2025
ALZHEIMER'S DISEASE FACTS AND FIGURES

SPECIAL REPORT
American Perspectives on Early Detection of Alzheimer's Disease in the Era of Treatment

ALZHEIMER'S ASSOCIATION®

About this report

2025 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. A Special Report examines Americans' attitudes toward early detection, diagnosis and new treatments for Alzheimer's disease.

The statistics, facts, figures, interpretations, opinions, recommendations and descriptions 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. 2025 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2025;21(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 18).

Number of Americans with Alzheimer's dementia nationally (page 29) and for each state (page 34).

Proportion of women and men with Alzheimer's and other dementias (page 31).

Racial and ethnic differences in the prevalence and risk of dementias (page 37).

Number of deaths due to Alzheimer's disease nationally (page 42) and for each state (page 45), and death rates by age (page 47).

Number of family caregivers, hours of care provided, and economic value of unpaid care nationally and for each state (page 53).

The impact of caregiving on caregivers (page 54).

The impact of COVID-19 on dementia caregiving (page 61).

The roles of the paid workforce involved in diagnosing, treating and caring for people with Alzheimer's or other dementias (page 65).

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 77).

Medicare payments for people with dementia compared with people without dementia (page 78).

American attitudes about early detection, diagnosis and treatment of Alzheimer's disease (page 100).

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 population identifiers used in source documents when describing study findings. [A1]

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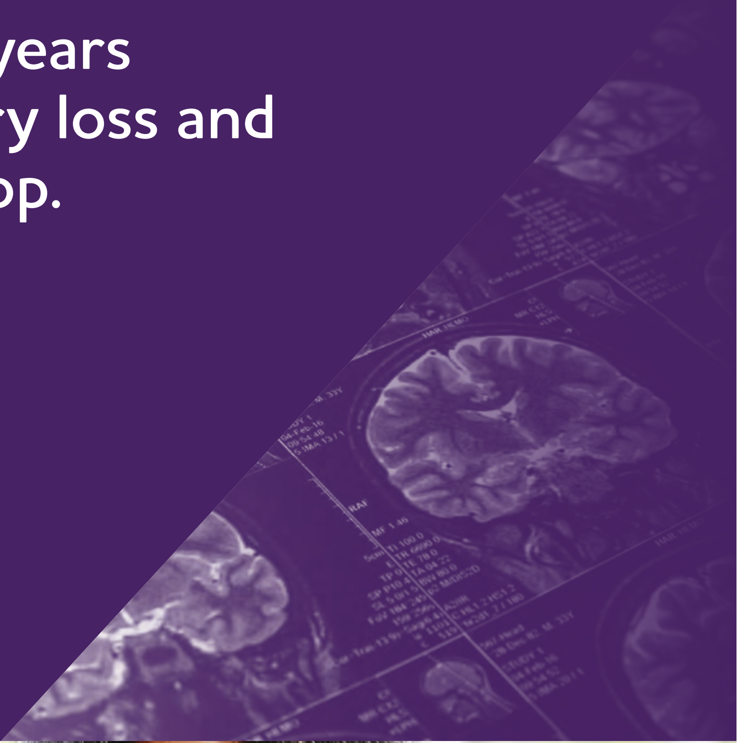
OVERVIEW

Alzheimer's begins 20 years or more before memory loss and other symptoms develop.



The brain, like the heart, is an organ. Just as coronary artery disease is a type of heart disease, Alzheimer's disease is a type of brain disease. In Alzheimer's, nerve cells in the brain (called neurons) are damaged and destroyed. The brain's neurons are essential to all human activity, including thinking, talking and walking. The neurons damaged first are those in parts of the brain responsible for memory, language and thinking, which is why the first symptoms of Alzheimer's disease tend to be memory, language and thinking (cognitive) problems. Individuals may also develop changes in mood, personality or behavior, such as apathy, confusion and increased suspicion and fear.

Although these symptoms are new to the individuals affected, the brain changes that cause them are thought to begin 20 years or more before symptoms start.[1-8] During those years, the brain compensates for the changes by using alternate networks of neurons to enable individuals to continue to function normally. When the brain can no longer compensate and cognitive problems interfere with a person's ability to perform everyday tasks such as driving, cooking or cleaning, a person is said to have dementia.

While Alzheimer's disease is the most common cause of dementia, it is not the only one (see Table 1, page 6). Other causes include cerebrovascular disease, degeneration of the front and temporal lobes of the brain, and accumulation of proteins called Lewy bodies. Often, individuals have the brain changes of more than one cause of dementia. When imaging studies, cerebrospinal fluid analysis or other tests show that the brain changes are caused by Alzheimer's disease, individuals are said to have dementia due to Alzheimer's disease or Alzheimer's dementia.

Alzheimer's disease is progressive, meaning the brain changes and symptoms worsen with time. How quickly it progresses from year to year and what abilities are affected vary from person to person. Like all people, individuals with Alzheimer's have good days and bad days. On good days, their cognitive skills may be markedly improved and they may be better able to carry out everyday activities. On bad days, their cognitive skills may be worse and they may have more difficulty carrying out everyday activities. Each day may be quite different.

Dementia or Alzheimer's Disease?

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

Dementia is an overall term for a particular group of symptoms. Dementia symptoms include trouble with memory, language and problem-solving; difficulty concentrating; and struggling to understand and express thoughts. Other symptoms are confusion, poor judgment and acting impulsively, among others. Dementia symptoms are the result of changes in the brain. Many different conditions can cause dementia symptoms (see Table 1, page 6).

Alzheimer's disease is one cause of dementia symptoms. The brain changes of Alzheimer's disease include the excessive accumulation of the protein fragment beta-amyloid and of an abnormal form of the protein tau. Other brain changes include inflammation and decreased ability of the brain to use glucose, its main fuel. When imaging studies, cerebrospinal fluid analysis or other tests show that the brain changes are caused by Alzheimer's disease, individuals are said to have dementia due to Alzheimer's disease or Alzheimer's dementia.

Family members, friends and professional caregivers play critical roles in keeping individuals with Alzheimer's safe, healthy and engaged in the activities that are most meaningful to them (see the Caregiving section, page 48). Increased help from caregivers is needed as the disease progresses. For example, individuals in the mild functional impairment stage of Alzheimer's may require little or no help with basic activities of daily living (ADLs), such as getting into and out of a bed or chair, bathing, dressing, using the toilet, eating, and grooming, while individuals in the moderate functional impairment stage do require help with ADLs. Caregiving demands further increase when neuronal damage and death extends to parts of the brain that enable basic physical function such as swallowing and walking. Individuals in this severe functional impairment stage of Alzheimer's require help with all ADLs.

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.
Limbic-predominant age-related TDP-43 encephalopathy (LATE)	A protein called transactive response DNA-binding protein 43 (TDP-43) accumulates in the brain. TDP-43 is a naturally occurring protein that helps with nerve development. In LATE, it usually accumulates in parts of the brain involved in memory, emotion, behavior and mood (limbic system).
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.[34] As PD progresses, alpha-synuclein can also accumulate in the cortex.

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.[25,26] 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.[25,26] 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.[25,26]	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.[27] 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.[28]	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.[29] 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.[29]	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.[30]	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.
While the percentage of dementia cases caused by LATE is unknown, autopsy studies of more than 6,000 people found that 40% had the TDP-43 deposits characteristic of LATE, and that LATE was associated with deficits in memory and thinking in approximately 25% of the individuals.[31]	Symptoms are similar to those of Alzheimer's but begin at an older age (75 or older), are milder and worsen more slowly. Individuals initially have fewer cognitive and functional problems than individuals living with Alzheimer's.
More than 50% of people diagnosed with Alzheimer's dementia who were studied at Alzheimer's Disease Research Centers had mixed dementia.[26] In community-based studies, the percentage is considerably higher.[25] Mixed dementia is most common in people age 85 or older.[32,33]	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.[35]	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.

Because of mobility limitations in this stage of Alzheimer's, individuals may spend most of their time in a wheelchair or on a bed. This loss of mobility, along with cognitive limitations, can lead to the need for around-the-clock care. However, even in this stage of Alzheimer's when individuals often have difficulty communicating verbally, it's common for them to have short, temporary periods of lucidity when they may be able to communicate coherently and regain some functional abilities.[9-11] Behaviors such as clapping, dancing and singing along to music can also occur.[9] Ongoing research is investigating these spontaneous events.[12-14]

Alzheimer's disease is ultimately fatal, although many people with Alzheimer's die of other common, coexisting conditions of older age. Studies indicate that people 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.[15-23] Many factors influence this. They include age at diagnosis, how far the disease has progressed at diagnosis, and whether individuals have other health conditions that may shorten lifespan or complicate care.

There is no proven way to prevent Alzheimer's disease, and there is currently no cure. However, several modifiable risk factors for dementia have been identified and addressing those risk factors may delay the onset of symptoms and result in more years lived in good health (see page 20). In addition, several treatments are available to help with symptoms, and two are available that change the underlying biology of Alzheimer's and slow disease progression (see page 14). Many studies are underway to expand and diversify available treatments as well as improve the quality of life of individuals living with dementia and their caregivers.

Brain Changes of Alzheimer's Disease

The symptoms of Alzheimer's disease are caused by changes in the brain. In Alzheimer's, the brain's neurons are especially affected. 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 form the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

Researchers have identified many brain changes that may interfere with communication at the synapses and contribute to the neuronal damage and death seen in Alzheimer's. Two of the most prominent brain changes are (1) the accumulation of the protein fragment beta-amyloid into clumps (called beta-amyloid plaques) *outside* neurons and other brain cells and (2) the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons. Other changes include inflammation, decreased ability of the brain to metabolize glucose (the brain's main fuel) and brain atrophy (decreased brain volume). 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.[24] Neuronal damage and death (neurodegeneration) are believed to contribute to brain atrophy.

Timing of Brain Changes

Researchers have gained insight into the timing of these brain changes by studying 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 up to 22 years (average, 18.9 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] Abnormal levels of the neurofilament light chain protein, a biomarker of neurodegeneration, were found to start an average of 22 years before the median estimated age of symptom onset.[7] Levels of abnormally folded tau protein increase when beta-amyloid clumps together as amyloid plaques, and levels 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 up to 18 years (average, 14.1 years) before expected symptom onset, and brain atrophy up to 13 years (average, 4.7 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 symptoms from a disease. For example, the level of glucose in blood is a biomarker of diabetes, and cholesterol level is a biomarker of disordered lipid metabolism, which is a risk factor for cardiovascular disease. 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 accelerate 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 because all the details of a decision were not considered.
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 Alzheimer's disease continuum represents the progression of Alzheimer's disease from brain changes that are unnoticeable by the person affected to brain changes and symptoms that severely impair daily function.[53] How long individuals spend in each part of the continuum varies and is influenced by age, genetics and other factors.[54] In 2024, revised criteria for diagnosing Alzheimer's and identifying where it is on this continuum (called staging) were published.[53] These criteria incorporate recent advances in biomarkers to provide objective data for making a diagnosis and assigning a clinical stage (0 to 6) to the progression of the disease (see Table 3a). The criteria also create a biological staging scheme for Alzheimer's (see Table 3b) and an integrated biological and clinical staging scheme (see Table 3c).

Clinical Stage 0

In clinical stage 0, individuals do not have symptoms of Alzheimer's disease, but have a deterministic gene that virtually guarantees that they will develop Alzheimer's (to learn more about deterministic genes, see page 19). Deterministic genes are responsible for an estimated 1% or fewer cases of Alzheimer's. In stage 0, biomarker levels are in the normal range. Biomarkers are biological factors that can be measured to indicate the presence or absence of a disease or the risk of developing symptoms from a disease (e.g., Alzheimer's disease). For example, the level of glucose in blood is a biomarker of diabetes, and cholesterol level is a biomarker of disordered lipid metabolism, which is a risk factor for cardiovascular disease. In stage 0, there is no evidence of clinical change (that is, no evidence of changes in cognition such as thinking, language and memory, and no evidence of changes in function such as the ability to work, drive and perform other everyday activities).

Clinical Stage 1

In clinical stage 1, individuals do not have symptoms but do have biomarker evidence of Alzheimer's disease, such as the accumulation of the protein fragment beta-amyloid or an abnormal form of the protein tau in the brain. When these biomarker changes occur, the brain compensates for them, enabling individuals to continue to function normally. In stage 1 individuals perform within the expected range on objective tests of cognitive function. There is no evidence of recent cognitive decline or new symptoms.

Clinical Stage 2

Clinical stage 2 is a transitional stage from being asymptomatic to having a mild decline in cognitive or neurobehavioral function. Decline represents a change from baseline within the previous one to three years, and the declines have lasted for at least six months. People in stage 2 may have subtle decreases in performance on longitudinal cognitive testing (but results are still in the normal range); have self-reported subjective cognitive decline; and/or have the recent onset of changes in mood, anxiety or motivation not explained by life events. Individuals in stage 2 remain fully independent with no or minimal functional impact on activities of daily living.

Clinical Stage 3

Individuals in stage 3 perform in the impaired/abnormal range on objective cognitive tests. The individual or a friend or family member notices a change in cognitive function from baseline, or there is a change in results of longitudinal cognitive testing or neurobehavioral assessments. Individuals in stage 3 perform daily life activities independently but cognitive difficulties may make it hard to perform complex activities of daily living (i.e., they may require more time to complete a task or may be less efficient in completing a task, but they are able to complete it).

Clinical Stage 4

In stage 4 of Alzheimer's disease, individuals have dementia symptoms with mild functional impairment. Most individuals are able to independently perform basic activities of daily living such as bathing and dressing, but may need help with instrumental activities of daily living, such as paying bills, cooking, shopping and managing medications. They 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 and may rely on reminders more than in the past.

Clinical Stage 5

In stage 5, individuals have dementia symptoms with moderate functional impairment and require assistance in performing activities of daily living. They experience more problems with memory and language, are more likely to become confused, and find it harder to complete multistep basic 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.

Clinical Stage 6

Individuals in stage 6 have dementia symptoms and severe functional impairment. They depend on others to perform activities of daily living. Their ability to communicate verbally is 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 on a 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).

TABLE **3a**

Clinical Staging for Individuals on the Alzheimer's Disease Continuum

Stage 0 **Asymptomatic, deterministic gene***	No evidence of clinical change. Biomarkers in normal range.
Stage 1 **Asymptomatic, biomarker evidence only**	Performance within expected range on objective cognitive tests. No evidence of recent cognitive decline or new symptoms.
Stage 2 **Transitional decline: mild detectable change, but minimal impact on daily function**	Normal performance within expected range on objective cognitive tests. Decline from previous level of cognitive or neurobehavioral function that represents a change from individual baseline within the past one to three years, and has been persistent for at least six months. May be documented by evidence of subtle decline on longitudinal cognitive testing, which may involve memory or other cognitive domains but performance still within normal range. May be documented through subjective report of cognitive decline. May be documented with recent-onset change in mood, anxiety and/or motivation not explained by life events. Remains fully independent with no or minimal functional impact on activities of daily living (ADLs).
Stage 3 **Cognitive impairment with early functional impact**	Performance in the impaired/abnormal range on objective cognitive tests. Evidence of decline from baseline, documented by the individual's report or by an observer's (e.g., study partner) report or by change on longitudinal cognitive testing or neurobehavioral assessments. Performs daily life activities independently but cognitive difficulty may result in detectable functional impact on complex ADLs (i.e., may take more time or be less efficient but still can complete — either self-reported or corroborated by an observer).
Stage 4 **Dementia with mild functional impairment**	Progressive cognitive and mild functional impairment on instrumental ADLs, with independence in basic ADLs.
Stage 5 **Dementia with moderate functional impairment**	Progressive cognitive and moderate functional impairment on basic ADLs requiring assistance.
Stage 6 **Dementia with severe functional impairment**	Progressive cognitive and functional impairment, and complete dependence for basic ADLs.

*Individuals with Down syndrome may not be fully independent even in stage 0 because of underlying intellectual disability. In these individuals, decline in functional independence from baseline may be a more appropriate indicator of stage.

Created from data from Jack et al.[53]

Alzheimer's Disease Continuum (cont.)

TABLE **3b**

Biological Staging by Positron Emission Tomography (PET)

	Amyloid PET	Tau PET Medial Temporal Lobe Uptake	Tau PET Moderate Neocortical Uptake	Tau PET High Neocortical Uptake	AT_2 Notation
A	+	—	—	—	$A+T_2^-$
B	+	+	—	—	$A+T_{2MTL}^+$
C	+	+	+	—	$A+T_{2MOD}^+$
D	+	+	+	+	$A+T_{2HIGH}^+$

Created from data from Jack et al.[53]

TABLE **3c**

Integrated Biological and Clinical Staging

	Stage 0	Clinical Stage 1	Clinical Stage 2	Clinical Stage 3	Clinical Stages 4-6
Initial biological stage (A)	X	1A	2A	3A	4-6A
Early biological stage (B)	X	1B	2B	3B	4-6B
Intermediate biological stage (C)	X	1C	2C	3C	4-6C
Advanced biological stage (D)	X	1D	2D	3D	4-6D

Note: The typical expected progression trajectory is along the diagonal white cells, from 1A to 4-6D. However, considerable individual variability exists in the population. Individuals above the diagonal (i.e., worse clinical stage than expected for biological stage) often have greater than average comorbid pathology. Individuals below the diagonal (i.e., better clinical stage than expected for biological stage) may have exceptional cognitive reserve or resilience.

Created from data from Jack et al.[53]

Mixed Dementia

Most people with dementia have brain changes associated with more than one cause.[25, 36-41] 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.[25, 26] 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.[25] Studies suggest that mixed dementia is the norm, not just for those diagnosed with Alzheimer's dementia based on symptoms, but also for those diagnosed with other types of dementia.[42, 43]

Mixed dementia is especially common at advanced ages.[36, 44] 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.[32, 33] 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.[25, 36] 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 an individual is experiencing are due to which cause of dementia. The brain changes of Alzheimer's disease are the most common contributor to dementia.

Cognitive and Behavioral Changes of Alzheimer's Dementia

The differences between normal age-related cognitive changes and the cognitive and behavioral changes of Alzheimer's can be subtle, especially in the first dementia stage of Alzheimer's, called stage 4 or dementia with mild functional impairment (see Tables 2 and 3, pages 9 and 11, respectively).

An example of a subtle change is difficulty making sound financial decisions. 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.[45] 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.[46] 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.[47] 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. As the underlying disease progresses, these changes can become more pronounced, leading to difficulties with tasks needed for independent living, such as paying bills. The Federal Reserve Bank of New York found that in the years prior to diagnosis of a memory disorder, average credit scores begin to weaken and payment delinquency begins to increase, both overall and for mortgage and credit card accounts specifically.[48] Credit outcomes consistently deteriorate over the quarters leading up to diagnosis.

Other common symptoms in stage 4 include problems coming up with the right word or name, new or increased trouble with planning or organizing, losing or misplacing objects, forgetting material that was just read, and difficulty remembering names when introduced to new people.

The brain changes of Alzheimer's continue over the course of the disease, and as brain changes increase, behavioral changes become more pronounced. In stage 5, dementia with moderate functional impairment, individuals may become confused about where they are and unable to remember their address or phone number; require help choosing the proper clothing for the season or occasion; experience changes in sleep patterns, such as sleeping during the day and becoming restless at night; and have personality and behavioral changes, including suspiciousness, delusions and compulsive, repetitive actions such as hand-wringing or tissue shredding.

A behavioral change of special concern is known as wandering. Wandering is when individuals walk away from caregivers, home, or other people or settings. It is estimated that between 35% and 60% of people with dementia will wander at least once.[49, 50] For the person with dementia, wandering is likely an intentional effort to reach a destination, such as work (although the person may no longer be employed) or important people or places from their present or past. Because of memory problems and other cognitive changes, the individual may not be able to retrace their steps and may become lost. Wandering puts individuals at risk of significant injury and death.[51] Although research is limited, a systematic review of studies examining unexplained absences and risk of death and injury among nursing home residents with dementia calculated a rate of 82 deaths and 61 injuries per 1,000 incidents of unexplained absence.[52]

In stage 6, dementia with severe functional impairment, individuals have increased difficulty communicating and may lose awareness of recent experiences as well as their surroundings. Many require around-the-clock assistance with daily personal care. They also experience changes in physical abilities, including walking and sitting. In addition, damage to areas of the brain that control swallowing impedes eating and drinking. 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 41).

While individuals in stage 6 may not be able to initiate engagement as much as in the earlier stages, they can still benefit from interaction in ways that are appropriate, like listening to relaxing music or receiving reassurance through gentle touch.

When Dementia Symptoms May Be Temporary

It is important to note that some individuals may have dementia symptoms without the progressive brain changes of Alzheimer's or other dementias. Causes of these symptoms include but are not limited to depression, stress, 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. These symptoms may be temporary if the cause is treated. People experiencing symptoms should seek help from a health care professional to determine if the symptoms are reversible with treatment, reflect normal cognitive aging, or are signs of Alzheimer's or other dementias.

Treatments

Drug Treatments

Several U.S. Food and Drug Administration (FDA)–approved treatments for Alzheimer's disease are available (see Figure 1, page 15). Two of these drugs change the underlying biology of Alzheimer's and slow cognitive and functional decline in some individuals. The remaining drugs treat the symptoms of Alzheimer's dementia. In general, people taking drugs for symptoms may continue on these drugs if they are prescribed drugs that change the underlying biology of Alzheimer's; however, always contact your doctor if you have questions about taking medications.

Treatments to Slow Alzheimer's Disease

The drugs lecanemab (Leqembi®) and donanemab (Kisunla™) change the underlying biology of Alzheimer's disease and delay disease progression. They target and remove beta-amyloid from the brain. Aducanumab (Aduhelm®) was the first FDA-approved treatment to slow the progression of Alzheimer's disease. Approved in 2021, it was discontinued in 2024 when the manufacturer opted to prioritize the production of Leqembi®.

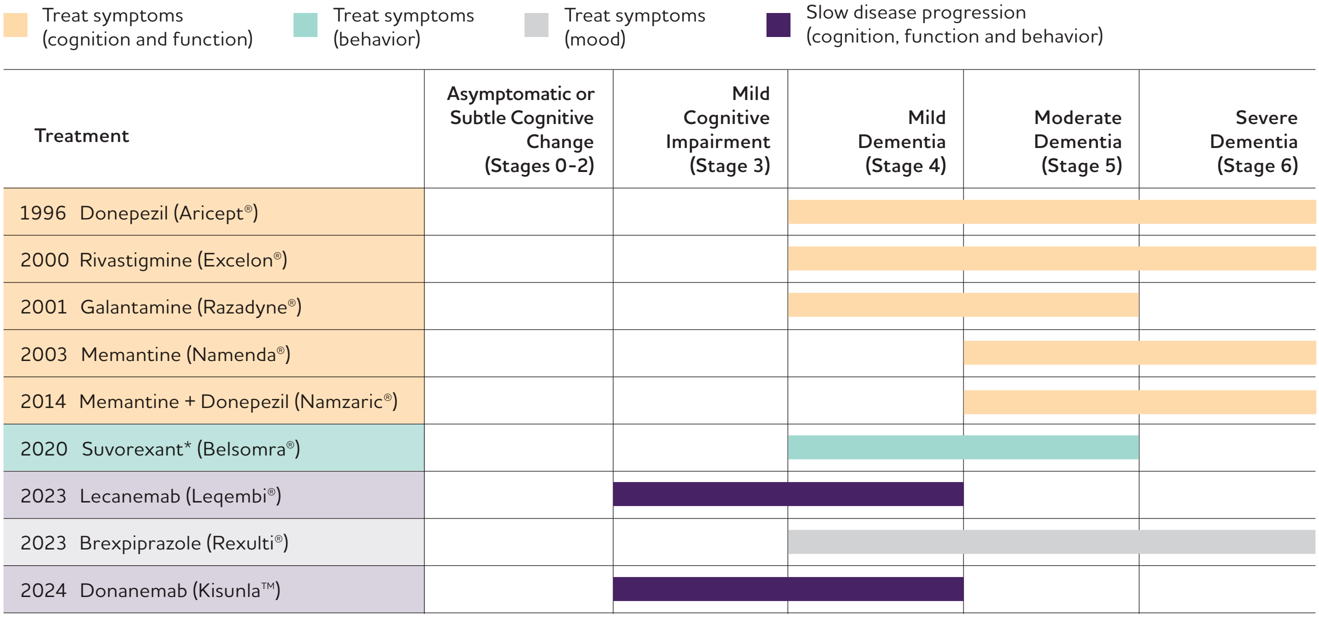
Lecanemab and donanemab are approved for use in individuals with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's (stages 3 and 4) and confirmation of elevated levels of beta-amyloid in the brain. Both drugs are administered via intravenous infusion. Lecanemab is administered every two weeks, and donanemab is administered every four weeks. They have not been tested in people in the moderate or severe stages of Alzheimer's dementia (stages 5 and 6) or those without clinical symptoms (stages 0-2). Their safety and effectiveness have only been established in individuals living with MCI or mild dementia due to Alzheimer's disease.

Clinical trials of lecanemab showed moderate slowing of cognitive and functional decline in individuals with MCI or mild dementia due to Alzheimer's and evidence of beta-amyloid accumulation based on brain imaging or CSF analysis.[55] Clinical trials of donanemab showed significant slowing of disease progression in individuals with MCI or mild dementia due to Alzheimer's and evidence of beta-amyloid and tau accumulation.[56] Lecanemab and donanemab are not cures for Alzheimer's disease and not appropriate for all individuals living with Alzheimer's.

While clinical trials showed statistically significant differences in cognitive outcomes between people randomized to receive lecanemab or donanemab and those randomized to receive placebo, the benefits of treatment in the short term may be imperceptible to

FIGURE 1

U.S. Food and Drug Administration-Approved Treatments for Alzheimer's Disease



🟧 Treat symptoms (cognition and function)
🟩 Treat symptoms (behavior)
⬜ Treat symptoms (mood)
🟪 Slow disease progression (cognition, function and behavior)

Treatment	Asymptomatic or Subtle Cognitive Change (Stages 0-2)	Mild Cognitive Impairment (Stage 3)	Mild Dementia (Stage 4)	Moderate Dementia (Stage 5)	Severe Dementia (Stage 6)
1996 Donepezil (Aricept®)			🟧	🟧	🟧
2000 Rivastigmine (Exelon®)			🟧	🟧	🟧
2001 Galantamine (Razadyne®)			🟧	🟧	
2003 Memantine (Namenda®)				🟧	🟧
2014 Memantine + Donepezil (Namzaric®)				🟧	🟧
2020 Suvorexant* (Belsomra®)			🟩	🟩	
2023 Lecanemab (Leqembi®)		🟪	🟪		
2023 Brexpiprazole (Rexulti®)			⬜	⬜	⬜
2024 Donanemab (Kisunla™)		🟪	🟪		

*Approved for insomnia, not Alzheimer's, but safe and effective in people living with Alzheimer's.

those receiving it. Because lecanemab and donanemab have been approved recently (in 2023 and 2024, respectively), their effectiveness beyond the length of their clinical trials is not yet fully established. This is expected to change, as systems have been established to track the health outcomes of people receiving these medications. The data these systems produce will be used by researchers to answer remaining questions about safety and effectiveness, including the impact of use over longer follow-up periods.

Among these systems is the Alzheimer's Network for Treatment and Diagnostics (ALZ-NET, alz-net.org). ALZ-NET is a voluntary provider-enrolled patient network that collects data from the clinical visits and physician-ordered brain imaging procedures of people evaluated for or treated with new FDA-approved Alzheimer's therapies, including treatments designed to slow disease progression and those that treat cognitive, behavioral or neuropsychiatric symptoms of Alzheimer's.

Anti-amyloid treatments such as lecanemab and donanemab 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 or vision changes.

To ensure that ARIA is identified should it occur, the appropriate use recommendations for lecanemab suggest health care professionals obtain MRI scans of the brain prior to the 5th, 7th, 14th and 26th infusions, in addition to a baseline scan before starting treatment.[57] Appropriate use recommendations for donanemab are being developed. Management of ARIA may include discontinuation of the medication either temporarily or indefinitely.

Individuals who are taking anticoagulants (blood thinners), have cerebral amyloid angiopathy (CAA)/amyloid beta-related angiitis (ABRA), or carry two copies of the apolipoprotein E (APOE)-e4 gene are at increased risk of developing ARIA.[57] The FDA encourages APOE-e4 testing before starting treatment with anti-amyloid medications. Prior to testing, doctors should discuss with patients the risk of ARIA and the implications of genetic testing results. The Alzheimer's

Association Clinical Meaningfulness Workgroup has developed recommendations and suggested language to help health care providers explain treatment eligibility, risks, benefits and costs to patients and caregivers.[58]

Before beginning any medication, 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.

Beyond anti-amyloid therapies, a variety of other treatments targeting the underlying biological changes 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).[59, 60] As of January 1, 2024, 132 clinical trials were underway testing additional disease-modifying therapies.[61]

Treatments to Address Cognitive and Behavioral Symptoms

Five of the FDA-approved drugs for Alzheimer's disease — donepezil, rivastigmine, galantamine, memantine and memantine combined with donepezil — are aimed at treating cognitive symptoms. They do not slow, stop or reverse the underlying brain changes that cause Alzheimer's, nor do they slow or stop the course of the disease. Instead, they help compensate for the brain changes of Alzheimer's by altering neurotransmitter levels. Neurotransmitters are chemicals that brain cells use to communicate with each other. Memantine protects the brain from excessive levels of a neurotransmitter called glutamate, which overstimulates neurons and can damage them, while the remaining drugs increase the amount of the neurotransmitter acetylcholine.

These five drugs may have side effects, such as headaches and nausea. These are not all the possible side effects. As with lecanemab and donanemab, individuals should talk with their doctors to develop a treatment plan that is right for them, including weighing the benefits and risks of all therapies.

One of the FDA-approved drugs, brexpiprazole, treats agitation that can occur in Alzheimer's. Agitation is common in Alzheimer's disease, with 60% of people with MCI due to Alzheimer's disease and 76% of people with Alzheimer's dementia experiencing agitation.[62] 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 in people without Alzheimer's. It's important to note that brexpiprazole falls into a category of drugs called atypical antipsychotic drugs. Atypical antipsychotic drugs have been associated with an increased risk of stroke and death in older people with dementia-related psychosis.[63-65] Non-drug interventions should be tried first.

In addition, the drug suvorexant, approved for insomnia in the general public, 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 dementia. 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, developing complex sleep behaviors (such as sleep-walking and sleep-driving), and experiencing sleep paralysis.

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, 2024, 30 clinical trials were underway testing new agents to treat Alzheimer's cognitive, behavioral and neuropsychiatric symptoms.[61]

Non-Drug Treatments

There are also non-drug treatments for the symptoms of Alzheimer's disease. These include physical activity, reminiscence exercises, music- and art-based therapies, pet therapy, light therapy and many others. Non-drug treatments do not change the underlying biology of Alzheimer's or cure the disease. They are often used with the goals of maintaining or improving cognitive and functional health, overall quality of life and engagement, and the ability to perform activities of daily living. Non-drug treatments may also be used to reduce behavioral and psychological symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. A review and analysis of non-drug treatments for agitation and aggression in people with dementia concluded that they seemed to be

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 primary care providers and other members of the health care workforce.

Actions by the Person Living with Dementia and Their Caregivers

These actions include:

- Becoming educated about dementia.
- 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.
- Identifying support and social groups where you feel safe to share your experiences.
- Planning for the future, including future health care needs, changes in employment and financial changes.

Actions by Primary 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 physicians, 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.
- Proactive management of anticipated functional and decisional changes including supportive discussions about driving and health care wishes.

To learn more, see the Caregiving (page 48) and Workforce (page 64) sections. Visit alz.org to learn more about Alzheimer's disease, as well as practical information for living with Alzheimer's and being a caregiver.

more effective than pharmacologic interventions for reducing aggression and agitation.[69] In addition to, in some cases, being more effective than pharmacological interventions, non-drug interventions pose minimal risk or harm to people living with Alzheimer's.

Non-drug treatments should be the first-line approach for behavioral and psychological symptoms of dementia (BPSD). Determining the effectiveness of non-drug treatments can be difficult because of the large number of unique treatments tested; the diversity of treatment aims (from improved overall quality of life to improvement in specific symptoms); the range of dementia stages in which treatments are tested; the multiple types of dementia that may be present among participants given the pervasiveness of mixed dementia; and the lack of a standard method for carrying out any individual treatment. With these multiple factors to consider, it is challenging to group together and compare non-drug treatments.

Nevertheless, researchers have combined results from multiple studies of non-drug treatments to provide insight into their potential effectiveness:

- A systematic review of non-pharmacological interventions to treat behavioral disturbances in older patients with dementia found that, overall, music therapy and behavioral management techniques (e.g., cognitive-behavioral therapy and progressive muscle relaxation) were effective for reducing BPSD.[70]
- An umbrella review of non-pharmacological interventions for neuropsychiatric symptoms of dementia in residential aged care settings reported that tailored interventions that included music and social elements appeared to be most beneficial for depressive symptoms and mood.[71]
- A review of non-pharmacological interventions for people with dementia found that the strongest evidence for reducing responsive behaviors (behaviors in response to sensations such as pain, hunger, thirst, fatigue, and feeling too hot or too cold) involved music,

sensory stimulation, simulated presence and validation therapies.[72] The same review reported that exercise and light therapy improved/maintained activities of daily living, while cognitive stimulation and reminiscence therapy improved cognition. The strongest evidence for reducing emotional disorders involved music therapy, psychological interventions and reminiscence therapy.[73]

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.

Non-Modifiable Risk Factors: Age, Genetics and Family History

The greatest risk factors for Alzheimer's dementia are older age,[74, 75] genetics — especially the e4 form of the apolipoprotein E (APOE) gene[76, 77] — and having a family history of Alzheimer's dementia.[78-81]

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 29). The aging of the population, by which older adults comprise a larger share of the population, will significantly increase the number of people in the United States with Alzheimer's dementia.[82] 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.[83]

Genetics

Researchers have found variants of many genes that increase or decrease the risk of Alzheimer's disease. At least 75 genetic variants are associated with an increased risk of Alzheimer's.[84] 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 late-onset 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.[83-85] 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.[86] 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.[87]

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.[88] 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.[89]

Most of the research to date associating APOE-e4 with increased risk of late-onset 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,[90-92] while other studies have found that it significantly increased risk.[93-96] In addition, researchers have found differences in the frequency of APOE pairs among racial and ethnic groups.[97-100] For instance, data show that a higher percentage of Black Americans have at least one copy of the e4 allele (see Table 4) than White Americans, Hispanic Americans and American Indian individuals.[90, 91, 97, 98, 100] 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.[101] Researchers have also found that a form of another gene, the gene for 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.[94]

TABLE **4**

Percentage of American Indians and Black, Hispanic and White Americans With Specified APOE Pairs*

APOE Pair	American Indians†	Black Americans	Hispanic Americans	White Americans
e3/e3	71.6 - 73.2	43.3	61.3	50.5
e3/e4	22.7 - 23.9	31.2	24.8	31.8
e3/e2	2.6 - 3.0	14.2	8.4	8.5
e2/e4	0.5	4.7	1.7	2.2
e4/e4	1.0 - 1.2	5.7	3.3	6.6
e2/e2	0.0 - 0.1	0.9	0.4	0.4

*Data for APOE pairs in other populations were 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 Kataoka et al[98] and Belloy et al.[100]

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.[102] 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. An additional study found that among Hispanic Americans, APOE-e4 was associated with fewer cases of mild cognitive impairment compared with White Americans, and APOE-e2 was associated with more cases of Alzheimer's disease compared with White Americans.[99] Results of a third study suggest that APOE-e2 is less protective in Black, East Asian and Hispanic Americans than in White Americans.[100]

These differences point to the need for more research to better understand the genetic mechanisms involved in Alzheimer's risk among different populations.

Genetics are also at play in younger-onset Alzheimer's, in which symptoms develop before age 65. About 10% of those with younger-onset Alzheimer's have known genetic mutations that cause Alzheimer's.[103] For the remaining 90%, having a copy of APOE-e4 is the primary genetic risk factor, although variants in about 20 other genes have been identified that may increase risk.

While routine genetic testing for APOE-e4 is not recommended at this time, physicians request APOE-e4 testing for individuals considering the treatments lecanemab and donanemab, as people with the APOE-e4 gene are at increased risk of side effects from the treatments.

Genetic Mutations/Deterministic Genes

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.[104] (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 precursor protein 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.[105] However, rare cases of individuals who have one of these mutations and do not develop dementia symptoms until late life have been reported.[106, 107] 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.

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

This report keeps the population identifiers used in source documents when describing findings from specific studies.

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.[108] In a study of 132,720 individuals age 18 and older with Down syndrome who were enrolled in Medicaid and/or Medicare between 2011 and 2019, 23% had diagnoses of Alzheimer's dementia.[109] Among those who were 55 or older when data collection began in 2011, prevalence was 42%; in the same group, prevalence was about 50% in 2019. The mean age of dementia onset was 54.5.

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.[110] 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.

Family History

A family history of Alzheimer's dementia is not necessary for an individual to develop Alzheimer's. Nor does having a family history of Alzheimer's dementia guarantee that an individual will develop Alzheimer's in older age. However, individuals who have or had a parent or sibling (first-degree relative) with Alzheimer's dementia are more likely to develop Alzheimer's than those who do not have a first-degree relative with Alzheimer's dementia.[78, 85] Those who have more than one first-degree relative with Alzheimer's dementia are at even higher risk.[81] A large, population-based study found that having a parent with Alzheimer's dementia increases risk independent of known genetic risk factors such as APOE-e4.[111] 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 (see Figure 2, page 23). However, there is growing awareness that more research is needed to disentangle risk factors that are specific to Alzheimer's disease from those that are specific to other causes of dementia.[73] As mentioned earlier, most people living with dementia have the brain changes of Alzheimer's disease as well as one or more other causes of dementia. Because Alzheimer's is the most common cause of dementia, modifiable risk factors for dementia are often assumed to support a link between the risk factors and Alzheimer's disease specifically. However, this may not be true. Additional research will help identify whether these risk factors are shared across multiple causes of dementia or are cause-specific. In this section we discuss risk factors for cognitive decline and dementia generally, recognizing that it is unclear whether these are risk factors for Alzheimer's disease specifically.

There is increasing recognition that risk factors might accrue over the life course to result in dementia. For example, the risk of developing dementia in later life can be influenced by health factors present years (or even decades) earlier. Midlife obesity,[112-114] hypertension[95, 112, 115, 116] and high cholesterol[117] 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 the life course, such as during adolescence and young adulthood, to understand how health factors experienced throughout one's life span may affect later life cognitive health.[118-123] This life course approach offers the potential to inform preventive measures across multiple stages of life.

The 2024 report of *The Lancet* Commission on dementia prevention, intervention and care identified 14 modifiable risk factors that, if eliminated, might prevent nearly half of dementia cases worldwide.[124] These factors are: education, vision loss, high cholesterol, head injury, physical inactivity, smoking, excessive alcohol consumption, hypertension, obesity, diabetes, hearing loss, depression, infrequent social contact and air pollution. With the exceptions of education, vision loss, air pollution and infrequent social contact, these are midlife risk factors. Similar to *The Lancet* Commission report, a 2022 study involving more than 375,000 participants estimated that nearly 37% of dementia cases 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.[125] The other risk factors were depression, smoking, diabetes, hearing loss and midlife hypertension.

Researchers are interested in not only the types of modifiable risk factors but also how those risk factors affect different populations. For example, a 2024 study of nearly 92,000 participants in the Multiethnic Cohort Study with an average age of 59 found that after an average follow-up of nine years, slightly more than 16,500 had developed Alzheimer's or another dementia. Looking more closely at the data, researchers calculated that modifiable risk factors accounted for 33% of cases among Latinos, 29% among Native Hawaiians, 28% among African Americans, 22% among White Americans and 14% among Japanese Americans.[126]

A number of reports other than that by *The Lancet* Commission also point to the promising role of addressing modifiable factors to reduce risk of dementia and cognitive decline, including those from the World Health Organization (WHO) and the National Academy of Medicine.[127, 128] There are many potentially modifiable risk factors for cognitive decline and dementia — 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.

Cardiovascular Health, Exercise and Diet

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.[129] 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.[130]

Many mid- and late life factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia.[131] These factors include untreated or uncontrolled hypertension,[95, 112, 115, 116, 132, 133] diabetes[134-136] and smoking.[137, 138] Likewise, many factors that decrease risk of cardiovascular disease are associated with decreased risk of dementia.[139]

Physical activity in mid- or late life is an example of a modifiable factor that reduces risk of cardiovascular disease and may also reduce risk of dementia.[140-151] 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 reducing risk. A recent systematic review and meta-analysis of 104 studies involving more than 340,000 participants age 20 or older offers a different view of the impact of physical activity, stating that while physical activity was associated with better late-life cognition, the association was weak.[152] In contrast, a recent meta-analysis of data from nearly 12,000 study volunteers age 55 or older from 10 studies suggests that three to six hours of physical activity per week may reduce risk of dementia[151] in older adults. More research is needed to better understand the differences in the study outcomes and the mechanisms by which physical activity may affect cognitive function across the lifespan.

In addition to physical activity, many but not all studies suggest that consuming a healthy diet during mid- and/or late life may be associated with reduced dementia risk.[153-161] A healthy diet emphasizes fruits, vegetables, whole grains, fish, chicken, nuts, legumes and certain fats such as olive oil while limiting saturated fats, red meat and sugar. Examples of 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.[162-164] Related to diet, some studies suggest that taking a multivitamin daily in later life may be beneficial to thinking, learning and memory in older age, but these data are preliminary.[165, 166] It's important to keep in mind that individuals' metabolic and neurobiological responses to diet vary, and that a "one size fits all" approach to diet may not be effective in reducing risk of cognitive decline and dementia. The addition or avoidance of no single food, beverage, ingredient, vitamin, multivitamin or supplement has been proven to prevent, delay, treat or cure Alzheimer's or any other dementia.[167]

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.[90, 168-173] Much of the research linking formal education to decreased risk of Alzheimer's dementia was conducted without the benefit of technological advances such as PET imaging of the brain that might shed light on whether education affects Alzheimer's biomarkers such as beta-amyloid and tau accumulation that lead to dementia symptoms. More recent research incorporating these technological advances suggests that rather than reducing the risk of developing Alzheimer's brain changes, formal education may help sustain cognitive function in mid- and late life and delay the development of symptoms even though brain changes may be present.[174, 175]

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.[176, 177] 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.[178-181] Recent research has found that among individuals at increased risk of dementia, higher occupational complexity is associated with better cognition.[178]

Today researchers are investigating a wide range of education-related factors in addition to the number of years of formal education to better understand how education may affect cognitive function and dementia risk. One of these factors is education quality, with emerging research suggesting that lower early-life educational quality is associated with increased dementia risk[182, 183] and lower level of late-life cognitive function.[184, 185]

Social and Cognitive Engagement

Remaining socially and cognitively active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.[140, 186-196] For example, a study of more than 39,000 individuals from 13 longitudinal studies of aging found associations between good social connections (e.g., frequent contact with family and friends, having a confidante or never feeling lonely) and lower risk of dementia.[195] Another study found that the least socially active older adults (lowest 10th percentile) developed dementia an average of five years earlier than the most socially active older adults (90th percentile).[197]

In terms of cognitive activity, a study of more than 7,000 individuals found that those who had cognitively stimulating occupations in their 30s, 40s, 50s and 60s had a lower risk of MCI and dementia when they were 70 or older.[198] Another large study examined data on main lifetime occupation for 7,637 individuals 65 or older in the Chicago Health and Aging Project study and found that higher occupational cognitive requirements corresponded to significantly better late-life cognitive performance at baseline and to slower decline in global cognitive function over time.[179] Further, in a multicohort study of 107,896 participants, the risk of dementia in older age was found to be lower in individuals with cognitively stimulating jobs than in those with non-stimulating jobs.[199]

While socially and cognitively stimulating activities appear to help build cognitive reserve, 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.[192] 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.

Sleep

Among the many dementia risk factors being studied is inadequate sleep or poor sleep quality.[200-202] Researchers have found that an important function of sleep is the removal of toxic beta-amyloid and other substances from the brain.[203, 204] 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.[205, 206] 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.[207-209] For example, increases in beta-amyloid and tau may interrupt the sleep-wake cycle,[210] leading to increased sleep fragmentation and wakefulness and decreased slow-wave sleep.[66] Poor sleep may have similar bidirectional relationships with other causes of dementia, including poor cerebrovascular health.[211]

Sensory Loss

Problems with smell (olfactory dysfunction), hearing, vision and other sensory abilities have been reported to increase one's risk of cognitive decline and dementia.[212, 213] Olfactory dysfunction is linked to MCI as well as neurodegenerative diseases including Alzheimer's disease.[214-218] Problems with smell typically precede cognitive and motor symptoms and may occur as a result of the accumulation of beta-amyloid and hyperphosphorylated tau in olfactory regions of the brain.[219] A community-based study of 380 older adults without dementia who were followed up for up to 15 years found that olfactory impairment was associated

FIGURE 2

Factors That May Impact Risk of Cognitive Decline and Dementia

*See page 25 to learn more about social determinants of health.

with faster cognitive decline and lower volume in the fusiform gyrus and the middle temporal cortex regions of the brain.[220] These regions include the hippocampus and entorhinal cortex, structures that play key roles in memory and language.

Age-related hearing loss has also been associated with faster rates of cognitive decline and dementia.[221-224] Among the reasons being examined are that hearing loss places a burden on cortical processing, which directs increased resources to auditory processing at the expense of other cognitive functions such as memory. Another possible explanation being explored is that hearing loss leads to social isolation, which has been linked to an increased risk of dementia.[225, 226] An additional explanation under investigation is that hearing loss is an early manifestation of the underlying brain changes that cause the various forms of dementia. Researchers recognize that these explanations may not be mutually exclusive but may all contribute to the link between hearing loss and increased risk of dementia. More research is needed to better understand how sensory loss increases risk of dementia.

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.[227] Studies specific to dementia and related outcomes have reported that higher long-term exposure to $PM_{2.5}$ is associated with worse cognitive decline,[228, 229] reduced brain volumes[228] and increased rates of incident (newly onset) dementia.[229-231] $PM_{2.5}$ takes on a chemical composition that depends on what produces this pollutant, and there is emerging evidence that exposure to $PM_{2.5}$ generated by wildfire or burning wood may confer a notable uptick in dementia risk.[230, 232, 233] Whether air pollution promotes the brain changes of Alzheimer's or other dementias is unclear.

Urgent and Emergency Hospitalizations in Older Adults

A growing body of evidence suggests that urgent and emergency hospitalizations in older adults are associated with increased risk of long-term cognitive impairment and dementia.[234-238] There are a number of ways that critical illness and aspects of the hospital experience may affect the brain.[239] One example is that experiencing hospitalization may make older adults more vulnerable to the existing brain changes of dementia.[240] 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.[239, 241] 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.[239] Modifying these aspects of hospitalization (i.e., making hospitals more dementia friendly) 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.

Traumatic Brain Injury (TBI)

TBI is a head injury caused by an external force that results in disruption of normal brain function.[242] TBI is associated with an increased risk of dementia.[243-245]

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.[246] In 2018 and 2019, falls were the leading cause of TBI-related deaths among those 75 and older.[242]

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia and by the individual's initial score on the 15-point Glasgow Coma Scale.[247, 248]

- *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; alteration in mental state at the time of the accident, such as feeling disoriented, confused or dazed; and focal neurological deficits (problems with nerve, spinal cord or brain function focused at a particular location on the body), which may or may not be temporary. About 75% of TBIs are mild.[249]
- *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 two- and four-fold compared with risk among individuals without a history of moderate or severe TBI.[250] 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.[243-245] 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.[251, 252] Whether TBI causes dementia, other conditions that lead to dementia or both is being investigated.

Repetitive TBI can cause a brain disorder called chronic traumatic encephalopathy (CTE) that results in dementia symptoms.[253, 254] The details of how this occurs is an ongoing area of research. Like Alzheimer's disease, CTE is characterized by tangles of an abnormal form of the protein tau in the brain.[255] Beta-amyloid plaques may also be present, with one study indicating that more than 50% of individuals with CTE had beta-amyloid plaques.[255, 256] 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, defined as repeated, forceful blows to the head that do not, individually, result in symptoms.[257] Among former amateur and professional football players, the odds of developing CTE increased 30% per year played.[258]

Socioeconomic Status, Social Determinants of Health and Risk of Cognitive Decline and Dementia

Socioeconomic Status

Socioeconomic status (SES) is typically defined as access to economic resources, including income, education, employment and occupation, but also includes factors such as financial security and perceived social standing. 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,[259] having a higher risk of diabetes,[260-262] and being more likely to have hypertension[263] and to smoke[264] — all of which are risk factors for dementia (see Cardiovascular Health, Exercise, and Diet, page 21). In fact, in 2022 researchers reported that SES was associated with changes in brain anatomy, including gray matter volume, that may affect overall cognitive ability.[265] WHO points out that "In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health."[266]

Social Determinants of Health
Similar to SES, social determinants of health (SDOH) affect the risk of developing Alzheimer's and other dementias.[267-269] According to WHO, "Social determinants of health are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life".

SDOH may decrease one's access to and ability to afford 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 safe housing, employment and outdoor areas in which to exercise. Furthermore, housing and employment conditions can influence one's exposure to substances that are toxic to the nervous system such as air pollution,[228] lead[270] and pesticides.[271]

Lowering Risk

While there is no proven method for preventing Alzheimer's disease, there are things we can do today that may reduce risk:[272]

- Control high blood pressure. Talk to your doctor about medications and behavior changes that may help.
- Maintain a healthy weight.
- Manage blood sugar. Talk to your doctor to learn how to reduce your risk of diabetes or better manage diabetes.
- Quit smoking.
- Get enough sleep and restful sleep. Seek treatment for sleep apnea and other factors that affect your sleep.
- Eat a healthy diet that emphasizes fruits, vegetables, whole grains, fish, chicken, nuts, legumes and healthy fats such as olive oil while limiting saturated fats, red meat and sugar.
- Keep physically active.
- Take care of your mental and physical health. Get help if you're concerned about your mental or physical well-being.
- Stay socially active (e.g., meet friends and family for celebrations or even just a cup of coffee, volunteer for events you enjoy or organizations you support, join a book club or walking club).
- Stay mentally active (e.g., challenge your mind by taking classes, learning new skills, playing cards and board games, reading, or sharing your knowledge with others through a blog or podcast).
- Protect your hearing and treat hearing problems; use a hearing aid if needed.
- Avoid head trauma (e.g., wear your seat belt, wear a helmet when playing sports, and prevent falls in your home by minimizing clutter and improving lighting).

To learn more about brain health, visit alz.org.

Perspectives on Risk Factors and Prevention

Some things to keep in mind about the research underlying much of our current knowledge about risk factors and prevention:

- Insights about potentially modifiable risk factors apply to large population groups. Studies can show that factor X is associated with outcome Y in these groups, but cannot guarantee that any specific person with factor X will have outcome Y. As a result, you can "do everything right" and still have a serious health problem or "do everything wrong" and live to be 100.
- Much of our current evidence comes from large epidemiological studies such as the Honolulu-Asia Aging Study, the Nurses' Health Study and the Adult Changes in Thought Study. These studies explore pre-existing behaviors and use statistical methods to relate those behaviors to health outcomes. This type of study can show an "association" between a factor and an outcome but cannot "prove" cause and effect.
- The gold standard for showing cause and effect is a clinical trial in which participants are randomly assigned to a prevention or risk management strategy or to a control group. Researchers follow the two groups over time to see if their outcomes differ significantly. It is important to note that the eligibility criteria for volunteers to participate in clinical trials may make them different from other people at risk for the outcome.
- It is unlikely that some prevention strategies will ever be tested in randomized trials for ethical or practical reasons. One example is exercise. Definitively testing the impact of multiple different exercise programs, practiced over the long term, on Alzheimer's risk would require a huge trial enrolling thousands of people and following them for many years. The expense and logistics of such a trial would be prohibitive, and it would require some people to go without exercise, which has other known health benefits. Other risk factors such as smoking with known health risks cannot ethically be studied in a trial where persons are randomized to smoking or not smoking.

Looking to the Future

Importance of Biomarkers

The identification and validation of biomarkers for Alzheimer's disease has changed the landscape of Alzheimer's research. For example, biomarkers have enabled the discovery that Alzheimer's disease begins 20 years or more before the onset of symptoms. This discovery suggests that there is a substantial window of time in which we may be able to intervene in the progression of the disease. Biomarkers were critical in the research leading to FDA approval of lecanemab and donanemab, both of which slow disease progression in individuals with mild symptoms (stages 3 and 4). Scientific advances are already helping the field to make progress in the presymptomatic years. For example, advances in the identification of biomarkers for Alzheimer's disease make it possible to identify individuals who may qualify for clinical trials of treatments that target these biomarkers and 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 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.

While blood tests for Alzheimer's disease biomarkers are available for use in research settings and some are used in clinical settings to aid diagnosis of individuals with symptoms, at press time none had been approved by the FDA for use in clinical settings. The further development of blood and other biomarker tests holds much promise. For example, a study of more than 1,200 individuals in Sweden with cognitive symptoms showed that a blood test improved the accuracy of diagnosis.[273] Without the blood test, primary care physicians were accurate 61% of the time in diagnosing Alzheimer's based on standard diagnostic tests and practices. With the blood test, accuracy increased to 91%. Accuracy also increased for dementia care specialists, whose diagnosis was accurate 73% of the time using standard tests and procedures. Accuracy increased to 91% for dementia care specialists when the blood test was incorporated.

However, much remains to be understood about biomarkers and how they can best be used for diagnosis. For example, some studies have found that comorbidities can affect biomarker results and that biomarker levels associated with elevated risk of dementia may differ by race and ethnicity.[274-276] Fine-tuning diagnostic cut-off points for populations with different dementia risks and incorporating an understanding of how coexisting conditions may affect biomarkers are among the factors that will be of paramount importance in putting biomarker tests into everyday practice.

Once blood biomarker tests are confirmed in large, diverse populations to be accurate and are widely available, they will have great potential for increasing early and accurate diagnosis and accelerating access to Alzheimer's treatments for better clinical outcomes. Until then, clinicians considering using a blood test to help with diagnosis are encouraged to refer to the 2022 Alzheimer's Association Appropriate Use Recommendations for Blood Biomarkers in Alzheimer's Disease, 2024 Revised Criteria for Diagnosis and Staging of Alzheimer's Disease, and 2024 Alzheimer's Association Clinical Practice Guideline for the Diagnostic Evaluation, Testing, Counseling, and Disclosure of Suspected Alzheimer's Disease and Related Disorders (DETeCD-ADRD).[277-280]

When validated blood 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 testing, make informed decisions about whether to undergo biomarker testing, and know what to expect in care after testing.

On a broader scale, disclosure of biomarker test results 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.[281]

Importance of Communicating Study Results to Study Participants

According to the National Institutes of Health, keeping study participants informed about research findings is as important as gathering the data.[282] Yet, in a survey involving 1,488 individuals who had participated in health research or been a guardian of a minor participating in health research, 51.8% indicated they were given no opportunity to request study results, 33% reported receiving results, 9.0% chose not to receive results and 6.2% indicated they never received results they had requested.[283] However, almost all individuals said researchers should always or sometimes offer the results to participants.

Likewise, a study of 414 researchers from 44 academic medical institutions found that 64.5% of researchers reported that results should always be shared with participants, yet 60.8% of respondents could identify studies in which they had a leadership role where results were not shared.[284] According to the study, financial barriers (e.g., lack of money to fund efforts to share results with participants), systems barriers (e.g., lack of career-related incentives to share results with participants), logistical/methodological/skill-related barriers (e.g., lack of knowledge about how to disseminate results to lay audiences) and ethical concerns (e.g., concerns about how participants will understand or use the results) were each considered by over 80% of respondents to be barriers to sharing results for at least some of their studies.

To detail the wishes of participants in dementia studies, one group has developed a study participant's bill of rights focusing on participants' right to receive study results.[285] This bill of rights was created by a committee of study participants, care partners, representatives of dementia advocacy organizations, and other stakeholders in dementia research for the Advisory Group on Risk Education for Dementia. The authors describe this bill of rights as "a call to action" for researchers in Alzheimer's disease and related dementias to proactively design clinical studies that provide the option for research participants to learn their individual research results if they choose, and in a manner that ensures study integrity.

The bill of rights states:

- I have the right to receive my individual results, collected in the course of my research participation, if I so choose; I can also ask how to receive them. This may be done in person or by tele-health, and either alone or with a person of my choosing.
- I have the right to exercise this right in an informed manner, including receiving information on validated decision-making tools if they are available, knowing who can access my results, and knowing how the law does or does not protect me after receiving my results. In order to protect myself, I may need to finish any care, legal and financial planning in advance of receiving my results.
- I have the right to be told what my test results mean in easy-to-understand terms and with sensitivity, compassion and patience. This information should also be provided in writing so that I may review it later.
- I have the right for my questions to be answered to the best of the researcher's knowledge and to take all the time I need to process the information I received.
- I have the right to be contacted or decline to be contacted to check on my well-being after receiving a result suggesting increased risk of dementia, and to be referred to additional resources for more information and support related to my health and wellbeing.
- I have the right to decide what actions I take after receiving my test results, such as pursuing medical and/or psychological care, engaging in legal or financial planning, and informing my family and friends of my results.
- I have the right to turn my results into action for my own wellbeing and the betterment of others by exploring additional research studies I may qualify for.
- The[se] rights should apply regardless of my cognitive status.

The Need for Increased Diversity in Research Participation

Gaining a more comprehensive understanding of Alzheimer's — from its causes to how to prevent, manage and treat it — requires more than research advances in basic science, epidemiology, clinical care and other topics. It requires inclusion of increased numbers of participants from diverse sociodemographic groups, including racial and ethnic groups, in research.

Without adequate data from these groups, the current and future burden of Alzheimer's disease and Alzheimer's dementia in the United States cannot be accurately measured.[286] Such data are 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.[287] Moreover, 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), and underrepresentation may exacerbate disparities by largely ignoring populations who bear the greatest risk. Other smaller groups, including older adults who are American Indian or Alaska Native, or Asian American, or who identify with multiple races, are also underrepresented in Alzheimer's research. Lack of inclusion also 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.[288]

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

Over 7 million Americans are living with Alzheimer's dementia.

Millions of Americans are living with Alzheimer's or other dementias. As the size of the U.S. population age 65 and older continues to grow, so too will the number and proportion of Americans with Alzheimer's or other dementias.

This section reports on the number and proportion of people with Alzheimer's dementia to describe the magnitude of the burden of Alzheimer's 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.[289] By 2030, all members of the of the baby-boom generation (Americans born between 1946 and 1964) will be age 65 or older,[290] the age range of greatest risk of Alzheimer's dementia;[291] 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" on page 39). 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[292] 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. Even so, 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.[293]

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

An estimated 7.2 million Americans age 65 and older are living with Alzheimer's dementia in 2025.[A2,293] Seventy-four percent are age 75 or older (Figure 3).[293]

Of the total U.S. population:

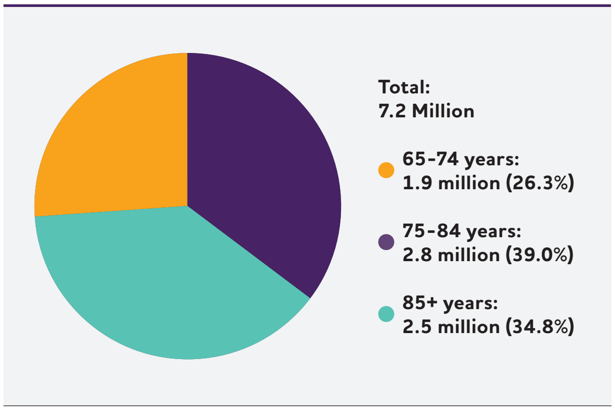
- About 1 in 9 people (11%) age 65 and older has Alzheimer's dementia.[A2, 293]
- The percentage of people with Alzheimer's dementia increases with age: from 5.1% of people age 65 to 74 up to 33.4% of people age 85 and older have Alzheimer's dementia (Figure 4).[A2, 293]
- People younger than 65 can 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.[294]

A Note on the Term "Alzheimer's Dementia" in this Section

Please note that the term "Alzheimer's dementia" used in the Prevalence section is based on studies that use this term to refer to dementia that is believed to be due to Alzheimer's disease based on clinical symptoms only but not confirmed by tests or biomarkers indicating the brain changes of Alzheimer's disease. The state of the science for the term "Alzheimer's dementia" is dementia that has been confirmed to be due to the brain changes of Alzheimer's disease (see "Dementia or Alzheimer's Disease?" in the Overview, page 5); however, population-based prevalence studies do not yet exist that have the data to provide an estimate of the prevalence of biomarker-confirmed Alzheimer's dementia. When such estimates do become available, we will report them, which could result in differences in reported prevalence (see "Prevalence Estimates" on page 32).

FIGURE 3

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2025*



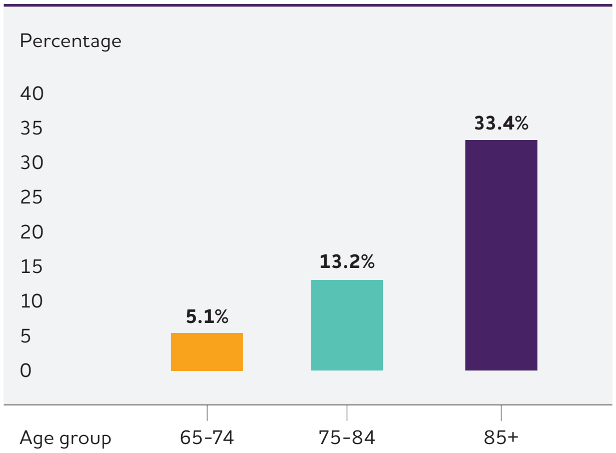
*Percentages do not total 100 due to rounding.

Created from data from Rajan et al.[A2, 293]

The denominator for each percentage is the total number of people with Alzheimer's dementia in the U.S. in 2025: 7.2 million.

FIGURE 4

Percentage of People with Alzheimer's Dementia by Age Group, 2025



*Percentages do not total 100 due to rounding.

Created from data from Rajan et al.[A2, 293]

The denominator for each percentage is the U.S. Census population projection for the specific age group of interest.

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.[293]

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, 173]

Underdiagnosis of Alzheimer's and Other Dementias in Dementias in Health Care Settings

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 clinician.[305-314] 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.[315-319] 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.[320] Some studies indicate that underdiagnosis is higher in Black and Hispanic older adults.[313, 314, 321] A number of potential harms may result from a missed or delayed dementia diagnosis. These include delayed access to treatment and supportive services, less time for care planning, higher costs of care, and negative impact on the individual's physical and 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.[322] Underdiagnosis is most pronounced at the earliest stages of dementia when symptoms are mild.[321] Even fewer people living with mild cognitive impairment (MCI), a precursor to dementia, receive a diagnosis despite this being the stage where treatment and planning may be most effective.[323] One recent study estimates that only 8% of older Americans living with MCI receive a diagnosis.[324]

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.[325-329] Not all those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.[330-332] 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.[333] Subjective cognitive decline is often an indicator of other, treatable conditions, such as sleep apnea, depression or anxiety. Seeking care for subjective cognitive decline may be beneficial to one's physical and mental health. One study showed those who consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia.[334] 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.[335] Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

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

Understanding these regional differences can help guide the allocation of resources to public health programs for Alzheimer's in the U.S. Table 5 displays the prevalence (both number and percentage) of Alzheimer's dementia for each state. 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.[336] As shown in both Table 5 and Figure 5, 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 (see "Racial and Ethnic Differences in the Prevalence of Alzheimer's and Other Dementias," page 37) — comprise larger percentages of the population. Although these estimates did not incorporate information related to health-related behaviors or health conditions, it is notable that the Southeast is the region with the highest prevalence of conditions such as hypertension, stroke and diabetes that raise the risk of dementia (see "Modifiable Risk Factors" in the Overview, page 20).[337]

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 2025 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 2025 if updated CHAP estimates were available.[338] 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).[338] 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.[15] 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.[339]

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, 340] As shown in Figure 6, 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.[340]

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.[293] Of the 7.2 million people age 65 and older with Alzheimer's dementia in the United States, 4.4 million are women and 2.8 million are men.[293] This represents 12% of women and 10% of men age 65 and older in the United States.[341]

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 in the Overview.

The estimate of 7.2 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, 293] 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.

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.

Estimated Prevalence 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 7.2 million figure reported here. This is because autopsy- and biomarker-based studies[25, 83, 295-297] 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 met the criteria for clinical Alzheimer's dementia based on symptoms did not have Alzheimer's-related brain changes. Thus, these studies indicate that prevalence 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 5 million Americans age 65 and older being classified as having dementia due to Alzheimer's disease in 2025.

Estimated Prevalence 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). 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.[298] The HRS HCAP study more recently estimated the prevalence of MCI in people age 65 and older to be 22%.[173] 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.[299, 300] Therefore, roughly 8% to 11% of the 65 million Americans who are age 65 and older in 2025 — or approximately 5 to 7 million older Americans — may have MCI due to Alzheimer's disease.[301] This estimate needs to be refined with population-based studies involving biomarkers and more precise estimates from narrower age ranges.

Estimated Prevalence 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 5 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 2025. 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.

Estimated Prevalence 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.[302] While this is still the subject of ongoing research, estimates are emerging of the prevalence of preclinical Alzheimer's disease in the population.[303, 304] 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 exceed all 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 7.2 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 5

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

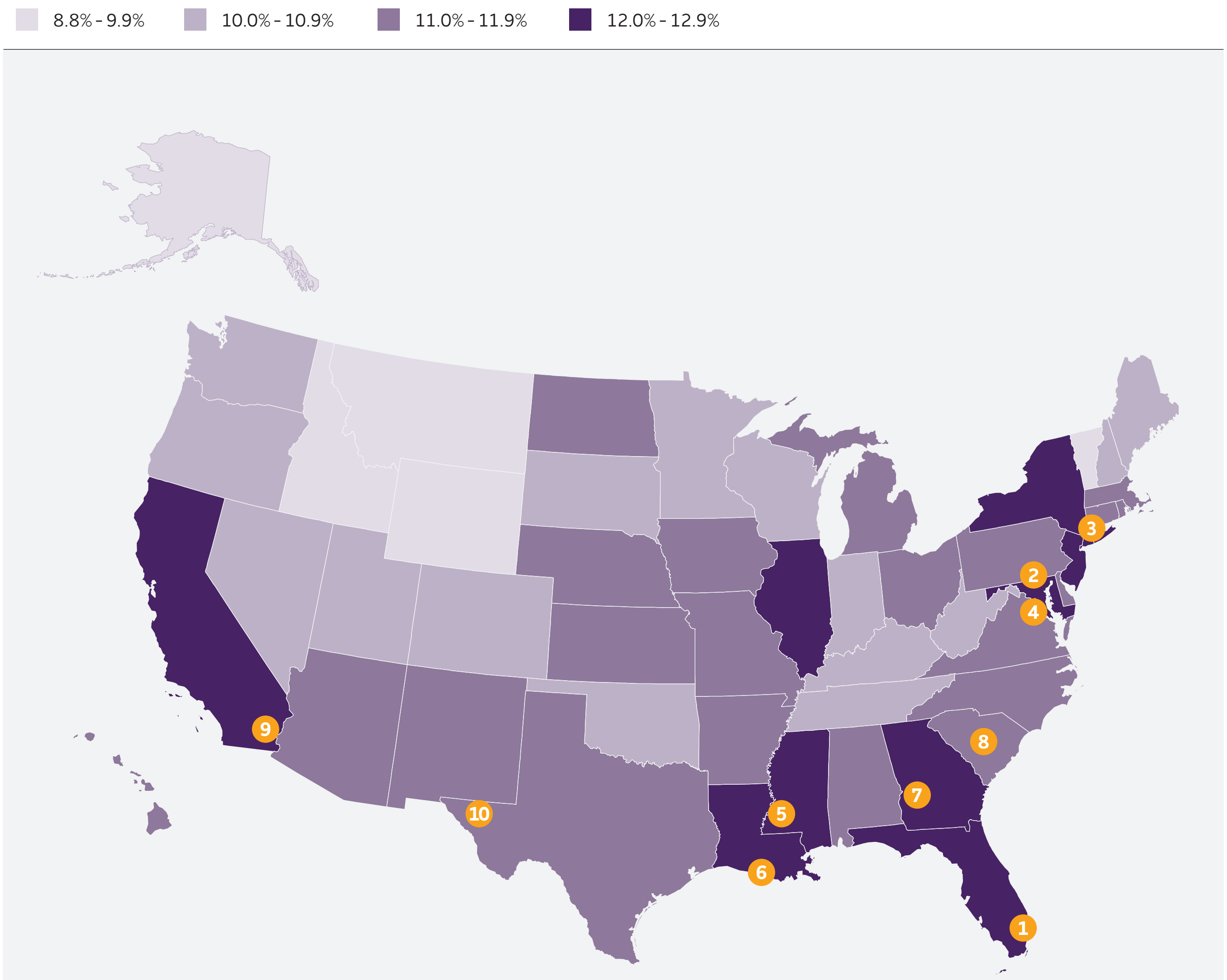
State	Number (in thousands)	Percentage
Alabama	103.6	11.8
Alaska	8.4	8.8
Arizona	151.5	11
Arkansas	60.4	11.3
California	719.7	12
Colorado	90.8	10.4
Connecticut	76.8	11.9
Delaware	22.3	11.3
District of Columbia	15.1	16.8
Florida	579.9	12.5
Georgia	188.3	12
Hawaii	31.2	11.3
Idaho	29.9	9.8
Illinois	250.6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

Created from data from Dhana et al.[336]

Prevalence estimates were derived from age, sex and race distributions of state and county populations.

FIGURE **5**

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



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. For detailed prevalence data for all U.S. counties, visit https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13081 and click on the last file in the Supporting Information section.

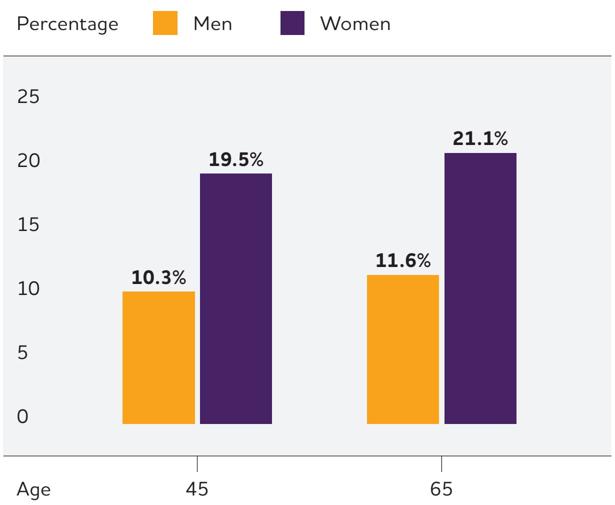
Created from data from Dhana et al.[336]

Older age is the greatest risk factor for Alzheimer's and other dementias, and women live longer than men on average; this survival difference contributes to higher prevalence of Alzheimer's and other dementias in women than in men.[340, 342-344] 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.[15, 90, 343, 345, 346] Similarly, some European studies have reported a higher incidence among women at older ages,[347, 348] while others have reported higher incidence among men.[349] One multi-country study found that incidence of all-cause dementia was greater in women than men, with this difference more pronounced in low- and middle-income countries than in high-income countries, and more pronounced in Africa and South America, than in Asia, Europe, and North America. Therefore, differences in the risk of dementia between men and women may depend in part on age, birth cohort, survival differences related to sex/gender, and/or geographic region.[350-352]

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.[342] Recent studies have supported the notion that survival bias contributes to reports of sex and gender differences in Alzheimer's dementia risk.[339, 353, 354] More research is needed to support this interpretation.

FIGURE **6**

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



Created from data from Chene et al.[340]

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[355] (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.[350, 356-358] 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.[359] 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.[360] In addition to differences in educational attainment relating to dementia risk differences in men and women, the same level of education may affect men's and women's dementia risk differently. Studies have found that the association of lower educational attainment with dementia and cognitive outcomes may be stronger in women than men.[361-363]

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.[364, 365] More recently, gender differences during the lockdown phase in the early part of the COVID-19 pandemic included increased child care responsibilities and job loss in sectors where women were more likely to be employed.[366-368] 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.[367]

It is unclear whether genetic risk operates differently in women and men in the development of Alzheimer's disease or susceptibility to the brain changes of Alzheimer's disease.[369] 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[370, 371] and neurodegeneration[372] 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.[373] It is unclear whether the influence of APOE-e4 may depend on the sex hormone estrogen.[358, 374, 375]

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 individuals. 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.[376-382] 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.[293] 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.[173, 338, 383, 384] 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,[384-386] though others have shown similar prevalences among Hispanic older adults and White older adults.[173] 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).[387, 388]

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.[389, 390] Genetic factors do not account for the large differences in prevalence and incidence among groups.[389, 391] 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[92-96, 392] — these differences in genetic influence do not operate in a way that explains the large elevated risk among Black individuals.

Instead, research suggests that differences in life experiences, socioeconomic indicators and health conditions most likely explain the difference in risk for Alzheimer's and other dementias among groups.[393-400] These health conditions include cardiovascular disease and diabetes, which increase Alzheimer's risk.[119, 394-398]

The cumulative stress resulting from social inequality 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, longstanding inequities contribute to racial and ethnic differences 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[399-402] and diabetes.[403, 404] 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.[92, 393, 405, 406] Many studies suggest that differences in dementia risk do not persist in rigorous analyses that account for health and socioeconomic factors.[169, 389, 407]

Some studies indicate that early life experiences can have detrimental effects on the cognitive health of Black Americans in later life.[119, 396, 397, 408-410] This points to a need for researchers to identify factors that may put some groups at increased risk for Alzheimer's and other dementias.[393, 406]

Many of the factors that influence the development of dementia 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.[307, 309, 312] 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.[411] 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 of 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.[390] 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.[412] 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.[413] 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.[387] We have limited understanding of Alzheimer's disease as experienced by people of Middle Eastern and North African descent,[414] and findings about dementia from American Indian older adults from certain regions of the U.S. may not generalize to those from other regions.[415] The combination of people from distinct countries and regions of Asia may mask important socioeconomic, political, and cultural influences on dementia.[416, 417] More studies, especially those involving community-based cohorts, are necessary to draw conclusions about the prevalence of Alzheimer's and other dementias in different groups and subgroups.

Non-Hispanic White populations also experience differences in Alzheimer's prevalence, including differences based on rural versus urban residence.[418, 419] More research is needed to understand rural versus urban differences in the prevalence of Alzheimer's and other dementias.

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

There are other groups that may experience different risks of Alzheimer's and other dementias. This includes members of sexual and gender minority (SGM) groups. SGM is a common term among scientific researchers that refers to individuals who identify as lesbian, gay, bisexual, queer and additional identities (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), commonly referred to as a whole as the LGBTQIA+ community.

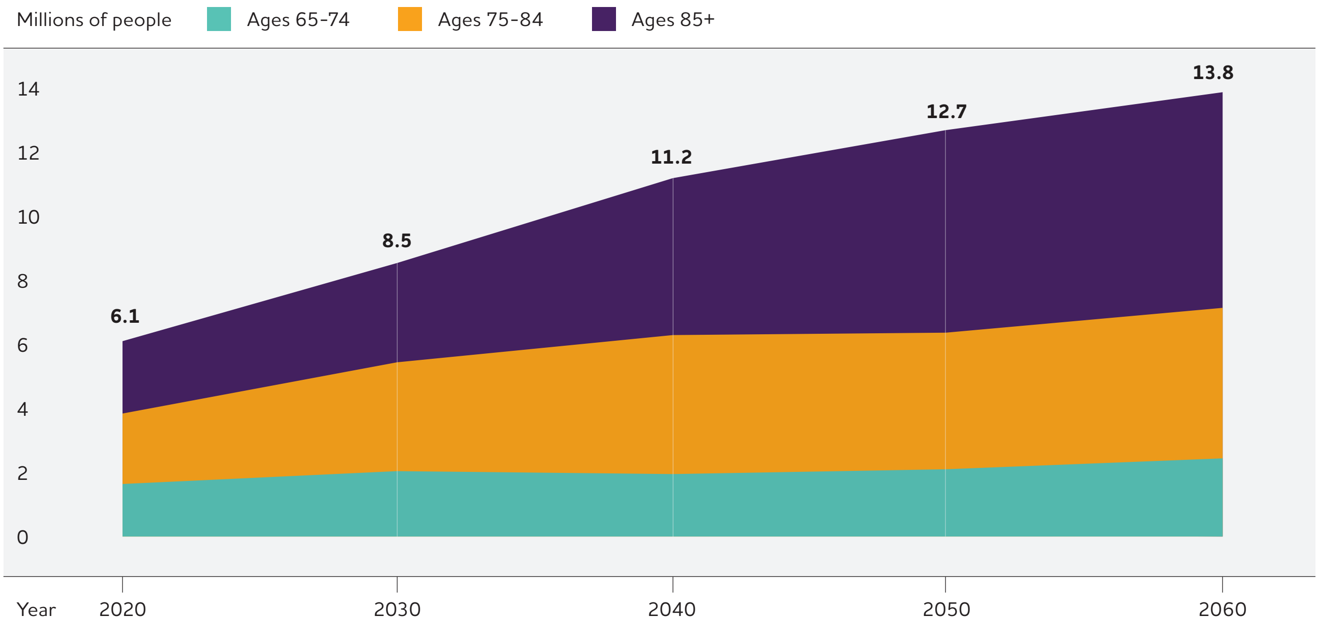
SGM older adults may face an increased dementia risk through exposure to discrimination, disadvantage and/or exclusion from social organizations and enterprises. Those enterprises include Alzheimer's research, and, until recently, little has been known about the dementia risks of people who identify as SGM. Although few studies have been designed to investigate whether SGM older adults are at greater risk for dementia than are 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 memory and thinking problems than non-SGM older adults.[420] Two population-based studies found higher rates of cognitive impairment among SGM older adults than among non-SGM older adults,[421, 422] 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.[423] Two studies found indications of potentially elevated dementia risk among transgender adults. Studies of Medicare beneficiaries estimated that 18%-21% of transgender adults age 65 and older had dementia, compared with 12%-13% of cisgender adults age 65 and older.[424, 425] 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.[426] 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.[427] More research is necessary to establish whether SGM older adults face elevated dementia risk.

Researchers have begun to examine what experiences are common among SGM individuals that might place them at increased risk for Alzheimer's and other dementias later in life.[357] The stressors SGM adults often face could take a toll on their physical and mentalhealth.[428] 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.[429] SGM 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.[430] 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.[431] Finally, research has tied HIV/AIDS and its burden of illness, mortality and social stigma to the SGM population, particularly gay and bisexual men and transgender people. HIV/AIDS is now a

This report keeps the population identifiers used in source documents when describing findings from specific studies.

FIGURE 7

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.[A5,293]

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 social stressors and health care access, HIV/AIDS itself can cause dementia.[432, 433]

Other areas of research examine the risk of subjective cognitive decline among transgender adults from different populations; the importance of delivering more effective and compassionate dementia care to a variety of populations; and the importance of considering the entirety of an individual's and a population's experience when addressing dementia risk.[434-437]

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

Several studies indicate that the prevalence (i.e., proportion)[312, 345, 411-413, 438-440] and incidence[349, 438-447] of Alzheimer's and other dementias in the U.S. and other high income countries may have declined from the 1970s to 2018,[349, 360, 438-446, 448-452] though results are mixed.[74, 338, 453, 454] One systematic review found that incidence of dementia decreased worldwide from 1977-2017 while incidence of Alzheimer's dementia, specifically, has held steady. More research on this distinction is needed, especially in low- and middle-income countries.[455] Declines in dementia risk have been attributed to increasing levels of education and improved control of cardiovascular risk factors.[360, 441, 444, 448, 456, 457] 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 have persisted past 2018 and will continue into the future. 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.[439, 458-461] It is also not clear that the encouraging trends pertain to all racial and ethnic groups.[338, 382, 456, 457, 462, 463] 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.[464] 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[465] 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 height of the pandemic, which may have resulted in death prior to the onset of Alzheimer's dementia, or death with fewer years lived with Alzheimer's dementia.[466]

Looking to the Future

Continued Population Aging

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).[289] 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 increased survival at older ages. Fertility, the average number of children per woman, has decreased since 1960 in the United States.[467] 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 7.[A5, 293] 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 breakthroughs to prevent or cure Alzheimer's disease.[A5, 293]

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.[289] 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.[468] This will result in an additional 10 million people age 85 and older — individuals at the highest risk for developing Alzheimer's dementia.[468]

- In 2025, about 2.5 million people living with Alzheimer's dementia are expected to be age 85 or older, accounting for 33% of all people with Alzheimer's dementia.[293]
- 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.[293]

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.[469]

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.[470] In parallel these generations of women came of age during a decrease in the birth rate, resulting in smaller family size.[471] Whether and how these social and economic experiences influence women's risk of and resilience to Alzheimer's and other dementia will become clearer in the decades ahead.

Since the 1970s, the gaps in income and net wealth, the value of an owned home, retirement accounts, and pensions minus debt, in the U.S. between lower-income, middle-income, and upper-income households has been widening.[472, 473] This means that the many people who are age 65 and older experienced their adulthood during this trend, which may have influenced health and health behaviors prior to age 65. In older adulthood, income and net wealth inequality may have implications for health care, health behaviors and social determinants of health that influence Alzheimer's risk, particularly in 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 highest risk for dementia in the coming decades.[447, 474, 475]

MORTALITY AND MORBIDITY

Among people aged 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 seventh-leading cause of death across all ages in the United States in 2022,[476] the most recent year for which final national mortality data is available. Before COVID-19 became the third-leading cause of death in 2020, Alzheimer's disease was the sixth-leading cause of death; preliminary data for 2023 indicates that Alzheimer's will once again be the sixth-leading cause of death.

Alzheimer's disease was the sixth-leading cause of death among individuals age 65 and older in 2022.[476] 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.[477] 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 2022, 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 Effect of the COVID-19 Pandemic on Deaths from Alzheimer's Disease" on page 43 for a discussion of the effect of the pandemic on Alzheimer's mortality). In 2022, Alzheimer's mortality trends were starting 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 the Prevalence section of this report (see page 29); to remain consistent with the U.S. Centers for Disease Control and Prevention (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 CDC, 120,122 people died from Alzheimer's disease in 2022.[476] 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."[478]

The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's deaths. In 2022, some form of dementia was the officially recorded underlying cause of death for 292,881 individuals (this includes the 120,122 from Alzheimer's disease).[476] This is more than twice 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.[479-482] 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.[480] Death certificates of individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[480, 481] 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."[483]

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 expected to occur in that year if the individuals did not have Alzheimer's dementia.[479] A more recent study using data from the nationally representative Health and Retirement Study estimated that about 14% of deaths among Americans age 70 and older from 2000 to 2009 were attributable to dementia, while only 5% of death certificates listed dementia as the underlying cause of death for this age group, suggesting underreporting on death certificates.[484] 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.[485] Based on data from the Chicago Health and Aging Project, in 2020 an estimated

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

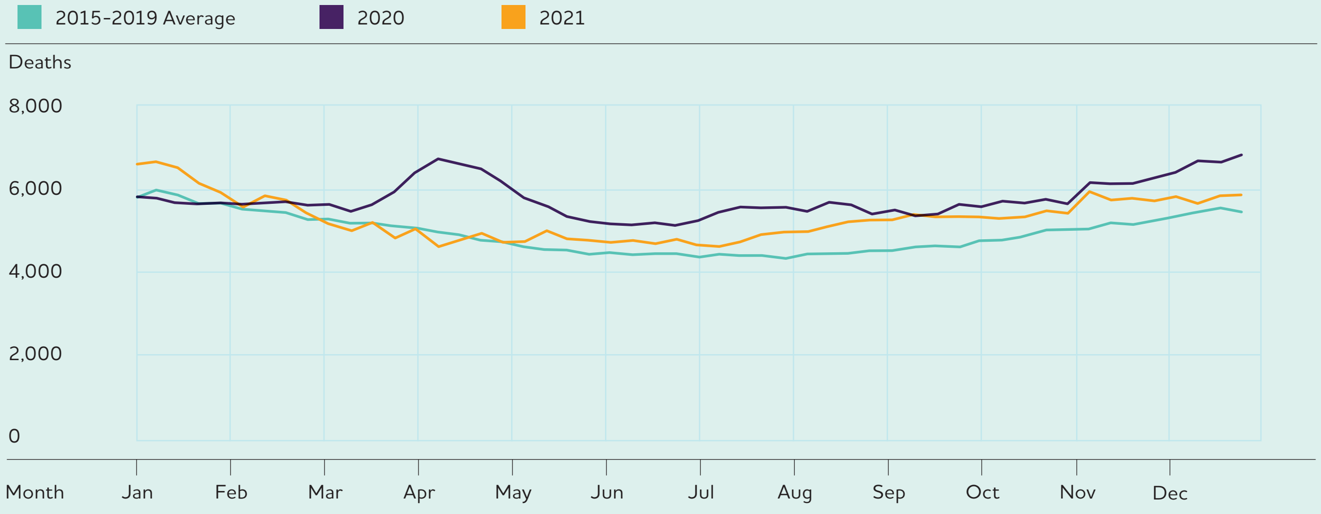
In 2020 and 2021, COVID-19 was the third-leading cause of death in the United States, pushing Alzheimer's disease from the sixth- to the seventh-leading cause of death.[488] Data for more recent years were still being compiled as of the time this report was written. Despite the change in rankings on 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.[476] COVID-19 was likely a significant contributor to the large increase in deaths from Alzheimer's. Data from the U.S. Centers for Disease Control and Prevention show that excess mortality (the difference between the observed number of deaths and the expected number of deaths during a given period) from any cause was very high during the height of the pandemic, especially among older adults.[489] Many of these excess deaths were in vulnerable older adults with Alzheimer's disease and other dementias. Among Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias, overall mortality increased 26% between 2019 and 2020, which is twice as high as the increase among beneficiaries without Alzheimer's disease and other dementias.[490] Furthermore, increased mortality between 2019 and 2020 among Medicare beneficiaries with Alzheimer's disease and other dementias was greater among Black, Hispanic and Asian beneficiaries than among White beneficiaries and the nursing home population.[490] As shown in Figure 8, 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.[489] 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.[476] 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. By contrast, in 2021, the number who died from Alzheimer's 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.[491]

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.[488]

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. With COVID-19 no longer as likely to be 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 **8**

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

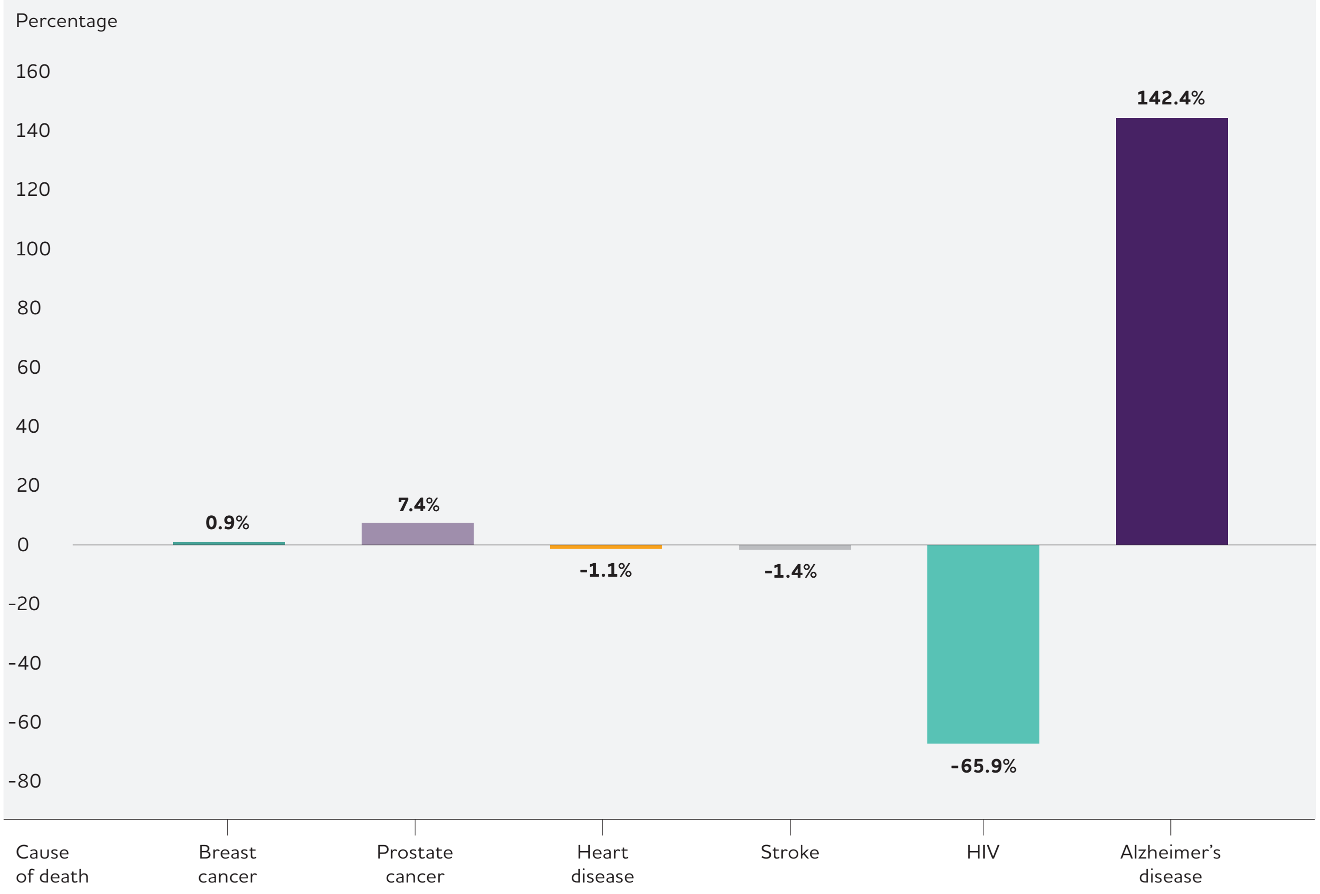


*Data for 2021 are as of February 7, 2022.

Created from data from the National Center for Health Statistics.[489]

FIGURE 9

Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2022



Created from data from the National Center for Health Statistics.[476, 492]

700,000 people age 65 and older in the United States had Alzheimer's dementia at death.[486] 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.

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 brain changes of another cause of dementia (see Table 1, page 6).[25, 83, 295-297] 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.[487]

Public Health Impact of Deaths from Alzheimer's Disease

Although the number of deaths from other major causes *decreased* significantly or remained approximately the same in the past two decades, official records indicate that deaths from Alzheimer's disease *increased* significantly. Between 2000 and 2022, the number of deaths from Alzheimer's disease as recorded on death certificates more than doubled, increasing 142.4%, while the number of deaths from the number-one cause of death (heart disease) decreased 2.1% (Figure 9).[476, 492] The increase in the number of death certificates listing Alzheimer's as the underlying cause of death probably

This report keeps the population identifiers used in source documents when describing findings from specific studies.

TABLE **6**

Number of Deaths and Annual Mortality Rate (per 100,000 People) From Alzheimer's Disease by State, 2022

State	Number of Deaths	Mortality Rate
Alabama	2,655	52.3
Alaska	178	24.3
Arizona	2,823	38.4
Arkansas	1,577	51.8
California	17,363	44.5
Colorado	1,871	32.0
Connecticut	1,080	29.8
Delaware	435	42.7
District of Columbia	70	10.4
Florida	6,397	28.8
Georgia	4,219	38.7
Hawaii	575	39.9
Idaho	848	43.7
Illinois	4,111	32.7
Indiana	2,259	33.1
Iowa	1,348	42.1
Kansas	944	32.1
Kentucky	1,509	33.4
Louisiana	2,094	45.6
Maine	543	39.2
Maryland	1,186	19.2
Massachusetts	1,596	22.9
Michigan	4,200	41.9
Minnesota	2,358	41.2
Mississippi	1,679	57.1
Missouri	2,620	42.4
Montana	338	30.1
Nebraska	746	37.9
Nevada	863	27.2
New Hampshire	462	33.1
New Jersey	2,320	25.0
New Mexico	733	34.7
New York	3,265	16.6
North Carolina	4,272	39.9
North Dakota	336	43.1
Ohio	4,953	42.1
Oklahoma	1,613	40.1
Oregon	2,030	47.9
Pennsylvania	4,011	30.9
Rhode Island	475	43.4
South Carolina	2,429	46.0
South Dakota	435	47.8
Tennessee	2,933	41.6
Texas	10,427	34.7
Utah	1,057	31.3
Vermont	329	50.8
Virginia	2,506	28.9
Washington	3,695	47.5
West Virginia	755	42.5
Wisconsin	2,361	40.1
Wyoming	240	41.3
Total	**120,122**	**36.0**

Created from data from the National Center for Health Statistics.[A6,476] 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.[493]

State-by-State Deaths from Alzheimer's

Table 6 provides information on the number of deaths due to Alzheimer's by state in 2022, 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 from Alzheimer's disease across states with varying population sizes. For the United States as a whole, in 2022, the mortality rate for Alzheimer's disease was 36 deaths per 100,000 people.[A6, 476]

Alzheimer's Death Rates

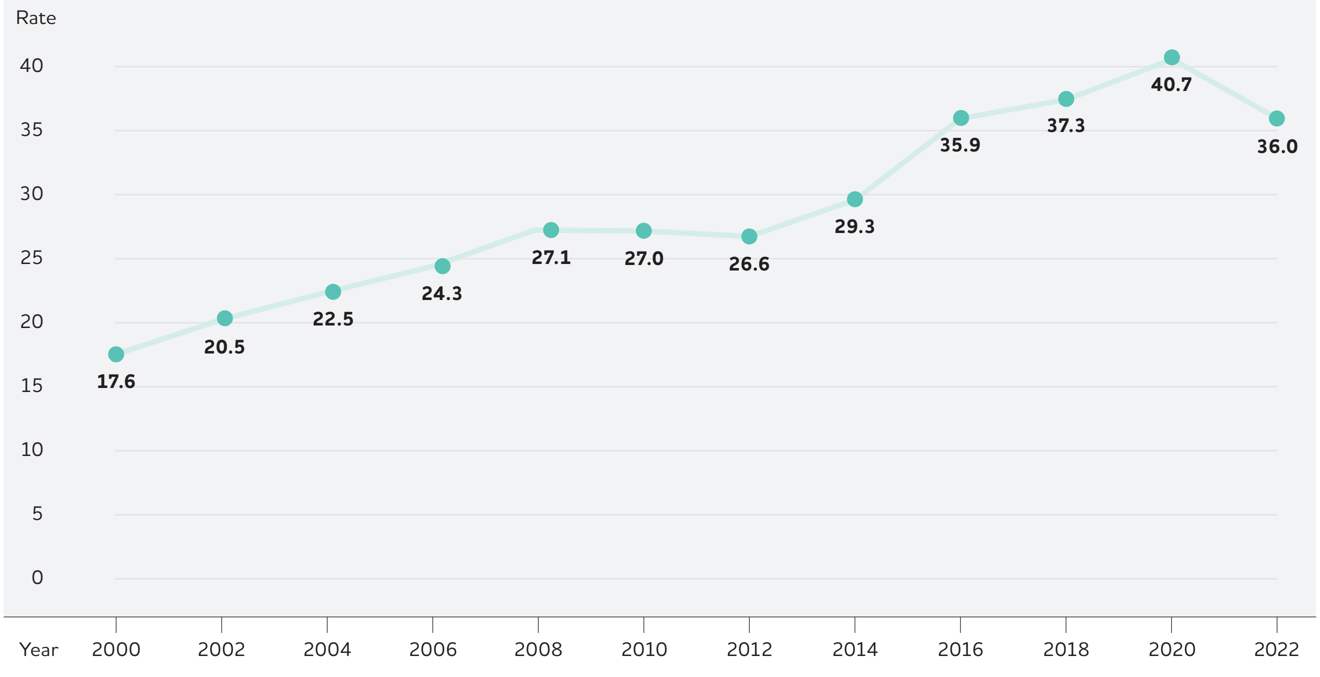
As shown in Figure 10, the annual rate of deaths from Alzheimer's — that is, the number of Alzheimer's deaths per 100,000 people in the population — has risen substantially since 2000.[476] Table 7 shows that the annual rate of death from Alzheimer's increases dramatically with age, especially after age 65.[A6, 476] The increase in the Alzheimer's death rate over time has disproportionately affected people age 85 and older.[492] Between 2000 and 2022, the death rate from Alzheimer's increased 43% for people age 65 to 74, 48% for people age 75 to 84 and 70% for people age 85 and older.[476] 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.[493] 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.[493]

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

Studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of

FIGURE **10**

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



Created from data from the National Center for Health Statistics.[476]

TABLE **7**

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	2022
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	3.5
65-74	18.7	19.6	19.5	19.9	21.1	19.8	17.9	19.6	23.6	24.7	28.6	26.7
75-84	139.6	157.7	168.5	175.0	192.5	184.5	175.4	185.6	214.1	213.9	229.3	206.2
85+	667.7	790.9	875.3	923.4	1,002.2	987.1	936.1	1,006.8	1,216.9	1,225.3	1,287.3	1,131.5

Created from data from the National Center for Health Statistics.[476]

Alzheimer's dementia, yet some live as long as 20 years with Alzheimer's dementia.[15-23] 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.[487] Much of this time will be spent in a nursing home (see the Use and Costs of Health Care, Long-Term Care and Hospice section, page 76). 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.[487] In all, an estimated two-thirds of those who die from dementia do so in nursing homes, compared with 20% of people with cancer and 28% of people dying from all other conditions.[494]

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 a combination 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.[477] In 2016, Alzheimer's disease was the fourth highest disease or injury in terms of YLLs and the 19th in terms of YLDs.[477]

These disability estimates are based on data across U.S. states and should be interpreted with consideration of the comparability of data across time[495] and how disability is incorporated. The 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, attitudes and economic and social resources, which may vary widely both across and within countries.[496-498] 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 the population aging, the percentage of deaths from 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

Nearly 12 million Americans provide unpaid care for a family member or friend with dementia, a contribution to the nation valued at more than $413 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.[499, 500] 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 8). 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).**

TABLE **8**

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 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 dementia, 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.

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.[501] Nearly half of all unpaid caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.[502] More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A7] Table 9 provides details about unpaid caregivers.

In 2024, caregivers of people with Alzheimer's or other dementias provided an estimated 19.2 billion hours[A8] of informal — that is, unpaid — assistance, a contribution valued at $413.5 billion.[A9] This is approximately 64% of the net value of Walmart's total revenue in fiscal year 2024 ($648.1 billion)[503] and nearly 16 times the total revenue of McDonald's in 2023 ($25.9 billion).[504] The total lifetime cost of care for someone with dementia was estimated at $405,262 in 2024 dollars.[505] 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. The remaining costs encompass payments by Medicare and Medicaid (see the Use and Costs of Health Care, Long-Term Care and Hospice section, page 78).[505, 506] Current estimates of the lifetime costs of care may underestimate the financial impact of a relative's dementia on family caregivers' health and caregivers' 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.[507]

TABLE 9

Who Are the Caregivers?

Sex/gender	• Approximately two-thirds of dementia caregivers are women.[A10, 516, 517]
Race/ethnicity	• Two-thirds of caregivers are White,[A10, 517, 518] 10% are Black, 8% are Hispanic, and 5% are Asian American.[A10] The remaining 10% represent a variety of other populations.
Living status	• Most caregivers (66%) live with the person with dementia in the community.[510] • Over 60% of caregivers are married, living with a partner or in a long-term relationship.[A10, 517] • 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, 518, 519]
Caring for parents	• Over half of caregivers are providing assistance to a parent or in-law with dementia.[518] • 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.[520-522]
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, 517, 518]
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.[523]
Caring for spouse	• Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.[518]

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.[508]

One-third of people living with dementia have received help from family members at least two years prior to a positive dementia screen from a health care provider.[509] 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.[510] 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.[510] 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.[511]

Living alone with dementia may be a particular challenge for certain subgroups, such as sexual and gender minority (SGM) individuals, who may experience greater isolation due to social stigma and a diminished social network of available family or friend caregivers.[512-515]

Caregiving and Women

The responsibilities of caring for someone with dementia are often assumed by women. Approximately two-thirds of dementia caregivers are women.[A10, 516, 517, 522] 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).[524] Over one-third of dementia caregivers in the United States are daughters caring for a parent.[501, 510] It is more common for wives to provide informal care for a husband than vice versa.[525] On average, female caregivers spend more time caregiving than male caregivers.[510] The 2021-2022 Behavioral Risk Factor Surveillance System surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 70% were women.[519] Two and a half times as many women as men reported living with the person with dementia full time.[526] Of those providing care to someone with dementia for more than five years, 64% were women.[519] 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.[527-529]

Race, Ethnicity and 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%).[530] Although Black individuals have more kin (children, grandchildren, other family members) available as potential caregivers than their White counterparts, Black individuals are also more likely to have more kin with dementia when compared to White individuals.[531] Indeed, when compared with White caregivers, Black caregivers are more likely to provide more than 40 hours of care per week (54.3% versus 38.6%) and more likely to care for someone with dementia (31.7% versus 11.9%). Black caregivers of people with dementia are also more likely to provide help with ADLs than White caregivers of people with or without dementia.[532, 533] Among Hispanic and non-White dementia caregivers, support service use (e.g., respite, support groups) was higher in metropolitan (35%) than in non-metropolitan (15%) communities.[534]

Black male dementia caregivers are 3.3 times more likely to experience financial burdens when compared with White male or female dementia caregivers.[535] White dementia caregivers report less severity of cognitive and functional decline in care recipients when compared to all other race/ethnic groups.[536] Hispanic, Black and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use and greater depression compared with White caregivers.[537-541] Unlike White individuals, Black and Hispanic individuals who assume dementia care responsibilities are in poorer health than non-caregivers.[542] In addition, the stress of caregiving may exacerbate adverse health outcomes.[543]

Black caregivers are more likely than White caregivers to report positive aspects of caregiving.[532] 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.[544] Support from family and friends is associated with better self-rated health for Black dementia caregivers but not for White or Hispanic caregivers.[539] A more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among Black and White caregivers.[539, 545]

The need for culturally informed theories, research frameworks, and services for people living with dementia and their caregivers is pronounced.[546-550] 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.[551, 552] 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.[553] Black/African American dementia caregivers' needs include more information about dementia treatment, diagnosis and care strategies; more support when navigating the health care system; improved access to affordable transportation and health care services; more information 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.[538, 554-557] Also, 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.

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 populations.[541] This will help ensure that all caregivers receive the benefits of prevention, treatment and care innovations.[539, 541, 558] In addition, establishing stronger relationships with existing organizations and resources in Black, Indigenous and other communities offers the potential for research-based partnerships to enhance representation in dementia research and result in more culturally appropriate and effective services.[547, 553, 559-573]

Caregiving Tasks

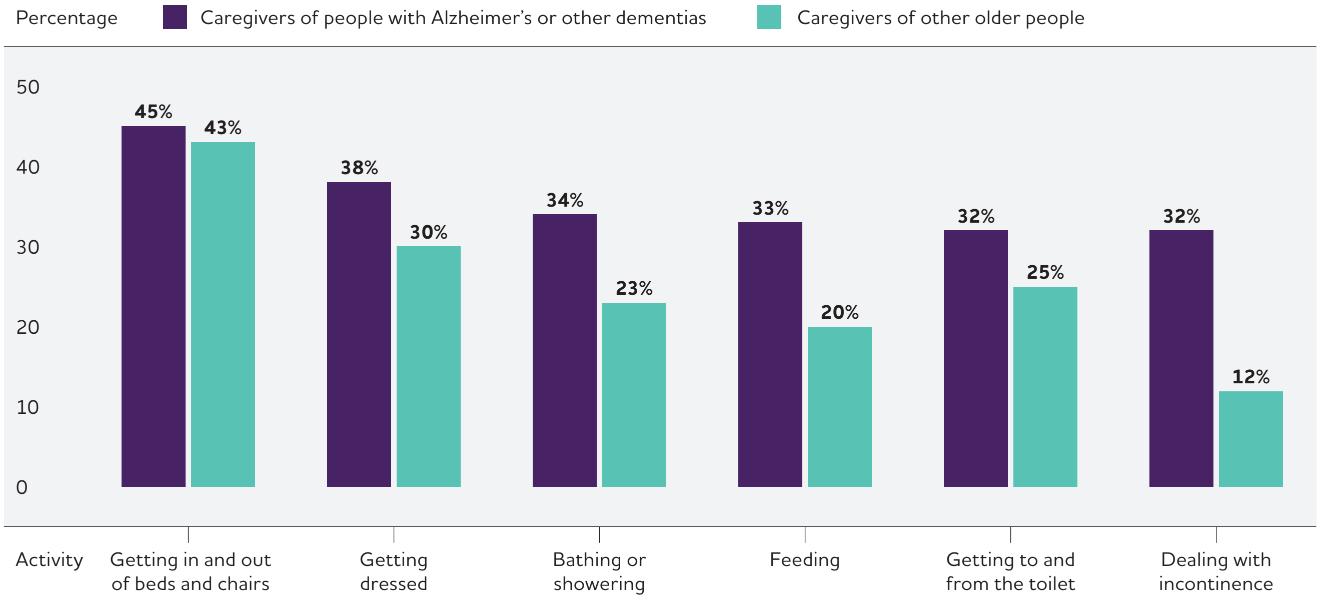
The care provided to people with Alzheimer's or other dementias is wide-ranging and in some instances all-encompassing. Table 8 (see page 49) summarizes some of the most common types of dementia care provided.

Although the care provided by family members of people with Alzheimer's or other dementias can be similar to that provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance.[574] Family caregivers of people with dementia are more likely to monitor the health of the care recipient than

This report keeps the population identifiers used in source documents when describing findings from specific studies.

FIGURE **11**

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.[518]

are caregivers of people without dementia (79% versus 66%).[575] Data from the 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%).[502, 516] Figure 11 illustrates how caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.[518]

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.[576]

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 8 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.[577, 578]

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.[510]

Hours of Unpaid Care and Economic Value of Caregiving

In 2024, the 11.9 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 19.2 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 $413.5 billion in 2024. Table 10 shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's or other dementias provided care valued at more than $5 billion in each of 27 states. Unpaid caregivers provided care valued at more than $22 billion in each of the four most populous states — California, Texas,

TABLE **10**

Number of Caregivers of People with Alzheimer's or Other Dementias, Hours of Unpaid Care and Economic Value of Unpaid Care by State, 2024*

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Alabama	219	391	$5,918
Alaska	25	39	887
Arizona	240	377	9,563
Arkansas	173	265	5,426
California	1,396	1,894	50,670
Colorado	178	309	8,152
Connecticut	130	205	5,266
Delaware	32	47	1,052
District of Columbia	15	15	334
Florida	870	1,367	29,401
Georgia	384	775	13,273
Hawaii	62	111	2,891
Idaho	73	116	2,278
Illinois	316	488	12,450
Indiana	219	325	6,875
Iowa	80	118	2,663
Kansas	90	127	2,367
Kentucky	160	307	4,944
Louisiana	252	420	6,766
Maine	66	102	2,887
Maryland	258	292	7,001
Massachusetts	218	252	6,670
Michigan	385	883	19,242
Minnesota	166	228	5,491
Mississippi	92	174	2,539
Missouri	226	354	9,511
Montana	17	25	$578
Nebraska	41	63	1,520
Nevada	87	146	3,068
New Hampshire	48	77	1,820
New Jersey	279	506	13,017
New Mexico	67	119	2,501
New York	656	893	22,555
North Carolina	381	739	13,028
North Dakota	19	26	502
Ohio	452	679	13,329
Oklahoma	108	189	3,322
Oregon	192	218	4,544
Pennsylvania	470	831	15,901
Rhode Island	37	52	1,432
South Carolina	224	369	7,247
South Dakota	27	35	925
Tennessee	386	675	13,243
Texas	1,089	1,878	33,093
Utah	115	137	2,886
Vermont	20	29	773
Virginia	346	670	14,202
Washington	254	390	11,036
West Virginia	65	116	1,950
Wisconsin	205	297	5,979
Wyoming	16	21	486
U.S. Total	**11,926**	**19,161**	**413,454**

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

Created from data from the 2016, 2020, 2021, 2022, and 2023 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]

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.[579] 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.[510, 580]

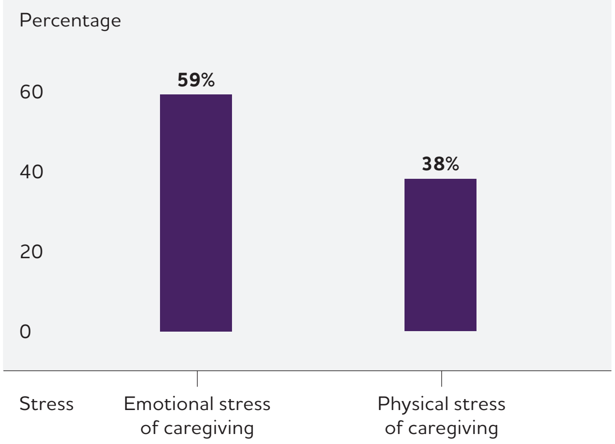
Apart from its long duration, caregiving involves time-intensive demands. Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.[516] An analysis of national caregiving trends from 1999 to 2015 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.[581] 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 five hours a day to nine 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).[582, 583] 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.[584] 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 per month; for those without dementia, an additional self-care need was associated with an increase of 15 hours of family care per month.[585] Among caregivers seeking emergency care, dementia caregivers provided more hours of care per day on average (14 hours per day) when compared to caregivers of those with undiagnosed cognitive impairment (10 hours per day) and caregivers of those with no cognitive impairment (two hours per day).[586]

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.[587-589] 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; neglect of their own health due to caregiving priorities;[590, 591] 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.[592-599]

FIGURE **12**

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 memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of dementia. In the 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.[522] In the National Study of Caregiving, greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends.[600] Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,[A10, 601-609] 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.[516, 574]
- 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 12).[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.[610]
- 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.[611]

Depression and Mental Health (see also Table 11, page 57)

- A meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers.[529] Dementia caregivers also indicate more depressive symptoms than non-dementia caregivers.[612]
- 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%).[613, 614]
- Caring for a spouse with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.[615]
- In a meta-analysis, relationship type 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.[613]
- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).[613]
- 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).[524]
- 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.[616, 617]
- 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.[618]
- 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 (an exact age comparator is not available).[619, 620]
- Providing physical and medical care is associated with worse mental health among dementia caregivers than among non-dementia caregivers.[574]

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 or nursing-related tasks (for example, injections, tube feedings and catheter or colostomy care) was difficult.[575]
- Dementia caregivers often experience challenges managing medications for individuals with dementia, such as non-adherence.[621-624]
- Compared with non-dementia caregivers, dementia caregivers indicate a greater decrease in their social networks (e.g., other relatives, friends, acquaintances).[625]
- 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.[626]
- Many caregivers of people with Alzheimer's or other dementias are at risk of social isolation.[627] 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 living in high-income neighborhoods.[628]
- In a survey of caregivers from a large health care system, fewer than 4 in 10 respondents (39.2%) agreed that their primary care providers help them with managing symptoms of a care recipient with dementia.[629]
- A growing literature has considered positive aspects of dementia caregiving (feelings of "finding meaning, satisfaction, gains, uplift, rewards, esteem, gratification, and coping" associated with care provision).[601, 607, 630] A systematic review has found that positive aspects of caregiving have been found to be negatively associated with dementia caregivers' depressive symptoms, other negative mental health symptoms (e.g., anxiety), and burden and positively associated with dementia caregivers' quality of life, psychological well-being and perceptions of competence/self-efficacy.[601]

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.[631] However, those caregivers of individuals with a formal dementia diagnosis were also more engaged in communication during doctors' visits and 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.[631] Care partners of those with mild cognitive impairment did not indicate more significant burden following scans resulting in elevated amyloid in care recipients. Care partners did anticipate increasing responsibility related to caregiving tasks and duties, however.[632]
- 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.[578, 633-635]
- The demands of caregiving may intensify as people with dementia approach the end of life.[636] 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.[637] The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.[637]
- 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).[638]

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.[639] As shown in Figure 12, 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.[640] 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.[641-644] 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.[642]

Tables 11 and 12 present data on caregiver physical and mental health. Table 11 presents state-by-state data on the health status of dementia caregivers, and Table 12 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.[522, 645, 646] 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.[647-650]

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.[651-658] 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.[659] However, a

TABLE 11

Percentage of Dementia Caregivers Reporting Health Conditions by State, 2016 to 2023

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	59.3	24.0	13.8
Arkansas	69.2	30.3	18.2
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	61.0	21.3	12.2
Idaho	64.3	28.9	17.5
Illinois	64.2	29.0	†
Indiana	57.3	34.1	18.2
Iowa	62.2	27.2	12.4
Kansas	60.6	33.8	18.7
Kentucky	65.5	39.8	21.4
Louisiana	67.8	32.6	16.2
Maine	71.5	29.7	20.0
Maryland	62.6	21.3	11.6
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	61.8	18.4	13.4
North Carolina	58.8	41.0	18.1
North Dakota	60.1	30.4	8.6
Ohio	62.8	27.3	14.9
Oklahoma	68.2	39.6	17.2
Oregon	63.2	31.8	14.8
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	67.3	33.4	16.4
Texas	56.4	23.9	16.0
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.[519]

TABLE **12**

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	4.1	3.8	3.3
Coronary heart disease	8.6	7.2	6.4
Cardiovascular disease†	11.1	9.8	8.6
Diabetes	13.3	12.7	11.7
Cancer	18.4	14.3	11.8
Obesity	37.0	38.6	38.2

*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.[519]

study of physiological changes before and after the start of caregiving found no change in six biomarkers of inflammation among dementia caregivers.[660]

Health Care

Dementia caregivers have twice the odds of experiencing a hospitalization than non-caregivers.[661] Nearly 1 in 5 dementia caregivers are hospitalized when assisting spouses with dementia, and almost 70% of these hospitalizations are unexpected. One in three spousal dementia caregivers are "not all prepared" for hospitalization.[662] 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.[663, 664] 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.[664]

Mortality

Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.[665, 666] 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).[667] In addition, caregivers who perceived higher strain due to care responsibilities were at higher risk for death than caregivers who perceived little or no strain.[668] 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.[665] 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. Eighteen percent of spousal caregivers die before their partners with dementia.[669]

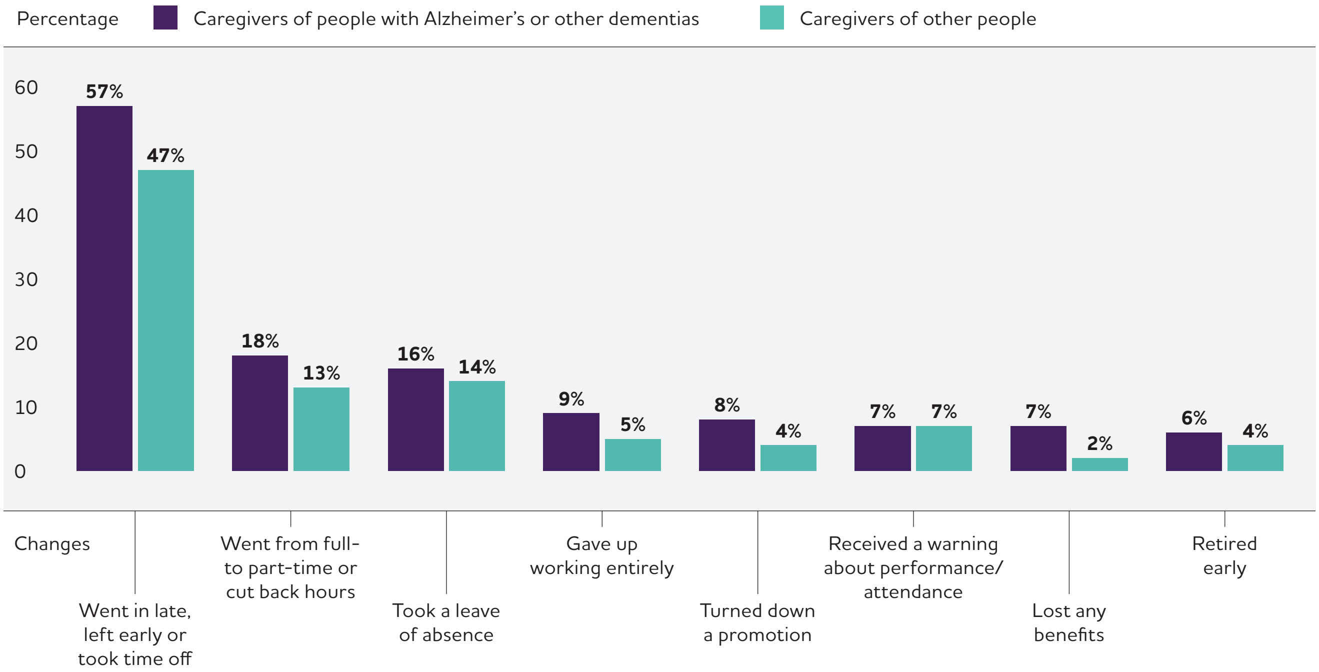
Caregiver Employment and Finances

Six in 10 caregivers of people with Alzheimer's or another dementia were employed or had been employed while providing care in the prior year.[518] These individuals worked an average of 35 hours per week while caregiving.[518] 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 were 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 13.[518] In the 2018 National Health and Wellness Survey, nearly 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.[524] In addition, caregivers living with a family member with dementia pay for 64% of total uncompensated care costs (e.g., total health care spending and out-of-pocket costs) incurred during their relatives' last seven years of life.[670]

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).[506, 671] 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.[672, 673] National survey data among "care contributors" (a friend or relative who paid for

FIGURE 13

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.[518]

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.[598] 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.[598]

One in five caregivers of people with Alzheimer's or other dementias (22%) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia, compared with 9% of caregivers of people without dementia.[518]

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.[674] 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.[586] People with dementia whose care networks featured more complex care arrangements (e.g., involvement of nonimmediate family members and caregivers who assist with a broad range of tasks) are significantly more likely to experience an emergency department visit.[675] In addition, care recipients with dementia who rely on more caregivers or whose caregivers indicate greater distress are also more likely to experience hospitalization.[676-678] 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 placement in a residential care home. However, effects sizes are small.[679]

TABLE 13

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.,[596] Gaugler et al.[680] and Walter and Pinquart.[692]

Interventions Designed to Assist Caregivers

For almost 40 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 13.[596, 680]

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.

The following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers but of people living with dementia as well.[681] 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.[682] 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.[683-688] 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,[689] other meta-analyses report that specific intervention types (such as psychoeducation; see Table 13) 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.[679, 690-694] 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.[695]

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.[747-757] 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.[758] For these reasons, the pandemic has created a crisis for dementia caregivers.[747, 759, 760]

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.[761] 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.[762, 763] 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.[763, 764] Studies of end-of-life care during the pandemic indicated that dementia caregivers felt that physical and social isolation adversely influenced the death and dying experience of relatives during the pandemic.[765] Adult day programs and other community-based services in many states were also interrupted or closed.[766] These and other factors shaped by the COVID-19 pandemic were associated with emotional distress and other negative outcomes among caregivers.[712, 767] 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.[767]

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.[533] In a survey, women dementia caregivers were more likely to indicate a need (e.g., requiring more support for medical care, food, housing, mental health, financial services, transportation, support with caregiving, employment) for help providing care during the pandemic, whereas men indicated more need for help with medical care and employment. Men were also more likely to report psychological distress.[768] Together, these findings suggest 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.[769, 770]

Studies have shown that family caregivers who were able to engage in more 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.[771] 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.[772-775] 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.[763] Health care professionals who provided 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.[776-778]

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.[779] 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.[780, 781] Concerns remain, however, about the "digital divide" facing caregivers who do not have reliable broadband access or do not regularly use the internet. Although some degree of "normalization" has occurred in dementia caregiving, there are likely lasting effects from the lockdowns and other responses to the pandemic. The significant ramifications of the COVID-19 pandemic for people living with dementia and those who care for them continues to raise questions about how we can address these concerns to alleviate caregiver burden/stress in future public health emergencies.

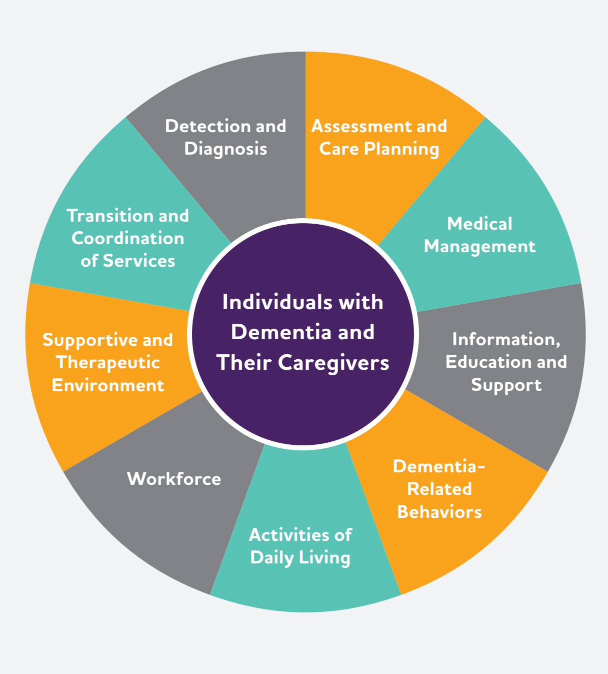
Interventions for dementia caregivers that have demonstrated efficacy in scientific evaluations have been gradually implemented in the community, but are still not widespread or available to all family caregivers.[696-698] When interventions are implemented, they are generally successful at improving 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).[699-702] 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.[703] 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),[704-712] while others have disseminated evidence-based dementia care interventions into community-based programs and health care systems.[699, 713, 714] Dissemination efforts, such as *Best Programs for 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.[715]

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.[716-720] Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.[721-726] 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.[513, 541, 727-734] Additional research on interventions focused on disease stages is also required, as is research on specific intervention needs for LGBTQIA+ 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-LGBTQIA+ dementia caregivers.[515, 735, 736]

In 2019, the National Institute on Aging (NIA) awarded funding to create the NIA Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory. The Collaboratory included 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 was 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.[737, 738]

FIGURE 14

Person-Centered Care Delivery



Created from data from the Alzheimer's Association.[739]

The Alzheimer's Association has also undertaken several efforts to improve dementia care interventions and services. Its dementia care practice recommendations[739] place individuals with dementia and their caregivers at the center of how care should be delivered. 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.[740, 741] Frameworks such as the Alzheimer's Association dementia care practice recommendations are designed to shift how researchers and care providers think about dementia and may point the way to a greater understanding of the resilience, adaptability and possibilities of maintenance or even improvement of skills and abilities when living with dementia.[742, 743] 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).[581] 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 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.[744] 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).[745] 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.[737, 746]

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 U.S. 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.[782] In a 2024 progress report, almost all of the 350 federal actions recommended in the 2022 National Strategy are implemented or in process to support family caregivers. This includes $20 million in funding to support the strategy's implementation and federal guidance to states so that new or updated state plans on aging align with the National Strategy's recommendations.[783]

On July 1, 2024, the Centers for Medicare & Medicaid Services (CMS) launched the Guiding an Improved Dementia Experience (GUIDE) Model. Three-hundred and ninety organizations are participating as GUIDE Model sites across the U.S. 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 (see the Workforce section, page 74, for more information about the GUIDE Model).[784]

WORKFORCE

Nearly 900,000 additional direct care workers will be needed between 2022 and 2032 — more new workers than in any other single occupation in the United States.

As the prevalence of Alzheimer's and other dementias increases, so does the need for more members of the paid workforce to be knowledgeable about and skillful in working with diverse populations living with these conditions as well as with their families.[785, 786] A collaborative, multidisciplinary dementia-capable workforce is needed to cover the full spectrum of health and social care for people living across the disease continuum — from identifying a cognitive or memory concern, through screening for and diagnosing its cause, to treating it, monitoring its progression and providing hands-on care for those affected.

This multidisciplinary workforce includes, but is not limited to, primary care providers (PCPs), including physicians 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 that interacts with the public, including community health workers as well as non-medical professionals such as police officers, bank tellers, librarians, hairdressers, bus drivers, attorneys, faith leaders and others.

Each of these professionals plays a crucial role in addressing the diverse needs of people living with Alzheimer's disease and other dementias and their families. However, the current siloed approach to dementia diagnosis and management often leads to fragmented care and missed opportunities for early intervention and ongoing support. In contrast, a more collaborative, integrated workforce can lead to earlier detection and diagnosis of cognitive impairment, more comprehensive and coordinated care planning, improved management of coexisting conditions, enhanced support for family caregivers, better utilization of community resources and, overall, increased sensitivity to the needs of people living with dementia and their families.

Defining the Members of the Dementia-Capable Workforce

Primary Care Providers

Individuals, family caregivers and PCPs alike view the PCP as the first or key point of contact for managing health care.[787, 788] Therefore, PCPs are central to the dementia care workforce.

A PCP is a physician (M.D. [medical doctor] or D.O. [doctor of osteopathic medicine]), nurse practitioner, clinical nurse specialist or physician assistant who provides, coordinates or helps patients access a range of health care services, as allowed under each state's laws.[789] PCPs are well-situated to detect dementia because they often have long-standing relationships with patients[790, 791] 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 increased emergency department visits or hospitalizations.

While more evidence is needed to support screening of asymptomatic individuals,[792] 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.[298, 793, 794] Based on patients' ages and other factors, we can expect a certain number of patients to present with mild cognitive impairment (MCI). However, a recent survey of 226,756 primary care clinicians and 54,597 primary care practices found that only 0.1% of clinicians and practices had MCI detection rates within the expected range (as indicated by a predictive model).[324]

If a person shows signs of cognitive impairment during a routine doctor's visit, Medicare covers a separate visit to more thoroughly assess the person's cognitive function and develop a care plan, reimbursed through billing code 99483.[795, 796] Medicare covers a second visit six months or more after the initial assessment and care plan visit. The U.S. Government Accountability Office (GAO) analyzed data for this billing code, finding that use of the cognitive assessment and care plan service in traditional fee-for-service Medicare tripled from 32,099 to 99,720 visits between 2018 and 2022. Despite this tripling, the overall use of the service was relatively low among Medicare beneficiaries diagnosed with cognitive impairment; the GAO estimated that in 2021, the most recent year for which data for this analysis were available, only 2.4% of beneficiaries with a dementia diagnosis had received the service through traditional Medicare.[797] Since similar services can be delivered using other billing codes, it is difficult to determine whether beneficiaries are not getting cognitive assessment and care plan services at all or are simply not getting them under billing code 99483.[797]

PCPs report numerous barriers to detecting cognitive impairment and diagnosing dementia.[320] 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 busy primary care practice settings.[790, 798] The vast majority of initial dementia diagnoses are made by PCPs, but studies have found that 50% or more of patients with Alzheimer's dementia are not diagnosed until the moderate or advanced stage of dementia.[305, 799] Delays are even longer, on average, among individuals from racial and ethnic minority groups.[311, 313, 800-802] For example, a recent study of 88 African Americans with cognitive impairment found that dementia was diagnosed in less than two years for 55% (after baseline cohort evaluation), while for 18%, there was no diagnosis for up to 10 years or more. Twenty-seven percent were diagnosed between two and 9.9 years after cohort evaluation. These results suggest that the health care system may miss opportunities for early dementia diagnosis and intervention in African American adults.[313]

In addition to barriers to detection and diagnosis, PCPs may experience barriers to disclosing a dementia diagnosis and providing follow-up care, with many PCPs reporting low confidence in their ability to communicate a dementia diagnosis and provide post-diagnostic care.[790, 803] 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. Indeed, 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, more than 25% reported being "never" or "only sometimes" comfortable answering patients' questions about Alzheimer's or other dementias, and 50% did not feel adequately prepared to care for individuals who had been diagnosed.[804] 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.[320]

The timeliness of dementia detection and diagnosis can profoundly impact the quality of life and care trajectory for affected individuals and their families. Early detection of cognitive impairment opens up crucial opportunities that can make a substantial difference in outcomes. These opportunities include the ability to plan for future care needs; participate in clinical trials; access FDA-approved disease-modifying therapies and therapies for symptom management; make informed decisions about medical, financial and legal matters; and pursue appropriate services and supports, such as participating in support groups for people living with dementia.

While PCPs play a vital role in early detection and diagnosis, they have a sustained role through all stages of disease progression, and are therefore central to the collaborative, coordinated management of dementia care, as described throughout this section. The Special Report from *2024 Alzheimer's Disease Facts and Figures* described the ideal future state of dementia care, highlighting the role of PCPs within a collaborative model, linking dementia care management and navigation to better dementia care.[805]

Geriatricians and Other Specialists

A study of Medicare beneficiaries found that 85% of people living with dementia were diagnosed by providers who do not specialize in dementia (primarily PCPs); however, among the remaining 15% diagnosed by providers who specialize in dementia, 47% were diagnosed by psychiatrists, including geriatric psychiatrists and neuropsychiatrists, 44% by neurologists and 9% by geriatricians.[806] This distribution highlights the need for enhanced training and support for PCPs, who are often the first point of contact for individuals with cognitive concerns — but it also underscores the importance of access to specialist care, particularly geriatricians, because of the often complex, multifaceted needs related to the diagnosis and care of someone living with dementia as well as their caregivers.

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. While an estimated 30% of people age 65 and older who have complex medical needs — including frailty or other geriatric conditions, disability, dementia, or require palliative and end-of-life care— would benefit from geriatrician care; the remaining 70% of older adults can often be effectively cared for by PCPs.[807, 808-811] The U.S. Department of Veteran Affairs' experience has indicated that each geriatrician can care for an average of 700 older adults with complex medical needs compared with each PCP who can care for an average of 1,200 older adults.[807, 809] Based on these assumptions, among the 55.8 million adults age 65 and older in the United States in 2021,[812] approximately 16.7 million people (30% of all those age 65 and older) needed geriatrician care and at least 23,953 geriatricians were needed to serve the care of these individuals.[807, 809] However, that year, there were only 7,454 certified geriatricians, a sizable and potentially consequential shortage relative to need.[813]

If geriatrician supply and the aging of the United States population continue at their current paces, an estimated 18,142 geriatricians will be needed to effectively care for the approximately 12.7 million individuals age 65 and older who are projected to have Alzheimer's dementia in 2050 — more than double the number of geriatricians who were practicing in 2021.[293, 813] However, the number of geriatricians has remained at approximately 7,000 each year for the past decade.[814]

The projected increase in demand for geriatricians by 2050 is expected to far exceed the supply in nearly every region of the United States.[807, 813, 815] Table 14 shows state-specific numbers of board-certified geriatricians in 2021 and estimates of geriatricians needed in 2050, assuming again that each geriatrician cares for 700 patients. [807, 809, 816] The projections address two levels of need. The first projection is the number of geriatricians needed to care for those age 65 and older who will be living with Alzheimer's dementia, about 11% of all older adults in 2050.[293] The second projection is the number of geriatricians needed for 30% of the older adult population with complex medical needs in 2050, that is, the proportion currently estimated to need a geriatrician.[807, 809] The shortage of geriatricians will affect states differently. In 2021, the number of geriatricians in Connecticut, the District of Columbia, Hawaii, Maryland, Massachusetts, New York and Pennsylvania was sufficient to match the number of people projected to have Alzheimer's dementia in 2050. In contrast, five states, Kentucky, Mississippi, South Carolina, Tennessee, and Utah need at least three times the number of practicing geriatricians to care for those projected to have Alzheimer's dementia and at least eight times the number to care for the 30% of the population age 65 and older projected to need geriatrician care by 2050. Two states, Idaho and Oklahoma, will need to increase the number of geriatricians by at least four times to meet the care needs of those projected to have Alzheimer's dementia and by at least 11 times to care for the 30% of the population age 65 and older projected to need geriatrician care in 2050.

The projections in Table 14 assume that the proportion of older adults who are living with Alzheimer's dementia is 11% in all states and that, within each state, the geographic availability of geriatricians matches where the need is. However, while the shortage of geriatricians is observable across many states, it appears to be most acute in rural settings — with many rural counties facing a shortage of health care providers overall.[817-819] For instance, according to the 2019 Alzheimer's Association survey, almost one-third of PCPs reported referring patients to specialists for diagnosis, yet most PCPs (55%) reported that there were not enough specialists (e.g., geriatricians) in their area to meet demand, including 71% of PCPs in rural areas compared with 44% of PCPs in large cities and 54% in suburban areas.[820] Another indicator of the shortage of geriatricians is that, in 2023, there were 411 geriatric medicine fellowship positions available, but more than half (234) went unfilled — suggesting a need for better recruitment into these specializations.[821]

The shortage of specialists extends to neurologists as well. The National Center for Health Workforce Analysis (NCHWA) projects that there will be a continued shortfall of neurologists until 2037, though the growing number of physician assistants in neurology could help address this workforce gap.[822] Fewer than 700 geriatric psychiatrists were certified by the American Board of Psychiatry and Neurology (ABPN) in the last decade (from 2012 to 2022)[823] and, according to 2015 data, more than half of geriatric psychiatrists certified by the ABPN were concentrated in just seven states.[824] Using 2020 county-level data, researchers recently assessed the density of dementia specialists altogether — including neurologists, geriatricians and geriatric psychiatrists — per 100,000 people age 65 and older, estimating that 33 to 45 dementia specialists per 100,000 older adults are needed to care for older adults with mild cognitive impairment and dementia.[825] Based on this threshold, they estimated that 34% to 59% of those age 65 years and older reside in areas with potential dementia specialist shortfalls.

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.[826, 827] Some of these factors are modifiable and must be addressed in order to increase the number of providers available to offer specialized dementia diagnosis and care.[814]

Advanced practice providers, including nurse practitioners and physician assistants, also play key roles in caring for people living with dementia.[828, 829] In 2023, more than 385,000 nurse practitioners were licensed in the United States, up from 91,000 in 2010, with 87% prepared in primary care and 15.1% whose primary care preparation was in adult and geriatrics care.[830, 831] By contrast, as of 2018, less than 1% of physician assistants were certified in geriatric medical care.[828] Therefore, advanced practice providers may be a growing segment of the dementia care workforce, but with key gaps remaining in the specialized capacity of this workforce.

TABLE **14**

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 Those 65 and Older With Alzheimer's Dementia	Number of Geriatricians Needed in 2050 to Serve Those 65 and Older (With and Without Dementia) Who Need Geriatrician Care
Alabama	66	171	467
Alaska	10	19	51
Arizona	115	334	911
Arkansas	60	97	265
California	802	1,362	3,715
Colorado	110	218	596
Connecticut	146	116	315
Delaware	17	44	119
District of Columbia	25	18	48
Florida	418	1,121	3,056
Georgia	139	388	1,057
Hawaii	83	61	166
Idaho	20	81	222
Illinois	303	387	1,056
Indiana	87	215	586
Iowa	50	105	287
Kansas	47	90	247
Kentucky	48	144	393
Louisiana	52	143	390
Maine	46	53	146
Maryland	224	201	548
Massachusetts	283	246	672
Michigan	196	325	887
Minnesota	134	203	553
Mississippi	29	94	256
Missouri	111	197	538
Montana	15	43	117
Nebraska	27	64	174
Nevada	48	134	366
New Hampshire	44	53	145
New Jersey	259	300	819
New Mexico	39	76	207
New York	714	644	1,755
North Carolina	253	408	1,112
North Dakota	19	27	73
Ohio	218	375	1,022
Oklahoma	30	124	337
Oregon	100	176	479
Pennsylvania	455	433	1,182
Rhode Island	32	38	104
South Carolina	70	220	601
South Dakota	17	32	88
Tennessee	74	246	672
Texas	431	1,078	2,941
Utah	38	119	326
Vermont	20	24	65
Virginia	193	292	797
Washington	180	303	827
West Virginia	31	55	151
Wisconsin	131	207	563
Wyoming	7	18	49

The number of geriatricians in 2021 was retrieved from the American Geriatrics Society.[813]

The number of geriatricians needed assumes that 30% of people age 65 and older who have complex medical needs would benefit from geriatrician care and that each geriatrician can care for up to 700 patients. These estimates were retrieved from the American Geriatrics Society[807] and Fried & Hall.[809]

The number of geriatricians needed to serve those with Alzheimer's dementia assumes that the percentage of people age 65 and older with Alzheimer's dementia remains at approximately 11%. This prevalence rate was retrieved from Rajan et al.[293]The underlying state-specific estimates of the 2050 population age 65 and older were retrieved from the University of Virginia, Weldon Cooper Center for Public Service.[816]

Nurses, Psychologists, Therapists, Social Workers and the Direct Care Workforce

Registered nurses, licensed practical nurses, licensed psychologists, licensed therapists and social workers comprise other critical segments of the dementia care workforce. These professionals offer nursing, rehabilitation and supportive services across community settings, skilled nursing homes and other locations. Their services encompass medication administration, intravenous injections, wound and catheter care, physical and occupational therapy, behavioral consultation and more. Additionally, nurses and social workers most often provide care navigation, coordination and management services, 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. For instance, a survey of Master of Social Work graduates from 2017 to 2019 revealed that only 4.2% specialized in aging or gerontology.[832] Nonetheless, 20% to 48% of social work students expressed high interest in working with older adults.[833-837] This discrepancy may be due to the profession's broad scope, which may direct student interest toward social issues rather than age-specific populations.[838]

The largest segment of the workforce that supports people living with dementia is the direct care workforce.[839] 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.[840] 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 activities of daily living (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, vital signs and medication administration (depending on the setting and regulatory context).[841, 842]

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 and provide emotional support and, with additional training, help prevent or reduce distress associated with dementia through the delivery of person-centered, non-pharmacological interventions.[843-846]

Direct care workers also support quality outcomes and, as a result, cost savings. Direct care workers providing in-home care enable individuals to continue living at home and help prevent or delay nursing home placement.[847] 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.[848-851] 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.[852, 853] Research suggests that with enhanced dementia-specific training, direct care workers may also play a role in implementing non-pharmacological interventions,[854] as noted above, and reducing inappropriate antipsychotic prescribing for individuals living with dementia in nursing homes.[855]

Between 2014 and 2023, the number of direct care workers increased from 3.5 million to 5 million due to growing demand for long-term care.[840] Looking ahead, researchers have estimated that just over 861,000 additional direct care workers will be needed between 2022 and 2032 — more new workers than in any other single occupation in the United States.[840] Growth in job opportunities 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.[856]

This projected growth in the direct care workforce — which is estimated from previous workforce growth rates driven by increasing demand — is expected across the country. As shown in Table 15, in every state except Maine, between 2022 and 2032, double-digit percentage increases have been predicted in the number of needed home health and personal care aides. Eleven states are expected to see a 30% or higher increase in this workforce. 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 privately paid, 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 older adult or a person living with dementia rely on the gray market (rather than a home care agency or other formal care provider).[857]

Even as demand for direct care workers continues to increase, 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 80% annually for direct care workers providing home care[858] and 99% for nursing assistants in nursing homes[859] — and recruitment and retention are long-standing challenges.[860-862] 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.[863, 864]

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),[840] as well as ageism and disablism (impacting the individuals receiving care and, by extension, those providing it).[865] In 2023, the year for which the most recent national data are available, the median wage for direct care workers was $16.72 per hour.[840] Despite their complex and critical role in supporting the health and well-being of older adults and people with disabilities, direct care workers earned a lower median wage than workers in other occupations with similar or lower entry-level requirements, such as janitors, retail salespeople and customer service representatives.[866] Furthermore, due to low wages and the high prevalence of part-time positions, the median annual earnings of direct care workers is approximately $25,000.[840]

Direct care workers also receive limited training and professional development opportunities, another indicator of poor job conditions. Nursing assistants in various care settings 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).[862] 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 — including those working in private homes, assisted living communities, adult day services and other settings — vary by state and setting. With regard 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 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.[867] 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 five times more likely than U.S. workers overall to experience workplace injuries in 2022 (the most recent year for which occupation-specific data on injuries in nursing homes were available).[840] These data reflect the impact of the COVID-19 pandemic on this workforce — as COVID-19 was classified as a "workplace injury"[868] — as well as long-standing occupational risks.[869] 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.[870]

The Community-Based Workforce

"Dementia-friendly communities" are environments and health and social systems that are designed to support people with dementia to live and age in place, thereby preventing or delaying admission into nursing homes and other congregate care settings.[871, 872] 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.[873] 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.[874] DFA was built on the leadership of ACT on Alzheimer's, a community-led initiative in Minnesota that began in 2013.[875]

Essential to dementia-friendly communities is a community-based workforce that holds sufficient dementia-related knowledge, skills and competencies. For instance, gatekeeper programs, which are designed to train local businesses and organizations that serve older adults to identify and refer them to services they may need, have had some success in identifying and supporting people with dementia by training postal workers, bank tellers, ministers and other personnel to identify signs of cognitive impairment and direct customers to appropriate resources or services.[876] Additional workforces that play a role in creating dementia-friendly environments include librarians who provide supportive services and programming;[877]

TABLE 15

Expected Growth in Home Health and Personal Care Aide Jobs, 2022 to 2032

	Number in 2022 and Projected Number Needed in 2032		Percentage Increase
State	**2022**	**2032**	**2022-2032**
Alabama	22,030	24,720	12.2
Alaska	4,550	5,260	15.6
Arizona	68,550	96,120	40.2
Arkansas	20,310	24,670	21.5
California	796,900	1,060,200	33.0
Colorado	38,300	48,710	27.2
Connecticut	47,750	57,730	20.9
Delaware	9,530	12,350	29.6
District of Columbia	11,530	13,630	18.2
Florida	72,410	88,750	22.6
Georgia	36,890	46,020	24.7
Hawaii	*	*	*
Idaho	17,960	23,500	30.8
Illinois	108,190	124,190	14.8
Indiana	44,830	54,650	21.9
Iowa	25,390	32,770	29.1
Kansas	27,140	32,990	21.6
Kentucky	24,650	30,540	23.9
Louisiana	36,540	44,950	23.0
Maine	17,090	17,770	4.0
Maryland	32,420	38,640	19.2
Massachusetts	39,480	46,500	17.8
Michigan	85,480	100,320	17.4
Minnesota	113,680	129,520	13.9
Mississippi	17,560	22,720	29.4
Missouri	79,380	91,510	15.3
Montana	8,850	11,790	33.2
Nebraska	10,120	12,360	22.1
Nevada	16,000	21,330	33.3
New Hampshire	8,760	10,780	23.1
New Jersey	94,150	115,060	22.2
New Mexico	36,890	50,200	36.1
New York	551,740	710,140	28.7
North Carolina	62,750	77,390	23.3
North Dakota	7,310	9,010	23.3
Ohio	95,690	108,260	13.1
Oklahoma	19,090	23,300	22.1
Oregon	36,900	46,170	25.1
Pennsylvania	188,340	217,220	15.3
Rhode Island	8,070	10,000	23.9
South Carolina	32,340	43,300	33.9
South Dakota	4,620	5,340	15.6
Tennessee	32,820	46,870	42.8
Texas	313,670	367,500	17.2
Utah	15,000	19,730	31.5
Vermont	7,460	9,600	28.7
Virginia	60,230	81,100	34.7
Washington	66,330	75,654	14.10
West Virginia	20,130	25,780	28.1
Wisconsin	80,600	94,000	16.6
Wyoming	3,260	4,210	29.1
U.S. Total	**3,579,660**	**4,464,824**	**24.7**

* Long-term occupational projections for home health aides and personal care aides in Hawaii were not available at the time of publication; therefore these data are missing from U.S. total projections.

Created from Projections Managing Partnership, Projections Central: Long-Term Occupational Projections (2022-2032). Available at: https://projectionscentral.org/longterm. Accessed January 15, 2025.

architects and others who design floor plans, landscapes, soundscapes and sonic environments;[878, 879] adult protective service workers who handle elder abuse cases;[880, 881] police officers and other members of law enforcement agencies who interact with the public;[882, 883] and hairdressers,[884] bus drivers and building superintendents, among others.[885]

Community health workers (CHWs) also play a key and growing role in dementia-friendly communities. CHWs are frontline public health workers tasked with serving as a trusted link between community members and health and social care systems, and therefore helping improve care access, quality and cultural competence. In the context of Alzheimer's disease and other dementias, CHWs can help dispel misconceptions and stigma, encourage earlier screening and clinical trial participation, and improve access and navigation to support services for members within their communities. Their established rapport and trust as community members enable them to communicate information in a culturally and linguistically appropriate manner. One recent global scoping review found five broad areas for the potential role of CHWs in addressing dementia: education and awareness-building; screening for dementia; screening for HIV-associated dementia; assistance with utilizing health care resources; and services to dementia caregivers.[886]

Collaborative Workforce Models for Dementia Care

A major barrier to improving dementia care is fragmentation of care delivery, which occurs when patients receive care from many providers, but no single provider accounts for a substantial proportion of visits.[887] Although seeing multiple providers may be clinically appropriate, providers do not often communicate or coordinate with each other in the care of their common patients. Gaps in coordinated care are common and can increase the risk of medical errors and suboptimal care.[888-893]

Several decades of research supports the value of collaborative, primary care-based models that bring together different members of the health care and community-based workforces to care for people and their caregivers across the Alzheimer's disease continuum.[894, 895] These collaborative 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.[895-897]

As one example of collaborative dementia care, the Alzheimer's and Dementia Care Program is a health systems-based model in which nurse practitioners with extensive training in dementia care, known as dementia care specialists (DCSs), co-manage care with PCPs and community-based partners. 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.[714] This model has been found to reduce nursing home admissions for participating Medicare beneficiaries.[898] In a quasi-experimental study of 3,249 patients with dementia from 2012 through 2015, the program was associated with $601 lower costs of health care per patient per quarter ($2,404 per year), while the cost of running the program was $317 per patient per quarter ($1,268 per year). This translated to a net savings to Medicare of $284 per patient per quarter ($1,136 per year).[898]

The Gerontological Society of America's Kickstart, Assess, Evaluate, Refer (KAER) model provides another example of collaborative approaches to better detect and manage dementia.[899] Among other strategies, this model leverages the role of non-clinical office staff as part of the primary care team. Receptionists or schedulers, for example, can take note when patients miss their appointments, show up at the wrong time, or defer to family members while completing paperwork or answering questions.

As a third 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.[900, 901] With regard to cost savings, participation in the original Care Ecosystem program reduced the total cost of care by $3,290 per person from one to six months after enrollment and by $3,027 from seven to 12 months post-enrollment, corresponding to a mean monthly cost reduction of $526 across 12 months.[901] The model has been successfully tested in a non-academic health care system (i.e., in a non-research setting).[902] An implementation toolkit for the Care Ecosystem is publicly available online.[903]

Further supporting the cost-saving potential of collaborative dementia care team models, the Healthy Aging Brain Center, an interprofessional memory care clinic, demonstrated a reduction in net annual per-person health care costs of $2,856 for individuals with memory impairments compared with those receiving care overseen by a PCP only.[896] More than half of these savings were attributed to reduced inpatient hospital costs. With an average annual program cost of $618 per person, this represents a nearly 6-to-1 return on investment.

Taken together, this evidence suggests that collaborative dementia care models can generate cost savings of just under $1,000 to more than $6,000 per person per year after accounting for programmatic costs, depending on the model.

See a description of the new Guiding an Improved Dementia Experience (GUIDE) Model in the Caregiving section (see page 63) and later in this section to learn about efforts to disseminate collaborative dementia care more broadly. See the Special Report from *2024 Alzheimer's Disease Facts and Figures* that explores mapping a better future for dementia care navigation.[904]

Looking to the Future

In 2020, the American Public Health Association (APHA) identified "strengthening the dementia care workforce" as a public health priority.[785] "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 areas that will continue to strengthen the dementia care workforce into the future.

Dementia-Friendly Initiatives

To create dementia-friendly communities that support aging in place, it is essential to continue enhancing the dementia knowledge and skills of non-medical professionals across the broader community-based workforce, including postal workers, bank tellers, church leaders, librarians, police officers, building superintendents, bus drivers and hair dressers.[564, 713, 876, 877, 882-885] For instance, Bank of America, recognizing that Alzheimer's dementia is a significant concern among its clients, has instituted training programs for financial advisors on Alzheimer's dementia and caregiving.[905] In 2024, California Governor Gavin Newsom signed a bill mandating training for law enforcement on preventing and responding to wandering behaviors in people with Alzheimer's disease, other dementias or autism.[906]

There are other dementia-friendly efforts that encompass both medical and non-medical professionals who work in a range of settings and contexts, including dementia-friendly care for people living in hospitals;[907-909] dementia-friendly design for nursing homes, senior centers and similar settings;[878, 910, 911] and dementia-friendly neighborhoods to improve quality of life for local residents.[912, 913] More research is needed on the effectiveness of these dementia-friendly efforts as well as their implications for workforce development.

Health Care Workforce Development

Dementia care is inadequately covered in health care training programs, both in curricula and in opportunities for clinical practice.[914] Yet more dementia training and specialization among PCPs and across the health care workforce are critically needed, not just to build clinicians' skills and confidence in detecting and diagnosing dementia, but also to overcome the widespread shortage of geriatricians and other specialists and to expand the direct care workforce to meet growing needs.[790, 804, 805, 814]

More broadly, geriatric care principles such as the 4Ms — what matters, medication, mentation and mobility — should be integrated across all health care professionals' educational curricula to ensure widespread delivery of age-friendly care.[915-917] Moreover, 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, ethnic, sexual and gender minority groups. Complementing this training, language-concordant and culturally tailored resources and referrals are needed to help overcome the 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.[918-923]

A number of efforts are underway to build the health care workforce that is needed to support the growing older population and individuals with Alzheimer's disease and other dementias in particular. One key example is the Geriatrics Workforce Enhancement Program (GWEP) funded by the Health Resources and Services Administration, which comprises a network of 42 individual GWEPs across 37 U.S. states.[924] The goals of this program are to educate and train the health care workforce to provide care for older adults in a way that integrates geriatrics and primary care, 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. Additional innovative workforce expansion approaches include flexible geriatric medicine fellowship training for mid-career physicians, the pilot of a Medicine-Geriatrics Integrated Residency and Fellowship Pathway (Med-Geri Pathway), and a combined Geriatrics & Palliative Medicine (Geri-Pal) Fellowship.

One specific training model is the Alzheimer's and Dementia Care ECHO® (Extension for Community Healthcare Outcomes) Program, which pairs PCPs with multidisciplinary specialist teams through telementoring to develop PCPs' 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 PCPs participating in the program reported making changes in their delivery of dementia care due to the program and 87% reported higher job satisfaction.[925]

In addition, 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, or ARIA (see "Treatments to Slow Alzheimer's Disease," page 14).[57, 60] 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 care 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.

Of note, 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 is building 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.[926] The first year of data from the NDWS surveys is anticipated in spring 2025.

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.[897, 927, 928] One development in this area, as described earlier, is that since 2017 Medicare has reimbursed physicians, nurse practitioners, physician assistants and nurse specialists for health care visits that result in a comprehensive dementia care plan. (As of January 1, 2024, Medicare reimbursed approximately $268 to physicians and other eligible billing practitioners, through billing code 99483, for providing a comprehensive clinical visit that resulted in a written care plan; the rate may be geographically adjusted.[795, 929, 930]) However, as noted, use of this benefit has been limited, likely because providers, especially in smaller practices and rural areas, are insufficiently aware of the appropriate billing codes, and/or may be billing for similar services under different codes.[797, 931] In the future, providers could be better informed about these codes. Dementia Care Aware is one example of a statewide program in California that proactively provides PCPs with information and tools to successfully administer cognitive health assessments and determine appropriate next steps for patients, as well as to use the correct procedural terminology codes for billing.[932, 933] Furthermore, 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 Model, announced by the Centers for Medicare & Medicaid Services (CMS) in 2023.[784] Through the GUIDE Model, participating organizations will offer dementia care programs that provide ongoing, interdisciplinary care and support for community-dwelling Medicare fee-for-service beneficiaries living with dementia, as well as their caregivers. Each interdisciplinary GUIDE team must include a knowledgeable and skilled care navigator to help individuals 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 support. CMS is testing an alternative payment for participating organizations, which must be Medicare Part B–enrolled providers/suppliers and eligible to bill for Medicare Physician Fee Schedule services. To address inequities in dementia care, CMS is actively seeking safety-net organizations that provide care to underserved communities, including disproportionately Black/African American and Hispanic communities, to participate in the GUIDE Model. For these organizations, CMS will provide financial and technical supports to ensure they can develop their infrastructure, improve their workforce and care delivery capabilities, and participate successfully.[784]

Financing and other public policy reforms are also needed to strengthen and stabilize the direct care workforce. In recent years, the federal government and states have taken unprecedented action to improve job quality and bolster this workforce, particularly through Medicaid. These actions have included but are not limited to overhauling training and credentialing systems, designing new career development opportunities, implementing reimbursement rate increases tied to increased compensation, and developing new recruitment campaigns and pipeline programs.[934, 935] 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

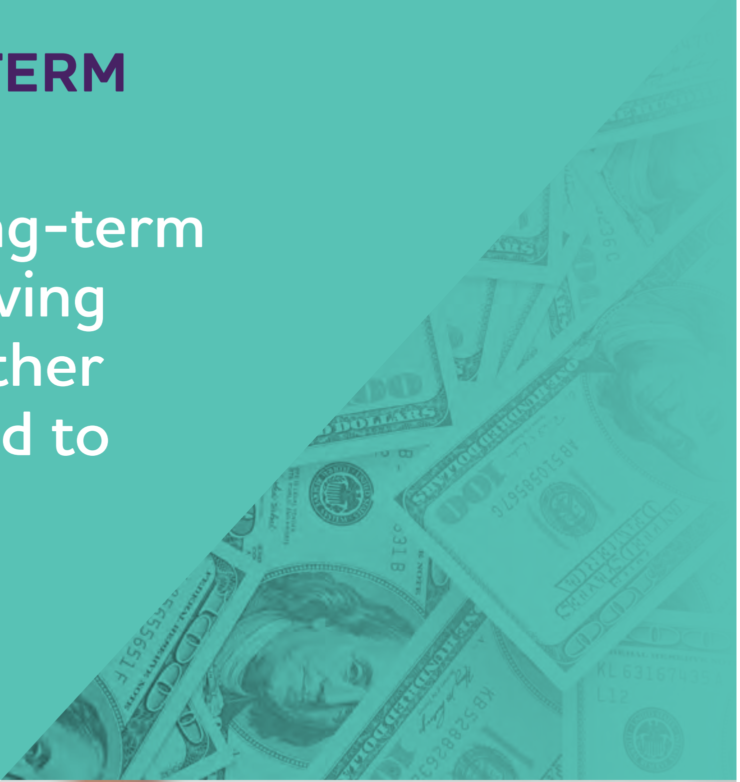
Major advances in technology are optimizing the time and effectiveness of the dementia care workforce. As one example, e-learning programs can greatly increase access to dementia care training, although evidence suggests that the effectiveness of such programs relies on the relevance of the content and the inclusion of interactive learning strategies.[936]

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.[937] The study described earlier of the telephone-based Care Ecosystem project in California, Nebraska and Iowa found that this remote intervention resulted in better quality of life, reduced emergency department visits and decreased caregiver depression and burden.[900] A systematic review of telehealth for dementia care found that telehealth achieved similar results on cognitive assessment and diagnosis as in-person services.[938] More research is needed to identify the ways in which telehealth both excels and falls short of expectations, and how it can be utilized appropriately in the diagnosis and treatment of individuals living with dementia, as well as in supporting their caregivers.

Furthermore, assistive, therapeutic and remote monitoring technologies, which range from smart home devices to automated medication prompts, robotic animals, and devices that support personalized activities, can be used to augment the role of the dementia care workforce.[939] As with telehealth, more research is needed to understand the efficacy of these myriad technologies and to address concerns and unintended consequences related to privacy, autonomy and interpersonal interactions. As indicated by the 2024 report of *The Lancet* Commission on dementia prevention, intervention, and care, “Technologies should, where possible, supplement rather than replace existing face-to-face care to avoid leading to harmful social isolation.”[73]

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

In 2025, health and long-term care costs for people living with Alzheimer's and other dementias are projected to reach $384 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.[940] Total payments in 2025 (in 2025 dollars) for all individuals with Alzheimer's or other dementias are estimated at $384 billion (Figure 15), not including the value of informal caregiving that is described in the Caregiving section. Medicare and Medicaid are expected to cover $246 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 $97 billion, or 25% of total payments.[A11] For the remainder of this section, costs are reported in 2024 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.

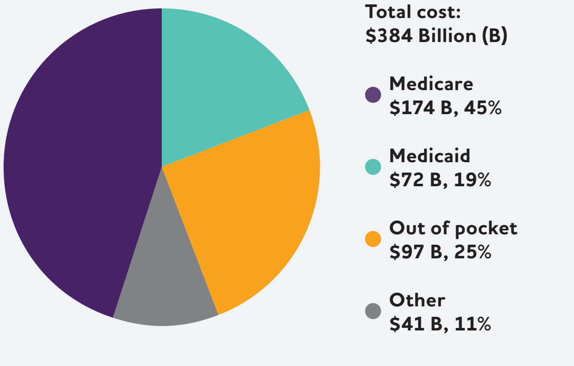
Total Cost of Health Care and Long-Term Care

Table 16 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-A15] 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. Total average per-person health care and long-term care payments in 2024 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 ($44,814 per person for those with dementia compared with $15,053 per person for those without dementia).[A15, 941]

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 are expenses that individuals must pay themselves, rather than being paid by insurance or other sources. Out-of-pocket costs include 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 $10,564 out of pocket annually for health care and long-term care services not covered by other sources (Table 16).[941] This includes the cost of long-term nursing home care for individuals not eligible for Medicaid. One group of researchers found that out-of-pocket and informal caregiving costs for a family member with dementia totaled $203,117 in 2016 dollars ($246,480 in 2024 dollars) in the last seven years of life, compared with $102,955 in 2016 dollars ($124,935 in 2024 dollars) for those without dementia.[670] However, informal caregiving costs during this same interval were considerably higher for households with a family member with dementia living in the community than for households with a family member with dementia living in a nursing home ($231,730 versus $165,910 in 2016 dollars [$281,202 versus $201,330 in 2024 dollars]), due to Medicaid covering the cost of nursing home care for many individuals.[670]

FIGURE **15**

Costs of Care by Payment Source for Americans Age 65 and Older with Alzheimer's or Other Dementias, 2025*



*Data are in 2025 dollars. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Created from data from the Lewin Model.[A11]

TABLE **16**

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 2024 Dollars*

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$22,562	$8,130
Medicaid	6,952	313
Uncompensated	198	246
Health maintenance organization	2,004	2,353
Private insurance	1,575	983
Other payer	958	430
Out of pocket†	10,564	2,597
All sources	44,814	15,053

*Payments include payments for community-dwelling beneficiaries and beneficiaries residing in other facilities.

†Costs that individuals paid themselves. These costs include 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.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[941, A13]

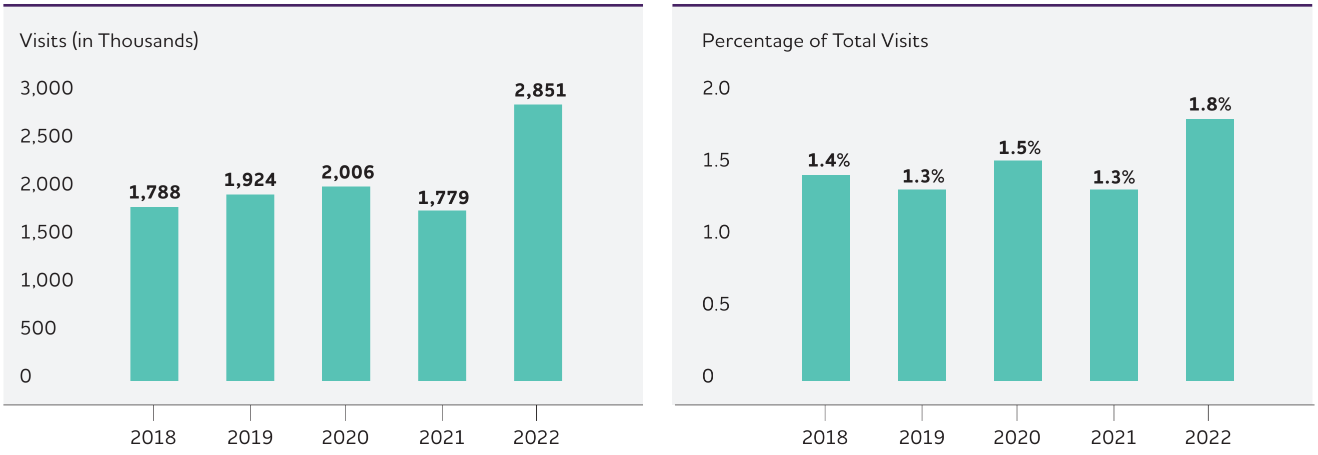
Researchers have evaluated the additional or "incremental" health care, residential long-term care and family caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics).[506, 940, 942, 943] 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 ($405,262 in 2024 dollars), more than twice the estimated lifetime cost for individuals without Alzheimer's dementia.[505] 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.[944] 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 ($41,286 in 2024 dollars).[A16, 940] 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.[505, 944, 945] The incremental five-year cost of care for dementia paid by Medicare has been estimated at nearly $16,000 per person in 2017 dollars ($18,940 in 2024 dollars), with nearly half of these costs incurred in the year after diagnosis and 87% concentrated in the two years after diagnosis.[945, 946] However, these estimates include costs for individuals who died during the five-year 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 than do individuals without dementia. 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; $3,674, $4,415 and $4,657 in 2024 dollars).[947] 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.[948, 949] Furthermore, individuals with Alzheimer's dementia spend 12% of their (individual and spouse/partner) 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.[949]

Another perspective to examine incremental costs for individuals with Alzheimer's and other dementias is through the costs of care at the end of life. 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.[950] 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 ($415,502 and $265,095, respectively, in 2024 dollars), a difference of 57%.[951] Out-of-pocket costs represent a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% versus 11%).

FIGURE **16**

Emergency Department Visits for Individuals with Alzheimer's Disease, 2018 to 2022



Created from data from the National Hospital Ambulatory Medical Care Survey.[955, 957-960]

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.[485] 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.[485] 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 stays of 5.1 days versus 4.5 days, respectively.[485] Common reasons that people with Alzheimer's or other dementias were hospitalized in 2021 include septicemia, COVID-19, urinary tract infections, neurocognitive disorders and hip fractures, accounting for 29.2% of hospitalizations in 2021 (Table 17).[952] Among Medicare beneficiaries with Alzheimer's or other dementias, approximately 22% of hospital stays are readmissions occurring within 30 days after discharge from another hospitalization.[953] One statewide study reported that 30-day readmission rates were 6.8 percentage points higher for patients with Alzheimer's or other dementias than for patients without Alzheimer's (21.5% versus 14.7%).[954]
- Emergency department. There were nearly 2.85 million emergency department visits for people with Alzheimer's in 2022, representing 1.8% of all emergency department visits (including visits for people of all ages) (Figure 16).[955] Between 2018 and 2022, the number of emergency department visits for individuals with Alzheimer's disease increased by 44%, from 1.79 million to 2.85 million, outpacing the increase in emergency department visits overall (Figure 16). The most common reasons for emergency department visits by individuals with Alzheimer's include accidents, psychological or mental disorder symptoms, general weakness, shortness of breath, chest pain, and disorders of motor function and falls, together representing 31% of visits. Furthermore, emergency department visits more frequently occur for individuals with Alzheimer's than for other older

adults. 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 are Medicare beneficiaries without Alzheimer's or other dementias.[956] 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.

TABLE **17**

Most Common Reasons (Primary Diagnoses) for Hospitalization for People with Alzheimer's or Other Dementias, 2021

Reason	Percentage of Hospitalizations
Septicemia	10.3
COVID-19	5.3
Urinary tract infections	4.8
Neurocognitive disorders	4.8
Hip fracture (initial encounter)	4.4
Bacterial infections	4.4
Acute and unspecified renal (kidney) failure	3.6
Cerebral infarction (stroke)	3.1
Heart failure	2.9
Hypertension with complications	2.4
Pneumonia (not caused by tube feeding)	2.3
Gastrointestinal hemorrhage	2.3
Fluid and electrolyte disorders	2.1
Other nervous system disorders (not hereditary or degenerative)	1.8
Cardiac dysrhythmias	1.8
Complication of genitourinary device	1.8
Aspiration pneumonitis	1.7
Traumatic brain injury	1.7
Acute myocardial infarction	1.5
Epilepsy; convulsions	1.3

Created from the Healthcare Cost and Utilization Project National Inpatient Sample for 2021.[952]

- 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.[961] 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.[485] 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.[485]

Costs of Health Care Services

Average per-person payments for health care and long-term care services (hospital, outpatient, 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 18).[A13, 941]

TABLE **18**

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 2024 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	$8,012	$2,998
Outpatient events	2,946	2,318
Medical provider*	6,016	3,883
Skilled nursing facility	4,079	411
Nursing home	15,045	582
Hospice	2,384	140
Home health care	1,907	282
Prescription medications†	5,017	3,384

*"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 living in a nursing home or assisted living residence.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[A13, 941]

TABLE **19**

Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2024 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 Fee-For-Service Payments†		
			Medicare Only	Dual Eligible	All Medicare
Alabama	1,410.8	21.2	$27,264	$31,024	$28,272
Alaska	1,477.6	19.3	29,250	33,448	30,830
Arizona	1,436.2	20.2	29,050	36,698	29,984
Arkansas	1,530.4	21.5	26,903	30,163	27,945
California	1,496.3	23.0	38,387	53,254	45,486
Colorado	1,424.8	18.6	28,783	32,194	29,590
Connecticut	1,635.4	22.7	34,595	38,434	35,996
Delaware	1,577.6	21.5	32,463	36,065	33,418
District of Columbia	1,741.7	25.6	34,429	47,416	40,928
Florida	1,551.9	23.0	32,227	41,905	35,223
Georgia	1,573.2	22.5	29,586	36,009	31,282
Hawaii	1,248.2	16.0	24,409	30,122	25,223
Idaho	1,389.2	17.2	25,165	28,628	25,914
Illinois	1,624.1	23.4	34,025	44,008	35,770
Indiana	1,514.2	21.3	29,603	34,222	31,288
Iowa	1,310.7	18.0	23,115	22,264	22,890
Kansas	1,406.0	19.8	27,386	30,544	28,182
Kentucky	1,735.5	23.1	29,440	33,964	30,450
Louisiana	1,709.9	22.1	32,676	40,938	35,241
Maine	1,665.3	19.7	24,470	25,707	24,906
Maryland	1,524.1	24.4	36,262	44,947	38,631
Massachusetts	1,668.4	24.7	37,339	40,227	38,057
Michigan	1,691.4	24.0	30,036	36,169	31,327
Minnesota	1,467.1	21.6	27,477	33,463	28,179
Mississippi	1,714.8	22.1	30,290	35,280	32,192
Missouri	1,529.6	22.6	28,650	32,774	29,351

TABLE **19** (cont.)

Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2024 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 Fee-For-Service Payments†		
			Medicare Only	Dual Eligible	All Medicare
Montana	1,328.6	16.6	$22,663	$25,435	$23,128
Nebraska	1,153.6	18.7	25,858	28,546	26,251
Nevada	1,711.5	25.8	39,264	50,694	42,770
New Hampshire	1,493.8	20.4	29,137	32,945	29,487
New Jersey	1,456.3	22.9	38,491	43,602	39,932
New Mexico	1,563.7	20.6	26,282	32,715	28,143
New York	1,461.3	23.7	44,222	46,417	44,833
North Carolina	1,683.8	21.5	27,497	31,020	28,484
North Dakota	1,173.3	18.4	22,209	26,701	22,774
Ohio	1,618.7	22.5	30,433	35,493	31,695
Oklahoma	1,692.1	21.6	32,231	40,089	33,630
Oregon	1,628.4	18.7	24,818	30,816	26,289
Pennsylvania	1,470.5	22.0	31,622	35,570	32,271
Rhode Island	1,605.6	23.2	31,415	35,256	31,741
South Carolina	1,558.2	21.7	29,454	35,988	30,600
South Dakota	1,200.1	18.6	25,409	27,044	25,713
Tennessee	1,548.6	21.5	28,528	33,544	29,420
Texas	1,549.1	22.1	37,404	44,260	38,896
Utah	1,194.3	16.7	25,990	33,443	27,148
Vermont	1,528.4	19.6	23,436	26,101	24,037
Virginia	1,621.7	21.6	28,374	30,569	28,825
Washington	1,479.2	18.6	25,291	29,014	26,166
West Virginia	1,811.4	24.1	29,367	32,786	30,223
Wisconsin	1,519.9	19.9	27,814	30,173	28,275
Wyoming	1,445.9	17.4	26,227	27,349	26,540

*Based on Medicare utilization for 2018.

†Based on traditional Medicare utilization for 2022. Dual Eligible refers to individuals enrolled in both Medicare and Medicaid.

Created from data from the U.S. Centers for Medicare & Medicaid Services.[953,963]

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 19). Emergency department visits, including visits that result in a hospital admission, range from 1,154 per 1,000 beneficiaries annually in Nebraska to 1,811 per 1,000 beneficiaries annually in West Virginia, and the percentage of hospital stays followed by hospital readmission within 30 days ranges from 16% in Hawaii to 25.8% in Nevada. Medicare spending per capita ranges from $22,774 in North Dakota to $45,486 in California.[962] Medicare spending per capita is substantially higher for dually eligible beneficiaries compared to those with only Medicare coverage in all states except for Iowa.

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.[964] 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 their diagnosis than spending for other individuals without Alzheimer's,[965-967] 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,[966] 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.[967]

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 ($8,599 in 2024 dollars)[945] to $17,852 in 2014 dollars ($23,075 in 2024 dollars)[966] for 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.[968]

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 [$9,471 in 2024 dollars]).[966] Another research team found that, compared with health care costs for individuals without a dementia diagnosis, costs for individuals with a dementia diagnosis remained higher in the second through fourth years after their diagnosis but were not significantly higher in the fifth year after diagnosis.[945] Incremental costs decreased over time, from $4,241 in 2014 dollars ($5,020 in 2024 dollars) in year two to $1,302 ($1,541 in 2024 dollars) in year four, although costs increase dramatically in the last year and last month of life.[931] 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.[966] 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 obtained care from a specialist (that is, a neurologist, psychiatrist or geriatrician) had a shorter time to diagnosis of Alzheimer's disease.[969] 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.[485] Additionally, they are more likely than those without dementia to have other chronic conditions.[485] 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.[485] Table 20 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.[485]

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 21[A13] 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

TABLE 20

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.[485]

not have Alzheimer's or another dementia.[A13, 485] Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except physician care. One group of researchers found that larger proportions of individuals with dementia and behavioral disturbances, such as agitation, used medications including antihypertensives, dementia treatments, antipsychotics, antidepressants, antiepileptics and hypnotics compared with individuals with dementia but without behavioral disturbances.[970]

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.[941] Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.[941] 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. Additionally, people with Alzheimer's or other dementias make up a large proportion of all older adults who receive residential care and nursing home care.[971]

- Home health services and other home-based services. Medicare covers the following types of services: (1) medically necessary skilled nursing care, such as wound care for pressure ulcers, intravenous or nutrition therapy, and monitoring serious illness and unstable health status; (2) physical, occupational and speech-language therapy services; and (3) medical social services in the home.[972] Additionally, individuals receiving medically necessary skilled nursing care or therapy services can also receive part-time or intermittent home care at the same time, such as help with bathing, toileting and dressing. Home health agencies provide the majority of home health care services.[973] 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 these homemaker services are the only care that is needed; however, Medicare Advantage plans (Medicare Part C) are allowed to offer these services as supplemental benefits. In 2024, 13% of Medicare Advantage enrollees were enrolled in plans that offered some type of in-home support services (e.g., personal care services, medication management) as a benefit.[974] Additionally, approximately 24% of Medicare Advantage plan enrollees were offered food and produce as a supplemental benefit, and 7% were offered meals beyond a limited basis.[974] 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). For example, 49% of Special Needs Plan enrollees were in plans that offered a food and produce benefit compared to 15% of individual Medicare Advantage plan enrollees. Although Medicare Advantage Special Needs Plans can be offered to individuals with specific chronic conditions, including dementia, only 12% of Special Needs Plan enrollees are enrolled in a plan for chronic or disabling conditions, representing approximately 1.2% of all Medicare enrollees.[975, 976] The vast majority of Special Needs Plan enrollees are individuals also enrolled in Medicaid (i.e., Dual Eligible Special Needs Plan enrollees).

TABLE **21**

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 2024 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	**$29,181**	$8,943	$4,863	$4,574	$2,513	$3,903
Without A/D	**18,458**	6,468	4,766	1,418	964	433
Diabetes						
With A/D	**28,817**	8,960	4,883	4,632	2,418	3,352
Without A/D	**16,151**	5,510	4,267	1,287	850	299
Congestive heart failure						
With A/D	**32,277**	10,293	5,057	5,167	2,666	4,423
Without A/D	**26,097**	9,863	5,533	2,501	1,600	820
Chronic kidney disease						
With A/D	**29,933**	9,300	4,840	4,773	2,538	3,963
Without A/D	**20,262**	7,103	4,968	1,705	1,112	483
Chronic obstructive pulmonary disease						
With A/D	**32,839**	10,628	5,279	5,335	2,693	3,947
Without A/D	**23,396**	8,546	5,427	1,990	1,333	727
Stroke						
With A/D	**31,371**	9,675	5,120	5,089	2,655	3,856
Without A/D	**22,791**	7,726	5,279	2,447	1,591	670
Cancer						
With A/D	**29,113**	8,590	5,253	4,274	2,495	3,862
Without A/D	**18,822**	5,344	5,775	1,083	752	752

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[A13,485]

Medicare and Medicaid Support for People Living With Dementia

When individuals are diagnosed with Alzheimer's or another dementia, it's easy for them and their families to feel overwhelmed. There's so much to learn about dementia, and in the months and years ahead they will encounter new challenges about how to best take care of the individuals with dementia and themselves. The role of public programs such as Medicare and Medicaid in supporting the needs of individuals living with dementia can be an afterthought. However, there are important reasons for individuals and families to take time to understand these programs. These programs can affect the care received. Individuals' and families' financial well-being can also be affected, depending on whether these programs pay for specific aspects of needed care.

Medicare is a federal program for individuals age 65 and older, though individuals younger than 65 with certain disabilities, end-stage kidney disease or amyotrophic lateral sclerosis (ALS) also qualify for Medicare. Medicaid is a joint federal and state program intended for individuals with low incomes and/or low resources. Because it is a joint program, benefits vary by state.[996] Those who are enrolled in both Medicare and Medicaid are sometimes referred to as being "dually eligible." (The information that follows reflects what Medicare and Medicaid covered at the time of printing, but as government programs, coverage and coverage requirements are subject to change.)

One main difference between Medicare and Medicaid that is of special relevance to people living with dementia is that Medicaid covers the cost of long-term care (i.e., stays of more than 90 days) in a nursing home while Medicare does not cover this cost.[997] As noted in the Mortality and Morbidity section (page 41), 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.[487] Much of this time will be spent in a nursing home. At age 80, approximately 75% of people with Alzheimer's dementia live in a nursing home. While Medicaid covers the cost of a long-term nursing home stay, only individuals with low income and assets qualify for Medicaid (see "Medicaid Costs," page 92). Nursing home care is costly. The 2023 average cost for care in a nursing home ranges from $104,025 to $116,800 per year for a private and semi-private room, respectively ($108,740 to $122,094 per year in 2024 dollars).[992]

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.[995] It is especially important to know that 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 coverage has different parts:
Part A: Also referred to as hospital insurance.[998] 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.

Part B: Also referred to as medical insurance. Part B covers medically necessary services and durable medical equipment to diagnose or treat a medical condition, as well as preventive services, which are services to prevent illness or detect it at an early stage when treatment is likely to work best. Part B is a voluntary program that requires enrollees to pay a monthly premium.

Part C: Medical Advantage plans. These are privately offered Medicare plans that combine Parts A and B and often include prescription drug coverage (Part D).[999] Enrollment in Medicare Advantage plans is becoming more common, with more than one-half (54%) of Medicare beneficiaries enrolled in this type of plan in 2023.[1000] Medicare Advantage plans are voluntary and require enrollees to pay premiums.

Part D: Prescription drug coverage. Part D is voluntary and requires enrollees to pay premiums.

Individuals receiving Medicare may also opt to purchase Medicare Supplement Insurance, also known as Medigap. Medigap is extra insurance individuals can buy from a private health insurance company to help pay for out-of-pocket costs not paid by Medicare, such as deductibles and copayments.

While Medicare does not cover long-term care in a nursing home, it does cover care in a long-term care hospital, post-acute skilled nursing facility care, and hospice care. 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.[1001] Benefits work in the same way that Medicare covers other acute care hospitalizations.

Medicare also covers post-acute skilled nursing care, which is nursing and therapy care that must be performed or supervised by medical professionals, such as registered or licensed nurses.[1002] 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.[1003] 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 $209.50 per day in coinsurance.[1004]

For those who are qualified for and enrolled in Medicaid, the program covers some services that Medicare either does not cover or only partially covers, such as nursing home care as mentioned earlier and home- and community-based care.

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 are costs individuals themselves must pay. They 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, individual 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.[941] This excludes the cost of long-term nursing home care for individuals not eligible for Medicaid. For more details, see Total Cost of Health Care and Long-Term Care, page 77.

For more information about Medicare and Medicaid benefits for individuals living with dementia, visit alz.org. Visit Medicare.gov and Medicaid.gov for additional details about Medicare and Medicaid.

Thirty-six percent of individuals using home health services have Alzheimer's or other dementias.[977] Of Medicare beneficiaries 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 65 and older without Alzheimer's or other dementias 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.[485, 973] 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.[978]

- 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.[977] Fourteen percent of adult day service centers in the U.S. specialized in caring for individuals with Alzheimer's disease or other dementias in 2020, up from 10% in 2016.[977, 979]
- Residential care facilities. Forty-two percent of individuals 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.[977, 980] Sixty-one percent of residential care communities are small (four to 25 beds), 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 39% in facilities with more than 50 beds).[980, 981] Fifty-eight percent of residential care facilities offer activities or programs for residents with Alzheimer's or other dementias.[982] Average aide staff hours per resident per day in residential care communities range from 2.2 hours in facilities with less than 25% of residents diagnosed with dementia to 2.7 hours in facilities with more than 75% of residents diagnosed with dementia.[980]
- Nursing home care. Overall, 46% of nursing home residents have Alzheimer's or other dementias,[977] 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.[941] 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.[487]

- 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 community 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.[977] Less than 1% (0.3%) of nursing homes and 11% of other residential care facilities provide care exclusively to individuals with dementia.

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

In 2021, 71% of spending for long-term care services and supports was covered by public payers, including Medicaid (44%), Medicare (20%) and other public payers, including federal COVID-19 pandemic assistance (7%). Out-of-pocket payments covered 14% of these costs, including direct payments and deductibles and copayments for services covered by another payment source. Private insurance covered only 8% of long-term services and supports, and the remaining 7% of costs were covered by other private sources, including philanthropic contributions.[983] Thirty-three percent of Medicaid's total expenditures cover long-term care services and supports.[984] Nationally, state Medicaid programs are shifting long-term care services from institutional care to care that is home- and community-based 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%.[985] 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 total Medicaid long-term care services and supports in Oregon, despite evidence demonstrating that Medicaid spending on these services reduces overall costs.[984] 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.[985] Similar to overall trends of increased use of home- and community-based services, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias increased dramatically between 2004 and 2018.[985] 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.[986] 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, although research that has evaluated both the costs and benefits of enhanced home support interventions is scant.[987, 988]

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%).[989] 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,[990] although the number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.[991]

TABLE **22**

Total Medicaid Payments for Americans Age 65 and Older Living with Alzheimer's or Other Dementias by State in 2025, in 2024 Dollars

State	2025 (in millions of dollars)
Alabama	$1,222
Alaska	119
Arizona	591
Arkansas	492
California	5,677
Colorado	856
Connecticut	1,287
Delaware	339
District of Columbia	146
Florida	3,745
Georgia	1,729
Hawaii	309
Idaho	213
Illinois	2,385
Indiana	1,337
Iowa	859
Kansas	589
Kentucky	1,029
Louisiana	1,013
Maine	297
Maryland	1,665
Massachusetts	2,203
Michigan	1,885
Minnesota	1,179
Mississippi	791
Missouri	1,233
Montana	$220
Nebraska	446
Nevada	300
New Hampshire	363
New Jersey	2,835
New Mexico	303
New York	6,839
North Carolina	1,765
North Dakota	233
Ohio	3,188
Oklahoma	663
Oregon	344
Pennsylvania	4,369
Rhode Island	613
South Carolina	887
South Dakota	230
Tennessee	1,493
Texas	4,282
Utah	255
Vermont	158
Virginia	1,373
Washington	747
West Virginia	565
Wisconsin	1,002
Wyoming	120

Created from data from the Lewin Model.[A11]

Costs of Long-Term Care Services

- Home care. The median cost in 2023 for care from a nonmedical home health aide was $33 per hour and $6,292 per month ($34 and $6,453 in 2024 dollars).[992] Nonmedical home care costs increased 9.5% annually on average between 2019 and 2023. The cost of homemaker services was $30 per hour and $5,720 per month ($31 and $5,866 in 2024 dollars).
- Adult day services. The median cost of adult day services was $95 per day in 2023 ($99 in 2024 dollars).[992] The cost of adult day services increased 6.3% annually on average between 2019 and 2023.
- Assisted living residences. The median cost for care in an assisted living residence was $5,350 per month, or $64,200 per year in 2023 ($5,592 and $67,110 in 2024 dollars).[992] The cost of assisted living increased 7.4% annually on average between 2019 and 2023.
- Nursing homes. The 2023 average cost for a private room in a nursing home was $320 per day, or $116,800 per year ($335 and $122,094 in 2024 dollars), and the average cost of a semi-private room was $285 per day, or $104,025 per year ($298 and $108,740 in 2024 dollars).[992] The cost of nursing home care increased 3.4% annually on average for a private room.

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.[993]
- 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 $103,800 or less in 2023 dollars ($106,636 in 2024 dollars), and 25% had savings of $9,650 or less in 2019 dollars ($9,914 in 2024 dollars). Differences in median savings by race and ethnicity further undermine affordability of long-term care for certain groups. 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.[994]
- 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.[995] 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 of long-term care (in 2022 dollars; $42,789 and $96,276, respectively, in 2024 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.[1005]

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 care services and supports in 2019.[983] Industry reports estimate that between 5.3 and 7.1 million Americans had private long-term care insurance in 2020-2021.[1006, 1007] However, the long-term care insurance market is shrinking, with only 57,000 new policies sold in 2018, compared with 754,000 in 2002.[1008] The average premium for a long-term care insurance policy was $155 per month in 2021 ($179 in 2024 dollars).[1007] 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.[1002, 1006] 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 the third most common (16%) for insurance claims lasting one year or less, after cancer and musculoskeletal conditions (31% and 25% of claims, respectively).[1006] 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.[974]

TABLE **23**

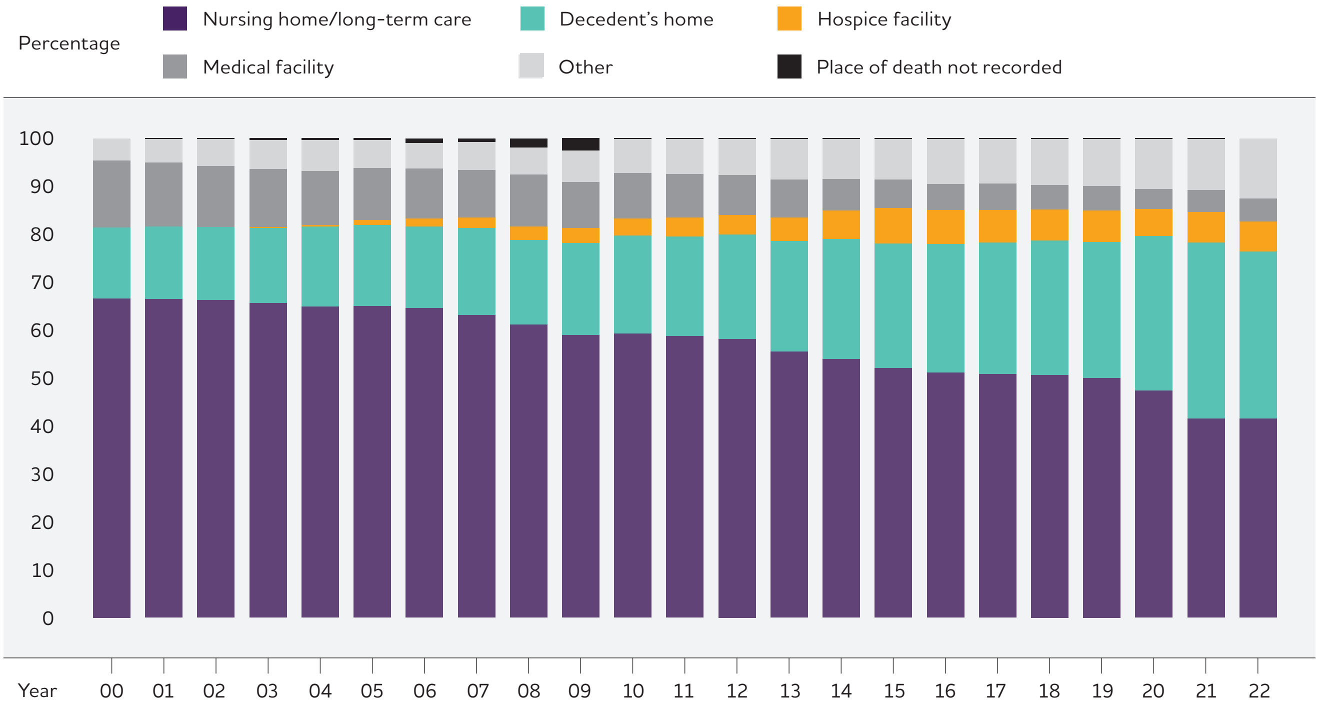
Number and Percentage of Medicare Beneficiaries Admitted to Hospice with a Primary Diagnosis of Dementia by State, 2017

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

Created from data from the U.S. Centers for Medicare & Medicaid Services.[1016]

FIGURE **17**

Place of Death due to Alzheimer's disease, 2000 to 2022



Created from data from the National Center for Health Statistics.[1033]

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.[1009] 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.[1010] Although other states have contemplated implementing a long-term care tax to fund long-term care insurance, none have yet passed legislation.[1011]

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.[1012] 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.[941] 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 ($6,952) were 22 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($313) (see Table 16, page 78).[941] 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 $72 billion in 2025.[A11] Actual and estimated state-by-state Medicaid spending for people with Alzheimer's or other dementias in 2025 (in 2024 dollars) is reported in Table 22.

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.[1013] Medicare pays for nearly all costs of care related to the terminal illness for individuals receiving hospice care. Individuals may pay a copayment for outpatient prescription drugs for pain and symptom management (up to $5 per prescription) and inpatient respite care (5%).[1014]

Nearly two-thirds (63%) of Medicare decedents (i.e., beneficiaries 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.[1015] 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 23).[1016] 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.[977]

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.[1017] 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.[1018] 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 individuals with other diagnoses.[1017, 1018] 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.[1019] Hospice providers are required to assess individuals every 60 days, beginning at six months, to ensure they continue to meet eligibility requirements. 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.[1020, 1021]

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 $2,384 for individuals with Alzheimer's compared with $140 for all other Medicare beneficiaries.[941] 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. There is 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 2025, the routine home care rates are $223.82 per day for days 1 to 60 and $176.39 per day for days 61 and beyond.

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 average 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.[1015] 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.[1022] 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.[1023] Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life and more likely to receive regular treatment for pain.[1024, 1025] 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.[1026] 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).[1027] 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.[1027] Black and Hispanic beneficiaries were also more likely to have an emergency department visit and/or a hospitalization after hospice enrollment.

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

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.[1045]

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.[1046] 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.[1047, 1048] 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.[1048] 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.[1047]

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.[1049] 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.[1049]

TABLE **24**

Average Annual Per-Person Payments by Type of Service and Race and Ethnicity for Medicare Beneficiaries Age 65 and Older, with Alzheimer's or Other Dementias, in 2024 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Care	Home Health Care	Hospice Care
White	$22,904	$6,121	$3,763	$3,457	$1,964	$4,250
Black	28,560	9,518	4,574	4,549	2,023	2,990
Hispanic	26,420	8,282	4,341	3,946	2,436	3,509
Other	23,478	7,673	3,956	3,841	2,012	2,894

Created from unpublished data from the National 100% Sample Medicare Fee-for-Service Beneficiaries for 2019.[485, A13]

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.[1028] 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.[1028] 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.[1029] 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 who had completed advance care planning was less than half that of White beneficiaries.[1027]

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.[1030] 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.[1031] The odds of having a feeding tube inserted at the end of life vary across the country and are not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. 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.[1015, 1022] 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.[1032] 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.[1030]

Place of Death for Individuals with Alzheimer's Disease

Between 2002 and 2022, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 67% to 41%, and the proportion who died in a medical facility decreased from 14% to 5%. During the same period, the proportion of individuals who died at home increased from 15% to 35% (Figure 17). Between 2019 and 2022, the proportion of individuals dying in nursing homes decreased by nearly nine percentage points, representing a 17% relative decline. This was the largest absolute change in place of death since 2000.

Use and Costs of Health Care and Long-Term Care Services Among Populations

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 ($28,560 versus $22,904, respectively) (Table 24). 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 ($9,518 versus $6,121).[485] 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.[1034] However, after adjusting for socioeconomic characteristics and functional status, total health care spending did not differ significantly among groups.

In a study of Medicare-Medicaid dually eligible beneficiaries diagnosed with Alzheimer's dementia, researchers found significant differences in the costs of care by race and ethnicity.[1035] 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 were either 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).[1036] The total cost to Medicare of these potentially preventable hospitalizations was $4.7 billion (in 2013 dollars; $6.2 billion in 2024 dollars).[1036] 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.[1036] 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.[1036]

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.[1037] A substantially higher proportion of Black older adults (31%) had preventable hospitalizations than Hispanic and White older adults (22% for each group).

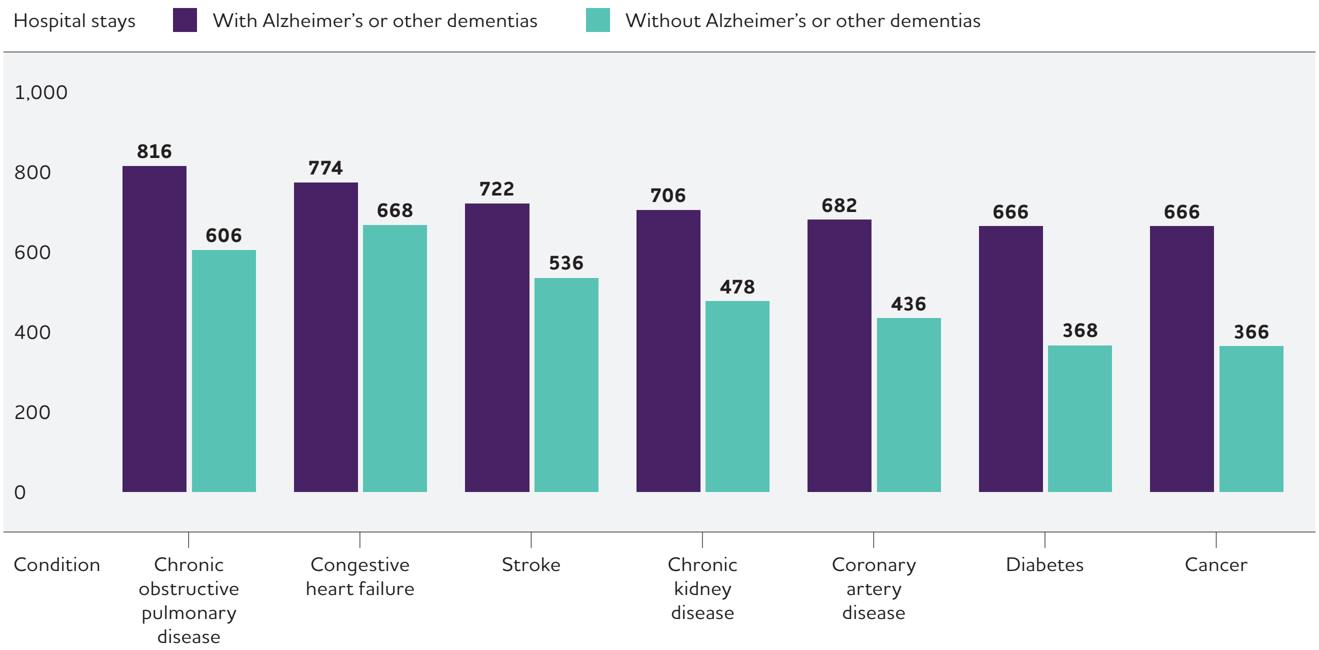
Based on data from the Health and Retirement Study (HRS) and Medicare, after controlling for demographic variables, clinical characteristics (e.g., presence of chronic medical conditions and number of hospitalizations in the prior year) and health risk factors, individuals with dementia had a 30% greater risk of having a preventable hospitalization than those without a neuropsychiatric disorder (that is, dementia, depression or cognitive impairment without dementia).[1038] Moreover, individuals with both dementia and depression had a 70% greater risk of preventable hospitalization than those without a neuropsychiatric disorder.[1038] 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.[1039]

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 18).[485] One research team found that individuals hospitalized with heart failure were more likely to be readmitted or die after hospital discharge if they also had cognitive impairment.[1040] Another research team found that Medicare beneficiaries with Alzheimer's or other dementias had more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly have been prevented through proactive care management in the

This report keeps the population identifiers used in source documents when describing findings from specific studies.

FIGURE **18**

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.[485, A13]

outpatient setting.[1041] 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.[1042]

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.[1043] 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 discharged to the community. The skilled nursing facilities that maintain these relationships have modestly better outcomes,[1044] 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 $384 billion in 2025 to just under $1 trillion in 2050 (in 2025 dollars). This dramatic rise includes 2.6- and 2.4-fold increases in government spending under Medicare and Medicaid and in out-of-pocket expenses, respectively.[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.[1050]

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 and slow disease progression for some people have recently become available (lecanemab and donanemab). 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, in the short-term its effects may be imperceptible to those being treated.[1051] Additionally, people who receive lecanemab and donanemab are at risk of developing a serious side effect known as ARIA — 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.[1052] Additionally, the current market price of treatment is high, at $26,500 per person per year.[1053, 1054] 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 eligible for and the total cost of these treatments is a potential concern. The Centers for Medicare & Medicaid Services covers the cost of the medications for Medicare beneficiaries diagnosed with MCI due to Alzheimer's disease or mild dementia due to Alzheimer's dementia who have documented evidence of beta-amyloid accumulation in the brain and whose physicians participate in a qualifying patient registry with an appropriate clinical team and follow-up care.[1055] According to Medicare, beneficiaries with traditional Medicare will pay the standard 20% coinsurance of the Medicare-approved amount once they meet their Part B deductible. Costs may be different for people with Medicare supplemental coverage (such as a Medigap plan) or other secondary insurance, or those enrolled in a Medicare Advantage plan. Medicare advises beneficiaries to contact their plan for more specific cost information.

Although lecanemab and donanemab are for individuals with MCI due to Alzheimer's disease or mild dementia due to Alzheimer's disease, the actual number of people who may be eligible to receive the treatments is projected to be much smaller due to strict eligibility criteria. 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.[1056]

Before the approval of lecanemab and donanemab, 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.[506, 1057-1059] 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,[1057] 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.[1058] 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 ($4,887 in 2024 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 ($856 in 2024 dollars).[505] 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,[1059] 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.[1060, 1061] 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.[1060] 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.

More research is needed about how changing the trajectory of Alzheimer's disease will affect the use and costs of care for the disease both individually and for the society as a whole.

SPECIAL REPORT

American Perspectives on Early Detection of Alzheimer's Disease in the Era of Treatment

In 2017, the *Alzheimer's Disease Facts and Figures* Special Report highlighted the promise of biomarkers, stating, "… we envision a future in which Alzheimer's disease is placed in the same category as other chronic diseases, such as cardiovascular disease or diabetes, which can be readily identified with biomarkers and treated before irrevocable disability occurs."[1062] Less than a decade later, we are close to realizing that promise. Highly accurate blood-based biomarker tests for detecting Alzheimer's disease may soon be available in physicians' offices.

There have also been great strides in treatment of Alzheimer's disease. The U.S. Food and Drug Administration (FDA) has approved new treatment options that address the underlying biology and slow the decline of memory, thinking and function in a meaningful way for some people diagnosed with Alzheimer's disease in the early stages. By slowing the progression of Alzheimer's, individuals could have more time to participate in daily life and live independently — underscoring the importance of early detection and diagnosis.

Implications of Early Detection and Diagnosis for Treatment to Slow Alzheimer's Progression

People diagnosed in the earlier stages — mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease — are the only ones for whom the new anti-amyloid medications donanemab (Kisunla™) and lecanemab (Leqembi®) are approved.[1063] Both medications remove beta-amyloid to reduce cognitive and functional decline, thereby slowing the typical progression of the disease (see Treatments to Slow Alzheimer's Disease section, page 14).

Throughout this Special Report, "anti-amyloid medication" is used interchangeably with "treatments to slow progression." To be eligible for treatment to slow disease progression, an Alzheimer's diagnosis must be confirmed with tests showing elevated levels of beta-amyloid in the brain. Establishing this with diagnostic testing can be a lengthy process, often involving multiple steps and various clinicians.

People considering anti-amyloid treatments should discuss the risks and benefits of all approved therapies and other health care considerations with their physicians to develop a tailored treatment plan.[1063] Considerations include:

- Current anti-amyloid medications are administered as infusions at specialty outpatient clinics.
- Possible side effects of anti-amyloid medications include amyloid-related imaging abnormalities (ARIA), infusion-related reactions, headaches or falls; some of these can be serious.
- Appropriate use recommendations that require magnetic resonance imaging (MRI) scans before select infusions to identify and manage ARIA.
- Incorporation of other approaches, such as medications that manage symptoms or non-drug treatments.
- Insurance coverage of the desired treatment.
- Personal preferences for interventions and care.

Early Detection and Diagnosis Could Ease Other Concerns

In addition to determining eligibility for and facilitating access to treatment, early detection and diagnosis of Alzheimer's disease could have emotional and practical benefits, such as:[526,1059,1064-1067]

- Reducing anxiety and promoting peace of mind associated with knowing one's status, even in light of a diagnosis, and the improved clarity, education and understanding that follow.
- Empowering individuals through knowledge to promote a sense of self-control and agency over decisions.
- Improving personal and financial planning in conversation with family and caregivers to allow for informed decision-making.
- Promoting healthy behaviors, such as physical activity and a nutritious diet.
- Prompting proactive safety measures, such as managing driving ability, medication adherence and home modifications.
- Creating the potential for better outcomes as a result of earlier intervention and improved quality of life.

Current State of Early Detection and Diagnosis

While not everyone experiencing cognitive decline has or will develop Alzheimer's disease, early detection and diagnosis can offer deeper insight to help navigate potential next steps, including treatment options. Today, early detection and diagnosis of Alzheimer's are closely linked. Unlike screening tests for other diseases that may pick up biological signals before outward physical symptoms appear, detecting and diagnosing Alzheimer's depends on physician assessment, often prompted by the individual's or a family member's observations of memory and thinking problems.

Clinically, early diagnosis is recognized as when an individual meets the requirements for cognitive impairment with early functional impact or mild dementia with functional impairment (Stages 3 and 4; see the Alzheimer's Disease Continuum, page 10, for more information).[53] "Functional impact" means self-reported or observed increases in the amount of time it takes to independently complete complex activities of daily living, whereas "functional impairment" describes more noticeable difficulties with everyday tasks.[53] Accurate diagnosis currently hinges on combining evidence from medical history, neurological exams, cognitive assessments and brain imaging. No one test can definitively establish that the cause of cognitive symptoms is Alzheimer's or another dementia. This diagnostic complexity currently limits early diagnosis.

Barriers to accessing health care — including logistical issues, e.g., work schedules and access to transportation, staff workforce shortages and financial constraints — present additional challenges to early detection and timely diagnosis. Although primary care physicians (PCPs) can perform standardized cognitive assessments, they may not feel equipped to administer the screening or interpret and discuss the results. Furthermore, PCPs often refer patients to specialists for additional confirmatory testing to evaluate the cause of memory issues before an official diagnosis. Patients may encounter long wait times for comprehensive testing, in part due to the scarcity of dementia specialists. Additionally, brain imaging equipment or specialized expertise to perform other diagnostic tests may not be locally available, further delaying confirmatory diagnosis.

Early Detection With Blood-Based Biomarker Tests Could Lead to More Timely Diagnosis

The limitations of current detection methods, including their complexity and accessibility challenges, highlight the need for more efficient and readily available tools. The latest promising advancement in Alzheimer's detection is blood-based biomarker tests (see the Looking to the Future: Importance of Biomarkers section, page 26). Blood tests are relatively simple to administer in a clinical setting and are commonly used to monitor health status, detect medical conditions and, in some cases, definitively diagnose a disease. Alzheimer's blood-based biomarker tests signal a shift to a more accessible method of early detection, potentially prevailing over currently expensive and/or invasive methods that are not always within reach for patients.

Blood tests for Alzheimer's disease offer potential advantages. Experts believe blood-based biomarker tests could improve the accuracy and speed of diagnosis when used as a complement to other testing, offering a viable path to earlier Alzheimer's detection and diagnosis. As of the writing of this Special Report, such tests are limited to use in

At a Glance: Alzheimer's Disease Biomarkers and Biomarker Testing

What are biomarkers?
Biomarkers are measurable biological changes that can:

- Indicate the presence or absence of disease.
- Assess the risk of developing symptoms of a disease.

What are biomarkers for Alzheimer's disease?
Biomarkers for Alzheimer's disease include the proteins beta-amyloid and phosphorylated tau (p-tau). Researchers are studying other possible biomarkers.

What biomarker tests are used to detect Alzheimer's disease?
When Alzheimer's disease is suspected, a physician can order medical tests to measure biomarkers, specifically brain imaging scans or samples of cerebrospinal fluid (CSF).

What do Alzheimer's biomarker tests look for?
Current biomarker tests primarily measure accumulation of beta-amyloid or p-tau as evidence of the hallmark brain changes of Alzheimer's disease.

What's the state of biomarker testing?
Current research is investigating novel, simple medical tests to detect biomarkers of Alzheimer's disease. Blood-based biomarker tests that detect p-tau or beta-amyloid are the furthest along and the closest to being widely available. A number of researchers are also exploring retinal biomarkers (e.g., proteins associated with retinal neurodegeneration and changes in the thickness and cell structure of the retina), cerebrovascular changes or even changes in sleep quality. Other emerging biomarker research includes examining components in saliva and the skin for signals that may indicate early biological changes in the brain.

Can biomarker tests diagnose Alzheimer's disease?
No, the presence of these biomarkers alone is not sufficient to determine an Alzheimer's diagnosis at this time.

specialty care clinics to aid in the diagnostic workup of symptomatic individuals and are still being validated in clinical trials. The Alzheimer's Association® does not recommend their use in asymptomatic individuals at this time.

Much remains to be learned about Americans' willingness to pursue testing, diagnosis and treatment to slow Alzheimer's disease progression, which was the impetus for the *2025 Alzheimer's Disease Facts and Figures* Special Report survey.

Attitudes About Early Detection and Treatment of Alzheimer's Disease

This year's Special Report offers new insights into the public's knowledge, interest and views regarding detection and treatment of Alzheimer's disease.

To better understand these topics, the Alzheimer's Association commissioned Versta Research to survey U.S. adults age 45 and older. The survey aimed to identify key knowledge gaps, measure public awareness, and uncover attitudes and beliefs about Alzheimer's across different demographic groups.

Key Findings

Attitudes about early detection and diagnosis

***The vast majority of Americans believe diagnosis at the early stages of Alzheimer's disease is important*.**

- Nearly all (99%) Americans said it is important to diagnose Alzheimer's in the early stages of the disease.
- Most (59%) also viewed cognitive screening for Alzheimer's or other dementia as a very important aspect of preventive health care.

***Most Americans would want to know if they have Alzheimer's disease when they have no symptoms or minor symptoms of cognitive decline*.**

- Nearly 4 in 5 Americans (79%) would want to know if they had Alzheimer's disease before experiencing symptoms or before symptoms interfere with daily activities.

***Consistent with interest in early diagnosis, nearly all Americans would want to undergo a simple test, e.g., a blood-based biomarker test, to detect Alzheimer's disease if it were available*.**

- More than 9 in 10 Americans would definitely or probably want a simple medical test if it were available.
  - 91% would want testing before symptoms appear (presymptomatic).
  - 95% would want testing when experiencing early symptoms (postsymptomatic).
- Four in 5 Americans (80%) said they would ask for a simple medical test rather than wait for their doctor to suggest it; this was consistent across all populations surveyed.

The top reason to seek a simple medical test is the potential for earlier health care intervention.

- More than 4 in 5 Americans (83%) would want to undergo simple medical testing for Alzheimer's because it would allow for earlier treatment and care.
- Other leading reasons included that detection allows time for planning (76%), encourages action to preserve existing cognitive function (68%) and helps with understanding what is happening (67%).

Implications for future insurance coverage are the major concern related to testing that detects Alzheimer's.

- More than 2 in 5 Americans (44%) had concerns about insurance companies not covering subsequent care after testing.
- Other leading concerns about being given a simple medical test included test accuracy (41%), losing confidence in one's ability to carry out daily activities (40%) and the cost of testing (39%).

Attitudes about anti-amyloid medications

The option for treatment to slow progression elevates the importance of an early Alzheimer's diagnosis.

- Nearly 3 in 4 survey respondents (73%) said being able to take medication to slow the progression of Alzheimer's during its early stages would influence their feelings about an early diagnosis.

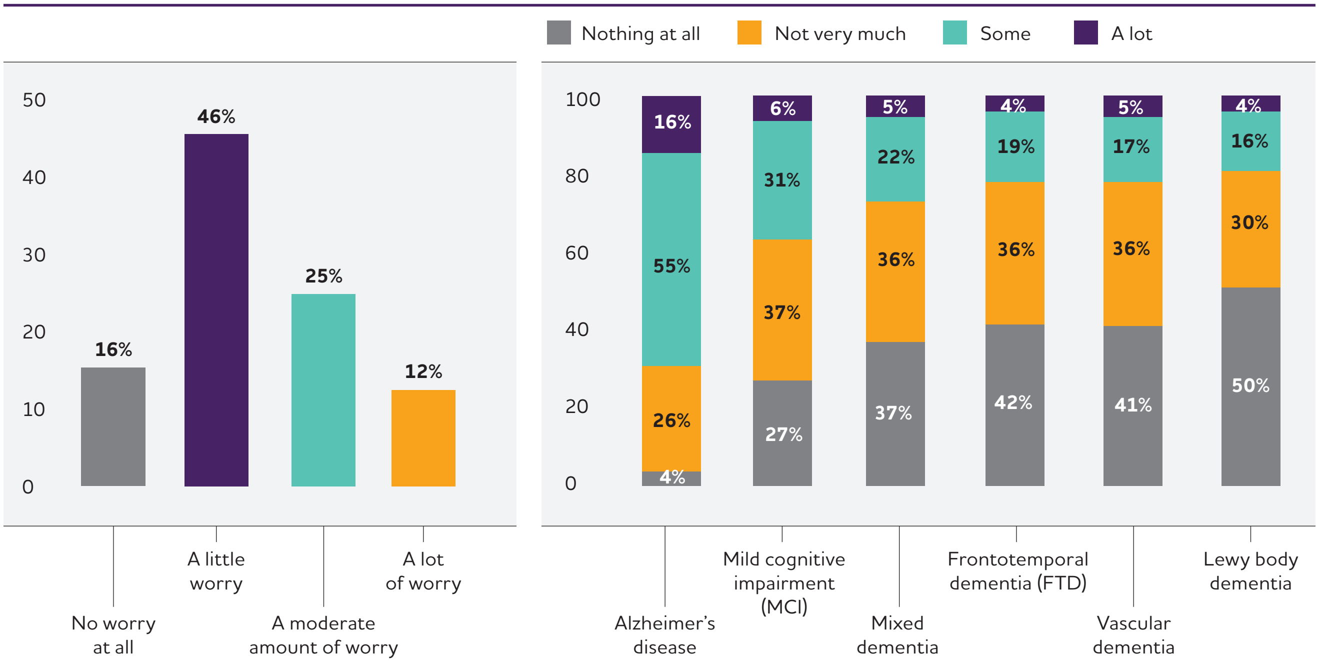
If diagnosed with Alzheimer's, most Americans would want medication to slow the progression of the disease and highly value information about it.

- More than 9 in 10 Americans (92%) would probably or definitely want a medication that could slow the progression of Alzheimer's disease following a diagnosis.
  - Nearly 2 in 3 Americans (64%) knew that anti-amyloid medications targeting underlying causes to slow disease progression exist.
- Information about treatments that slow the progression of the disease (72%) and information about Alzheimer's disease (69%) top the list of most valued information people want to receive following a diagnosis.
- Survey participants expressed equally strong interest in other options to manage and treat Alzheimer's disease — 94% would want medications that lessen symptoms, and 90% would want education and support for lifestyle changes.

Treatment risks and logistics do not diminish interest in anti-amyloid medication.

- Nearly 3 in 5 Americans (58%) would accept moderate or high levels of medication risk to slow the progression of Alzheimer's disease.
- Three in 4 Americans (74%) said visiting an outpatient clinic at least once a month for treatment would not affect their interest in an anti-amyloid medication.

FIGURE 19



Worry About Developing Alzheimer's Disease

Knowledge of Alzheimer's Disease and Related Conditions

Attitudes about the future of Alzheimer's treatment

Americans expressed high expectations and optimism for the next 10 years, as well as a desire to contribute to progress in Alzheimer's disease treatment.

- Up to 4 in 5 Americans feel optimistic about new Alzheimer's treatments in the next decade.
  - 81% expect new treatments to ***stop*** progression.
  - 66% expect new treatments to ***prevent*** Alzheimer's disease.
  - 49% expect new treatments to ***cure*** Alzheimer's disease.
- If diagnosed with Alzheimer's disease, more than 4 in 5 Americans (83%) said they would be interested in participating in a clinical trial to evaluate a medication that would slow or cure Alzheimer's.

Survey design and research methods

A survey of 1,702 U.S. adults age 45 and older was conducted from Nov. 7-18, 2024. The sample was sourced via NORC's AmeriSpeak Panel at the University of Chicago. AmeriSpeak is a probability-based panel of all U.S. households. The full sample included oversampling of Hispanic (n=296), Black (n=309), Asian (n=282) and Native (n=166) Americans for robust analysis of subgroups. The final data was weighted by select criteria to match population totals from the U.S. Census Bureau. The survey was offered in both English and Spanish as an online or phone survey.

Survey results

Americans Are Worried About Alzheimer's Disease Despite Knowing Little About It

Worry about developing Alzheimer's disease is common. In the survey, more than 4 in 5 U.S. adults (83%) expressed some level of worry, with more than 1 in 10 (12%) expressing a lot of worry (Figure 19). Hispanic Americans and those with a family history worried most about Alzheimer's disease (see box, Perspectives of Individuals with a Family History of Alzheimer's, page 112). Hispanic Americans reported significantly higher levels of worry than all other groups surveyed, with nearly 1 in 3 (29%) saying they had a lot of worry compared with 14% of Native Americans, 12% of Asian Americans, 13% of Black Americans and 9% of White Americans.

Although worry is prevalent, understanding of both Alzheimer's and other diseases that cause dementia remains considerably limited. Fewer than 1 in 5 Americans (16%) said they knew a lot about Alzheimer's disease, and even fewer said they knew much about MCI or other diseases that cause dementia (Figure 19). MCI due to Alzheimer's disease is the symptomatic precursor to Alzheimer's dementia.

These findings echo those of the *2022 Alzheimer's Disease Facts and Figures Special Report, More Than Normal Aging: Understanding Mild Cognitive Impairment*, which surveyed American adults ages 18 and older about their awareness of MCI.[1064] That survey found that 42% of Americans had some level of worry about developing MCI due to Alzheimer's disease, with 14% worrying "a lot."[1064] The 2022 Special Report also found that knowledge of MCI was limited.[1064]

Most U.S. Adults Want to Know Early If They Have Alzheimer's Disease

Americans overwhelmingly viewed early diagnosis of Alzheimer's disease as important (99%), with 4 in 5 (79%) indicating that early diagnosis of Alzheimer's disease is very important (Figure 20).

White Americans were less likely to say early diagnosis was very important (76%) versus Black Americans (91%), Native Americans (87%), Hispanic Americans (86%) and Asian Americans (80%).

Strong Preference for Diagnosis Before Noticeable Symptoms or When Symptoms Are Minor

Americans indicated a strong preference for diagnosis as early as possible. Half of Americans (50%) would want to know if they had Alzheimer's disease even before experiencing symptoms, and 1 in 3 (29%) would want to know at the point where they are experiencing minor symptoms (Figure 21). Fewer survey participants said that they wanted to know their diagnosis as symptoms worsened — 11% when experiencing mild symptoms, 3% when experiencing moderate symptoms and 2% when symptoms were severe. Only 5% said they would never want to know if they had Alzheimer's disease (Figure 21).

This preference for the timing of diagnosis varied among different population groups. Black Americans most wanted to know about Alzheimer's disease at the earliest stage before symptoms arise, especially when compared with White Americans (58% versus 48%, respectively). Greater percentages of Native and Hispanic Americans said they would never want to know compared with other groups (11% and 13%, respectively, versus 1% of Asian Americans, 7% of Black Americans and 4% of White Americans).

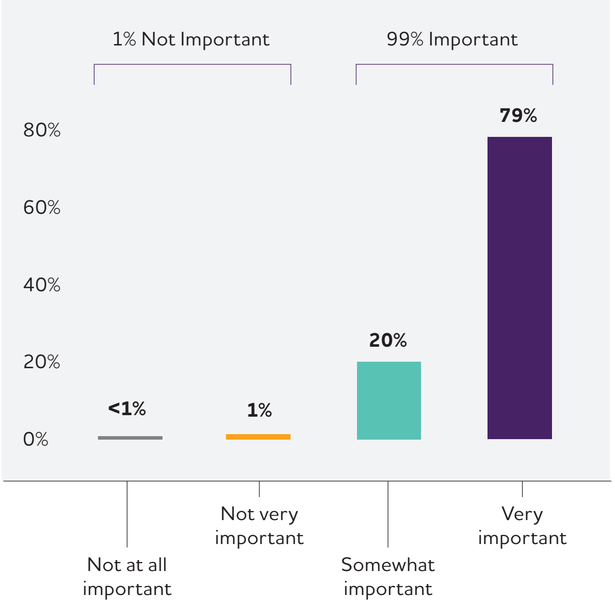
Again, these responses are consistent with the 2022 Special Report, which found that 54% of Americans ages 18 and older would want to know they had Alzheimer's disease at the MCI stage, and only 5% would never want to know their diagnosis.[1064] As with this year's findings, very few people were interested in waiting until the severe stages of the disease to be diagnosed.[1064] Taken together with current findings, the public sentiment appears to be "earlier is better" when it comes to an Alzheimer's diagnosis.

The Public Values Cognitive Assessments and Is Aware of Diagnostic Tests but Lacks Biomarker Test Knowledge

Preventive health care screenings and services — such as cholesterol or cancer screening — become a more frequent part of recommended care as one ages and are essential tools for risk assessment and identifying diseases in their early stages. Most Americans (59%) believed cognitive screening for Alzheimer's or other dementia is very important, albeit less so than other preventive services and screenings (Figure 22). (*Note: While routine screening for Alzheimer's and other dementias is not recommended without recognizable cognitive signs and symptoms, assessment for any potential cognitive impairment is part of the Medicare Annual Wellness Visit.*[792])

FIGURE 20

Perceived Importance of Early Alzheimer's Disease Diagnosis



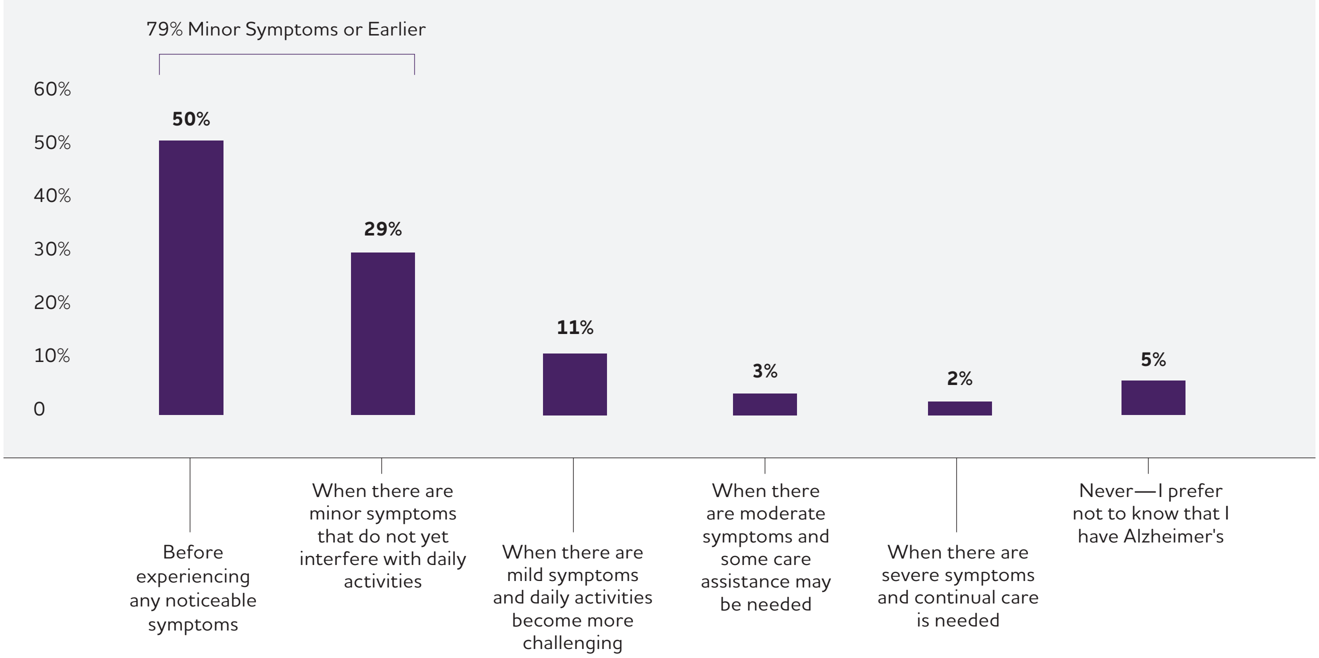
Americans reported high awareness of medical tests to aid in diagnosing Alzheimer's disease, including cognitive testing, brain imaging and neurological exams.

However, only 1 in 3 (31%) were aware of blood tests being evaluated in clinical trials and available primarily in specialty care settings to aid in the diagnostic workup of symptomatic individuals. The percentage aware of various testing methods is:

- Tests to measure memory, activities and emotional/psychological changes (70%).
- Brain imaging (67%).
- Neurological exams (65%).
- Medical history interviews (55%).
- Computerized cognitive tests (49%).
- Genetic testing (46%).
- Physical exams (43%).
- Blood tests (31%).
- Autopsy (29%).
- Cerebrospinal fluid (CSF) tests (14%).

FIGURE 21

Stage at Which U.S. Adults Age 45+ Would Want to Know If They Had Alzheimer's Disease



Overall, survey participants reported very limited knowledge about biomarker tests to support Alzheimer's disease diagnoses, with fewer than 1 in 10 Americans (9%) feeling they knew much about them.

Nearly All Americans Would Want a Simple Medical Test for Alzheimer's if Available, and Many Would Proactively Request It

Although Americans reported little knowledge of biomarker tests, there was strong interest in them when framed as a hypothetical simple medical test. More than 9 in 10 Americans reported that they would want a simple medical test for Alzheimer's (Figure 23, left and middle panels). Ninety-one percent expressed interest in being tested before experiencing symptoms (presymptomatic; Figure 23, left panel). The appearance of symptoms did not seem to influence interest level, with only slightly more (95%) wanting a test if they noticed problems with their ability to think, understand or remember things (postsymptomatic; Figure 23, middle panel). Four in 5 Americans (80%) indicated they would ask for a simple medical test to detect Alzheimer's rather than waiting for a doctor to suggest it (Figure 23, right panel). Overall, interest in a simple medical test to detect Alzheimer's disease remained strong across all populations surveyed.

Preparedness Tops Benefits, While Loss of Insurance Coverage Is Noted as a Risk of Testing

Americans cited feeling prepared as a reason to want a simple Alzheimer's test. Preparedness encompasses allowing for earlier treatment and care, general planning for the future, encouraging action to preserve cognitive function for as long as possible, addressing safety issues in advance, and assembling medical and caregiving teams.

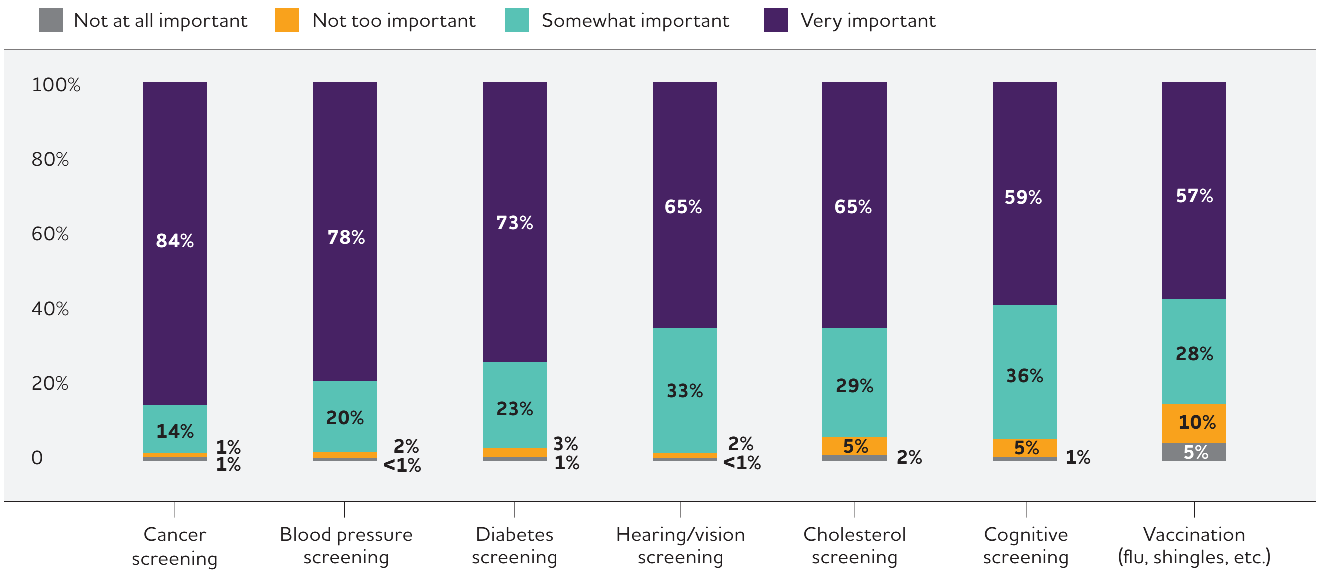
The top reason for wanting a test to detect Alzheimer's disease was that it would allow for earlier treatment and care (4 in 5 respondents, 83%). Three in 4 (76%) respondents said another reason is it would allow them to better plan for the future with their family, and 2 in 3 (68%) said it would encourage them to take actions that could help preserve their cognitive function (Figure 24, top panel).

Wanting education is also a reason for seeking testing. Americans said they would want a test because it could help them understand what is happening (67%) and encourage them to seek support and education (58%; Figure 24, top panel).

Regarding the medical benefits of simple tests for Alzheimer's disease, there was stronger than anticipated interest in testing to inform clinical trial participation, with nearly 1 in 2 respondents (48%) saying this would be a reason for them to undergo testing. More than half (55%) also indicated interest if the test could rule out other causes of memory problems (Figure 24, top panel).

FIGURE 22

Perceived Importance of Preventive Health Care Services or Screenings



Insurance was the most prominent concern about being tested. More than 2 in 5 Americans (44%) reported apprehension about how this would affect coverage of future care (Figure 24, bottom panel). Other common concerns included test accuracy (41%), losing confidence in abilities to carry out daily tasks (40%), cost of testing (39%) and being prohibited from activities such as driving (38%). Concerns related to worry, access and stigma were less common but still meaningful to some survey participants (Figure 24, bottom panel). Nearly 1 in 5 respondents (17%) had no concerns about testing. Only a few respondents believed that testing would not matter because treatment options are limited (14%) or there is no cure (13%).

In the 2022 Special Report survey, Americans age 18 and older indicated their top reasons for wanting to know early if they had Alzheimer's disease were to plan for the future, allow for earlier treatment of symptoms, take steps to preserve cognitive function and understand what was happening.[1064] Participation in clinical trials was another, but less prominent, reason for wanting an early diagnosis of Alzheimer's disease. Reasons for wanting early detection overlap with those for seeking early diagnosis. In this year's Special Report, Americans 45 and older cited these same reasons for wanting a simple medical test to detect Alzheimer's disease, supporting the trend toward early Alzheimer's diagnosis first identified in the 2022 Special Report.[1064]

Americans Are More Inclined to Want an Early Alzheimer's Diagnosis When They Have the Option of Treatment to Slow Cognitive Decline

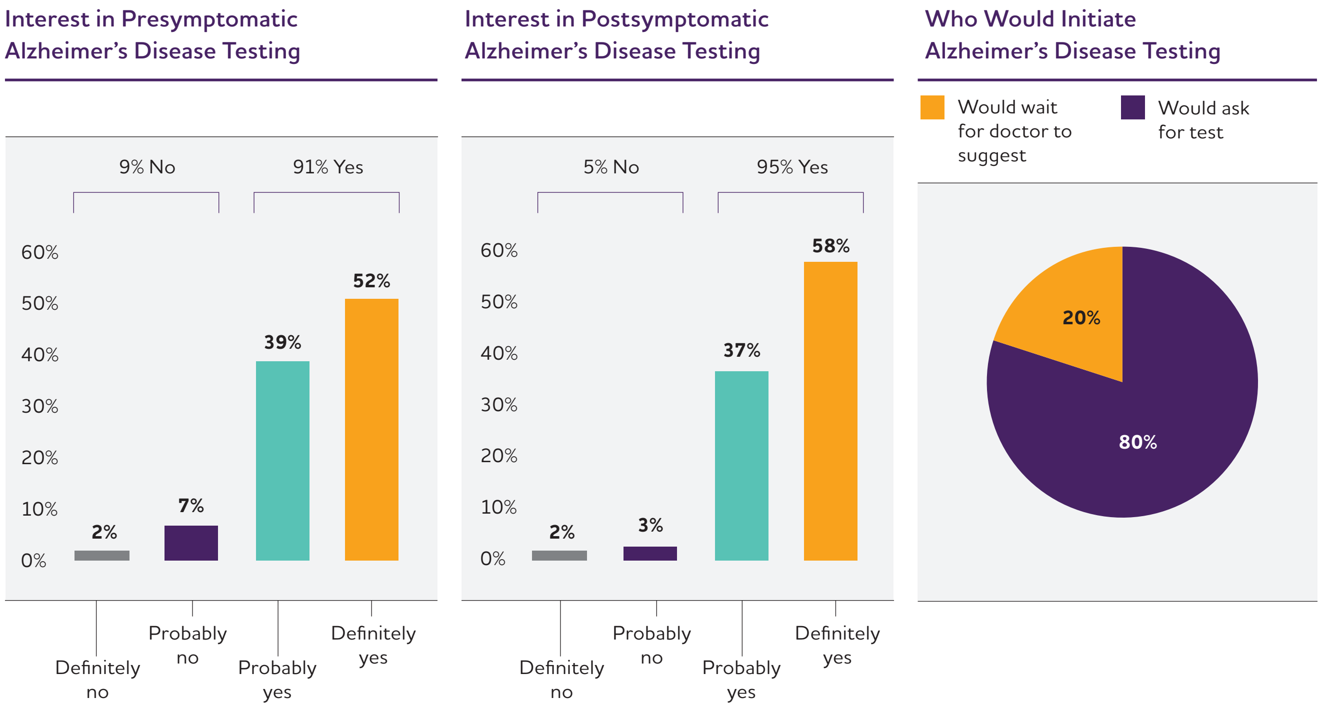
There was high awareness of current treatment options for Alzheimer's disease. Many Americans (73%) were aware of medications to lessen symptoms. Nearly 2 in 3 Americans (64%) said they knew of medications that can now slow the progression of Alzheimer's disease (anti-amyloid medications). However, aside from general awareness, familiarity with treatments that can slow the disease progression was low (15% familiar versus 85% not familiar).

A higher percentage of Hispanic Americans were not sure of options for treatment and management of Alzheimer's disease. They also reported lower awareness than other populations of all current options; for example, 1 in 2 (52%) indicated they had heard of medications that could slow Alzheimer's disease progression, and 57% were aware of medications to lessen symptoms.

Many people were also aware of alternatives to medication that could help manage Alzheimer's disease, such as community resources (56%), lifestyle changes (55%), and counseling and psychotherapy (43%).

When asked, "If you could take a medication that would slow the progression of Alzheimer's disease during the early stages of the disease, would that change your feelings about when you would want to know if you had Alzheimer's?", nearly 3 in 4 survey respondents (73%) said it would change their preference (Figure 25, left panel).

FIGURE 23



Interest in Presymptomatic Alzheimer's Disease Testing

Interest in Postsymptomatic Alzheimer's Disease Testing

Who Would Initiate Alzheimer's Disease Testing

Americans Expressed Strong Interest in Anti-Amyloid Medications if Diagnosed with Alzheimer's Disease

Nine in 10 Americans (92%) surveyed said they would want to take medication to slow progression if they were diagnosed with Alzheimer's at a stage when experiencing only mild symptoms (Figure 25, right panel). Assuming they were diagnosed early, participants also expressed similarly strong interest in taking medications to lessen symptoms (94%), as well as receiving education and support for lifestyle changes (90%) (Figure 25, right panel).

Apart from expressing interest in being treated with anti-amyloid medication, Americans reported that if they were diagnosed with Alzheimer's disease, information about such treatments would be the most valuable. More broadly, they said they wanted education on the health impacts of the disease and health care planning. If diagnosed with Alzheimer's, survey respondents would most value:

- Information about treatments that slow progression (72%).
- Information about the disease (69%).
- Information about the treatments to address disease-related symptoms (62%).
- A point of contact on the care team to answer questions and connect to resources (otherwise known as a care navigator, 59%).
- Information about financial and legal resources and protections (59%).
- Information about non-medication management of symptoms (57%).
- Information about Alzheimer's clinical trials (50%).
- Information about caregiver support (49%).
- Information about local support resources (44%).

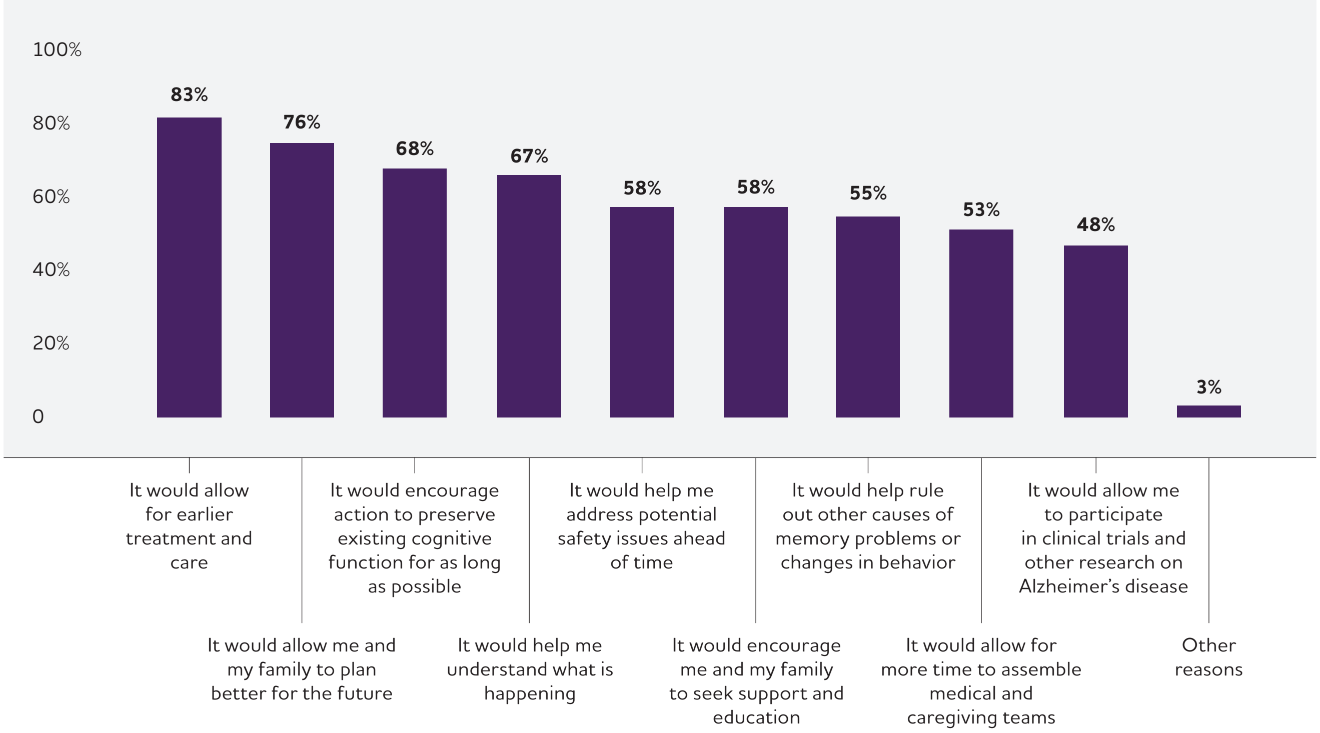
Interest in Treatment to Slow Alzheimer's Progression Is Not Diminished by Barriers to Access or Potential Risks Associated with Medication

Today's anti-amyloid treatments are administered as infusions at least once per month in a clinical setting, such as a hospital or specialty outpatient clinic. This schedule may create barriers to access for some individuals due to clinic location or distance, scheduling and transportation. These barriers had little impact on attitudes, with 3 in 4 Americans (74%) saying it would not change their interest in receiving treatment (Figure 26, top left panel). Of those who were less likely to want outpatient treatment, insurance coverage was their top concern (60%), followed by experiencing side effects at home (52%; Figure 26, top right panel).

Additionally, nearly 3 in 5 Americans (58%) would accept moderate to very high levels of medication risk to slow the progression of Alzheimer's disease in the early stages. More than 1 in 3 (36%) expressed willingness to accept moderate risk, 8% were willing to accept a high amount of risk, and 14% responded that they would be willing to do everything possible to slow progression (Figure 26, lower panel).

FIGURE **24**

Reasons for Wanting a Simple Test for Alzheimer's



Concerns about Alzheimer's Testing

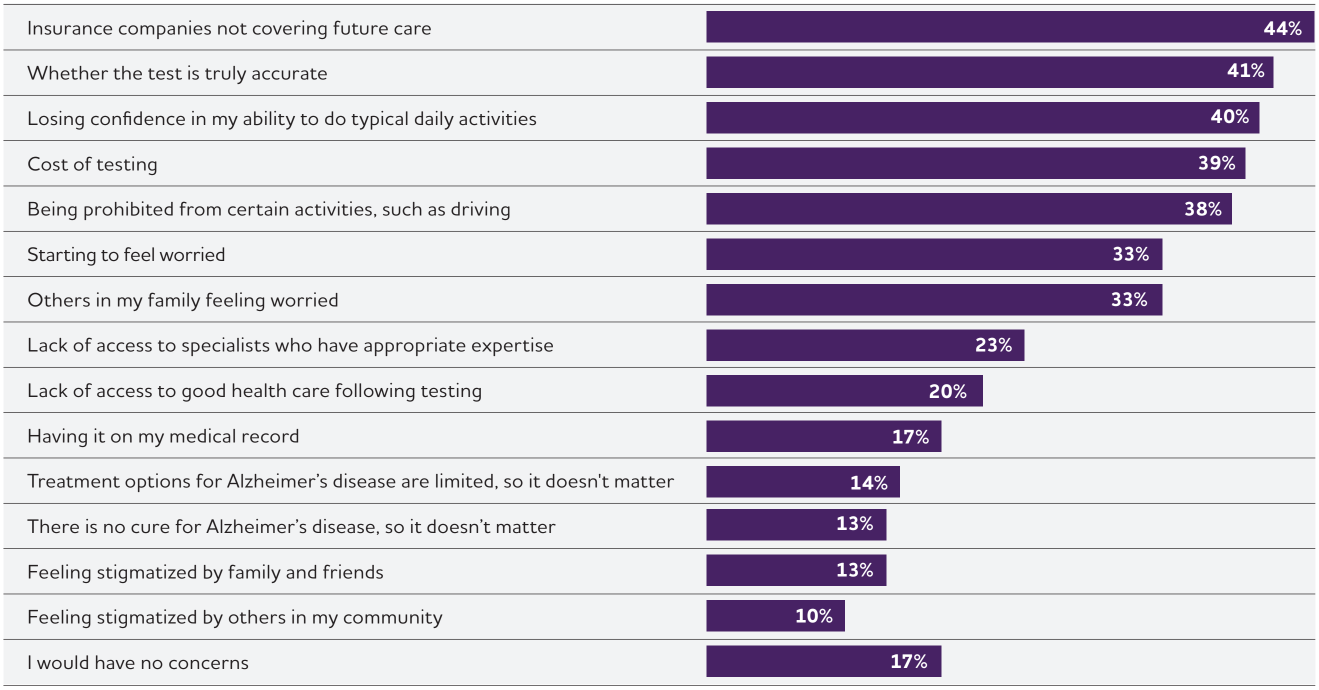
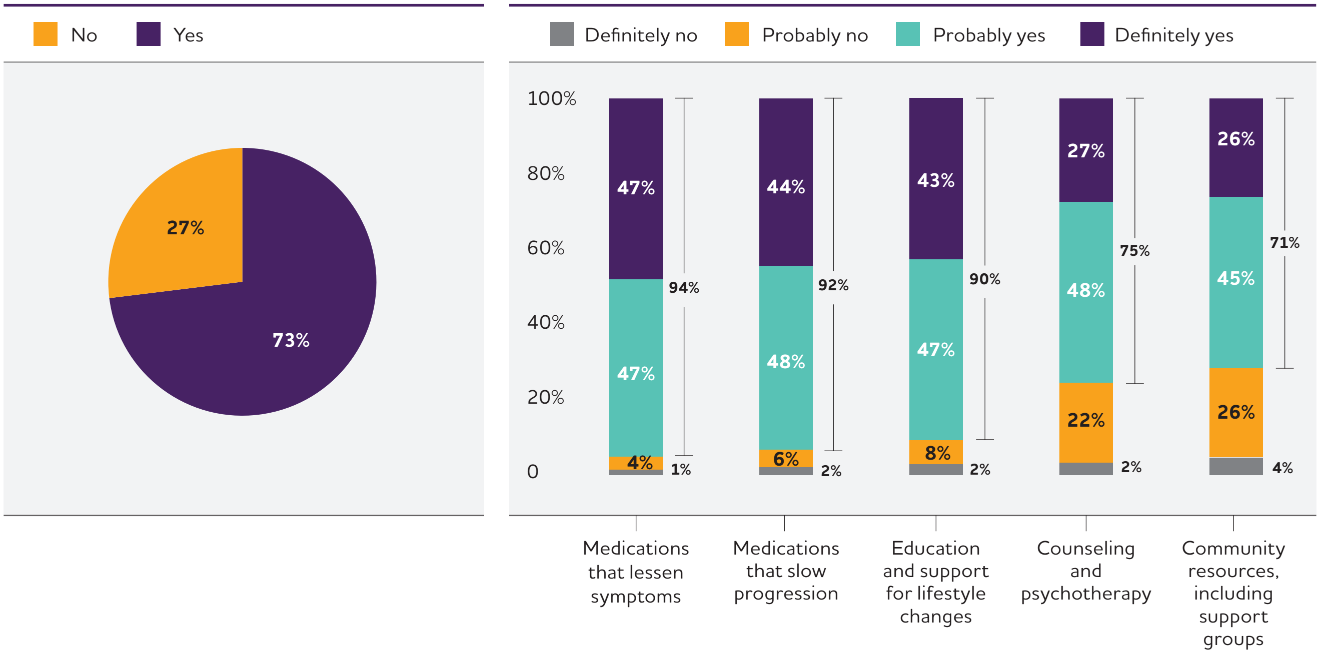


FIGURE **25**



Whether Anti-Amyloid Treatment Potential Changes Preference for Earlier Diagnosis

Interest in Options for Managing and Treating Alzheimer's Disease

White Americans had somewhat higher risk tolerance, with 61% saying they would accept moderate to very high levels of risk with anti-amyloid treatment versus 48% of Asian Americans and 45% of Black Americans. Many Native and Hispanic Americans also said they would accept moderate to very high levels of risk (58% and 53%, respectively).

Americans Envision a Bright Future for Alzheimer's Treatment

Although Alzheimer's disease continues to affect the lives of many across the nation, Americans remain hopeful about the potential for new treatments and signaled strong support for research that aims to advance medical breakthroughs. More than 4 in 5 Americans (83%) expressed interest in participating in clinical trials that could help slow or cure Alzheimer's disease. Additionally, survey respondents were optimistic about treatment advances in the next 10 years:

- Four in 5 (81%) believe treatments to ***stop*** the progression of Alzheimer's disease are within reach.
- Two in 3 (66%) say treatments to ***prevent*** Alzheimer's disease are likely.
- Half (49%) think there might be a treatment to ***cure*** Alzheimer's disease.

These responses mostly align with public views on future Alzheimer's treatment reported in 2022, with a shift toward greater optimism about a future treatment to stop disease progression (60% of Americans 18 and over in 2022 versus 81% of Americans 45 and older in 2025).[1064]

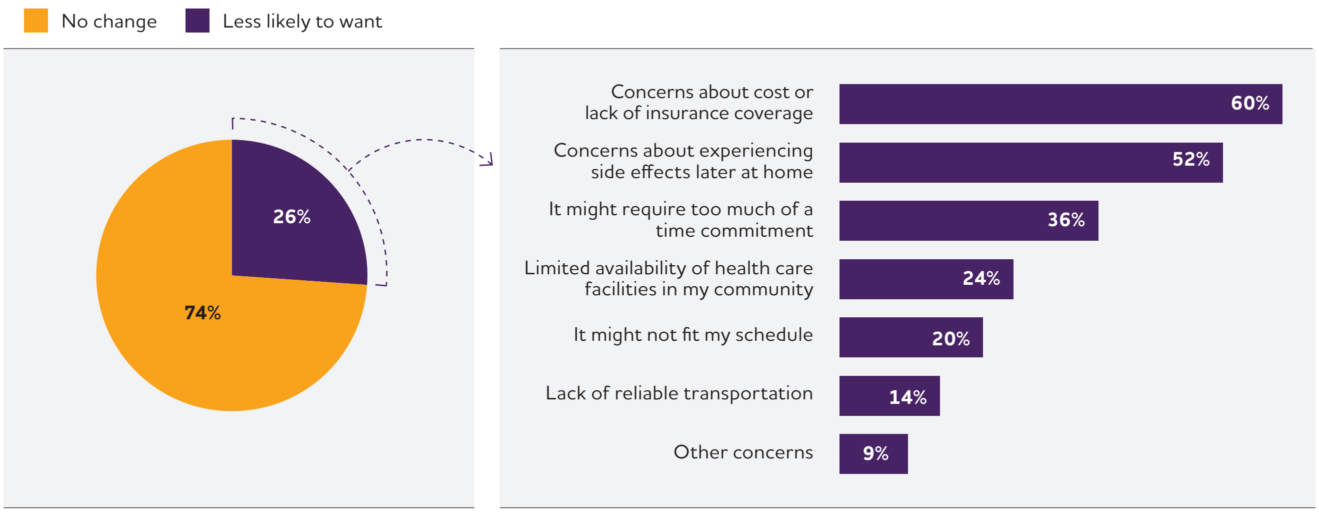
White respondents were generally less optimistic about future progress in preventing and treating Alzheimer's disease. Among those surveyed, a majority of Hispanic (80%), Black (77%), Native (74%), and Asian Americans (73%) believed it likely that a treatment will be developed in the next decade to prevent Alzheimer's disease. A smaller majority of White Americans (62%) shared this belief. Many Black (65%), Asian (63%), Native (61%) and Hispanic Americans (60%) also thought that a cure was likely on the horizon. White Americans were the least hopeful, with 43% believing a cure for Alzheimer's disease was plausible in this timeframe.

A Path Forward: Facilitating the Future of Alzheimer's Detection, Diagnosis and Treatment

The *2025 Alzheimer's Disease Facts and Figures* Special Report underscores the need to strengthen early detection and diagnosis of Alzheimer's disease for more Americans. Possible steps include:

- Continuing research to discover, validate and advance biomarker testing modalities.
- Establishing clinical practice guidelines to assist with detection and diagnosis and to ensure that evaluation and treatment are grounded in actionable evidence.

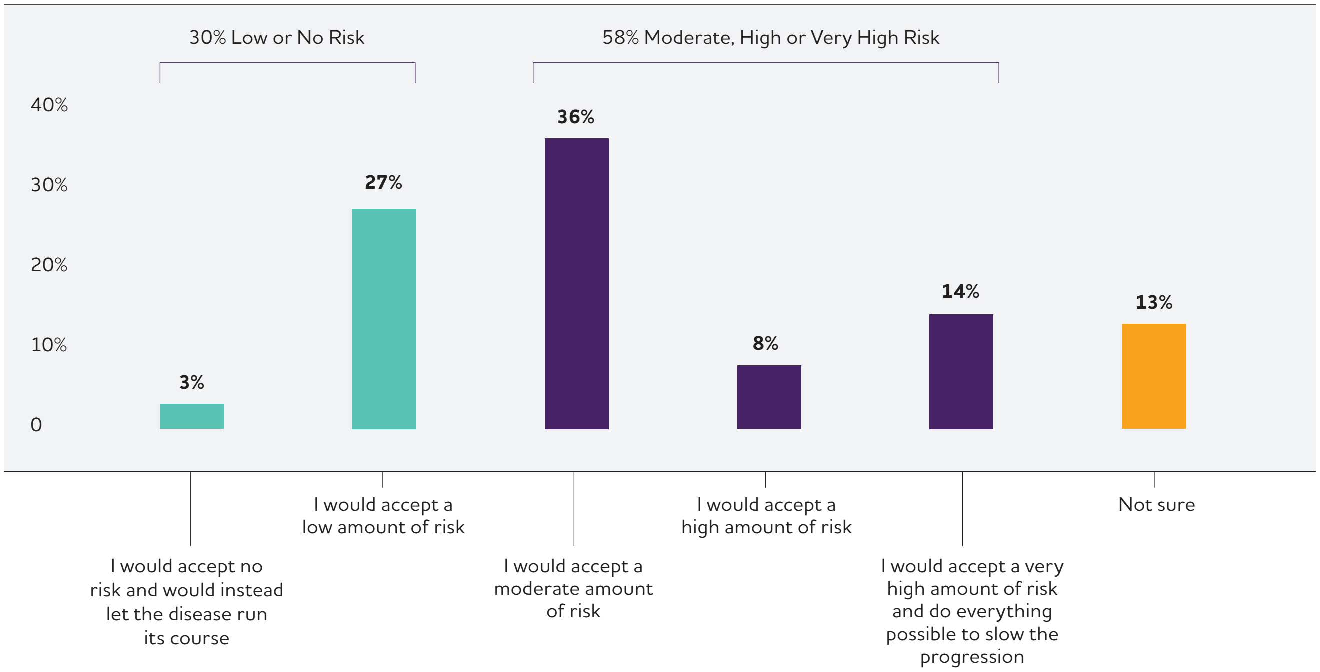
FIGURE **26**



Impact of Monthly Outpatient Care on Interest in Anti-Amyloid Treatment

Reasons for Less Interest in Anti-Amyloid Treatment Requiring Monthly Outpatient Care

Acceptable Levels of Risk for Treatments that Slow the Progression of Alzheimer's Disease



- Improving conversations among patients, caregivers and clinicians about testing, diagnosis and treatment.
- Recognizing potential ethical concerns with early detection.
- Securing future access to biomarker testing through legislation and policy initiatives that aim to guarantee insurance coverage.
- Leveraging public health efforts to promote the importance of early detection and diagnosis through awareness campaigns and provider education.

Ensuring Support for Research, Development and Validation of Novel Biomarker Tests

Research advancements on clinical assessments, psychometric testing, and emerging blood-based and established biomarker tests are increasing the likelihood of being able to detect hallmarks of neurodegenerative diseases at their earliest stages.[1068]

The Alzheimer's Association has been at the forefront of these cutting-edge research efforts, investing millions annually to propel a variety of aspects of dementia research.[1069] In 2024, 15% of funded projects focused on developing tools and methods for earlier diagnosis, timelier interventions and more effective monitoring of disease progression.[1069] These efforts encompass studies that develop and expand the use of brain scans, fluid biomarkers such as blood tests, and clinical tools, as well as studies that integrate these measures to further their development, standardization and validation.

In addition, more than 10 years ago, the Alzheimer's Association established the Global Biomarker Standardization Consortium (GBSC) to convene key researchers, clinicians, industry members and regulatory and government leaders.[1068] The GBSC's objective is to achieve consensus on the best ways to standardize and validate biomarker tests — a critical part of ensuring consistent test results — for Alzheimer's and other dementia for use in global clinical practices.

In 2018, the Alzheimer's Association launched a working group under the GBSC umbrella to focus on consensus procedures for standardizing collection and processing of blood samples. This working group, the Standardization of Alzheimer's Blood Biomarkers (SABB) Program, brings together those with expertise in fluid biomarkers from academia, government and industry. The SABB published standardized procedures for handling blood samples and continues to research new and emerging biomarkers to inform the scientific and clinical communities.[1070] Furthermore, in 2024, the GBSC launched a new workgroup, the Alzheimer's Association Certified Reference Material for Plasma p-tau217, to facilitate global standardization measurements and improve diagnostic accuracy of this key biomarker for Alzheimer's disease.

Perspectives of Individuals With a Family History of Alzheimer's

In this year's survey, 1 in 4 U.S. adults reported having a biological grandparent, parent or sibling with Alzheimer's disease. This personal experience was a significant differentiator of attitudes, awareness and interest in early detection, diagnosis and treatment.

Compared with survey participants who did not report having a relative with Alzheimer's disease, those with a family history:

- Worried more about developing Alzheimer's disease themselves (38% worried a moderate amount and 21% worried a lot versus 20% and 9% for those without a family history, respectively).
- Saw cognitive screening as being more important (66% perceived it as very important versus 56% of those without a family history).
- Expressed stronger interest in blood-based biomarker testing (62% were definitely interested in presymptomatic and 67% were definitely interested in postsymptomatic testing versus 48% and 54% without a family history, respectively).
- Were somewhat more familiar with anti-amyloid treatments (20% versus 13%) and expressed the strongest interest in this treatment option (50% would definitely want treatment versus 42%).
- Expressed somewhat greater interest in participating in future clinical trials studying treatments to slow or possibly cure Alzheimer's disease (46% were very interested in future clinical trials versus 37%).

Focus Groups Mirror Survey Findings

As part of its Healthy Brain Initiative Cooperative Agreement with the Centers for Disease Control and Prevention, the Alzheimer's Association initiated focus groups to gather perceptions and attitudes about the early detection and treatment of Alzheimer's disease beyond what could be gleaned from the survey. Focus groups reiterated several of the Special Report survey findings, and views overlapped in many areas.

Most participants understood early detection to be regular health screenings and preventive care, and personal experiences through family members significantly shaped views of early detection of Alzheimer's disease.

Thoughts on Early Detection

"When you have knowledge, you are that much more powerful." — American Indian participant who indicated they would want to know if they had Alzheimer's disease before noticeable symptoms.

The preference for early-stage detection (before noticeable or with only minor symptoms) was clear in the focus groups. Attitudes and opinions on the advantages were consistent with the survey responses. However, the focus groups were able to probe deeper into the disadvantages of early detection, particularly the potential emotional drawbacks.

The focus groups also explored whether knowing about medication to treat the early stages of Alzheimer's influenced the timing of diagnosis. Knowledge about new medication to slow disease progression reinforced preferences to know their diagnosis in the early stages of the disease. However, this information raised questions for many participants about medication access and affordability, including access to insurance coverage, efficacy and side effects.

Advantages

"Even if it's not in your family, you should still be doing things to protect your brain or your health. I'm not going to do anything that's going to jeopardize my brain because I don't want to get Alzheimer's. I'm going to prevent it [in] any way possible." — Asian American and Pacific Islander participant

Cross-cutting findings and themes:

Planning and preparation

- Ability to get affairs in order while cognitively capable.
- Ability to express care preferences.
- Time for family to prepare and plan for care.
- Opportunity to make financial and legal arrangements.

Medical benefits

- Potential access to treatment.
- Opportunity to participate in research or clinical trials.
- Better chance to participate in care decisions.

Safety and support

- Time to build a support network.
- Ability to make living arrangements.
- Prevention of crisis situations.

Disadvantages

"I would not want to know too early. I wouldn't want to deal with the anxiety." — White participant

Cross-cutting findings and themes:

Psychological impact

- Anxiety about the future.
- Stress of knowing that there is no cure.
- Potential depression or hopelessness.
- Fear about the loss of independence.

Emotional burden

- Living with diagnosis while still functioning well.
- Uncertainty about progression timeline and treatment options.
- Challenge of timing disclosure to others.

Practical challenges

- Insurance coverage.
- Limited treatment options or access to care.

Family and social concerns

- Family stress and worry.
- Changes in relationships.
- Stigma and social implications.
- Potential isolation.

Focus group methodology

L&M Policy Research was engaged to conduct 11 focus groups with 69 participants (14 White, 14 African American, 18 American Indian/Alaska Native [AI/AN], nine Asian American and Pacific Islander [AAPI], and 14 Hispanic, Spanish-speaking [HIS-SPA]).

In 2022, the Association published *Appropriate Use Recommendations for Blood Biomarkers in Alzheimer's Disease*, which provides guidance for clinicians and researchers using these tests in clinical trials, as well as priorities for future research in this area.[277]

Establishing Clinical Practice Guidelines to Bridge Scientific Advances and Clinical Care

The Alzheimer's Association is building an updated library of clinical guidance that distills the latest scientific evidence and translates it into clear and actionable recommendations for clinical practices. This process involves close collaboration with clinical and subject-matter experts, methodologists, peer organizations, early-career researchers and patient representatives. Expert panels will move from evidence to recommendations using a transparent methodology called the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach to vet the quality of evidence used to inform recommendations. Numerous reputable organizations, including the World Health Organization, the American College of Physicians and the Cochrane Collection follow the GRADE principles and format for systematic reviews and clinical guidelines.[1071]

Recognizing that specialists need more detailed and comprehensive recommendations to provide high-quality care and promote early detection and diagnosis, the Association is currently preparing guidelines on:

- Blood-based biomarker tests: Specialized health care settings (anticipated in 2025).
- Cognitive assessment tools: Primary health care settings (anticipated in 2025).
- Clinical implementation of Alzheimer's disease staging criteria and treatment (anticipated in 2026).

These guidelines are expected to be updated annually to reflect the rapidly evolving science, new evidence and practical experiences of health care professionals.

Fostering Better Conversations About Testing, Diagnosis and Treatment

Clinical practice guidelines provide the framework for high-quality dementia care, but the foundation of trust is built on communication among patients, caregivers and clinicians.

Effective communication is absolutely necessary for improving testing, diagnosis and treatment for Alzheimer's and other dementias. Primary Care Physicians (PCPs) are often on the frontlines of dementia diagnosis and care. However, the *2020 Alzheimer's Disease Facts and Figures* Special Report found that PCPs feel inadequately prepared to care for patients with Alzheimer's and other dementias, citing difficulty answering questions, making diagnoses and staying current with the latest developments in management, treatment and screening/testing.[1072] Beyond these challenges faced by PCPs, communication barriers exist between patients and clinicians. Both groups are often uncomfortable raising concerns or discussing cognitive symptoms, which can hinder crucial next steps for detection, diagnosis and treatment.

Enhancing patient-clinician dialogue is paramount not only for improving communication about next steps but for engaging patients and caregivers in the dementia care journey. To achieve this, it is essential to develop and invest in training that increases comfort with difficult conversations and prioritizes listening to patient concerns, responding with empathy and providing clear, jargon-free explanations of complex medical information.[1073] Furthermore, training should teach techniques for collaborative decision-making that integrate patient preferences and values into the discussion.[918]

Future clinical guidelines will offer recommendations on how to broach the topic of blood-based biomarkers with patients. In the meantime, there is a growing body of language to help clinicians, including PCPs and dementia specialists, convey information about diagnosis and treatment in a balanced and realistic way. In 2024, The Alzheimer's Association Clinical Meaningfulness Workgroup presented recommendations and suggested language to help health care providers communicate clearly, accurately and empathetically about newly approved anti-amyloid medications to patients diagnosed with early Alzheimer's disease and their caregivers.[58]

The workgroup's recommendations for discussing and personalizing care plans encapsulated the following core themes:

- Balanced, accurate communication.
- Eligibility and personalization.
- Informed consent and risks.
- *APOE* genetic testing.
- Ongoing monitoring and safety.
- Financial and logistical considerations.
- Support for caregivers.
- A holistic care approach.

Many of these themes are directly applicable to eventual discussions about early detection. For example, patients and caregivers will need accurate information about how tests work, the meaning of test results, and the risks and benefits associated with receiving positive test results, which may lead to early diagnosis.

The Alzheimer's Association provides a range of resources to support health systems and clinicians in these critical areas, including materials on early detection and diagnosis, management of Alzheimer's and other dementias, care planning and support services. Prioritizing communication efforts and using available resources creates a dementia care environment where patients and caregivers feel heard, respected and empowered — ultimately resulting in higher quality of care and strengthening the patient-clinician relationship. For a complete listing of available Association resources to support health systems and clinicians, visit alz.org/professionals/health-systems-clinicians.

Examining Potential Ethical Considerations Associated with Advances in Biomarker Testing

The evolving ability to detect protein signals of Alzheimer's disease in presymptomatic individuals, particularly through blood-based biomarker tests, raises important ethical considerations.[281,1066,1074] As stated earlier in the Special Report, no guidance today recommends biomarker testing for individuals who are not experiencing cognitive symptoms. Experts must establish a clear delineation between detection, which measures indicators of potential risk, and formal diagnosis of Alzheimer's disease, which is a multifaceted process involving cognitive screening, other assessments and, ultimately, clinical judgment.

Possible ethical considerations are heightened by the anticipated FDA approval of these tests for use in primary care settings, where health care professionals may not be as familiar with the critical distinction between detection and diagnosis as specialists are, nor as equipped to accurately convey this to patients as they weigh the benefits and risks of such tests. The health care community can learn from approaches used in clinical research settings, where presymptomatic biomarker information is carefully disclosed to study participants and care partners.[281,1074] A pattern has been observed of participants in research studies sharing biomarker test results with their care partners, a practice that may well continue when test results are available in the clinic.[1066,1074]

Pre-counseling patients is an additional proactive approach to respond to possible concerns related to biomarker test results. This approach can set realistic expectations about what these tests can and cannot do, explain the possible implications of results both now and in the future, and educate patients on the distinctions between detection and diagnosis of Alzheimer's disease. Laying this groundwork for patients is vital given the increasing availability of medical test results, including blood tests and imaging, through patient portals — often without sufficient context or clinical interpretation. Premature release of results to patients before physicians are able to provide context and interpretation can lead to misinterpretation and emotional distress.

Furthermore, the potential for discrimination based on the results of biomarker testing, whether in medical settings, the workplace or the community, must be carefully considered to determine how and with whom to share results. In the clinical research setting, concerns about stigma and discrimination are cited as reasons not to share biomarker test results.[1066,1074]

This year's Special Report found that individuals are pragmatic about the use of simple medical tests, such as blood-based biomarker tests, for Alzheimer's detection. They stated that they would use the results to plan ahead, be more aware of potential symptoms and seek treatment earlier if symptoms appear.

Advancing Legislative and Policy Initiatives to Secure Insurance Coverage for Current and Future Biomarker Tests

Currently, insurance coverage for biomarker testing, which includes imaging and blood tests, has not kept pace with scientific discoveries and progress in treatment. The majority of states do not require insurance carriers to cover biomarker testing, which gives private insurance plans significant latitude in what they cover. As a result, individuals in these states may not have access to necessary biomarker testing. State Medicaid programs may elect to not cover biomarker testing for a wide variety of reasons, further challenging access. Existing health care disparities and challenges to obtaining a dementia diagnosis may be exacerbated if new biomarker testing opportunities cannot be accessed.

> **"By ensuring access to necessary biomarker testing, states can reduce the time it takes to receive a diagnosis and enable access to new disease-modifying treatments and care planning."**

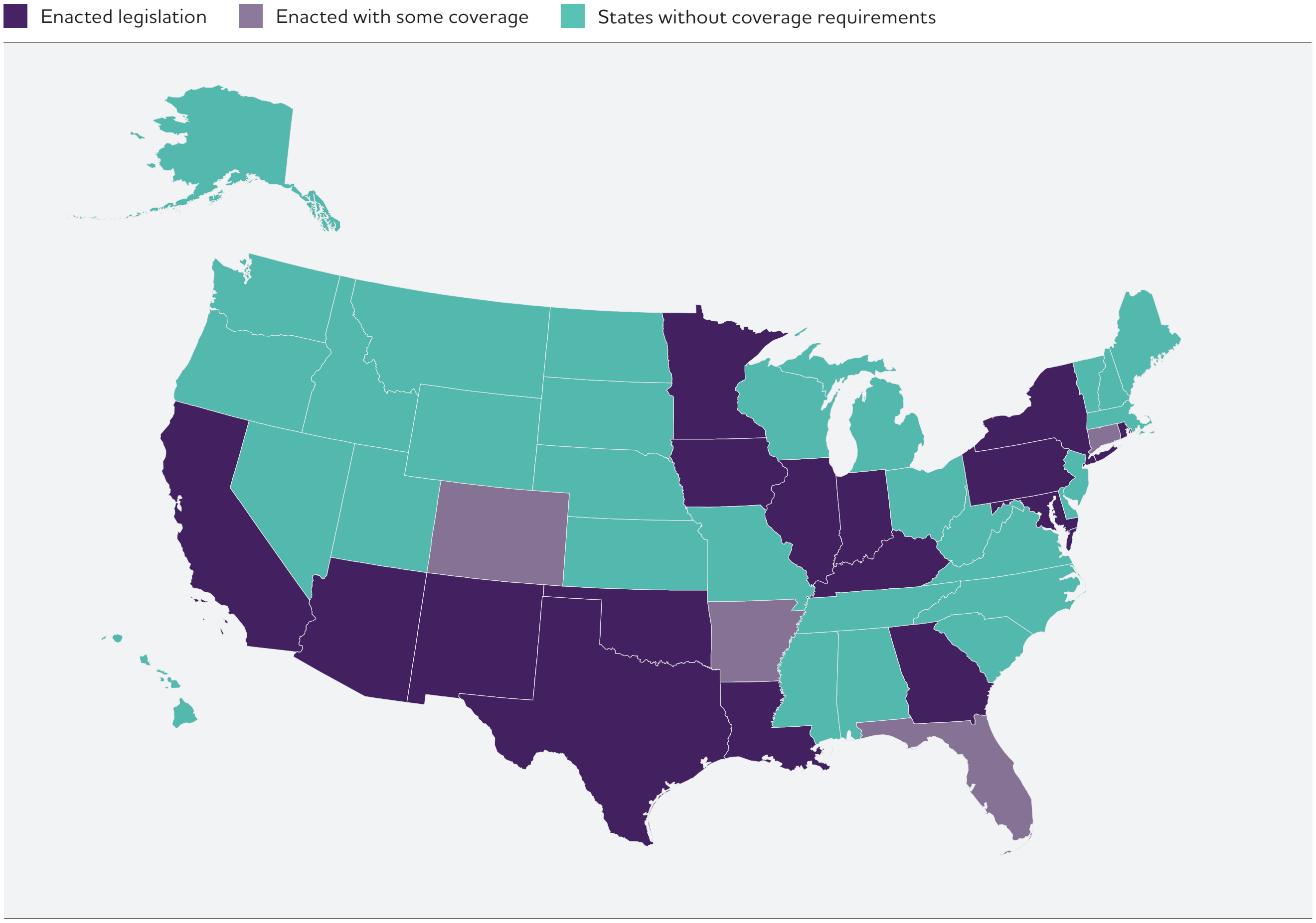
With new evidence in the field of biomarker testing and FDA consideration of blood-based amyloid biomarker testing tools expected in the near future, the Association is engaging state governments to ensure adequate coverage of biomarker tests and future access to diagnosis and treatment — reflecting the Association's commitment to these priorities.

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) are part of a national coalition of patient advocates committed to ensuring insurance coverage for comprehensive biomarker testing. National coalition members include the American Cancer Society Cancer Action Network (ACS CAN), the ALS Association and the Arthritis Foundation. AIM is working with policymakers to advance and pass state legislation requiring insurers to cover biomarker testing (Figure 27). As of January 2025:

- 16 states require coverage in both public and private insurance plans (AZ, CA, GA, IA, IL, IN, LA, KY, MD, MN, NM, NY, RI, OK, PA, TX).
- Two states require private pay only (AR, CO).
- Two states require public pay only (CT, FL).

FIGURE **27**

Successful AIM Insurance Coverage Legislation Efforts (As of January 2025)*



* AIM = Alzheimer's Impact Movement

Implementing Public Health Efforts to Promote Early Detection and Diagnosis

As more treatments become available, early detection and diagnosis of Alzheimer's disease become essential to improving the health of communities. Public health agencies play a critical role in educating the public and health care providers about the latest research, best practices and importance of early detection and diagnosis.

Alzheimer's Association initiatives with public health agencies to increase understanding emphasize education about warning signs of dementia and improve access to diagnostic services and supports. Efforts also include working to lessen stigma around discussing memory and thinking problems in communities and normalizing these conversations in health care settings to help make early detection and diagnosis more commonplace. The resulting materials and campaigns to promote early detection and diagnosis must be leveraged in every community and developed in culturally sensitive and relevant ways. The survey and focus group results from this and previous Special Reports can provide valuable insights to guide these efforts.

Beyond education, the Alzheimer's Association also collaborates with state and local public health departments, tribal health organizations, health systems and other stakeholders to establish population-based strategies covering risk reduction, early detection and diagnosis, and quality of care. These collaborative efforts are vital for creating a comprehensive and coordinated approach to addressing Alzheimer's and dementia across the life course.

Through broad, ongoing initiatives and collaborations, public health has the power to significantly lessen the burden of Alzheimer's disease on individuals, families and the nation as a whole.

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 2025: The estimated 7.2 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.[293] The number, 7.2 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.[293] 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).[173] 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.340 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.[293] Other projections are somewhat lower (see, for example, Brookmeyer et al.[1075]) 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 2024, using U.S. Census Bureau data available at: https://www.census. gov/programs-surveys/popest/data/tables.html. This resulted in a total of 11,926 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,[517] 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 19.161 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[1076] 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.)[992] 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 $413.452 billion for dementia caregiving in the United States in 2024.

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). The Lewin Model's state-specific Medicaid costs for 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) and are inflated to 2024 dollars.

A12. All cost estimates were inflated to year 2024 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 for the Medicare Current Beneficiary Survey and 2019 for Medicare claims data, prior to the COVID-19 pandemic, and do not reflect any post-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.[1077] With traditional Medicare, beneficiaries can receive care from any doctor or hospital in the United States that accepts Medicare. 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 with 29% in 2013.[1000]

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.[941] 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 *2025 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 2018. 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 G30.0, G30.1, G30.8, G30.9, G31.01, G31.09, G31.83, F.01.50, F01.51, F02.80, F02.81, F03.90, F03.91 and F10.27.

Costs from the MCBS analysis are based on responses from 2018 and reported in 2024 dollars.

A16. Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues[940] 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 *2025 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).

Appendices

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

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