2024 ALZHEIMER'S DISEASE FACTS AND FIGURES

SPECIAL REPORT

MAPPING A BETTER FUTURE FOR DEMENTIA CARE NAVIGATION

ALZHEIMER'S ASSOCIATION®

About this report

2024 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. The Special Report provides a comprehensive look into dementia care navigation, revealing significant insights into the experiences and challenges faced by caregivers and health care workers in helping people living with Alzheimer's or other dementia navigate the health care system.

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

Alzheimer's Association. 2024 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2024;20(5).

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

Brain changes that occur with Alzheimer's disease (page 8).
Risk factors for Alzheimer's dementia (page 15).
Number of Americans with Alzheimer's dementia nationally (page 22) and for each state (page 26).
Lifetime risk for developing Alzheimer's dementia (page 28).
Proportion of women and men with Alzheimer's and other dementias (page 28).
Number of deaths due to Alzheimer's disease nationally (page 35) and for each state (page 38), and death rates by age (page 40).
Number of family caregivers, hours of care provided, and economic value of unpaid care nationally (page 43) and for each state (page 47).
The impact of caregiving on caregivers (page 48).
The impact of COVID-19 on dementia caregiving (page 55).
Members of the paid workforce involved in diagnosing, treating and caring for people with Alzheimer's or other dementias (page 59).
Expected home health and personal care aide job growth, 2020-2030 (page 63).
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 71).
Medicare payments for people with dementia compared with people without dementia (page 72).
Care navigator services that would be valuable to dementia caregivers (page 105).

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 and other population identifiers used in source documents when describing study findings.

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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 all human activity, including thinking, talking and walking.

In Alzheimer's disease, the neurons damaged first are those in parts of the brain responsible for memory, language and thinking, which is why 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] When symptoms become severe enough to interfere with a person's ability to perform everyday tasks, a person is said to have Alzheimer's dementia.

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 everyday activities. Eventually, people may need help with activities of daily living. These are activities a person typically performs without assistance, including getting into and out of a bed or chair, bathing, dressing, using the toilet, eating and grooming.

Individuals living with Alzheimer's dementia may develop changes in mood, personality or behavior. One behavior of special concern is wandering. For the person with dementia, wandering is likely an intentional effort to reach a destination. However, they may not be able to retrace their steps and may become lost. Wandering puts individuals at risk of significant injury and death.[9]

Alzheimer's Disease or Dementia?

Many people wonder what the difference is between Alzheimer's disease and dementia.

Dementia is an overall term for a particular group of symptoms. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Changes to the brain cause dementia, and many different brain changes can lead to dementia (see Table 1, page 6).

Alzheimer's disease is one cause of dementia. The brain changes of Alzheimer's disease include the excessive accumulation of the protein fragment beta-amyloid and an abnormal form of the protein tau, as well as damage to and destruction of neurons. The brain changes of Alzheimer's disease are the most common contributor to dementia. Dementia caused by Alzheimer's disease is called Alzheimer's dementia.

Eventually, the neuronal damage of Alzheimer's extends to parts of the brain that enable basic bodily functions such as walking and swallowing. Because of mobility limitations, individuals may spend most of their time in a wheelchair or on a bed. This loss of mobility, along with cognitive limitations, means they often require around-the-clock care. Ultimately, Alzheimer's disease is fatal, although many people die of other conditions before Alzheimer's becomes 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] Many factors influence how long

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-synuclein 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.

individuals live after receiving a diagnosis. They include age at diagnosis, how far the disease has progressed at diagnosis, whether the individual has other health conditions such as diabetes or kidney disease that may limit remaining lifespan and complicate care and treatment, and whether the individual has mixed dementia — the brain changes of not only Alzheimer's disease but also another type of dementia.

There is no proven way to prevent Alzheimer's disease, and there is currently no cure. However, because of the large number of people living with Alzheimer's and other dementias worldwide (more than 55 million)[19] and the devastating effect of dementia on individuals, families, communities and health care systems, finding ways to prevent, slow, better manage and cure Alzheimer's and other dementias is a top priority for research centers around the globe.

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 are the basis of memories, thoughts, sensations, emotions, movements and skills.

Over the years, researchers have identified many changes in the brain that may interfere with chemical signaling and lead to problems with thinking, learning and everyday function that arise as a result of Alzheimer's disease. 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 disease.

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 while harming connections between neurons.

Beta-amyloid and tau accumulation are followed by damage to and destruction of neurons (called neurodegeneration) and other brain cells. Neurodegeneration, along with beta-amyloid and tau accumulation, are key features of Alzheimer's disease. 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 and 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.

Another brain change associated with Alzheimer's disease is atrophy (decreased brain volume) resulting from neurodegeneration and other factors. While some degree of brain atrophy is common in older age, even in people who are cognitively healthy, atrophy is accelerated in people with Alzheimer's dementia.[20] Normal brain function is further compromised by decreases in the brain's ability to metabolize glucose, its main fuel.

Timing of Brain Changes

Researchers have gained insight into the timing of these brain changes. Among people with rare genetic mutations that cause Alzheimer's disease for whom long-term data have been collected, researchers have found that levels of beta-amyloid 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] In another study, abnormal levels of the neurofilament light chain protein, a biomarker of neurodegeneration, were also found to start 22 years before symptoms were expected to develop.[7] A third group of researchers found that levels of different types of tau protein increase when beta-amyloid clumps together as amyloid plaques, and that levels of these types of tau increase as early as two decades before the characteristic mature tau tangles of Alzheimer's disease appear.[8] Researchers also found that glucose metabolism starts decreasing 18 years before expected symptom onset, and brain atrophy begins 13 years before expected symptom onset.[5]

Brain Changes as Biomarkers

These brain changes are biomarkers of Alzheimer's disease. Biomarkers are biological changes that can be measured to indicate the presence or absence of a disease or the risk of developing a disease. For example, the level of glucose in blood is a biomarker of diabetes, and cholesterol level is a biomarker of cardiovascular disease risk. Great progress has been made in measuring Alzheimer's disease biomarkers. For example, we can now identify abnormal levels of beta-amyloid and tau in cerebrospinal fluid (CSF, the fluid surrounding the brain), and an imaging technique known as positron emission tomography (PET) can produce pictures showing where beta-amyloid and tau have accumulated in the brain. In addition, many research groups are working on blood tests for Alzheimer's disease. If these blood tests prove effective they could simplify and greatly speed-up diagnosis of Alzheimer's.

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.

Alzheimer's Disease Continuum

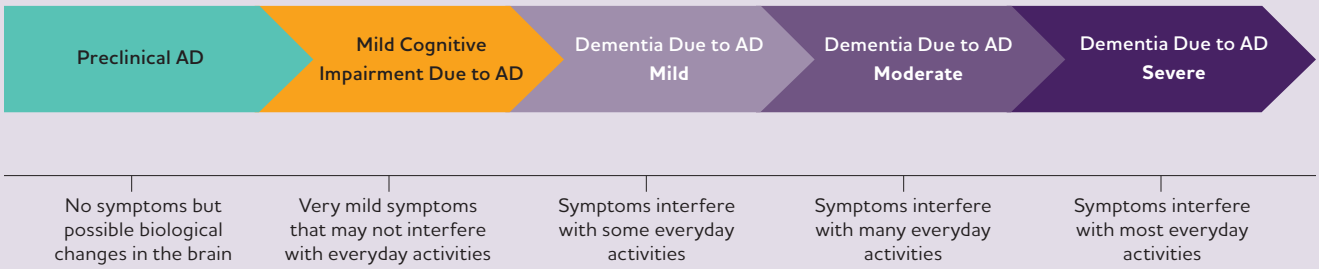
The progression of Alzheimer's disease from brain changes that are unnoticeable by the person affected to brain changes that cause problems with memory and thinking, and eventually physical disability, is called the Alzheimer's disease continuum.

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 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, but they have not yet developed symptoms such as memory loss or difficulty thinking. Examples of Alzheimer's brain changes that might be detected in this phase include abnormally increased levels and distribution of beta-amyloid and tau and decreased metabolism of glucose as shown on positron emission tomography (PET) scans, as well as changes in tau protein in cerebrospinal fluid (CSF).[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 disease, 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 disease before their deaths, even if they live for many years or decades after these biomarkers are detected.[48-50]

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 the individual's ability to carry out everyday activities.

Everyone who develops Alzheimer's dementia first experiences MCI, although it might not be recognized or diagnosed because of the subtlety of symptoms. 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 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 disease 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 individuals are able to function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe. They may still be able to drive, work and participate in their favorite activities. They may need more time to complete common daily tasks.

Paying bills and making financial decisions may be especially challenging. The U.S. Social Security Administration notes that people living with dementia are at an especially high risk of becoming victims of fraud and financial abuse.[54] This may be because handling finances is a particularly complex cognitive activity made even harder by declines in executive function. Executive function comprises the higher-level cognitive skills used to control and coordinate other cognitive abilities and behaviors.[55] Declines in executive function can play out as difficulty planning, organizing and carrying out tasks, as well as poor judgment, socially inappropriate behavior, and inability to understand how one's behavior or choices affect others.[56] Impaired executive function not only makes it challenging for individuals with Alzheimer's dementia to manage finances, but may also make them especially vulnerable to financial abuse and scams because their ability to discern between well-intentioned and ill-intentioned behavior and language in others may be diminished.

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, begin to have problems recognizing loved ones, and start showing personality and behavioral changes, including suspiciousness and agitation.

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 may be unable to walk. As a result, they may spend most of their time in a wheelchair or bed. This loss of mobility increases their vulnerability to physical complications including blood clots, skin infections and sepsis (a condition that 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). As a result, food particles may be deposited in the lungs and cause a type of lung infection called aspiration pneumonia. Aspiration pneumonia is a contributing cause of death among many individuals with Alzheimer's dementia (see Mortality and Morbidity section, page 34).

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, head injury, blood clots or tumors in the brain, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, the dementia caused by these conditions often may be reversed with treatment.

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.

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 report that the majority of people with the brain changes of Alzheimer's disease also have the brain changes of a second cause of dementia on autopsy.[21, 22] One autopsy study showed that of 447 older people who were believed to have Alzheimer's dementia when they died, only 3% had the brain changes of Alzheimer's disease alone, while 15% had the brain changes of an entirely different cause of dementia, and 82% had the brain changes of Alzheimer's disease 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 dementia 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 having Alzheimer's brain changes alone.[21, 31] Mixed dementia 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.

Treatments

Drug Treatments

A total of eight drugs are available for the treatment of Alzheimer's disease. Two of these drugs change the underlying biology of Alzheimer's and slow cognitive and functional decline in some individuals. A third such drug was under review by the FDA for potential approval at press time. Six additional drugs have been approved that treat the symptoms of Alzheimer's dementia.

Treatments to Slow Alzheimer's Disease

The drugs aducanumab and lecanemab change the underlying biology of Alzheimer's disease and delay disease progression. They do this by helping remove plaques and a form of beta-amyloid called protofibrils that plays a role in the development of beta-amyloid plaques. Earlier this year, the manufacturer of aducanumab announced that the drug was being discontinued.[57] The manufacturer said aducanumab is being discontinued in order for the company "to reprioritize its resources in Alzheimer's disease." Aducanumab is not being discontinued for reasons related to safety or efficacy. People who are now receiving the drug as part of a clinical trial will continue to have access to aducanumab until May 1, 2024, and aducanumab will continue to be available until November 1, 2024, for people who are now receiving it by prescription.

Focusing on lecanemab, clinical trials of the drug showed moderate slowing of cognitive and functional decline in individuals with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's.[58] Only individuals with MCI or mild dementia due to Alzheimer's and evidence of beta-amyloid buildup in the brain based on brain imaging or CSF analysis were eligible to participate in clinical trials of lecanemab. Lecanemab is not a cure for Alzheimer's disease and not appropriate for all individuals living with Alzheimer's. Safety and effectiveness have only been established in individuals living with MCI due to Alzheimer's disease and mild dementia due to Alzheimer's disease.

It's important to note that while clinical trials showed statistically significant differences in cognitive outcomes between people randomized to receive lecanemab and those randomized to receive placebo, the benefits of lecanemab in the short term may be imperceptible to those receiving them. Because lecanemab has been approved fairly recently, we don't know its effectiveness over the long term, although extension studies, in which people who volunteer for a clinical trial continue to receive treatment after a trial is completed, are underway.

Anti-amyloid treatments such as aducanumab and lecanemab can have side effects. They can cause serious allergic reactions as well as amyloid-related imaging abnormalities (ARIA), infusion-related reactions, headaches and falls.

ARIA is a common side effect that does not usually cause symptoms but can be serious. It is typically a temporary swelling in areas of the brain and usually resolves over time. Some people may also have small spots of bleeding in or on the surface of the brain along with swelling. Most people with swelling who experience ARIA do not have symptoms. Those who do experience symptoms of ARIA may have headache, dizziness, nausea, confusion and vision changes. Management of ARIA may include discontinuation of the medication either temporarily or indefinitely.

Individuals with two copies of the APOE-e4 gene are at higher risk of developing ARIA.[59] The FDA encourages APOE-e4 testing before starting treatment. Prior to testing, doctors should discuss with patients the risk of ARIA and the implications of genetic testing results.

These are not all the possible side effects. Individuals should talk with their doctors to develop a treatment plan that is right for them, including weighing the benefits and risks of all approved therapies.

Appropriate use recommendations have been developed to guide physicians in determining which individuals should and should not receive treatment with lecanemab.[59] The recommendations also discuss ARIA monitoring and management, key points to share with individuals living with dementia and their care partners, and incorporating treatments into clinical practice.

A variety of other treatments targeting the underlying biology of Alzheimer's disease are being developed. They address many of the known brain changes associated with Alzheimer's disease, including but not limited to tau accumulation, inflammation, altered cell metabolism and oxidative stress (damage from toxic oxygen molecules).[60,61] As of January 1, 2023, 156 clinical trials were underway testing additional disease-modifying therapies.[62]

Treatments to Address Cognitive and Behavioral Symptoms

Five of these eight drugs — donepezil, rivastigmine, galantamine, memantine and memantine combined with donepezil — are aimed at treating cognitive symptoms. They do not affect the underlying brain changes that cause Alzheimer's, nor do they slow or stop the course of the disease. With the exception of memantine, they treat symptoms by increasing the amount of chemicals called neurotransmitters in the brain. Neurotransmitters help brain cells communicate with each other. 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 headaches and nausea. These are not all the possible side effects. As with lecanemab, individuals should talk with their doctors to develop a treatment plan that is right for them, including weighing the benefits and risks of all approved therapies.

One of the eight drugs, brexpiprazole, has been approved by the FDA to treat agitation that can occur in Alzheimer's. Agitation is common in Alzheimer's disease, with 60% of people with MCI and 76% of people with Alzheimer's dementia experiencing agitation.[63] Brexpiprazole is thought to lessen agitation through its effects on dopamine and serotonin receptors in the brain. Brexpiprazole is also FDA-approved for the treatment of major depressive disorder. It's important to note that brexpiprazole is an atypical antipsychotic drug, Atypical antipsychotics have been associated with an increased risk of stroke and death in older patients with dementia-related psychosis.[64, 65] Non-drug interventions should be tried first.

In addition to these eight drugs, the drug suvorexant, approved for insomnia, has been shown in clinical trials to be effective in treating problems with falling asleep and staying asleep that can occur in people with mild to moderate Alzheimer's disease. Suvorexant inhibits the activity of orexin, a type of neurotransmitter involved in the sleep-wake cycle. Possible side effects include, but are not limited to, impaired alertness and motor coordination (including impaired driving), worsening of depression or suicidal thinking, complex sleep behaviors (such as sleep-walking and sleep-driving), sleep paralysis and compromised respiratory function.

Why insomnia and other sleeping problems occur in people living with Alzheimer's is unclear. However, researchers have found that Alzheimer's brain changes disrupt the sleep-wake cycle, leading to increased sleep fragmentation and wakefulness and decreased slow-wave sleep.[66] Researchers have also found that sleep abnormalities accelerate the accumulation of beta-amyloid and release of toxic tau in the brain, increasing the risk of dementia. In this way, sleep problems may be bidirectional, with Alzheimer's disease increasing the risk of sleep disturbances and sleep disturbances increasing the risk of Alzheimer's.[66, 67] More research is needed to better understand the relationship between sleep abnormalities and Alzheimer's. About one-quarter of people with dementia have problems sleeping, and the problems can worsen as the disease progresses.[68]

As of January 1, 2023, 31 clinical trials were underway testing additional agents to treat Alzheimer's cognitive, behavioral and neuropsychiatric symptoms.[62]

Non-Drug Treatments

There are also non-drug treatments for the symptoms of 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, music- and art-based therapies, and many others. 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. For example, a review and analysis of nonpharmacologic treatments for agitation and aggression in people with dementia concluded that non-drug interventions seemed to be more effective than pharmacologic interventions for reducing aggression and agitation.[69]

Risk Factors for Alzheimer's Dementia

The vast majority of people who develop Alzheimer's dementia are age 65 or older. This is called late-onset Alzheimer's dementia. Experts believe that Alzheimer's dementia, like other common chronic diseases and conditions, develops as a result of multiple factors rather than a single cause. Exceptions are cases of Alzheimer's related to trisomy 21 in Down syndrome and rare cases of Alzheimer's disease related to specific genetic mutations.

Age, Genetics and Family History

The greatest risk factors for Alzheimer's dementia are older age,[70, 71] genetics — especially the e4 form of the apolipoprotein E (APOE) gene[72, 73] — and having a family history of Alzheimer's dementia.[74-77]

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, 13.2% of people age 75 to 84, and 33.4% of people age 85 or older have Alzheimer's dementia (see Prevalence section, page 22). The aging of the population, including the baby-boom generation, will significantly increase the number of people in the United States with Alzheimer's dementia.[78] 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.[79]

Actions to Proactively Manage Dementia

Proactive management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers. Proactive management includes actions by the person living with dementia and their caregivers and actions by health care providers and other members of the health care workforce.

Actions for the Person Living with Dementia and Their Caregivers

These actions include:

- Becoming educated about the disease.
- Maintaining a sense of self and relationships with others.
  - Identifying and participating in activities that are meaningful and bring purpose to one's life.
  - Identifying opportunities to connect with others living with dementia and their caregivers and participating in related activities.
- Planning for the future, including future health care needs, changes in employment and financial changes.

Actions for Health Care Providers and Other Members of the Health Care Workforce

These actions include:

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.
- Coordination of care among health care providers, other health care professionals and lay caregivers.
- Directing family caregivers to resources to help them learn how to manage the day-to-day needs of the individual living with dementia.

To learn more, see the Caregiving section (page 42) and Workforce section (page 58). Visit alz.org to learn more about Alzheimer's disease, as well as practical information for living with Alzheimer's and being a caregiver.

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

*Data for APOE pairs in other populations are not available. 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[93] and Kataoka et al.[94]

Genetics

Researchers have found many genes that increase or decrease the risk of Alzheimer's dementia. In fact, in 2022 researchers identified 31 new genes that appear to affect biological processes known to be at play in Alzheimer's disease.[80] Of the many genes that increase risk, APOE-e4 has the strongest impact on risk of late-onset Alzheimer's dementia. 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 dementia compared with having the e3 or e2 forms but does not guarantee that an individual will develop Alzheimer's dementia. Having the e2 form may decrease one's risk compared with having the e3 or e4 form. Individuals with the e2 form who develop Alzheimer's dementia generally do so later in life than those without the e2 form. The e3 form is thought to have a neutral effect on Alzheimer's dementia risk.

In general, the risk of developing Alzheimer's dementia increases with inheriting one copy of the e4 form and increases further still with inheriting two copies of the e4 form, compared with inheriting only copies of the e2 or e3 forms.[79-81] For example, based on data from a study in Europe and a study in the United States, of people age 65-69, the risk of developing dementia by the early to mid-80s was 5% to 7% among those with no copies of the e4 form, 15% to 16% among those with one copy, and 31% to 40% among those with two copies.[82] 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.[83]

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 dementia found that 56% had one copy of the APOE-e4 gene, and 11% had two copies of the APOE-e4 gene.[84] 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.[85]

Most of the research to date associating APOE-e4 with increased risk of Alzheimer's dementia 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 Black people,[86-88] while other studies have found that it significantly increased risk.[89-92] In addition, researchers have found differences in the frequency of APOE pairs among 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 American and American Indian people.[86, 87, 93, 94] Among individuals of African ancestry who have one copy of e3 and one of e4, those with a particular variant of e3 called R145C are at increased risk of developing Alzheimer's dementia compared with those who do not have this variant.[95] Researchers have also found that another genetic factor, the ATP-binding cassette transporter (ABCA7) protein, doubles the risk of Alzheimer's dementia in Black people with ABCA7 compared with Black people without ABCA7.[90]

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.[96]

This report keeps the racial, ethnic and other population identifiers used in source documents when describing findings from specific studies.

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 dementia, 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 dementia 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.[97] 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 dementia.[98] Emerging research suggests that Alzheimer's brain changes in people with Down syndrome may be even more common than these percentages indicate.[99, 100]

As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's dementia. Life expectancy of people with Down syndrome has more than doubled in the last 70 years, which corresponds to a growing population of adults living with both this condition and dementia. Dementia is the leading cause of death for adults with Down syndrome.[101] Care for people with Down syndrome and dementia is especially challenging due to the intellectual, cognitive and communication impairments associated with Down syndrome that are present in addition to the cognitive impairments of dementia. Making advances in the care of people living with Down syndrome and dementia is stymied by the common exclusion of people with Down syndrome from research studies.

Genetic Mutations

An estimated 1% or less of people living with Alzheimer's dementia develop the disease as a result of mutations to any of three specific genes.[102] (A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes.) This is called dominantly inherited or autosomal dominant Alzheimer's dementia. These mutations involve the amyloid protein precursor gene and the genes for the presenilin 1 and presenilin 2 proteins. Symptoms tend to develop before age 65 and sometimes as young as age 30. Because of this, individuals with these mutations may also be referred to as having younger-onset Alzheimer's dementia. People who inherit an Alzheimer's mutation to these genes are virtually guaranteed to develop the disease if they live a normal life span.[103] However, rare cases of individuals who have one of these mutations and do not develop dementia symptoms until late life have recently been reported.[104, 105] The experiences of these individuals highlight the possibility of being resilient to Alzheimer's dementia despite genetic mutations, and point to new areas of investigation to better understand resilience.

Family History

A family history of Alzheimer's dementia 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 dementia are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's dementia.[74, 81] Those who have more than one first-degree relative with Alzheimer's dementia are at even higher risk.[77] A large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-e4.[106] 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 Lancet* Commission report on dementia prevention, intervention and care suggests that up to 40% of dementia cases may be attributable to modifiable risk factors.[107] A 2022 study found that nearly 37% of cases of dementia in the United States were associated with eight modifiable risk factors, the most common being midlife obesity, followed by physical inactivity and low educational attainment.[108]

In addition to *The Lancet* Commission report, a number of other influential reports point to the promising role of addressing these factors to reduce risk of dementia and cognitive decline. These include the 2019 World Health Organization (WHO) recommendations to reduce risk of cognitive decline and dementia and a report from the National Academy of Medicine.[109, 110] There are many potentially modifiable risk factors for Alzheimer's disease — too many to discuss in a single report. This section focuses on some of the modifiable risk factors with substantial supportive evidence identified in *The Lancet* Commission report, the WHO recommendations and the National Academy of Medicine report.

As mentioned earlier, most people living with dementia have the brain changes of Alzheimer's disease as well as another form of dementia (see mixed dementia, page 12), and it can be difficult to tell which brain changes are the cause of dementia. As a result, research linking risk factors to dementia is often assumed to support a link between risk factors and Alzheimer's disease. However, additional research is needed to disentangle risk factors that are specific to Alzheimer's disease from those that are specific to other causes of dementia.[111]

Cardiovascular Health Factors

Brain health is affected by the health of the heart and blood vessels. Although the brain makes up just 2% of body weight, it consumes 20% of the body's oxygen and energy supplies.[112] 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, which occurs when a blood vessel in the brain is blocked or bursts, markedly increases dementia risk.[113]

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia.[114] These factors include hypertension,[91, 115-117] diabetes[118-120] and smoking.[121, 122] Likewise, factors that decrease risk of cardiovascular disease are associated with decreased risk of dementia. Physical activity is an example of a modifiable factor that reduces risk of cardiovascular disease and may also reduce risk of dementia.[123-133] Although researchers have studied a wide variety of physical activities, they do not know if specific types of physical activity are more effective at decreasing risk, or how the frequency or duration of physical activity may influence the effectiveness of physical activity.

In addition to physical activity, many but not all studies suggest that consuming a heart-healthy diet may be associated with reduced dementia risk.[134-142] 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 include but are not limited to the Mediterranean, DASH (Dietary Approaches to Stop Hypertension) and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets.[143-145] However, a recent trial of the MIND diet did not show a difference in cognitive change for people following the diet compared with a control group over three years.[141] It's possible that dietary changes take many years to influence dementia risk. No single food, beverage, ingredient, vitamin or supplement has been proven to prevent or cure Alzheimer's or any other dementia.[146]

The risk of developing dementia in later life can be influenced by health factors present years and decades earlier. For example, midlife obesity,[115, 147, 148] hypertension[91, 115-117] and high cholesterol[149] are among the midlife factors associated with an increased risk of dementia in later life.

Today, researchers are looking at potential risk factors present even earlier in life, such as in young adulthood, to understand how health factors experienced throughout one's life span may affect later life cognitive health.[150-154] This life course approach offers the potential to inform preventive measures across multiple stages of life.

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.[86, 155-160] Much of the research linking formal education to decreased risk of Alzheimer's dementia was conducted without the benefit of technological advances such as positron emission tomography (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.[161, 162]

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.[163, 164] 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.[165-170]

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 access to economic resources, including income, education, employment and occupation, but also includes factors such as financial security and perceived social standing. Having fewer years of formal education is associated with lower median income and lower SES.[171] 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,[172] having a higher risk of diabetes,[173-175] and being more likely to have hypertension[176] and to smoke[177] — 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.[178]

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. Housing and employment conditions can also influence brain health–promoting activities and health care, as well as influence one's exposure to substances that are toxic to the nervous system such as air pollution,[179] lead[180] and pesticides.[181]

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 cognitively active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.[123, 182-190] 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.[188] 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 that results in disruption of normal brain function.[191] TBI is associated with an increased risk of dementia.[192-194]

According to the Centers for Disease Control and Prevention (CDC), in 2020, 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.[195] In 2018 and 2019, falls were the leading cause of TBI-related deaths among those 75 and older.[191]

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia[196] and by the individual's initial score on the 15-point Glasgow Coma Scale.[197]

- *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.[198]
- *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.

Moderate and severe TBIs increase risk of dementia between 2- and 4-fold compared with risk among individuals without a history of moderate or severe TBI.[199] In this case, the cause of dementia is almost always brain damage attributable to the TBI, not Alzheimer's disease. The risk of dementia increases with the number of TBIs sustained.[192-194] In addition, studies have found that people with a history of TBI who develop dementia do so at a younger age than those without a history of TBI.[200, 201] Whether TBI causes dementia, other conditions that lead to dementia, or both, is being investigated.

The relationship between TBI and chronic traumatic encephalopathy (CTE) is a growing area of research. Like Alzheimer's disease, CTE is characterized by tangles of an abnormal form of the protein tau in the brain. Beta-amyloid plaques may also be present, with one study indicating that more than 50% of individuals with CTE had beta-amyloid plaques.[202, 203] The brain changes of CTE can only be identified at autopsy. 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.[204] Among former amateur and professional football players, the odds of developing CTE increased 30% per year played.[205] A review of published articles examining CTE suggests that the relationship between these repeated impacts and CTE is likely causal.[206]

Other Risk Factors

As mentioned earlier, there are many potentially modifiable risk factors for dementia. Among those with growing supportive evidence are the following.

Sleep

Among the many factors being studied is inadequate sleep or poor sleep quality.[207-209] Researchers have found that an important function of sleep is the removal of toxic beta-amyloid and other substances from the brain.[210, 211] Inadequate or poor sleep may compromise the brain's ability to remove beta-amyloid and other toxins, enabling levels of toxins to remain elevated. In addition, 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.[212, 213] As discussed earlier, many researchers believe that the relationship between sleep and Alzheimer's disease is bidirectional, meaning that not only may poor sleep increase one's risk of Alzheimer's, but also that the brain changes of Alzheimer's may increase the risk of poor sleep.[214-216] For example, increases in beta-amyloid and tau may interrupt the sleep-wake cycle,[217] leading to increased sleep fragmentation and wakefulness and decreased slow-wave sleep.[63] Poor sleep may have similar bidirectional relationships with other causes of dementia, including poor cerebrovascular health.[218]

Air Pollution

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 (PM) air pollution. PM consists of tiny solid particles and liquid droplets generated by fuel combustion, fires and processes that produce dust. $PM_{2.5}$, particulate matter that is 2.5 microns in diameter or smaller, is small enough to be inhaled deeply into the lungs. This subset of PM particles has been shown to have the greatest health impact and is the focus in most studies. Based on its sweeping review in 2019, the U.S. Environmental Protection Agency judged long-term exposure to $PM_{2.5}$ as "likely to be causal" in relation to "nervous system effects."[219] Studies specific to dementia and related outcomes have reported that higher long-term exposure to $PM_{2.5}$ is associated with worse cognitive decline,[179, 220] reduced brain volumes[179] and increased rates of incident (newly onset) dementia.[220-222] Whether air pollution promotes the brain changes of Alzheimer's or other dementias is unclear.

Critical illness in older adults

A growing body of evidence suggests that critical illness and medical encounters such as hospitalization in older people increase their risk of long-term cognitive impairment and dementia.[223-227] There are a number of ways that critical illness and aspects of the hospital experience may affect the brain.[228] One example is that experiencing hospitalization may make older adults more vulnerable to the existing brain changes of dementia.[229] This is not to suggest that hospitalization should be avoided if one is ill; rather, researchers are focusing on specific aspects of hospitalization, such as prolonged sedation, immobilization, and lack of family engagement that may increase risk of cognitive impairment.[228] Furthermore, experiencing delirium — a sudden and transient state of confusion common in hospitalized older adults — has been linked to long-term cognitive decline and dementia.[228,230] Modifying these aspects of hospitalization may decrease risk of cognitive decline. In addition, better preventive health measures and improved and expanded health care coordination may help to prevent critical illness and subsequent hospitalization and the negative cognitive outcomes that may follow.

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

Looking to the Future

Importance of Biomarkers

The 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 disease 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 doing so prevent or delay the onset of symptoms. Biomarkers also enable earlier detection of the brain changes of Alzheimer's disease, 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.

When validated biomarker tests become available for routine use in health care providers' offices and other clinical settings, it will be important to provide educational materials to help individuals and their families understand the risks and benefits of biomarker tests, make informed decisions about whether to have biomarker testing, and know what to expect in care after testing.[231, 232] On a broader scale, biomarker disclosure may have social and societal implications. For example, biomarker results that are positive for increased dementia risk and that are shared with others may result in individuals experiencing the social stigma and discrimination so often experienced by people living with dementia, even though individuals with increased risk may never develop dementia.[233] In addition, disclosure may well highlight the need for reform in societal areas such as health insurance coverage and costs, the capacity of the health care workforce, and health equity.[233]

The Need for Increased Diversity in Research Participation

A fuller understanding of Alzheimer's — from its causes to how to prevent, manage and treat it — depends on crucial factors outside of biomarker, basic science and other research advances. Among these is the inclusion of participants from diverse racial and ethnic groups in research. The lack of inclusion has several consequences. First, without adequate data from diverse racial and ethnic groups, the current and future burden of Alzheimer's disease and Alzheimer's dementia in the United States cannot be accurately measured.[234] Such data is necessary because the populations of older adults from these groups make up nearly a quarter of the nation's older adult population, and that share is projected to grow.[235] Second, current data indicate that, compared with non-Hispanic White older adults, Black and Hispanic older adults are at increased risk for Alzheimer's dementia (see Prevalence section). Alzheimer's research with too few Black and Hispanic participants to reflect the proportion of these groups in the overall population 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 dementia risk factors and interventions work in populations that carry different baseline susceptibility to Alzheimer's disease including those with Down syndrome.

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.[236] 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 dementia research.

Prevalence

An estimated 6.9 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 dementia 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, often expressed as the number of people per 100,000 who newly develop the condition in a year. This section reports estimates from several studies of the number of people and proportion of the population with Alzheimer's or other dementias. 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 2022 to 82 million by 2050.[237] By 2030, all members of the of the baby-boom generation (Americans born between 1946 and 1964) will be age 65 or older,[238] the age range of greatest risk of Alzheimer's dementia;[239] in fact, the oldest members of the baby-boom generation turned age 75 in 2021. A number of recent studies have reported that the incidence rate of Alzheimer's and other dementias appears to have declined in recent decades (see "Trends in the Prevalence and Incidence of Alzheimer's Dementia Over Time" in this section). This decline in incidence has been attributed to improvements over the 20th century in modifiable risk factors for dementia, such as increased prevention and treatment of hypertension and greater educational attainment.[240] 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 dementia in years to come. However, even with this potentially lower incidence rate and the impact of COVID on people at risk of dementia, the absolute number of people with Alzheimer's and other dementias is expected to continue growing because of the large increase in the number of adults age 65 and older, the age group that is at increased risk of Alzheimer's and many other dementias.

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

An estimated 6.9 million Americans age 65 and older are living with Alzheimer's dementia in 2024.[A2,241] Seventy-three percent are age 75 or older (see Figure 2, page 23).[241]

Of the total U.S. population:

- About 1 in 9 people (10.9%) age 65 and older has Alzheimer's dementia.[A2,241]
- The percentage of people with Alzheimer's dementia increases with age: 5.0% of people age 65 to 74, 13.2% of people age 75 to 84, and 33.4% of people age 85 and older have Alzheimer's dementia.[A2, 241] People younger than 65 can also develop Alzheimer's dementia. Although prevalence studies of younger-onset dementia in the U.S. are limited, researchers believe about 110 of every 100,000 people age 30 to 64 years, or about 200,000 Americans in total, have younger-onset dementia.[242]

The estimated number of people age 65 and older with Alzheimer's dementia comes from an updated study using the latest data from the 2024 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.[241]

Whereas CHAP generated estimates specific to Alzheimer's dementia, national estimates of the prevalence of all dementias combined 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 U.S. had dementia in 2016.[A3, 160]

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

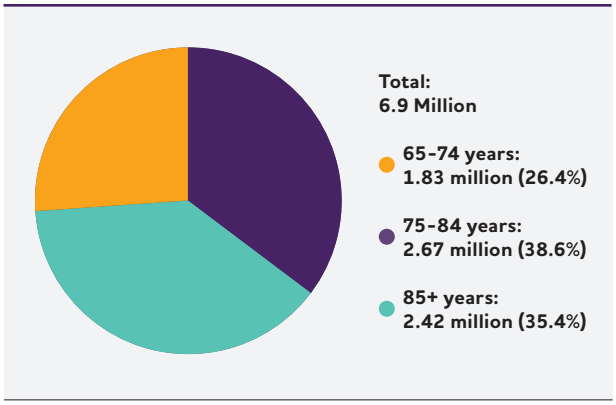
Prevalence studies such as CHAP and HRS are designed so that everyone in the study undergoes evaluation for dementia. But outside of research settings, a substantial portion of those who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed with dementia by a physician.[252-261] 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.[262-266] Because dementia is often underdiagnosed — and if it is diagnosed by a clinician, some people appear to be unaware of their diagnosis — a large portion of Americans with dementia may not know they have it.[267] Some studies indicate that underdiagnosis is higher in Black and Hispanic older adults.[260, 261, 268] A number of potential harms may result from a missed or delayed dementia diagnosis. These include delayed access to treatment, less time for care planning, higher costs of care, and negative impact on the individual's physical or mental health or even the mental health of their family members and potential caregivers; more research is needed to better understand the potential harms of delayed or lack of diagnosis.[269] Underdiagnosis is most pronounced at the earliest stages of dementia when symptoms are mild.[268] Even fewer people living with mild cognitive impairment (MCI), a precursor to dementia (see Overview page 10), receive a diagnosis despite this being a stage where treatment and planning may be most effective.[270] One recent study estimates that only 8% of older Americans living with MCI receive a diagnosis.[271]

Prevalence of Subjective Cognitive Decline

Subjective cognitive decline refers to an individual's perception that their memory or other thinking abilities are worsening, independent of cognitive testing or a physician's diagnosis. Subjective cognitive decline is one of the earliest warning signs of dementia and may be a way to identify people who are at high risk of developing Alzheimer's or other dementias, as well as MCI.[272-276] Not all those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.[277-279] Subjective cognitive decline often prompts medical attention, and a formal diagnosis can help distinguish experiences potentially related to higher dementia risk from experiences less likely to be related, such as other underlying health conditions.[280] One study showed those who consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia.[281] The Behavioral Risk Factor Surveillance System survey, a large cross-sectional, telephone-based survey of community-dwelling people across the U.S. 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.[282] Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

Figure **2**

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2024*



*Percentages do not total 100 due to rounding.

Created from data from Rajan et al.[A2, 241]

Prevalence Estimates

The prevalence numbers included in this report are based on estimates of how many people in the U.S. are living with Alzheimer's dementia; that is, the number of people living with the clinical symptoms described in the "Dementia Due to Alzheimer's Disease" (mild, moderate, or severe) portion of the "Alzheimer's Disease Continuum" described on pages 10-11 of the Overview.

The estimate of 6.9 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 dementia were classified as having Alzheimer's dementia. [A2, 241] 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 substantial undercount (i.e., "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 estimation process attempted to account for the demographics of the entire U.S. population). In the future, *Facts and Figures* could report estimates of Alzheimer's dementia prevalence from multiple longitudinal studies or using different symptom-based diagnostic criteria; these differences in criteria could result in different prevalence estimates from what we report here.[A3, 160]

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 using biomarkers. 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
Prevalence estimates of *dementia due to Alzheimer's disease* based on Alzheimer's brain changes, as well as overt clinical dementia symptoms, are likely to be lower than the 6.9 million figure reported here. This is because autopsy- and biomarker-based studies[21, 79, 243-245] indicate that some individuals counted as having Alzheimer's dementia based on symptoms do not have the biological brain changes defined as 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 estimates using biomarkers of Alzheimer's disease could be up to 30% lower than prevalence estimates based only on symptoms. This would translate to roughly 4.8 million Americans age 65 and older being classified as having dementia due to Alzheimer's disease in 2024.[A3, 160]

Prevalence Estimates of MCI due to Alzheimer's Disease Based on Biomarkers and Mild Cognitive Symptoms
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 10). With the recent advent of biomarkers that detect the brain changes believed to characterize Alzheimer's disease, it may now be possible to determine which individuals diagnosed with MCI have MCI due to Alzheimer's disease. The number and proportion of older adults who have MCI due to Alzheimer's disease are currently difficult to estimate because they require studies with both population-based prevalence measures of MCI and tests of 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 all-cause 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%.[160] 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.[246, 247] Therefore, roughly 8% to 11% of the 63 million Americans who are age 65 and older in 2024 — or approximately 5 to 7 million older Americans — may have MCI due to Alzheimer's disease.[248] This broad prevalence estimate needs to be refined with population-based studies involving biomarkers and more precise estimates from narrower age ranges.

Prevalence Estimates of Alzheimer's Disease Based on Biomarkers and any Cognitive Symptoms (MCI or Dementia)

Combining the estimates of the prevalence of dementia due to Alzheimer's disease and the prevalence of MCI due to Alzheimer's disease provides an estimate of people living with the brain changes of Alzheimer's disease and some form of cognitive impairment. This estimate would include older adults with the earliest detectable stages of cognitive impairment who have the brain changes of Alzheimer's but may or may not have the overt symptoms of dementia that interfere with their ability to carry out everyday activities. Combining the estimates of roughly 4.8 million Americans age 65 and older with dementia due to Alzheimer's disease based on Alzheimer's brain changes and the 5 to 7 million older Americans with MCI due to Alzheimer's disease translates to approximately 10 to 12 million older Americans with Alzheimer's disease and some form of cognitive impairment in 2024. Furthermore, 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 the 10 to 12 million estimate could be even higher if we consider Americans of all ages, not just those 65 or older.

Prevalence Estimates of Alzheimer's Disease Across the Entire Cognitive Spectrum

Finally, as measurements of the brain changes of Alzheimer's disease become more widely available in research, we will be able to estimate how many people have Alzheimer's disease regardless of the presence or absence of dementia or any form of cognitive impairment. The total number of people living with the brain changes of Alzheimer's disease is likely to be much larger than the number with MCI or dementia due to Alzheimer's disease given 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 10).[249] While this is still the subject of ongoing research, estimates are emerging of the prevalence of preclinical Alzheimer's disease in the population.[250, 251] 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, it will be possible to estimate the number of 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). The resulting estimated prevalence 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, currently estimated at 6.9 million Americans, in addition to the best available estimated prevalence of MCI due to Alzheimer's disease. Accurate, up-to-date estimates of the number of people living with these conditions will remain essential to understanding the demands on affected families, health systems, social and health safety nets, and, of course, the people living with these conditions. When biomarker-based prevalence estimates become available, *Facts and Figures* will also report the estimated prevalence of individuals with any clinical cognitive impairment and 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) epidemiologic studies have estimated 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 population of Americans age 65 and older, the group most at risk for developing cognitive symptoms.

Table **4**

Estimated Prevalence (Number and Percentage) of Alzheimer's Dementia (AD) in the 50 U.S. States and District of Columbia Among Adults Age 65 Years and Older in 2020

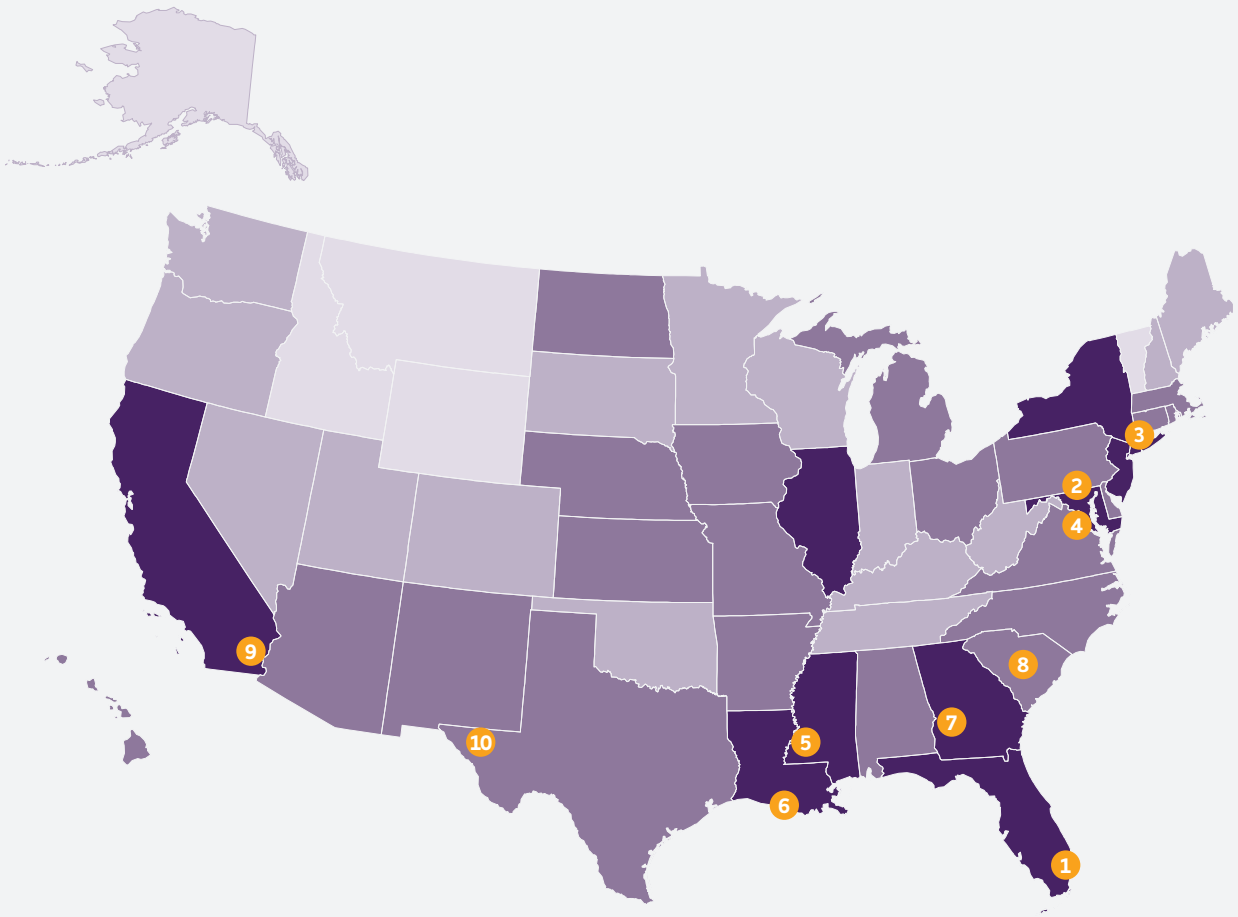
State	Number (in thousands)	%	State	Number (in thousands)	%
Alabama	103.6	11.8	Montana	21	9.8
Alaska	8.4	8.8	Nebraska	35.1	11
Arizona	151.5	11	Nevada	54.9	10.6
Arkansas	60.4	11.3	New Hampshire	26.5	10.1
California	719.7	12	New Jersey	185.3	12.3
Colorado	90.8	10.4	New Mexico	46	11.8
Connecticut	76.8	11.9	New York	426.5	12.7
Delaware	22.3	11.3	North Carolina	210.5	11.6
District of Columbia	15.1	16.8	North Dakota	13.7	11.1
Florida	579.9	12.5	Ohio	236.2	11.3
Georgia	188.3	12	Oklahoma	70.5	10.8
Hawaii	31.2	11.3	Oregon	79.1	10
Idaho	29.9	9.8	Pennsylvania	282.1	11.5
Illinois	250.6	12	Rhode Island	22	11.4
Indiana	121.3	10.9	South Carolina	112.5	11.5
Iowa	62.1	11	South Dakota	16.5	10.5
Kansas	54.5	11.2	Tennessee	129.2	10.9
Kentucky	80.5	10.4	Texas	459.3	11.9
Louisiana	94.7	12.4	Utah	38.3	10
Maine	29.6	10.1	Vermont	12.8	9.9
Maryland	127.2	12.9	Virginia	164	11.7
Massachusetts	135.2	11.3	Washington	126.7	10.2
Michigan	202.8	11.2	West Virginia	38.1	10.2
Minnesota	101.9	10.7	Wisconsin	110.9	10.6
Mississippi	62.5	12.5	Wyoming	10.3	9.9
Missouri	122.3	11.2			

Created from data from Dhana et al.[283]

Figure **3**

Prevalence of Alzheimer's Disease in the 50 U.S. States, and the 10 Counties with the Highest Prevalence, 2020*

8.8% - 9.9% | 10.0% - 10.9% | 11.0% - 11.9% | 12.0% - 12.9%



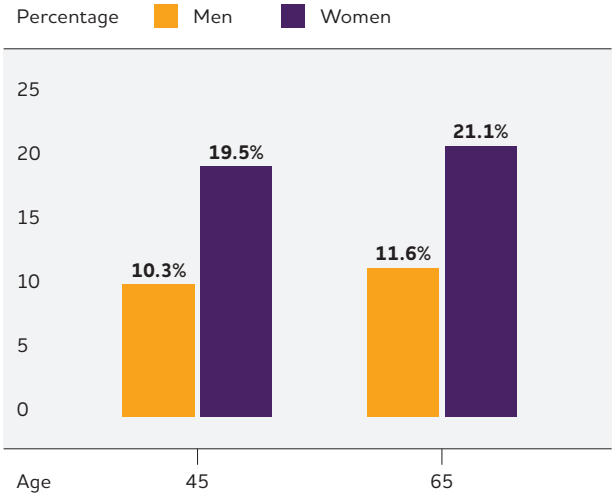
1 Miami-Dade County, FL (16.6%)
2 Baltimore City, MD (16.6%)
3 Bronx County, NY (16.6%)
4 Prince George's County, MD (16.1%)
5 Hinds County, MS (15.5%)
6 Orleans Parish, LA (15.4%)
7 Dougherty County, GA (15.3%)
8 Orangeburg County, SC (15.2%)
9 Imperial County, CA (15.0%)
10 El Paso County, TX (15.0%)

* Only counties with 10,000 or more residents age 65 or older were included in the ranking.

Created from data from Dhana et al.[283]

Figure **4**

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



Created from data from Chene et al.[286]

Estimates of the Prevalence of Alzheimer's Dementia by State and County

Recently, an analysis was conducted using the same data sources that generated the national prevalence estimate in this report that provides estimates of the prevalence of Alzheimer's dementia by state and, for the first time, by county.[283] As shown in Figure 3, states and counties in the eastern and southeastern U.S. have the highest prevalence of Alzheimer's dementia; eight of the 10 counties (with at least 10,000 older adults) with the highest prevalence are in the East and Southeast. In these regions, older people and Black and Hispanic residents — groups that are at higher risk of Alzheimer's dementia — comprise larger percentages of the population (see Racial and Ethnic Differences in the Prevalence of Alzheimer's and Other Dementias on pages 29-31). Table 4 displays the prevalence (both number and percentage)of Alzheimer's dementia for each state. Understanding these regional differences can help guide the allocation of resources to public health programs for Alzheimer's in the U.S.

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 2024 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 U.S. in 2011, a number that would be expected to be even higher in 2024 if CHAP estimates were available for that year.[284] 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).[284] A 2015 study using data from the Adult Changes in Thought Study, a cohort of members of a health care delivery system in the Seattle area, reported similar incidence rates to the CHAP study.[10] Because of the increasing number of people age 65 and older in the U.S., particularly those age 85 and older, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050.[285]

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 through 2009 from the Framingham Heart Study were used to estimate lifetime risk of Alzheimer's dementia by age and sex.[A4, 286] As shown in Figure 4, the study estimated that the 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.[286]

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

Almost two-thirds of Americans with Alzheimer's are women.[241] Of the 6.9 million people age 65 and older with Alzheimer's dementia in the United States, 4.2 million are women and 2.7 million are men.[241] This represents 11% of women and 9% of men age 65 and older in the United States.[287]

Women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.[286, 288, 289] This survival difference contributes to higher prevalence of Alzheimer's and other dementias in women compared with men. However, it is not clear that the risk of developing Alzheimer's or other dementias differs between men and women of the same age. 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, 86, 289-291] while some European studies have reported a higher incidence among women at older ages,[292, 293] or higher incidence among men.[294] Therefore, differences in the risk of dementia between men and women may depend in part on age, birth cohort and/or geographic region.[295, 296]

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 appeared 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.[288] Recent studies have supported the notion that selection bias contributes to reports of sex and gender differences in Alzheimer's dementia risk.[285, 297] 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[298] (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.[295, 299, 300] Gender differences may exist in the distribution of or even the effect of known risk factors for dementia, such as education, occupation, cardiovascular disease 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.[301] 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.[302] In addition to differences in educational attainment relating to dementia risk differences in men and women, the same level of education affect men's and women's dementia risk differently. European studies have found that the association of lower educational attainment with dementia outcomes may be stronger in women than men.[303, 304]

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.[297, 305, 306] More recently, 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.[307-309] 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.[308]

It is unclear whether genetic risk operates differently in women and men in the development of, or susceptibility to, Alzheimer's pathology.[310] 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[311, 312] and neurodegeneration[313] in women than in men. However, a 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 and 70, when APOE is thought to exert its largest effects.[314] It is unclear whether the influence of APOE-e4 may depend on the sex hormone estrogen.[315, 316]

It should be recognized that sex and gender identities cannot 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 and Risk of Alzheimer's and Other Dementias

The risk of Alzheimer's and other dementias appears to vary by race and ethnicity in the U.S. While risk is poorly characterized in smaller racial and ethnic groups in the U.S., multiple studies have reported on differences in risk across non-Hispanic Black, non-Hispanic White, and Hispanic Americans. In the U.S., non-Hispanic Black and Hispanic older adults are more likely than White older adults to have Alzheimer's or other dementias.[317-323] 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.[241] In line with these observations, most other prevalence studies indicate that Black older adults are about twice as likely to have Alzheimer's or other dementias as White older adults.[160, 284, 324, 325] 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,[325-327] though others have shown similar prevalences among Hispanic older adults and White older adults.[160] 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).[328, 329]

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.[330, 331] Race is a social construct with little to no genetic or biological basis. Instead, race is an idea created and used throughout history by groups in power to justify their control and dominance over other groups, and genetic factors do not account for the large differences in prevalence and incidence among racial groups.[330, 332] 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[88-92, 333] — these small differences in genetic influence do not account for the large differences in dementia risk across racial groups. Instead, research suggests that the historic and continued marginalization of Black and Hispanic people in the U.S. has produced disparities between older Black and Hispanic populations and older White populations in life experiences, socioeconomic indicators and, ultimately, health conditions. It is these disparities that most likely explain the difference in risk for Alzheimer's and other dementias among racial and ethnic groups.[334] These health and socioeconomic disparities are rooted in the history of discrimination against Black individuals and other people of color in the U.S., not only during interpersonal interactions, but also as codified in the rules, practices and policies of U.S. banks, laws, health care and other systems — that is, structural racism.[335, 336] Structural racism pervades many aspects of life that may directly or indirectly alter dementia risk, including where people can live, the quality of schools in their communities, exposure to harmful toxicants and pollutants, 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.[337-340]

The cumulative stress imparted by the effects of structural racism and the resulting differences in social and physical environments 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, 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.[88, 334, 341, 342] Many studies suggest that racial and ethnic differences in dementia risk do not persist in rigorous analyses that account for health and socioeconomic factors.[156, 330, 343]

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.[337-339] This points to a need for health disparities researchers to employ a life course perspective and to seek the insights of race equity scholars to account for the cumulative interplay of many environmental and sociopolitical factors that may put some groups of people at increased risk for Alzheimer's and other dementias.[334, 342]

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.[254, 256, 259, 344, 345] 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.[346] 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 prevalence and incidence of Alzheimer's and other dementias in racial and ethnic groups other than White, Black and Hispanic populations are relatively sparse.[331] Among the few studies, one examined electronic medical records of members of a large health plan in California. Its findings indicated that dementia incidence — determined by the first presence of a dementia diagnosis in members' medical records — was highest among 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 among Asian American older adults.[347] A follow-up study with the same cohort showed differences across Asian American subgroups, but all

subgroups studied had lower dementia incidence than the White population.[348] A 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.[328] We have limited understanding of Alzheimer's disease as experienced by people of Middle Eastern and North African descent,[349] those who identify with more than one race or ethnicity, and subgroups of origin within racial or ethnic groups.[346] 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 nonbinary, 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, through pervasive exposure to systematic discrimination, marginalization, disadvantage and/or exclusion from social organizations 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. Although few studies have been designed to investigate whether SGM older adults are at greater risk for dementia than non-SGM older adults, 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.[350] Two population-based studies found higher rates of cognitive impairment among SGM older adults than among non-SGM older adults,[351, 352] yet a third study reported that the risks for dementia and mild cognitive impairment were similar for people in same-sex relationships and people in another-sex relationships.[353] 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.[354] 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.[355] A recent review of the evidence found that most studies examining subjective cognitive decline as an outcome showed higher prevalence among SGM older adults, while those examining objective measures of cognitive performance showed more mixed results.[356]

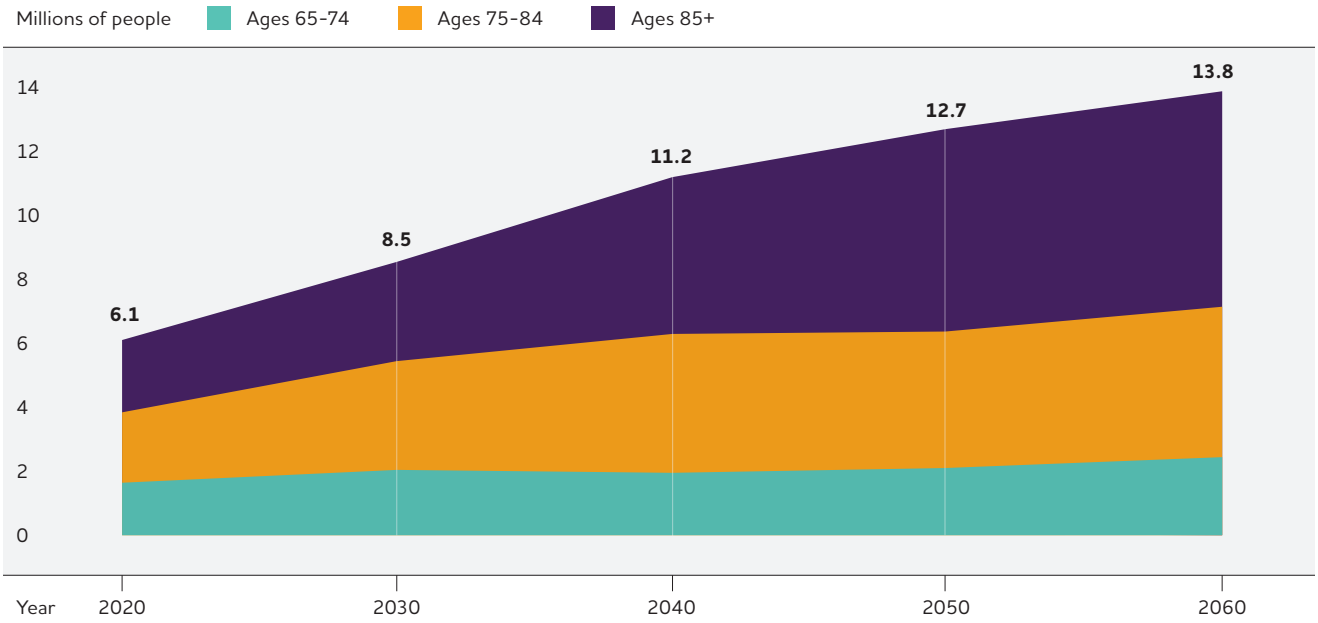
More research is necessary to establish whether SGM older adults face elevated dementia risk and if so, to understand reasons for it. Researchers have hypothesized that stressors experienced by SGM older adults, such as discrimination and marginalization, may elevate their risk for Alzheimer's and other dementias.[300] These stressors could take a toll on the physical and mental health of SGM older adults.[357] One study showed that SGM older adults who were experiencing depression were more likely to report subjective cognitive decline than SGM older adults without depression.[358] SGM older adults experience disparities in other health-related factors that elevate the risk of Alzheimer's and other dementias, including higher rates of alcohol and tobacco use, obesity and other cardiovascular risk factors compared with non-SGM older adults. SGM older adults also have lower rates of health care access and preventive health screenings, in part due to experiencing barriers such as discrimination and heterosexist attitudes in health care settings.[359] 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. 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.[360] 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 not 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. For example, a recent study showed that

This report keeps the racial, ethnic and other population identifiers used in source documents when describing findings from specific studies.

Figure 5

Projected Number of People Age 65 and Older (Total and by Age) in the U.S. Population with Alzheimer's Dementia, 2020 to 2060



Created from data from Rajan et al.[A5,241]

transgender adults from minoritized ethnoracial groups are more likely to report subjective cognitive decline than other transgender adults.[361] This "intersectionality" framework is important for developing more informative dementia research and more effective and compassionate dementia care in these communities.[362] It is important that research and care efforts consider how systems of oppression based on gender, race, ethnicity, class, sexual orientation and HIV status may intersect and influence dementia.[363, 364]

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

A growing number of studies indicate that the prevalence (i.e., proportion)[239, 259, 290, 345-349, 365-367] and incidence[294, 365-374] of Alzheimer's and other dementias in the U.S. and other high income countries may have declined in the past 25 years,[294, 302, 365-373, 375-379] though results are mixed.[70, 284, 380, 381] One recent systematic review found that incidence of dementia has decreased worldwide 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.[382] Declines in dementia risk have been attributed to increasing levels of education and improved control of cardiovascular risk factors.[302, 368, 371, 375, 383, 384] 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 U.S. 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. For example, worldwide increases in diabetes and obesity, which are risk factors for dementia, among people younger than 65 may lead to a rebound in dementia risk in coming years.[366, 385-388] It is also not clear that the encouraging trends pertain to all racial and ethnic groups.[284, 323, 383, 384, 389, 390] Thus, while recent findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow. Moreover, 68% of the projected increase in the global prevalence and burden of dementia by 2050 will take place in low- and middle-income countries, where current evidence does not support a decline in the risk of Alzheimer's and other dementias.[391] 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[392] 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 and examine whether the impact is time-limited or long term. On the other hand, the number of people living with Alzheimer's dementia could be influenced in the opposite direction by increased mortality due to COVID-19 and other causes of death during the pandemic in 2020–2023, which may have resulted in death prior to the onset of Alzheimer's dementia, or death with fewer years lived with Alzheimer's dementia.[393]

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 71 million older Americans will make up over 20% of the total population (up from 17% in 2022).[237] Additionally, the size of 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, has decreased since 1960 in the United States.[394] 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, page 32.[A5, 241] 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 or cure Alzheimer's disease.[A5, 241]

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 population aging.[237] This will lead to an increase in the number and percentage of Americans 85 and older. This age group is expected to comprise 11% of the population age 65 and older in 2025 and 21% of the population age 65 and older in 2050.[395] This will result in an additional 10 million people age 85 and older — individuals at the highest risk for developing Alzheimer's dementia.[395]

- In 2024, about 2.4 million people living with Alzheimer's dementia are expected to be age 85 or older, accounting for 34% of all people with Alzheimer's dementia.[241]
- 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.[241]

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% compared with an increase of 32% in the White population.[396]

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.[397] In parallel these generations of women came of age during a decrease in the birth rate, resulting in smaller family size.[398] Whether and how these social and economic experiences influence women's risk of and resilience to Alzheimer's will become clearer in the decades ahead.

Since the 1970s, the gap in income in the U.S. between lower-income, middle-income, and upper-income households has been widening.[399] This means that the many people who are age 65 and over experienced their adulthood during this trend, which may have influenced health and health behaviors prior to age 65. In older adulthood, income inequality may influence a wealth gap, which may have implications for health care, health behaviors, and social determinants of health that influence Alzheimer's risk in particular among low-income households.

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 and 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.[400-402]

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;[403] in the years 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 more recent years are still being compiled.[404]

Alzheimer's disease was the fifth-leading cause of death among individuals age 65 and older in 2021.[403] 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.[405] 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 2021, the latest year for which finalized death data are available. Starting in 2020, the COVID-19 pandemic had a dramatic effect on deaths in the United States (see the box "The Effect of the COVID-19 Pandemic on Deaths from Alzheimer's Disease" for a discussion of the effect of the pandemic on Alzheimer's mortality). In 2021, Alzheimer's mortality trends started to more closely resemble the year-by-year trends from before the COVID-19 pandemic.

In this section, "deaths from Alzheimer's disease" refers to what is officially reported on death certificates. 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 when referring to officially reported statistics gleaned from 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 Centers for Disease Control and Prevention (CDC), 119,399 people died from Alzheimer's disease in 2021.[403] 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."[406]

The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's deaths. In 2021, some form of dementia was the officially recorded underlying cause of death for 279,704 individuals (this includes the 119,399 from Alzheimer's disease).[403] 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 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.[407-410] 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.[408] Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[408, 409] 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."[411]

Another way to determine the number of deaths from Alzheimer's dementia is through calculations that compare the estimated risk of death in those who have Alzheimer's dementia with the estimated risk of death in those who do not have Alzheimer's dementia. A study using data from the Rush Memory and Aging Project and the Religious Orders Study estimated that 500,000 deaths among people age 75 and older in the United States in 2010 could be attributed to Alzheimer's dementia (estimates for people age 65 to 74 were not available), meaning that those deaths would not be

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

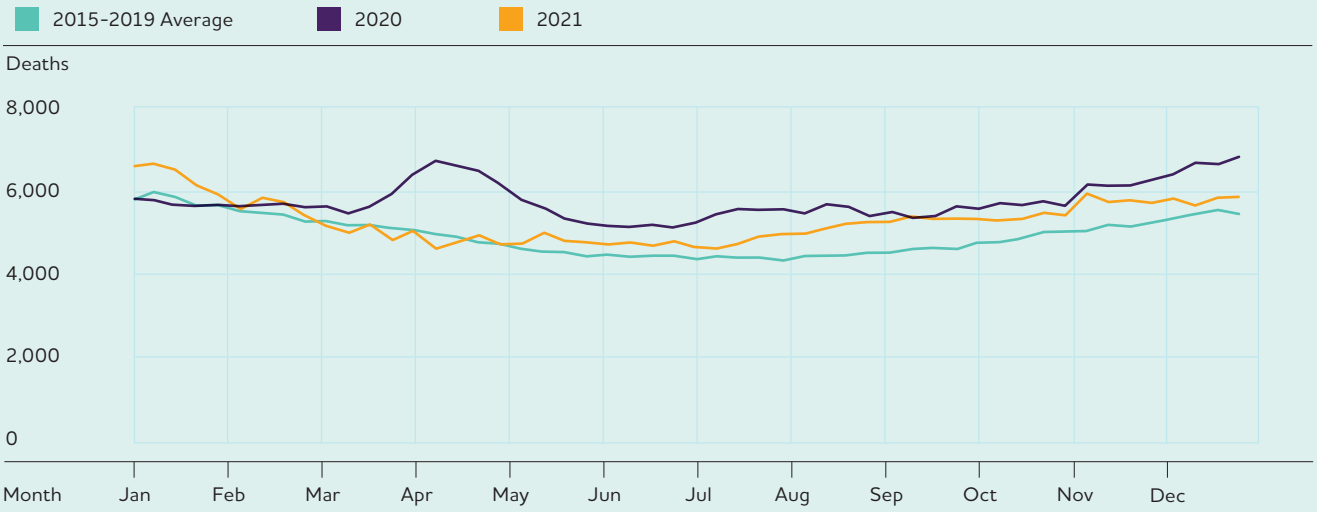
In 2020 and 2021, COVID-19 was the third-leading cause of death in the United States, pushing Alzheimer's disease from the sixth- to the seventh-leading cause of death.[404] Data for more recent years were still being compiled as of the time this report was written. Despite the change in rankings on 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.[403] 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 during the height of the pandemic, especially among older adults.[416] Many of these excess deaths were in vulnerable older adults with Alzheimer's disease and other dementias. Among Medicare beneficiaries age 65 and over with Alzheimer's disease and other dementias, overall mortality increased 26% between 2019 and 2020, which is twice as high as the increase among beneficiaries without Alzheimer's disease and other dementias.[417] Furthermore, increased mortality between 2019 and 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.[417] As shown in Figure 6, compared with the average annual number of deaths in the five years before 2020, there were 13,925 more deaths from Alzheimer's disease and 44,729 more deaths from all dementias, including Alzheimer's, in 2020. This is, respectively, 12% and 17% more than expected.[403] In 2021, there were 1,082 more deaths from Alzheimer's disease and 20,449 more deaths from all dementias compared with the average of the five years before 2020.[403] The number of people dying from Alzheimer's has been increasing over the last two decades, but the number of excess deaths from Alzheimer's disease in 2020 far exceeded what would have been expected from this pre-pandemic trend. The number for 2021, by contrast, is closer to the pre-pandemic trend. Data for more recent years are still being compiled, but one study found that deaths due to all dementias, including Alzheimer's, decreased between March 2021 and February 2022, in particular among residents of nursing homes and long-term care facilities.[418]

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.[404]

The COVID-19 pandemic 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 now that the COVID-19 pandemic has subsided. 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. What is clear is that for at least the first years of the pandemic, having Alzheimer's or another dementia made older adults more vulnerable to COVID-19 and increased the risk 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*

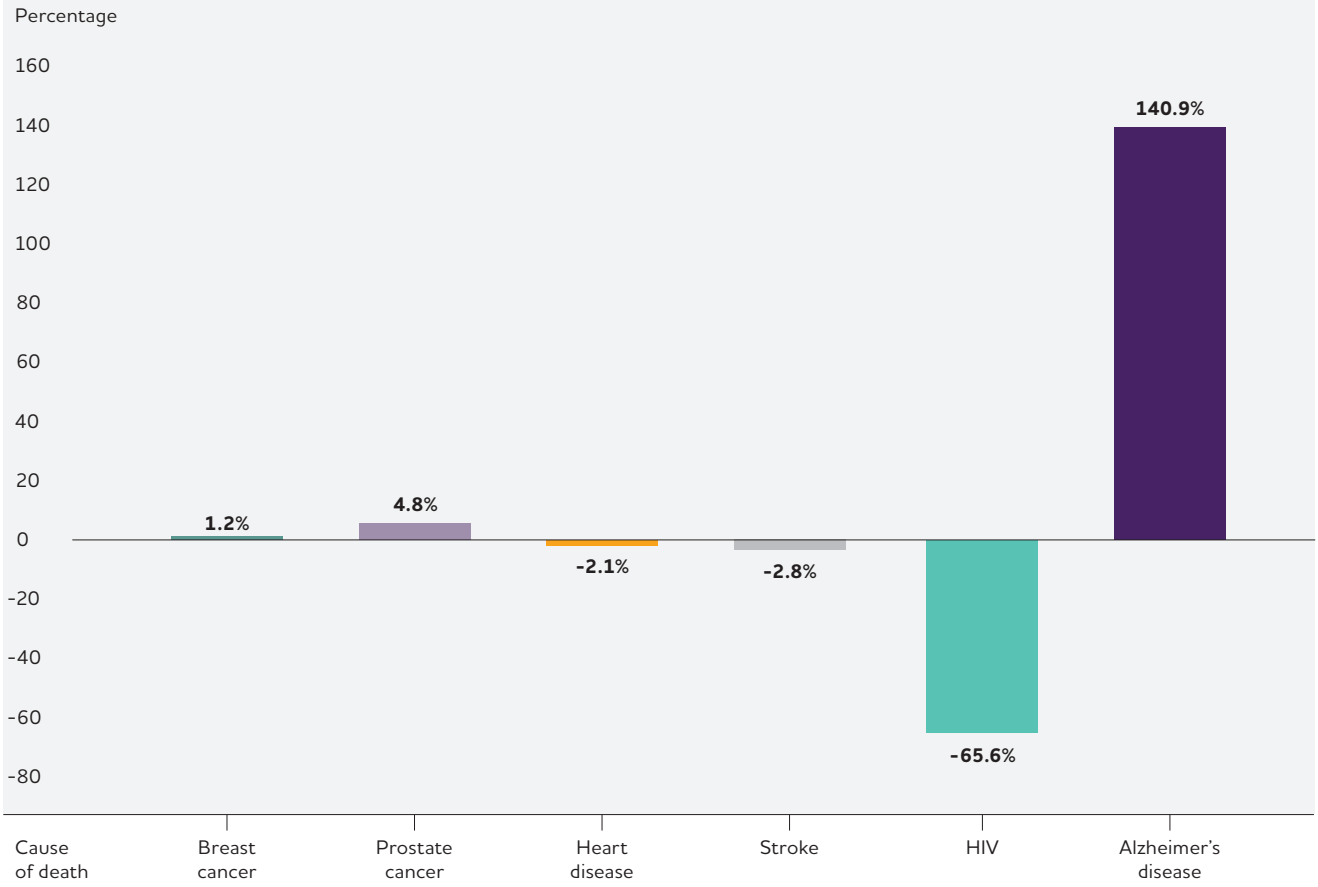


*Data for 2021 are as of February 7, 2022.

Created from data from the National Center for Health Statistics.[416]

Figure **7**

Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2021



Created from data from the National Center for Health Statistics.[403,419]

expected to occur in that year if the individuals did not have Alzheimer's dementia.[407] 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, indicating underreporting on death certificates.[412] 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.[413] 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.[414] 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.

Adding 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

This report keeps the racial, ethnic and other population identifiers used in source documents when describing findings from specific studies.

Table **5**

Number of Deaths and Annual Mortality Rate (per 100,000 People) Due to Alzheimer's Disease by State, 2021

State	Number of Deaths	Mortality Rate	State	Number of Deaths	Mortality Rate
Alabama	2,725	54.1	Montana	341	30.9
Alaska	135	18.4	Nebraska	687	35.0
Arizona	2,754	37.8	Nevada	804	25.6
Arkansas	1,559	51.5	New Hampshire	422	30.4
California	16,911	43.1	New Jersey	2,399	25.9
Colorado	1,778	30.6	New Mexico	634	30.0
Connecticut	1,049	29.1	New York	3,582	18.1
Delaware	381	38.0	North Carolina	4,260	40.4
District of Columbia	66	9.9	North Dakota	325	41.9
Florida	6,716	30.8	Ohio	4,947	42.0
Georgia	4,378	40.5	Oklahoma	1,580	39.6
Hawaii	562	39.0	Oregon	2,047	48.2
Idaho	789	41.5	Pennsylvania	4,109	31.7
Illinois	4,025	31.8	Rhode Island	445	40.6
Indiana	2,238	32.9	South Carolina	2,419	46.6
Iowa	1,185	37.1	South Dakota	396	44.2
Kansas	805	27.4	Tennessee	2,879	41.3
Kentucky	1,632	36.2	Texas	10,437	35.3
Louisiana	2,121	45.9	Utah	998	29.9
Maine	539	39.3	Vermont	337	52.2
Maryland	1,129	18.3	Virginia	2,582	29.9
Massachusetts	1,558	22.3	Washington	3,644	47.1
Michigan	4,198	41.8	West Virginia	851	47.7
Minnesota	2,251	39.4	Wisconsin	2,371	40.2
Mississippi	1,694	57.4	Wyoming	208	35.9
Missouri	2,517	40.8	**Total**	**119,399**	**36.0**

Created from data from the National Center for Health Statistics.[A6,403]

brain changes of another cause of dementia (see Table 1, pages 6-7).[21, 79, 243-245] 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.[415]

Public Health Impact of Deaths from Alzheimer's Disease

In the past two decades, although the number of 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 2021, the number of deaths from Alzheimer's disease as recorded on death certificates more than doubled, increasing 141%, while deaths from the number-one cause of death (heart disease) decreased 2.1% (Figure 7).[403, 419] 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.[420]

State-by-State Deaths from Alzheimer's

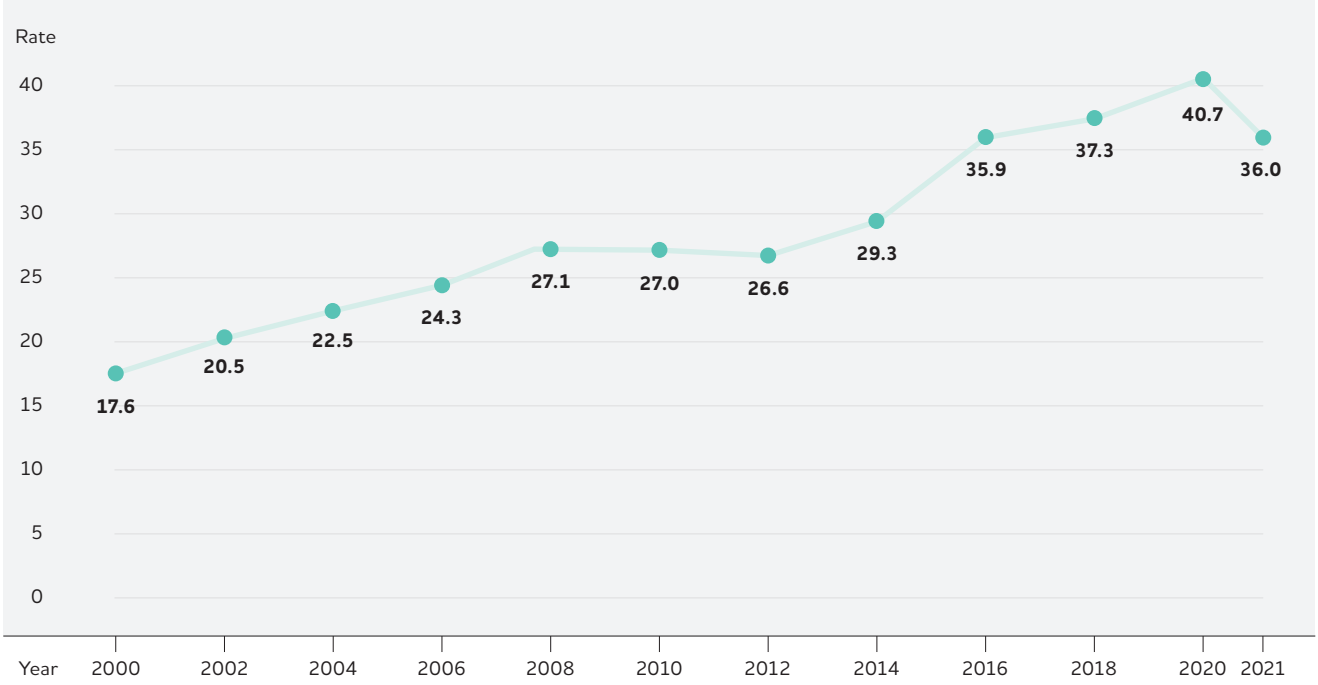
Table 5 provides information on the number of deaths due to Alzheimer's by state in 2021, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician or other medical personnel who filled 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 2021, the mortality rate for Alzheimer's disease was 36 deaths per 100,000 people.[A6, 403]

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 100,000 people in the population — has risen substantially since 2000.[403] Table 6 shows that the annual rate of death from Alzheimer's increases dramatically with age, especially after age 65.[A6, 403] The increase in the Alzheimer's death rate over time has disproportionately affected people age 85 and older.[419] Between 2000 and 2021, the death rate from Alzheimer's increased 41% for people age 65 to 74, 54% for people age 75 to 84 and 86% for people age 85

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.[403]

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	2020	2021
45-54	0.2	0.1	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.3	0.2	0.3
55-64	2.0	1.9	1.8	2.1	2.2	2.1	2.2	2.1	2.7	2.9	3.3	3.2
65-74	18.7	19.6	19.5	19.9	21.1	19.8	17.9	19.6	23.6	24.7	28.6	26.4
75-84	139.6	157.7	168.5	175.0	192.5	184.5	175.4	185.6	214.1	213.9	229.3	214.3
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	1,287.3	1,243.6

Created from data from the National Center for Health Statistics.[403]

and older.[403] 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 U.S. increased substantially between 1999 and 2014.[420] 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 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.[420]

Duration of Illness from Diagnosis to Death and Time Spent in Nursing Home

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.[415] Much of this time will be spent in a nursing home (see Use and Costs section, page 70). 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.[415] 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.[421]

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, informal caregivers and communities at large. 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.[405] In 2016, Alzheimer's disease was the fourth highest disease or injury in terms of YLLs and the 19th in terms of YLDs.[405]

These estimates should be interpreted with consideration of the comparability of data across time and[422] 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. Estimates do not account for the context in which disability is experienced, including social support and economic resources,[423] which vary widely. Estimates may not fully account for variation in disability levels between individuals and along the stages of Alzheimer's dementia. These variations in data sources and consideration of disability may limit the value of these metrics and the comparability of 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 Alzheimer's and other dementias are contributing to more and more cases of poor health and disability in the U.S. With population aging, the percentage of deaths related to Alzheimer's and other dementias will likely continue to increase. The health and well-being of people with Alzheimer's and other dementias should continue to be prioritized. Thus, it will remain important to develop a comprehensive understanding of how Alzheimer's and other dementias contribute to poor health, disability and mortality. That understanding requires innovation in research methods that are more inclusive and that fully capture the lived experience of disability of people living with dementia and of their families and caregivers.

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 $350 billion.

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

When supporting a person living with Alzheimer's dementia, caregiving often includes assistance with one or more activities of daily living (ADLs), such as bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation.[424, 425] Caregivers also provide emotional support to people with Alzheimer's dementia, help them manage health conditions, and communicate and coordinate care with other family members and health care providers (see Table 7). In addition to providing descriptive information about caregivers of people with Alzheimer's or other dementias, this section characterizes caregivers of people with dementia in comparison with either caregivers of people with other medical conditions or, if that comparison is not available, with 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.[426] Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.[427] More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A7] Table 8 provides details about unpaid caregivers.

In 2023, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours[A8] of informal — that is, unpaid — assistance, a contribution valued at $346.6 billion.[A9] This is approximately 57% of the net value of Walmart's total revenue in fiscal year 2023 ($611.3 billion)[428] and nearly 15 times the total revenue of McDonald's in 2022 ($23.3 billion).[429] The total lifetime cost of care for someone with dementia was estimated at almost $400,000 in 2023 dollars. Seventy percent of this 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 payments by Medicare and Medicaid (see the Use and Costs of Health Care, Long-Term Care and Hospice section, page 70).[430, 431] 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 always considered in cost estimates.[432]

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.[A10, 440, 441]
Race/ethnicity	• Two-thirds of caregivers are White,[A10, 441, 442] 10% are Black, 8% are Hispanic, and 5% are Asian American.[A10] 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.[434] • Over 60% of caregivers are married, living with a partner or in a long-term relationship.[A10, 441] • 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.[A10, 442, 443]
Caring for parents	• Over half of caregivers are providing assistance to a parent or in-law with dementia.[442] • 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.[444-446]
Income	• Forty-one percent of caregivers have a household income of $50,000 or less.[A10]
Education	• Approximately 40% of dementia caregivers have a college degree or more of education.[A10, 441, 442]
Age	• About 30% of caregivers are age 65 or older.[A10] • Twenty-three percent of caregivers ages 18 to 49 help someone with dementia, which is an increase of 7% between 2015 and 2021.[447]
Caring for spouse	• Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.[442]

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%).[A10] 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.[433]

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.[434] Only a small percentage (8%) of older adults with dementia do not receive help from family members or other informal care providers. Of these individuals, nearly half live alone, perhaps making it more difficult to ask for and receive informal care.[434] 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.[435]

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.[436-439]

Caregiving and Women

The responsibilities of caring for someone with dementia often fall to women. Approximately two-thirds of dementia caregivers are women.[A10, 440, 441, 446] 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).[448] Over one-third of dementia caregivers in the United States are daughters caring for a parent.[426, 434] It is more common for wives to provide informal care for a husband than vice versa.[449] On average, female caregivers spend more time caregiving than male caregivers.[434] The 2015-2017 BRFSS surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.[443] Two and a half times as many women as men reported living with the person with dementia full time.[450] Of those providing care to someone with dementia for more than five years, 63% were women.[443] Similarly, caregivers who are women may experience slightly higher levels of burden, impaired mood, depression and impaired health than do 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.[451-453] 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%).[443]

Race, Ethnicity and Dementia Caregiving[A1]

Only recently have population-based studies examined racial disparities in dementia caregiving. Close to half of Black and Hispanic individuals with dementia live with adult children (47.1%), compared with less than a quarter of White individuals with dementia (24.6%).[454] 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.[455, 456] 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% to 71% less likely than White female dementia caregivers to indicate emotional burden.[457] 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.[458, 459] Hispanic, Black and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use and greater depression compared with White caregivers.[460-462] In a nationally representative study,[463] 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.[464]

Black caregivers are more likely than White caregivers to report positive aspects of caregiving.[455] 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.[465] 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.[460] 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.[460] Non-Hispanic Black dementia family caregivers are less likely to exercise and live with diabetes than non-Hispanic White and non-Hispanic Asian dementia family caregivers.[466]

The need for culturally informed theories, research frameworks, and services for people living with dementia and their caregivers is pronounced.[467-471] 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.[472, 473] 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.[474] 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.[459, 475-477]

Dementia caregiving is experienced by many, regardless of race or ethnicity. The comparisons above suggest that the experience of caregiving often varies depending on racial and ethnic context. Studies of caregivers often lack sufficient numbers of diverse participants to confirm these findings or delve deeper into them for important insights. Recent reviews and national summits have emphasized the need to revise recruitment strategies to capture the range of dementia care experiences among caregivers of diverse racial and ethnic identity.[462] 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 dementia caregiving research. Furthermore, if individuals continue to lack representation in dementia research, they will not receive the benefits of racially and ethnically sensitive prevention, treatment or care innovations.[460, 462] 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 dementia research and result in more culturally appropriate and effective services.[468, 474, 478-490]

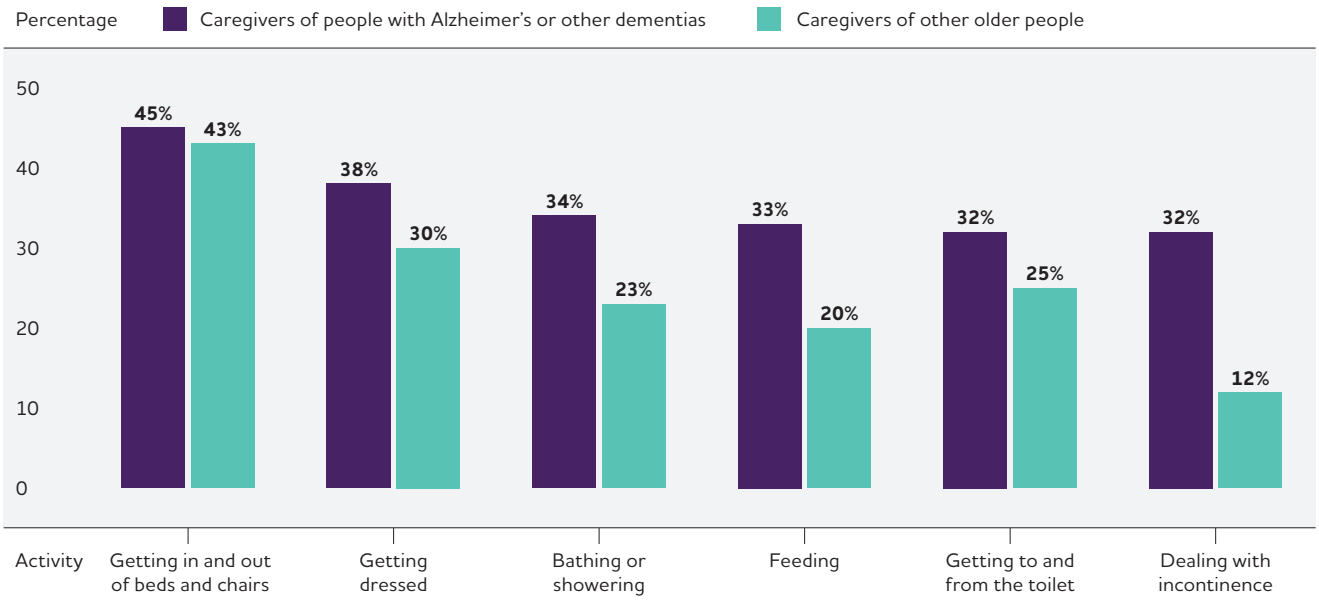
Caregiving Tasks

The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all-encompassing. Table 7, page 43, summarizes some of the most common types of dementia care provided.

This report keeps the racial, ethnic and other population identifiers used in source documents when describing findings from specific studies.

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.[442]

Although the care provided by family members of people with Alzheimer's or other dementias can be similar to that provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance.[491] Family caregivers of people with dementia are more likely to monitor the health of the care recipient than are caregivers of people without dementia (79% versus 66%).[492] 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%).[427, 440] Figure 9 illustrates how caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.[442]

People with dementia tend to have larger networks of family and friends involved in their care compared with people without dementia. More family members and friends in dementia care networks tend to provide help for household activities, mobility and functional needs, and transportation than family members and friends in non-dementia care networks.[493]

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 caregivers 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.[494, 495]

Duration of Caregiving

One national poll found that 86% of dementia caregivers provided assistance for at least the past year.[A10] 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.[434]

Hours of Unpaid Care and Economic Value of Caregiving

In 2023, the 11.5 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid help. This number represents an average of nearly 31 hours of care per caregiver per week, or 1,612 hours of care per caregiver per year.[A8] 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),[A9] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was $346.6 billion in 2023. Table 9, page 47, shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the

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, 2023*

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Alabama	217	387	$5,310	Montana	17	25	$478
Alaska	25	39	796	Nebraska	40	62	1,188
Arizona	292	483	10,228	Nevada	84	142	2,681
Arkansas	155	270	4,448	New Hampshire	48	77	1,529
California	1,373	1,864	44,272	New Jersey	272	494	10,882
Colorado	177	307	7,249	New Mexico	67	118	2,142
Connecticut	128	201	4,331	New York	543	879	18,996
Delaware	31	46	909	North Carolina	373	723	10,939
District of Columbia	14	15	343	North Dakota	19	25	465
Florida	840	1,321	24,437	Ohio	414	624	11,427
Georgia	374	755	11,417	Oklahoma	108	189	3,099
Hawaii	60	91	1,907	Oregon	170	229	5,285
Idaho	66	105	1,875	Pennsylvania	465	822	13,668
Illinois	311	480	9,840	Rhode Island	36	51	1,132
Indiana	216	322	5,186	South Carolina	219	361	5,550
Iowa	98	125	2,284	South Dakota	27	34	716
Kansas	89	125	1,989	Tennessee	369	499	7,804
Kentucky	157	302	4,869	Texas	1,016	1,532	23,937
Louisiana	168	256	3,428	Utah	112	132	2,465
Maine	51	87	1,911	Vermont	19	28	615
Maryland	247	405	8,144	Virginia	342	662	12,572
Massachusetts	213	246	5,668	Washington	247	378	9,499
Michigan	380	872	17,044	West Virginia	65	115	1,585
Minnesota	164	225	5,276	Wisconsin	205	297	5,528
Mississippi	93	175	2,380	Wyoming	16	21	385
Missouri	223	350	6,478	**U.S. Total**	**11,457**	**18,376**	**$346,585**

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

Created from data from the 2016, 2020, 2021, and 2022 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, National Alliance for Caregiving, AARP, U.S. Department of Labor and Genworth.[A7,A8,A9]

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 25 states. Unpaid caregivers provided care valued at more than $18 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.[496] In contrast, family care costs are reduced up to 24% in situations where caregivers indicated they were emotionally close to the person with dementia.[497] 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, particularly since many existing economic studies only consider primary caregivers when there are often multiple relatives and others helping an older person with dementia.[434, 498]

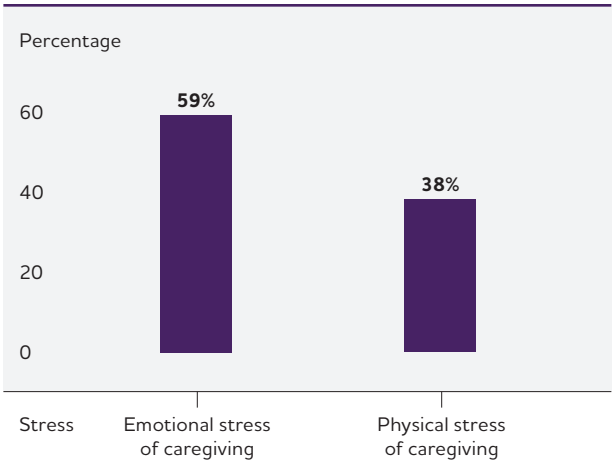
Apart from its long duration, caregiving involves demands that are time-intensive. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.[440] An analysis of national caregiving trends from 1999 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.[499] 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 this increased to 283 hours per month eight years later. This is an increase from approximately 5 hours a day to 9 hours a day (it is important to note that some family members/caregivers provide assistance to someone due to cognitive issues before a formal diagnosis of Alzheimer's disease or a related dementia).[500, 501] 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.[502] Over a two-year period, one national study found that impairment in one additional self-care activity (e.g., bathing, dressing, eating and using the toilet) for those with dementia resulted in 28 additional hours of family care required per month; for those without dementia, an additional self-care need was associated with an increase in 15 hours of family care per month.[503]

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 dementia manage these issues. The personality and behavior of a person with dementia are affected as well, and these changes are often among the most challenging for family caregivers.[504-506] Individuals with dementia 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.[507-514]

Figure **10**

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



Created from data from the Alzheimer's Association.[A10]

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 dementia. 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.[446] In the 2011 National Study of Caregiving, greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends.[515] Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,[A10, 516-524] they also frequently report higher levels of burden and stress; depression or other adverse mental health outcomes; strain; and problems with navigating care transitions when compared with other caregivers or non-caregivers.

Burden and Stress

- Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial and physical difficulties.[440, 491]
- 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).[A10]
- 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.[525]
- Many people with dementia have co-occurring chronic conditions, such as hypertension or arthritis, which may complicate caregiving. For example, a national study 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.[526]

Depression and Mental Health (see also Table 10, page 51)

- A meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers.[453] Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.[527]
- 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%).[528, 529]
- Caring for a spouse with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.[530]
- 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.[528]
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).[528]
- 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).[448]
- 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.[531, 532]
- 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.[533]
- A systematic review found the prevalence of suicidal 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 (please note that an exact age comparator is not available).[534, 535]
- Providing physical and medical care is associated with worse mental health among dementia caregivers than non-dementia caregivers.[491]

Other Key Findings About the Challenges of Dementia Caregiving

- 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.[492]
- Dementia caregivers often experience challenges managing medications for individuals with dementia, such as non-adherence.[536-539]
- Compared with non-dementia caregivers, dementia caregivers indicate a greater decrease in their social networks (e.g., other relatives, friends, acquaintances).[540]
- According to a national Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.[A10]
- The poll also found that more than half (53%) of women with children under age 18 felt that caregiving for someone with dementia was more challenging than caring for children.[A10]
- Non-heterosexual 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.[541]
- Many caregivers of people with Alzheimer's or other dementias are at risk of social isolation.[542] Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.[A10]

- Among dementia caregivers of care recipients who have experienced severe psychiatric symptoms (e.g., aggression, anxiety), those who live in low- or medium-income neighborhoods indicate higher distress than those caregivers living in high-income neighborhoods.[543]
- In a survey of caregivers from a large health care system, less than 4 in 10 respondents (39.2%) agreed that their primary care providers help them with managing symptoms of a care recipient with dementia.[544]

Stress of Care Transitions

- Caregivers who helped someone with a formal diagnosis of dementia indicated more emotional difficulty and family disagreement than caregivers of individuals without a formal diagnosis. However, those caregivers of individuals with a formal dementia diagnosis were also more engaged in communication during doctors' visits and also more likely to receive caregiver training than those who assisted someone without a diagnosis of dementia, suggesting the importance of linking support to dementia diagnostic procedures.[545]
- Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of dementia 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.[495, 546-548]
- The demands of caregiving may intensify as people with dementia approach the end of life.[549] 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.[550] The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.[550]
- 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).[551]

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.[552] As shown in Figure 10, page 48, 38% of Alzheimer's and other dementia caregivers indicate that the physical stress of caregiving is high to very high.[A10] Dementia caregivers are 1.5 times more likely to indicate substantial physical difficulty providing assistance to their care recipients compared with non-dementia caregivers.[553] 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.[554-557] 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.[555]

Tables 10 and 11 present data on caregiver physical and mental health. Table 10, page 51, presents state-by-state data on the health status of dementia caregivers, and Table 11, page 52, 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.[A10] A 2017 poll found that 27% of dementia caregivers delayed or did not do things they should to maintain their own health.[446, 558, 559] Data from the Health and Retirement Study showed that dementia caregivers who provided care to spouses were much more likely (41% increased odds) than other spousal caregivers of similar age to become increasingly frail during the time between becoming a caregiver and their spouse's death.[560-563]

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.[564-571] 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.[572] However, a study of physiological changes before and after the start of caregiving found no change in six biomarkers of inflammation among dementia caregivers.[573]

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 without these challenges.[574, 575] Increased depressive symptoms among caregivers are linked to more frequent caregiver doctor visits, increased outpatient tests and procedures, and greater use of over-the-counter and prescription medications.[575] Dementia caregivers also have twice the odds of experiencing an overnight hospitalization than non-caregivers.[576]

Table **10**

Percentage of Dementia Caregivers Reporting Health Conditions by State, 2016-2022

State	Percentage Reporting at Least One Chronic Condition	Percentage Reporting Depression	Percentage Reporting Frequent Poor Physical Health
Alabama	57.5	30.9	15.0
Alaska	53.7	27.7	15.2
Arizona	66.7	27.7	15.5
Arkansas	72.8	38.0	25.0
California	61.0	18.6	13.1
Colorado	58.0	36.7	15.5
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	64.9	33.2	15.1
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	62.4	37.2	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	57.0	25.9	22.2
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	66.2	28.4	14.7
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	63.7	27.8	17.4
Oklahoma	68.2	39.6	17.2
Oregon	57.4	33.6	8.5
Pennsylvania	76.6	32.5	16.0
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	59.3	34.6	14.9
Vermont	61.5	35.4	10.7
Virginia	64.1	31.2	15.1
Washington	61.1	39.0	18.0
West Virginia	63.5	32.2	12.0
Wisconsin	62.9	27.8	18.9
Wyoming	59.8	22.8	†

*Data are for caregivers of individuals whose main reason for needing care is Alzheimer's or other dementia. For other states, the individuals' main reason for needing care could be another condition, but the individuals also were living with Alzheimer's or other dementia.

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

Created from data from the Behavioral Risk Factor Surveillance System Survey.[443]

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

*Table includes caregivers age 18 and older.

†Combination of coronary heart disease and stroke.

Created from data from the Behavioral Risk Factor Surveillance System survey.[443]

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.[577, 578] For example, spouses of hospitalized care recipients with 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).[579] In addition, caregivers who perceived higher strain due to care responsibilities were at higher risk for death than caregivers who perceive little or no strain.[580] In contrast, a longitudinal analysis of the Health and Retirement Study found that dementia caregivers were less likely to die than non-caregivers of similar age over a 12-year period. These results are consistent with a protective effect of dementia care, at least as it pertains to mortality.[577] 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.[581]

Caregiver Employment and Finances

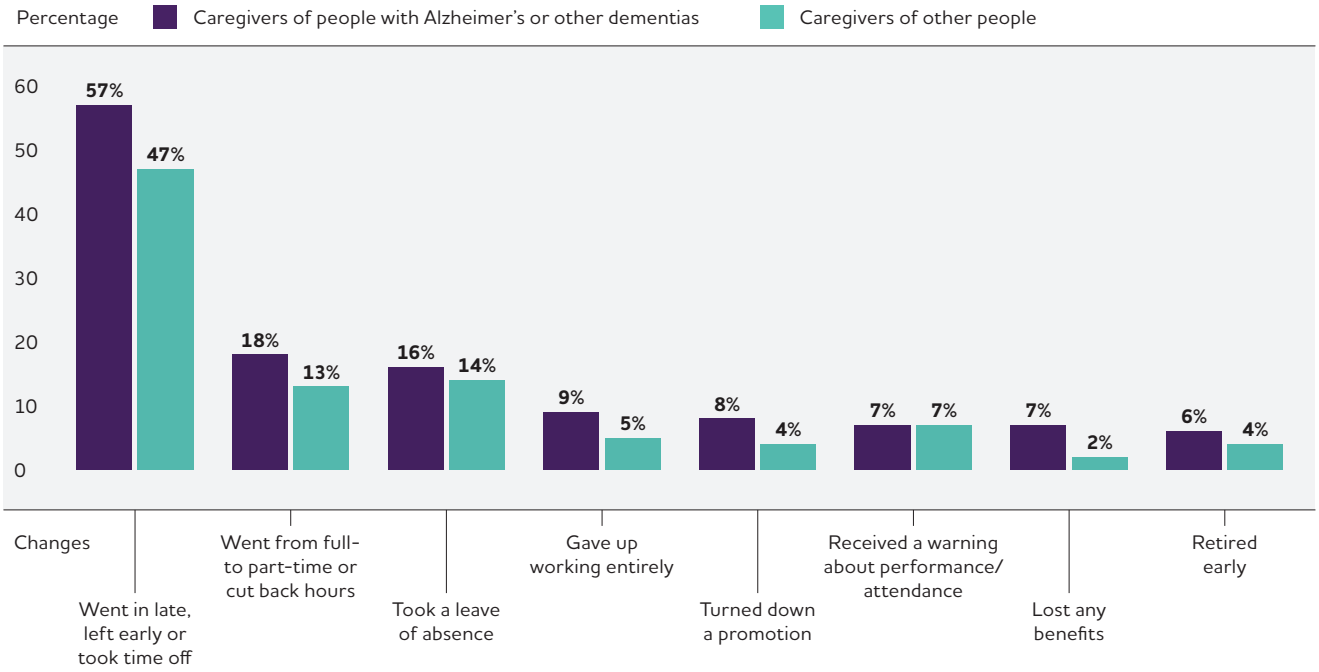
Six in 10 caregivers of people with Alzheimer's or another dementia were employed or had been employed in the prior year while providing care.[442] These individuals worked an average of 35 hours per week while caregiving.[442] Among people who were employed in the past year while providing care to someone 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. In particular, adult daughters with less than a high school degree are most likely to reduce work hours when compared with other 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.[442] 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.[448] In addition, caregivers living with a family member with dementia pay for 64% of total care costs (e.g., total health care spending and out-of-pocket costs) incurred during their relatives' last seven years of life.[582]

In 2021, it was estimated that dementia caregivers bore nearly twice the average out-of-pocket costs of non-dementia caregivers ($12,388 versus $6,667).[431, 583] 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.[584, 585] National survey data among "care contributors" (or, 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) revealed that 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.[513] Due to care responsibilities, 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.[513]

One in 5 caregivers of people with Alzheimer's or other dementias (22%) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia, compared with 9% of caregivers of people without dementia.[442]

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.[442]

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 entry for the person with dementia, exacerbated behavioral and psychological challenges in the person with dementia, and increased likelihood of someone with dementia being abused.[586] 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.[587] In addition, care recipients with dementia whose caregivers indicate greater distress are also more likely to experience hospitalization.[587, 588] A synthesis of available qualitative studies found that "personhood," or the extent to which others value, support and establish meaningful relationships with someone with dementia, is enhanced through personal interactions with family, friends, other people with dementia and professional caregivers as well as through opportunities for ongoing engagement in social and occupational activities/roles.[589] Some meta-analyses suggest that care coordination/case management and psychoeducational and multi-component programs delivered to dementia caregivers may improve important care recipient outcomes, including improvements in behavior, mood and quality of life and delayed institutionalization. However, effects sizes are small.[590]

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.[511, 591]

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

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.,[511] Gaugler et al.[591] and Walter and Pinquart.[603]

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.[592] 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.[593] A prior report examined randomized, controlled studies of caregiver interventions and identified 44 interventions that benefited individuals with dementia as well as caregivers, and more such interventions are emerging each year.[594-599] 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,[600] 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.[590, 601-605] 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.[606]

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.[607-609] 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).[610-613] In one example, researchers utilized an "agile implementation" process to more rapidly select, locate, 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.[614] 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),[615-623] while others have disseminated evidence-based dementia care

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.[657-667] 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.[668] For these reasons the pandemic has created a crisis for dementia caregivers.[657, 669, 670]

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.[671] 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.[672, 673] 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.[674] Adult day programs and other community-based services in many states were interrupted or closed.[675] These and other factors shaped by the COVID-19 pandemic have caused emotional distress and other negative outcomes among caregivers.[623, 676] 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.[676] 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.[677, 678]

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 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.[679] 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.[680-683] In studies 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.[673, 684] 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.[673] There is also evidence of racial and gender 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.[456] 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 reduce distress.[685, 686] In a survey, women dementia caregivers were more likely to indicate needs related to carrying out caregiving responsibilities during the pandemic, whereas men indicated more needs for health and social resources. Men were also more likely to report psychological distress.[687]

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.[688] The Alzheimer's Association also provided regularly updated guidance for dementia caregivers and professional care providers as the pandemic unfolded. 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.[689, 690] Concerns remain, however, about the "digital divide" facing caregivers who do not have reliable broadband access or do not regularly use the internet.

interventions into community-based programs and health care systems.[610, 624, 625] Dissemination efforts, such as *Best Practice Caregiving*, have attempted to provide tools and resources to providers and others to facilitate the implementation of successful interventions into community-based organizations, health care systems and other "real-world" settings.[626]

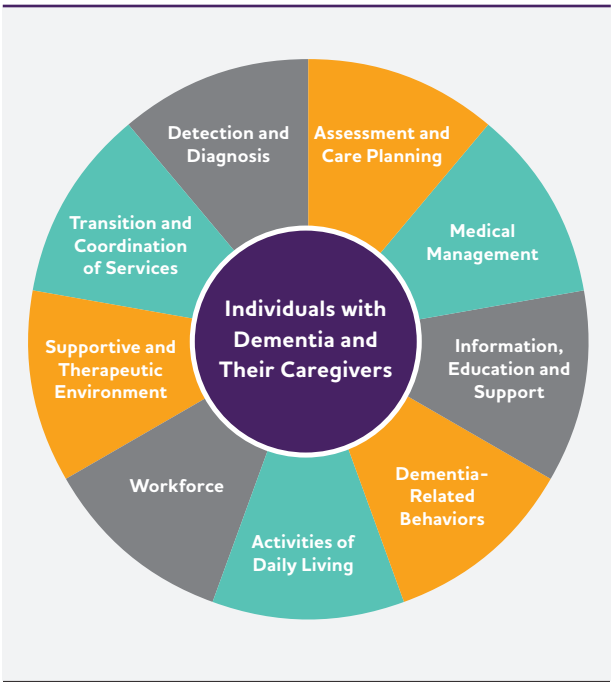
Because caregivers and the settings in which they provide care are diverse, more studies are required to define which interventions are most effective for specific situations and how these interventions are successful.[627-631] Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.[632-637] 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.[462, 638-646] Additional research on interventions focused on disease stages is also required, as is research 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.[439, 647, 648]

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 universities/centers 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 on dementia to disseminate best practices and tools to local, tribal and state public health organizations throughout the United States; one of those Centers focuses on dementia caregiving.

The Alzheimer's Association has also undertaken several efforts to improve dementia care interventions and services. Its dementia care practice recommendations[649] 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.[589, 650] Frameworks such as the Alzheimer's

Figure **12**

Person-Centered Care Delivery



Created from data from the Alzheimer's Association.[649]

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.[651, 652] 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 and their caregivers.

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).[499] 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.[653] 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).[654] The need to bridge this impending "family care gap" and other dementia caregiving challenges and concerns through new policies, services and research is a growing public health concern.[655, 656]

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. It 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.[691]

On July 31, 2023, the Centers for Medicare & Medicaid Services (CMS) announced that beginning July 2024 it will support the Guiding an Improved Dementia Experience (GUIDE) Model until 2032. The GUIDE Model features the provision of comprehensive dementia care coordination and management, caregiver education and support, and respite services. Individuals living with dementia and their caregivers will also have access to a 24/7 support line. The GUIDE Model is unique in that it incentivizes providers to incorporate both the person with dementia *and* the caregiver (or caregivers) into the collaborative, multidisciplinary service approach. Critically, CMS will include policies to ensure that underserved communities have equal access to GUIDE Model services to address disparities in access to and quality of dementia care.[692]

Workforce

More than 1 million additional direct care workers will be needed between 2021 and 2031 — 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 more members of the paid workforce to be knowledgeable and skillful about working with a diverse population of people living with dementia as well as with their families.[693, 694]

A dementia-capable workforce addresses the full arc of care — from identifying a concern to screening, detecting and diagnosing within clinical settings, to treating, monitoring and caring for those living with these diseases in residential or home and community-based settings. 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; members of the direct care workforce, including personal care aides, home health aides and nursing assistants; and the broader community-based workforce who interact with the public and help meet the needs of people living with dementia, such as police officers, bank tellers, librarians, hairdressers, bus drivers and others.

Screening, Detecting and Diagnosing Workforce

Improving dementia screening, detection and diagnosis is a high priority.[267, 695-697] A recent study of Medicare beneficiaries found that only about 8% of expected mild cognitive impairment (MCI) cases are diagnosed on average, suggesting there may be as many as 8 million people with undiagnosed MCI (acknowledging that not all individuals with MCI develop dementia; see Overview, page 4).[271, 698] Among over 200,000 clinicians and practices surveyed, only 0.1% had diagnosis rates within the expected range, likely due to limited expertise and confidence and other factors discussed on the following pages.[271] See the Special Report from *2022 Alzheimer's Disease Facts and Figures* that examines consumers' and primary care physicians' perspectives on awareness, diagnosis and treatment of MCI, including MCI due to Alzheimer's disease.[697]

With early detection of cognitive impairment comes opportunities for individuals and their families to plan for future care and to participate in clinical trials or be treated with FDA-approved disease-modifying therapies. Suboptimal detection and diagnosis of dementia, conversely, reduces the ability of individuals and their families to make informed decisions, access appropriate medical care, create financial and legal plans, and pursue services and support. Timely and accurate detection is particularly important considering that dementia is progressive. While more evidence is needed to support screening of asymptomatic individuals,[699] it is generally accepted that clinically significant cognitive concerns that arise in the primary care setting should be followed by an evaluation for cognitive impairment using a standardized and validated assessment.[700-702] See the Special Report from *2019 Alzheimer's Disease Facts and Figures* that explores the state of cognitive assessment in the primary care setting and identifies potential solutions for existing barriers to widespread adoption of assessment in primary care settings.[267]

Health care professionals who are involved in screening for, detecting, and/or diagnosing Alzheimer's and other dementias include PCPs (e.g., family medicine and internal medicine physicians), advanced practice clinicians (e.g., 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. However, limited skill and confidence in diagnosing dementia,[703, 704] time constraints among PCPs during routine office visits[705, 706] and a widespread shortage of geriatricians and other specialists has resulted in delayed screening, detection and diagnosis of Alzheimer's disease and other dementias.

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

Primary Care Physicians

PCPs are most likely to make the initial diagnosis of dementia.[707, 708] A study of Medicare beneficiaries found that 85% of people living with dementia were diagnosed by providers who do not specialize in dementia (e.g., PCP, emergency medicine physician, nurse practitioner, clinical psychologist). Among the remaining 15% diagnosed by a provider who specializes in dementia, 47% were diagnosed by a psychiatrist, including geriatric psychiatrists and neuropsychiatrists, 44% by a neurologist and 9% by a geriatrician.[709]

PCPs are well-situated to detect dementia because they often have long-standing relationships with patients and may witness clinical manifestations of cognitive decline — both overt functional and communication changes and subtle signs, such as irregularities in medication or appointment adherence, loss of control of chronic disease, weight loss, or increase in emergency room visits or hospitalizations. Even though the vast majority of initial dementia diagnoses are made by PCPs, studies have found that diagnosis is delayed until moderate or advanced stages in 50% or more patients with Alzheimer's,[710, 711] with greater delays among individuals from racial and ethnic minority groups.[712-715] It is important to reiterate that many people living with dementia never receive a diagnosis in the primary care setting (see Prevalence section). During these delays or lack of diagnosis, people living with dementia could otherwise have been enrolled in potentially life-changing clinical trials of new treatments, begun taking currently approved treatments, receiving emotional support through a support group of others living with dementia, and started planning for financial, caregiving and accommodation changes they may experience as their condition progresses.

If a person shows signs of cognitive impairment during a routine doctor's visit, Medicare covers a separate visit to assess the person's cognitive function and develop a care plan.[716, 717] As of January 1, 2024, Medicare reimbursed approximately $268 to physicians and other eligible billing practitioners for providing a comprehensive clinical visit that results in a written care plan (current procedural terminology code 99483; rate may be geographically adjusted).[716, 718-720] Although screening is now a reimbursable service by Medicare,[716] PCPs experience numerous barriers to detecting cognitive impairment and diagnosing dementia.[267] For instance, commonly used cognitive assessments take time and training to administer, interpret, document and follow up on, which makes them hard to use in a busy practice setting.[704, 721] Furthermore, the next steps following detection can be seen as a barrier as many PCPs report low confidence disclosing a dementia diagnosis and providing post-diagnostic care.[704, 722] Even if dementia is diagnosed, providers sometimes wait to disclose this information to the patient due to diagnostic uncertainty, time constraints, stigma and fear of causing emotional distress. The U.S. Government Accountability Office (GAO) found that use of the cognitive assessment and care plan service in traditional fee-for-service Medicare tripled from 2018 through 2022. However, use of the service was relatively low among Medicare beneficiaries diagnosed with a cognitive impairment; GAO estimated that in 2021, the most recent year of data available, only 2.4% of beneficiaries with a dementia diagnosis received the service through traditional Medicare.[723]

Among PCPs surveyed by the Alzheimer's Association in 2019, nearly 40% reported that they were "never" or "only sometimes" comfortable making a diagnosis of Alzheimer's or another dementia.[703] 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 specialists; however, most PCPs (55%) reported that there were not enough specialists (e.g., geriatricians) in their area to meet the demand.[703] See the Special Report from *2020 Alzheimer's Disease Facts and Figures* that examines the gaps and projected shortages in specialty care for Alzheimer's and other dementias.[724]

Geriatricians and Other Specialists

There is a particular need for geriatricians to screen for, detect, and diagnose possible dementia. Geriatricians are family physicians or board-certified internists who are specially trained to evaluate and manage the unique health care needs and treatment preferences of older adults.

Up to 30% of people age 65 and older are estimated to need a geriatrician.[725] There were approximately 5,170 to 7,454 geriatricians in the United States in 2021, depending on the source of the estimate,[726, 727] indicating a sizable and potentially consequential shortage relative to need. Indeed, the National Center for Health Workforce Analysis (NCHWA) determined that there was already a shortage of geriatricians a decade ago,[728] and the projected increase in demand for geriatricians by 2050 is expected to far exceed the supply in every region of the United States.[725, 728, 729]

Table 13 shows state-by-state projections for the number of geriatricians needed in 2050, using December 2021 data from IQVIA as a starting point.[727] If things continue at the current pace, 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. 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.[725]

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 and older 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 age 65 and older who are projected to need geriatrician care in 2050.

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.[730, 731] For instance, 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.[703] Another indicator of the growing shortage of geriatricians is that, in 2023, there were 411 geriatric medicine fellowship positions available, but more than half (234) went unfilled.[732]

The shortage of specialists extends to neurologists as well. The National Center for Health Workforce Analysis (NCHWA) projected that there will be a shortfall of neurologists by 2025, but suggested that the growing number of physician assistants in neurology could help address this workforce gap.[733] Twenty 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.[734]

The shortage of geriatricians and other relevant specialists has been attributed to a combination of factors, including growth in demand due to population aging; a smaller percentage of working aged adults; 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.[735, 736] Many of these factors are modifiable and must be addressed in order to increase the number of providers available to provide specialized dementia diagnosis and care. Moreover, beyond increasing the supply of dementia specialists, geriatric care principles should be integrated across all health care professionals' educational curricula to ensure widespread delivery of age-friendly care.

Medical Treatment and Care Team Workforce

As well as screening for, detecting and diagnosing dementia, PCPs are responsible for managing treatment for people living with dementia.[737] Even so, dementia care is inadequately covered in health care training programs, both in curricula and in opportunities for clinical practice.[738]

Advanced practice providers, including physician assistants and nurse practitioners, 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 licensed in the United States, up from 91,000 in 2010, but less than 1% had a certification in gerontology, 6.1% had a certification in gerontology acute care, and 8.9% had a certification in gerontology primary care.[739, 740] Also, less than 700 geriatric psychiatrists were certified by the American Board of Psychiatry and Neurology (ABPN) in the last decade (from 2012 to 2020)[741] and over half of geriatric psychiatrists certified by the ABPN are concentrated in just seven states (2015).[742]

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),[743] 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 provide therapeutic services to people living with dementia and their caregivers.

Specialization in caring for older adults, however, remains limited across these occupational groups as well. For instance, a survey of Masters of Social Work students who

Table **14**

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

State	Number in 2020 and Projected Number Needed in 2030		Percentage Increase
	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 Central: Long-Term Occupational Projections (2020-2030). Available at: https://www.projectionscentral.org/Projections/LongTerm. Accessed January 17, 2024.

graduated from 2017 to 2019 found that only 4.2% were specializing in aging or gerontology.[744] Despite these low percentages, between 20% to 48% of social work students have high interest in working with older adults.[745-749] Since the social work profession has a broad scope, student interest may focus on social problems rather than age-based populations.[750] Other reports indicate that less than 1% of registered nurses are certified in geriatrics[751, 752] and only 1.2% of psychologists specialize in geropsychology.[753]

Collaborative Workforce Models for Dementia Care Management

Several decades of research supports the value of collaborative primary care models that bring different health professionals together, such as social workers, registered nurses and non-clinical care managers, in addition to physicians and advanced practice providers, to care for people living with dementia.[754, 755] Researchers and practitioners have identified eight essential elements of comprehensive dementia care to improve outcomes and lower costs: treatment of related conditions, coordination of care, continuous monitoring and assessment, ongoing care plan, psychosocial interventions, self-management, caregiver support and medication management.[756] These collaborative and comprehensive 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.[755, 757, 758]

As one collaborative dementia care example, the Alzheimer's and Dementia Care (ADC) Program is a health systems-based model in which clinical providers with extensive training in dementia care, known as dementia care specialists (DCSs), co-manage care with the PCP. DCSs provide comprehensive care addressing medical, behavioral and social aspects of dementia through the development of care plans tailored to the needs and goals of each patient living with dementia and their caregiver. In this co-management model, the PCP is responsible for the patient's primary care needs but shares responsibility for the dementia-related aspects of care with the DCS, including reviewing and providing input on the dementia care plan. The care plan is then implemented by a team, led by the DCS, that includes family members, other health professionals and community-based organizations.[625] This model was found to reduce nursing home admissions for participating Medicare beneficiaries. The findings were $601 per patient per quarter ($2,404 per year) in savings, while the cost of running the program was $317 per patient per quarter ($1,268 per year), for a net savings of $284 per patient per quarter ($1,136 per year) for Medicare.[759]

As a second example, the Care Ecosystem — a collaborative, 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 and lower total cost of care compared with usual care.[760, 761] A non-academic health care delivery organization which adopted the Care Ecosystem found that the model can be successfully implemented and integrated into purely clinical settings.[762] With regard to cost savings, participation in the Care Ecosystem reduced the total cost of care by $3,290 from 1 to 6 months post-enrollment and by $3,027 from 7 to 12 months post-enrollment, corresponding to a mean monthly cost reduction of $526 across 12 months.[761] An implementation toolkit for the Care Ecosystem is publicly available at: https://memory.ucsf.edu/sites/memory.ucsf.edu/files/wysiwyg/CareEcosystemToolkit.pdf.[763]

As further evidence of the cost-saving potential of collaborative dementia care team models, an interprofessional memory care clinic called the Healthy Aging Brain Center 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.[761] 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. See a description of the new Guiding an Improved Dementia Experience (GUIDE) Model in the Caregiving section on page 57 and later in the Workforce section on page 69 to learn more about efforts to disseminate collaborative dementia care widely.

Direct Care Workforce

The largest segment of the workforce that supports people living with dementia is the direct care workforce.[764] 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.[765] 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).[766, 767]

Beyond these distinct tasks, direct care workers play a broader role in promoting nutrition, exercise, functional ability, social engagement and emotional well-being for those living with dementia. With training in active listening, empathic response and other relevant skills, direct care workers can reduce social isolation, provide emotional support and, with additional training, help administer nonpharmacological treatments — such as music and pet therapy and person-centered bathing — to prevent or reduce distress associated with dementia.[768-771]

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.[772] Across settings, they also provide care to individuals returning from a hospital stay and can help reduce the risk of readmission, as well as assist with end-of-life care transitions.[773-776] Thanks to their daily caregiving role, direct care workers are well-placed to observe and report changes of status to clinical colleagues, 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.[777, 778] Research suggests that with enhanced dementia-specific training, direct care workers may also play a role in reducing inappropriate antipsychotic prescribing for individuals living with dementia in nursing homes.[779]

Between 2012 and 2022, the number of direct care workers increased from 3.2 million to 4.8 million due to growing demand for long-term care.[765] Looking ahead, just over 1 million additional direct care workers will be needed between 2021 and 2031 — more new workers than in any other single occupation in the United States.[765] 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.[780]

This projected growth in the direct care workforce is seen across the country. As shown in Table 14, page 63, 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. (Unlike the national workforce projections, updated state-specific projections will not be available until mid-2024.) 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 sizable, these employment projections fall short of true workforce demand, as they do not account for the additional workers who will be needed through the "gray market," meaning private-pay, usually unreported employment arrangements. One study using a nationally representative sample of adults found that nearly a third of people who arrange paid care for an aging adult or person living with dementia rely on the gray market (rather than a home care agency or other formal care provider).[781]

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 — with an estimated median rate of 77% annually for direct care workers providing home care[782] and 99% for nursing assistants in nursing homes[783] — and recruitment and retention are long-standing challenges.[784-786] In turn, instability in the workforce and understaffing across care settings can lead to stress, injury and burnout among direct care workers, thereby further contributing to turnover while also compromising care access and quality.[787, 788]

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 (that marginalize this workforce composed predominantly of women and people of color),[765] as well as ageism and disablism (toward the individuals receiving care and, by extension, those providing it).[789] According to the most recent national data available, the median wage for direct care workers is just $15.43 per hour and, due to low wages and the high prevalence of part-time positions, median annual earnings are less than $24,000.[765] Research shows that, despite their complex and critical role in supporting the health and well-being 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.[790]

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 (although many states have set higher training requirements).[786] Care for individuals 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. With regards to dementia-specific training, a 2015 review found that only 13 states had established dementia care training requirements for direct care workers who provide in-home

Impact of COVID-19 on the Workforce

The COVID-19 pandemic has had a significant and enduring 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 living with Alzheimer's disease and other dementias.[816]

At the onset of the pandemic, the number of people employed in health care fell from 16.2 to 14.9 million, an unprecedented decrease of more than 8%.[817, 818] As of October 2023, the number of people employed in the health sector was 3.9% higher than in February 2020, compared with 2.9% higher in all other sectors — but health sector employment still remained below expected levels (i.e., there were nearly 482,000 fewer jobs in October 2023 than would have been expected without the pandemic).[817, 818] 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 and direct care workforce shortages remain acute.[817] As of October 2023, employment was nearly 10% lower in nursing homes and 1.3% lower in assisted living and continuing care retirement communities than in February 2020.[817, 818]

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, more than 1.7 million COVID-19 cases had been confirmed among nursing home staff as of October 2023 and over 3,000 nursing home staff had died from the disease.[819]

Working during the COVID-19 pandemic has also taken a significant emotional and psychological toll on the health care workforce.[820–822] 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."[823] A systematic review of research published in the first year of the pandemic found evidence for increased levels of burnout, emotional exhaustion, depersonalization and compassion fatigue among health care workers, with nurses, women and those working directly with COVID-19 patients most impacted.[824] One survey of nearly 21,000 U.S. health care workers in 2020 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.[825] Researchers are now assessing these outcomes over time; one example is the longitudinal COVID-19 Study of Healthcare and Support Personnel (CHAMPS), which aims to document the effects of the pandemic on the long-term physical and mental health of the health care workforce.[826] Participants were recruited for the initial CHAMPS study in 2020–2021 and, if they consented to be recontacted, were surveyed at six months' follow-up and will be surveyed annually thereafter.

The workforce employed by home and community-based services who assist community-dwelling older adults, including people living with dementia and their caregivers, such as those in adult day programs or who deliver congregate meals, developed new strategies to provide services and programming to maintain safety, improve socialization and reduce isolation and loneliness during lockdown periods. These strategies included providing home-delivered groceries or grab-and-go meals; facilitating virtual and remote socialization activities; engaging in vaccine education and distribution; and deploying technology, digital literacy and device support,[827–829] with many of these remote and virtual activities still ongoing.

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 significant.[830] Given the preexisting shortages among different segments of this workforce, the longer-term impact of this crisis on workforce recruitment and retention — as well as on individual health and well-being — must be closely monitored.[826]

care. According to the same review, 44 states and the District of Columbia had 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.[791] 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 (the most recent available year of occupation-specific data on injuries in nursing homes).[765] These data reflect the impact of the COVID-19 pandemic on this workforce — as COVID-19 was classified as a "workplace injury"[792] — as well as long-standing occupational risks.[793] 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.[794]

Dementia-Friendly Initiatives and the Community-Based Workforce

The term "dementia-friendly" has become increasingly common to describe initiatives to make local communities, environments and health and social systems more supportive of people living with dementia and their caregivers.[795] Work on dementia-friendly communities began in Japan as early as 2004, with a nationwide campaign to better understand dementia and build supportive community networks, which inspired growth of the movement worldwide.[796] In the U.S., the Dementia-Friendly America (DFA) initiative launched in 2015 and was described as a first-of-its-kind national effort that was announced at the White House Conference on Aging.[797] DFA was built on the leadership of ACT on Alzheimer's, a community-led initiative in Minnesota that began in 2013.[798] There are other ever-evolving dementia-friendly efforts as well that encompass a range of settings and contexts, including dementia-friendly care for people living in hospitals;[799-801] dementia-friendly design for nursing homes, senior centers, and similar settings;[802-804] and dementia-friendly neighborhood efforts to improve quality of life for local residents.[805, 806] Research is still needed on the effectiveness of these various dementia-friendly efforts.

To support people living with dementia in their homes and communities, as well as their family caregivers, greater dementia-related knowledge, skills and competencies are needed in the workforce beyond health care. For instance, dementia gatekeeper programs have had some success identifying and supporting people with dementia by training postal workers, bank tellers, ministers and other personnel to identify signs of cognitive impairment in older adults and provide appropriate direction to services.[807] Additional workforces that play a role in creating dementia-friendly environments include librarians who provide supportive services and programming;[808] architects and others who design floor plans, landscapes, soundscapes and sonic environments;[802, 809] adult protective service workers who handle elder abuse cases;[810, 811] police officers and law enforcement agencies that interact with the public;[812, 813] and hairdressers,[814] bus drivers and building superintendents among others.[815]

Looking to the Future

In 2020, the American Public Health Association (APHA) identified "strengthening the dementia care workforce" as a public health priority.[831] "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 four emergent areas that will strengthen the dementia care workforce into the future.

Health Care Workforce Development

First, the health care workforce must expand overall 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 21).[832] More PCPs, geriatricians, physician assistants, nurse practitioners, psychologists, therapists, social workers, direct care workers, other health care workers and community-based workers who are specifically trained in caring for people living with dementia will be critically needed in the years ahead.

One important effort to build the health care 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.[833] The goals of this program are to educate and train the health care workforce to provide value-based care for older adults in integrated geriatrics and primary care models and to deliver community-based programs that improve health outcomes for older adults. One particular goal for the GWEPs is to provide dementia training to a broad range of health care professionals, educators, individuals and families.

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.

In 2023, the National Institute on Aging funded the National Dementia Workforce Study (NDWS) under the leadership of a team of experts in survey research, health workforce research, and clinical care of people living with dementia. The NDWS will build a data infrastructure to inform efforts to strengthen the workforce of clinicians and other care providers required by the growing population of people living with dementia in the United States.[834]

Dementia Training and Specialization

Targeted dementia training and specialization among PCPs and across the health care workforce is also needed,[835, 836] including training to address PCPs' lack of confidence in diagnosing dementia and communicating that diagnosis, as discussed earlier. Training in cultural and linguistic competency is also needed to help the dementia care workforce better support individuals from diverse populations, including individuals from various racial and ethnic and sexual and gender minority groups. Moreover, language-concordant and culturally tailored resources and referrals are important for overcoming misunderstandings, biases, misdiagnoses and related disparities experienced by people of color and other individuals in minority populations who are living with dementia and by their families.[837-842]

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 providers participating in the program reported making changes in their delivery of dementia care due to the program and 87% reported higher job satisfaction.[843]

Another burgeoning program is Dementia Care Aware, a state-wide program in California that equips PCPs with information and tools to successfully administer cognitive health assessments and determine appropriate next steps for patients.[844] Once they have completed the online training, PCPs can receive $29 for providing an annual screening for cognitive impairment (current procedural terminology code 1494F) for California Medicaid patients who are fee-for-service and do not have Medicare.[845] If the initial screening leads to concerns regarding cognitive impairment, providers can receive $246 for conducting a cognitive assessment and providing care plan services (current procedural terminology code 99483) for California Medicaid patients (Medicare reimburses approximately $266).[716, 845, 846]

The Gerontological Society of America's Kickstart, Assess, Evaluate, Refer (KAER) model provides another example of how to expand the workforce to better detect and manage dementia.[847] Among other strategies, this model suggests that non-clinical office staff are well-positioned to participate in the primary care team's efforts to detect cognitive impairment. Receptionists or schedulers, for example, can take note when patients miss their appointments, show up at the wrong time, defer to family members while completing paperwork or answering questions, or have difficulty following care plans.

Nurse practitioners, physician assistants and other care providers can also play a greater role in dementia care delivery, particularly for rural and underserved communities.[743, 848] 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 recording changes to clinical team members; and educating and supporting family members.[849]

Furthermore, as new therapies for Alzheimer's and other dementias develop, the composition and size of the dementia care workforce must continue to evolve. For example, the U.S. Food and Drug Administration recently approved two drugs 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 amyloid-related imaging abnormalities (ARIA, for more information, see the Overview, page 4). 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 treatments, as those who do not experience improvements in cognitive skills and the ability to perform ADLs may be advised to discontinue treatment.

Many people living with dementia move to a nursing home or other group home setting because there are inadequate community-based services and supports in their local area.[850] To create dementia-friendly communities that support people to age in place, it will be important to also bolster the dementia knowledge and skills of the broader community-based workforce — such as postal workers, bank tellers, ministers, church leaders, librarians, police officers, building superintendents, bus drivers and hair dressers.[483, 624, 807, 808, 812-815] For instance, financial advisors

are on the frontline with their clients. Research conducted by Bank of America found that Alzheimer's dementia was the most feared condition in later life among the bank's clients across all ages and genders. Given this insight, Bank of America created training programs for their financial advisors on both Alzheimer's dementia and caregiving.[851]

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.[758, 852, 853] One development in this area is that since 2017 Medicare reimburses 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.[854] 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 other professionals such as social workers and psychologists as billing entities.

Another development in the area of payment models is the nationwide voluntary GUIDE (Guiding an Improved Dementia Experience) Model, announced by CMS in 2023.[692, 855] Through the GUIDE Model, participating organizations will offer dementia care programs that provide ongoing, longitudinal care and support for dually eligible Medicare and Medicaid people living with dementia and their caregivers, through an interdisciplinary team. Each team must include a knowledgeable and skilled care navigator to help people living with dementia and their caregivers access clinical and non-clinical services and supports, such as person-centered assessments and care plans, care coordination, caregiver training and education, meals and transportation through community-based organizations, and 24/7 access to a support line. CMS will test an alternative payment for participating organizations, who must be Medicare Part B enrolled providers/suppliers and eligible to bill for Medicare Physician Fee Schedule services. To address racial health disparities and inequities in dementia care, CMS will actively seek out safety-net organizations that provide care to underserved communities to participate in the GUIDE Model and will provide financial and technical supports to ensure they can develop their infrastructure, improve their workforce and care delivery capabilities, and participate successfully.[855]

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.[856, 857] The challenge will be to sustain these investments into the future, as the need for direct care services continues to escalate.

Technology to Augment Dementia Care Delivery

Major advances in technology are optimizing 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.[858]

Technology is also helping to improve access to care for people living with dementia, especially for those in rural areas and those with mobility limitations.[859] A randomized clinical trial of more than 1,500 individuals across urban and rural areas in California, Nebraska and Iowa to determine whether telephone- and internet-based delivery of the Care Ecosystem (a program described on page 64) was effective in improving outcomes found that the intervention resulted in better quality of life, reduced emergency department visits and decreased caregiver depression and burden.[760] 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.[860] 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.[861] 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 2020 report of *The Lancet* Commission on dementia prevention, intervention, and care concluded, "technology is not a replacement for human contact."[107]

Use and Costs of Health Care, Long-Term Care and Hospice

In 2024, health and long-term care costs for people living with Alzheimer's and other dementias are projected to reach $360 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.[862]

Total payments in 2024 (in 2024 dollars) for all individuals with Alzheimer's or other dementias are estimated at $360 billion (Figure 13), not including the value of informal caregiving that is described in the Caregiving section. Medicare and Medicaid are expected to cover $231 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 $91 billion, or 25% of total payments.[A11] For the remainder of this section, costs are reported in 2023 dollars unless otherwise indicated.[A12] 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 the pandemic will have on these patterns.

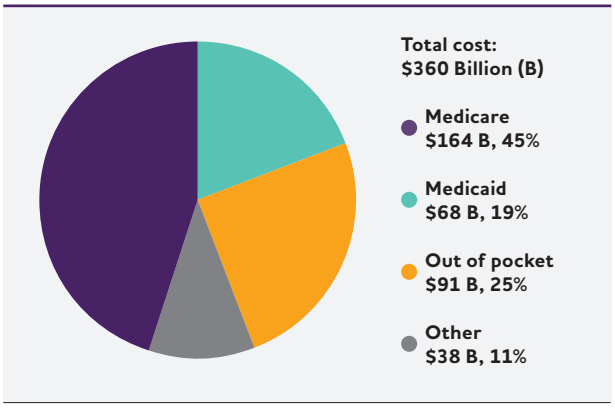
Total Cost of Health Care and Long-Term Care

Table 15 reports the average annual per-person payments for health care and long-term care services for fee-for-service (i.e., traditional) Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias based on data from the 2018 Medicare Current Beneficiary Survey.[A13] Unless otherwise noted, cost and health care utilization statistics for Medicare beneficiaries are for fee-for-service Medicare and do not represent those enrolled in Medicare Advantage.[A14] Total per-person health care and long-term care payments in 2023 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 ($43,644 per person for those with dementia compared with $14,660 per person for those without dementia).[A15, 863]

Despite having 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 other sources of support. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid $10,289 out of pocket annually for health care and long-term care services not covered by other sources (Table 15).[863] 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 ($240,046 in 2023 dollars) in the last seven years of life, compared with $102,955 in 2016 dollars ($121,674 in 2023 dollars) for those without dementia.[582] However, informal caregiving costs in the last seven years of life 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 [$273,862 versus $196,075 in 2023 dollars]), due to Medicaid covering the cost of nursing home care for many individuals.[582]

Figure **13**

Distribution of Aggregate Costs of Care by Payment Source for Americans Age 65 and Older with Alzheimer's or Other Dementias, 2024*



*Data are in 2024 dollars. "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. Before rounding, Medicare and Medicaid costs totaled $231 billion.

Created from data from the Lewin Model.[A11]

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 2023 Dollars*

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$21,973	$7,918
Medicaid	6,771	305
Uncompensated	192	240
Health maintenance organization	1,952	2,292
Private insurance	1,534	958
Other payer	933	419
Out of pocket	10,289	2,529
All sources	43,644	14,660

*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.[863]

Researchers have evaluated the additional or "incremental" health care, residential long-term care and family caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics).[431, 862, 864, 865] 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 expenses, Medicare and Medicaid expenditures, and informal caregiving is estimated at $321,780 per person with Alzheimer's dementia in 2015 dollars ($394,683 in 2023 dollars), more than twice the estimated lifetime cost for individuals without Alzheimer's dementia).[430] 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 having a longer duration of illness and spending more time in a nursing home.[866] Annual incremental health care and nursing home costs for individuals with dementia (that is, the additional costs compared with those for individuals without dementia) are estimated at $28,501 per person per year in 2010 dollars ($40,209 in 2023 dollars).[A16, 862] 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.[430, 866, 867] The incremental five-year cost of care for dementia paid by Medicare has been estimated at nearly $16,000 per person in 2017 dollars ($22,573 in 2023 dollars), with nearly half of these costs incurred in the year after diagnosis and 87% concentrated in the two years after diagnosis.[867, 868] However, these estimates include costs for individuals who died during the five-year time period, and the incremental costs for individuals who survive at least five years after diagnosis are even higher.

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. Although incremental Medicare expenditures peak in the year after diagnosis and decrease in the subsequent four years, out-of-pocket costs have been shown to increase over time, from $3,104 in the first two years after diagnosis to $3,730 in years three to four after diagnosis, to $3,934 in years seven to eight after diagnosis (in 2017 dollars; $3,579, $4,300 and $4,535 in 2023 dollars).[869] 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.[870, 871] Furthermore, individuals with Alzheimer's dementia spend 12% of their annual income on out-of-pocket health care services on average, excluding nursing home and informal care, compared with 7% for individuals without Alzheimer's dementia.[871]

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.[872] 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 ($404,949 and $258,175, respectively, in 2023 dollars), a difference of 57%.[873] 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

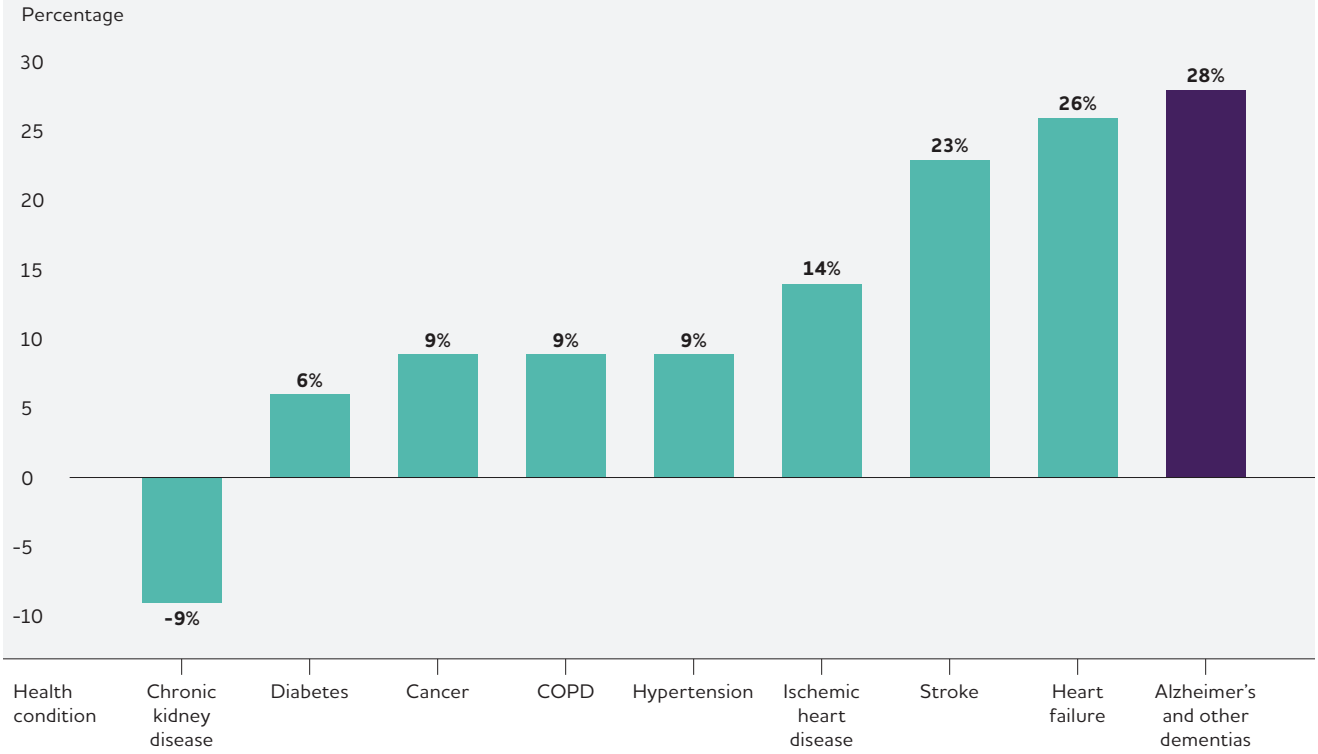
Unadjusted data (that is, data that don't account for differences in the characteristics of people with versus without Alzheimer's or other dementias) show that people with Alzheimer's or other dementias have more than twice as many hospital stays per year as other older people.[413] Moreover, the use 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, 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 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.[413] 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.[413] 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%),[874] 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.[875] Among Medicare beneficiaries with Alzheimer's or other dementias, 22% of hospital stays are followed by a readmission within 30 days.[854] Although not directly comparable, one study of a random sample of Medicare beneficiaries from 50 U.S. hospital referral regions found an overall 30-day readmission rate of 18%.[876] The proportion of hospital stays followed by a readmission within 30 days remained relatively constant between 2008 and 2018 for Medicare beneficiaries with Alzheimer's and related dementias (23% in 2008 versus 22% in 2018).[877]
- Emergency department. There were nearly 1.8 million emergency department visits for people with Alzheimer's in 2021, representing 1.3% of all emergency department visits.[878] 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.[877] 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.[876] Emergency department visits for people with Alzheimer's or other dementias increased 22% between 2008 and 2018 (from 1,265 to 1,545 per 1,000 Medicare beneficiaries), exceeding the increases in emergency department visits for individuals with cancer, ischemic heart disease and heart failure among others (Figure 14, page 74).[877] One group of researchers found that individuals with Alzheimer's or another dementia seen in the emergency department are more likely to be admitted to the hospital or a nursing home from the emergency department than Medicare beneficiaries without Alzheimer's or other dementias.[879] Additionally, individuals with Alzheimer's or other dementias are more likely to have at least one hospitalization, have at least one subsequent emergency department 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 around-the-clock personal care services.[880] There are 188 skilled nursing facility stays covered by Medicare per 1,000 Medicare 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 high.[413] 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.[413]

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 the U.S. Centers for Medicare & Medicaid Services.[877]

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).[A13, 863]

Use and Costs of Health Care Services by State

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (see Table 17, page 77). 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 ranged from $21,711 in North Dakota to $44,310 in California.[877]

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.[882] 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 for people diagnosed with Alzheimer's or other dementias in the year prior to diagnosis,[883-885] although the sources of increased spending differed across these studies. In one study, the largest differences in spending were due to inpatient and post-acute care,[884] while in another study the differences in spending were primarily due to outpatient care, home care and medical day services, with only a small difference in inpatient care costs.[885]

Three groups of researchers have found that spending in the year after diagnosis was substantially higher than spending for individuals who had similar characteristics but did not have Alzheimer's or dementia, by amounts ranging from $7,264 in 2017 dollars ($8,374 in 2023 dollars)[867] based on individuals with fee-for-service (i.e., traditional) Medicare coverage, to $17,852 in additional costs in 2014 dollars ($22,473 in 2023 dollars)[884] based on another group of individuals with fee-for-service Medicare. One group of researchers, however, did not find a significant difference in health care spending in the two years after diagnosis.[886]

Researchers have found that health care costs remain higher beyond the year after diagnosis. One group of researchers also found the incremental costs remained higher in the second year after diagnosis ($7,327 in additional costs in 2014 dollars [$9,224 in 2023 dollars]).[884] 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 from costs for individuals without the diagnosis in the fifth year after diagnosis.[867] Incremental costs decreased over time, from $4,241 in 2014 dollars ($4,889 in 2023 dollars) in year two to $1,302 ($1,501 in 2023 dollars) in year four, although costs increase dramatically in the last year and last month of life.[854] Researchers have also found a similar increase in health care costs in the year before and two years after a diagnosis of MCI, although the additional costs were lower than costs for Alzheimer's.[884] 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.[887] 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.[413] Additionally, they are more likely than those without dementia to have other chronic conditions.[413] 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.[413] Table 18, page 78, reports the percentage of people with Alzheimer's or other dementias who had certain coexisting medical conditions. In 2019, 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.[413]

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 2023 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	$7,580	$2,836
Outpatient events	2,867	2,256
Medical provider*	5,956	3,844
Skilled nursing facility	3,890	392
Nursing home	14,347	555
Hospice	2,321	136
Home health care	1,857	274
Prescription medications†	5,016	3,383

*"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.[A13, 863]

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[A13], page 79, 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.[A13, 413] Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except physician care. Additionally, one group of researchers found that individuals with dementia and behavioral disturbances, such as agitation, had more psychiatric comorbidities than individuals with dementia but without behavioral disturbances.[888] 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. 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.[863] Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.[863] 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 and other home-based services. 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. Home health agencies provide the majority of home health care services.[889] Fee-for-service 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; however, Medicare Advantage plans (Medicare Part C) are allowed to offer these services as supplemental benefits, and 17% offered in-home support services as a benefit in 2023.[890] Additionally, 16% of Medicare Advantage plans offered food and produce as a supplemental benefit, and 8% offered meals beyond a limited basis.[890] These supplemental benefits are more common in Medicare Advantage Special Needs Plans (i.e., plans that are designed for Medicare enrollees with specific needs, such as individuals with a chronic condition, individuals who are also enrolled in Medicaid, and institutionalized enrollees), with 41% offering a food and produce benefit, 31% offering in-home support services, and 15% offering meals beyond a limited basis. Although Medicare Advantage Special Needs Plans can be offered to individuals with specific chronic conditions, including dementia, only 8% of Special Needs Plan enrollees are enrolled in a plan for chronic or disabling conditions, representing less than 1% of all Medicare enrollees.[891, 892] The vast majority of Special Needs Plan enrollees are individuals also enrolled in Medicaid (i.e., Dual Eligible Special Needs Plan enrollees).

  Thirty-six percent of individuals using home health services have Alzheimer's or other dementias.[893] Of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias, 26% 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[413] and they 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.[889] Receipt of home health services after hospital discharge has been shown to increase the likelihood of remaining in the community for at least 30 days after hospital discharge, with greater benefits from longer durations of home health care.[894]
- Adult day services. The fourth most common chronic condition in participants using adult day services is Alzheimer's disease or other dementias, and 25% of individuals using adult day services have Alzheimer's or other dementias.[893] Fourteen percent of adult day service centers in the United States specialized in caring for individuals with Alzheimer's disease or other dementias in 2020, up from 10% in 2016.[893, 895] 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.[895]
- Residential care facilities. Forty-two percent of residents in residential care facilities (that is, housing that includes services to assist with everyday activities, such as personal care, medication management and meals), including assisted living facilities, had Alzheimer's or other dementias in 2020, up from 34% in 2016.[893, 896] Sixty-one percent of residential care communities are small (four to 25 beds),[896] 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 47% in facilities with 26 to 50 beds and

Table **17**

Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2023 Dollars by Medicare Beneficiaries with Alzheimer's or Other Dementias

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	$27,369
Alaska	1,477.6	19.3	29,741
Arizona	1,436.2	20.2	29,111
Arkansas	1,530.4	21.5	27,092
California	1,496.3	23.0	44,310
Colorado	1,424.8	18.6	28,687
Connecticut	1,635.4	22.7	34,958
Delaware	1,577.6	21.5	32,413
District of Columbia	1,741.7	25.6	39,378
Florida	1,551.9	23.0	34,142
Georgia	1,573.2	22.5	30,219
Hawaii	1,248.2	16.0	24,763
Idaho	1,389.2	17.2	25,057
Illinois	1,624.1	23.4	34,637
Indiana	1,514.2	21.3	30,219
Iowa	1,310.7	18.0	22,067
Kansas	1,406.0	19.8	27,260
Kentucky	1,735.5	23.1	29,473
Louisiana	1,709.9	22.1	34,182
Maine	1,665.3	19.7	24,119
Maryland	1,524.1	24.4	37,381
Massachusetts	1,668.4	24.7	36,930
Michigan	1,691.4	24.0	30,432
Minnesota	1,467.1	21.6	27,300
Mississippi	1,714.8	22.1	31,174
Missouri	1,529.6	22.6	28,324
Montana	1,328.6	16.6	$22,360
Nebraska	1,153.6	18.7	25,345
Nevada	1,711.5	25.8	41,608
New Hampshire	1,493.8	20.4	28,663
New Jersey	1,456.3	22.9	38,795
New Mexico	1,563.7	20.6	27,258
New York	1,461.3	23.7	43,601
North Carolina	1,683.8	21.5	27,591
North Dakota	1,173.3	18.4	21,711
Ohio	1,618.7	22.5	30,661
Oklahoma	1,692.1	21.6	32,584
Oregon	1,628.4	18.7	25,470
Pennsylvania	1,470.5	22.0	31,112
Rhode Island	1,605.6	23.2	30,782
South Carolina	1,558.2	21.7	29,657
South Dakota	1,200.1	18.6	24,776
Tennessee	1,548.6	21.5	28,543
Texas	1,549.1	22.1	37,679
Utah	1,194.3	16.7	26,233
Vermont	1,528.4	19.6	23,329
Virginia	1,621.7	21.6	27,870
Washington	1,479.2	18.6	25,274
West Virginia	1,811.4	24.1	29,240
Wisconsin	1,519.9	19.9	27,335
Wyoming	1,445.9	17.4	25,452

*Based on Medicare utilization for 2018.
†Based on Medicare utilization for 2022.

Created from data from the U.S. Centers for Medicare & Medicaid Services.[877, 881]

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.[413]

39% in facilities with more than 50 beds).[897] Fifty-eight percent of residential care facilities offer activities or programs for residents with Alzheimer's or other dementias.[898] 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.[896]

- Nursing home care. Overall, 46% of nursing home residents have Alzheimer's or other dementias,[893] 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.[863] 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.[415]
- 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. Thirteen percent of nursing homes and 21% of assisted living and other residential care communities have a dementia special care unit.[893] Less than 1% (0.3%) of nursing homes and 11% of other residential care facilities exclusively provide care to individuals with dementia.

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

Overall, 70% of spending for long-term care services and supports is covered by public payers, including Medicaid (43%), Medicare (21%) and other public payers (6%), and 15% is covered by out-of-pocket payments, including direct payments and deductibles and copayments for services covered by another payment source (15%). Private insurance covers only 9% of long-term services and supports.[899] 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 2020, home- and community-based services represented the majority (62%) of the $199.4 billion spent by Medicaid on long-term care services and supports, with institutional care representing the remaining 38%.[900] However, there is substantial variation across states in spending on home- and community-based services, ranging from 32% of total Medicaid long-term care services and supports in Mississippi to 84% of long-term care services and supports spending in Oregon, despite evidence demonstrating that Medicaid spending on these services reduces costs.[901] Thirty-three percent of Medicaid's total expenditures cover expenditures related to long-term care services and supports.

Between 2010 and 2020, Medicaid spending on home- and community-based services increased from 48% to 62% of total long-term services and supports expenditures.[900] Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias increased dramatically between 2004 and 2018.[902] 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.[902] 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 research that has evaluated both the costs and benefits of enhanced home support interventions is scant.[903, 904]

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 2023 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	**$28,418**	$8,462	$4,815	$4,362	$2,446	$3,799
Without A/D	**17,976**	6,119	4,718	1,353	938	421
Diabetes						
With A/D	**28,064**	8,478	4,834	4,417	2,353	3,263
Without A/D	**15,729**	5,213	4,225	1,227	827	291
Congestive heart failure						
With A/D	**31,433**	9,739	5,006	4,928	2,595	4,305
Without A/D	**25,415**	9,331	5,478	2,385	1,557	798
Chronic kidney disease						
With A/D	**29,151**	8,799	4,791	4,552	2,471	3,857
Without A/D	**19,733**	6,720	4,918	1,626	1,082	470
Chronic obstructive pulmonary disease						
With A/D	**31,981**	10,055	5,226	5,088	2,622	3,842
Without A/D	**22,785**	8,086	5,372	1,898	1,298	708
Stroke						
With A/D	**30,551**	9,154	5,069	4,854	2,584	3,753
Without A/D	**22,196**	7,310	5,226	2,334	1,548	652
Cancer						
With A/D	**28,352**	8,127	5,200	4,076	2,429	3,760
Without A/D	**18,330**	5,056	5,717	1,032	732	732

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[A13,413]

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%).[905] 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,[906] although the number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.[907]

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 $5,341 in 2023 dollars).[908] 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 $5,143 in 2023 dollars) and increased 5.4% annually on average between 2017 and 2021.
- Adult day centers. The median cost of adult day services was $78 per day in 2021 ($85 in 2023 dollars).[908] The cost of adult day 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 ($4,921 and $59,047 in 2023 dollars).[908] 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 ($325 and $118,536 in 2023 dollars), and the average cost of a semi-private room was $260 per day, or $94,900 per year ($284 and $103,769 in 2023 dollars).[908] 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.

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.[909]
- 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 ($92,188 in 2023 dollars), and 25% had savings of $9,650 or less in 2019 dollars ($10,610 in 2023 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.[910] In a 2022 survey of adults about the affordability of long-term care, less than one-third (31%) of adults age 65 and older reported being very confident that they would have the financial resources to pay for necessary care as they age.[911] Additionally, of adults age 50 and older, nearly two-thirds reported feeling anxious about being able to afford nursing home or assisted living care, if they should need it. Although individuals from lower income households were more likely to report feeling anxious about the affordability of long-term care (77% with household incomes less than $40,000 reported being anxious about the affordability of long-term care), nearly half of individuals from households with incomes $90,000 or greater also reported being anxious about the affordability (in 2022 dollars; $41,553 and $93,495, respectively, in 2023 dollars).

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.[921]

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 (i.e., stays more than 90 days) in a nursing home.[912]

Results from a 2022 survey about the affordability of long-term care revealed that 23% of adults believed that Medicare would cover the cost of nursing home care, and 28% were not sure who would pay for nursing home care. Even more concerning, 45% of individuals age 65 and older believed that Medicare would cover the cost of nursing home care.[911] 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.[913] 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.[914] 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 $204 per day in coinsurance.[915]

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.[916] 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.[917] Individuals are eligible to receive Medicare Part A at no cost if they have worked and paid Medicare taxes for at least 10 years (i.e., have a sufficient earnings history) or a spouse, parent or child has a sufficient earnings history. Medicare Part B (medical insurance) is a voluntary program that requires enrollees to pay a monthly premium. Medicare Advantage Plans, also referred to as Medicare Part C, are becoming more common, with more than one-half (51%) of Medicare beneficiaries enrolled in this type of plan in 2023.[918] Advantage Plans are privately offered Medicare plans that combine Medicare Parts A and B and often also include prescription drug coverage (Medicare Part D).[919]

While Medicare is a federal program, Medicaid is a joint federal and state program, and benefits vary state-to-state.[920] Individuals with low incomes and/or low resources may qualify for Medicaid 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/.

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.[899] Industry reports estimate that between 5.3 and 7.1 million Americans had private long-term care insurance in 2020-2021.[922, 923] However, the long-term care insurance market is shrinking, with only 57,000 new policies sold in 2018, compared with 754,000 in 2002.[924] The average premium for a long-term care insurance policy was $155 per month in 2021.[923] The private long-term care insurance market 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 60% in 2020.[913, 922] Cognitive conditions are the most common final diagnosis for long-term care insurance claims lasting more than one year, representing 49% of claims; however, these conditions are third most common (16%) for insurance claims lasting one year or less, after cancer and musculoskeletal conditions (31% and 25% of claims, respectively).[922] Medicare Advantage plans are allowed to provide supplemental benefits, such as adult day care, caregiver support and in-home support services for chronically ill beneficiaries. However, only 17% of individual plans offered in-home support services as a benefit in 2023, and these supplemental benefits are unlikely to offset a substantial portion of long-term care costs.[890]

To address the dearth of private long-term care insurance options and the high out-of-pocket cost of long-term care services, Washington became the first state in the country to create a public state-operated long-term care insurance program.[925] The Long-Term Services and Supports Trust Program (WA Cares Fund) is funded by a payroll tax on employees of 58 cents per $100 earned that began 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.[926] Although other states have contemplated implementing a long-term care tax to fund long-term care insurance, none have yet passed legislation.[927]

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.[928] To receive coverage, beneficiaries must have low incomes. Beneficiaries with financial resources above Medicaid thresholds may spend down their assets and income to become eligible for coverage. Once enrolled, most nursing home residents with 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.[863] 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 ($6,771) were 22 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($305) (see Table 15, page 72).[863] 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 $68 billion in 2024.[A11] Actual and estimated state-by-state Medicaid spending for people with Alzheimer's or other dementias in 2020 and 2025 (in 2020 dollars) is included in Table 20, page 83.

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.[929] Based on data from the National Hospice Survey for 2008 to 2011, nearly all hospices (99%) cared for

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.

Created from data from the Lewin Model.[A11]

individuals with dementia, and 67% of hospices had residents with a primary diagnosis of dementia.[930] 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.[931]

Nearly two-thirds (63%) of Medicare decedents (i.e., people who have died) with Alzheimer's or other dementias used hospice in their last six months of life in 2017 compared with 36% of Medicare decedents without Alzheimer's or other dementias.[932] 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 85).[931] Alzheimer's or other dementias are even more common in individuals receiving hospice care when taking into account the disease as a coexisting or secondary condition. Forty-five percent of hospice users in 2020 had a diagnosis of Alzheimer's or other dementias.[893]

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.[930] 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 dementia 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 six months.[933] 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 six months in hospice than patients with other diagnoses.[930, 933] 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.[934] For hospice enrollments of at least six months, hospice providers are required to assess individuals every 60 days, beginning at six 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; however, more research is needed to understand the implications of these policies for individuals with dementia in hospice.[935, 936]

Overall, 12.2% of Medicare beneficiaries with Alzheimer's had at least one hospice claim in 2018, compared with 1.4% of Medicare beneficiaries without the disease, translating into per-person hospice payments (for all beneficiaries, regardless of whether they used any hospice services) of $2,321 for individuals with Alzheimer's compared with $136 for all other Medicare beneficiaries.[863] 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 2024, the routine home care rates are $218.33 per day for days 1 to 60 and $172.35 per day for days 61 and beyond.[935]

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 six months of life decreased from 15.3 to 11.8 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.[932] 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.[937] 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.[938] Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life[939] and more likely to receive regular treatment for pain.[940] 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.[941] Despite the important role of end-of-life care for individuals with Alzheimer's, differences in hospice use by race/ethnicity exist. One group of researchers found substantially smaller proportions of Black and Hispanic Medicare beneficiaries with dementia enrolled in hospice in the last six months of life compared with White Medicare beneficiaries with dementia (38% and 43% versus 51% respectively).[942] Furthermore, larger proportions of Black and Hispanic beneficiaries with dementia had at least one emergency department visit (80% and 77% respectively) and at least one hospitalization (77% for both groups) compared with White beneficiaries with dementia (71% and 68% respectively) in the last six months of life.[942] Black and Hispanic beneficiaries were also more likely to have an emergency department visit and/or a hospitalization after hospice enrollment.

Table **21**

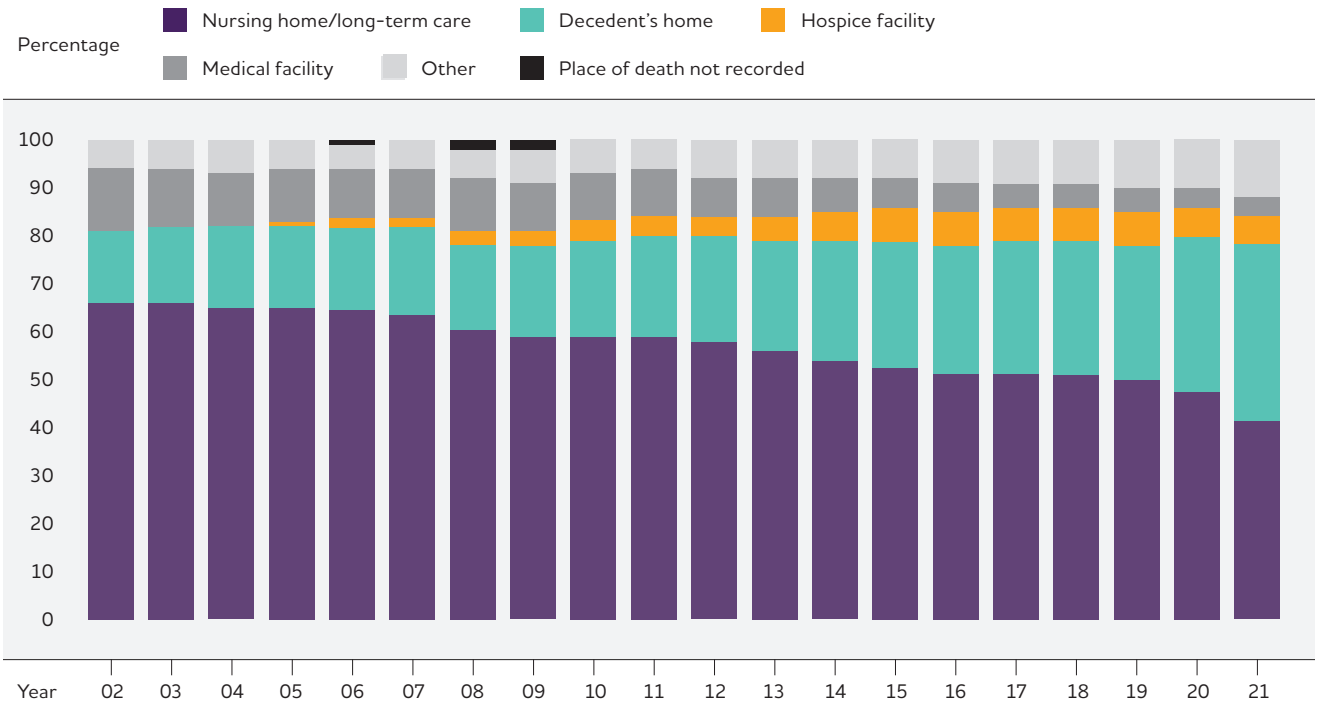
Number and Percentage of Medicare Beneficiaries Admitted to Hospice with a Primary Diagnosis of Dementia by State, 2017

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

Created from data from the U.S. Centers for Medicare & Medicaid Services.[931]

Figure **15**

Place of Death Due to Alzheimer's Disease, 2002 to 2021



Created from data from the National Center for Health Statistics.[948,949]

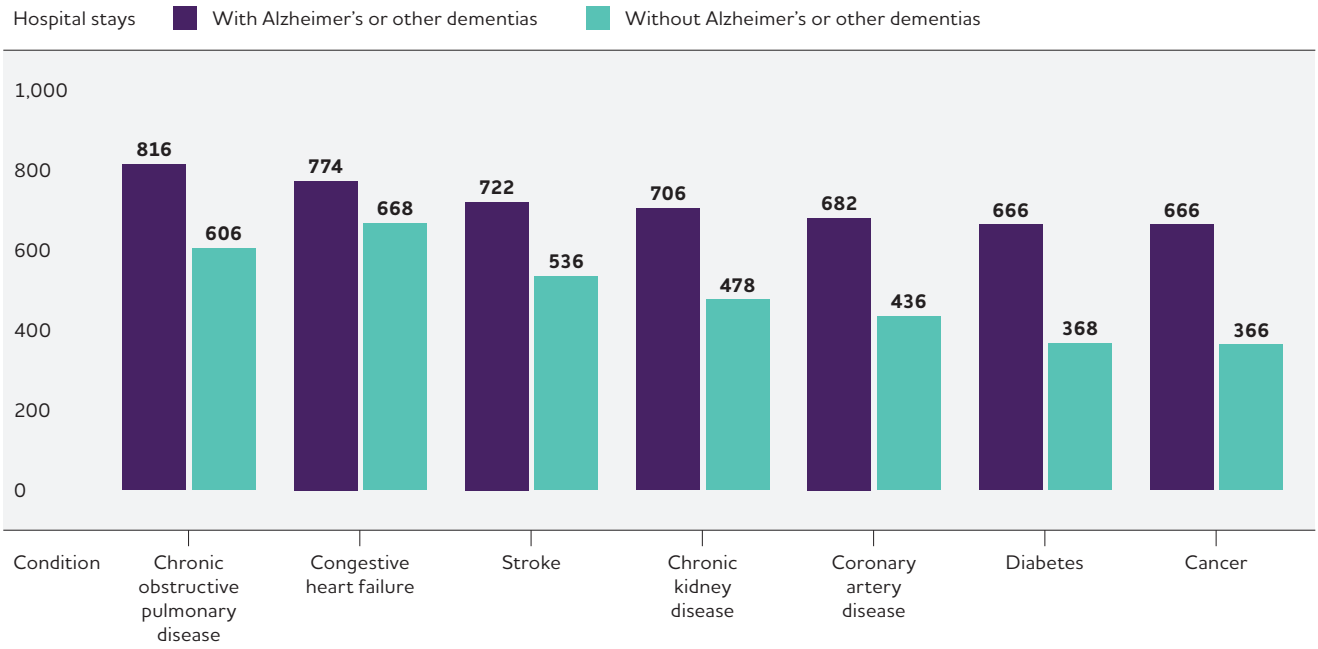
Researchers have found similar reductions in hospitalizations at the end of life for individuals receiving palliative care. For nursing home residents with moderate-to-severe dementia, those who received an initial palliative care consultation between one and six months before death had significantly fewer hospitalizations and emergency department visits in the last seven and 30 days of life compared with those who did not receive palliative care.[943] 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.[943] One essential component of palliative care is 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 their own decisions). Although Medicare reimburses physicians for visits related to advance care planning, these visits rarely occur. In 2017, less than 3% of fee-for-service Medicare beneficiaries had at least one claim for advance care planning.[944] 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. Racial/ethnic disparities in the completion of advance care planning in the last six months of life are concerning. One group of researchers found that the proportion of Black and Hispanic Medicare beneficiaries with dementia with advance care planning was less than half that of White beneficiaries.[942]

Life-Sustaining Interventions at the End of Life

Life-sustaining interventions, such as mechanical ventilation, tracheostomy, tube feeding and resuscitation can be especially harmful to individuals with Alzheimer's. Although these interventions may not be consistent with patient preferences, individuals with Alzheimer's may be at greater risk for receiving these treatments. One group of researchers found that Medicare beneficiaries with advanced dementia who lived in the community were 1.8 times as likely to receive life-sustaining treatments in the last three months of life, compared with individuals without dementia living in the community.[945] 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.[946] The odds of having a feeding tube

Figure **16**

Number of 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.[413]

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. With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last three to six months of life has decreased for individuals with Alzheimer's or other dementias.[932, 937] 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.[947] However, individuals with advanced dementia are significantly more likely to receive tube feeding in the last three months of life compared with those without dementia.[945]

Place of Death for Individuals with Alzheimer's Disease
Between 2002 and 2021, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 67% to 42%, and the proportion who died in a medical facility decreased from 13% to 5%. During the same period, the proportion of individuals who died at home increased from 15% to 37% (Figure 15).[948, 949]

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 ($27,814 versus $22,306, respectively) (Table 22, page 88). 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 ($9,006 versus $5,791).[413] 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.[950] However, after adjusting for socioeconomic characteristics and functional status, total health care spending did not differ significantly among groups.

This report keeps the racial, ethnic and other population identifiers used in source documents when describing findings from specific studies.

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.[951] 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.

Use of Potentially Avoidable Health 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

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. Individuals living and working in care communities have been extremely vulnerable to COVID-19 due to the communal nature of these settings. Overall, 21% of all U.S. COVID-19 deaths occurred in either residents or staff of long-term care facilities.[961]

Through November 2021, of all people with fee-for-service Medicare coverage who were hospitalized due to COVID-19, 27% had a diagnosis of Alzheimer' disease or another dementia.[962] 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 of COVID-19.[963, 964] 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.[964] 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.[963]

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 the 20 other common chronic conditions analyzed (including chronic kidney disease, diabetes, hypertension and obesity) in 2020.[965] 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.[965]

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 2023 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Care	Home Health Care	Hospice Care
White	$22,306	$5,791	$3,725	$3,297	$1,912	$4,137
Black	27,814	9,006	4,528	4,338	1,970	2,910
Hispanic	25,729	7,836	4,298	3,763	2,371	3,416
Other	22,864	7,260	3,917	3,663	1,959	2,817

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[413]

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).[952] The total cost to Medicare of these potentially preventable hospitalizations was $4.7 billion (in 2013 dollars; $6.1 billion in 2023 dollars).[952] 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.[952] 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.[952]

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.[953] Black older adults had a substantially higher proportion of preventable hospitalizations (31%) than 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).[954] Moreover, individuals with both dementia and depression had a 70% greater risk of preventable hospitalization than those without a neuropsychiatric disorder.[954] Another group of researchers found that individuals with dementia and a caregiver with depression had 73% higher rates of emergency department use over six months than individuals with dementia and a caregiver who did not have depression.[955]

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 87).[413] 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.[956] 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 have been prevented through proactive care management in the outpatient setting.[957] 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 other chronic conditions.[958]

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 than community-residing individuals without dementia.[959] For individuals residing in a nursing home, there were no differences between those with and without dementia in the likelihood of being hospitalized or having an emergency department visit.

Health Care Delivery Models with Skilled Nursing Facilities

Changes in health care delivery and payment models, such as the integration of care across different health care settings and the structure of health care payments, may impact health care utilization for individuals with Alzheimer's disease or other dementias. 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 skilled nursing facilities that shared providers with at least one hospital were more likely to have an Alzheimer's unit, had fewer 30-day readmissions, and had more patients successfully discharged to the community. The skilled nursing facilities that maintain these relationships have modestly better outcomes,[960] 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.

Looking to the Future

Absent additional treatment breakthroughs, total annual payments for health care and long-term care for people with Alzheimer's or other dementias are projected to increase from $360 billion in 2024 to just under $1 trillion in 2050 (in 2024 dollars). This dramatic rise includes nearly three-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.[A11] 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 growth, overall health care spending trends and population aging.[966]

Potential Impact of Changing the Trajectory of Alzheimer's Disease

While there are currently no treatments approved by the U.S. Food and Drug Administration (FDA) that prevent or cure Alzheimer's disease, two drugs that change the underlying biology of Alzheimer's disease (aducanumab and lecanemab) have recently been approved. They were tested in people with confirmed beta-amyloid accumulation in the brain who were living with MCI due to Alzheimer's disease or 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. These treatments are promising for changing the course of the disease.

Although these treatments, and others on the horizon, have the potential to improve quality of life for millions of adults and their families, there are some considerations. For example, while lecanemab demonstrated clinically significant changes in cognition and function, its effects may be imperceptible to those being treated.[967] Additionally, there is an increased risk of adverse events with lecanemab and other anti-amyloid therapies, including amyloid-related imaging abnormalities with edema or effusions. Another concern is the affordability of treatment to both payers, such as Medicare, and to individuals and their families, who may bear out-of-pocket costs due to deductibles, copayments and coinsurance.[968] Additionally, the current market price of treatment is high, at $26,500 per person per year.[969, 970] Lack of affordability of Medicare supplemental insurance is also likely to widen disparities in access to treatment for Medicare enrollees with low incomes given these market prices.

From a societal perspective, the number of people potentially eligible and the total cost of these treatments is a potential concern. The Centers for Medicare & Medicaid Services covers Medicare beneficiaries diagnosed with MCI or Alzheimer's dementia, and has a physician participating in a registry for these treatments.[971] Although aducanumab and lecanemab are for individuals with mild Alzheimer's dementia and MCI due to Alzheimer's disease, the actual number of people who may be eligible is projected to be much smaller. One group of researchers applied the clinical trial eligibility criteria to a sample of adults with dementia or MCI and a positive brain amyloid PET scan and found that only 8% of the sample would meet the lecanemab clinical trial inclusion and exclusion criteria.[972]

Before the approval of aducanumab and lecanemab, several groups of researchers had estimated the health and long-term care cost implications of hypothetical interventions that either slow the onset of dementia or reduce the symptoms.[431, 973-975] One analysis assumed a treatment that delayed onset of Alzheimer's by five years 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 by 2050,[973] and another study projected a 14% reduction in total health care spending for people age 70 and older 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 by 2050.[974] 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 ($4,759 in 2023 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 ($834 in 2023 dollars).[431] However, these studies did not take into account the current market price for FDA-approved drugs.

Therapies that change 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,[975] 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 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.[976, 977] 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

Mapping a Better Future for Dementia Care Navigation

"Following a dementia diagnosis too many individuals and families are left on their own groping in the dark for services that can help them. I don't want others to go through what I did. I lost two to three years searching for answers. It was time I could have spent differently."

— Pamela, individual living with early-onset Alzheimer's disease

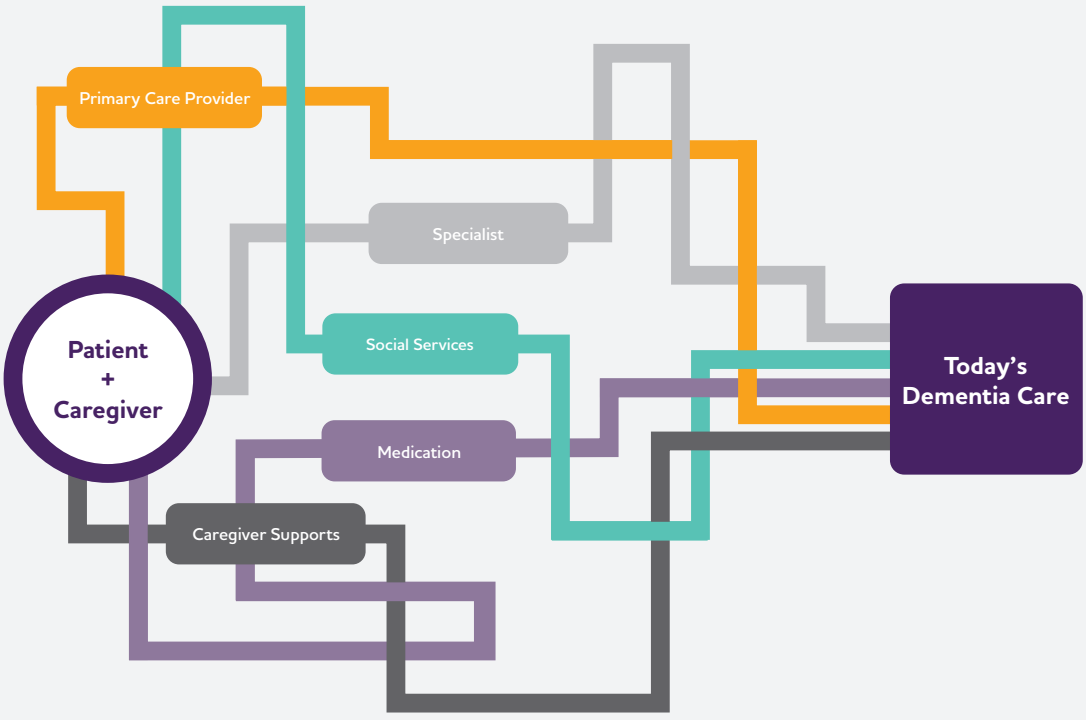
Dementia care is a complex maze encompassing interactions with primary care providers, specialists (including those involved in managing chronic conditions coexisting with cognitive issues), social services, medication management and caregiver support (Figure 17).[978]

Navigating this maze is difficult and often frustrating for people living with Alzheimer's or other dementia and their caregivers. Without a clear path forward, any roadblock or detour along the way can have considerable ramifications.

This could materialize as delayed detection, diagnosis and treatment of early-stage cognitive issues or mild cognitive impairment (MCI). For caregivers, a detour could cause them to miss valuable or necessary educational opportunities, miss connections with community-based services for respite and behavioral health support or be unable to locate resources that could help reduce their stress. Breakdowns in transitions of care between health care providers and settings limit high-quality, comprehensive and/or appropriate dementia care, as evidenced by an increase in emergency room visits and hospitalizations and decreased quality of life.[979]

Figure **17**

Today's Dementia Care[978]



Caregiver Burden and Stress Are Compounded by the Complexity of Dementia Care

Unpaid caregivers (sometimes referred to as care partners), who can be a spouse, family member or friend, provide extensive, sometimes all-encompassing care for people living with Alzheimer's or other dementia. In 2023, 11.5 million family members and other caregivers of people living with Alzheimer's or other dementia provided an estimated 18.4 billion hours of unpaid help. On average, this represents nearly 31 hours of care per caregiver per week or 1,612 hours per caregiver per year.[A8] Caregivers spend much of this time interacting with the health care system or learning more about dementia caregiving, and nearly 2 in 3 (63%) help with health or medical care.[427, 440] Daily health care activities may include scheduling appointments with health care providers, attending doctor's visits, and scheduling social and community support for themselves and the person living with dementia, such as in-home assistance, adult day programs or meal delivery. Collectively, performing these activities and the organization of care across multiple health care providers can be described as care coordination.[980, 981]

The effort expended trying to find their way through the health care system can add to the already high emotional and physical stress levels that caregivers experience. Caregivers need assistance to gather dementia care information, synthesize it and act upon it in a way that does not add to their stress level — support that primary care providers and health systems have historically been ill-equipped or unprepared to provide. (For more information on supporting people living with Alzheimer's or other dementia and the impact of unpaid caregiving, see the Caregiving section, page 42.)

Nationwide Movement to Improve Care While Reducing Strain on Caregivers

For more than a decade, the National Plan to Address Alzheimer's Disease has included goals to improve health care quality and expand support for individuals living with Alzheimer's disease or other dementia and their families.[982] Recently, the Alzheimer's Association and the Alzheimer's Impact Movement (AIM) — a separately incorporated advocacy affiliate of the Alzheimer's Association — championed critical legislation to help unravel the health care maze.[983] This legislation, the bipartisan Comprehensive Care for Alzheimer's Act, proposed a new approach to dementia care management covering care coordination and navigation, caregiver education and support, and alternative payment models for physician reimbursement.[983, 984]

In July 2023, the Centers for Medicare & Medicaid Services (CMS) announced the culmination of policy, working group and legislative efforts like the Comprehensive Care for Alzheimer's Act with the introduction of the Guiding an Improved Dementia Experience (GUIDE) Model.[985] The new model represents a pivotal opportunity to reshape and enhance dementia care in the United States.

What is GUIDE?[986]

The Guiding an Improved Dementia Experience (GUIDE) Model is an eight-year pilot program in dementia care management designed to help dementia patients and caregivers better navigate health care and social support systems to improve dementia care. Three primary aims of GUIDE are to:

- Improve quality of life for people living with dementia.
- Reduce strain on their unpaid caregivers.
- Enable people living with dementia to remain in their homes and communities.

Beginning in July 2024, health care providers who participate in GUIDE will deliver supportive services to people living with dementia, including comprehensive, person-centered assessments and care plans, care coordination and 24/7 access to a support line. They will also provide access to a care navigator to help patients and caregivers access services and support.

GUIDE acknowledges that current fee-for-service payment structures prevent many practices from implementing sustainable dementia care management programs.[984-986] To overcome this challenge, GUIDE is testing an alternative payment model (APM) to incentivize health systems and increase the likelihood that smaller practices, rural practices and inner-city health centers that traditionally do not have the financial resources of larger entities will be able to deliver this type of program.[984, 986] The APM shifts payments from a fee for individual services to a monthly per-patient payment for all services under the GUIDE Model umbrella, including those not typically reimbursed by Medicare.[984, 986]

Recognizing that some health care providers will face resource, staffing and capability constraints, a second GUIDE Model track will engage those who do not have experience offering comprehensive dementia care services. The Centers for Medicare & Medicaid Services will offer these organizations technical assistance, learning support and a preparatory pre-implementation year to facilitate their participation in the model. (For more information about GUIDE and other national strategies to support caregivers, see the Caregiving section, page 42, and the Workforce section, page 58.)

Navigators as Dementia Health Care Wayfinders

What is Care Navigation?

Care navigation is a critical process that assists patients and caregivers with various aspects of obtaining health care, such as helping them understand and overcome the complex logistics of the health care system.[987-989] The concept originated in cancer clinics in the 1990s to address the overwhelming experience cancer patients faced trying to manage their care.[989] It has since expanded to support individuals with chronic diseases, including kidney disease, diabetes and dementia.[987, 990-992]

This assistance aims to be holistic and spans both medical and nonmedical needs. On the medical side, care navigation encompasses:[988, 991]

- Scheduling appointments.
- Coordinating diagnostic testing or follow-ups.
- Providing disease education.
- Facilitating communication and referrals across clinical specialties and organizations.
- Offering insurance and benefits assistance.
- Medication management.

Beyond medical support, care navigation programs may connect patients and caregivers to nonmedical resources, such as education, social services and community support.[991]

Providing both types of navigation services underscores the importance of a comprehensive approach to health care.[991] By addressing medical and nonmedical needs, care navigation programs strive to ensure better access to health care, improve health outcomes and reduce disparities in care.[990-992]

What is Dementia Care Navigation?

Dementia care navigation shares many features of care navigation programs in other specialties. However, dementia care navigation emphasizes person-centered, empowered support throughout the dementia care journey.[990] This includes addressing nonmedical needs unique to dementia care, such as behavioral symptom management and access to community-based services and supports for individuals with dementia and their caregivers.[987, 990, 992, 993] The approach remains nimble to adapt to emerging treatments and diagnostic tests, disease progression, or other individual needs as they arise.

A key tenet of dementia care navigation is recognizing the importance of the "care dyad"— the partnership between people living with Alzheimer's disease or other dementia and their caregivers — in all aspects of dementia care.[987, 992] As described previously, caregivers are prone to information overload and may feel lost and overwhelmed as they try to find their way to quality dementia care for the person living with dementia. Dementia care navigation programs are primed to offer assistance in this area.

> "Due to high incidence, duration and medical-social complexity, dementia is an ideal candidate for patient-centric health care delivery models such as care navigation."[990]

In 2023, an expert workgroup convened by the Alzheimer's Association defined dementia care navigation as "a program that provides tailored, strengths-based support to persons living with dementia and their care partners across the illness continuum and settings to mitigate the impact of dementia through collaborative problem solving and coaching."[990]

The workgroup outlined seven essential principles for dementia care navigation, which underscore person-centered care. According to the workgroup, dementia care navigation should:[990, 993]

1. Be person- and family-centered to ensure collaboration and enhance engagement.
2. Be culturally responsive and address disparities in access to health care and support services.
3. Include well-defined roles and responsibilities for all members of the dementia care navigation team.
4. Address barriers relating to medical, legal, financial, emotional and other domains facing the person living with dementia and their care partners.
5. Provide coaching, education, and coordination in a manner that is empowering, solution-focused and strengths-based.
6. Focus on the family unit as defined by the person living with dementia.
7. Ensure processes and protocols are evidence-based.

By adhering to these principles, dementia care navigation programs can achieve more coordinated care for patients. Health systems are already finding that dementia care navigation can improve health outcomes, decrease the number of emergency room visits, lower hospital readmissions, shorten hospital stays and minimize delays in long-term care placement.[993]

What is a Care Navigator?

Care navigators are staff who guide patients and caregivers through the health care system and help overcome barriers that prevent them from getting the care they need.[991, 995] As integral members of interprofessional care teams, care navigators are connectors — liaising, communicating and facilitating medical and nonmedical needs.[991, 992, 995] Unlike other care team members, their work spans various settings, making them crucial touchpoints for care coordination.[991, 992] Common synonyms for "care navigator" include patient navigator, care consultant and care team coordinator.[990, 992, 995]

Prioritizing Person-Centered Care in Dementia Care Navigation[990, 992-994]

Person-centered care is the foundation of quality dementia care. It challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs. Instead, person-centered care stresses knowing the person living with dementia, including their values, beliefs, interests, abilities, likes and dislikes — both past and present. A person-centered approach to care assures the individual living with dementia and their caregivers that health professionals know the person, understand the person's unique needs and circumstances, and put these needs at the forefront in making decisions and directing the person's care.

Anchoring dementia care navigation in the principles of person-centered care prioritizes the humanity of each individual living with dementia while also committing to a standard of care that elevates their dignity, autonomy and quality of life at every stage.

Qualifications, training and time dedicated to the care navigator role vary based on the care team structure and the health system. They range from paraprofessionals to licensed health care professionals, including nurses, physician assistants, social workers, community health workers or even former caregivers.[991] Care navigators, including dementia care navigators, frequently share the racial, ethnic or cultural background of those they assist, enhancing the delivery of culturally competent care and building stronger patient-navigator relationships.[987, 991]

Dementia care navigators work with care dyads, but evidence suggests that the primary recipients of navigation services are caregivers.[987]In addition to the typical navigation services, dementia caregivers frequently look to care navigators for emotional support.[987] Through these interactions, navigators and caregivers establish trusting, long-term relationships.

In summary, care navigators are pivotal in helping patients and caregivers find their way through an increasingly intricate dementia care landscape.

Awareness and Understanding of Dementia Care Navigation: Caregiver and Health Care Workforce Surveys

This year's Special Report takes a deeper look into how dementia caregivers interact with the health care system and how the non-physician health care workforce currently employs care navigation. To better understand these aspects of dementia care, the Alzheimer's Association commissioned Versta Research to conduct surveys of (1) current or recent caregivers of adults age 50 or older with cognitive issues (referred to in this report as dementia caregivers) and (2) health care workers who are likely to assume care navigation responsibilities in their role, including nurses, social workers, and community health workers (referred to in this report as the non-physician health care workforce).

Key Findings

Dementia Caregivers

Dementia caregivers experience difficulty and stress interacting with the health care system.

- Seven in 10 dementia caregivers (70%) report that coordinating care is stressful. More than half of caregivers (53%) said navigating health care is difficult. Two in 3 dementia caregivers (66%) also have difficulty finding resources and support for their needs.

Cost and care coordination are top stressors for dementia caregivers.

- Two in 5 caregivers (42%) cite cost as a stressor in getting care for their recipient. More than 1 in 3 caregivers report coordinating care with multiple doctors (36%), securing appointments (35%) and getting help taking a break (35%) as leading stressors in navigating care for their recipient.
- Despite these and other stressors, only half of the caregivers (51%) report ever talking with a health care professional to help address their challenges.

Care navigation is an unfamiliar term for most dementia caregivers, although many receive help akin to care navigation.

- Three in 4 dementia caregivers (75%) report little or no familiarity with the term "care navigator." Half of caregivers (50%) say they receive help with dementia health care, support and services for the care recipient from someone within their physician's office or hospital.
- Nurses (42%) and social workers (35%) most often provide navigation help to dementia caregivers.

Overwhelmingly, caregivers would welcome dementia care navigator support and believe it would benefit both the person living with dementia and the caregiver.

- More than 4 in 5 dementia caregivers (85%) say having access to a care navigator would influence their choice of dementia health care provider for the person they care for.
- Three in 5 dementia caregivers (61%) cite improvement in quality of life for their care recipient as a benefit of having a care navigator. Two in 5 caregivers (43%) believe access to a care navigator would improve the overall health of their care recipient.
- Three in 5 dementia caregivers say less stress (62%) and more peace of mind (62%) would be valuable outcomes of having a care navigator. More than half (56%) say having a care navigator could help them be better caregivers.

Top services that would be helpful to dementia caregivers include around-the-clock support, care coordination and help understanding their care recipient's condition.

- The vast majority of dementia caregivers (97%) say they would find navigation services helpful.
- Nearly 2 in 5 dementia caregivers (36%) say a 24/7 helpline would be valuable in helping navigate care for someone living with Alzheimer's or other dementia. Coordinating care and communication between different specialists (34%) and getting help in understanding their care recipient's condition (34%) are also viewed as valuable services.
- Almost 1 in 3 dementia caregivers say it would be helpful to have assistance with insurance or public benefits (32%), scheduling appointments (31%), caregiver training (31%), managing behavioral symptoms (31%), understanding the health care system (30%) and finding services to help with respite care (30%).
- The most helpful community-based resources cited to help dementia caregivers include local caregiver support groups (41%), respite programs (38%) and availability of financial resources in the community (37%).

Non-Physician Health Care Workforce

The findings below reflect the views of the non-physician health care workforce currently providing navigator-type services to patients and caregivers in addition to the other responsibilities of their role. The health care workers surveyed included medical professionals (nurse practitioners, physician assistants and registered nurses) and nonmedical professionals (health care social workers, community health workers and home health aides).

Most health care workers who provide navigator-type services are familiar with the concept of care navigation, even if that is not their focus.

- Three in 4 survey respondents (77%) are familiar with the term "care navigator." They spend roughly half their time providing navigator-type services, even if they do not refer to themselves as care navigators.
- Nearly 2 in 3 survey respondents (62%, predominantly nonmedical professionals) help people living with Alzheimer's or other dementia and caregivers understand the health care system, and more than 1 in 2 health care workers (57%) say they coordinate care and communication with specialists.
- The most frequently provided navigator services are referrals to community support services and resources (75%), helping with emotional and cultural support (68%), and screening for safety needs (66%).

Most health care workers providing navigator-type services have experience in other medical specialties, with few focusing exclusively on dementia.

- Four in 5 survey respondents (80%) have navigation experience in non-dementia medical specialties, and fewer than 1 in 10 (7%) focus primarily on offering navigator-type support and services to people living with dementia.
- Most providing navigation services (93%) feel at least somewhat knowledgeable about MCI, Alzheimer's disease and other dementia but only 1 in 3 (36%) report they are very knowledgeable.
- Nearly 9 in 10 (86%) feel knowledgeable about directing patients with dementia and caregivers to appropriate health care resources, but less than 1 in 3 (30%) feel very knowledgeable. Four in 5 (82%) feel knowledgeable about directing patients with dementia and caregivers to community resources, but only 31% say they are very knowledgeable.

Training in dementia care navigation is lacking and not standardized.

- Three in 4 health care workers providing care navigation (75%) indicate they received no formal training in dementia care navigation.
- Those who did receive training were predominantly nonmedical professionals, receiving a median of 30 hours of formal training. Medical professionals who were trained received a median of 20 hours of formal training.

Nonmedical professionals are viewed as best suited to help people with dementia and their caregivers navigate care.

- Nine in 10 health care workers offering navigation support (92%) say social workers, community health workers or home health aides are best suited to help people living with dementia and their caregivers navigate health care.

Health care workers say more can be done to help patients and families navigate dementia care but point out current barriers.

- Six in 10 survey respondents (60%) believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care.
- Nearly half surveyed (46%) say their organizations do not have a clearly defined process for care coordination and clinical pathways for patients with MCI, Alzheimer's disease or other dementia.
- More than 3 in 4 (77%) identified a lack of community-based resources as a barrier, and 44% viewed it as the greatest barrier. Seven in 10 (70%) called out current reimbursement as a barrier, with 41% saying this was the greatest barrier.
- Nearly 9 in 10 (87%) say developing alternative payment models is important in providing future care coordination for people diagnosed with dementia.

Survey Design and Research Methods

The surveys were designed to elicit in-depth responses from both dementia caregivers and the non-physician health care workforce about the current state and challenges of navigation in dementia care.

The dementia caregiver survey analyzed distinct aspects of the caregiving journey, including:

- Time spent on caregiving and top stressors.
- Challenges in navigating health care services.
- Challenges in locating or accessing community supports and services.
- Awareness of dementia care navigators and/or navigation programs.
- Which health care workers help with care navigation.
- Communication preferences for care navigation.
- Value of navigation services and community-based resources.
- Anticipated benefits and outcomes of care navigation.

The non-physician health care workforce survey covered various aspects of care navigation, including:

- Familiarity with navigator terminology.
- Focus areas for care navigation services being delivered.
- Frequency and preferred method of communication.
- Perceived value of care navigation.
- Which health care workers deliver navigation services.
- Barriers to care navigation.
- Background and training in care navigation.

Dementia Caregiver Survey

A survey of 1,533 U.S. adults who were current or recent unpaid caregivers for a relative or friend age 50 or older experiencing problems with thinking, understanding, or remembering things or who sometimes have physical problems or behavioral changes was conducted from November 20, 2023, through December 20, 2023. The sample included White (n=629), Hispanic (n=309), Black (n=308), Asian (n=206) and Native American (n=24) caregivers and caregivers who identified as belonging to other ethnic or racial groups (n=57). While Native Americans were oversampled in an attempt to get subgroup estimates, the sample size was still insufficient; thus, Native American respondents were included in the "all caregivers" grouping. Respondents were recruited via non-probability online panels used exclusively for research, with full population screening data weighted to match U.S. Census data on age, gender, income, education and race/ethnicity to ensure accurate representation of the caregiving population and to establish weighting benchmarks for demographic oversamples. The survey was offered in both English and Spanish. Differences noted in the report between racial and ethnic groups were tested and found to be statistically significant at the $p<.05$ level.

Non-Physician Health Care Workforce Survey

A survey of 1,204 U.S. health care workers was conducted from November 13, 2023, through December 6, 2023. The survey collected the views of medically-trained and nonmedically-trained professionals who perform navigation duties, regardless of whether they describe themselves as navigators or hold a formal navigator position at their organization.[A17] For brevity, medically-trained professionals are referred to as "medical professionals" and nonmedically-trained professionals as "nonmedical professionals" throughout the remainder of the report. The report refers to the combined group of medical and nonmedical professionals as "health care workers."

Medical professionals (n=708) included:

- Registered nurses (RN, n=526).
- Nurse practitioners (NP, n=145).
- Physician assistants (PA, n=46).

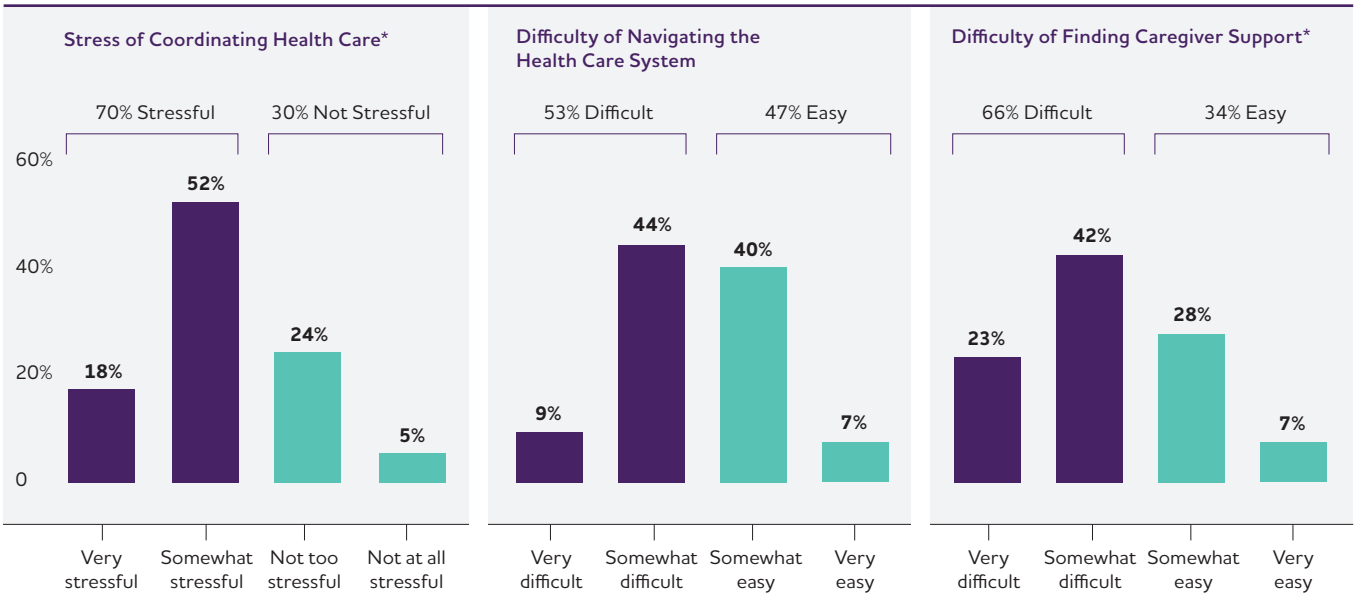
Nonmedical professionals (n=503) included:

- Social workers (MSW, n=458).
- Community health workers (CHW, n=32).
- Home health aides (HHA, n=14).

Health care workers are classified as both medical and nonmedical professionals if they indicate both types of training (e.g., RN with MSW degree). Because of this, the total of the numbers of medical and nonmedical professionals shown above exceeds 1,204. Likewise, if health care workers are classified as having more than one role in the medical or nonmedical category (e.g., community health worker and home health aide), they are included in the count for each role. As a result, the total of the specific roles in the medical and nonmedical categories exceeds the 708 and 503 shown above.

Figure **18**

Difficulties and Stressors That Caregivers Experience



*Percentages of bars may not total the percentages above due to rounding.

Dementia Caregiver Survey Results

Dementia Caregiving is a Demanding Job That Can Last for Years

People with memory and thinking problems see an average of four different doctors every year, with more than 1 in 4 (27%) seeing five or more doctors annually. Scheduling and managing doctor's visits can be time-consuming, and more than 1 in 3 dementia caregivers (35%) coordinate health care needs (communicating with doctors, taking care of insurance, getting appointments, picking up medication, etc.) at least once daily, with some caregivers saying they coordinated care several times per day.

Caregivers for people with Alzheimer's and other dementia provide approximately 26 hours of care per week. This is consistent with other reports that caregivers spend almost 31 hours per week on caregiving.[A8] Additionally, a large majority of dementia caregivers surveyed spend years providing care, with nearly 1 in 2 acting as a caregiver for one to three years and almost 1 in 3 spending four years or more as a caregiver.

Black Caregivers Report More Time on Caregiving Responsibilities Than Other Groups

The need to coordinate health care is common for dementia caregivers, and this is especially true for Black and Hispanic caregivers, who are more likely to coordinate health care at least once per day than White caregivers (43%, 45%, and 31%, respectively). This likely influences the overall time spent providing care, with Black caregivers reporting the most time at 30 hours per week followed by White caregivers (27 hours), Hispanic caregivers (25 hours) and Asian caregivers (19 hours).

Dementia Caregivers Experience Difficulty and Stress Interacting With the Health Care System and Addressing Their Own Needs

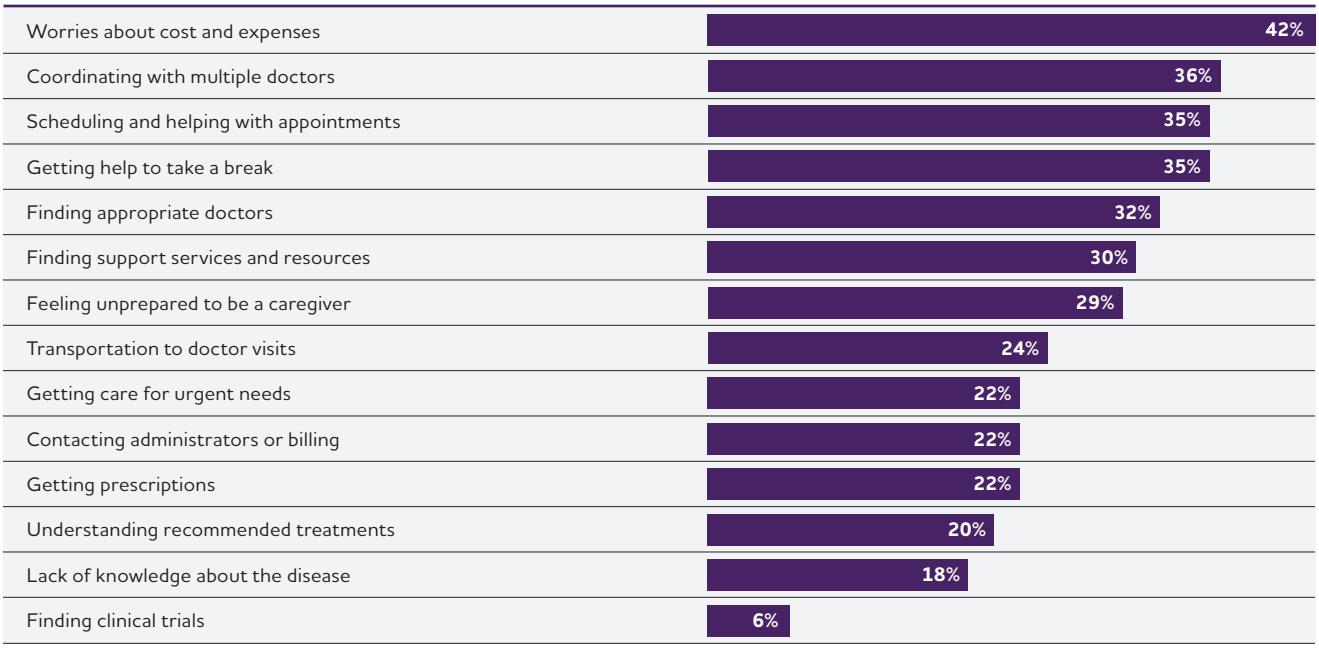
A majority of caregivers surveyed (70%) indicated that coordinating care is stressful. More than half (53%) said navigating health care for the person they care for was difficult. Finding resources and support for their needs is also a challenge for 2 in 3 caregivers (66%; Figure 18).

Black Caregivers Report Less Stress and Difficulty With Dementia Care

Black caregivers find coordinating dementia care somewhat less difficult and stressful than all other groups. Three in 5 Black caregivers (58%) reported that coordinating care was somewhat or very stressful compared with Hispanic caregivers (71%), White caregivers (72%) and Asian caregivers (76%). When asked about difficulty coordinating health care, Asian caregivers expressed the greatest challenges, with 7 in 10 (68%) indicating that they found it somewhat or very difficult (vs. Black caregivers, 37%; White caregivers, 54%; and Hispanic caregivers, 57%). Additionally, Black caregivers have less difficulty finding support for their own needs as a caregiver than other groups (52% report somewhat or very difficult vs. White caregivers, 66%; Hispanic caregivers, 70%; and Asian caregivers, 77%).

Figure **19**

Stressors When Getting Health Care for Care Recipients



Worries About Costs and Coordinating Health Care Are Top Stressors

The most often cited worry for dementia caregivers is cost (42% of caregivers), followed by the stress of coordinating with multiple doctors (36%), securing appointments (35%) and getting help taking a break (35%; Figure 19). Finding appropriate doctors (32%) rounded out the top five stressors. When viewed together, these top five stressors underscore challenges in coordinating dementia health care without greater assistance from a care navigator.

Asian caregivers report worries about costs and expenses (51%) as the top stressor, more so than other groups (Black caregivers, 37%; Hispanic caregivers, 42%; White caregivers, 41%). Asian caregivers also are more likely to report stress in finding appropriate doctors (41%) and understanding recommended treatments (30%) than other groups. Finding respite care is the top stressor for Black caregivers (39%), and concerns about cost and expenses are top of mind for Hispanic caregivers.

Despite these current stressors, only half of the dementia caregivers surveyed (51%) have ever talked with a health care professional about challenges finding their way through the health care system or asked for help with dementia care.

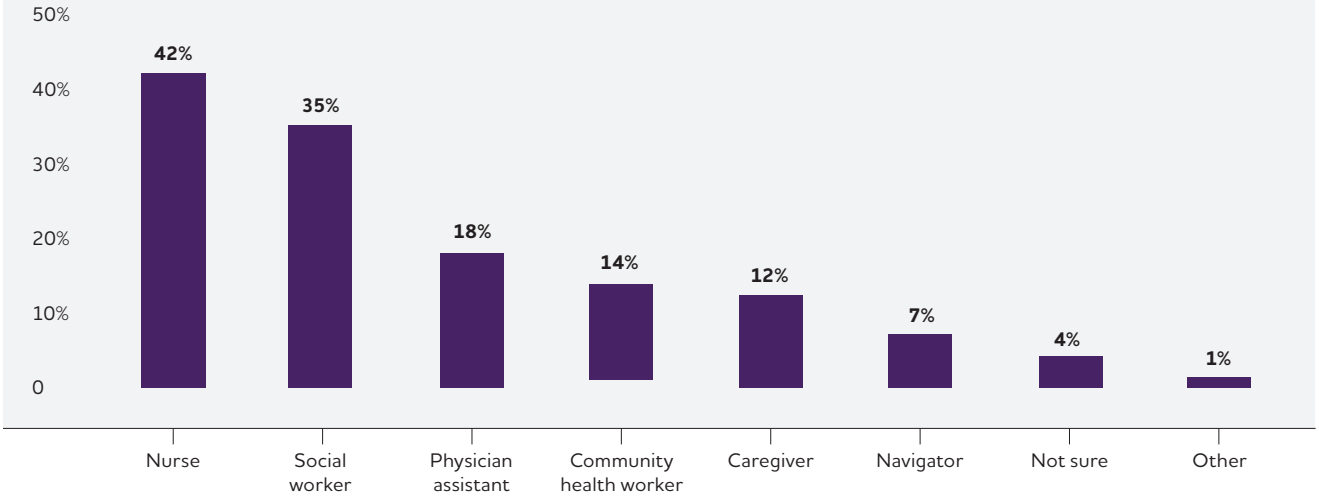
Although Largely Unfamiliar With the Term "Care Navigator," Dementia Caregivers Receive Help Navigating Care

Three in 4 dementia caregivers surveyed report little or no familiarity with the term "care navigator," with 30% saying they know very little about the term and 45% reporting they have never heard of the term. Yet half of caregivers (50%) receive help with dementia health care, support and services for the care recipient from someone within their physician's office or hospital. These health care workers may or may not be serving in a formalized navigator role. Nurses (42%) or social workers (35%) most often provide navigation help to dementia caregivers, with physician assistants (18%), community health workers (14%), other caregivers (12%) or actual care navigators (7%) providing health care guidance to a lesser degree (Figure 20).

Nearly 7 in 10 Black caregivers (68%) report receiving help navigating care. Asian caregivers (52%), Hispanic caregivers (51%), and White caregivers (47%) also report currently receiving help navigating care.

Figure **20**

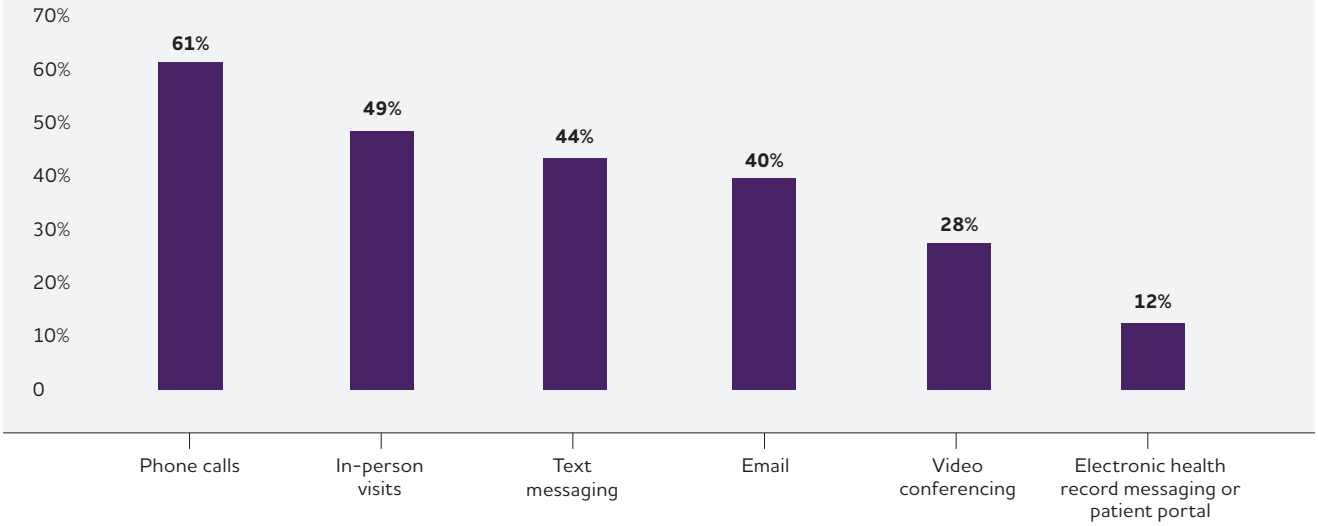
Navigator's Professional Role



When working with staff helping with care navigation, a majority of caregivers would prefer that they communicate via more traditional channels, with nearly 2 in 3 saying a phone call was best and 1 in 2 saying they desired in-person communication during a visit (Figure 21). Overall, very few caregivers wanted to communicate through electronic health record (EHR) messaging or a patient portal (12%).

Figure **21**

Preferred Channels for Communicating With a Care Navigator

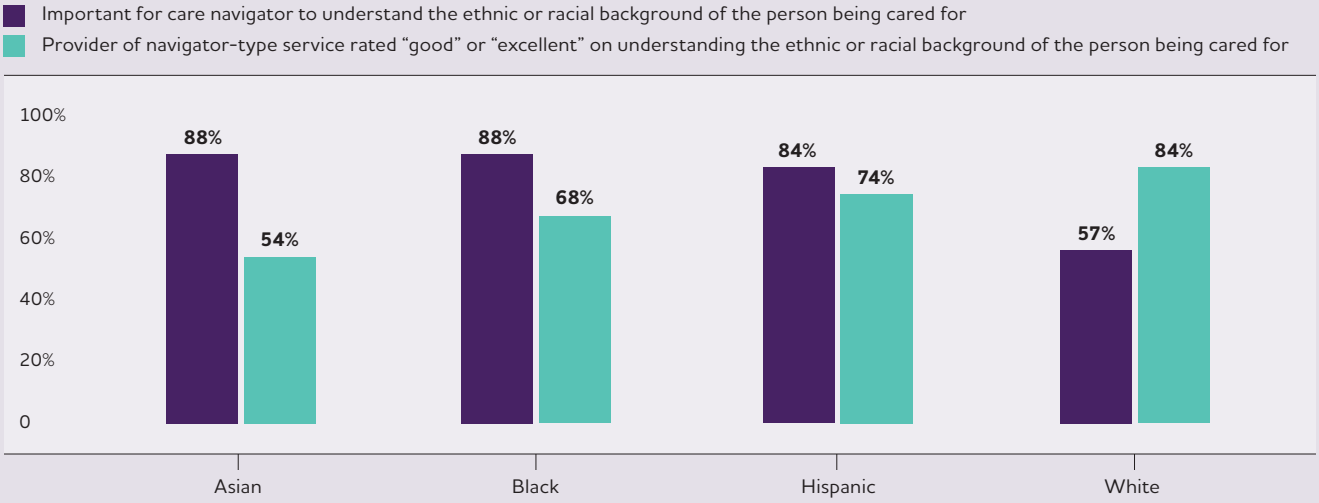


Cultural Competency is Fundamental for Dementia Care Navigation

Caregivers for people living with dementia stressed that it is essential for care navigators to understand their ethnic or racial background. Significantly, 9 in 10 Asian, Black, and Hispanic caregivers felt it crucial for navigators to be aware of the background of the person they are caring for (Figure 22). In contrast, White caregivers placed less importance on this shared experience. Among White caregivers who received navigation help, 84% believed the person helping them had a good or excellent grasp of their care recipient's background, a confidence level higher than that for other racial and ethnic groups. Confidence in the cultural competency of the person providing navigation assistance was lower for all other groups, and lowest for Asian caregivers, with only 54% rating understanding of the person helping them as "good" or "excellent."

Figure **22**

Access to Care Navigators With Cultural Competency by Race/Ethnicity of Care Recipient



Health care workers surveyed echoed that empathy for racial, ethnic and cultural backgrounds and experiences is key. They overwhelmingly agreed that effective dementia care navigation requires cultural competence, with 99% saying that it is important for navigators to understand (Figure 23). Four in 5 health care workers believe their organization has an effective understanding of the racial, ethnic, and cultural backgrounds and experiences of people with dementia and their caregivers.

Figure **23**

Health Care Professionals' Views on Cultural Competence

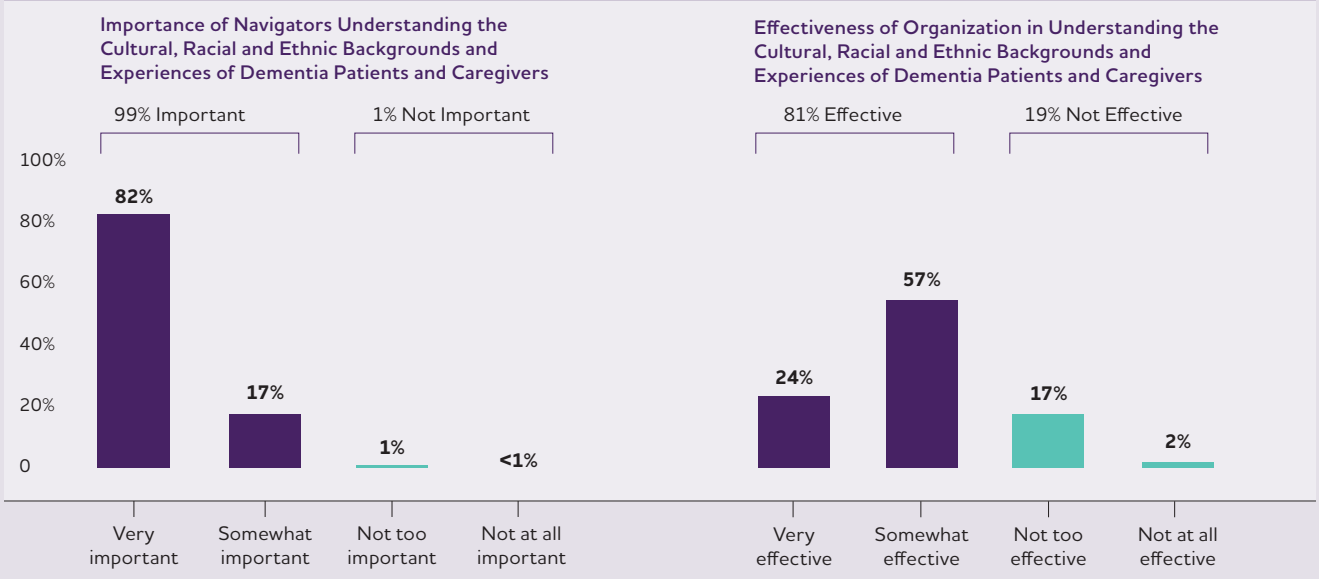
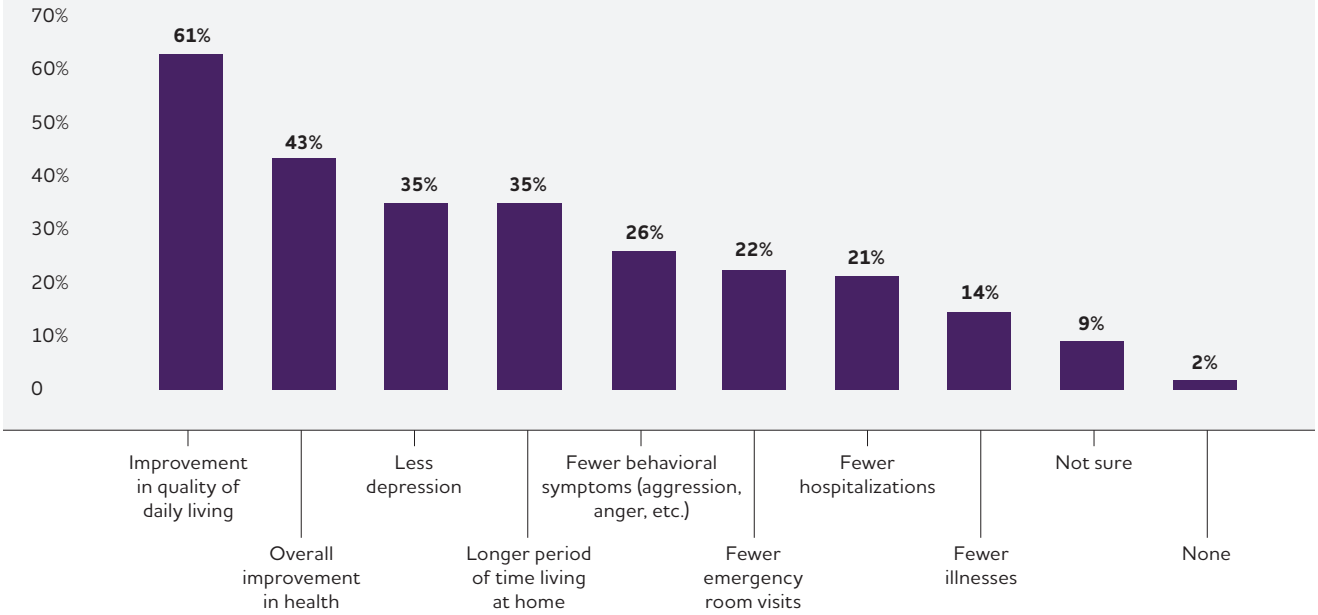


Figure **24**

Anticipated Outcomes for Care Recipients of a Navigator Program



Caregivers Welcome Dementia Navigation Support

Overwhelmingly, dementia caregivers surveyed would welcome navigator support, with 4 in 5 caregivers (85%) indicating that having access to a care navigator would influence their choice of a dementia health care provider for the person they care for. This sentiment was strongest among Black caregivers, with 52% saying it would influence their choice a great deal, followed by Hispanic caregivers (44%), White caregivers (43%) and Asian caregivers (38%).

Less Stress and Better Outcomes are Biggest Benefits of Working With a Dementia Care Navigator

Caregivers see improvement in quality of life (61%) and health (43%) for the person they care for as being the greatest positives of working with a dementia care navigator (Figure 24). Other benefits for the person living with Alzheimer's or other dementia include less depression (35%), longer period of time at home (35%) and fewer behavioral symptoms (26%).

For themselves, 2 in 5 caregivers surveyed see less stress (62%) and more peace of mind (62%) as the most valuable outcomes of having a navigator as part of the dementia care team (Figure 25). They also think a care navigator could help them be better caregivers (56%), improve their mental health (45%) and help them find opportunities to take a break from their care responsibilities (38%). Overall, very few dementia caregivers believed a care navigator would make caregiving less expensive (18%); however, there was a clear difference in this view among caregivers from different racial and ethnic groups. Nearly twice as many Asian, Black and Hispanic caregivers thought working with a navigator could make caregiving less expensive compared with White caregivers (26%, 23% and 22%, respectively, vs. 14%)

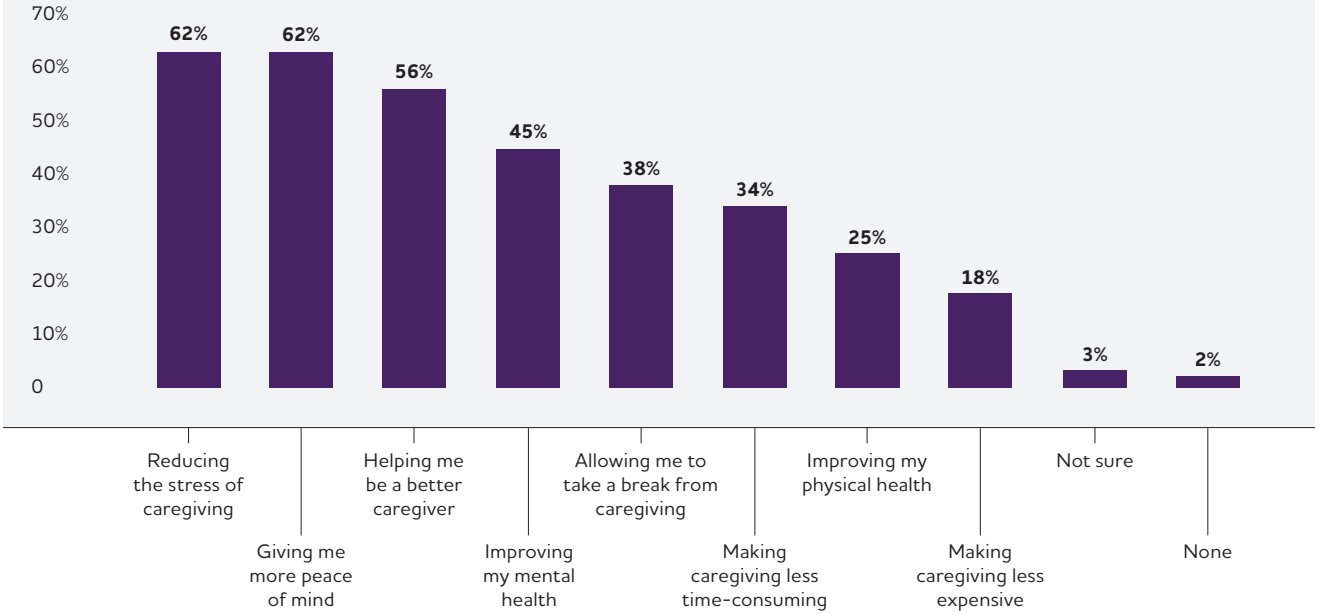
Around-the-Clock Support, Care Coordination and Help Understanding the Care Recipient's Condition Viewed as Most Valuable Navigation Services Overall

Nearly all dementia caregivers (97%) say they would find navigation services helpful. Almost 2 in 5 caregivers (36%) said a 24/7 helpline to call is the top service a care navigation program should provide (Figure 26). Coordinating care and communication between different specialists (34%) and helping to understand their care recipient's condition (34%) are also viewed as valuable services. Overall, caregivers see value in a mix of medical and nonmedical navigation services. Other helpful services, according to 1 in 3 caregivers, included:

- Assistance with insurance or public benefits (32%).
- Help with scheduling appointments (31%).
- Training on how to care for someone with thinking or memory problems (31%).
- Help managing behavioral symptoms (31%).
- Help understanding the health care system (30%).
- Help finding services to take a temporary break from caregiving (30%).

Figure **25**

Anticipated Outcomes for Caregivers of a Navigator Program



The findings highlight services more relevant to dementia care navigation than care navigation for other health conditions, such as respite services, managing behavioral symptoms and support for unanticipated needs outside of regular clinic hours in the form of the helpline. Typically, community-based organizations provide these services. Although 1 in 3 caregivers (30%) have received nonmedical supports and services, such as meal delivery, home care aides, or companions to give time away from caregiving, only 17% found these resources with the help of a person providing care navigation services.

Community-Based Resources May Address Some Stressors

Community-based resources and services can play an important role in supporting caregivers. While many of these services are delivered outside traditional health care settings, finding ways to connect caregivers to these resources should be viewed as an essential deliverable in dementia care navigation.

The three most helpful community-based resources cited by caregivers in the survey were local caregiver support groups (41%), respite programs (38%) and availability of financial resources in the community (37%). These resources could alleviate some of the top stressors, like worries about costs and expenses and getting help taking a break (Figure 27).

Caregivers of all races and ethnicities surveyed pointed to connections to local adult daycare programs as a valuable navigation service (Asian, 45%; Black, 36%; Hispanic, 35%; White, 28%).

Non-Physician Health Care Workforce Survey Results

"Care Navigator" is a Known Term in Health Care

Three in 4 health care workers who provide navigator-type services (77%) are familiar with the term "care navigator." Nonmedical professionals (CHW, HHA or MSW) were the most familiar, with 4 in 5 (83%) indicating they had heard this term before.

Many Professionals Already Provide Navigation Services, but This is not Their Focus

Health care workers participating in the survey spend roughly half (53%) their time providing navigator-type services, even if they do not refer to themselves as care navigators (Figure 28, page 106). Nearly 1 in 3 of the patients they provide navigation services for have cognitive issues, including MCI, Alzheimer's disease or other dementia (Figure 28, page 106). The vast majority of respondents (93%) say that caregivers or family are almost always involved in discussions of navigation-type services — with or without the person they are caring for.

Figure **26**

Care Navigator Services That Would Be Valuable to Dementia Caregivers

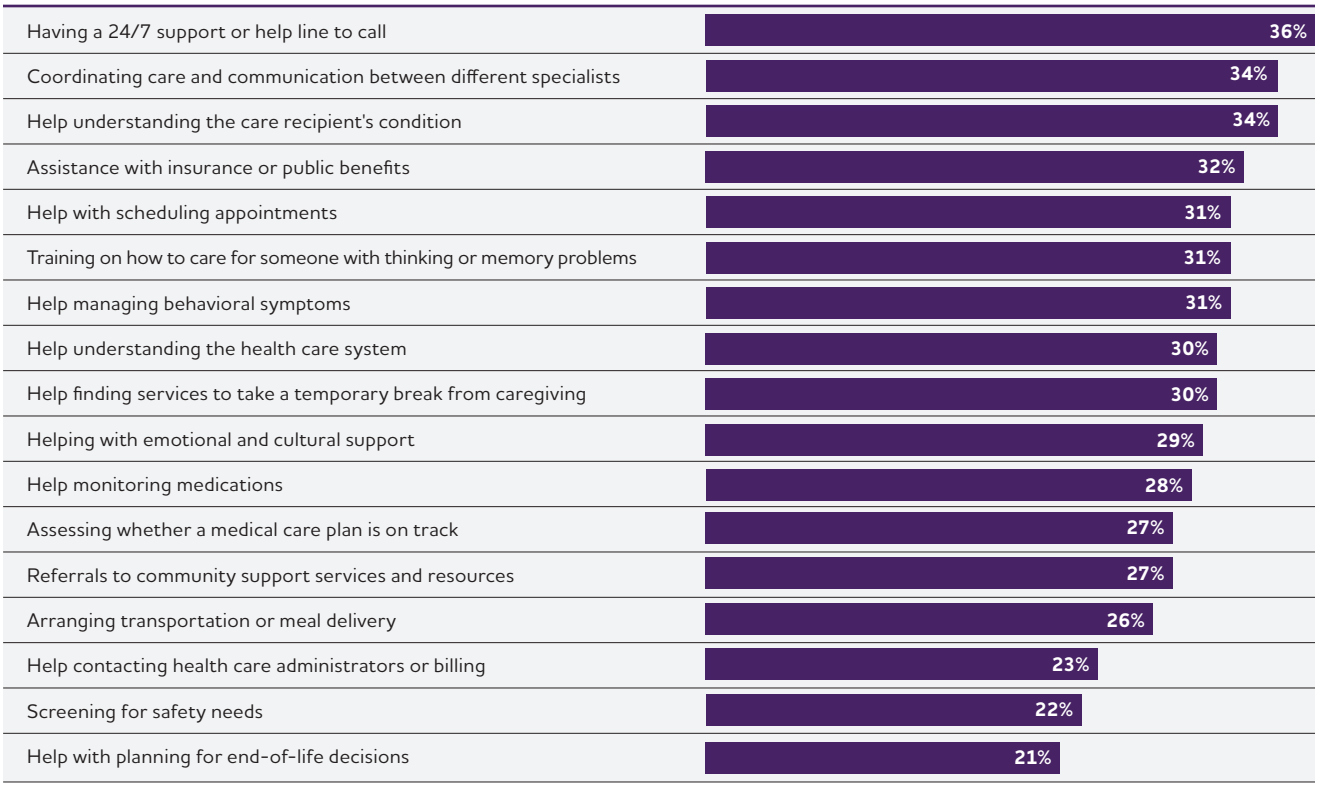


Figure **27**

Community-Based Services That Would Be Valuable to Dementia Caregivers

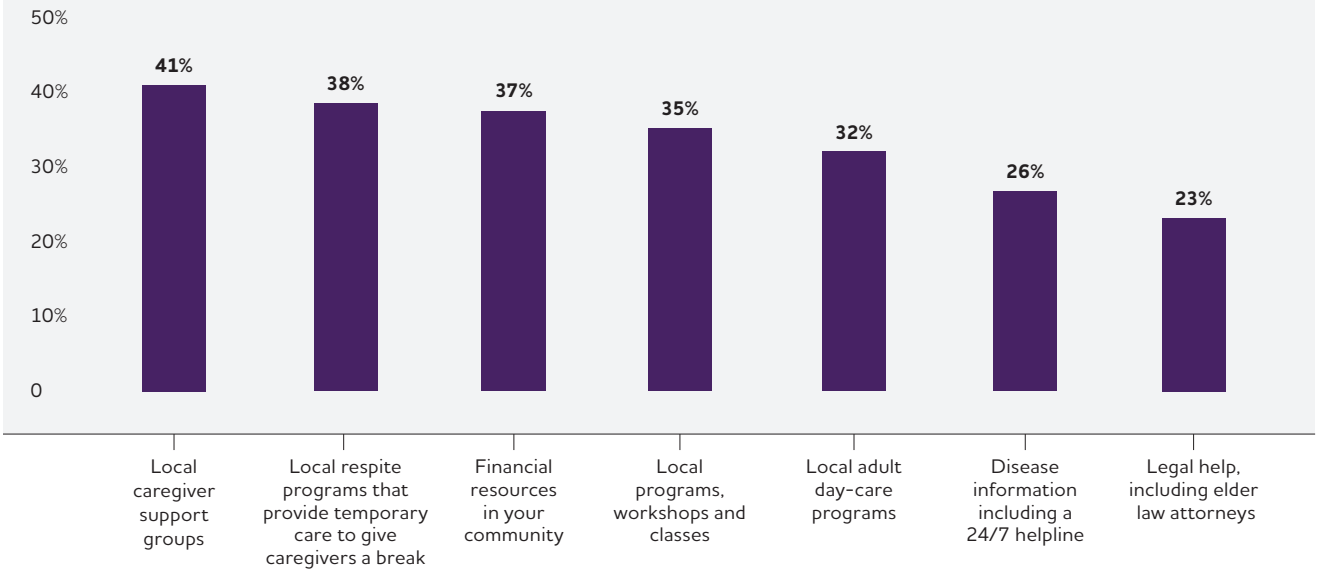
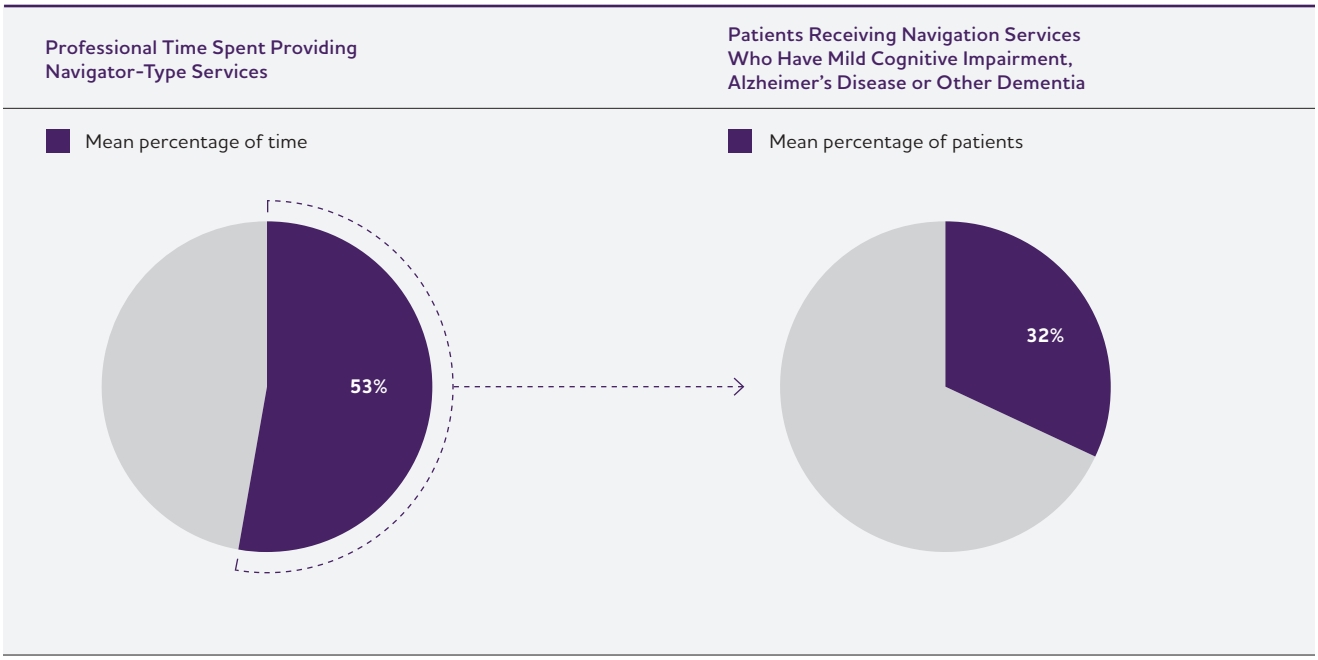


Figure **28**

Time Spent on Navigator-Type Services and Percentage of Patients with Cognitive Issues Receiving Navigation Services



Nearly all health care workers in the survey provide support for medical and nonmedical needs, with only 5% focusing exclusively on one type of need (Figure 29). The most frequently provided navigator services are referrals to community support services and resources (75%), helping with emotional and cultural support (68%) and screening for safety needs (66%) (Figure 30). Of those top navigation services, referrals to community support are more often provided by nonmedical professionals, whereas screening for safety needs is most often performed by medical professionals.

Unsurprisingly, medical professionals tend to offer more medically-related navigation services, such as screening for safety, assessing if the medical plan is on track, monitoring medications and staffing helplines (Figure 30). They also viewed these services as more valuable to patients and families than nonmedical professionals did. Nonmedical professionals, on the other hand, report that they are more often involved in making referrals to community resources, disease education, assisting caregivers looking for respite care, arranging transportation or meal delivery and insurance-related support such as working with billing or insurers (Figure 30).

Further illustrating the complicated nature of dementia care and the need for navigation as outlined earlier in the Special Report, health care workers also report that they are heavily involved in guiding patients and families through the health care system. Nearly 2 in 3 health care workers (62%; predominantly nonmedical professionals) help patients and caregivers understand the health care system, and more than 1 in 2 health care workers say they coordinate care and communication with specialists (Figure 30).

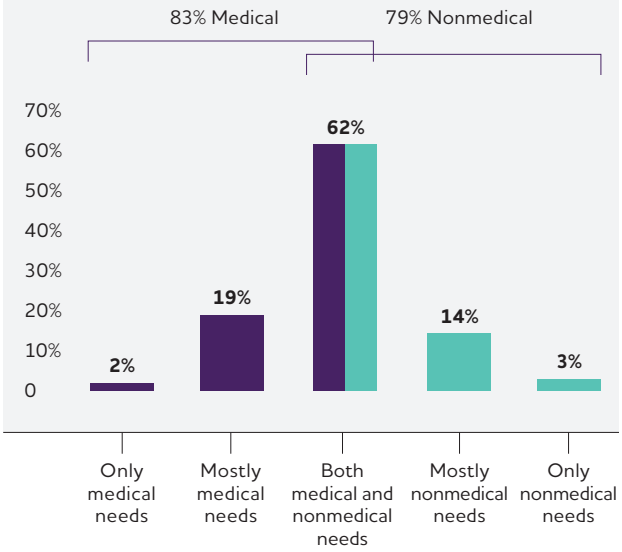
Greatest Value From Navigators is in Connections to Community Support and Services

More than 2 in 3 health care workers (68%) said the top service provided, referrals to community support services and resources, was the most valuable navigation offering (Figure 31). The top five most valuable navigation services according to survey respondents were:

- Referrals to community support services and resources (68%).
- Training on how to care for someone with dementia (63%).
- Help managing behavioral symptoms (62%).
- Helping with emotional and cultural support (59%).
- Coordinating care and communication between different specialists (59%).

Figure **29**

Focus of Dementia Care Support Provided



More than half of respondents also said that finding respite services to take a temporary break from caregiving, understanding the health care system, and screening for safety needs were valuable.

Interestingly, there were two notable disconnects between what health care workers perceive as valuable and what they deliver in the form of navigation services. The first is training for family members on how to care for someone with dementia. Whereas 63% of survey respondents rated this as valuable, only 2 in 5 (40%) provide such training. The second disconnect was in the utility of a 24/7 helpline. This feature of navigation was valued by 1 in 3 health care workers (33%), yet only 15% are currently providing this service.

Figure **30**

Services Provided That Support Dementia Care for Patients and Their Families

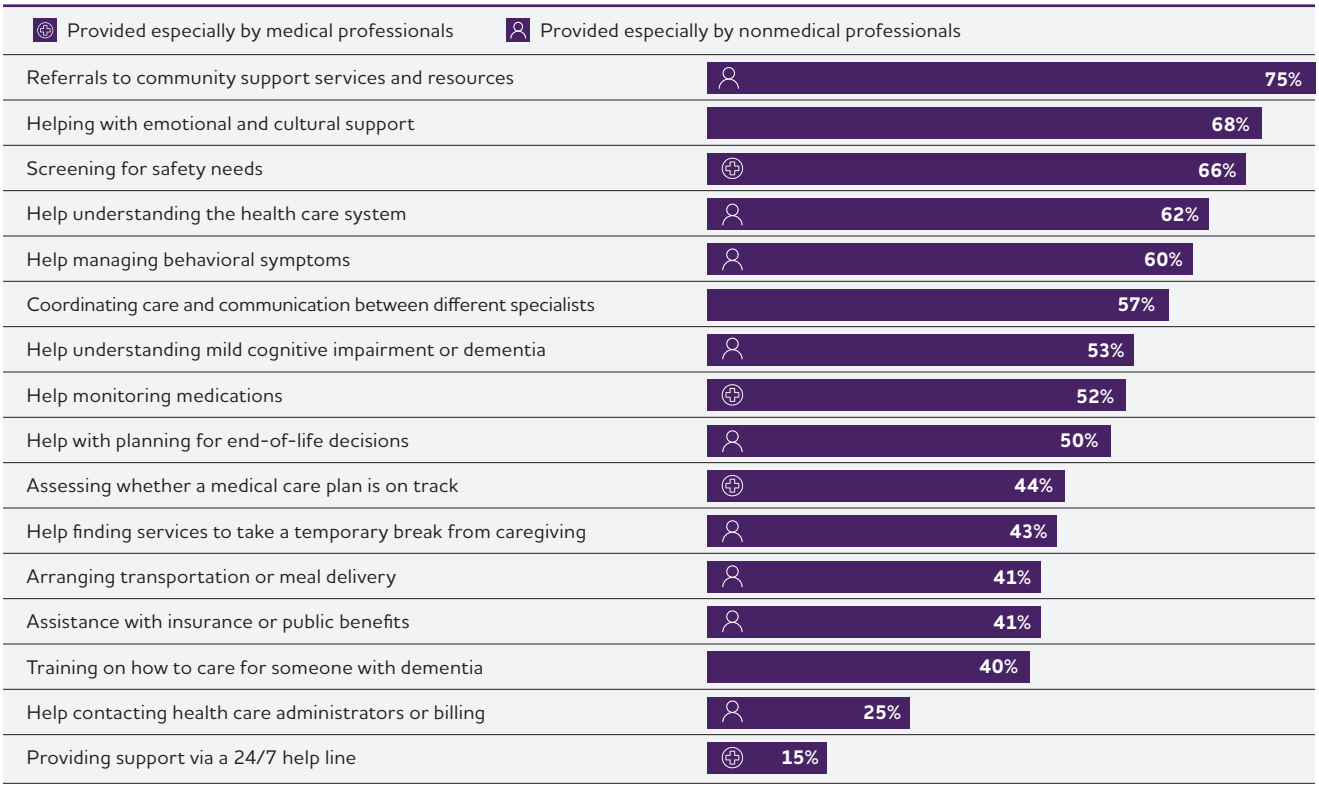


Figure **31**

Most Valuable Services in Supporting Dementia Care for Patients and Their Families

Nonmedical Professionals Communicate More Frequently With Patients and Families

Two in 5 nonmedical professionals (39%) report they connect with individuals living with dementia and their families every two weeks, and 1 in 3 (32%) make contact every month. Medical professionals typically communicate with patients every two weeks (28%) and every month (24%). However, medical professionals report that they are more likely to communicate every 3 months and 6 months than nonmedical professionals (15% vs. 7% and 5% vs. 1%). This distinction between medical and nonmedical professionals may be a result of the cadence of follow-up visits with a physician, and medical professionals may be more likely to incorporate navigation services into a routine visit. Across groups, 1 in 4 health care workers (23%) discuss dementia care services only as needed.

On average, nonmedical professionals interact most often with patients and families:

- All health care workers: 12 times per year.
- All medical professionals (NP, PA or RN): 11 times per year.
- All nonmedical professionals (CHW, HHA or MSW): 14 times per year.

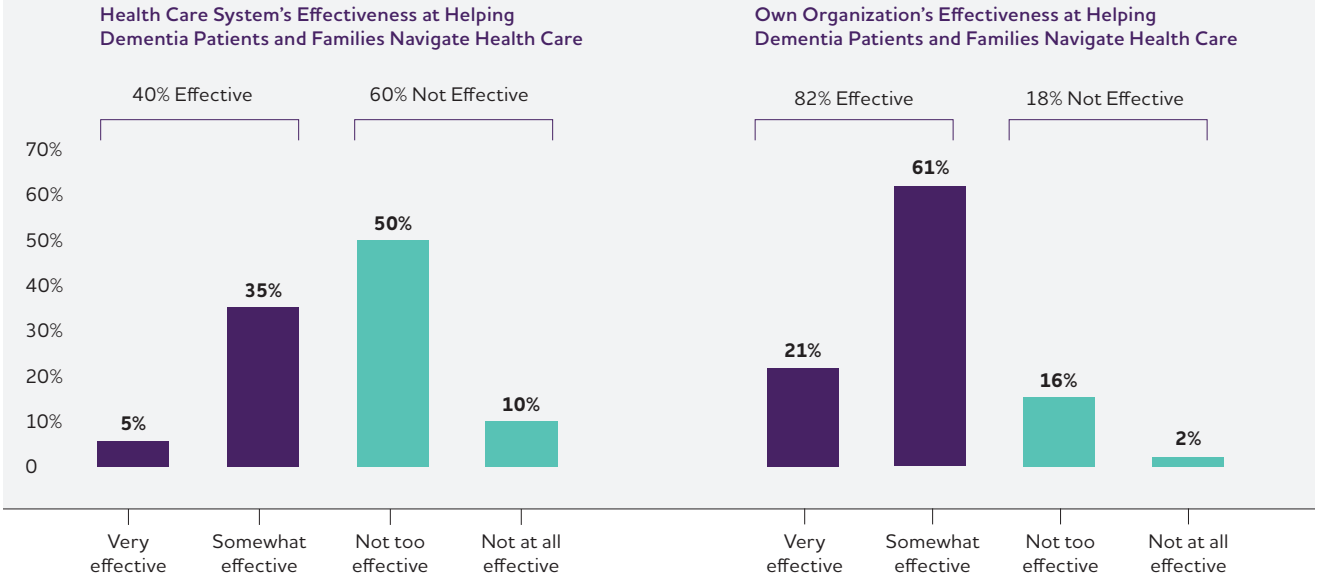
Health Care Workers Providing Navigation-Type Services Use Traditional Communication Channels Instead of Newer Technologies

In-person visits and phone calls are by far the most common channels for dementia care navigation and dramatically outpace usage of newer technologies like video conferencing, email, patient portals and text messaging. Care navigation services are 3 to 4 times more likely to be provided in-person or by phone than other channels, and most communication still occurs at in-person visits.

There are some distinctions in how medical and nonmedical professionals deliver navigation services. Medical professionals communicate more often via a patient portal than nonmedical professionals (19% vs. 14%). The most striking difference is how nonmedical professionals appear to have gravitated toward digital communication, possibly because they engage with patients and families more regularly. Nonmedical professionals use video conferencing and email to reach patients and families twice as often as medical professionals (29% vs. 11% and 26% vs. 12%, respectively). Nonmedical professionals also report using a phone call to communicate more often than medical professionals (76% vs. 62%).

Figure **32**

Health Care Workers' Views on the Effectiveness of Dementia Care Navigation



Training in Dementia Care Navigation is Lacking and Not Standardized

Three in 4 health care workers providing navigation services indicated that they received no formal training in dementia care navigation. The 1 in 4 health care workers who did receive some kind of training were predominantly nonmedical professionals and received a median of 30 hours of formal training. On the other hand, medical professionals received a median of 20 hours of formal training.

If they received formal training, more than 1 in 2 surveyed received it from their employer (59%), not from colleges, universities or other outside programs, such as a certificate or public health program. Except for nonmedical professionals being more likely than medical professionals to have exposure to navigation training during college or university coursework (47% vs. 23%), there were no differences between the groups surveyed.

Dementia Care is Rarely the Sole Focus of Navigation Activities, but Health Care Workers Still Feel Knowledgeable

Four in 5 health care workers (80%) have navigation experience in non-dementia medical specialties, and fewer than 1 in 10 (7%) focus primarily on providing navigator support and services to people living with dementia. Most providing navigation services (93%) feel at least somewhat knowledgeable about MCI, Alzheimer's disease and other dementia but only about 1 in 3 (36%) report they are very knowledgeable.

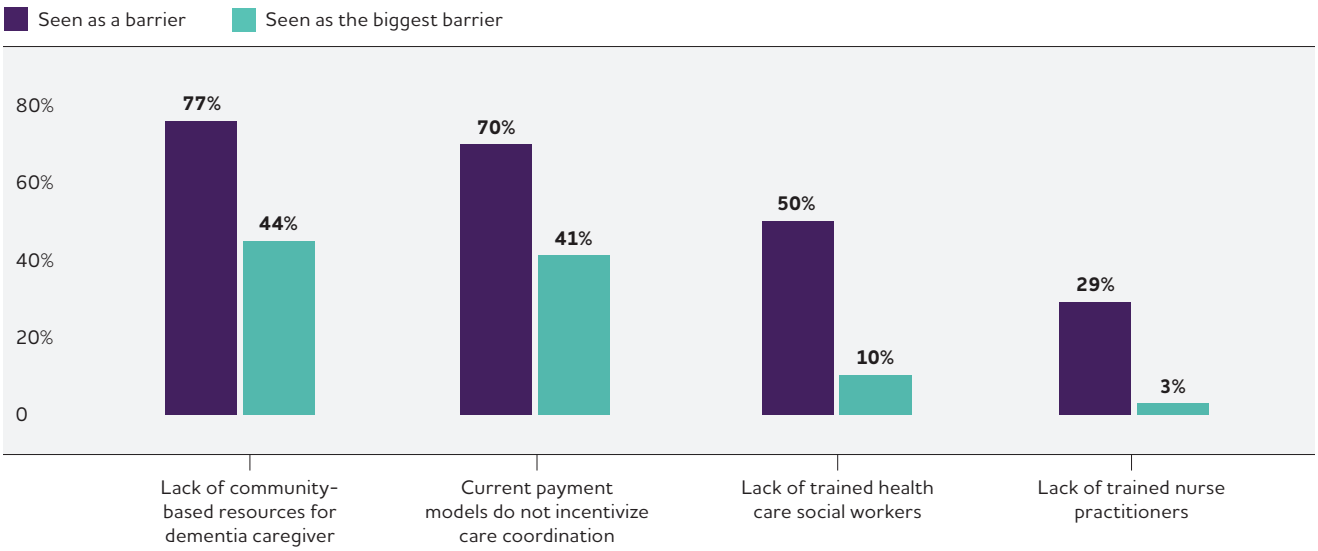
Central to effective, valuable navigation that benefits patients and families is a strong knowledge of dementia care support and resources in health care settings and the community. Nearly 9 in 10 health care workers (86%) feel knowledgeable about directing dementia patients and caregivers to appropriate health care resources, but fewer than 1 in 3 (30%) report feeling very knowledgeable. Four in 5 (82%) feel knowledgeable about directing dementia patients and caregivers to community resources, but only 31% say they are very knowledgeable.

When the group is separated into medical or nonmedical professionals, nonmedical professionals report feeling better equipped and more knowledgeable than medical professionals about health care resources (93% vs. 81%) and community-based resources (92% vs. 75%). Understandably, nonmedical professionals feel more capable, given that they are more likely to communicate regularly with patients and caregivers and could have received formal training on delivering navigation services. Additionally, some health care workers categorized as nonmedical professionals in this survey, such as community health workers or home health aides, may have direct exposure or interaction with resources in the community.

A crucial component of dementia care today is familiarity with new and emerging treatment options and awareness of clinical trials. Nearly all health care workers surveyed believe it is important to be familiar with new treatments (98%) and with clinical trial options (93%).

Figure **33**

Barriers to Dementia Care Navigation



The Health Care System Could Do More to Help People Navigate Dementia Care

Health care workers shed light on current deficits in dementia care. Sixty percent believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care (Figure 32). They perceive their own organization's efforts more positively, however, with 4 in 5 saying that their organization is effective (somewhat effective [61%] or very effective [21%]) at providing dementia care; Figure 32). Nearly half surveyed (46%) say their organizations do not have a clearly defined process for care coordination and clinical pathways for patients with MCI, Alzheimer's disease or other dementia.

Health care workers pointed to a lack of community-based resources for dementia caregivers and current payment models that do not incentivize care coordination as the greatest barriers to dementia care navigation (Figure 33). More than 3 in 4 of the health care workers surveyed (77%) identified a lack of community-based resources as a barrier, and 44% viewed it as the greatest barrier. Seven in 10 (70%) called out restrictions in current reimbursement as a barrier, with 41% saying this was the greatest barrier. Interestingly, health care workers did not identify workforce shortages as a top limitation for dementia care navigation (Figure 33). There were no differences in perceived barriers to dementia care navigation between medical and nonmedical professionals.

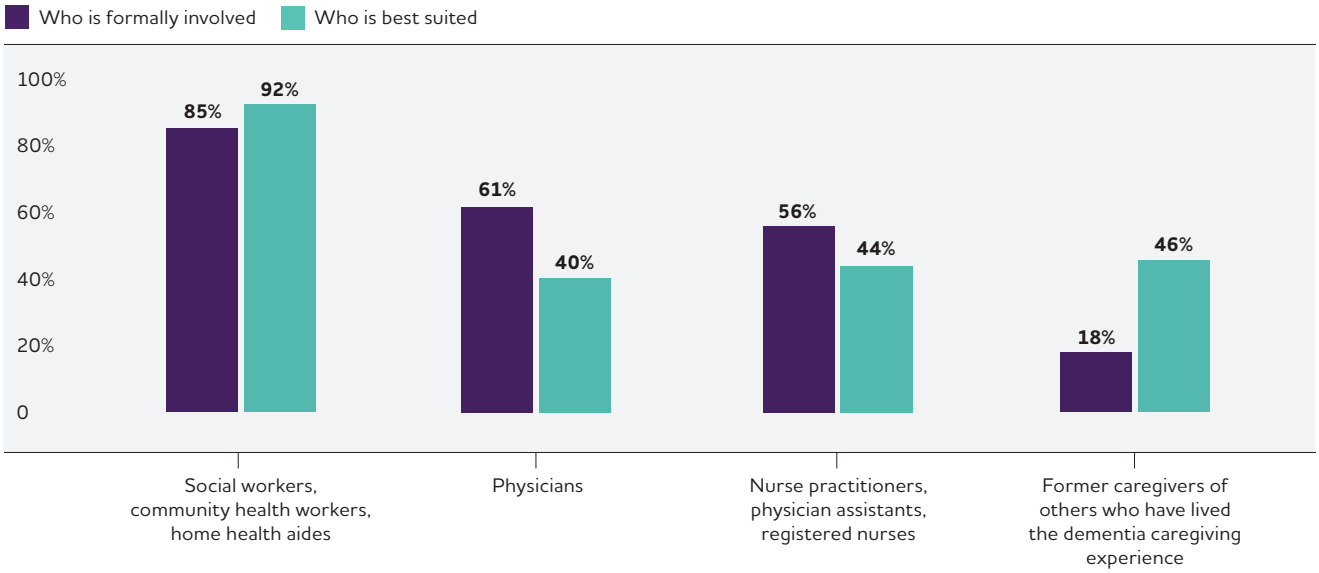
Almost 9 in 10 health care workers (87%) feel that developing alternative payment models is important in providing future care coordination for people diagnosed with dementia.

Nonmedical Professionals Are Best Suited to be Dementia Care Navigators

Survey respondents overwhelmingly agreed that nonmedical professionals are best suited to provide navigation services (Figure 34). Within their organizations, those surveyed reported that social workers, community health workers, and home health aides are more often formally involved in care navigation, and 9 in 10 reported that these individuals are best suited to offer navigation services. The next group of individuals health care workers believed are suited for navigation roles are former caregivers or others who have lived the caregiving experience, but few reported that these individuals are formally involved in dementia care navigation at their organizations. Surprisingly, nearly 2 in 3 health care workers indicated that physicians at their organization are involved in helping patients and caregivers navigate health care but fewer than half of the health care workers surveyed think that physicians are best suited for this work.

Figure **34**

Professionals Who Help Dementia Patients and Caregivers Navigate Health Care



A Path Forward: Revolutionizing Dementia Care With Person-Centered Navigation

As the complexity of health care for Alzheimer's and other dementias continues to challenge individuals living with dementia and caregivers alike, the Alzheimer's Association dementia caregiver and non-physician health care workforce surveys call attention to the urgent need for person-centered dementia care navigation and care delivery solutions for health systems, health care professionals, caregivers and people living with dementia.

Dementia care management is emerging as an ideal model to unravel dementia care complexity, improve outcomes and lower costs (Figure 35).[978] Care navigation is a crucial component that touches all other aspects of care management, such as caregiver education and training, care coordination, medication management, management of chronic conditions, safety assessments, and advance care planning.[978] Dementia care navigation, as part of comprehensive dementia care management, has the potential to revolutionize care if it is:

- Person-centered to meet the evolving, unique needs of all individuals living with Alzheimer's or other dementia.
- Durable yet adaptable to accommodate new treatments, new diagnostics and other improvements to care.
- Comprehensive to cover medical and nonmedical needs.
- Coordinated to connect disparate care teams and community resources.
- Feasible regardless of health system structure.
- Cognizant of geographic and socioeconomic barriers.

Ultimately, the goal of care navigation is to improve the quality of life for people living with dementia, reduce caregiver stress and enable people living with dementia to live in their homes and communities as long as possible.

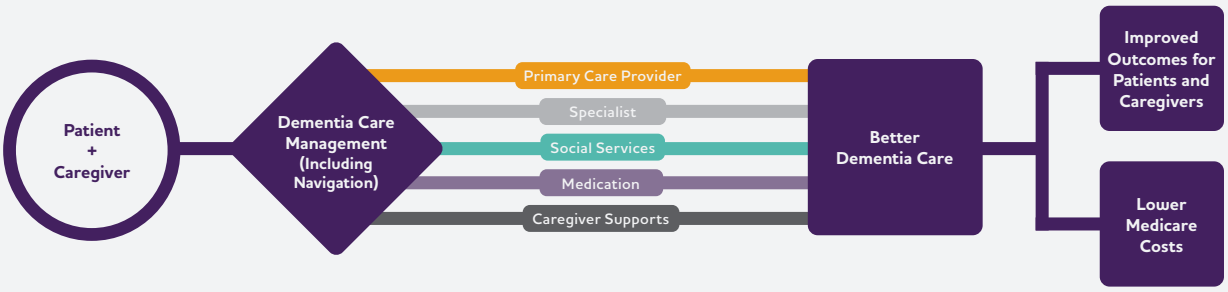
The GUIDE Model is a reason for optimism that emphasizes streamlined care coordination and robust support for caregivers — including forging a vital connection with a dedicated care navigator — and creating an alternative payment model to reimburse physicians (see What is GUIDE? on page 94).[986] However, while the GUIDE Model offers one potential approach toward enhancing dementia care navigation, it is a limited pilot program that will not be delivered by all health care providers nor available to all patients with dementia. Therefore, it is important for health systems, private insurers and other stakeholders to develop their own strategies to help people living with dementia and their caregivers navigate care.

The Special Report survey results brought to light three themes to advance dementia care navigation efforts:

1. Formalizing the dementia care navigator role and increasing navigator proficiency in dementia care.
2. Scaling and expanding access to dementia care navigation programs.
3. Creating direct lines to dementia care navigators.

Figure **35**

The Ideal Future State of Dementia Care[978]



Formalize the Dementia Care Navigator Role

Survey responses revealed a noteworthy trend: many health care workers are undertaking navigator duties in addition to their usual responsibilities. Ideally, practices and health systems should transition from ad hoc navigation support to formalizing dedicated dementia care navigator roles that are recognized for their vital and essential contributions to interdisciplinary, person-centered dementia care.

As mentioned in the Workforce section (see page 64), several decades of research support the value of collaborative models that bring different health professionals together, such as social workers, registered nurses and non-clinical care managers, physicians and advanced practice providers, and direct care workers, including nurse aides, nursing assistants, home health aides and personal care aides.[754, 755] If these individuals are the spokes in the dementia care wheel, the care navigator is the hub — supporting patients and caregivers as they find their way through the dementia care ecosystem. Given that this is a relatively new role in the dementia workforce, it's crucial for organizations to create a practice framework to seamlessly integrate dementia care navigators into existing teams and workflows to effectively coordinate longitudinal care that spans the disease course.

Increase Dementia Proficiency to Cultivate Specialist Navigators

In identifying ideal candidates for navigator roles, medical and nonmedical professionals agreed that community health workers, social workers and home health aides are best suited to be dementia care navigators. Despite receiving some formal education in navigation, often as part of college coursework or employer-provided training, these professionals are typically trained as generalists. Supplemental training and resources are necessary to build a solid foundation in both the practical and emotional aspects of dementia care. Their skills and compassion for the challenges caregivers and individuals living with dementia face could be enhanced with supplemental dementia-specific training and resources, such as:

- Materials for health care workers from the Health Resources & Services Administration.[996]
- Professional development programs in dementia care recognized by the Alzheimer's Association.[997]
- The Care Ecosystem Toolkit from the University of California, San Francisco (UCSF) Memory and Aging Center.[998]
- Home health clinician manuals from the Wisconsin Alzheimer's Institute.[999]
- Caregiver training videos from UCLA Health.[1000]
- Resources, webinars, presentations and toolkits from the National Alzheimer's and Dementia Resource Center.[1001]
- Community health worker training for participants in programs funded by the Administration for Community Living-Alzheimer's Disease Program Initiative (ACL-ADPI).[982]
- Resources and webinars on brain health and dementia from the National Association of Community Health Centers.[1002]

To bolster the training and resources outlined here, the Alzheimer's Association is developing a person-centered navigator training curriculum and certification that is slated for release in late 2024. This curriculum, which

incorporates the Alzheimer's Association's evidence-based Dementia Care Practice Recommendations, has the potential to increase the proficiency of care navigators, ensuring that they are well-equipped to meet the distinct needs of individuals living with dementia and their caregivers. Investment in navigator training and development could yield a marked improvement in the overall quality and effectiveness of dementia care.

Incentivize Scalability of Dementia Care Navigation to Expand Reach

Fee-for-service payment has dominated the health care market. Under these structures, health care providers are paid for individual services they perform, such as office visits or tests.[1003] Experts have long argued that fee-for-service is inefficient because it encourages the delivery of more potentially unnecessary care while discouraging care coordination.[1004] The U.S. health care system is increasingly transitioning from fee-for-service structures to alternative payment models, including value-based payment.[1004] Often called "volume to value," the goal of value-based payments is to restructure the approach "from one that incentivizes volume to one that rewards value."[1005]

Dementia care is not immune from financial incentives.[984, 1006, 1007] Health care workers in this year's survey believed that current reimbursement systems fail to incentivize dementia care and are one of the greatest barriers to dementia care navigation. They strongly believe that alternative payment models are important in providing future care coordination for people diagnosed with dementia.

Work to Make Existing and Future Dementia Care Navigation Programs Visible and Accessible

According to this year's caregiver survey, awareness of dementia care navigators remains low despite the recognized value of navigation. This may, in part, be due to variations in terminology used by different health care providers, inconsistent definitions or that these individuals simply do not yet exist within organizations. Depending on the setting, what is defined as dementia care navigation in this Special Report may also be called memory care navigation, care navigation, a navigator program, dementia navigation or not have terminology at all, but simply be services provided to patients.[990, 992]

Future programs must focus on elevating the visibility of navigation services through targeted outreach efforts. This involves leveraging community resources, social media and health care settings to inform and educate dementia caregivers about the support available to them. A compendium that defines terms and lists programs by region could be a useful tool to empower individuals living with Alzheimer's or other dementia and their caregivers. Furthermore, integrating care navigation into primary care and specialty clinics can ensure that more patients and families benefit from these services from the onset of their dementia care journey.

Another key factor limiting access to existing dementia care navigation programs is their location. Existing dementia care navigation programs are typically housed within large health systems or academic medical centers, putting them out of reach for many individuals from rural and underrepresented communities who receive care from hospitals or clinics within their community.[992] In anticipation of the growing need for dementia care navigation programming, the Alzheimer's Association created the Dementia Care Navigation Roundtable, which will help organizations establish best practices, support implementation and increase access to navigation programs.

Leverage 24/7 Helplines and Technology to Create Direct Lines to Care Navigators

Dementia caregivers reported that the most valuable service that care navigation could offer would be a 24/7 helpline. The Alzheimer's Association currently offers a 24/7 helpline that performs some navigation activities, such as assisting individuals with Alzheimer's or other dementia and their caregivers with recommendations for finding qualified care providers, general information about legal, financial and care decisions, and referrals to local programs and services.[1008] Ideally, access to 24/7 assistance would be connected directly with an individual's interdisciplinary care team. This allows the care team to manage longitudinal care, proactively assess any changes needed in care and potentially mitigate unnecessary emergencies.

While dementia caregivers and health care workers acting as navigators still prefer traditional communication methods such as phone calls and in-person visits for everyday communication, there is an opportunity to integrate technology solutions to streamline care coordination and support; these solutions should be viewed as complementary to existing person-centered approaches rather than replacements. Several companies are exploring on-demand virtual and app-based dementia care navigation, and the GUIDE Model supports contracting with suppliers to meet care delivery requirements that participants in the model wouldn't otherwise be able to meet on their own.[986] Digital platforms can offer caregivers and patients easier access to resources, appointment scheduling and direct communication with care navigators. However, any technological solution must be user-friendly and accessible to all caregivers, regardless of their familiarity

with digital tools, and compatible with any platforms used by health care providers. Navigators should be trained on how to communicate effectively through different channels.

Conclusion

The path forward for person-centered dementia care navigation is illuminated by the insights and experiences of dementia caregivers and health care professionals. The first step on this path is to establish proficient, dedicated dementia care navigators as a new role in the interdisciplinary dementia care workforce. Then, by addressing these key areas — training, person-centered care, accessibility, collaboration, novel payment models, and technology — future dementia care navigation programs can build on the learnings of their predecessors. Such efforts strive to improve the quality of life for individuals living with dementia and their caregivers and pave the way for a more sustainable, efficient and compassionate health care system.

Appendices

End Notes

A1. Racial and ethnic identifiers: *Facts and Figures* keeps the racial and ethnic terms used in source documents when describing study findings. When not referring to data from specific studies, adjectives such as "Black," "Hispanic" and "White" may be used (for example, Black populations and Hispanic communities).

A2. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer's dementia for 2024: The estimated 6.9 million individuals ages 65 years and older with Alzheimer's dementia and the estimated numbers of individuals 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.[241] The number, 6.9 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 individuals. The proportion of the population with Alzheimer's dementia (among people age 65 and older and by age group) is calculated using as the numerators the numbers of people with Alzheimer's dementia, as reported by the recent study in CHAP.[241] 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).[160] 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. 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.[286] Diagnosis of dementia was made according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than six months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.

A5. Projected number of people with Alzheimer's dementia, 2020-2060: This figure comes from the CHAP study.[241] Other projections are somewhat lower (see, for example, Brookmeyer et al.[1009]) 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.

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

A7. Number of family and other unpaid caregivers of people with Alzheimer's or other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS) survey. Since 2016, all states and the District of Columbia utilized the BRFSS caregiver module. This module identified respondents age 18 and over who had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. The module asks a series of follow-up questions, including asking the caregiver to identify what the main health problem, long-term illness, or disability that the person they care for has. One of the reported condition categories is "Alzheimer's disease, dementia, or other cognitive impairment." In the 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 all states and the District of Columbia who are caregivers for individuals living with Alzheimer's or another dementia. These percentages were applied to the estimated number of people age 18 and older in each state in July 2023, using U.S. Census Bureau data available at: https://www.census. gov/programs-surveys/popest/data/tables.html. This resulted in a total of 11.457 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.

A8. 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,[441] the Alzheimer's Association assumed the midpoint of each time frame was the average number of hours for each caregiver within that time frame and then calculated the overall average number of hours of weekly care provided by dementia caregivers in each state. This number was then converted to a yearly average and multiplied by the number of caregivers in each state[A7] to determine the total number of hours of care provided. 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 18.376 billion hours.

A9. Value of unpaid caregiving: For each state, the hourly value of care was determined as the average of the state minimum hourly wage[1010] 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.)[908] The average for each state was then multiplied by the total number of hours of unpaid care in that state[A8] 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 $346.585 billion for dementia caregiving in the United States in 2023.

A10. 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.

A11. Lewin Model on Alzheimer's and dementia costs: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at: alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 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[241] and included in this report (6.9 million in 2024), 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. The Lewin Model's state-specific Medicaid costs for 2020 and 2025 are based on an earlier estimate of state prevalence than reported here (Weuve J, Hebert LE, Scherr PA, Evans DA. Prevalence of Alzheimer disease in U.S. states. Epidemiology 2015;26(1):E4-6).

A12. All cost estimates were inflated to year 2023 dollars using the Consumer Price Index (CPI): All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

A13. 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 any pandemic-related changes in utilization.

A14. Enrollment in fee-for-service Medicare versus Medicare Part C: Individuals eligible for Medicare can enroll in traditional Medicare, also referred to as fee-for-service Medicare and original Medicare, or Medicare Advantage, also referred to as Medicare Part C.[1011] With traditional Medicare, beneficiaries can receive care from any doctor or hospital that accepts Medicare in the United States. Generally, beneficiaries can seek care from a specialist without a referral. Traditional Medicare has fixed cost sharing, which includes coinsurance of 20% of the Medicare-approved amount for services covered by Part B after the deductible is met. Individuals enrolled in traditional Medicare can also enroll in Medicare Supplemental Insurance (also referred to as Medigap) to help cover the out-of-pocket costs. Traditional Medicare does not have an annual limit on the amount beneficiaries pay out-of-pocket. Benefits are the same for all individuals enrolled in traditional Medicare. Individuals enrolled in traditional Medicare can also enroll in a Medicare Part D plan to cover some of the costs of prescription drugs. Medicare Part D enrollment has a separate premium. With Medicare Advantage, individuals must enroll in a specific private plan. Premiums, benefits and out-of-pocket costs may vary across plans. Medicare Advantage plans have an annual limit on the amount individuals pay out-of-pocket. Individuals enrolled in a Medicare Advantage plan are not allowed to enroll in Medigap. Medicare Advantage plans are also allowed to offer additional benefits not included in traditional Medicare, such as vision, hearing and dental services as well as some non-health care benefits, such as transportation costs and gym memberships. Many Medicare Advantage plans include prescription drug coverage (Medicare Part D). Individuals enrolled in a Medicare Advantage plan have a specific network of doctors and hospitals that enrollees need to use for services to be paid by the Medicare Advantage plan. Additionally, individuals enrolled in a Medicare Advantage plan may need a referral to see a specialist. Enrollment in Medicare Advantage has increased dramatically over the past decade, with 51% of all Medicare beneficiaries enrolled in a Medicare Advantage plan in 2023 compared to 29% in 2013.[918]

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.[863] 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 *2024 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 2023 dollars.

A16. Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues[862] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. 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 *2024 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. For the health care workforce survey, medical and nonmedical respondents were required to meet the following screening criteria:

- Spend at least 20% of professional time interacting directly with patients or caregivers.
- Report at least 10% of their patients being age 60 or older.
- Spend at least 10% of professional time performing navigation-type services.
- Report at least 10% of patients for whom they perform these services having Alzheimer's disease, other dementia or mild cognitive impairment (MCI).

Dementia care navigation was defined as the following for this group:

Whether or not you consider yourself a care navigator, do you provide any of these types of care, support or services in your current role?

- Patient education around diagnosis, treatment options and resources.
- Patient referrals to clinical specialists.
- Patient referrals to clinical trials.
- Patient referrals to social workers.
- Patient referrals to community-based services.
- Patient scheduling (labs, care team appointments, etc.)
- Patient assistance with insurance.

Appendices

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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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