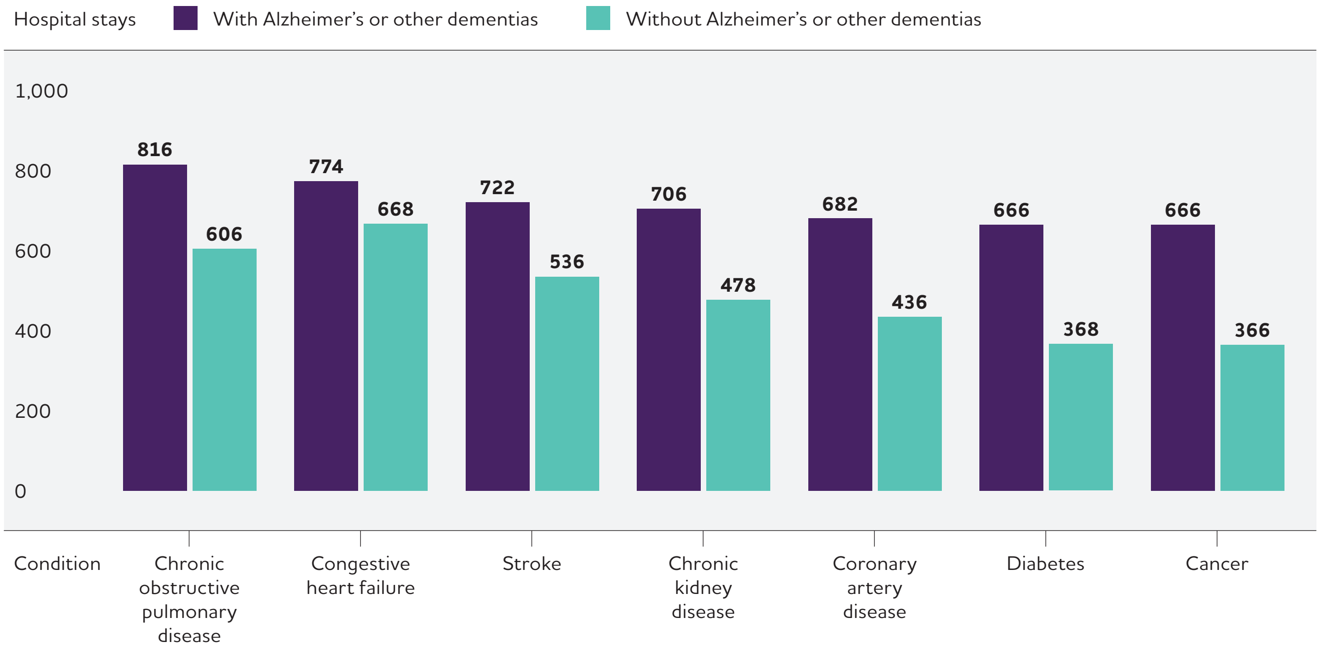
Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to, or quality of, preventive and primary care. Unplanned hospital readmissions within 30 days are another type 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).[788] The total cost to Medicare of these potentially preventable hospitalizations was $4.7 billion (in 2013 dollars; $6.0 billion in 2022 dollars).[788] 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.[788] 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.[788]

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.[789] 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 (HRS) and Medicare, after controlling for demographic variables, clinical characteristics (e.g., presence of 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.[790] Another group of researchers found that individuals with dementia and a caregiver with depression had 73% higher rates of emergency department use over 6 months than individuals with dementia and a caregiver who did not have depression.[791]

Figure **16**

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.[382]

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 16, page).[382] 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.[792] 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.[793] 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 or more chronic conditions.[794]

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 HRS, 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.[795] 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 Delivery 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.[796] The skilled nursing facilities that maintain these relationships have modestly better outcomes,[796] 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.

Table **22**

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 2022 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Care	Home Health Care	Hospice Care
White	$22,203	$5,636	$3,713	$3,130	$1,918	$4,150
Black	27,686	8,765	4,514	4,120	1,976	2,919
Hispanic	25,611	7,626	4,284	3,573	2,379	3,427
Other	22,759	7,065	3,904	3,479	1,965	2,826

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[382]

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 developing severe illness due to COVID-19. Nearly 50% of nursing home residents and 39% of residents in other care communities have Alzheimer's or other dementias.[739] Individuals living in care communities have been extremely vulnerable to COVID-19 due to the communal nature of these settings. More than 161,000 residents of long-term care communities had died of COVID-19 as of December 2022.[797]

Through August 2021, of all people with fee-for-service Medicare who were hospitalized due to COVID-19, 32% had a diagnosis of dementia.[798] 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 were at higher risk for contracting and dying from COVID-19.[799, 800] 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 contracting COVID-19 compared with White adults with dementia.[800] 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.[799]

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 concern 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 compared with individuals with any of 20 other common chronic conditions analyzed (including chronic kidney disease, diabetes, hypertension and obesity) in 2020.[801] This risk was not limited to congregate 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.

Projections for the Future

Total annual payments for health care and long-term care for people with Alzheimer's or other dementias are projected to increase from $345 billion in 2023 to just under $1 trillion in 2050 (in 2023 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 based on projections of economic growth, overall health care spending trends and population aging. On balance these projections suggest that broad changes to Medicare are needed.[802]

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, two recently approved treatments removed beta-amyloid from the brain and slowed cognitive decline in some individuals. These treatments were tested in people with confirmed beta-amyloid accumulation in the brain who were living with MCI due to Alzheimer's disease and mild dementia due to Alzheimer's. Several other treatments that target beta-amyloid accumulation and other well-established brain changes of Alzheimer's disease are in late-stage development.

Several groups of researchers have estimated the health and long-term care cost implications of hypothetical interventions that either slow the onset of dementia or reduce the symptoms.[399, 803-805] 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.[803] A second study estimated how much would be saved with treatments that delayed the onset of Alzheimer's disease by one to five years.[804] 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.[804] 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 ($4,737 in 2022 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 ($830 in 2022 dollars).[399]

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,[805] 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.[655,806] 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

THE PATIENT JOURNEY IN AN ERA OF NEW TREATMENTS

Better Alzheimer's disease care requires conversations about memory at the earliest point of concern and a knowledgeable, accessible care team that includes physician specialists to diagnose, monitor disease progression and treat when appropriate. This is especially true now, in an era when treatments that change the underlying biology of Alzheimer's are available.

The Food and Drug Administration (FDA) approval of two new treatment options in the last two years has generated excitement and hope — and possibly some apprehension — for individuals with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease, their families and their health care providers. In this new era of treatment, it is essential to (1) establish what motivates or dissuades people from discussing memory concerns with their health care providers and (2) investigate the current patient volume of the specialist physician workforce who will be involved in the diagnosis, care and eventual treatment of a possible influx of patients.

Cognitive Issues Have Several Causes

Nearly 10% of Americans age 45 and older experience subjective cognitive decline (SCD): self-perceived worsening of or more frequent difficulties with thinking or memory.[256] For some people, this is normal aging, but for others, these symptoms can be a warning sign of future Alzheimer's disease.[246-250] Individuals with SCD may eventually be diagnosed with MCI, MCI due to Alzheimer's disease, or another form of dementia.[251-253] SCD may also be caused by other underlying health conditions (see Prevalence of Subjective Cognitive Decline, page 21).[254]

Americans and Their Physicians Are Not Talking About Cognitive Issues or a Medical Diagnosis

Many people do not discuss cognitive symptoms with their health care provider because they believe what they are experiencing is to be expected with getting older rather than a diagnosable medical condition. Separate surveys of Americans of all ages and those 65 years and older demonstrate that cognitive issues are commonly misconstrued as normal aging.[245, 808] The Special Report from *2022 Alzheimer's Disease Facts and Figures* found that most Americans without current memory and thinking problems did not understand the distinction between normal aging and a medical diagnosis of mild cognitive impairment (MCI).[808] In the Special Report from *2019 Alzheimer's Disease Facts and Figures*, nearly all older

Subjective cognitive decline

An individual's perception that their memory and other thinking skills are worsening, independent of cognitive testing, a physician's diagnosis or anyone else noticing (see Prevalence of Subjective Cognitive Decline, page 21).

Mild cognitive impairment (MCI)

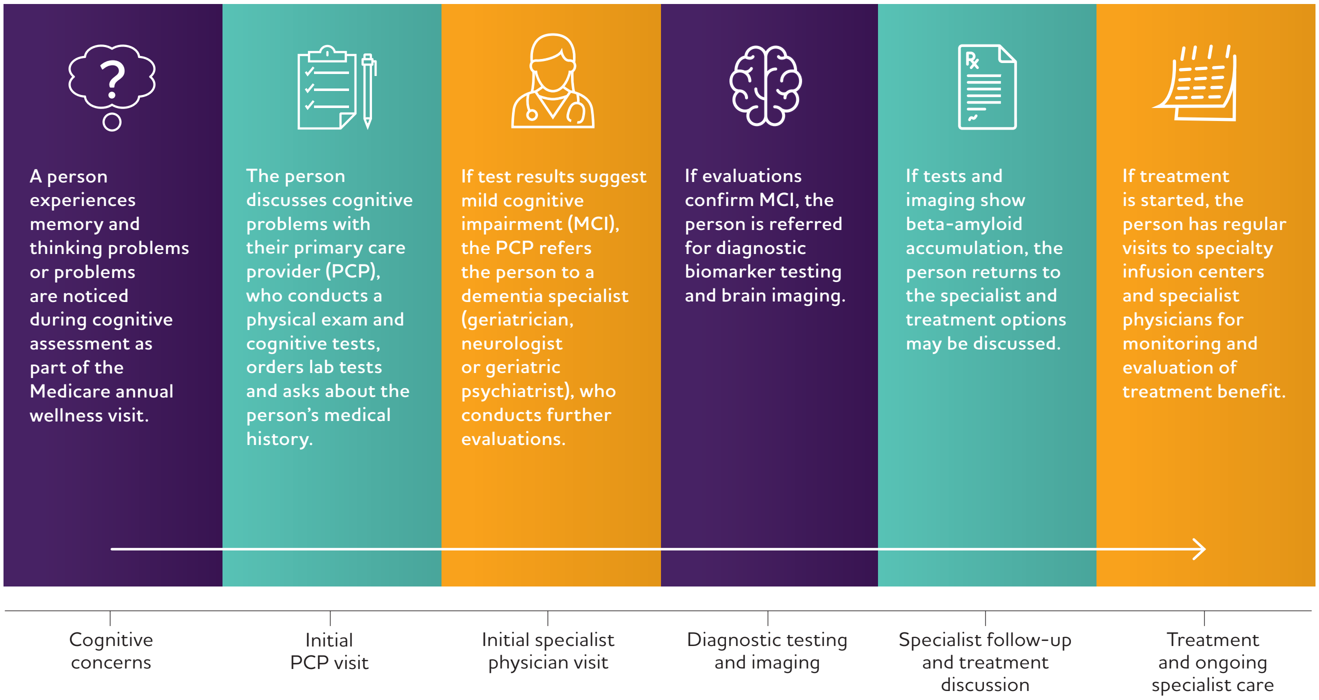
"Early stage of memory loss or other cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living."[807]

MCI due to Alzheimer's disease

Symptoms of MCI along with brain changes characteristic of Alzheimer's disease; MCI due to Alzheimer's disease is the symptomatic precursor to Alzheimer's dementia.

Figure **17**

Patient Journey from Awareness of Cognitive Issues to Care from a Physician Specialist and Treatment[655, 809]



Cognitive concerns	A person experiences memory and thinking problems or problems are noticed during cognitive assessment as part of the Medicare annual wellness visit.
Initial PCP visit	The person discusses cognitive problems with their primary care provider (PCP), who conducts a physical exam and cognitive tests, orders lab tests and asks about the person's medical history.
Initial specialist physician visit	If test results suggest mild cognitive impairment (MCI), the PCP refers the person to a dementia specialist (geriatrician, neurologist or geriatric psychiatrist), who conducts further evaluations.
Diagnostic testing and imaging	If evaluations confirm MCI, the person is referred for diagnostic biomarker testing and brain imaging.
Specialist follow-up and treatment discussion	If tests and imaging show beta-amyloid accumulation, the person returns to the specialist and treatment options may be discussed.
Treatment and ongoing specialist care	If treatment is started, the person has regular visits to specialty infusion centers and specialist physicians for monitoring and evaluation of treatment benefit.

adults surveyed (93%) reported that cognitive changes they experienced seemed like a part of normal aging and indicated that these changes were not severe.[245]

Most Americans are reluctant to see a doctor early if they have cognitive issues and tend to wait until the symptoms have a noticeable impact on their lives. The *2022 Alzheimer's Disease Facts and Figures* Special Report found that only four in 10 Americans would talk to their doctor right away when experiencing symptoms of MCI.[808] The rest indicated that they would live with their symptoms for a while, potentially until they become worse or others expressed concern.[808]

Concerns about health care also make people reluctant to broach the topic of cognitive impairment. The most commonly cited reasons for not discussing cognitive issues are receiving an incorrect diagnosis, learning of a serious health problem, receiving unnecessary treatment and believing symptoms might go away.[808] However, 70% of Americans would want to know early if they have Alzheimer's disease if it could allow for earlier treatment.[808]

Even people already experiencing memory and thinking problems are hesitant to speak with a physician. A large survey in the United States found that of the 10% of individuals age 45 and older who reported SCD, 54% had not consulted a health care professional about their symptoms.[256] When symptoms interfered with function, 41% had not talked to a health care provider.[256] The reasons that people with SCD do not approach their health care providers with their symptoms are explored further in this year's Special Report.

Physicians are not taking the initiative to talk with patients either. Nearly all primary care physicians (PCPs) report waiting for patients (97%) or family members (98%) to make them aware of symptoms or request an assessment.[245]

A collective breakdown in communication about cognitive issues at any point in the patient journey is detrimental to care, especially in an era when treatments that alter the underlying biology of Alzheimer's disease could change the course of the disease if started early enough (Figure 17).

Specialists in the Spotlight: Essential for Timely Diagnosis and Ongoing Alzheimer's Disease Care

If those with cognitive concerns overcome their hesitations, the first medical professional many people approach is their primary care provider (PCP). But PCPs have reported they don't have enough time during a visit to perform a thorough cognitive evaluation and are not entirely comfortable using existing cognitive assessment tools.[245] Instead, they point to specialists who are more qualified to assess, diagnose and manage care for people who may have Alzheimer's disease or other dementia.[245, 810] More than one in three PCPs (38%) say that specialists are better equipped to assess and diagnose patients with cognitive impairment, and 43% say that specialists are better equipped to discuss the results of cognitive assessments.[245] Nearly all PCPs (99%) refer patients to a specialist when they detect cognitive impairment.[245] While in the future emerging digital technologies might reduce barriers to diagnosis and help PCPs feel more confident in their diagnoses, the next steps for patients would again lead them to physician specialists because they are best versed in the advantages and disadvantages of treatment options.

Physician specialists involved in Alzheimer's care include geriatricians (geriatric internal medicine, geriatric family medicine and geriatric psychiatry), neurologists, psychologists and neuropsychologists (see Screening and Diagnosing Workforce, page 57). Emergency medicine physicians also play a role in addressing symptoms and behaviors of Alzheimer's disease in the emergency department; in some instances, they may be the first to evaluate an individual for dementia.[628] Specialists are essential care team members for people with Alzheimer's disease, providing ongoing care and considering potential treatment options (see Medical Treatment and Care Team, page 59).

If Millions of Americans Decide to Seek an Early Diagnosis for Cognitive Issues, Will There Be Enough Specialists?

Millions of Americans could potentially be eligible for available treatments for MCI due to Alzheimer's disease or mild dementia due to Alzheimer's disease (sometimes described as early-stage Alzheimer's disease), assuming they receive a timely diagnosis and want medical intervention. A shortage of crucial dementia care specialists has broad implications for people with memory and thinking problems who seek medical care, including:

- Decreased or delayed access to health care professionals.
- Delayed diagnosis of potential medical conditions.
- Perpetuated uncertainty about the availability of and access to treatment.
- Incomplete understanding of the risks and benefits of treatment.
- Delayed treatment (if appropriate) and delayed access to treatment centers.
- Delayed access to services and support.

5 to 7 MILLION

Estimated number of older Americans (age 65+) with MCI due to Alzheimer's disease in 2023 (see Prevalence Estimates, page 22).

PCPs raised concerns in the *2020 Alzheimer's Disease Facts and Figures* Special Report about insufficient numbers of specialists to receive their patient referrals.[810] More than half of PCPs said there were not enough specialists in their area to meet patient demand; this shortage was particularly evident in rural areas.[810]

Health care workforce shortages that were problematic before have only worsened due to the COVID-19 pandemic. One major concern is that with workforce shortages in many health care sectors, there won't be enough physicians, including specialists, to diagnose and care for the millions of patients seeking an Alzheimer's diagnosis or treatment. Another concern is the waiting period to see the limited number of specialists currently in practice.

Burnout attributed to COVID-19 is one reason health care providers are leaving the workforce in droves, and the burnout rate is at an all-time high. A 2021 survey found that nearly 63% of physicians in all specialties were experiencing at least one manifestation of burnout.[811] Of note, PCPs and specialists who diagnose Alzheimer's disease or provide ongoing care for those with Alzheimer's disease exhibit some of the highest rates of burnout.[811]

Numerous reports predict nationwide shortages of specialists, including geriatricians and neurologists, over the next few decades; this shortage will be felt most acutely in rural settings.[630, 631, 633-635] In fact, 20 states are already described as "dementia neurology deserts," with fewer than 10 neurologists per 10,000 people projected to be available in 2025.[632] The Screening and Diagnosing Workforce section on page 57 covers contributing factors to workforce shortages and additional insights on the gravity of this situation.

The State of Patient-Provider Dialogue About Cognitive Issues and Specialist Physicians' Patient Panel Makeup: Quantitative and Qualitative Evaluations of Individual and Physician Perspectives

This year's Special Report builds on previous Special Reports to inform our understanding of why Alzheimer's disease is not detected and diagnosed promptly and, for the first time, gathers perspectives from specialist physicians who are involved in Alzheimer's disease care.

In 2019 and 2020, the Special Report highlighted challenges to detection and diagnosis in the primary care setting.[245, 810] The 2021 Special Report uncovered how perceptions and experiences of different racial and ethnic groups act as barriers to diagnosis and better care.[694] And in 2022, the Special Report looked at the lack of understanding of MCI and its impact on an early diagnosis of Alzheimer's disease.[808] This year, the Special Report examines two additional concerns:

1. Why do Americans not talk to physicians about memory issues at the earliest sign of a problem?
2. How many patients are specialist physicians seeing, and do they care for patients at all phases of the Alzheimer's disease continuum?

The Alzheimer's Association commissioned two studies for this year's Special Report. The first, funded through the Association's Healthy Brain Initiative grant from the Centers for Disease Control and Prevention (CDC), is a qualitative inquiry conducted by L&M Policy Research (L&M) that consisted of focus groups of PCPs and Americans with SCD. The second is a quantitative survey of physician specialists conducted by Versta Research.

Key Findings

Focus groups revealed persistent challenges for patients and their PCPs in communicating effectively about memory and thinking issues.

Focus Groups of Individuals with SCD

- Barriers to effective communication about memory and thinking problems were attributable to gaps in knowledge and awareness of cognitive health issues.
- Individuals with SCD exhibit a great tolerance for their symptoms, leading them to delay discussing them with their health care providers.
- People with SCD do not discuss symptoms with their PCP because they are waiting for the problem to have a meaningful impact on their life first, suggesting that the problem is serious and not normal aging.
- Ideal circumstances to initiate a conversation varied, but across the board, individuals desired health care providers who engaged them as partners in planning and management. Most participants said they would be more comfortable talking to a friend about memory and thinking problems than a medical professional.
- Personal preferences, social expectations and cultural beliefs dissuaded some conversations; in particular, participants identified wanting a holistic approach instead of prescription medication as a factor.
- Individuals with SCD also indicate that they do not bring up issues with their physician because they do not want medication to be their PCP's first treatment recommendation.

Focus Groups of PCPs

- Informal conversation at the beginning of a visit was the first step toward cognitive assessment.
- PCPs saw family members as crucial facilitators to initiate conversations about memory and thinking problems; increasing the availability of telemedicine visits enabled more communication with family members.
- PCPs felt that limitations related to diagnosis, lack of treatment options, and the ability to refer to specialists and social support services impeded their conversations with patients and their ability to assuage patient concerns.

Specialist Physician Survey

- Emergency medicine specialists report seeing the most patients age 60 and older each year and encounter the most patients with Alzheimer's disease at all stages of the disease continuum, followed by geriatric subspecialists and neurologists.
- Neuropsychologists consistently report seeing the fewest number of patients overall and the fewest number of patients age 60 and older.
- Specialists resoundingly point to their geriatrician colleagues, followed by neurologists, as best equipped to diagnose, treat and manage Alzheimer's disease.
- Specialist physicians report that they see patients with Alzheimer's disease at all phases of the disease continuum, however, most are patients living with MCI or mild dementia.
- Three of the four specialty physician groups indicate that they are seeing the highest number of Alzheimer's patients at the MCI phase of the disease.
- Two in three geriatricians and neurologists report being familiar with clinical trials related to Alzheimer's disease.
- All specialists likely overestimate the percentage of patients they see who are non-White based on overall U.S. population demographics.

Focus Group Design and Research Methods

The Alzheimer's Association worked with L&M to conduct focus groups with individuals experiencing SCD who had not talked to their PCP or another health care provider about their cognitive changes.[A17] The main objective was to collect and assess perspectives on factors that underlie the lack of patient-physician communication about memory and thinking issues.

Six focus groups included individuals with SCD who had not talked to a health care provider. Participants represented diverse backgrounds (Black Americans, Hispanic Americans [English and Spanish-speaking], Asian Americans and Pacific Islanders [AA/PI], American Indians and Alaska Natives [AI/AN] and non-Hispanic White

Americans). Three focus groups were conducted with PCPs. All focus groups took place from June 2 to August 4, 2022.[A18]

This report uses approximate terms to indicate the number of participants who expressed a given view rather than numbers or percentages (see box).[A19]

Most: two-thirds of participants or more

Many: more than half of participants

Some or several: more than one-third of participants

Few: less than one-third of participants

Focus Groups: Individuals with SCD

Emotional Reactions and Limited Vocabulary to Express Cognitive Issues Impede Conversations With Medical Professionals

All focus groups revealed that many participants contextualized memory and thinking problems within the personal experiences of family members or friends diagnosed with Alzheimer's disease or dementia. Watching a family member's struggles with these diseases made them more fearful, yet at the same time more tolerant, of their cognitive problems. Furthermore, their experiences with cognitive problems sparked "hot thoughts" — instant, automatic, negative reactions — that reflected worst-case scenarios, including perceptions of inevitable, precipitous cognitive decline. Speaking with a doctor meant risking a diagnosis, and a diagnosis was associated with loss: loss of self-confidence, independence and control.

> **"My parents are from India, and I feel like memory problems — if an adult or grandparent has them — they try not to discuss it and try to sweep it under the rug. They don't want it to be an issue."** – AA/PI focus group member

When participants faced the challenge of speaking about their problems in a medical context, the conversation reflected a dearth of language, vocabulary and health literacy regarding mild cognitive issues. Most were unfamiliar with the recommended assessments required for diagnoses. The participants proposed that having educational materials and assessment tools would help people learn the language and terms necessary to talk about cognitive health. AA/PI participants specifically wanted to see educational materials before seeing their doctors and to be able to access such materials at their doctor's office. Some participants were uncertain about the specialists they might need to see about memory and thinking issues. Furthermore, they worried about the time services would take and the cost or implications of a diagnosis on their insurance coverage.

Racial and ethnic groups shared their unique perspectives: [A20]

- Black Americans indicate that knowledge and awareness of memory and thinking issues and the potential causes of these problems have increased in their communities over time. However, they are still uncertain and fearful about the root causes of memory and thinking problems and how progression will impact their ability to perform in current caregiver roles.
- AI/AN Americans have culturally-specific beliefs about the causes of memory and thinking issues and the ramifications of these issues. They noted the impacts that trauma and loss of ancestral oral traditions have had on memory and thinking skills and expressed substantial concerns about being able to fulfill their responsibilities as Elders if they have memory or thinking issues.
- AA/PI, Hispanic English-speaking and Hispanic Spanish-speaking Americans indicated that they avoid discussing memory or thinking issues because they do not want to be a burden or are embarrassed by their symptoms.
- Hispanic Americans indicate that if they broach the subject of cognitive issues, they tend to do so with humor.
- White Americans indicate that they seek out information about their memory and thinking issues to help them manage these changes on their own.

> **"I don't want to use the word shame, but there's a discomfort, especially when we are in a ceremony, and I can't remember the order I'm supposed to do something [in], and I do feel embarrassed."** – AI/AN focus group member

Perceived Risks Seem to Outweigh Benefits of Speaking with a Physician About Cognitive Issues

Across all groups, participants thought there were risks associated with a diagnosis that outweighed any benefits, especially at the early stages. Many participants were willing to believe that their memory or thinking issues were part of the "normal" aging process. Feeling scared and anxious about the possibility of a diagnosis often resulted in avoidance and denial for many participants.

> **"I don't [speak to my doctor] because it doesn't seem like that big of a deal...not yet. It would have to be something dramatic. Losing my train of thought is not enough."**
> – Black American focus group member

To warrant a discussion with their physician, most participants said that their memory and thinking problems would need to have a significant negative impact on their quality of life or the lives of their family members. However, the "tipping point" is subjective and may be clouded by norms and expectations of aging. Concern about access to resources and support services, such as quality health care or assistance from family or friends, may be contributors to a higher tolerance for cognitive symptoms. Common examples of alarming memory or thinking problems shared by individuals with SCD that would prompt a conversation included forgetting where they were, getting lost in a familiar place or forgetting family members' names. A few participants felt that their problems would need to severely impact their work performance and productivity or threaten their financial ability to provide for themselves or their families before they would speak to a doctor. A few participants said that openly discussing these issues in a group moved them to talk with their doctors.

> **"Creo que si me empezara a fallar la memoria con mas frequencia o con mas importantes, si definitivamente iria con el doctor." (I think that if it were to begin to happen more frequently or [become] more important... then, yes, definitely, I would go see a doctor.)**
> – Hispanic Spanish-speaking focus group member

Assumptions About What Doctors Will Say and Do Prevent People From Speaking About Memory Issues

Many participants were reluctant to raise memory issues with their providers because they assumed their doctors' first response would be to take a medication-based approach. Several participants felt their physicians would first opt for prescriptions before creating a care plan. Many preferred a more holistic approach by planning around diet and exercise instead of medication. Several individuals from racial and ethnic minority groups said they relied on treatment strategies grounded in cultural beliefs and practices and shared a more holistic view of health and wellness. They opted to use herbal remedies, religion (e.g., prayer for healing) and music (e.g., drumming, piano) before, or in place of, seeking medical advice.[A21]

> **"I haven't talked to my doctor yet because I don't want prescription drugs to take to alleviate it. I don't want to be dependent on prescription drugs. I think I'm hesitant about taking any type of medication for this."** – AA/PI focus group member

Participants from the Black American and AI/AN groups alluded to historical racism in the medical field, making individuals feel that they do not receive adequate, culturally competent health care. Some participants also felt that their community's mistrust of doctors and/or Western medicine prevents them from talking to a doctor.

Different racial and ethnic groups expressed perceptions about ideal care and barriers to care that influenced their interactions with health care providers:[A21]

- Black Americans emphasized how institutional and societal barriers affect their ability to access high-quality, equitable care. Prejudice, racism and implicit bias limit trust in health care providers.
- Black Americans, AI/AN Americans and Hispanic Spanish-speaking Americans strongly preferred holistic approaches to treatment that minimize the use of biomedical interventions or prescription medication.
- Hispanic Spanish-speaking Americans tend to speak to a medical professional about memory or thinking problems before family or friends.
- White Americans were more likely to bring up concerns about insurance coverage if they discussed memory problems with their doctor.
- White Americans were the only group to mention that talking about memory or thinking issues to a specialist may be more appropriate than discussing them with their primary care physician.

> **"It's a matter of, is there enough to do about these things like eating healthy, working out, sleeping more? Should I practice this first, and if it doesn't get better, then let me talk to somebody?"**
> – Hispanic English-speaking focus group member

Ideal Conversations About Memory and Thinking Issues Would Emphasize Options for Diagnosis and Health Care

Participants provided a range of actions their doctors may take to evaluate their thinking and memory issues. Some participants expected their doctors to give referrals to specialists and recommend medication and lifestyle changes to help improve their cognitive health.

> **"At my doctor's office, they have a screening form that looks like it's for depression. If they had a screening form for forgetfulness, it might be easier to open the door for people if they have those issues. I would not want to take a drug for it, but I want to open up a discussion for it."**
>
> – AA/PI focus group member

Across individual focus groups, people with SCD expressed a desire for inclusive, culturally appropriate conversations and shared decision-making with their health care team.

- Black Americans preferred empathetic care that focuses on holistic wellness, education and an options-oriented approach to intervention. A key feature of improving opportunities for conversations and care is the doctor's ability to actively listen to patients' concerns and holistic health needs. Many participants expressed interest in a holistic approach to medicine that honors mental and physical wellness while putting less stress on biomedical interventions unless necessary. Further, participants shared a need for education about memory and thinking issues and wanted practical upstream intervention options.
- AI/AN participants expressed an interest in doctors doing more than diagnostics or pointing out problems or deficits. They wanted an action-oriented, strength-based plan that honors their connection to their cultural ways and the complex intergenerational trauma they connected to memory and thinking issues.
- The AI/AN group also expressed interest in improving communication and bedside manner between patients and providers through increased awareness and appreciation of local Indigenous Ways of Knowing. Within tribal communities, being an Elder is a revered and earned title that conveys the acquisition of important and transcendent knowledge. As a result, there are particular protocols for engaging and communicating with Elders respectfully.
- AA/PI participants want their doctors to reassure them, educate them and refer them to specialists experienced in dealing with thinking and memory issues. As mentioned, they did not want to be prescribed medications, preferring natural alternatives. They also wanted access to screening tools and tests to better diagnose problems.
- Hispanic English-speaking participants want answers, reassurance and honesty when discussing memory and thinking issues with doctors while expecting to be treated with respect and concern. The group expressed a need for guidance on what they could do to address their memory issues. For some, this included whether they should take medications, while for others, it consisted of whether there are lifestyle changes they should make.
- Some Hispanic English-speaking participants want their doctors to develop a specific action plan. The group wanted their doctors to document the progression of cognitive issues if any, so they could assess a baseline and monitor their situation over time. Some also wanted their doctor to administer tests to have a more concrete diagnosis and to be able to determine that baseline.
- Hispanic Spanish-speaking participants wanted their doctor to help them understand why they are having these issues and reassure them. Participants wished their family members were part of the conversations so doctors could guide them together.
- White focus group participants wanted their doctors to put them at ease and help them plan for and be optimistic about the future. They also wanted concrete guidance on knowing when their issues are serious enough to take significant steps. Some also wanted their doctors to develop an action plan for the future.

> **"I've been keeping it under wraps. It's just something I don't really think about all that often. I'm pretty sure [I] will talk to the doctor, but they would have to be the one to bring it up."**
>
> – White focus group member

Individuals Prefer to Discuss Cognitive Issues with Friends Instead of Medical Professionals or Family

Most participants said they would be more comfortable talking to a friend about memory and thinking problems than a medical professional. Talking about memory and thinking issues in a medical context elicited intense emotional responses, so participants preferred talking with their peers for reassurance and normalcy. With friends, participants said that they could "compare notes" on cognitive problems and commiserate with a sense of humor about sharing the journey of getting older together.

> **"My friend has the same issues. We laugh about it, but if he said to go to a doctor, I'd go in a minute. I respect what he says."**
>
> – Black American focus group member

Many individuals with SCD refrained from serious conversations with family members because they were "difficult." They spoke of experiences with other relatives who had memory problems, acknowledging that fear, respect for elders, aging norms and stigma surrounding aging and memory loss were all barriers to talking directly with their family members.

> "In my community, it's scary because it's been in my family. I don't want to say it's frowned upon, but my dad has been forgetting some things, but my mom says, 'Don't say anything, because he's scared about it too,' but he won't talk about it. For me, it's not discussed. It doesn't exist."
>
> – Hispanic English-speaking focus group member

Focus Groups: Primary Care Providers

An Informal Conversation is a Crucial First Step Toward Formal Cognitive Assessment

Many primary care provider participants described how they prefer to start a clinical visit with informal social conversation, which disarms patients and puts them at ease. Informally initiating the visit may provide important cues to help identify potential recall issues during the conversation.

> "People sometimes try to hide it as a coping mechanism. I pinpoint it by asking cognitive and other questions, and if the answer is not direct, I begin to think there may be a problem. When you press them a little, you find they can't count backward, for example."
>
> – Small practice PCP member

Once they suspect a patient may have memory problems, many construct subtle, indirect questions that could determine the extent of memory issues rather than asking them explicitly about problems. They ask a patient to describe their neighborhood, their daily routine or how they perform a specific task. Doctors feel this collaborative investigation is more accurate, as it prevents patients from denying any memory or thinking problems. Most expressed the importance of showing compassion and patience, techniques that build trust and decrease barriers to discussing sensitive topics.

> "One way I involve the patients in my observation and assessment is I say, hey, this is what I'm looking at. 'What do you think?' I get them involved if they are concerned or notice it as well. I ask family members about their opinions. It's more of a collaborative investigation or inquiry."
>
> – Large practice PCP member

Short appointment times make it difficult to notice subtle changes in a patient's thinking over time. Many PCPs noted that patients prioritize discussing physical health issues such as diabetes or high blood pressure over cognitive health issues. For PCPs to initiate conversations about cognitive concerns, they suggested a consistent, standardized process as an entry point. They felt that standardized processes (for example, conversation starters or other prompts to facilitate dialogue and uncover any cognitive concerns) would help overcome barriers to initiating conversations independently. By following a standard process, the decision to begin the conversation would be taken out of the patient's hands entirely, enabling the provider to assess the patient's cognitive health more frequently.

Family Members Are Crucial Facilitators of Dialogue and Follow-Up Care for Memory and Thinking Issues

If primary care providers want to ask directly about cognitive ability, most choose to speak with the family or family members instead of the patient; they see family members as crucial facilitators to initiate conversations about memory and thinking problems. Almost all participants learned of their patients' memory problems when a family member communicated concerns rather than hearing directly from the patients themselves. Many felt the issues were more serious when a relative provided an outside perspective.

> "When you ask, a large percentage of people say they forget things, but it's not particularly sensitive nor specific. I was always taught that if people come in and tell you they are having memory problems, the majority of the time it is not significant, compared to when relatives and friends come in and complain… If a family member says, 'Yes, I'm seeing things (with memory problems),' that to me is much more of a red flag." – Small practice PCP member

The uptake of telemedicine during the COVID-19 pandemic offered a window into home life and another avenue to engage with family members. Remote visits enabled primary care providers to observe home environments to gather insights into a patient's well-being, which would not be possible in a clinical setting. Many patients needed assistance with virtual visits, so family members often helped them set up and manage the technology — creating more opportunities for doctors to engage with family members about cognitive concerns.

Primary care providers noted that patients were generally more accepting of their issues and the need to address them when a family member or caregiver attended their visit. PCPs stated that family members also played a major role in making sure that the patient followed through on steps after cognitive assessments. At the same time, PCPs recognized that cultural factors might influence family members' and patients' decisions to avoid medical help. For example, they talked about their experiences with AI/AN and Hispanic cultures, with tightly knit extended families who placed value on caring for elders on their own, at home, instead of seeking care from the medical system.

Small and Rural Practices Have Unique Barriers to Effective Communication

PCPs shared insights about the barriers to effective conversations they experience in their practice type, including visit duration, patient preferences and emotions related to memory issues, and appointment frequency, among other factors.

PCPs in all three groups described the value of long-term, personal relationships with patients and their families and that this helps increase comfort in discussing sensitive issues. However, setting type (small, large or rural) affected providers' ability to initiate conversations with patients about cognitive issues.[A22]

PCPs in small practices tended to view thinking problems, such as forgetting car keys, as minimal. Even if a patient expresses concern about their brain health, the small-practice group discusses memory issues only when a family member communicates their concern. This system seems to rely on family members to be responsible for the patient's health and minimizes the patient's autonomy, which can delay or shut down conversations if family members are not present or aware. Professionals in small practices would also find it easier to initiate discussions if concerns were disclosed before the visit. This group felt exceptionally constrained by time limits on visits and could not have an extended conversation about the problem.

Another interesting finding from the small-practice focus group is that while physicians felt that medication could be a relatively effective treatment for memory issues, they recognized patients' resistance to prescriptions. This hesitancy prevents conversations with providers about memory issues and often comes from patients' research on the internet about specific medications and their potential side effects.

Rural providers were the only group to report that they do not routinely discuss memory issues with patients unless a family member brings it up first. In rural practices, distance, lack of transportation and availability of appointments are unique barriers that patients and their health care providers face when addressing memory issues. During times of inclement weather or harvest season for farmers or ranchers, these patients also lack the time or ability to visit their providers regularly. Limited appointment times and less frequent visits add to the challenge. In addition, some rural clinics are only open on certain days or times and thus offer a small number of appointments. Once at an appointment, patients tend to have many issues to address. Memory or thinking issues, when they exist, fall low on the list of priorities.

> **"The smaller clinic in one rural setting was only open two mornings a week, so if they wanted to get in, that's the time they had. There are also competing issues and a time barrier. They have a 15-minute appointment and have to prioritize diabetes, blood pressure, anything other than memory, until something like a bigger incident happens that triggers a visit to a provider."** **– Rural practice PCP member**

Primary Care Providers Say They Lack the Tools to Care for Patients Experiencing Cognitive Issues, Relying on Specialists to Fill This Gap

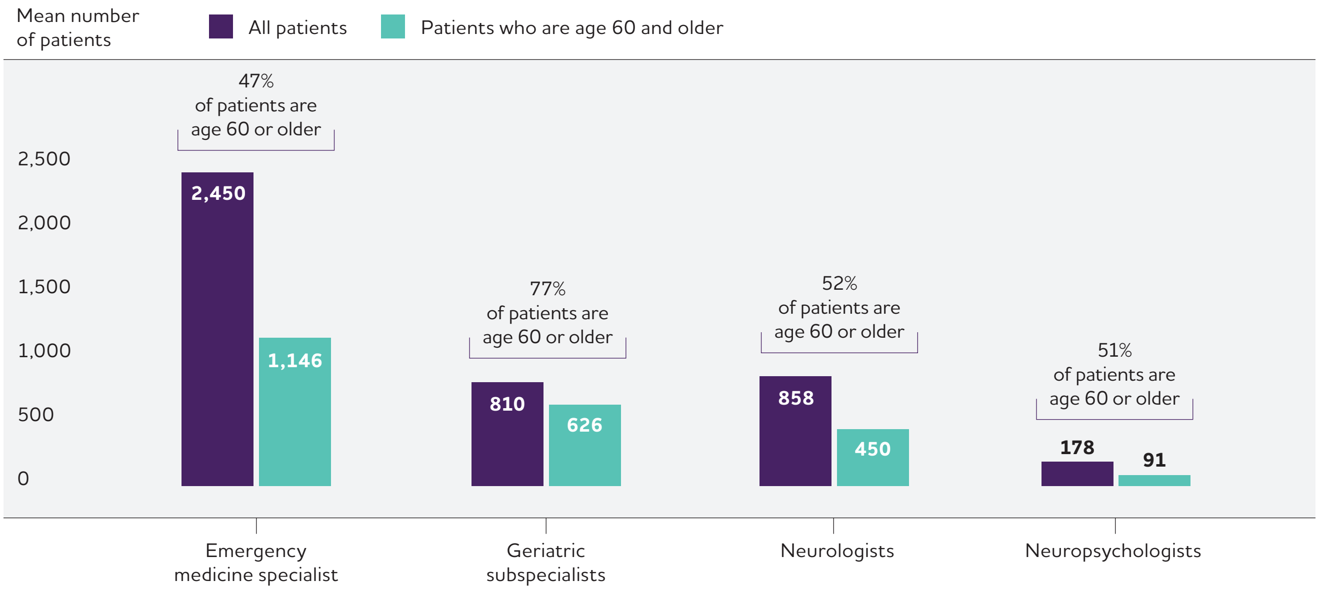
PCPs felt that their conversations with patients, and their ability to assuage patient concerns, are circumscribed by limitations related to diagnosis, lack of treatment options and ability to refer to specialists and social support services. They recognized that patients had strong feelings toward cognitive issues — anxiety, fear, hopelessness with a diagnosis, a sense of loss and shame — making it very difficult to acknowledge problems, let alone discuss them with a doctor. They recognized the push and pull between giving patients hope about the future while delivering an honest opinion about their prognosis.

Health care professionals felt it was challenging to keep up with medical standards, training about cognitive health problems and advances in management. They also recognized the social stigma surrounding cognitive decline. Patients' fears about losing their ability to care for themselves created a cascade of negative emotions, including anticipating feeling disconnected from, and devalued by, their families if they needed to be cared for outside of the home, in a nursing home or a memory care facility. PCPs in large practices indicated that they would like to be able to offer more educational resources to improve conversations, and those in rural practices felt that in-person education during appointments was crucial.

Discussions with PCPs also revealed some inconsistencies and gaps. Providers identified a variety of potential specialist referrals, but a consistent referral protocol was not reflected across groups. Access to specialists and community resource referrals varied, depending mainly on

Figure **18**

Mean Number of Unique Patients Each Specialist Reported Seeing in a Year



the practice location and the provider's professional network. For example, PCPs in rural areas indicated that referral options are limited. Most specialists are located hundreds of miles away; as a result, these providers rarely refer their patients. Even if they wanted to consider referring patients with memory issues to specialists via telehealth, many patients do not have the bandwidth available where they live, and/or the patients don't have or know how to utilize the technology.

Specialist Physician Survey Design and Research Methods

To document the current specialist physician workforce capacity for Alzheimer's care in the United States, the Alzheimer's Association commissioned Versta Research to conduct a nationwide survey of medical specialists (N=1,182) who diagnose and/or provide ongoing care for patients with Alzheimer's disease. Specialists were defined by their inclusion in the American Medical Association's (AMA) Masterfile of practicing U.S. physicians (including residents) or on a list maintained by IQVIA and practice in the following areas:

- Emergency medicine (n=636)
- Geriatric subspecialties, including geriatric internal medicine, geriatric family medicine, and geriatric psychiatry (n=123)
- Neurology (n=232)
- Neuropsychology (n=191)

The survey measured activity (self-reported number of unique patients seen where unique indicates a person, not a visit), including:

- The number of patients age 60 or older.
- How many patients have dementia.
- How many patients have Alzheimer's disease specifically.

The survey also measured perceptions of clinicians best suited to provide Alzheimer's care and physician estimates of the percentage of patients age 60 or older from different racial and ethnic groups.[A19]

Specialist Physicians See a Substantial Number of Patients Age 60 and Older Every Year

Specialist physicians describe seeing thousands of patients annually; a large portion are 60 or older.[A23] Emergency medicine specialists report seeing the most patients age 60 or older. Nearly four in five emergency medicine specialists noted they see 500 or more patients in this age group each year, and one in two (49%) report seeing 1,000 or more. Many geriatric specialists report seeing 500 or more older adult patients each year (42%). A little more than one in three neurologists (37%) indicate that they see more than 500 patients age 60 and older each year. Neuropsychologists report seeing the fewest number of patients in this age group per year (3% see 500 or more patients, and none see more than 1,000 patients). However, this specialty also reported the lowest annual patient volume of all specialties surveyed.

Specialists estimated how many unique patients they see in a year (see Figure 18, page 95). The number of patients age 60 or older specialists estimate they see in a year varies dramatically and may be related to higher patient traffic to some settings than others (for example, visits to the emergency department for immediate medical needs versus visits to specialists who require referrals and, in some instances, have lengthy wait times that may affect patient volume). Within the specialties, individual clinicians may see anywhere from fewer than 100 to more than 1,000 patients 60 or older each year (Figure 18):

- Emergency medicine: 1,146
- Geriatric subspecialists: 626
- Neurologists: 450
- Neuropsychologists: 91

Specialists Report Seeing More Patients in Early Stages of Alzheimer's Disease

The survey findings offer a glimpse into a typical specialist practice using self-reported estimates of (1) the number of patients with Alzheimer's disease seen each year and (2) patients with a diagnosis of MCI or dementia due to Alzheimer's disease (Figure 19). All specialists indicated that they see patients with MCI or dementia due to Alzheimer's disease. Emergency medicine specialists, geriatric subspecialists and neurologists report seeing patients who represent the entire continuum of Alzheimer's disease, from MCI to severe dementia (Figure 20a). Most of the patients are in the earlier phases of the Alzheimer's disease continuum. Neuropsychologists also estimate they currently see more patients at the early stages of the continuum than at later stages, likely because of their role in cognitive evaluation and assessment, and possibly, their essential role in evaluating treatment benefit (Figure 20b).

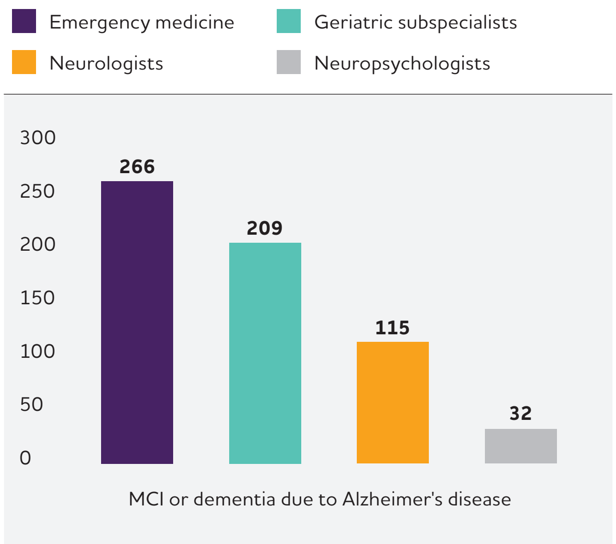
Specialists See Neurologists and Geriatricians as Best Equipped to Diagnose, Treat and Provide Ongoing Care

Specialists said their neurology and geriatrician colleagues could most effectively diagnose Alzheimer's disease (79% and 68%, respectively) (see Figure 21, page 98). Half of the specialists surveyed believed geriatric psychiatrists and neuropsychologists would be able to effectively diagnose Alzheimer's disease. Approximately one in three specialists said family medicine (31%), and one in four said psychiatrists (26%), internists (25%) and general practitioners (23%) would be able to effectively diagnose Alzheimer's disease.

Neurologists and geriatricians are also viewed by other specialists as most effectively able to recommend treatments for Alzheimer's disease (73% and 71%, respectively), followed by geriatric psychiatrists (57%) and neuropsychologists (32%).

Figure **19**

Mean Number of Unique Patients with Alzheimer's Disease Per Year by Specialist



Specialists report that by far, they view geriatricians as the specialists most effectively able to provide ongoing care for patients with Alzheimer's disease (79%), followed by neurologists (54%), geriatric psychiatrists (50%) and family medicine practitioners (46%).

Importantly for recommending treatment options to their patients with Alzheimer's disease, geriatric subspecialists were the most familiar with clinical trials related to the disease (68% familiar vs. 32% not familiar). Almost as many neurologists (65%) were familiar with clinical trials related to Alzheimer's disease. Approximately one in two neuropsychologists reported familiarity with ongoing clinical trials.

Specialists Overestimate the Proportion of Non-White Patients They See

Specialist estimates of the proportion of their patients age 60 or older who are non-White do not reflect U.S. Census Bureau estimates of the U.S. population (see Table 23, page 99). These likely over- and underestimates were similar across specialties. Specialists likely overestimate the proportion of their base that is Black, reporting they see two times more patients than observed in the overall U.S. population. They also overestimate the proportion of the multiracial or biracial patients they see. On the other

Figure **20a**

Mean Number of Unique Patients at Each Phase of the Alzheimer's Disease Continuum

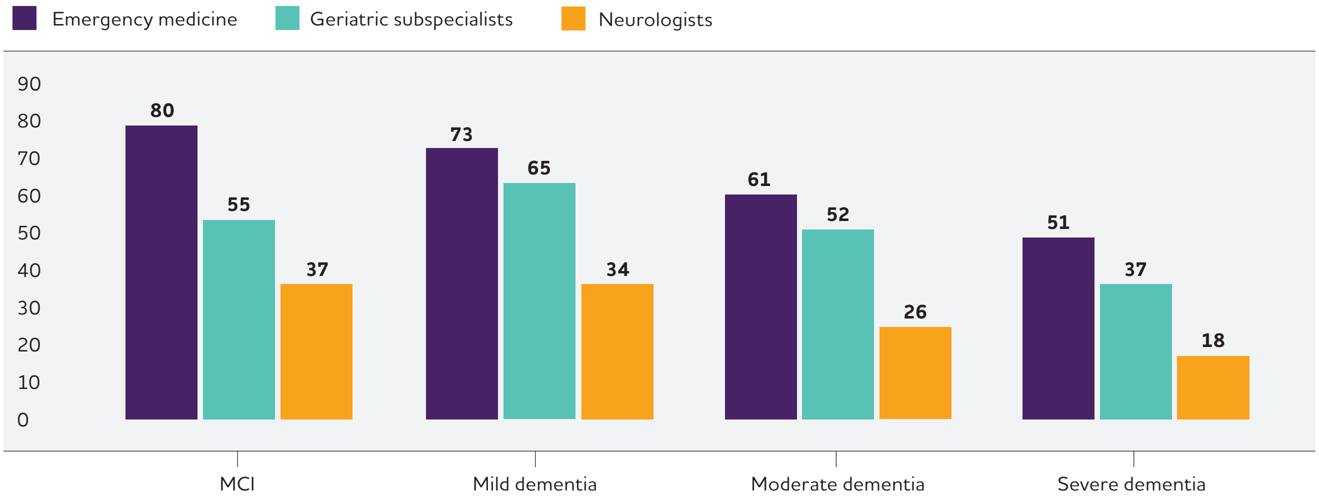
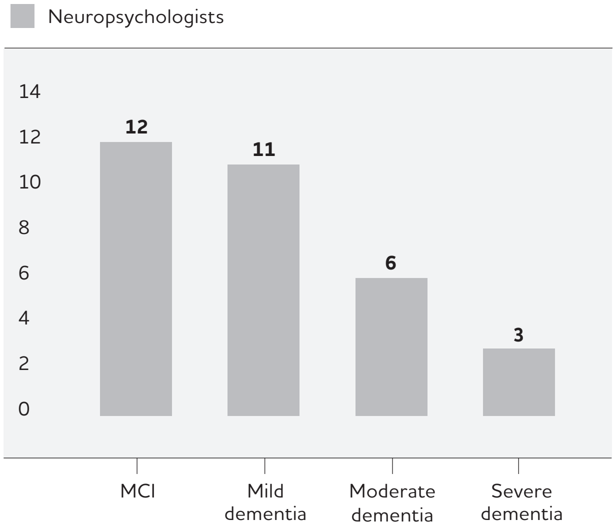


Figure **20b**

Mean Number of Unique Patients at Each Phase of the Alzheimer's Disease Continuum



hand, specialist estimates of the number of White patients they see in practice is dramatically low relative to the proportion in the overall U.S. population (see Table 23, page 99).

Recent research indicates that people frequently overestimate the sizes of minority groups and underestimate the size of majority groups in various circumstances—not just when it comes to racial and ethnic group sizes or in health care settings.[812, 813]

Reinforcing Foundational Specialist Physician Care

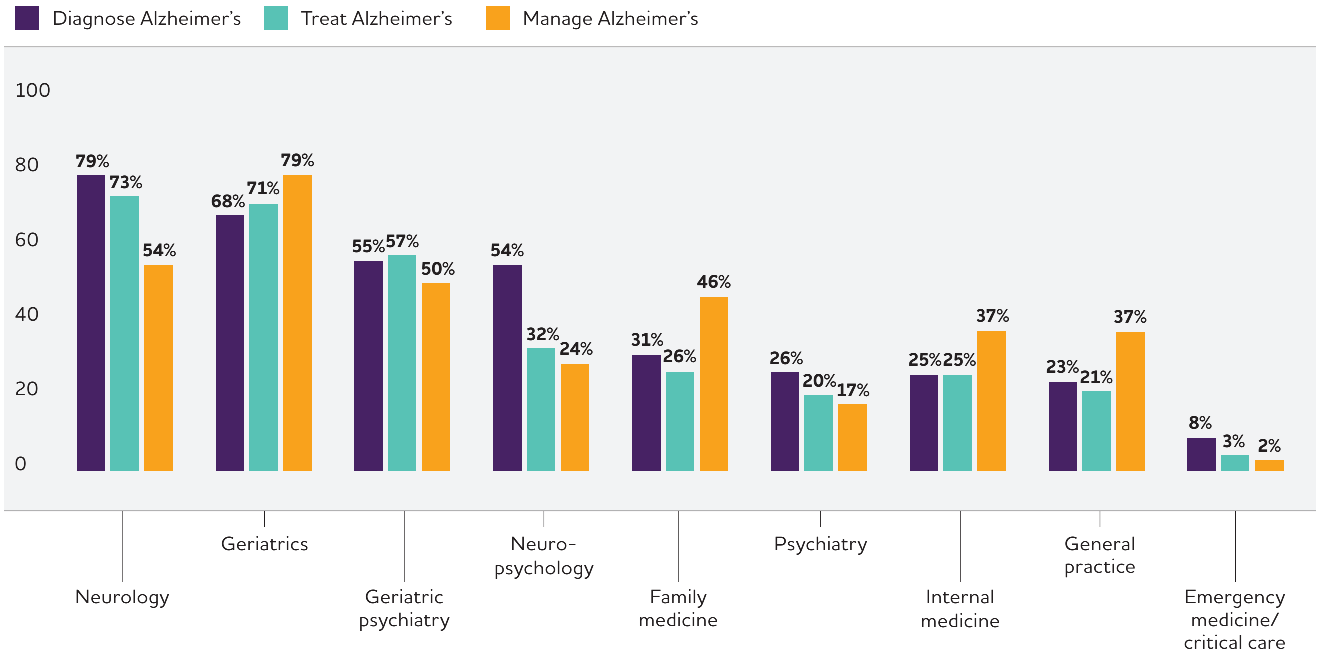
The FDA approval of treatments targeting the underlying biology of Alzheimer's disease is reframing the health care landscape for people with MCI due to Alzheimer's disease. Whether the approval of treatment options will stimulate more conversations between people experiencing cognitive decline and their health care providers remains to be seen. What we do know based on this year's Special Report is that a shortage of dementia care specialists could soon become a crisis for Alzheimer's disease care at all phases of the disease continuum.

In previous surveys, PCPs indicate that they will refer to a specialist if they detect cognitive impairment.[245, 810] In this year's survey, specialist physicians indicate that they believe their geriatrician and neurologist colleagues are best equipped to evaluate cognitive issues in older patients, suggesting that they would likely refer patients too. What happens when specialists receive an influx of referrals to evaluate new patients for cognitive impairment?

A shortage of specialists or specialists who are at capacity and no longer accepting new patients is likely to have the most immediate and obvious impact on people at the MCI phase of Alzheimer's disease who may be eligible for newly-approved treatments. Specialists indicate that most patients with Alzheimer's who already come to their clinics are in the earlier phases of Alzheimer's disease. They were not asked directly about their current capacity or ability to take on new patients; this is an area of interest to the Alzheimer's Association and may be the topic of future surveys.

Figure 21

Percentage of Specialists Citing Specific Specialties as Being Able to Effectively Diagnose, Treat and Manage Alzheimer's Disease*



* Specialists could choose more than one specialty.

A RAND® report issued in 2017, before treatments targeting the underlying biology of the disease were FDA-approved, projected that specialists (neurologists, geriatricians and geriatric psychiatrists) would be unlikely to have the capacity to care for an influx of patients either seeking a new diagnosis or requesting treatment for early-stage Alzheimer's disease.[655] The RAND report estimated that specialists would be able to have an initial evaluation visit with fewer than 4 million patients with MCI each year; patients would wait an average of 18.6 months to see a specialist if capacity was insufficient.[655] Delaying a diagnosis of Alzheimer's disease by more than a year translates to a delay in receiving potentially life-changing treatment or enrollment in a clinical trial, along with implications for myriad other personal caregiving and planning efforts as the condition progresses.

Individuals in the later phases of Alzheimer's disease (moderate and severe dementia) will also be negatively affected if specialists are overburdened. Long wait times for initial visits will likely result in long wait times for *any* visit, including ongoing management.

As described earlier, shortages of geriatricians and neurologists necessary to care for the aging U.S. population are imminent — or already evident (see Workforce, page 56). This Special Report reinforces the recommendations outlined previously (see Workforce, Looking to the Future, page 63), including efforts to:

- Expand the workforce through multidisciplinary programs that train PCPs and other health care professionals to care for older adults (e.g., GWEPs).
- Strengthen training and specialization in dementia care, such as with the Alzheimer's and Dementia Care ECHO® Program, so that clinicians other than geriatricians can take an active role in assessing cognitive impairment.
- Increase awareness of Medicare reimbursement for health care visits that result in a comprehensive dementia care plan and support efforts to develop alternative payment models such as the "dementia care management model."[707, 814] If more providers are aware that visits are reimbursable and can access guidance and education on how to conduct these visits, they may opt to perform more evaluations themselves, alleviating the burden on geriatricians by more evenly distributing assessment and management among collaborating care teams.
- Encourage clinicians, health systems and patients to participate in voluntary provider-enrolled patient networks, such as the Alzheimer's Network for Treatment and Diagnostics (ALZ-NET). ALZ-NET collects real world evidence about Alzheimer's patient care and long-term clinical and safety data for enrolled patients evaluated for and treated with novel FDA-approved Alzheimer's disease therapies. ALZ-NET will also track long-term health outcomes (effectiveness and safety) associated with the use of these

Table **23**

Estimated Proportions of Patients Age 60 or Older by Racial and Ethnic Backgrounds

Racial or Ethnic Background	Percentage of the U.S. population age 60 or older*	Estimated percentage of specialist's patient base			
		Emergency medicine physician	Geriatric subspecialist	Neurologist	Neuropsychologist
Asian American or Pacific Islander	**5%**	7%	8%	7%	5%
Black American	**10%**	22%	24%	19%	21%
Hispanic American	**9%**	20%	12%	16%	12%
Native American or Alaska Native	**1%**	2%	3%	1%	1%
White	**75%**	43%	46%	51%	54%
Multiracial or biracial	**1%**	5%	5%	5%	5%
Another race or ethnicity	**<1%**	1%	1%	1%	1%

*Based on 2019 U.S. Census Bureau estimates.

Percentages do not total 100 because of rounding.

FDA-approved therapies in real-world settings. Real-world data collection is particularly valuable for establishing health care resource utilization and gaps in care. Information collected from ALZ-NET may also help physicians answer important patient-care questions about treatments and diagnostics, and improve general dementia care. ALZ-NET also serves as a resource for evidence gathering, information sharing, and education across both national and international clinical and research communities, encouraging innovative, inclusive research and supporting opportunities to improve care.[815-817]

Another approach is to develop novel, sustainable collaborative care models.[818-821] One example is the ALIGN (Aging, Life Innovations, Goals & Needs) Program from Mt. Sinai.[822, 823] The ALIGN team, which includes a geriatrician, nurse practitioner and social worker, works closely with PCPs to support complex, high-risk patients who could benefit from an added layer of care temporarily.[822, 823]

Building Bridges to Better Patient-Physician Communication

Dementia care specialists are unlikely to be engaged if individuals experiencing memory and thinking problems and their families do not understand the potential implications of these cognitive changes or are not acknowledging and discussing them with a PCP.

The focus groups gave a glimpse into barriers to — and potential solutions for — how individuals and physicians approach conversations about cognitive issues. In their own words, participants reinforced what previous Special Report surveys found:

- Individuals are unconcerned about cognitive decline until it impacts their quality of life or ability to participate in regular activities — whether they are experiencing symptoms or not, most view memory and thinking problems as normal aging.[808]
- Individuals prefer to approach family and friends first with memory and thinking problems, which often happens long before they see a doctor with their concerns.[245]
- There is still stigma surrounding cognitive issues and a lack of awareness of what is more than normal aging in many communities, so people remain silent about potential problems.[694, 808]
- People do not want to receive a diagnosis of Alzheimer's disease or other dementia unless there is a treatment available or their physician has a detailed care plan.[694, 808]
- Individuals have a limited understanding of the patient journey to a diagnosis of Alzheimer's disease or other medical condition and beyond.[808]
- Personal experiences, along with sociocultural beliefs, shape perceptions of health care and are a significant barrier to conversations about cognitive issues.[694]
- People avoid conversations because they do not want medication and fear that their physician will reflexively offer a prescription first before trying other approaches.[694]

- PCPs hesitate to initiate conversations about cognitive decline and will wait until family members bring it to their attention.[245]
- PCPs are concerned about how people will be cared for if an assessment uncovers Alzheimer's disease or other dementia in light of specialist shortages and few referral options.[245]
- PCPs view family members as influential and necessary partners in care, often relying on them to initiate conversations about memory and thinking problems they observe in their loved ones.[245]

Many of the recommendations from previous Special Reports are even more relevant today in this era of new and emerging treatments, including:

- Developing public service announcements (PSAs) to destigmatize memory and thinking problems, educate on risk factors, connect people to resources and advocate for routine cognitive health assessments. This approach could help people feel more comfortable sharing their concerns with their friends, families and physicians.
- Establishing education programs tailored to diverse communities that take place in informal settings, such as libraries or community centers. This could guide conversations and help individuals build the vocabulary to communicate their cognitive issues to their health care providers effectively.
- Ensuring Alzheimer's and dementia care is informed by and responsive to cultural beliefs and health care teams are culturally competent.[694]

Continue to Educate Communities About Memory and Thinking Problems and Health Care

Increasing awareness of cognitive issues could encourage conversation and help stimulate productive discussions.

> **"Education is important. I need to know what I should do to delay the process. I want the doctor to provide strategies and education... what can I do to prevent it from [getting] worse."**
> **– Black American focus group member**

People with SCD who participated in the focus groups pointed to limitations in their understanding of what health care entails for people experiencing cognitive issues. There was uncertainty about whether the physician would discuss a care plan and if providers were only interested in managing symptoms with medication. Not knowing what to expect contributes to people's reluctance to talk with a health care provider.

One solution is to develop a patient roadmap of the typical process for assessment, referral coordination and care management to help set expectations and educate people navigating memory and thinking issues.

> **"My doctor has a patient advocate, and they call me once in a while. They ask how I'm doing and if they need to talk to my doctor. That makes me more comfortable expressing what is going on in my life...even if it is small like memory loss." – Black American focus group member**

Outreach and educational messages are likely to have the most impact to empower individuals when they do become concerned about cognitive issues. One takeaway from the focus groups is that incorporating themes of self-efficacy, locus of control and hope in messaging could help individuals and family members overcome the challenging and complex emotions that memory and thinking problems elicit — and that prevent them from speaking with their doctor. Any materials developed for individuals with cognitive issues should recognize the vital role that family members play in recognizing symptoms and potentially bringing them up to physicians.

The Alzheimer's Association launched a partnership with the Ad Council in 2019 to develop a national public awareness campaign to encourage 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 recognized how difficult it can be to take those first steps to share memory and thinking problems with a physician and provided tips to make the process easier.[824] The campaign resources include disease-related information and a discussion guide for use with doctors and health care professionals.[825] Recently, to improve engagement with the Hispanic community, the Alzheimer's Association partnered with the Ad Council and Lopez Negrete to develop a multimedia PSA campaign in English and Spanish.

Community-based, participatory educational campaigns are another way to reach people who may not believe their problems are serious enough to warrant a medical visit. Community engagement with trusted partner organizations, including informal discussion groups through the Community Recreation Centers, Park Districts or library programming on healthy aging and cognitive issues such as SCD or MCI, may instill confidence in people who are hesitant about discussing their problems. As described in the 2022 Special Report, *More Than Normal Aging: Understanding Mild Cognitive Impairment*, educational materials and programming about cognitive issues should use messaging that resonates with diverse communities.[808] The 2022 Special Report found differences in how racial and ethnic groups view and respond to concerns about cognitive impairment.[808] These differences were reflected in the focus group findings presented here.

A dialogue between individuals with cognitive concerns, their families, and their physicians is a crucial first step on a journey toward understanding the magnitude of the issue. For some, their journey may continue to an evaluation by a specialist clinician and an eventual diagnosis of MCI due to Alzheimer's disease. Only then can the possibly life-changing treatment be initiated. As the treatment landscape continues to evolve, research on the vital connections forged between patients and their physicians will become increasingly important. Robust research designs that include adequate representation of various population groups will also be crucial for a greater understanding of the dynamics between patients and care teams. This research will lead to insight into the ability of the specialist physician workforce to care for patients with Alzheimer's disease or other dementias wherever they are in the patient journey.

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 2023: The estimated 6.7 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.[222] The number, 6.7 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.[222] The denominators were the U.S. Census population projections for the specific age groups of interest.

A3. Differences between CHAP and HRS-HCAP estimates for Alzheimer's dementia prevalence: The number of people estimated to have any form of dementia in the U.S. in 2016 from the Health and Retirement Study's (HRS) Harmonized Cognitive Assessment Protocol (HCAP; 4.92 million) is lower than the CHAP estimate of how many people were living with Alzheimer's dementia only (6.07 million).[149] This is because of differences in dementia ascertainment between the two studies: both studies used scores on batteries of cognitive tests, but the HRS-HCAP study additionally required an informant report of functional impairment (i.e. disability). Because the more stringent threshold for dementia in HRS-HCAP may miss people with mild Alzheimer's dementia, 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.[257] 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 2023.

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.[261] 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.[222] Other projections are somewhat lower (see, for example, Brookmeyer et al.[826]) 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 2021, 48 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 BRFSS surveys conducted in 2019 and after, 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 48 states and the District of Columbia who are caregivers for individuals living with Alzheimer's or another dementia. For the two states without 2015-2021 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 2022, using U.S. Census Bureau data available at: https://www.census.gov/programs-surveys/popest/data/tables.html. This resulted in a total of 11.479 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.

A9. Number of hours of unpaid care: The BRFSS survey asks caregivers to identify, within five time frames, the number of hours they provide care in an average week. Using the method developed by Rabarison and colleagues,[407] 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 2 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 17.962 billion hours.

A10. Value of unpaid caregiving: For each state, the hourly value of care was determined as the average of the state minimum hourly wage[827] 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.)[753] The average for each state was then multiplied by the total number of hours of unpaid care in that state[A9] to derive the total value of unpaid care. Adding the totals from all states and the District of Columbia resulted in an economic value of $339.548 billion for dementia caregiving in the United States in 2022.

A11. 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.

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[222] and included in this report (6.7 million in 2023), 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) 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 2023, 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 2022 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. Additionally, payments are based on health care utilization and payments in 2018, prior to the COVID-19 pandemic, and do not reflect pandemic-related changes in utilization.

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.[258] 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 2022 dollars.

A16. Differences in Estimated costs reported by Hurd and colleagues: Hurd and colleagues[714] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2023 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 *2023 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).

A17. Focus group and report funding: The focus groups and report developed by L&M Policy Research were funded as part of the Healthy Brain Initiative (HBI) grant the Alzheimer's Association receives from the Centers for Disease Control and Prevention (CDC) (Grant #5 NU58DP006744-02-00). The content and views expressed are those of the Alzheimer's Association and do not necessarily represent the official views of, nor an endorsement by, the CDC, the U.S. Department of Health and Human Services, or the U.S. Government.

A18. L&M focus groups: *Focus groups of individuals with SCD*: L&M conducted focus groups (in-person and remote) with 36 individuals. All participants were aged 45 years or older and had a primary care provider as a usual source of care. They indicated that they had experienced memory or thinking problems in the last year and had not talked to their primary care provider about these problems. Focus groups were structured so that only individuals from specific racial and ethnic backgrounds participated in a group at a time to encourage comfort and candor. There were six focus groups, each consisting of two to six participants, to promote interactive discussion: Black Americans, Hispanic individuals (facilitated in English), Hispanic individuals (facilitated in Spanish), Asian Americans and Pacific Islanders, non-Hispanic White and American Indians and Alaska Natives (conducted virtually to increase geographic representation). *Focus groups of PCPs*: L&M conducted three focus groups with primary care providers in 3 practice types: large health care settings, small clinics and practices and rural areas. Focus groups were conducted over a virtual platform to increase geographic diversity. Ten physicians and one nurse practitioner (who served as primary care provider for patients in a rural practice) participated in the study. All participants' patient populations reflected the individual participant characteristics regarding age and race or ethnicity. The primary care providers reported that they initiated less than 50% of the conversations about memory or thinking problems with their patients. *Focus group data collection and analysis*: L&M collaborated with the Alzheimer's Association to develop a semi-structured discussion protocol to facilitate an interactive and informative discussion with participants. An experienced moderator led each discussion. After completing the research, L&M analyzed the data to detect common themes, barriers and facilitators to conversations between primary care providers and participants within each focus group and across groups.

A19. Limitations of focus groups and self-reported patient activity in the specialist physician survey: It is important to recognize the limitations of focus groups and put the specialist physician survey findings into context. (1) Focus groups do not represent a significant sample size for any key demographic; key findings are thematic and formative rather than representative of a specific population. (2) Several physicians may see one patient, contributing to overlap in self-reporting and estimated numbers. For example, an emergency medicine physician could see a patient exhibiting cognitive symptoms that make them suspect mild dementia, perform an assessment and then refer to another specialist for further evaluation. This single patient is then counted as one unique visit by two specialties. The estimated patient volume was reduced by half to account for patients seeing multiple physicians in emergency rooms or intensive care units, thus accounting for potential double-counting in the emergency department. (3) The number of specialists practicing in each area varies greatly, so estimated patient numbers should be interpreted in context. When this report was written, there were 54,957 emergency medicine physicians, 7,857 geriatric subspecialists, 17,475 neurologists and 5,332 neuropsychologists in practice.

A20. Observations about knowledge and awareness of cognitive issues from different racial and ethnic groups:

Black Americans

Participants acknowledged an increased awareness of personal health histories, genetics and environmental stressors as important variables influencing cognitive health. Participants described memory and thinking issues as expected parts of the aging process but noted a generational change in how these issues are perceived. Knowledge and awareness of the potential drivers of memory and thinking issues have increased over time. Participants emphasized the importance of monitoring memory and thinking issues and seeking help for issues when problems progress.

AI/AN

Participants have culturally specific beliefs about the causes of memory and thinking problems. Attitudes and beliefs were often connected to culture and previous or ongoing experiences with trauma. Some participants mentioned previous physical trauma, such as a traumatic brain injury or psychological trauma, such as experiencing post-traumatic stress resulting from the harmful impacts of colonization. In both cases, AI/AN participants associated their memory and thinking issues with previous trauma.

Some AI/AN group members attributed memory or thinking issues to environmental and sociocultural changes. Participants spoke of the changes in how knowledge is shared and conveyed today compared with their ancestors' traditions. Ancestors were educated and trained through lived experiences, oral tradition and careful observation of elders and kin, which helped hone memory and thinking skills. Contemporaries of those ancestors now struggle with memory and thinking issues because they did not acquire the traditionally oriented skills needed to maintain strong memory and thinking abilities.

AA/PI

Participants consider thinking and memory problems a normal part of aging but a topic to avoid in conversation. The group described these issues as expected or commonplace while aging. Cultural norms, however, prohibit discussing these problems depending on generational perspectives. Younger participants choose not to discuss these issues out of respect for their elders. Older participants decided not to talk about their memory and thinking problems because they did not want to be a burden.

Hispanic English-Speaking

Thinking and memory problems are associated with older adults, so younger age groups often avoid discussing them. While all the Hispanic English-speaking participants described experiencing or knowing peers or family members with thinking and memory problems, some acknowledged that they were not always proactive or open in discussing these issues with others, particularly their physicians.

Those who have initiated conversations with friends often use humor when talking about their memory issues or family history when talking about others' issues. Some participants described having conversations within the context of joking or making light of the problems. Others use family history as a segue for raising the topic of memory and thinking issues with other family members.

Feelings of embarrassment and even prejudice are beginning to evolve into empathy, or acceptance, in Hispanic communities. Some participants noted that because memory issues are becoming more recognized, there is a sense of increasing prevalence; with that prevalence comes a sense of understanding and empathy that these issues are somewhat common.

Hispanic Spanish-Speaking

Participants described denial and avoidance as reasons for not initiating discussions with friends or family, even though all acknowledged experiencing thinking and memory issues. For some, the topic is never raised or discussed, while for others, it is a point of discussion, mainly if they have older family members diagnosed with dementia or Alzheimer's. Still, even in those situations, the topic can cause tension.

Some Hispanic Spanish-speaking participants described using humor when talking about their memory issues. These participants described using humor to make the topic less severe or avoid offending friends or family members they observed experiencing memory issues.

White Non-Hispanic

Participants are worried about the 'inevitable' challenges from thinking and memory problems, as several of them have older family members who are experiencing, or have experienced, dementia.

All the White participants believed that there were things they could do to help them feel more confident about managing memory and thinking issues. In particular, they thought that looking for information and educating themselves about memory loss and lifestyle changes could help them manage their problems and the emotions that go with them.

A21. Observations about barriers to conversations with health care providers from different racial and ethnic groups:

Black Americans

Participants noted that intervention from family and friends would motivate them to talk to a doctor about memory and thinking issues. For many, a critical threshold is crossed when someone they care about expresses concern.

Participants highlighted significant institutional and societal barriers that affect their ability to access high-quality, equitable care. Participants shared meaningful lived experiences illustrating ongoing intergenerational and historical obstacles to receiving equitable health care. They shared experiences reflecting prejudice, racism and implicit bias, which for some, limits their ability to trust health care providers.

AI/AN

Participants noted a vital connection between traditional healing modalities and a holistic conception of health and wellness. The group conveyed the importance of balancing mind, body, spirit and emotional health. While the group spoke about the importance of Western medicine and talking to their doctors about experiences with memory or thinking issues, they also highlighted the healing power of their traditional ways. One Elder spoke about the important traditions underlying death, dying and disease. Some participants withhold their traditional healing practices because they believe the doctor does not believe in them. Another barrier mentioned was feeling dismissed by doctors because they are women or Native.

AA/PI

A few participants reported talking to a peer about their thinking and memory problems, while none reported talking to their doctors. The group's primary reason for choosing not to discuss these issues with their doctor was feeling that their problems were not "dire" enough. However, they described thinking and memory problems impacting their work or familial responsibilities as serious issues that would spur conversations with their doctors.

Resistance to prescription medications is a factor that influences willingness to speak with a doctor about memory and thinking issues. A couple of participants said they were unwilling to take medicines for their memory issues, which they assumed their doctor would prescribe. Another participant said they preferred to address memory issues holistically.

Hispanic English-Speaking

For some participants, fear drove the decision not to talk to their doctors. For others, they did not feel their memory and thinking issues warranted a discussion with their doctors; they needed to reach a "tipping point." Examples of tipping points included memory issues affecting work performance or their marriage, getting lost in an otherwise familiar area, or forgetting the names of family members.

Hispanic Spanish-Speaking

Some participants said they are more likely to discuss memory or thinking problems with doctors because they feel more comfortable talking to professionals than friends or family. In contrast, others consider this topic more personal and better discussed with their family.

Some avoid seeing a doctor because they assume their doctor will automatically prescribe medications. These participants tended to see their doctors more for physical or clinical reasons but less for non-physical issues such as memory loss. They also expressed concern that their doctors would prescribe medications rather than more holistic or natural remedies, which they prefer.

White Non-Hispanic

Participants did not want to pursue communication with their doctors about memory or thinking issues until they became "significant" or "catastrophic." These participants described choosing to ignore memory issues or feeling the need to talk to their doctors only when their problems became more extreme. Examples of issues ranged from forgetting how to get from one place to another, forgetting the names of family and friends, or not finding the exact words they were looking for.

White participants considered whether conversations with doctors about memory issues could impact their insurance coverage. A couple of participants did not want to pursue further communication with their doctor about memory or thinking issues because they were uncertain if it could affect future insurance coverage.

Some White participants felt it more appropriate to have these conversations with specialists rather than their primary care providers. These participants think their primary care providers may not have the necessary resources to understand and address memory issues.

A22. PCP perspectives on conversations and relationships with patients by practice type:

Small practice

Participants believe long-term relationships with their patients and their families allow patients to feel comfortable disclosing information about health issues. Most utilize techniques to create trusting environments for patients (e.g., interacting at eye level or inserting humor in conversations).

Most providers in small practices believe they can better address specific issues when patients or their family members disclose concerns before the scheduled visit. They noted how to facilitate extended conversations when patients communicate concerns before appointments. Without previous discussion of the issue, providers find it challenging to know the full extent of the problem within the limited time of a visit.

Large practice

Participants feel they can develop personal relationships with their patients, enabling them to build rapport and detect cognitive changes in their patients over time. The group knows and understands their patients and their family members, which helps facilitate conversations about memory and thinking problems. In addition, family members often bring these issues to the attention of their doctors.

They feel comfortable initiating conversations about memory issues with their patients. While they may wait for the "appropriate" time, participants from large practices shared they eventually directly address the issue with their patients. However, when memory issues are not the primary concern, these conversations can be difficult.

Once memory and thinking issues are detected, participants involve their patients and family members in the conversations. They recognize the importance of developing collaborative relationships.

Rural practice

Rural provider participants do not routinely discuss memory issues. Mostly, these providers initiate conversations around patient memory issues once family members have brought it to their attention. These conversations become more significant once these providers believe the patient's memory or thinking issues are more severe.

The rural provider participants focus on compassion, reassurance and understanding when addressing conversations about memory loss. These provider participants, like other groups, recognize the importance of treating their patients with dignity and respect, whether talking to them directly or holding these conversations with family members.

A23. Estimated annual patient volume by specialty:

Number of unique patients seen in a year	Specialists (% reporting in each category)			
	Emergency medicine	Geriatric subspecialist	Neurologist	Neuro-psychologist
All ages				
500 or more	91%	58%	70%	9%
1000 or more	83%	32%	38%	1%
2000 or more	64%	11%	9%	0%
3000 or more	35%	4%	2%	0%
Aged 60 and older				
500 or more	77%	42%	37%	3%
1000 or more	49%	15%	9%	0%
2000 or more	14%	5%	1%	0%
3000 or more	4%	2%	0%	0%

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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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