

## 2020 Alzheimer's disease facts and figures

### Abstract

This article describes the public health impact of Alzheimer's disease (AD), including incidence and prevalence, mortality and morbidity, use and costs of care, and the overall impact on caregivers and society. The Special Report discusses the future challenges of meeting care demands for the growing number of people living with Alzheimer's dementia in the United States with a particular emphasis on primary care. By mid-century, the number of Americans age 65 and older with Alzheimer's dementia may grow to 13.8 million. This represents a steep increase from the estimated 5.8 million Americans age 65 and older who have Alzheimer's dementia today. Official death certificates recorded 122,019 deaths from AD in 2018, the latest year for which data are available, making Alzheimer's the sixth leading cause of death in the United States and the fifth leading cause of death among Americans age 65 and older. Between 2000 and 2018, deaths resulting from stroke, HIV and heart disease decreased, whereas reported deaths from Alzheimer's increased 146.2%. In 2019, more than 16 million family members and other unpaid caregivers provided an estimated 18.6 billion hours of care to people with Alzheimer's or other dementias. This care is valued at nearly \$244 billion, but its costs extend to family caregivers' increased risk for emotional distress and negative mental and physical health outcomes. Average per-person Medicare payments for services to beneficiaries age 65 and older with AD or other dementias are more than three times as great as payments for beneficiaries without these conditions, and Medicaid payments are more than 23 times as great. Total payments in 2020 for health care, long-term care and hospice services for people age 65 and older with dementia are estimated to be \$305 billion. As the population of Americans living with Alzheimer's dementia increases, the burden of caring for that population also increases. These challenges are exacerbated by a shortage of dementia care specialists, which places an increasing burden on primary care physicians (PCPs) to provide care for people living with dementia. Many PCPs feel underprepared and inadequately trained to handle dementia care responsibilities effectively. This report includes recommendations for maximizing quality care in the face of the shortage of specialists and training challenges in primary care.

### KEY WORDS

Alzheimer's disease, Alzheimer's dementia, Alzheimer's disease continuum, Biomarkers, Caregivers, Dementia care training, Dementia, Family caregiver, Geriatrician, Health care professional, Health care costs, Health care expenditures, Incidence, Long-term care costs, Medicare spending, Medicaid spending, Mortality, Morbidity, Prevalence, Primary care physician, Risk factors, Spouse caregiver

## 1 | ABOUT THIS REPORT

2020 *Alzheimer's Disease Facts and Figures* is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia. Background and context for interpretation of the data are contained in the Overview. Additional sections address prevalence, mortality and morbidity, caregiving and use and costs of health care and services. A Special Report examines primary care physicians' experiences, exposure, training and attitudes in providing dementia care and steps that can be taken to ensure their future readiness for a growing number of Americans living with Alzheimer's and other dementias.

### 1.1 | Specific information in this report

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

- Brain changes that occur with Alzheimer's disease.
- Risk factors for Alzheimer's dementia.
- Number of Americans with Alzheimer's dementia nationally and for each state.
- Lifetime risk for developing Alzheimer's dementia.
- Proportion of women and men with Alzheimer's and other dementias.
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age.
- Number of family caregivers, hours of care provided, and economic value of unpaid care nationally and for each state.
- The impact of caregiving on caregivers.
- National cost of care for individuals with Alzheimer's or other dementias, including costs paid by Medicare and Medicaid and costs paid out of pocket.
- Medicare payments for people with dementia compared with people without dementia.
- Number of geriatricians needed by state in 2050.

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

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

## 2 | OVERVIEW OF ALZHEIMER'S DISEASE

Alzheimer's disease is a type of brain disease, just as coronary artery disease is a type of heart disease. It is also a degenerative disease, meaning that it becomes worse with time. Alzheimer's disease is thought to begin 20 years or more before symptoms arise,<sup>1–6</sup> with changes in the brain that are unnoticeable to the person affected. Only after years of brain changes do individuals experience noticeable symptoms such as memory loss and language problems. Symptoms

occur because nerve cells (neurons) in parts of the brain involved in thinking, learning and memory (cognitive function) have been damaged or destroyed. As the disease progresses, neurons in other parts of the brain are damaged or destroyed. Eventually, nerve cells in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. Individuals become bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

### 2.1 | Alzheimer's disease or dementia?

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

*Dementia* is an overall term for a particular group of symptoms. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Dementia has many causes (see Table 1). *Alzheimer's disease* is the most common cause of dementia.

### 2.2 | Brain changes associated with Alzheimer's disease

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form connections with other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by another neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain's neuronal circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

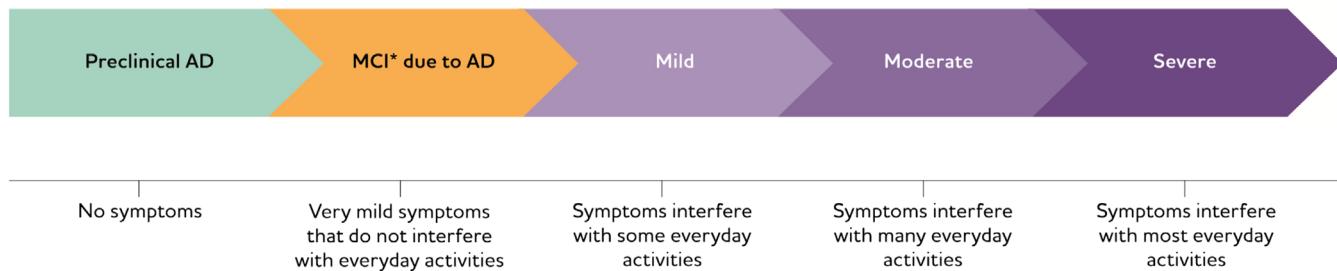
The accumulation of the protein fragment beta-amyloid (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes associated with Alzheimer's.

Plaques and smaller accumulations of beta-amyloid called oligomers may contribute to the damage and death of neurons (neurodegeneration) by interfering with neuron-to-neuron communication at synapses. Tau tangles block the transport of nutrients and other essential molecules inside neurons. Although the complete sequence of events is unclear, beta-amyloid may begin accumulating before abnormal tau, and increasing beta-amyloid accumulation is associated with subsequent increases in tau.<sup>7,8</sup>

Other brain changes include inflammation and atrophy. The presence of toxic beta-amyloid and tau proteins are believed to activate immune system cells in the brain called microglia. Microglia try to clear the toxic proteins as well as widespread debris from dead and dying cells. Chronic inflammation may set in when the microglia can't keep up with all that needs to be cleared. Atrophy, or shrinkage, of the brain occurs because of cell loss. Normal brain function is further compromised in Alzheimer's disease by decreases in the brain's ability to metabolize glucose, its main fuel.

**TABLE 1** Common Causes of Dementia and Associated Characteristics

Cause	Characteristics
Alzheimer's disease	<p>Alzheimer's disease is the most common cause of dementia, accounting for an estimated 60% to 80% of cases. Recent large autopsy studies show that more than half of individuals with Alzheimer's dementia have Alzheimer's disease brain changes (pathology) as well as the brain changes of one or more other causes of dementia, such as cerebrovascular disease or Lewy body disease. This is called mixed pathologies, and if recognized during life is called mixed dementia.</p> <p>Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioral changes and, ultimately, difficulty speaking, swallowing and walking.</p> <p>The hallmark pathologies of Alzheimer's disease are the accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are accompanied by the death of neurons and damage to brain tissue. Alzheimer's is a slowly progressive brain disease that begins many years before symptoms emerge.</p>
Cerebrovascular disease	<p>Cerebrovascular disease refers to the process by which blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients. People with dementia whose brains show evidence of cerebrovascular disease are said to have vascular dementia. About 5% to 10% of individuals with dementia show evidence of vascular dementia alone.<sup>9,10</sup> 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.</p> <p>Impaired judgment or impaired ability to make decisions, plan or organize may be the initial symptom, but memory may also be affected, especially when the brain changes of other causes of dementia are present. In addition to changes in cognitive function, people with vascular dementia commonly have difficulty with motor function, especially slow gait and poor balance.</p> <p>Vascular dementia occurs most commonly from blood vessel blockage or damage leading to areas of dead tissue or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.</p>
Lewy body disease	<p>Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia (called dementia with Lewy bodies or DLB) can result. People with DLB have some of the symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and visuospatial impairment. These symptoms may occur in the absence of significant memory impairment but memory loss often occurs, especially when the brain changes of other causes of dementia are present.</p> <p>About 5% of individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer's disease pathology.</p>
Frontotemporal lobar degeneration (FTLD)	<p>FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.</p> <p>Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease.</p> <p>Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein, TDP-43).</p> <p>The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60.<sup>11</sup> Scientists think that FTLD is the most common cause of dementia in people younger than 60.<sup>11</sup> In a systematic review, FTLD accounts 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.<sup>12</sup></p>
Parkinson's disease (PD)	<p>Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. Cognitive symptoms develop either just before movement symptoms or later in the disease.</p> <p>In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine.<sup>13</sup></p> <p>As PD progresses, it often results in dementia secondary to the accumulation of alpha-synuclein in the cortex (similar to dementia with Lewy bodies).</p>
Hippocampal sclerosis (HS)	<p>HS is the hardening of tissue in the hippocampus of the brain. The hippocampus plays a key role in forming memories. The most pronounced symptom of HS is memory loss, and individuals may be misdiagnosed as having Alzheimer's disease. HS brain changes are often accompanied by accumulations of a misfolded form of a protein called TDP-43.</p> <p>HS is a common cause of dementia in the "oldest-old," individuals age 85 or older.</p>
Mixed pathologies	<p>When an individual shows the brain changes of more than one cause of dementia, mixed pathologies are considered the cause. When these pathologies result in dementia symptoms during life, the person is said to have mixed dementia.</p> <p>Studies suggest that mixed dementia is more common than previously recognized, with more than 50% of people with dementia who were studied at Alzheimer's Disease Centers having pathologic evidence of more than one cause of dementia.<sup>10</sup> In community-based studies, the percentage of mixed dementia cases is considerably higher.<sup>9</sup> The likelihood of having mixed dementia increases with age and is highest in people age 85 or older.<sup>14,15</sup></p>



**FIGURE 1** Alzheimer's disease (AD) continuum. \*MCI is the acronym for mild cognitive impairment.

A study<sup>5</sup> of people with rare genetic mutations that cause Alzheimer's found that levels of beta-amyloid in the brain were significantly increased starting 22 years before symptoms were expected to develop (individuals with these genetic mutations usually develop symptoms at the same or nearly the same age as their parent with Alzheimer's). Glucose metabolism began to decrease 18 years before expected symptom onset, and brain atrophy began 13 years before expected symptom onset.

It is critical to note that while the field of Alzheimer's research has made great gains over the years in understanding the brain changes associated with the disease and how the disease progresses, much of the research to date has not included sufficient numbers of black/African Americans, Hispanics/Latinos, Asian Americans/Pacific Islanders and Native Americans to be representative of the U.S. population. Moreover, because some studies<sup>16-19</sup> find black/African Americans and Hispanics/Latinos to be at increased risk for Alzheimer's, the underrepresentation of these populations hampers the conduct of rigorous research to understand these health disparities. Additional research involving individuals from underrepresented ethnic and racial groups is necessary to gain a comprehensive understanding of Alzheimer's disease.

### 2.3 | Alzheimer's disease continuum

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

On this continuum, there are three broad phases: preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease (see Figure 1).<sup>20-23</sup> The Alzheimer's dementia phase is further broken down into the stages of mild, moderate and severe, which reflect the degree to which symptoms interfere with one's ability to carry out everyday activities.

While we know the continuum starts with preclinical Alzheimer's and ends with severe Alzheimer's dementia, how long individuals spend in each part of the continuum varies. The length of each phase of the continuum is influenced by age, genetics, gender and other factors.<sup>24</sup>

#### 2.3.1 | Preclinical Alzheimer's disease

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

While research settings have the tools and expertise to identify some of the early brain changes of Alzheimer's, additional research is needed to fine-tune the tools' accuracy before they become available for widespread use in hospitals, doctors' offices and other clinical settings. It is important to note that not all individuals with evidence of Alzheimer's-related brain changes go on to develop symptoms of MCI or dementia due to Alzheimer's.<sup>25,26</sup> For example, some individuals have beta-amyloid plaques at death but did not have memory or thinking problems in life.

#### 2.3.2 | MCI due to Alzheimer's disease

People with MCI due to Alzheimer's disease have biomarker evidence of Alzheimer's brain changes (for example, abnormal levels of beta-amyloid) plus subtle problems with memory and thinking. These cognitive problems may be noticeable to family members and friends, but not to others, and they do not interfere with individuals' ability to carry out everyday activities. The mild changes in thinking abilities occur when the brain can no longer compensate for the damage and death of nerve cells caused by Alzheimer's disease.

Among those with MCI, one analysis found that after 2 years' follow-up, 15% of individuals older than 65 had developed dementia.<sup>27</sup> Another study found that 32% of individuals with MCI developed Alzheimer's dementia within 5 years' follow-up.<sup>28</sup> A third study found that among individuals with MCI who were tracked for 5 years or longer, 38% developed dementia.<sup>29</sup> However, in some individuals MCI reverts to normal cognition or remains stable. In other cases, such as when a medication inadvertently causes cognitive changes, MCI is

mistakenly diagnosed and cognitive changes can be reversed with medication changes. Identifying which individuals with MCI are more likely to develop Alzheimer's or other dementias is a major goal of current research.

### 2.3.3 | Dementia due to Alzheimer's disease

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

#### *Mild Alzheimer's dementia*

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

#### *Moderate Alzheimer's dementia*

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

#### *Severe Alzheimer's dementia*

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

### 2.3.4 | When dementia-like symptoms are not dementia

It is important to note that some individuals have dementia-like symptoms without the progressive brain changes of Alzheimer's or

other degenerative brain diseases. Causes of dementia-like symptoms include depression, untreated sleep apnea, delirium, side effects of medications, Lyme disease, thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, these conditions often may be reversed with treatment. Consulting a medical professional to determine the cause of symptoms is critical to one's physical and emotional well-being.

The differences between normal age-related cognitive changes and the cognitive changes of Alzheimer's dementia can be subtle (see Table 2). People experiencing cognitive changes should seek medical help to determine if the changes are normal for one's age, reversible or a symptom of Alzheimer's or another dementia. The Medicare Annual Wellness Visit, which includes a cognitive evaluation, is an opportune time for individuals age 65 or older to discuss cognitive changes with their physician.

### 2.4 | Diagnosis of dementia due to Alzheimer's disease

There is no single test for dementia due to Alzheimer's disease. Instead, physicians (often with the help of specialists such as neurologists, neuropsychologists, geriatricians and geriatric psychiatrists) use a variety of approaches and tools to help make a diagnosis. They include the following:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member to provide input about changes in thinking skills and behavior.
- Conducting problem-solving, memory and other cognitive tests, as well as physical and neurologic examinations.
- Having the individual undergo blood tests and brain imaging to rule out other potential causes of dementia symptoms, such as a tumor or certain vitamin deficiencies.
- In some circumstances, using PET imaging of the brain to find out if the individual has high levels of beta-amyloid, a hallmark of Alzheimer's; normal levels would suggest Alzheimer's is not the cause of dementia.<sup>30</sup>
- In some circumstances, using lumbar puncture to determine the levels of beta-amyloid and certain types of tau in CSF; normal levels would suggest Alzheimer's is not the cause of dementia.<sup>31</sup>

Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause. Alzheimer's disease is the most common cause of dementia, but there are other causes as well.<sup>32,33</sup> As shown in Table 1, different causes of dementia are associated with distinct symptom patterns and brain abnormalities. Many people with dementia have brain changes associated with more than one cause of dementia.<sup>9,34-38</sup> This is called mixed dementia. Some studies<sup>9,10</sup> report that the majority of people with the brain changes of Alzheimer's also have the brain changes of a second cause of dementia on autopsy.

**TABLE 2** Signs of Alzheimer's or Other Dementias Compared with Typical Age-Related Changes\*

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

\*For more information about the symptoms of Alzheimer's, visit [alz.org/10signs](http://alz.org/10signs).

As discussed in the Prevalence section, many individuals who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed by a physician,<sup>39–42</sup> and fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records report (or their caregiver reports, if the beneficiary's cognitive impairment prevented him or her from responding) being told of the diagnosis.<sup>43–46</sup> It is important that individuals who are living with dementia receive a diagnosis and are aware of the diagnosis. It is also important that individuals receive an *accurate* diagnosis to ensure they receive treatment or follow-up care appropriate to their specific cause of dementia.

## 2.5 | Treatment of Alzheimer's dementia

### 2.5.1 | Pharmacologic treatment

None of the pharmacologic treatments (medications) available today for Alzheimer's dementia slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal. The U.S. Food and Drug Administration (FDA) has approved five drugs for the treatment of Alzheimer's — rivastigmine, galantamine, donepezil, memantine, and memantine combined with donepezil. With the exception of memantine, these drugs temporarily improve

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

No drugs are specifically approved by the FDA to treat behavioral and psychiatric symptoms that may develop in the moderate and severe stages of Alzheimer's dementia. If non-pharmacologic therapy is not successful and these symptoms have the potential to cause harm to the individual or others, physicians may prescribe medications approved for similar symptoms in people with other conditions. A type of medication called antipsychotics may be prescribed to treat hallucinations, aggression and agitation. However, research has shown that some antipsychotics are associated with an increased risk of stroke and death in individuals with dementia.<sup>47,48</sup> The decision to use antipsychotics must be considered with extreme caution. The FDA has ordered manufacturers to label such drugs with a "black box warning" about their risks and a reminder that they are not approved to treat dementia symptoms.

Many factors contribute to the difficulty of developing effective treatments for Alzheimer's. These factors include the slow pace of recruiting sufficient numbers of participants and sufficiently diverse participants to clinical studies, gaps in knowledge about the precise molecular changes and biological processes in the brain that cause Alzheimer's disease, and the relatively long time needed to observe whether an investigational treatment affects disease progression.

Researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function may be most effective when administered early in the disease continuum, either at the MCI due to Alzheimer's or preclinical Alzheimer's phase. Biomarker tests will be essential to identify which individuals are in these phases of the continuum and should receive treatments when they are available. Biomarkers also will be critical for monitoring the effects of treatment. Biomarker tests are already playing an important role in drug development because they enable researchers to recruit into clinical trials only those individuals with the Alzheimer's brain changes that a drug has been designed to affect.<sup>49</sup> The most effective biomarker test or combination of tests may differ depending on where the individual is on the disease continuum and other factors.<sup>50</sup>

## 2.5.2 | Non-pharmacologic therapy

Non-pharmacologic therapies are those that do not involve medication. They are often used for people with Alzheimer's dementia with the goal of maintaining or improving cognitive function, overall quality of life or the ability to perform activities of daily living. They also may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. A recent review and analysis of non-pharmacologic treatments for agitation and aggression in people with dementia concluded that non-pharmacologic interventions seemed to be more effective than pharmacologic interventions for reducing aggression and agitation.<sup>51</sup> Examples of

non-pharmacologic therapies include computerized memory training, listening to favorite music as a way to stir recall, and using special lighting to lessen sleep disorders. As with current pharmacologic therapies, non-pharmacologic therapies do not slow or stop the damage and destruction of neurons that cause Alzheimer's symptoms and make the disease fatal.

Determining the effectiveness of non-pharmacologic therapies can be difficult because of the large number of unique therapies tested; the diversity of therapeutic aims (from improved overall quality of life to improvements in specific symptoms); the diverse dementia stages represented (from mild to moderate to severe); the diverse types of dementia that may be present among participants in a particular study given the pervasiveness of mixed dementia; and the lack of a standard method for carrying out any individual therapy. With these multiple factors to consider, it is challenging to group together and compare non-pharmacologic therapies.

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

- A meta-analysis<sup>52</sup> found that aerobic exercise and a combination of aerobic and non-aerobic exercise had positive effects on cognitive function in people living with Alzheimer's dementia. A systematic review<sup>53</sup> found that exercise has a positive effect on overall cognitive function and may slow the rate of cognitive decline in people with Alzheimer's dementia.
- A systematic review<sup>54</sup> found that cognitive stimulation had beneficial effects on cognitive function and some aspects of well-being in people with Alzheimer's dementia. Another systematic review<sup>55</sup> reported that cognitive stimulation was associated with improved scores on tests of depression in people with mild-to-moderate Alzheimer's dementia. A 2019 summary<sup>56</sup> of systematic reviews reported that cognitive stimulation, music-based therapies and psychological treatment (for example, cognitive behavioral therapy) improved depression, anxiety and quality of life in people with dementia.
- A 2019 summary of systematic reviews<sup>57</sup> of cognitive training for people with mild-to-moderate dementia found cognitive training may show some benefits in overall cognition that may last for at least a few months.

## 2.6 | Active management of Alzheimer's dementia

Studies have consistently shown that active management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers.<sup>58-60</sup> Active management includes:

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.
- Providing family caregivers with effective training in managing the day-to-day life of the care recipient.

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

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

## 2.7 | Risk factors for Alzheimer's dementia

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

### 2.7.1 | Age, genetics and family history

The greatest risk factors for late-onset Alzheimer's are older age,<sup>61,62</sup> genetics<sup>63,64</sup> and having a family history of Alzheimer's.<sup>65–68</sup>

#### Age

Age is the greatest of these three risk factors. As noted in the Prevalence section, the percentage of people with Alzheimer's dementia increases dramatically with age: 3% of people age 65–74, 17% of people age 75–84 and 32% of people age 85 or older have Alzheimer's dementia.<sup>62</sup> It is important to note that Alzheimer's dementia is not a normal part of aging,<sup>69</sup> and older age alone is not sufficient to cause Alzheimer's dementia.

#### Genetics

Researchers have found several genes that increase the risk of Alzheimer's. The apolipoprotein-e4 (APOE-e4) gene is the gene with the strongest impact on risk of late-onset Alzheimer's. APOE-e4 provides the blueprint for a protein that transports cholesterol in the bloodstream. Everyone inherits one of three forms (alleles) of the APOE gene – e2, e3 or e4 – from each parent, resulting in six possible APOE pairs: e2/e2, e2/e3, e2/e4, e3/e3, e3/e4 and e4/e4. Researchers have found differences in the frequency of these pairs in different racial and ethnic groups. For example, data show that a higher percentage of black/African Americans than European Americans have at least one copy of the e4 allele (see Table 3).<sup>70–72</sup>

Having the e4 form of APOE increases one's risk of developing Alzheimer's compared with having the e3 form, but does not guarantee that an individual will develop Alzheimer's. Having the e2 form may decrease one's risk compared with having the e3 form. Those who

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

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

Created from data from Rajan et al.<sup>70</sup>

\*Percentages do not total 100 due to rounding

inherit one copy of the e4 form have about three times the risk of developing Alzheimer's compared with those with two copies of the e3 form, while those who inherit two copies of the e4 form have an eight- to 12-fold risk.<sup>73–75</sup> In addition, those with the e4 form are more likely to have beta-amyloid accumulation<sup>76</sup> and Alzheimer's dementia at a younger age than those with the e2 or e3 forms of the APOE gene.<sup>77</sup> A meta-analysis including 20 published articles describing the frequency of the e4 form among people in the United States who had been diagnosed with Alzheimer's found that 56% had one copy of the APOE-e4 gene, and 11% had two copies of the APOE-e4 gene.<sup>78</sup> Another study found that among 1,770 diagnosed individuals from 26 Alzheimer's Disease Centers across the United States, 65% had at least one copy of the APOE-e4 gene.<sup>79</sup>

However, studies of Alzheimer's risk based on APOE status among black/African Americans have had inconsistent results. For example, some have found that having the e4 allele did not increase risk among black/African Americans,<sup>71,72,80</sup> while other studies have found that it significantly increased risk.<sup>81,82</sup> More research is needed to better understand the genetic mechanisms involved in Alzheimer's risk among different racial and ethnic groups.

#### Family history

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, individuals who have a parent or sibling (first-degree relative) with Alzheimer's dementia are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.<sup>65,73</sup> Those who have more than one first-degree relative with Alzheimer's are at even higher risk.<sup>68</sup> A large, population-based study found that having a parent with dementia increases risk independent of known genetic risk factors such as APOE-e4.<sup>83</sup> When diseases run in families, heredity (genetics) and shared non-genetic factors (for example, access to healthy foods and habits related to physical activity) may play a role.

### 2.7.2 | Modifiable risk factors

Although age, genetics and family history cannot be changed, other risk factors can be changed or modified to reduce the risk of cognitive decline and dementia.

In 2019, the World Health Organization (WHO) published recommendations<sup>84</sup> to reduce risk of cognitive decline and dementia. WHO strongly recommends physical activity, quitting smoking, and managing hypertension and diabetes to reduce the risk of cognitive decline and dementia. A report<sup>85</sup> evaluating the state of the evidence on the effects of modifiable risk factors on cognitive decline and dementia concluded that there is sufficiently strong evidence, from a population-based perspective, that regular physical activity and management of cardiovascular risk factors (especially diabetes, obesity, smoking and hypertension) is associated with reduced risk of cognitive decline and may be associated with reduced risk of dementia. It also concluded that there is sufficiently strong evidence that a healthy diet, lifelong learning and cognitive training are associated with reduced risk of cognitive decline. A report from the National Academy of Medicine (formerly the Institute of Medicine) examined the evidence regarding modifiable risk factors for cognitive decline and reached similar conclusions.<sup>86</sup> More research is needed to understand the biological mechanisms by which these factors reduce risk.

It is important to note that “reducing risk” of cognitive decline and dementia is not synonymous with preventing cognitive decline and dementia. Individuals who take measures to reduce risk may still develop dementia, but may be less likely to develop it, or may develop it later in life than they would have if they had not taken steps to reduce their risk. It is also important to note that factors that increase or decrease the risk of cognitive decline and dementia may not necessarily do so by directly affecting the brain changes associated with Alzheimer’s disease.<sup>80</sup> For example, it is possible that smoking may contribute to cerebrovascular disease, which in turn increases the risk of dementia, but it may not directly contribute to the development of the amyloid plaques and tau tangles that characterize Alzheimer’s disease.

#### *Cardiovascular disease risk factors*

Brain health is affected by the health of the heart and blood vessels. Although it makes up just 2% of body weight, the brain consumes 20% of the body’s oxygen and energy supplies.<sup>87</sup> A healthy heart ensures that enough blood is pumped to the brain, while healthy blood vessels enable the oxygen- and nutrient-rich blood to reach the brain so it can function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia.<sup>88</sup> These factors include smoking<sup>89-93</sup> and diabetes.<sup>94-97</sup> Some studies propose that impaired glucose processing (a precursor to diabetes) may also result in an increased risk for dementia.<sup>98-100</sup> The age at which some risk factors develop appears to affect dementia risk. For example, midlife obesity,<sup>98,101-104</sup> hypertension,<sup>98,105-109</sup> prehypertension (systolic blood pressure from 120 to 139 mm Hg or diastolic pressure from 80 to 89 mm Hg)<sup>109</sup> and high cholesterol<sup>110,111</sup> are associated with an increased risk of dementia. However, late-life obesity<sup>112</sup> and hypertension onset after age 80<sup>113</sup> are associated with decreased risk of dementia. More research is needed to understand why the effects of some modifiable risk factors may change with age. Regarding blood pressure, there is now evidence from a large-scale clinical trial that intensive medical treatment to reduce blood pressure may safely

decrease the occurrence of MCI and dementia in older adults who have hypertension.<sup>114</sup>

Building on the connection between heart health and brain health, researchers have found that factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer’s or other dementias. Physical activity<sup>115-125</sup> appears to be one of these factors. Although researchers have studied a wide variety of exercises, they do not yet know which specific types of exercises, what frequency of exercise or what duration of activity may be most effective in reducing risk. In addition to physical activity, emerging evidence suggests that consuming a heart-healthy diet may be associated with reduced dementia risk.<sup>126-130</sup> A heart-healthy diet emphasizes fruits, vegetables, whole grains, fish, chicken, nuts and legumes while limiting saturated fats, red meat and sugar. A systematic review<sup>131</sup> of the use of supplements, including (but not limited to) vitamins C, D and E, omega-3 fatty acids, and ginkgo biloba, found little to no benefit in preventing cognitive decline, MCI or Alzheimer’s dementia.

Researchers have begun studying combinations of health factors and lifestyle behaviors (for example, blood pressure as a health factor and physical activity as a lifestyle behavior) to learn whether combinations of risk factors better identify Alzheimer’s and dementia risk than individual risk factors. They are also studying whether intervening on multiple risk factors simultaneously is more effective at reducing risk than addressing a single risk factor. Indeed, one such study,<sup>132</sup> the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), found that a multidomain lifestyle intervention was associated with beneficial effects on cognitive function in older adults at high risk for cognitive decline and dementia. The success of FINGER has led to the launch of multidomain lifestyle intervention studies in other countries, including the Alzheimer’s Association U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER).<sup>133</sup>

#### *Education*

People with more years of formal education are at lower risk for Alzheimer’s and other dementias than those with fewer years of formal education.<sup>71,134-138</sup> 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<sup>139,140</sup> such as beta-amyloid and tau accumulation. 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.<sup>141-144</sup>

A recent study<sup>145</sup> found that individuals with the APOE-e4 risk gene had a decreased risk of developing dementia if they had more years of early life education, had mentally challenging work in midlife, participated in leisure activities in late life, and/or had strong social networks in late life.

It is important to note that the underlying reason for the relationship between formal education and reduced Alzheimer’s risk is unclear. It is possible that the generally higher socioeconomic status of

individuals with more years of formal education is a protective factor. Having fewer years of formal education is associated with lower socioeconomic status,<sup>146</sup> which may:

- Increase one's likelihood of experiencing poor nutrition.
- Decrease one's ability to afford health care or medical treatments, such as treatments for cardiovascular disease risk factors that are so closely linked to brain health.
- Limit one's access to physically safe housing and employment, which could increase risk of being exposed to substances that are toxic to the nervous system such as air pollution,<sup>147</sup> lead<sup>148</sup> and pesticides.<sup>149</sup>

In addition, people with fewer years of education tend to have more cardiovascular risk factors for Alzheimer's, including being less physically active,<sup>150</sup> having a higher risk of diabetes,<sup>151-153</sup> and being more likely to have hypertension<sup>154</sup> and to smoke.<sup>155</sup>

#### *Social and cognitive engagement*

Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.<sup>116,156-167</sup> Remaining socially and mentally active might help build cognitive reserve, but the exact mechanism by which this may occur is unknown. It is possible that the association observed between social and cognitive engagement and reduced dementia risk reflects something else. Specifically, the presence of cognitive impairment could decrease one's interest in and ability to participate in activities involving social and cognitive skills. Therefore, the association may reflect the effect of cognitive impairment on social and cognitive engagement rather than the effect of engagement on dementia risk. More research is needed to better understand how social and cognitive engagement may affect biological processes that influence risk.

#### *Traumatic brain injury (TBI)*

TBI is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. TBI increases the risk of dementia.<sup>168</sup>

According to the Centers for Disease Control and Prevention (CDC), approximately 2.87 million TBI-related emergency department visits, hospitalizations and deaths occurred in 2014, the latest year for which information is available.<sup>169</sup> The leading causes of TBI that resulted in emergency department visits were falls, being struck by an object and motor vehicle crashes.<sup>169</sup>

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia<sup>170</sup> and by the individual's initial score on the 15-point Glasgow Coma Scale.<sup>171</sup>

- *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 13-15; about 75% of TBIs are mild.<sup>172</sup>

- *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 9-12.
- *Severe TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting 24 hours or more, or an initial Glasgow score of 8 or less.

The risk of dementia increases with the number of TBIs sustained.<sup>168</sup> Even those who experience mild TBI are at increased risk of dementia compared with those who have not had a TBI. A recent study found that mild TBI is associated with a two-fold increase in the risk of dementia diagnosis.<sup>173</sup> Another study found that people with a history of TBI who develop Alzheimer's do so at a younger age than those without a history of TBI.<sup>174</sup> Whether TBI causes Alzheimer's disease, other conditions that lead to dementia, or both, is still being investigated.

Chronic traumatic encephalopathy (CTE) is a neuropathologic diagnosis (meaning it is characterized by brain changes that can only be identified at autopsy) associated with repeated blows to the head, such as those that may occur while playing contact sports. Among former amateur and professional football players, the risk of developing CTE, which is associated with dementia, increases 30% per year played.<sup>175</sup> Currently, there is no test to determine if someone has CTE-related brain changes during life. A review article indicates that the greatest risk factor for developing CTE-related brain changes is repetitive brain trauma – repeated, forceful blows to the head that do not, individually, result in symptoms.<sup>176</sup> Like Alzheimer's disease, CTE is characterized by tangles of an abnormal form of the protein tau in the brain. Unlike Alzheimer's, beta-amyloid plaques are uncommon in CTE.<sup>177,178</sup> How the brain changes associated with CTE are linked to cognitive or behavioral changes is unclear.

### **2.7.3 | Uncommon genetic changes that increase risk**

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

#### *Genetic mutations*

A small percentage of Alzheimer's cases (an estimated 1% or less)<sup>179</sup> develop as a result of mutations to any of three specific genes. A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes. These mutations involve the gene for the amyloid precursor protein (APP) and the genes for the presenilin 1 and presenilin 2 proteins. Those inheriting an Alzheimer's mutation to these genes are virtually guaranteed to develop the disease if they live a normal life span.<sup>180</sup> Symptoms tend to develop before age 65, sometimes as young as age 30, while the vast majority of individuals with Alzheimer's have late-onset Alzheimer's.

### Trisomy in Down syndrome

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

Overall, people with Down syndrome develop Alzheimer's at an earlier age than people without Down syndrome. By age 40, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brains.<sup>181</sup> As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. According to the National Down Syndrome Society, about 30% of people with Down syndrome who are in their 50s have Alzheimer's dementia.<sup>58</sup> About 50% of people with Down syndrome who are in their 60s have Alzheimer's dementia.<sup>182</sup>

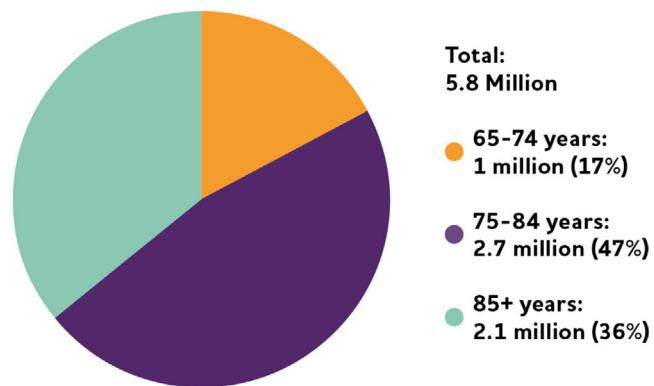
### 2.8 | Looking to the future

The identification of biomarkers for Alzheimer's enables early detection of the disease and will accelerate the development of new therapies by ensuring that appropriate people are enrolled in clinical trials. With the discovery that Alzheimer's may begin 20 years or more before the onset of symptoms, a substantial window of time has been opened to intervene in the progression of the disease. In the future, more will be understood about which therapies will be most effective at which points in the Alzheimer's disease continuum.

A fuller understanding of Alzheimer's — from its causes to how to prevent it, how to manage it and how to treat it — depends on other crucial factors. Among these factors is the inclusion of participants from diverse racial and ethnic groups in all realms of Alzheimer's research. Consistent with studies of other top 10 causes of death, studies of Alzheimer's disease in underrepresented ethnic and racial groups are relatively sparse. This reflects the urgent need for current and future research to include increased numbers of black/African Americans, Hispanics/Latinos, Asian Americans/Pacific Islanders and Native Americans in clinical trials, observational studies and other investigations so everyone benefits from advances in Alzheimer's science.

## 3 | PREVALENCE

Millions of Americans have Alzheimer's or other dementias. As the size of the U.S. population age 65 and older continues to increase, the number of Americans with Alzheimer's or other dementias will grow. Both the number and proportion will escalate rapidly in coming years, as the population of Americans age 65 and older is projected to grow from 56 million in 2020 to 88 million by 2050.<sup>183,184</sup> The baby boom genera-



**FIGURE 2** Number and ages of people 65 or older with Alzheimer's dementia, 2020. Created from data from Hebert et al.<sup>A2,62</sup>

tion has already begun to reach age 65 and beyond,<sup>185</sup> the age range of greatest risk of Alzheimer's dementia<sup>186</sup>; in fact, the oldest members of the baby boom generation turn age 74 in 2020.

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

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

An estimated 5.8 million Americans age 65 and older are living with Alzheimer's dementia in 2020.<sup>A1,62</sup> Eighty percent are age 75 or older (Figure 2).<sup>A2,62</sup>

Out of the total U.S. population:

- One in 10 people (10%) age 65 and older has Alzheimer's dementia.<sup>A3,62,184</sup>
- The percentage of people with Alzheimer's dementia increases with age: 3% of people age 65-74, 17% of people age 75-84, and 32% of people age 85 and older have Alzheimer's dementia.<sup>62</sup> People younger than 65 can also develop Alzheimer's dementia, but it is much less common and prevalence is uncertain.

The estimated number of people age 65 and older with Alzheimer's dementia comes from a study using the latest data from the 2010 U.S. Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health conditions of older people.<sup>62</sup>

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from other population-based

studies including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.<sup>184,187,188</sup> Based on estimates from ADAMS, 14% of people age 71 and older in the United States have dementia.<sup>187</sup>

These estimates refer to people who have Alzheimer's dementia based on symptoms such as memory loss and difficulty planning or solving problems. Biomarker-based prevalence estimates could significantly affect the reported number of people with Alzheimer's disease.<sup>189,190</sup> The estimated 5.8 million people with Alzheimer's dementia would be lower, but the total number of people in the continuum of Alzheimer's disease would be higher.

Some individuals now counted as having Alzheimer's dementia may not have the biological brain changes associated with Alzheimer's disease because their diagnosis was based on clinical symptoms rather than confirmed by biomarkers. Both autopsy studies and clinical trials have found that 15% to 30% of individuals who met the criteria for Alzheimer's dementia based on symptoms did not have the required Alzheimer's-related brain changes at death.<sup>9,69,191-193</sup> That is, these individuals had dementia caused by something other than Alzheimer's disease.

At the same time, a biomarker-based prevalence estimate would comprise people throughout the continuum of Alzheimer's disease, including those with mild cognitive impairment (MCI) due to Alzheimer's disease and preclinical Alzheimer's disease who are not counted in current Alzheimer's prevalence estimates, which are limited to those with Alzheimer's dementia.

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

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study undergoes evaluation for dementia. But outside of research settings, a substantial portion of those who would meet the diagnostic criteria for Alzheimer's and other dementias are not diagnosed with dementia by a physician.<sup>39-42</sup> Furthermore, fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer's or another dementia in their Medicare billing records (or their caregiver, if the beneficiary's cognitive impairment prevented him or her from responding) report being told of the diagnosis.<sup>43-46</sup> Because Alzheimer's dementia is often underdiagnosed — and if it is diagnosed, people are often unaware of their diagnosis — a large portion of Americans with Alzheimer's may not know they have it. A recent survey<sup>194</sup> by the Alzheimer's Association found that on average, primary care physicians inform their patients 92% of the time when cognitive impairment is detected, and 64% of the physicians reported they always inform patients. Of the 36% of surveyed physicians who do not always inform their patients, 73% say it is because it is premature to do so before a full diagnostic workup, and 41% say brief cognitive assessments have high rates of false positives or false negatives.

Since 2011, the Medicare Annual Wellness Visit has included a required cognitive evaluation. The same survey by the Alzheimer's

Association found that only one in three older adults were aware that these visits should include a cognitive assessment.<sup>194</sup> Furthermore, while 82% of older adults believe it is important to have their memory and thinking checked, only 16% report having their memory and thinking checked. Most (93%) older adults said they trust their doctor to recommend testing for memory and thinking problems; however, despite 94% of primary care physicians stating that it is important to assess all older patients for cognitive impairment, fewer than half (47%) say it is their standard protocol to do so. The primary reasons given by surveyed physicians for not assessing older patients for cognitive impairment are the patient presents with no symptoms or complaints (68%) and lack of time (58%).

### 3.1.2 | Prevalence of subjective cognitive decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's or other dementias as well as MCI.<sup>195-199</sup> Subjective cognitive decline refers to self-perceived worsening of memory and other thinking abilities by an individual, separate from cognitive testing, clinical diagnosis or anyone else noticing. There is a correlation between subjective cognitive decline and worse performance on cognitive tests, as recently reported using data from the National Health and Nutrition Examination Survey, a nationally representative sample of U.S. older adults.<sup>200</sup> Not all of those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.<sup>201-203</sup> One study showed those who over time consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia.<sup>204</sup> The Behavioral Risk Factor Surveillance System survey, which includes questions on subjective cognitive decline, found that in the United States, 11% of Americans age 45 and older reported subjective cognitive decline, but 54% of those who reported it had not consulted a health care professional.<sup>205</sup> Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

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

Table 4 lists the estimated number of people age 65 and older with Alzheimer's dementia by state for 2020, the projected number for 2025, and the projected percentage change in the number of people with Alzheimer's between 2020 and 2025.<sup>A5,206</sup>

As shown in Figure 3, between 2020 and 2025 every state across the country is expected to experience an increase of at least 6.7% in the number of people with Alzheimer's. These projected increases in the number of people with Alzheimer's are due solely to projected increases in the population age 65 and older in these states. Because

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

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

(Continues)

**TABLE 4** (Continued)

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

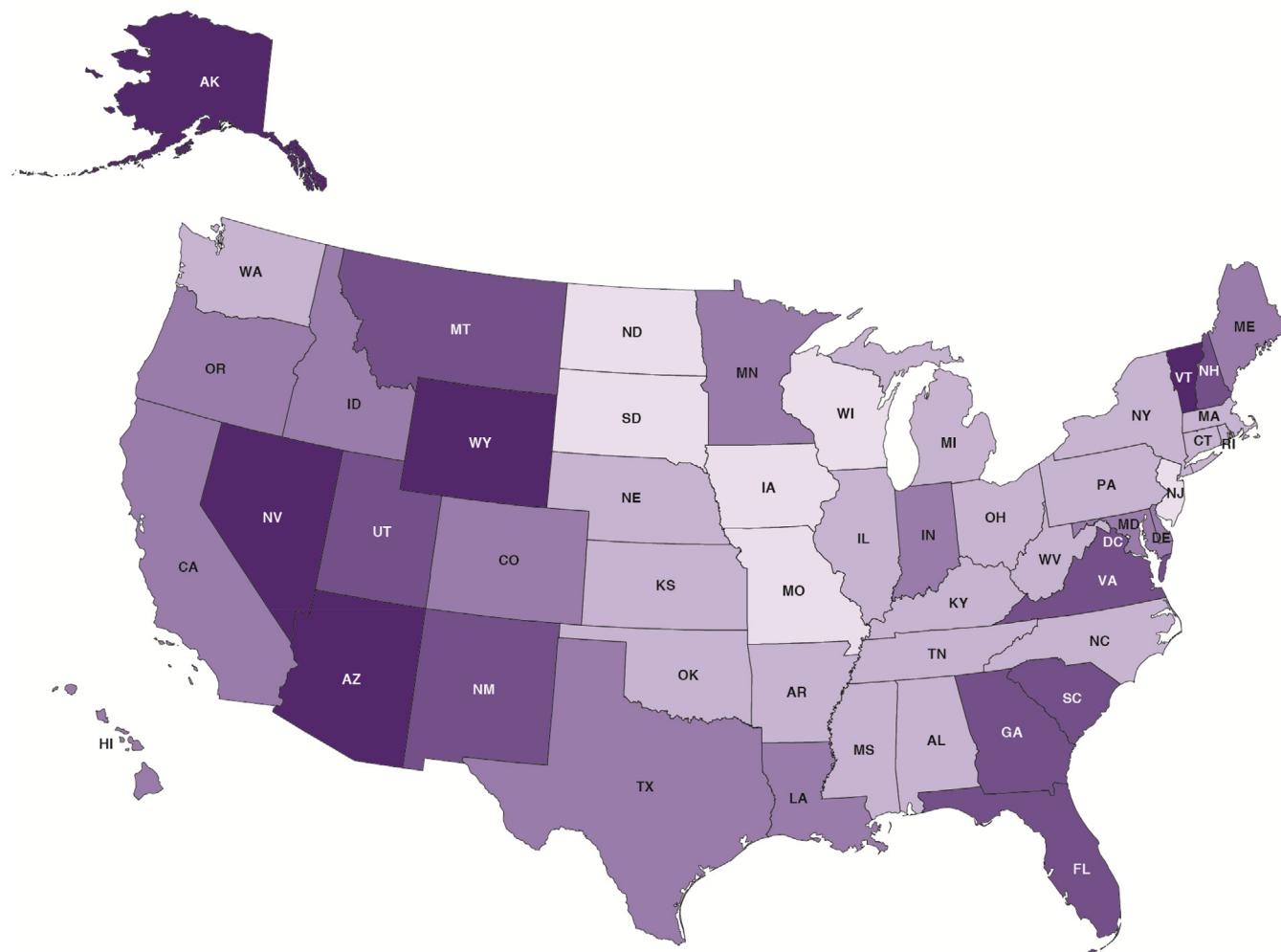
Created from data provided to the Alzheimer's Association by Weuve et al.<sup>A5,206</sup>

risk factors for dementia such as midlife obesity and diabetes can vary dramatically by region and state, the regional patterns of future burden may be different than reported here. Based on these projections, the West and Southeast are expected to experience the largest percentage increases in people with Alzheimer's dementia between 2020 and 2025. These increases will have a marked impact on states' health care systems, as well as the Medicaid program, which covers the costs of long-term care and support for many older residents with dementia, including more than a quarter of Medicare beneficiaries with Alzheimer's or other dementias.<sup>207</sup>

### 3.3 | Incidence of Alzheimer's dementia

While prevalence refers to existing cases of a disease in a population at a given time, incidence refers to new cases of a disease that develop in a given period of time in a defined population — in this case, the U.S. population age 65 or older. Incidence provides a measure of risk for developing a disease. According to one study using data from the Established Populations for Epidemiologic Study of the Elderly, approximately 491,000 people age 65 or older will develop Alzheimer's dementia in the United States in 2020.<sup>208</sup> Other studies have arrived at incidence estimates that are much higher. For example, according to CHAP estimates, approximately 910,000 people age 65 or older developed Alzheimer's dementia in the United States in 2011, a number that would be expected to be even higher in 2020 if CHAP estimates were available for that year.<sup>209</sup> A study using data from the Adult Changes in Thought study, a cohort of members of Kaiser Permanente (formerly Group Health), a health care delivery system in the Northwest United States, reported similar incidence rates to the CHAP study.<sup>210</sup> The number of new cases of Alzheimer's increases dramatically with age: according to estimates from CHAP, in 2011 the average annual incidence in people age 65-74 was 0.4% (meaning four of every 1,000 people age 65-74 developed Alzheimer's dementia in 2011); in people age 75-84, the annual incidence was 3.2% (32 of every 1,000

6.7% - 12%    12.1% - 17.3%    17.4% - 22.6%    22.7% - 27.9%    28.0% - 33.3%



**FIGURE 3** Projected increases between 2020 and 2025 in Alzheimer's dementia prevalence by state. Change from 2020 to 2025 for Washington, D.C.: 1.1%. Created from data provided to the Alzheimer's Association by Weuve et al.<sup>A5,206</sup>

people); and for age 85 and older (the “oldest-old”), the incidence was 7.6% (76 of every 1,000 people).<sup>209</sup> Because of the increasing number of people age 65 and older in the United States, particularly the oldest-old, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050.<sup>208</sup>

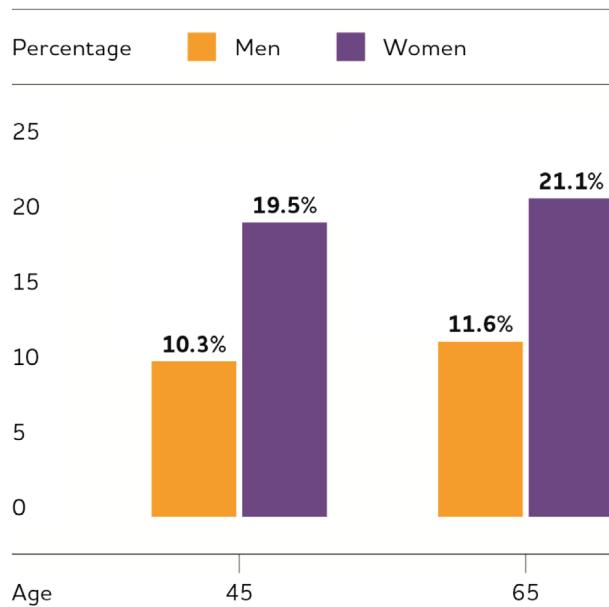
### 3.4 | Lifetime risk of Alzheimer's dementia

Lifetime risk is the probability that someone of a given age who does not have a particular condition will develop the condition during his or her remaining life span. Data from the Framingham Heart Study were used to estimate lifetime risks of Alzheimer's dementia by age and sex.<sup>A6,211</sup> As shown in Figure 4, the study found that the estimated lifetime risk for Alzheimer's dementia at age 45 was approximately one in five (20%) for women and one in 10 (10%) for men. The risks for both sexes were slightly higher at age 65.<sup>211</sup>

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

More women than men have Alzheimer's or other dementias. Almost two-thirds of Americans with Alzheimer's are women.<sup>A7,62</sup> Of the 5.8 million people age 65 and older with Alzheimer's in the United States, 3.6 million are women and 2.2 million are men.<sup>A7,62</sup> Based on estimates from ADAMS, among people age 71 and older, 16% of women have Alzheimer's or other dementias compared with 11% of men.<sup>187</sup>

The prevailing reason that has been stated for the higher prevalence of Alzheimer's and other dementias in women is that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.<sup>211-213</sup> But when it comes to differences in the actual risk of developing Alzheimer's or other dementias for men and women of the same age, findings have been mixed. Most studies of incidence in the United States have found no significant difference



**FIGURE 4** Estimated lifetime risk for Alzheimer's dementia, by sex, at ages 45 and 65. Created from data from Chene et al.<sup>211</sup>

between men and women in the proportion who develop Alzheimer's or other dementias at any given age.<sup>71,210,213-215</sup> However, some European studies have reported a higher incidence among women at older ages,<sup>216,217</sup> and one study from the United Kingdom reported higher incidence for men.<sup>218</sup> Differences in the risk of dementia between men and women may therefore depend on age and/or geographic region.<sup>219,220</sup>

If there is a difference in the risk of Alzheimer's or other dementias between men and women, there are a number of potential biological and social explanations.<sup>219,221</sup> One explanation may be differences in the distribution of or even the effect of risk factors for dementia between men and women. If women's risk for Alzheimer's or other dementias is higher, it is possible that lower educational attainment in women than in men born in the first half of the 20th century could account for some of the elevated risk, as limited formal education is a risk factor for dementia.<sup>222</sup> This explanation requires more research, but there is evidence that increases in educational attainment over time in the United States — which have been more substantial for women than men — have led to decreased risk for dementia.<sup>223</sup> Interestingly, European studies have found that the relationship of lower education with dementia outcomes may actually be stronger in women than men.<sup>224,225</sup> Some studies have attributed an observed difference in risk for dementia between men and women to differences in health factors. A study using Framingham Heart Study data suggested that men in the study appear to have a lower risk for dementia due to "survival bias," in which the men who survived beyond age 65 and were included in the study were the ones with a healthier cardiovascular risk profile (men have a higher rate of death from cardiovascular disease in middle age than women) and thus a lower risk for dementia.<sup>212</sup> More research is needed to support this interpretation.

Other research is assessing whether the risk of Alzheimer's could actually be higher for women at any given age due to genetic differences or different susceptibility to Alzheimer's pathology.<sup>226</sup> A number of studies have shown that the APOE-e4 genotype, the best known genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia<sup>227,228</sup> and neurodegeneration<sup>229</sup> in women than in men. However, a recent meta-analysis found no difference between men and women in the association between APOE genotype and Alzheimer's dementia overall, though there was an elevated risk for women with the APOE-e4 genotype at certain age ranges.<sup>230</sup> It is unknown why the APOE gene could convey different risk for women, but some evidence suggests that it may be due to an interaction between the APOE genotype and the sex hormone estrogen.<sup>231,232</sup> Finally, there is some evidence that women show more rapid cognitive decline and neurodegeneration than men despite having similar levels of beta-amyloid and tau, meaning the hallmark proteins of Alzheimer's disease may have more negative effects for women than men.<sup>233-235</sup>

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

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States (because non-Hispanic whites are the largest racial/ethnic group in the country), older black/African Americans and Hispanics/Latinos are disproportionately more likely than older whites to have Alzheimer's or other dementias.<sup>16,17,236-239</sup> Most studies indicate that older black/African Americans are about twice as likely to have Alzheimer's or other dementias as older whites.<sup>18,19,209</sup> Some studies indicate older Hispanics/Latinos are about one and one-half times as likely to have Alzheimer's or other dementias as older whites.<sup>18,19,240,241</sup> However, Hispanics/Latinos comprise a very diverse group in terms of cultural history, genetic ancestry and health profiles, and there is evidence that prevalence may differ from one specific Hispanic/Latino ethnic group to another (for example, Mexican Americans compared with Caribbean Americans).<sup>242,243</sup>

The higher prevalence of Alzheimer's dementia in minority racial and ethnic groups compared with whites appears to be due to a higher incidence of dementia in these groups.<sup>244</sup> Variations in medical conditions, health-related behaviors and socioeconomic risk factors across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias.<sup>239</sup> Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race,<sup>80,82,245</sup> genetic factors do not appear to account for the large differences in prevalence or incidence among racial groups.<sup>244,246</sup> Instead, health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for Alzheimer's and other dementias, are believed to account for these differences, as they are more prevalent in black/African American and Hispanic/Latino people.<sup>247,248</sup> Socioeconomic characteristics, including lower levels and quality of education, higher rates of

poverty, and greater exposure to adversity and discrimination, may also increase risk in black/African American and Hispanic/Latino communities (and may in turn contribute to the health conditions mentioned above).<sup>80,247-249</sup> Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such factors.<sup>135,187,244</sup>

There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among older black/African Americans and Hispanics/Latinos than among older whites.<sup>250,251</sup> Based on data for Medicare beneficiaries age 65 and older, it has been estimated that Alzheimer's or another dementia had been diagnosed in 10.3% of whites, 12.2% of Hispanics/Latinos and 13.8% of black/African Americans.<sup>252</sup> Although rates of diagnosis were higher among black/African Americans than among whites, according to prevalence studies that detect all people who have dementia irrespective of their use of the health care system, the rates should be even higher for black/African Americans.

There are fewer data from population-based cohort studies regarding the national prevalence of Alzheimer's and other dementias in racial and ethnic groups other than whites, black/African Americans and Hispanics/Latinos. However, a study examining electronic medical records of members of a large health plan in California indicated that dementia incidence – determined by the presence of a dementia diagnosis in members' medical records – was highest in black/African Americans, intermediate for Latinos (the term used in the study for those who self-reported as Latino or Hispanic) and whites, and lowest for Asian Americans.<sup>253</sup> A follow-up study with the same cohort showed heterogeneity within Asian-American subgroups, but all subgroups studied had lower dementia incidence than whites.<sup>254</sup> A recent systematic review of the literature found that Japanese Americans were the only Asian-American subgroup with reliable prevalence data, and that they had the lowest prevalence of dementia compared with all other ethnic groups.<sup>243</sup> More studies, especially those involving population-based cohorts, are necessary to draw conclusions about the prevalence of Alzheimer's and other dementias in different racial groups and subgroups.

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

A growing number of studies indicate that the prevalence<sup>223,255-263</sup> and incidence<sup>218,259,263-270</sup> of Alzheimer's and other dementias in the United States and other higher-income Western countries may have declined in the past 25 years,<sup>218,223,258-269</sup> though results are mixed.<sup>61,209,271,272</sup> These declines have been attributed to increasing levels of education and improved control of cardiovascular risk factors.<sup>223,258,264,267,273,274</sup> Such findings are promising and suggest that identifying and reducing risk factors for Alzheimer's and other dementias may be effective. Although these findings indicate that a person's risk of dementia at any given age may be decreasing slightly, the total number of people with Alzheimer's or other dementias in the United States and other high-income Western countries is expected to

continue to increase dramatically because of the increase in the number of people at the oldest ages.

It is unclear whether these encouraging trends will continue into the future given worldwide trends showing increases in diabetes and obesity – potential risk factors for Alzheimer's dementia – which may lead to a rebound in dementia risk in coming years,<sup>102,257,259,275,276</sup> or if these positive trends pertain to all racial and ethnic groups.<sup>209,255,273,274,277</sup> Thus, while recent findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow. Moreover, 68% of the projected increase in the global prevalence and burden of dementia by 2050 will take place in low- and middle-income countries, where there is currently no evidence that the risk of Alzheimer's and other dementias has been declining.<sup>278</sup>

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

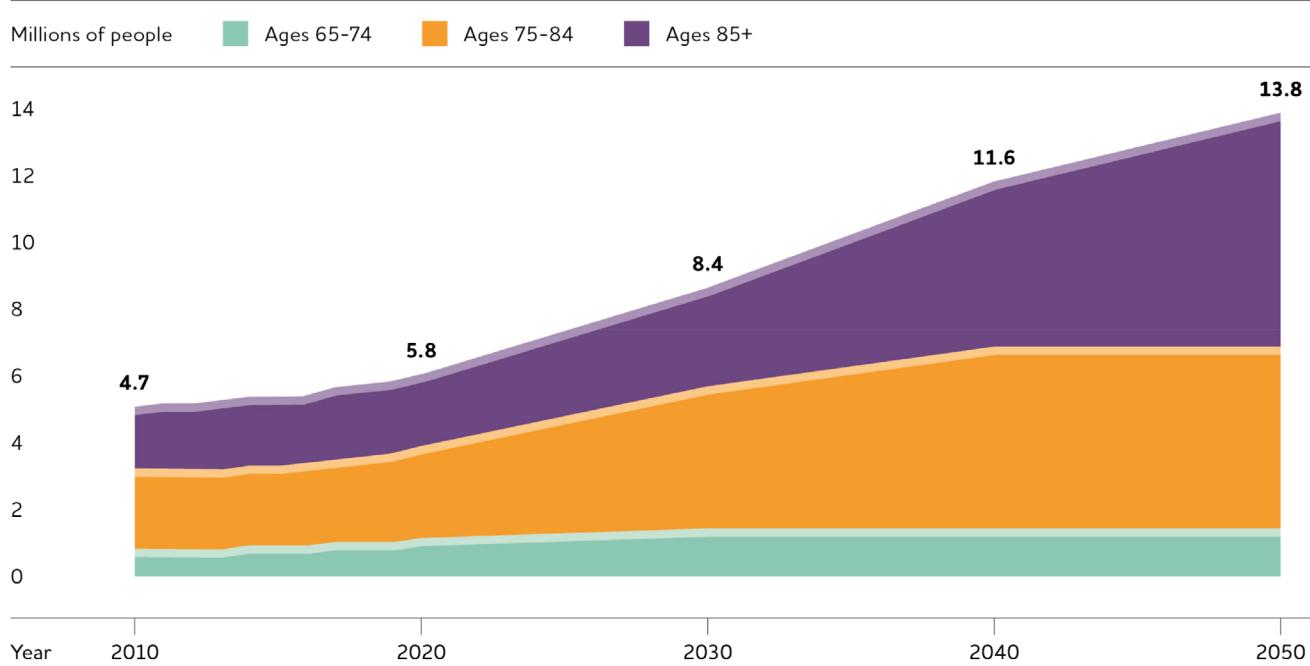
A large segment of the American population – the baby boom generation – has reached age 65 and older, when the risk for Alzheimer's and other dementias is elevated. By 2030, the segment of the U.S. population age 65 and older will increase substantially, and the projected 74 million older Americans will make up over 20% of the total population (up from 16% in 2020).<sup>184,279</sup> As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's dementia, as shown in Figure 5.<sup>A9,62</sup>

- By 2025, the number of people age 65 and older with Alzheimer's dementia is projected to reach 7.1 million – almost a 22% increase from the 5.8 million age 65 and older affected in 2020.<sup>A10,62</sup>
- By 2050, the number of people age 65 and older with Alzheimer's dementia is projected to reach 13.8 million, barring the development of medical breakthroughs to prevent, slow or cure Alzheimer's disease.<sup>A9,62</sup>

#### 3.7.2 | Growth of the oldest-old population

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to medical advances, as well as social and environmental conditions.<sup>279</sup> Longer life expectancies and the aging of the large baby boom cohort will lead to an increase in the number and percentage of Americans who will be 85 and older, the oldest-old. Between now and 2050, the oldest-old are expected to comprise an increasing proportion of the U.S. population age 65 and older – from 10% in 2020 to 19% in 2050.<sup>279</sup> This will result in an additional 4.8 million oldest-old people – individuals at the highest risk for developing Alzheimer's dementia.<sup>279</sup>

- In 2020, about 2.1 million people who have Alzheimer's dementia are age 85 or older, accounting for 35% of all people with Alzheimer's dementia.<sup>62</sup>



**FIGURE 5** Projected number of people age 65 and older (total and by age) in the U.S. population with Alzheimer's dementia, 2010 to 2050.  
Created from data from Hebert et al.<sup>A9,62</sup>

- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's dementia.<sup>62</sup>
- By 2050, 7 million people age 85 and older are projected to have Alzheimer's dementia, accounting for about half (51%) of all people 65 and older with Alzheimer's dementia.<sup>62</sup>

## 4 | MORTALITY AND MORBIDITY

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States.<sup>280</sup> It is the fifth-leading cause of death for those age 65 and older.<sup>281</sup> However, it may cause even more deaths than official sources recognize. Alzheimer's is also a leading cause of disability and poor health (morbidity). Before a person with Alzheimer's dies, he or she lives through years of morbidity as the disease progresses.

### 4.1 | Deaths from Alzheimer's disease

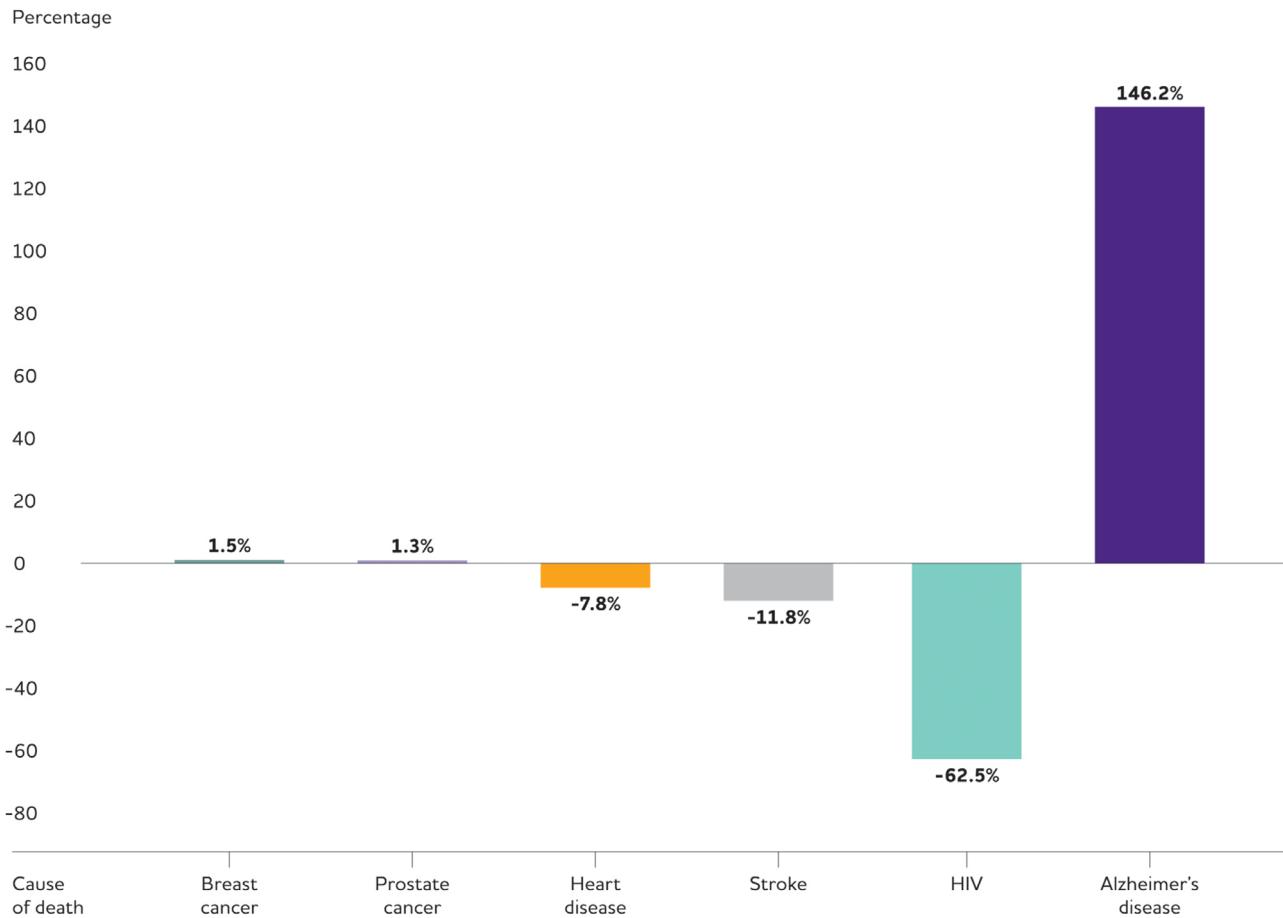
It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to data from the Centers for Disease Control and Prevention (CDC), 122,019 people died from Alzheimer's disease in 2018, the latest year for which data are available.<sup>281</sup> 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."<sup>282</sup>

In the United States, Alzheimer's disease is counted as a cause of death that can be ranked against other leading causes of death such

as cancer and heart disease, but deaths due to other types of clinically diagnosed dementia are not ranked in this manner. The number of deaths from dementia of any type is much higher than the number of reported Alzheimer's deaths. In 2018, some form of dementia was the officially recorded underlying cause of death for 266,957 individuals (this includes the 122,019 from Alzheimer's disease).<sup>281,283</sup> Therefore, the number of deaths from all causes of dementia, even as listed on death certificates, is more than twice as high as the number of reported Alzheimer's deaths alone.

To add further complexity, the vast majority of death certificates listing Alzheimer's disease or dementia as an underlying cause of death are not verified by autopsy, and research has shown that about 30% of those diagnosed with Alzheimer's dementia during life do not in fact have dementia due to Alzheimer's disease, but have dementia due to another cause (see Table 2). Therefore, an underlying cause of death listed as Alzheimer's disease may not be accurate. In this section, "deaths from Alzheimer's disease" refers to what is officially reported on death certificates, with the understanding that the person filling out the report believed dementia due to Alzheimer's disease was the underlying cause of death, usually without pathologic confirmation.

Severe dementia frequently causes complications such as immobility, swallowing disorders and malnutrition that significantly increase the risk of serious acute conditions that can cause death. One such condition is pneumonia (infection of the lungs), which is the most commonly identified immediate cause of death among older adults with Alzheimer's or other dementias.<sup>284,285</sup> One autopsy study found that respiratory system diseases were the immediate cause of death in more than half of people with Alzheimer's dementia, followed by circulatory system disease in about a quarter.<sup>285</sup> Death certificates for individuals with Alzheimer's often list acute conditions such as



**FIGURE 6** Percentage changes in selected causes of death (all ages) between 2000 and 2018. Created from data from the National Center for Health Statistics.<sup>281,294</sup>

pneumonia as the primary cause of death rather than Alzheimer's.<sup>286–288</sup> 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."<sup>289</sup>

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 those individuals did not have Alzheimer's dementia.<sup>290</sup>

The true number of deaths caused by Alzheimer's is somewhere between the number of deaths from Alzheimer's recorded on death certificates and the number of people who have Alzheimer's disease when they die. According to 2014 Medicare claims data, about one-

third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or another dementia.<sup>291</sup> Based on data from the Chicago Health and Aging Project (CHAP) study, in 2020 an estimated 700,000 people age 65 and older in the United States will have Alzheimer's when they die.<sup>292</sup> Although some older adults who have Alzheimer's disease at the time of death die from causes that are unrelated to Alzheimer's, many of them die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia.

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.<sup>293</sup>

#### 4.2 | Public health impact of deaths from Alzheimer's disease

Although deaths from other major causes have decreased significantly or remained approximately the same, official records indicate that deaths from Alzheimer's disease have increased significantly. Between 2000 and 2018, the number of deaths from Alzheimer's disease as recorded on death certificates has more than doubled, increasing 146%, while the number of deaths from the number one cause of death (heart disease) decreased 7.8% (Figure 6).<sup>281,294</sup> The increase in the

**TABLE 5** Number of Deaths and Annual Mortality Rate (per 100,000 People) Due to Alzheimer's Disease by State, 2018

State	Number of Deaths	Mortality Rate
Alabama	2,616	53.5
Arkansas	131	17.8
Arizona	3,012	42
Arkansas	1,457	48.3
California	16,627	42
Colorado	1,649	29
Connecticut	986	27.6
Delaware	412	42.6
District of Columbia	105	14.9
Florida	6,725	31.6
Georgia	4,513	42.9
Hawaii	480	33.8
Idaho	666	38
Illinois	4,030	31.6
Indiana	2,668	39.9
Iowa	1,439	45.6
Kansas	899	30.9
Kentucky	1,674	37.5
Louisiana	2,166	46.5
Maine	580	43.3
Maryland	1,122	18.6
Massachusetts	1,823	26.4
Michigan	4,474	44.8
Minnesota	2,436	43.4
Mississippi	1,547	51.8
Missouri	2,641	43.1
Montana	310	29.2
Nebraska	683	35.4
Nevada	704	23.2
New Hampshire	487	35.9
New Jersey	2,710	30.4
New Mexico	583	27.8
New York	3,755	19.2
North Carolina	4,495	43.3
North Dakota	356	46.8
Ohio	5,391	46.1
Oklahoma	1,739	44.1
Oregon	1,868	44.6
Pennsylvania	4,064	31.7
Rhode Island	470	44.5
South Carolina	2,616	51.5
South Dakota	437	49.5
Tennessee	3,488	51.5
Texas	9,763	34

(Continues)

**TABLE 5** (Continued)

State	Number of Deaths	Mortality Rate
Utah	1,024	32.4
Vermont	333	53.2
Virginia	2,592	30.4
Washington	3,752	49.8
West Virginia	791	43.8
Wisconsin	2,453	42.2
Wyoming	277	47.9
<b>U.S. TOTAL</b>	<b>122,019</b>	<b>37.3</b>

Created from data from the National Center for Health Statistics.<sup>A11,281</sup>

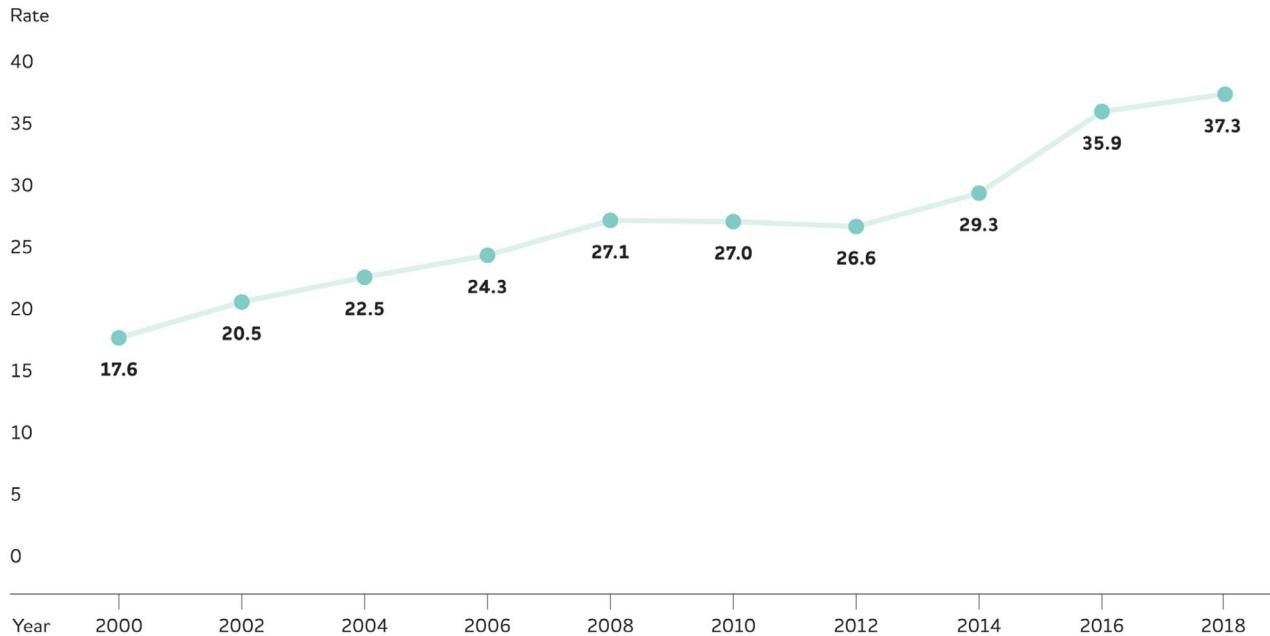
number of death certificates listing Alzheimer's as the underlying cause of death probably reflects both a real increase in the actual number of deaths from Alzheimer's due in large part to Alzheimer's becoming a more common cause of death as the population ages, as well as increased reporting of Alzheimer's deaths on death certificates over time by physicians, coroners and others who assign causes of death.<sup>295</sup>

### 4.3 | State-by-state deaths from Alzheimer's disease

Table 5 provides information on the number of deaths due to Alzheimer's by state in 2018, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death. The table also provides annual mortality rates by state to compare the risk of death due to Alzheimer's disease across states with varying population sizes. For the United States as a whole, in 2018, the mortality rate for Alzheimer's disease was 37.3 deaths per 100,000 people.<sup>A11,281</sup>

### 4.4 | Alzheimer's death rates

As shown in Figure 7, the rate of deaths due to Alzheimer's has risen substantially since 2000.<sup>281</sup> Table 6 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65.<sup>A11,281</sup> The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old.<sup>294</sup> Between 2000 and 2018, the death rate from Alzheimer's increased 32% for people age 65 to 74, but increased 53% for people age 75 to 84 and 84% for people age 85 and older.<sup>281</sup> A report by the CDC determined that even after adjusting for differences in age distributions over time, the annual Alzheimer's death rate in the United States increased substantially between 1999 and 2014.<sup>295</sup> Therefore, the growing proportion of older adults in the country is not the only explanation for the increase in Alzheimer's death rates. Other possible reasons include fewer deaths from other common causes of death in old age such as heart disease and stroke; increased diagnosis of Alzheimer's dementia; and increased reporting of Alzheimer's as a cause of death by physicians and others who fill out death certificates.<sup>295</sup>



**FIGURE 7** U.S. annual Alzheimer's death rate (per 100,000 people) by year. Created from data from the National Center for Health Statistics.<sup>281</sup>

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

Age	2000	2002	2004	2006	2008	2010	2012	2014	2016	2018
45-54	0.2	0.1	0.2	0.2	0.2	0.3	0.2	0.2	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
65-74	18.7	19.6	19.5	19.9	21.1	19.8	17.9	19.6	23.6	24.7
75-84	139.6	157.7	168.5	175.0	192.5	184.5	175.4	185.6	214.1	213.9
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

Created from data from the National Center for Health Statistics.<sup>281</sup>

#### 4.5 | Duration of illness from diagnosis to death

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's dementia, yet some live as long as 20 years with Alzheimer's dementia.<sup>210,296-303</sup> 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.<sup>293</sup> Much of this time will be spent in a nursing home. At age 80, approximately 75% of people with Alzheimer's dementia live in a nursing home compared with only 4% of the general population age 80.<sup>293</sup> In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20% of people with cancer and 28% of people dying from all other conditions.<sup>304</sup>

#### 4.6 | Burden of Alzheimer's disease

The long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease because much of that time is spent in a state of disability and dependence. Scientists have

developed methods to measure and compare the burden of different diseases on a population in a way that takes into account not only the number of people with the condition, but also the number of years of life lost due to that disease and the number of healthy years of life lost by virtue of being in a state of disability. The primary measure of disease burden is called disability-adjusted life years (DALYs), which is the sum of the number of years of life lost due to premature mortality (YLLs) and the number of years lived with disability (YLDs), totaled across all those with the disease or injury. These measures indicate that Alzheimer's is a very burdensome disease, not only to the individuals with the disease, but also to their families and informal caregivers, and that the burden of Alzheimer's has increased more dramatically in the United States than the burden of other diseases in recent years. According to the most recent Global Burden of Disease classification system, Alzheimer's disease rose from the 12th most burdensome disease or injury in the United States in 1990 to the 6th in 2016 in terms of DALYs. In 2016, Alzheimer's disease was the fourth highest disease or injury in terms of YLLs and the 19th in terms of YLDs.<sup>305</sup>

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

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

## 5 | CAREGIVING

Caregiving refers to attending to another person's health needs and well-being. Caregiving often includes assistance with one or more activities of daily living (ADLs), including bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation.<sup>306,307</sup> Caregivers also provide emotional support to people with Alzheimer's as well as many other forms of help (for example, communicating and coordinating care with other family members and health care providers, ensuring safety at home and elsewhere, and managing health conditions; see Table 7). In addition to providing descriptive information about caregivers of people with Alzheimer's or other dementias, this section compares caregivers of people with dementia to either caregivers of people with other medical conditions or, if that comparison is not available, to non-caregivers.

### 5.1 | Unpaid caregivers

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers.<sup>308</sup> Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer's or another dementia.<sup>309</sup> More than 16 million Americans provide unpaid care for people with Alzheimer's or other dementias.<sup>A12</sup>

It is important to note that the number of caregivers for people with Alzheimer's or other dementias is calculated using a model that incorporates, in part, data from 2009, the most recent date for which the data are available. There are indications that over the past decade, the number of family caregivers for all older Americans may have declined. The Alzheimer's Association is examining new data and recently released state-specific data on dementia caregivers and is working with experts to revise the model to take into account these recent trends. Preliminary evaluation indicates that, compared with the past, there are fewer family caregivers in total, and each individual caregiver is experiencing a greater burden by providing significantly more hours of care. If this preliminary analysis holds, future estimates of the number of Alzheimer's and dementia caregivers nationally and for each state will be lower than current estimates.

In 2019, caregivers of people with Alzheimer's or other dementias provided an estimated 18.6 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at nearly \$244 billion. This is approximately 47% of the net value of Walmart's total revenue in 2019 (\$514.4 billion)<sup>310</sup> and 11 times the total revenue of McDonald's in 2018 (\$21 billion).<sup>311</sup> The total lifetime cost of care for someone with dementia was estimated at \$357,297 in 2019 dollars. Seventy percent of the lifetime cost of care is borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses for items

**TABLE 7** Dementia Caregiving Tasks

Helping with instrumental activities of daily living (IADLs), such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.

Helping the person take medications correctly, either via reminders or direct administration of medications.

Helping the person adhere to treatment recommendations for dementia or other medical conditions.

Assisting with personal activities of daily living (ADLs), such as bathing, dressing, grooming and feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.

Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.

Finding and using support services such as support groups and adult day service programs.

Making arrangements for paid in-home, nursing home or assisted living care.

Hiring and supervising others who provide care.

Assuming additional responsibilities that are not necessarily specific tasks, such as:

- Providing overall management of getting through the day.
- Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver.
- Managing other health conditions (i.e., "comorbidities"), such as arthritis, diabetes or cancer.
- Providing emotional support and a sense of security.

ranging from medications to food for the person with dementia.<sup>312,313</sup> Current estimates of the lifetime costs of care may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity.<sup>314</sup>

Three of the main reasons caregivers provide care and assistance to a person with Alzheimer's or another dementia are (1) the desire to keep a family member or friend at home (65%), (2) proximity to the person with dementia (48%) and (3) the caregiver's perceived obligation to the person with dementia (38%).<sup>A13</sup> Caregivers often indicate love and a sense of duty and obligation when describing what motivates them to assume care responsibilities for a relative or friend living with dementia.<sup>315</sup> Individuals with dementia living in the community are more likely than older adults without dementia to rely on multiple unpaid caregivers (often family members); 30% of older adults with dementia rely on three or more unpaid caregivers, whereas 23% of older adults without dementia rely on three or more unpaid caregivers.<sup>316</sup> Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8%). Of these individuals, nearly half live alone, perhaps making it more difficult to ask for and receive informal care.<sup>316</sup> Of caregivers of spouses with dementia who are at the end of life, close to half provide care without the help of other family or friends.<sup>317</sup> Living alone with dementia may be a particular challenge for certain

subgroups, such as lesbian, gay, bisexual and transgender (LGBT) individuals, who may experience greater isolation for reasons ranging from social stigma to a diminished social network of available family or friend caregivers.<sup>318</sup>

### 5.1.1 | Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's or other dementias in the United States. They have found the following:<sup>A13,319-323</sup>

- Approximately two-thirds of dementia caregivers are women.<sup>A13,319,320</sup>
- About 30% of caregivers are age 65 or older.<sup>A13</sup>
- Over 60% of caregivers are married, living with a partner or in a long-term relationship.<sup>A13,320</sup>
- Over half of caregivers are providing assistance to a parent or in-law with dementia.<sup>323</sup> Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.<sup>323,324</sup>
- Two-thirds of caregivers are non-Hispanic white,<sup>A13,319,320,323</sup> while 10% are black/African American, 8% are Hispanic/Latino and 5% are Asian.<sup>A13</sup> The remaining 10% represent a variety of other racial/ethnic groups.
- Approximately 40% of dementia caregivers have a college degree or more education.<sup>A13,320,323</sup>
- Forty-one percent of caregivers have a household income of \$50,000 or less.<sup>A13</sup>
- 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.<sup>322,325,326</sup>
- Most caregivers (66%) live with the person with dementia in the community.<sup>316</sup>
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for a child.<sup>A13,323,324</sup>

### 5.1.2 | Caregiving and women

The responsibilities of caring for someone with dementia often fall to women. As mentioned earlier, approximately two-thirds of dementia caregivers are women.<sup>A13,319,320,325,326</sup> Over one-third of dementia caregivers are daughters.<sup>308,316</sup> It is more common for wives to provide informal care for a husband than vice versa.<sup>327</sup> On average, female caregivers spend more time caregiving than male caregivers.<sup>316</sup> According to the 2014 Alzheimer's Association Women and Alzheimer's Poll, which surveyed both men and women, of those providing care for 21 hours or more per week, 67% were women.<sup>328</sup> Similarly, the 2015-2017 Behavioral Risk Factor Surveillance System

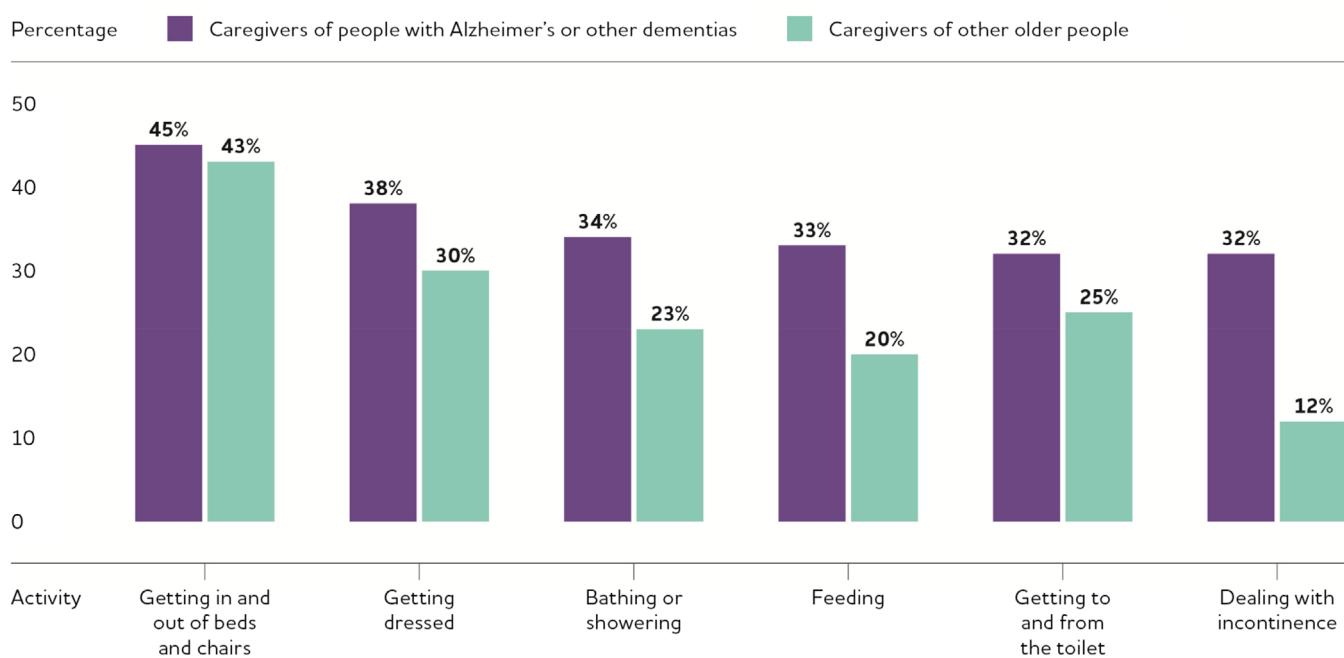
(BRFSS) surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women.<sup>324</sup> Two and a half times as many women as men reported living with the person with dementia full time.<sup>328</sup> Of those providing care to someone with dementia for more than 5 years, 63% are women.<sup>324</sup> Similarly, caregivers who are women may experience slightly higher levels of burden, impaired mood, depression and impaired health than 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.<sup>329,330</sup> Of dementia caregivers who indicate a need for individual counseling or respite care, the large majority are women (individual counseling, 85%, and respite care, 84%).<sup>324</sup>

### 5.1.3 | Caregiving tasks

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

Though the care provided by family members of people with Alzheimer's or other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely to monitor the health of the care recipient than are caregivers of people without dementia (79% versus 66%).<sup>331</sup> Data from the 2011 National Health and Aging Trends Study indicated that caregivers of people with dementia are more likely than caregivers of people without dementia to provide help with self-care and mobility (85% versus 71%) and health or medical care (63% versus 52%).<sup>309,319</sup> Figure 8 illustrates how family caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs.

In addition to assisting with ADLs, more caregivers of people with Alzheimer's or other dementias advocate for these individuals with community agencies and care providers (65%) and manage finances (68%) compared with caregivers of people without dementia (46% and 50%, respectively).<sup>323</sup> More caregivers of people with Alzheimer's or other dementias arrange for outside services (46%) and communicate with health care professionals (80%) compared with caregivers of people without dementia (27% and 59%, respectively).<sup>323</sup> 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.<sup>323</sup> Caring for a person with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms (for example, anxiety, apathy and lack of inhibition) and severe behavioral problems. Family caregivers of people with Alzheimer's or other dementias are more likely than family caregivers of people without dementia to help with emotional or mental health



**FIGURE 8** Proportion of caregivers of people with Alzheimer's or other dementias versus caregivers of other older people who provide help with specific activities of daily living, United States, 2015. Created from data from the National Alliance for Caregiving and AARP.<sup>323</sup>

problems (41% versus 16%) and behavioral issues (15% versus 4%).<sup>323</sup> People with dementia tend to have larger networks of family and friends involved in their care compared with people without dementia. Family members and friends in dementia care networks may provide help for a larger number of tasks than do those in non-dementia care networks, where family members and friends are more likely to focus on specific care tasks.<sup>332</sup>

When a person with Alzheimer's or another dementia moves to an assisted living residence or a nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 7 to providing emotional support, interacting with facility staff and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing and other ADLs.<sup>333-335</sup>

#### 5.1.4 | Duration of caregiving

Eighty-six percent of dementia caregivers have provided care and assistance for at least the past year, according to the national 2014 Alzheimer's Association Women and Alzheimer's Poll.<sup>A13</sup> According to another study, well over half (57%) of family caregivers of people with Alzheimer's or other dementias in the community had provided care for 4 or more years.<sup>316</sup> More than six in 10 (63%) Alzheimer's caregivers expect to continue having care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia (49%).<sup>323</sup>

#### 5.1.5 | Hours of unpaid care and economic value of caregiving

In 2019, the 16.3 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 18.6 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.<sup>A14</sup> With this care valued at \$13.11 per hour,<sup>A15</sup> the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was nearly \$244 billion in 2019. Table 8 shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's or other dementias provided care valued at more than \$4 billion in each of 22 states. Unpaid caregivers in each of the four most populous states — California, Florida, New York and Texas — provided care valued at more than \$15 billion. A longitudinal study of the monetary value of family caregiving for people with dementia found that the overall value of daily family care increased 18% with each additional year of providing care, and that the value of this care further increased as the care recipient's cognitive abilities declined.<sup>336,337</sup> Additional research is needed to estimate the future value of family care for people with Alzheimer's disease and other dementias as the U.S. population continues to age.

Apart from its long duration, the immediate demands of caregiving are also time-intensive. Caregivers of people with dementia report

**TABLE 8** Number of Caregivers of People with Alzheimer's or Other Dementias, Hours of Unpaid Care and Economic Value of Unpaid Care by State, 2019\*

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Alabama	306	349	\$4,576
Alaska	33	38	495
Arizona	346	394	5,165
Arkansas	178	203	2,663
California	1,624	1,849	24,245
Colorado	256	292	3,825
Connecticut	178	203	2,655
Delaware	55	63	822
District of Columbia	29	33	433
Florida	1,152	1,312	17,206
Georgia	540	615	8,063
Hawaii	65	74	975
Idaho	87	99	1,299
Illinois	587	668	8,759
Indiana	342	390	5,112
Iowa	136	155	2,036
Kansas	152	173	2,268
Kentucky	274	312	4,089
Louisiana	231	264	3,456
Maine	70	79	1,042
Maryland	294	335	4,389
Massachusetts	340	387	5,075
Michigan	518	590	7,733
Minnesota	257	293	3,838
Mississippi	207	235	3,085
Missouri	319	363	4,755
Montana	51	58	757
Nebraska	83	95	1,240
Nevada	153	175	2,289
New Hampshire	68	78	1,016
New Jersey	448	510	6,684
New Mexico	108	123	1,617
New York	1,011	1,151	15,089
North Carolina	479	545	7,151
North Dakota	30	35	454
Ohio	604	688	9,018
Oklahoma	226	257	3,371
Oregon	188	214	2,810
Pennsylvania	677	771	10,104
Rhode Island	54	61	800
South Carolina	318	362	4,749
South Dakota	39	44	575
Tennessee	444	506	6,628
Texas	1,449	1,650	21,628

(Continues)

**TABLE 8** (Continued)

State	Number of Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)
Utah	159	181	2,366
Vermont	30	34	449
Virginia	467	532	6,970
Washington	353	402	5,268
West Virginia	105	120	1,574
Wisconsin	195	223	2,918
Wyoming	28	31	413
<b>U.S. TOTAL</b>	<b>16,343</b>	<b>18,611</b>	<b>\$243,994</b>

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

Created from data from the 2009 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, Centers for Medicare & Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.<sup>A12,A14,A15</sup>

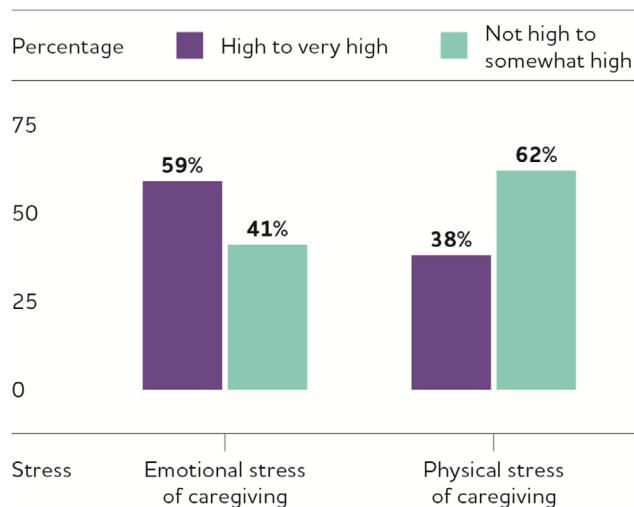
providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.<sup>319</sup> An analysis of national caregiving trends from 1999 to 2015 found that the average hours of care per week increased from 45 in 1999 to 48 in 2015 for dementia caregivers; over the same time period, weekly hours of care decreased for non-dementia caregivers from 34 to 24.<sup>338</sup>

### 5.1.6 | Impact of Alzheimer's caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the middle to later stages of Alzheimer's experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are affected as well, and these changes are often among the most challenging for family caregivers.<sup>339-341</sup> Individuals with Alzheimer's also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen, the care required by family members can result in increased emotional stress and depression among caregivers; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and people living with dementia.<sup>342-350</sup>

#### *Caregiver emotional and social well-being*

The intimacy, shared experiences and memories that are often part of the relationship between a caregiver and person living with dementia may be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's. In a national poll, however, 45% of caregivers of people with dementia indicated that providing help to someone with cognitive impairment was very rewarding.<sup>326</sup> Although caregivers



**FIGURE 9** Proportion of caregivers of people with Alzheimer's or other dementias who report high to very high emotional and physical stress due to caregiving. Created from data from the Alzheimer's Association.<sup>A13</sup>

report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,<sup>A13,351-357</sup> they also frequently report higher levels of stress.

#### Burden and stress.

- More dementia caregivers were classified as having a high level of burden than caregivers of people without dementia (46% versus 38%) based on the 2015 National Alliance for Caregiving/AARP survey's Burden of Care Index, which combined the number of hours of care and the number of ADL tasks performed by the caregiver into a single numerical score.<sup>323</sup>
- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.<sup>319</sup>
- 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 9).<sup>A13</sup> Nearly half of dementia caregivers (49%) indicate that providing help is highly stressful compared with 35% of caregivers of people without dementia.<sup>323</sup>

#### Depression and mental health.

- A meta-analysis reported that caregivers of people with dementia were significantly more likely to experience depression and anxiety than non-caregivers.<sup>330</sup> Approximately 30% to 40% of family caregivers of people with dementia report depression, compared with 5% to 17% of non-caregivers of similar ages.<sup>358-362</sup>
- The prevalence of depression is higher among dementia caregivers (30% to 40%) than other caregivers, such as those who provide help to individuals with schizophrenia (20%) or stroke (19%).<sup>362-365</sup>

- In a meta-analysis, the type of relationship was the strongest predictor of caregiver depression; caregivers of spouses had two and a half times higher odds of having depression than caregivers of people who were not spouses.<sup>362</sup>

- The prevalence of anxiety among dementia caregivers is 44%, which is higher than among caregivers of people with stroke (31%).<sup>362,363</sup>
- 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.<sup>366,367</sup>
- Caring for people with dementia who have four or more behavioral and psychological symptoms (for example, aggression, self-harm and wandering) represents a "tipping point" for family caregivers, as they are more likely to report clinically meaningful depression and burden (that is, negative emotional reactions to providing care).<sup>368</sup>

#### Strain.

- Caregivers of people with Alzheimer's or other dementias were twice as likely as caregivers of individuals without dementia (22% compared with 11%) to report that completing medical/nursing-related tasks (for example, injections, tube feedings and catheter/colostomy care) was difficult.<sup>331</sup>
- About half of caregivers (51%) of people with Alzheimer's or another dementia report having no experience performing medical/nursing-related tasks,<sup>331</sup> and they often lack the information or resources necessary to manage complex medication regimens.<sup>369-372</sup>
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.<sup>A13</sup>
- The poll also found that more than half of women with children under age 18 felt that caregiving for someone with dementia was more challenging than caring for children (53%).<sup>A13</sup>
- Many caregivers of people with Alzheimer's or other dementias provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.<sup>A13</sup>
- A population-based sample of caregivers found that although dementia caregivers indicated greater strain than non-dementia caregivers, no substantial differences in strain between white and black/African American dementia caregivers were evident.<sup>373</sup>

#### Stress of care transitions.

- Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility, but other studies have found that distress declines following admission.<sup>335,374,375</sup>
- The demands of caregiving may intensify as people with dementia approach the end of life.<sup>376</sup> 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.<sup>377</sup> The same study found that 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.<sup>377</sup>

#### Caregiver physical health

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.<sup>378</sup> As shown in Figure 9, 38% of Alzheimer's and other dementia caregivers indicate that the physical stress of caregiving is high to very high.<sup>413</sup> Building on this, a recent analysis found that 29% of caregivers of people with Alzheimer's or other dementias report that providing care results in high physical strain compared with 17% of caregivers of people without dementia.<sup>323</sup> 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.<sup>379-381</sup> 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.<sup>381</sup>

**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.<sup>413</sup> Forty-two percent of caregivers of people with Alzheimer's or another dementia report that their health is excellent or very good, which is lower than caregivers of people without dementia (50%).<sup>323</sup> In addition, 35% of caregivers of people with Alzheimer's or another dementia report that their health has worsened due to care responsibilities compared with 19% of caregivers of people without dementia.<sup>323</sup> A 2017 poll reported that 27% of dementia caregivers delayed or did not do things they should to maintain their own health.<sup>326</sup> Dementia caregivers indicate lower health-related quality of life than non-caregivers and are more likely than non-caregivers or other caregivers to report that their health is fair or poor.<sup>344,348,382-384</sup> 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.<sup>385</sup> Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.<sup>386</sup>

Recent research has examined variations in self-rated health among dementia caregivers of diverse racial and ethnic backgrounds. Support from family and friends is associated with better self-rated health for black/African American dementia caregivers, but not for white or Mexican American caregivers. A more positive perceived relationship between the caregiver and person with dementia was associated with better self-rated health among black/African American and white caregivers.<sup>387</sup>

**Physiological changes.** The chronic stress of caregiving may be associated with an increased incidence of hypertension<sup>342,388-395</sup> and a

number of physiological changes that could increase the risk of developing chronic conditions, including high levels of stress hormones,<sup>388</sup> impaired immune function,<sup>342,389</sup> slow wound healing<sup>390</sup> and coronary heart disease.<sup>391</sup> 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.<sup>396</sup> Additional studies of physiological changes before and after the start of caregiving in diverse populations are needed to better understand the physiological effects of caregiving.

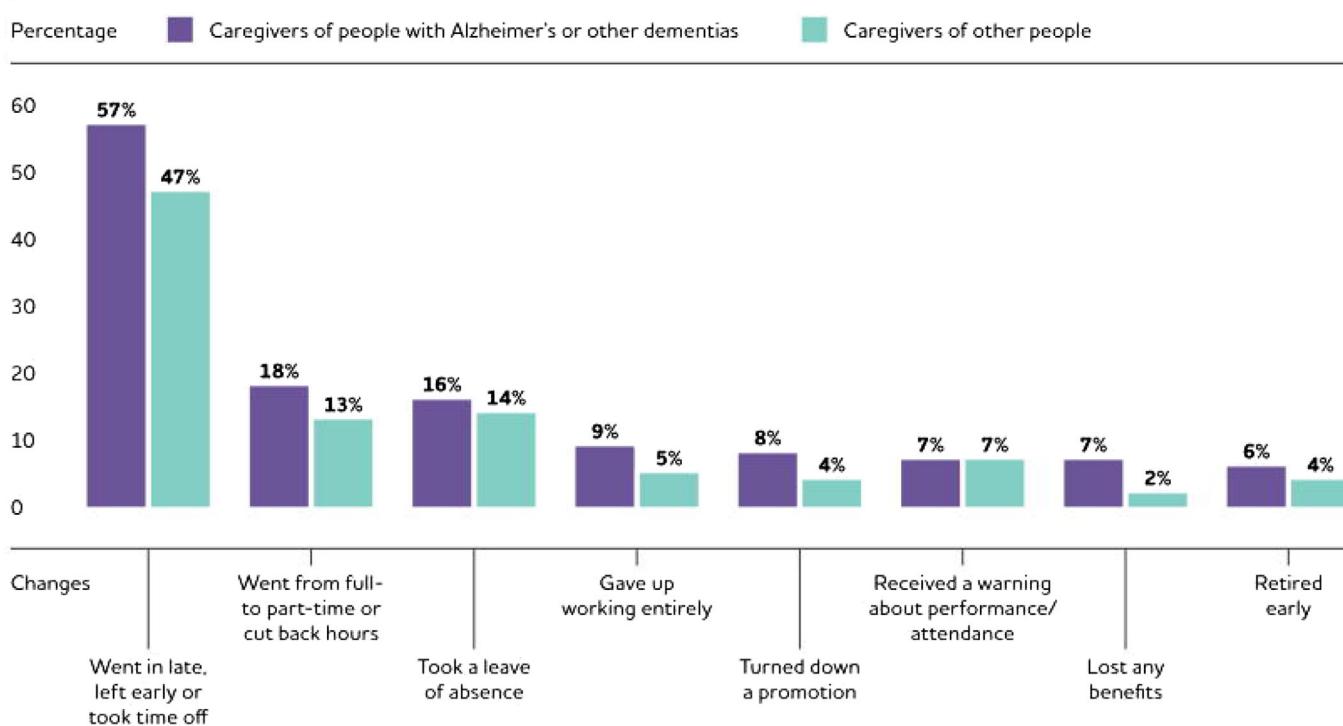
**Health care.** Caregivers of people with dementia who are depressed, have behavioral disturbances or have low functional status are more likely to be hospitalized and have emergency department visits<sup>397,398</sup> than caregivers of people with dementia who do not have these symptoms. Increased depressive symptoms among caregivers over time are linked to more frequent doctor visits, increased outpatient tests and procedures, and greater use of over-the-counter and prescription medications.<sup>398</sup>

**Mortality.** Studies of how the health of people with dementia affects their caregivers' risk of dying have had mixed findings.<sup>399,400</sup> For example, caregivers of spouses who were hospitalized and had dementia were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia (after accounting for differences in caregiver age).<sup>401</sup> In addition, caregivers who perceive higher strain due to care responsibilities were at higher risk for death than caregivers who perceive little or no strain.<sup>402</sup> In contrast, a longitudinal study of participants in the Health and Retirement Study found that dementia caregivers were less likely to die than non-caregivers of similar age over a 12-year period. These results are consistent with a protective effect of dementia care, at least as it pertains to death.<sup>399</sup> The findings are also consistent with the possibility that individuals who assume dementia care roles do so in part because their initial health allows them to do so. Eighteen percent of spousal caregivers die before their partners with dementia.<sup>403</sup>

#### Caregiver employment and finances

Six in 10 caregivers of people with Alzheimer's or another dementia were employed or had been employed in the prior year while providing care.<sup>323</sup> These individuals worked an average of 35 hours per week while caregiving.<sup>323</sup> Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 57% reported sometimes needing to go in late or leave early compared with 47% of non-dementia caregivers. Eighteen percent of dementia caregivers reduced their work hours due to care responsibilities, compared with 13% of non-dementia caregivers. Other work-related changes among dementia and non-dementia caregivers who had been employed in the past year are summarized in Figure 10.<sup>323</sup>

Costs of dementia caregiving for employers may include replacement costs for employees who quit due to their caregiving responsibilities and costs of absenteeism and workday



**FIGURE 10** Work-related changes among caregivers of people with Alzheimer's or other dementias who had been employed at any time since they began caregiving. Created from data from the National Alliance for Caregiving and AARP.<sup>323</sup>

interruptions.<sup>404</sup> In 2010, employers lost \$13 billion due to employees' elder care responsibilities.<sup>405,406</sup>

In 2019, it is estimated that dementia caregivers bore nearly twice the average out-of-pocket costs (for example, medical care, personal care and household expenses for the person with dementia and personal expenses and respite services for the caregiver) of non-dementia caregivers (\$11,372 versus \$6,121).<sup>407</sup> Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey indicated that among care contributors (a friend or relative who paid for dementia expenses and/or provided care for someone with dementia at least once a month in the prior year), 48% cut back on spending and 43% cut back on saving due to the out-of-pocket costs of providing help to someone with dementia.<sup>349</sup> Due to care responsibilities in the year prior to the survey, close to four in 10 care contributors indicated that the "food they bought just didn't last, and they didn't have money to get more," and three in 10 ate less because of care-related costs.<sup>349</sup>

#### Effects of caregiver stress on people with dementia

Research has emerged on the effects of caregiver stress on people with dementia and their use of health care services. For example, distress on the part of family caregivers is associated with increased odds of institutionalization of the person with dementia, exacerbated behavioral and psychological challenges in the person with dementia, and increased likelihood of people with dementia being abused.<sup>408</sup> See the Use and Costs of Health Care, Long-Term Care, and Hospice section for additional information.

#### 5.1.7 | Interventions designed to assist caregivers

For more than 30 years, strategies to support family caregivers of people with dementia have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 9.<sup>347,409</sup>

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

According to a publication on dementia caregiver interventions that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers, but of people living with dementia as well.<sup>410</sup> A 2012 report examined randomized, controlled studies of caregiver interventions and identified 44 interventions that benefited individuals with dementia as well as caregivers. More such

**TABLE 9** 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 a structured program that provides information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite care for a certain number of weekly hours.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of isolation.
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of interventions, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

Created from data from Pinquart et al. and Gaugler et al.<sup>346,409</sup>

interventions are emerging each year.<sup>411-416</sup> 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.<sup>417</sup>

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.<sup>418-432</sup> 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.<sup>433</sup> In one example, researchers utilized an “agile implementation” process to more rapidly select, localize, evaluate and replicate a collaborative care model for dementia care. This care model has successfully operated for nearly a decade in an Indianapolis health care system.<sup>434</sup> 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),<sup>435-442</sup> while others integrated evidence-based dementia care interventions into community-based, long-term service programs.<sup>443</sup> In 2019, the National Institute on Aging (NIA) awarded funding to create the NIA Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory. The Collaboratory includes experts from more than 30 top research institutions and will support up to 40 pilot trials to test non-drug, care-based interventions for people living with dementia in the next five years. The goal of IMPACT is to expedite the timeline of research implementation in real-world settings to improve care for people living with dementia and their caregivers.

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.<sup>444-447</sup> Improved tools and measures to personalize services for caregivers to maximize their benefits represent an emerging area of research.<sup>448-454</sup> 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.<sup>455-469</sup> Additional research on interventions focused on disease stages is also needed, as well as research on specific intervention needs for LGBT caregivers.<sup>318</sup>

## 5.2 | Paid caregivers

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

Direct-care workers, such as nurse aides, home health aides, and personal and home care aides, provide most of the paid long-term care to older adults living at home or in residential settings.<sup>470,471</sup> In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents.<sup>472-474</sup> Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and geographic backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.<sup>473,475-477</sup> Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.<sup>476,478</sup> Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments.<sup>479</sup> Studies have shown that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits.<sup>475,480-484</sup>

The National Academies of Sciences, Engineering, and Medicine have recommended changes to federal requirements for general direct-care worker training, including an increase in training hours from 75 to 120, and instructional content that focuses more on knowledge and skills related to caring for individuals with Alzheimer's and other dementias.<sup>476,477</sup>

### 5.2.2 | Shortage of geriatric health care professionals

Professionals who may receive special training in caring for older adults include physicians, nurse practitioners, registered nurses, social workers, pharmacists, physician assistants and case workers.<sup>476</sup> It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs.<sup>485</sup> As of 2016, there were 7,293 certified geriatricians in the United States, or one geriatrician for every 1,924 Americans age 65 or older in need of care.<sup>486</sup> The American Geriatrics Society estimates that, due to the increase in vulnerable older Americans who require geriatric care, an additional 23,750 geriatricians should be trained between now and 2030 to meet the needs of an aging U.S. population<sup>487</sup> (see the Special Report for additional information). There were 272,000 nurse practitioners in the United States in 2019. Eleven percent of nurse practitioners had special expertise in gerontological care.<sup>488</sup> Less than 1% of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.<sup>476</sup> Although 73% of social workers serve clients age 55 and older, only 4% have formal certification in geriatric social work.<sup>476</sup> Furthermore, the overall aging of the long-term care workforce may affect the number of paid caregivers.<sup>479</sup>

### 5.2.3 | Enhancing health care for family caregivers

There is a growing consensus that professionals caring for people with Alzheimer's and other dementias should acknowledge the role family caregivers play in facilitating the treatment of dementia, and that professionals should assess the well-being of family caregivers to improve overall disease management of the person with dementia.<sup>489-493</sup> The complex care challenges of people with dementia also require inter-professional collaboration and education.<sup>494-497</sup> Ongoing efforts have attempted to integrate innovative care management practices with traditional primary care for people with dementia. One example involves a skilled professional who serves as the care manager of the person with dementia. The care manager collaborates with primary care physicians and nurse practitioners to develop personalized care plans. These plans can provide support to family caregivers, help people with dementia manage care transitions (for example, a change in care provider or site of care) and ensure the person with dementia has access to appropriate community-based services. Other models include addressing the needs of family caregivers simultaneously with comprehensive disease management of people living with dementia to improve the quality of life of both.<sup>498</sup> Several evaluations have suggested that such approaches have considerable potential for improving outcomes for people with

dementia and their family caregivers (for example, delayed nursing home admission and reduction in caregiver distress).<sup>499-508</sup> Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate.<sup>509-512</sup>

In 2016, the National Academies of Sciences, Engineering, and Medicine released *Families Caring for an Aging America*, a seminal report that includes a number of recommendations to refocus national health care reform efforts from models of care that center on the patient (person-centered care) to models of care that also explicitly engage and support the patient's family (family-centered care).<sup>404</sup> These service models recognize the important role family members play in providing care and incorporate family caregivers during the delivery of health care to their relatives with dementia. Furthermore, these models encourage health care providers to deliver evidence-based services and support to both caregivers and people living with dementia.<sup>404,513</sup>

In January 2017, Medicare began reimbursing physicians, physician assistants, nurse practitioners and clinical nurse specialists for health care visits that result in a comprehensive dementia care plan. Comprehensive care planning is a core element of effective dementia care management and can result in the delivery of services that potentially enhance quality of life for people with dementia and their caregivers. In the first year the care planning benefit was available (2017), less than 1% of those with Alzheimer's disease or other dementias received a comprehensive dementia care plan. In seven states (Alaska, Montana, New Hampshire, North Dakota, Rhode Island, South Dakota and Vermont) and the District of Columbia, no fee-for-service Medicare beneficiaries received a comprehensive dementia care plan. Use of the Medicare care planning benefit did increase throughout the year, and the rate of use was 3.3 times greater in the fourth quarter of 2017 compared with the first quarter of 2017.<sup>514</sup> The Alzheimer's Association has developed a care planning kit ([alz.org/careplanning](http://alz.org/careplanning)) to help guide providers to deliver effective care planning for people with dementia and their family caregivers.

## 5.3 | Trends in dementia caregiving

There is some indication that families are now better at managing the care they provide to relatives with dementia than in the past. From 1999 to 2015, dementia caregivers were significantly less likely to report physical difficulties (from 30% in 1999 to 17% in 2015) and financial difficulties (from 22% in 1999 to 9% in 2015) related to care provision. In addition, use of respite care by dementia caregivers increased substantially (from 13% in 1999 to 27% in 2015).<sup>338</sup> However, as noted earlier, more work is needed to ensure that interventions for dementia caregivers are available and accessible to those who need them. A 2016 study of the Older Americans Act's National Family Caregiver Support Program found that over half (52%) of Area Agencies on Aging did not offer evidence-based family caregiver interventions.<sup>515</sup>

The Alzheimer's Association has undertaken several efforts to improve how dementia care is studied and delivered. Its recent dementia care practice recommendations<sup>516</sup> place individuals with dementia

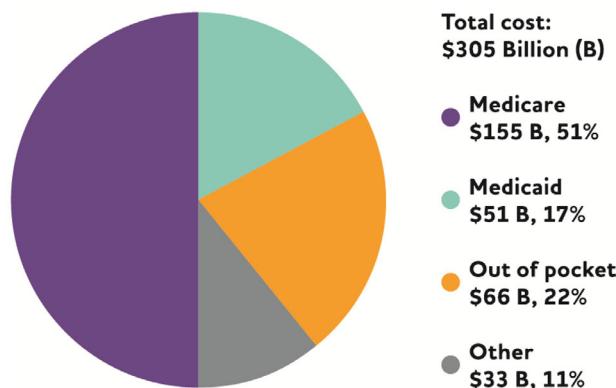


**FIGURE 11** Person-centered care delivery. Created from data from the Alzheimer's Association.<sup>516</sup>

and their caregivers at the center of how care should be delivered (see Figure 11). Essential to this model is the need to reconsider how we measure and design care for people with dementia by moving away from an approach that focuses on loss of abilities due to dementia to an approach that emphasizes the individual's unique needs, personal experiences and strengths. This person-centered care philosophy not only values and respects the individual with dementia, but also promotes well-being and health.<sup>517</sup> This new framework is designed to shift how researchers and care providers think about dementia, and may point the way to a greater understanding of the resilience, adaptability, and the possibilities of maintenance or even improvement of skills and abilities when living with dementia.<sup>518,519</sup> A core element of this and other frameworks is to ensure that every experience and interaction is seen as an opportunity to have meaningful engagement, which in turn helps create a better quality of life for the person with dementia.

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

The costs of health care and long-term care for individuals with Alzheimer's or other dementias are substantial, and dementia is one of the costliest conditions to society.<sup>520</sup> Total payments in 2020 (in 2020 dollars) for all individuals with Alzheimer's or other dementias are estimated at \$305 billion (Figure 12), not including the value of informal caregiving that is described in the Caregiving Section. Medicare and Medicaid are expected to cover \$206 billion, or 67%, of the total health care and long-term care payments for people with Alzheimer's or other dementias. Out-of-pocket spending is expected to be \$66 billion, or 22% of total payments.<sup>A16</sup> Throughout the rest of this section, all costs are reported in 2019 dollars unless otherwise indicated.<sup>A17</sup>



**FIGURE 12** Distribution of aggregate costs of care by payment source for Americans age 65 and older with Alzheimer's or other dementias, 2020. Data are in 2020 dollars. Percentages do not total 100 due to rounding. Created from data from the Lewin Model.<sup>A16</sup> "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

**TABLE 10** 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 2019 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	25,213	7,750
Medicaid	8,779	374
Uncompensated	390	392
Health maintenance organization	1,293	1,583
Private insurance	2,309	1,458
Other payer	961	248
Out of pocket	11,068	2,395
<b>TOTAL *</b>	<b>50,201</b>	<b>14,326</b>

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.<sup>207</sup>

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

Table 10 reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias. Total per-person health care and long-term care payments in 2019 from all sources for Medicare beneficiaries with Alzheimer's or other dementias were over three times as great as payments for other Medicare beneficiaries in the same age group (\$50,201 per person for those with dementia compared with \$14,326 per person for those without dementia).<sup>A18,207</sup>

Twenty-seven percent of older individuals with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11% of individuals without dementia.<sup>207</sup> Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias (\$8,779) were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias (\$374) (Table 10).<sup>207</sup>

Despite these and other sources of financial assistance, individuals with Alzheimer's or other dementias still incur high out-of-pocket costs. These costs are for Medicare, other health insurance premiums, deductibles, copayments and services not covered by Medicare, Medicaid or additional sources of support. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid \$11,068 out of pocket annually for health care and long-term care services not covered by other sources (Table 10).<sup>207</sup>

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).<sup>312,520-522</sup> In a recent systematic review of studies of older adults with Alzheimer's and other dementias enrolled in private Medicare managed care plans, researchers found a wide range of incremental costs attributable to Alzheimer's and other dementias.<sup>523</sup> One group of researchers found that the incremental health care and nursing home costs for those with dementia were \$28,501 per person per year in 2010 dollars (\$36,400 in 2019 dollars).<sup>A19,520</sup> Another group of researchers found that the incremental lifetime cost of Alzheimer's dementia was substantially higher for women than men, due to a greater lifetime risk of developing Alzheimer's dementia (see Prevalence section).<sup>524</sup> Additionally, because women are more likely to be widowed and living in poverty, the incremental Medicaid costs associated with Alzheimer's dementia were 70% higher for women than men. A third group of researchers found that the lifetime cost of care, including out-of-pocket costs, Medicare and Medicaid expenditures, and the value of informal caregiving, was \$321,780 per person with Alzheimer's dementia in 2015 dollars (\$357,297 in 2019 dollars).<sup>312</sup> The lifetime cost of care for individuals with Alzheimer's dementia was more than twice the amount incurred by individuals without Alzheimer's dementia, translating into an incremental lifetime cost of Alzheimer's dementia of \$184,500 (\$204,864 in 2019 dollars).

Several groups of researchers have examined the additional out-of-pocket costs borne by individuals with Alzheimer's or other dementias. In a recent analysis of the lifetime incremental cost of dementia, researchers found that individuals with dementia spent \$38,540 (in 2014 dollars; \$43,920 in 2019 dollars) more out-of-pocket between age 65 and death, due to nursing home care.<sup>525</sup> Another group of researchers found that community-dwelling individuals age 65 and older with Alzheimer's dementia had \$1,101 (in 2012 dollars; \$1,316 in 2019 dollars) higher annual out-of-pocket health

care spending than individuals without Alzheimer's dementia, after controlling for differences in patient characteristics, with the largest portion of the difference being due to higher spending on home health care and prescription drugs.<sup>526</sup> Furthermore, individuals with Alzheimer's dementia spend 12% of their income on out-of-pocket health care services compared with 7% for individuals without Alzheimer's dementia.<sup>527</sup> Another research team found that the five-year incremental cost of dementia was \$15,704 (in 2017 dollars; \$16,389 in 2019 dollars), with the additional costs of care in the first year after diagnosis representing 46% of the five-year incremental costs.<sup>527</sup>

Other researchers compared end-of-life costs for individuals with and without dementia and found that the total cost in the last 5 years of life was \$287,038 per person for individuals with dementia in 2010 dollars and \$183,001 per person for individuals without dementia (\$366,593 and \$233,721, respectively, in 2019 dollars), a difference of 57%.<sup>528</sup> Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% versus 11%).

## 6.2 | Use and costs of health care services

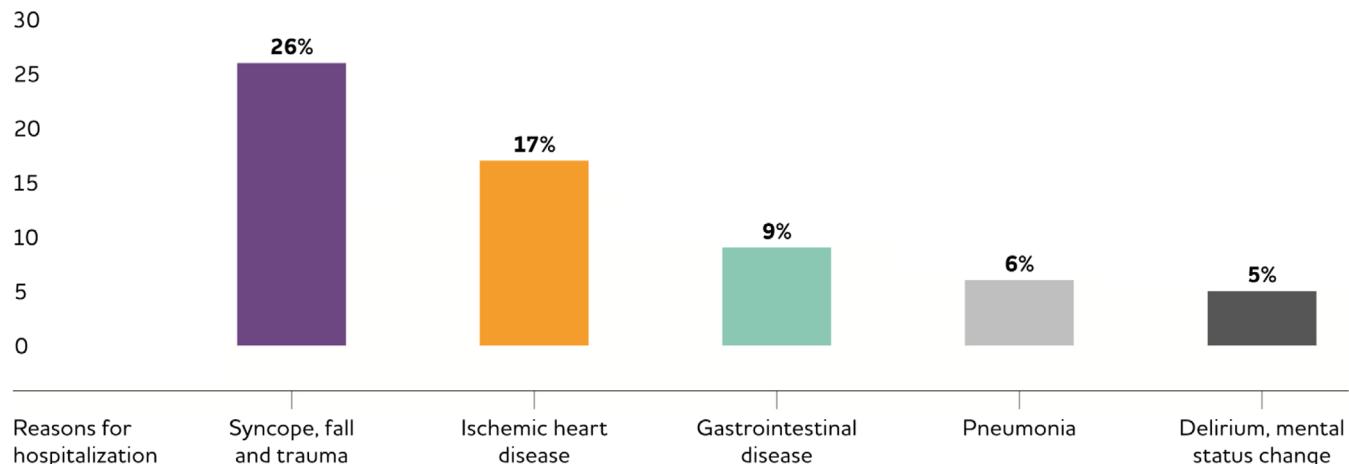
### 6.2.1 | Use of health care services

People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people.<sup>291</sup> Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

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

- **Hospital.** There are 538 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's or other dementias compared with 266 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions.<sup>291</sup> A person with dementia in 2012 had, on average, 23 inpatient days – defined as days in a hospital or skilled nursing facility – compared with 5 days for the Medicare population as a whole.<sup>529</sup> The most common reasons for hospitalization of people with Alzheimer's dementia are syncope (fainting), fall and trauma (26%); ischemic heart disease (17%); and gastrointestinal disease (9%) (Figure 13).<sup>530</sup> In a study of inpatient hospitalizations of adults age 60 and older, those with Alzheimer's dementia were at 7% greater risk of dying during the hospital stay and stayed nearly a day longer than individuals without Alzheimer's dementia.<sup>531</sup> Among Medicare beneficiaries with Alzheimer's or other dementias, 22% of hospital stays are followed by a

Percentage



**FIGURE 13** Reasons for hospitalization of individuals with Alzheimer's dementia: Percentage of hospitalized individuals by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's were used to calculate percentages. The remaining 37 percent of hospitalizations were due to other reasons. Created from data from Rudolph et al.<sup>530</sup>

readmission within 30 days.<sup>532</sup> While not directly comparable, one study of a portion of Medicare beneficiaries found an overall readmission rate of 18%.<sup>533</sup> The proportion of hospital stays followed by a readmission within 30 days remained relatively constant between 2007 and 2017 (23% in 2007 versus 22% in 2017).

- **Emergency department.** There are 1,548 emergency department visits per 1,000 Medicare beneficiaries with Alzheimer's or other dementias per year.<sup>532</sup> While not directly comparable, there were 640 emergency department visits per 1,000 Medicare beneficiaries per year based on a review of utilization patterns of a subset of Medicare beneficiaries.<sup>533</sup> Emergency department visits for people with Alzheimer's or other dementias per 1,000 Medicare beneficiaries increased 22% between 2007 and 2017 (from 1,265 to 1,548), similar to the increases in emergency department visits for individuals with cancer, ischemic heart disease and heart failure (Figure 14).<sup>532</sup>
- **Skilled nursing facility.** Skilled nursing facilities provide direct medical care that is performed or supervised by registered nurses, such as giving intravenous fluids, changing dressings and administering tube feedings.<sup>534</sup> There are 283 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's or other dementias per year compared with 73 stays per 1,000 beneficiaries without these conditions — a rate nearly four times as great.<sup>291</sup>
- **Home health care.** Twenty-five percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have at least one home health visit during the year, compared with 10% of Medicare beneficiaries age 65 and older without Alzheimer's or other dementias.<sup>291</sup> Medicare covers home health services, such as part-time skilled nursing care, home health aide (personal hands-on) care, therapies, and medical social services in the home, but does not include homemaker or personal care services.

## 6.2.2 | Costs of health care services

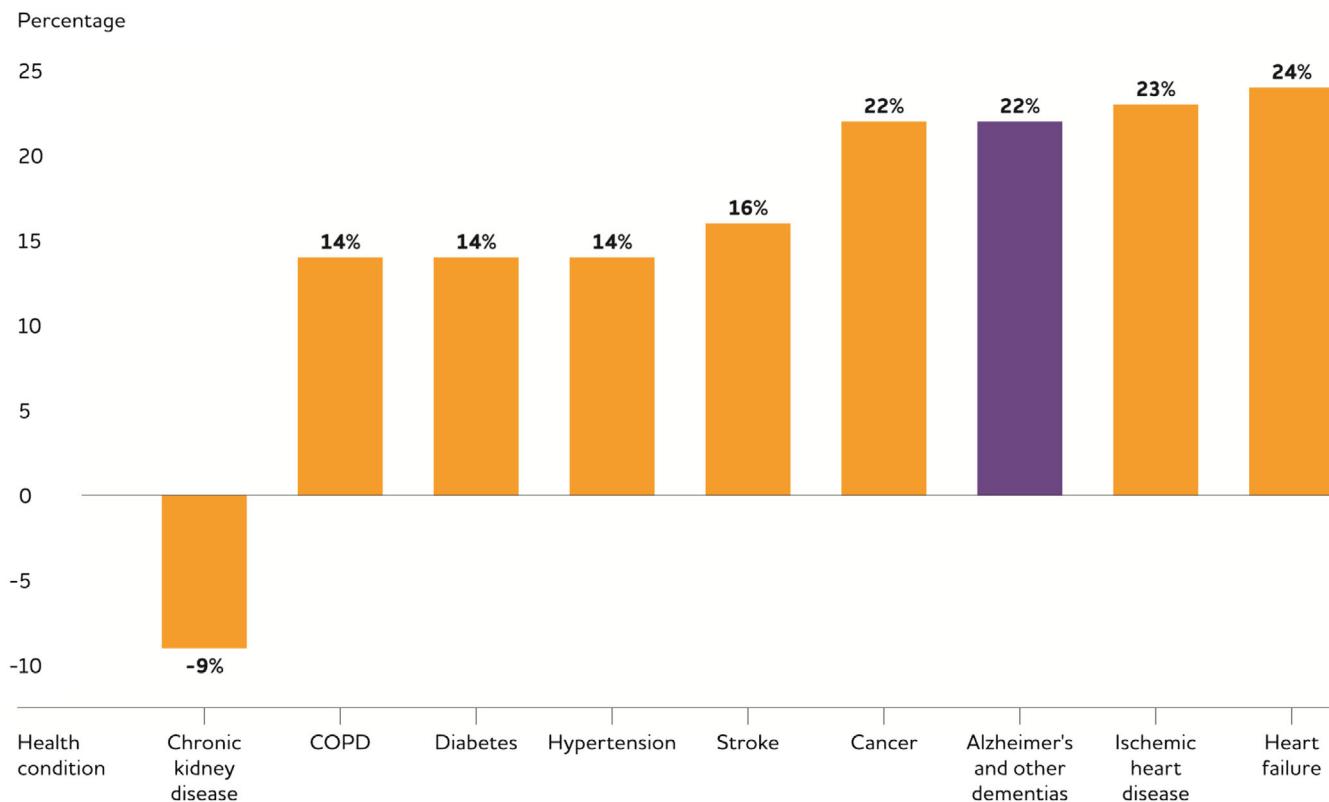
Average per-person payments for health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice and home health care) and prescription medications were higher for Medicare beneficiaries with Alzheimer's or other dementias than for other Medicare beneficiaries in the same age group (Table 11).<sup>207</sup>

## 6.2.3 | Use and costs of health care service by state

Substantial geographic variation exists in health care utilization and Medicare payments by individuals with Alzheimer's or other dementias (Table 12), similar to the geographic variation observed for Medicare beneficiaries with other medical conditions.<sup>535</sup> Emergency department visits range from 1,134 per 1,000 beneficiaries in South Dakota to 1,828 per 1,000 beneficiaries in West Virginia, and the percentage of hospital stays followed by hospital readmission within 30 days ranges from 15.4% in Utah to 26.8% in the District of Columbia. Medicare spending per capita ranges from \$17,572 in North Dakota to \$34,875 in Nevada (in 2019 dollars).<sup>532</sup>

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

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



**FIGURE 14** Percentage changes in emergency department visits per 1,000 fee-for-service Medicare beneficiaries for selected health conditions between 2007 and 2017. Includes Medicare beneficiaries with a claims-based diagnosis of each chronic condition. Beneficiaries may have more than one chronic condition. Created from data from U.S. Centers for Medicare & Medicaid Services.<sup>532</sup>

**TABLE 11** 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 2019 Dollars

Service	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	\$11,465	\$3,703
Medical provider*	5,762	3,589
Skilled nursing facility	7,213	493
Nursing home	16,523	800
Hospice	2,126	161
Home health care	2,661	386
Prescription medications**	3,481	2,986

\*“Medical provider” includes physician, other provider and laboratory services, and medical equipment and supplies.

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.<sup>207</sup>

those with either mild cognitive impairment (MCI) or without cognitive impairment.<sup>536</sup> Annual health care costs for individuals with MCI were not significantly different, however, from costs for individuals without cognitive impairment.

Several groups of researchers have found that both health care and prescription drug spending are significantly higher in the year prior to diagnosis,<sup>537–539</sup> 2 years prior to diagnosis,<sup>540</sup> and one year after diagnosis,<sup>527,537,538</sup> compared with otherwise similar individuals not diagnosed with Alzheimer's or another dementia, although there are differences in the sources of increased spending. In one study, the largest differences were in inpatient and post-acute care,<sup>538</sup> while in another study the differences in spending were primarily due to outpatient care, home care and medical day services.<sup>539</sup> In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment.<sup>540</sup> Additionally, three groups of researchers have found that spending in the year after diagnosis was higher than for individuals not diagnosed with the disease, by amounts ranging from \$7,264 in 2017 dollars, based on individuals with fee-for-service Medicare coverage (\$7,581 in 2019 dollars)<sup>527</sup> to \$17,852 in additional costs in 2014 dollars, based on another group of individuals with Medicare fee-for-service coverage (\$20,344 in 2019 dollars).<sup>538</sup> One group of researchers, however, found no difference in health care spending in the 2 years after diagnosis.<sup>540</sup> One possible explanation for the spike in health care costs in the year immediately prior to and

**TABLE 12** Emergency Department (ED) Visits, Hospital Readmissions and Per Capita Medicare Payments in 2019 Dollars by Medicare Beneficiaries with Alzheimer's or Other Dementias by State, 2017

State	Number of ED Visits per 1,000 Beneficiaries	Percentage of Hospital Stays		Per Capita Medicare Payments
		Followed by Readmission within 30 Days		
Alabama	1,426.8	21.5	22,555	
Alaska	1,447.9	19.6	24,801	
Arizona	1,491.3	20.6	25,490	
Arkansas	1,563.6	21.8	22,373	
California	1,497.6	23.1	32,940	
Colorado	1,437.1	18.3	23,060	
Connecticut	1,568.0	22.0	28,461	
Delaware	1,600.0	21.8	28,260	
District of Columbia	1,698.5	26.8	31,993	
Florida	1,564.9	23.4	28,606	
Georgia	1,568.5	21.9	24,228	
Hawaii	1,225.2	17.4	20,009	
Idaho	1,401.8	17.0	21,051	
Illinois	1,611.9	23.1	28,485	
Indiana	1,510.5	21.0	25,572	
Iowa	1,344.7	18.5	18,715	
Kansas	1,394.1	19.4	22,787	
Kentucky	1,718.4	23.0	24,991	
Louisiana	1,770.8	22.1	29,001	
Maine	1,666.3	19.8	21,787	
Maryland	1,525.6	24.6	30,331	
Massachusetts	1,618.0	24.3	30,535	
Michigan	1,711.5	24.1	28,325	
Minnesota	1,447.9	21.0	22,830	
Mississippi	1,723.3	22.6	26,566	
Missouri	1,515.1	22.4	23,441	
Montana	1,307.1	17.5	18,664	
Nebraska	1,166.5	18.1	21,012	
Nevada	1,712.2	25.4	34,875	
New Hampshire	1,508.9	21.6	25,147	
New Jersey	1,459.8	23.0	30,930	
New Mexico	1,566.1	20.7	22,711	
New York	1,446.1	23.7	31,353	
North Carolina	1,699.3	21.5	23,226	
North Dakota	1,193.4	19.2	17,572	
Ohio	1,633.7	22.6	26,502	
Oklahoma	1,700.7	21.5	26,351	
Oregon	1,582.9	18.5	21,210	
Pennsylvania	1,477.7	22.4	26,839	
Rhode Island	1,614.9	22.8	26,876	

(Continues)

**TABLE 12** (Continued)

State	Number of ED Visits per 1,000 Beneficiaries	Percentage of Hospital Stays Followed by Readmission within 30 Days	Per Capita Medicare Payments
South Carolina	1,563.8	21.4	23,917
South Dakota	1,134.0	19.1	19,070
Tennessee	1,574.3	22.1	24,199
Texas	1,544.9	22.0	30,383
Utah	1,205.4	15.4	22,229
Vermont	1,485.6	19.2	22,588
Virginia	1,637.2	22.0	23,846
Washington	1,483.7	18.5	22,007
West Virginia	1,827.7	23.6	24,762
Wisconsin	1,510.4	20.1	21,516
Wyoming	1,436.6	16.1	21,815
<b>U.S. AVERAGE</b>	<b>1,547.7</b>	<b>22.3</b>	<b>27,101*</b>

\*The average per capita Medicare payments differ slightly from the figure in Table 10 due to different underlying sources of data. Created from data from the U.S. Centers for Medicare & Medicaid Services.<sup>532</sup>

after diagnosis of Alzheimer's or another dementia relates to delays in timely diagnosis. One group of researchers found that individuals with cognitive decline who sought care from a specialist (that is, a neurologist, psychiatrist or geriatrician) had a shorter time to diagnosis of Alzheimer's disease.<sup>541</sup> 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. One research team found that health care costs were higher in each of the first four years after a dementia diagnosis, but were not significantly different in the fifth year after diagnosis.<sup>527</sup>

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

Medicare beneficiaries with Alzheimer's or other dementias are more likely than those without dementia to have other chronic conditions.<sup>291</sup> While 26% of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have five or more chronic conditions (including Alzheimer's or other dementias), only 4% of Medicare beneficiaries without Alzheimer's or other dementias have five or more chronic conditions.<sup>291</sup> Table 13 reports the percentage of people with Alzheimer's or other dementias who had certain coexisting medical conditions. In 2014, the latest year for which information is available, 38% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 37% had diabetes, 29% had chronic kidney disease, 28% had congestive heart failure and 25% had chronic obstructive pulmonary disease.<sup>291</sup>

**TABLE 13** Percentage of Medicare Beneficiaries Age 65 and Older with Alzheimer's or Other Dementias Who Have Specified Coexisting Conditions

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

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.<sup>291</sup>

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 14 shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have Alzheimer's or other

dementias and beneficiaries who do not have Alzheimer's or another dementia.<sup>291</sup> Medicare beneficiaries with Alzheimer's or other dementias have higher average per-person payments in all categories except hospital care payments for individuals with congestive heart failure. One group of researchers found that individuals with dementia and behavioral disturbances, such as agitation, had more psychiatric comorbidities than individuals with dementia but without behavioral disturbances.<sup>542</sup> Additionally, larger proportions of individuals with dementia and behavioral disturbances used medications including anti-hypertensives, dementia treatments, antipsychotics, antidepressants, antiepileptics and hypnotics.

### 6.3 | Use and costs of long-term care services

An estimated 70% of older adults with Alzheimer's or other dementias live in the community, compared with 98% of older adults without Alzheimer's or other dementias.<sup>207</sup> Of those with dementia who live in the community, 74% live with someone and the remaining 26% live alone.<sup>207</sup> As their disease progresses, people with Alzheimer's or other dementias generally receive more care from family

**TABLE 14** 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 2019 Dollars\*

Medical Condition by Alzheimer's/Dementia (A/D) Status	Average Per-Person Medicare Payment					
	Total Medicare Payments	Hospital Care	Physician Care	Skilled Nursing Facility Care	Home Health Care	Hospice Care
Coronary artery disease						
With A/D	\$28,136	\$8,644	\$2,401	\$4,832	\$2,516	\$3,087
Without A/D	17,560	6,226	1,709	1,553	1,043	402
Diabetes						
With A/D	27,237	8,225	2,351	4,673	2,434	2,780
Without A/D	15,036	5,152	1,506	1,350	906	273
Congestive heart failure						
With A/D	30,872	9,714	2,521	5,282	2,635	3,706
Without A/D	26,193	9,862	2,265	2,860	1,871	866
Chronic kidney disease						
With A/D	30,045	9,308	2,462	5,141	2,490	3,302
Without A/D	21,542	7,694	1,941	2,075	1,290	508
Chronic obstructive pulmonary disease						
With A/D	29,825	9,335	2,492	5,094	2,575	3,424
Without A/D	20,346	7,476	1,883	1,927	1,289	646
Stroke						
With A/D	28,549	8,531	2,377	5,028	2,420	3,435
Without A/D	20,567	6,940	1,914	2,527	1,562	649
Cancer						
With A/D	27,046	8,093	2,302	4,334	2,226	3,073
Without A/D	17,154	5,320	1,579	1,157	743	520

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

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.<sup>291</sup>

members and other unpaid caregivers. Many people with dementia also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times during the often long course of the disease. Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illnesses.

### 6.3.1 | Use of long-term care services by setting

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

- **Home health services.** Thirty-two percent of individuals using home health services have Alzheimer's or other dementias.<sup>543</sup>
- **Adult day services.** Thirty-one percent of individuals using adult day services have Alzheimer's or other dementias.<sup>543</sup> Overall, 69% of adult day service programs offer specific programs for individuals with Alzheimer's or other dementias, and 14% of adult day service centers primarily serve individuals with Alzheimer's or other dementias.<sup>544</sup>
- **Residential care facilities.** Forty-two percent of residents in residential care facilities (that is, housing that includes services to assist with everyday activities, such as medication management and meals), including assisted living facilities, have Alzheimer's or other dementias.<sup>543</sup> Small residential care facilities (four to 25 beds) have a larger proportion of residents with Alzheimer's or other dementias than larger facilities (51% in facilities with four to 25 beds compared with 44% in facilities with 26 to 50 beds and 39% in facilities with more than 50 beds).<sup>545</sup> Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's or other dementias.<sup>545</sup>
- **Nursing home care.** Overall, 48% of nursing home residents have Alzheimer's or other dementias,<sup>543</sup> while 37% of short-stay (less than 100 days) nursing home residents have Alzheimer's or other dementias, and 59% of long stay (100 days or longer) residents have these conditions. In 2014, 61% of nursing home residents with Alzheimer's or other dementias had moderate or severe cognitive impairment.<sup>546</sup> Four percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home,<sup>516</sup> and nursing home admission by age 80 is expected for 75% of people with Alzheimer's dementia compared with only 4% of the general population.<sup>293</sup>
- **Alzheimer's special care units and dedicated facilities.** An Alzheimer's special care unit is a dedicated unit, wing or floor in a nursing home or other residential care facility that has tailored services for individuals with Alzheimer's or other dementias. Fifteen

percent of nursing homes and 14% of other residential care facilities have a dementia special care unit,<sup>543</sup> even though 72% of Medicare beneficiaries with Alzheimer's dementia have a nursing home stay in the last 90 days of life.<sup>547</sup> Additionally, 9% of residential care facilities exclusively provide care to individuals with dementia, while less than 1% (0.4%) of nursing homes exclusively provide care to individuals with dementia.

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

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home- and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. The federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs. In 2016, home- and community-based services represented the majority (57%) of Medicaid spending on long-term services and supports, with institutional care representing the remaining 43%.<sup>548</sup> Between 2013 and 2016, Medicaid spending on home- and community-based services increased 26% overall, while spending on institutional care increased only 1.5% over the same period. Additionally, total spending on home care for Medicare beneficiaries with Alzheimer's or other dementias nearly doubled between 2004 and 2011, although increases in spending may be due to a variety of factors, including more people being diagnosed with Alzheimer's dementia, more people using home care, an increase in the number of coexisting medical conditions, more intensive use of home care services and an increase in Medicaid coverage by older adults.<sup>207,549</sup> In two recent systematic reviews of the cost-effectiveness of home support interventions for individuals with dementia, researchers found some evidence to support occupational therapy, home-based exercise and some psychological and behavioral treatments as potentially cost-effective approaches, although the research that has evaluated both the costs and benefits of home support interventions is scant.<sup>550,551</sup>

#### *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%).<sup>552</sup> 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.<sup>553</sup> The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.<sup>554</sup>

### 6.3.2 | Costs of long-term care services

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

- **Home care.** The median cost for a paid non-medical home health aide is \$23 per hour and \$1,012 per week.<sup>555</sup> Home care costs increased by 3.1% annually on average over the past 5 years.
- **Adult day centers.** The median cost of adult day services is \$75 per day.<sup>555</sup> The cost of adult day services has increased 2.9% annually on average over the past 5 years.
- **Assisted living facilities.** The median cost for care in an assisted living facility is \$4,051 per month, or \$48,612 per year.<sup>555</sup> The cost of assisted living has increased 3% annually on average over the past 5 years.
- **Nursing homes.** The average cost for a private room in a nursing home is \$280 per day, or \$102,200 per year, and the average cost of a semi-private room is \$247 per day, or \$90,155 per year.<sup>555</sup> The cost of nursing home care has increased 3.1% annually on average over the past 5 years for both private and semi-private rooms.

#### Affordability of long-term care services

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

- Income and asset data are not available for people with Alzheimer's or other dementias specifically, but 50% of Medicare beneficiaries have incomes of \$26,200 or less in 2016 dollars (\$27,852 in 2019 dollars), and 25% have incomes of \$15,250 or less in 2016 dollars (\$16,212 in 2019 dollars).<sup>556</sup>
- Fifty percent of Medicare beneficiaries had total savings of \$74,450 or less in 2016 dollars (\$79,145 in 2019 dollars), 25% had savings of \$14,550 or less in 2016 dollars (\$15,468 in 2019 dollars), and 8% had no savings or were in debt. Median savings were substantially lower for black/African American and Hispanic/Latino beneficiaries than for white Medicare beneficiaries.<sup>556</sup>

#### Long-term care insurance

Long-term care insurance typically covers the cost of care provided in a nursing home, assisted living facility and Alzheimer's special care facility, as well as community-based services such as adult day care and services provided in the home, including nursing care and help with personal care.<sup>557</sup> Results from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey revealed that 28% of adults believed Medicare covered the cost of nursing home care for people with Alzheimer's, and 37% did not know whether it covered the cost of nursing home care.<sup>349</sup> Although Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing facility and hospice care, it does not cover long-term care in a nursing home.<sup>558</sup>

Industry reports estimate that approximately 7.2 million Americans had long-term care insurance in 2014.<sup>559</sup> The median income for indi-

viduals purchasing long-term care insurance was \$87,500 in 2010 dollars (\$102,373 in 2019 dollars), with 77% having an annual income greater than \$50,000 (\$58,499 in 2019 dollars) and 82% having assets greater than \$75,000 (\$87,748 in 2019 dollars).<sup>559</sup> Private health care and long-term care insurance policies funded only about 8% of total long-term care spending in 2013, representing \$24.8 billion of the \$310 billion total in 2013 dollars (\$27.2 billion of the \$340 billion in 2019 dollars).<sup>560</sup> The private long-term care insurance market is highly concentrated and has consolidated since 2000. In 2000, 41% of individuals with a long-term care policy were insured by one of the five largest insurers versus 56% in 2014.<sup>559</sup>

To address the dearth of private long-term care insurance options and high out-of-pocket cost of long-term care services, Washington became the first state in the country to pass a law that will create a public state-operated long-term care insurance program.<sup>561</sup> The Long-Term Services and Supports Trust Program will be funded by a payroll tax on employees of 58 cents per \$100 earned that begins in 2022, and self-employed individuals will be able to opt in to the program. The program is currently structured to pay up to \$36,500 in lifetime benefits, beginning in 2025.

#### Medicaid costs

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

Total Medicaid spending for people with Alzheimer's or other dementias is projected to be \$51 billion in 2020 (in 2020 dollars).<sup>A16</sup> Estimated state-by-state Medicaid spending on people with Alzheimer's or other dementias in 2020 (in 2020 dollars) is included in Table 15. Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias were 23 times as great as Medicaid payments for other Medicare beneficiaries.<sup>207</sup> Much of the difference in payments for beneficiaries with Alzheimer's or other dementias and other beneficiaries is due to the costs associated with long-term care (nursing homes and other residential care facilities, such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid.

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

Hospice care provides medical care, pain management, and emotional and spiritual support for people who are dying, including people with

**TABLE 15** Total Medicaid Payments for Americans Age 65 and Older Living with Alzheimer's or Other Dementias by State\*

State	2020 (in millions of dollars)	2025 (in millions of dollars)	Percentage Increase
Alabama	\$925	\$1,127	21.8
Alaska	76	110	44.6
Arizona	414	545	31.7
Arkansas	396	454	14.6
California	4,197	5,235	24.7
Colorado	635	789	24.1
Connecticut	1,022	1,187	16.1
Delaware	253	313	23.6
District of Columbia	126	135	6.8
Florida	2,689	3,453	28.4
Georgia	1,265	1,594	26.0
Hawaii	240	285	18.7
Idaho	149	196	31.2
Illinois	1,787	2,199	23.1
Indiana	1,054	1,233	17.1
Iowa	676	792	17.2
Kansas	473	543	14.6
Kentucky	803	949	18.2
Louisiana	765	934	22.1
Maine	212	274	29.5
Maryland	1,231	1,535	24.7
Massachusetts	1,753	2,031	15.9
Michigan	1,487	1,738	16.9
Minnesota	905	1,087	20.1
Mississippi	606	729	20.4
Missouri	973	1,137	16.8
Montana	166	203	22.2
Nebraska	372	411	10.3
Nevada	203	277	36.5
New Hampshire	254	335	31.9
New Jersey	2,186	2,614	19.6
New Mexico	227	279	22.9
New York	5,453	6,306	15.6
North Carolina	1,332	1,628	22.2
North Dakota	190	215	13.2
Ohio	2,534	2,940	16.0
Oklahoma	516	611	18.3
Oregon	253	317	25.4
Pennsylvania	3,658	4,029	10.2
Rhode Island	470	565	20.1
South Carolina	652	818	25.4
South Dakota	182	212	16.6
Tennessee	1,109	1,377	24.2
Texas	3,202	3,949	23.3
Utah	185	235	27.0

(Continues)

**TABLE 15** (Continued)

State	2020 (in millions of dollars)	2025 (in millions of dollars)	Percentage Increase
Vermont	116	146	26.4
Virginia	1,000	1,266	26.6
Washington	547	689	26.0
West Virginia	445	521	17.1
Wisconsin	777	924	18.9
Wyoming	86	111	28.8
<b>U.S. AVERAGE</b>	<b>\$51,226</b>	<b>\$61,581</b>	<b>20.2</b>

\*All cost figures are reported in 2020 dollars. State totals may not add to the U.S. total due to rounding. Created from data from the Lewin Model.<sup>A16</sup>

Alzheimer's or other dementias, either in a facility or at home. Hospice care also provides emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid and other sources also pay for hospice care. Based on data from the National Hospice Survey for 2008 to 2011, nearly all (99%) hospices cared for individuals with dementia, although only 67% of hospices cared for individuals with a primary diagnosis of dementia.<sup>562</sup> Fifty-two percent of individuals in for-profit hospices had either a primary or comorbid diagnosis of dementia, while 41% of individuals in nonprofit hospices had a diagnosis of dementia. More research is needed to understand the underlying reasons for the differences in the percentage of people with dementia in for-profit versus nonprofit hospices.

Nineteen percent of Medicare beneficiaries with Alzheimer's and other dementias have at least one hospice claim annually compared with 2% of Medicare beneficiaries without Alzheimer's or other dementias.<sup>291</sup> 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.<sup>563</sup> In 2017, there were 4,254 hospice companies in the United States that provided hospice care in the home, assisted living facilities, long-term care facilities, unskilled nursing facilities, skilled nursing facilities, inpatient hospitals, inpatient hospice facilities and other facilities.<sup>564</sup> Additionally, 18% of Medicare beneficiaries who received hospice care had a primary diagnosis of dementia, including Alzheimer's dementia (Table 16).<sup>564</sup> Dementia was the second most common primary diagnosis for Medicare beneficiaries admitted to hospice overall, with cancer being the most common primary diagnosis. Forty-five percent of hospice users in 2014 had a primary or secondary diagnosis of Alzheimer's or other dementias, suggesting that a large proportion of hospice users have Alzheimer's as a comorbid condition.<sup>565</sup> The average length of hospice stay for individuals with a primary diagnosis of dementia was more than 50% longer than for individuals with other primary diagnoses, based on data from the 2008 to 2011 National Hospice Survey.<sup>562</sup> Individuals with a primary diagnosis of dementia stayed

**TABLE 16** 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

(Continues)

**TABLE 16** (Continued)

State	Number of Beneficiaries	Percentage of Beneficiaries
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
<b>U.S. TOTAL</b>	<b>278,192</b>	<b>18</b>

Created from data from the U.S. Centers for Medicare & Medicaid Services.<sup>564</sup>

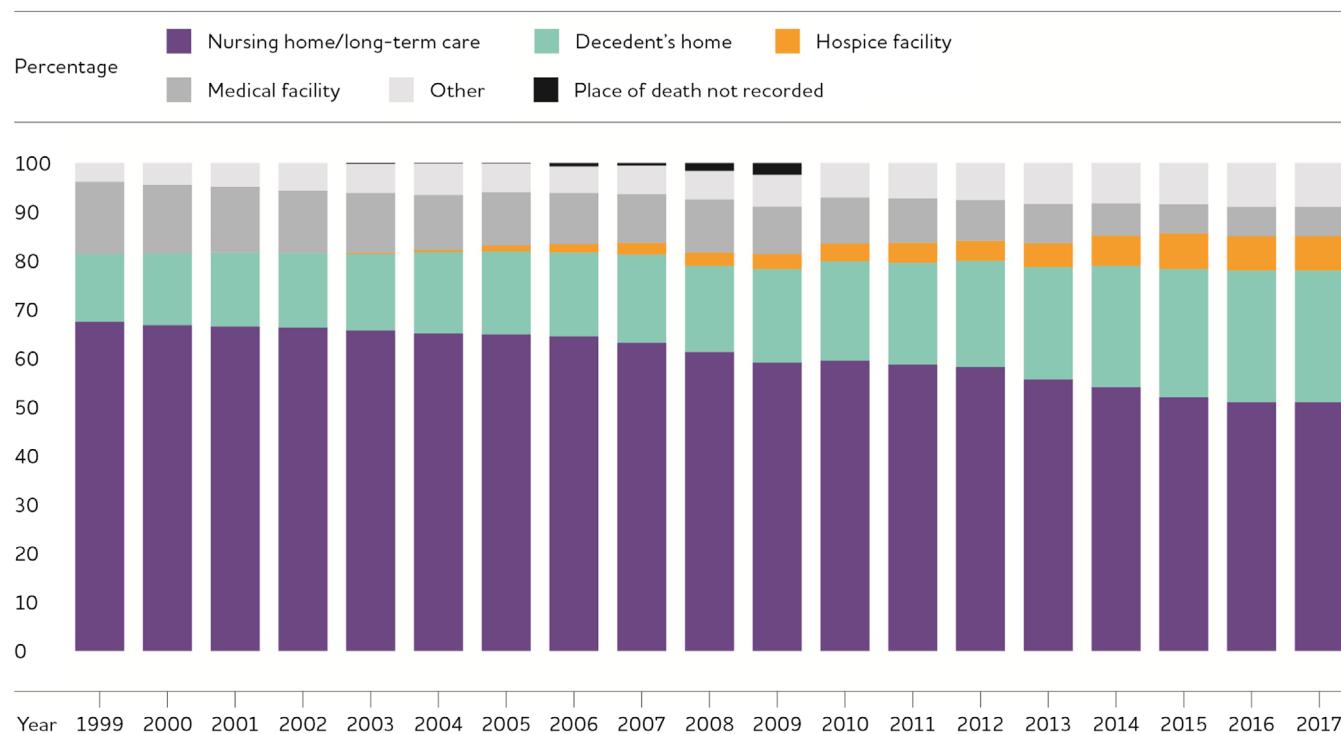
an average of 112 days versus 74 days for individuals with other primary diagnoses.

Per-person hospice payments among all individuals with Alzheimer's dementia averaged \$2,126 compared with \$161 for all other Medicare beneficiaries.<sup>207</sup> 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 1-60 than for subsequent days and a service intensity add-on payment for home visits by a registered nurse or social worker in the last 7 days of life. In fiscal year 2020, the routine home care rates are \$194.50 per day for days 1-60 and \$153.72 per day for days 61 and beyond.<sup>566</sup> In a simulation to evaluate whether the reimbursement change will reduce costs for Medicare, a group of researchers found that the new reimbursement approach is anticipated to reduce costs for Medicare, although individuals with dementia who receive hospice care will have higher Medicare spending overall than individuals with dementia who do not receive hospice care.<sup>567</sup>

For Medicare beneficiaries with advanced dementia who receive skilled nursing facility care in the last 90 days of life, those who are enrolled in hospice are less likely to die in the hospital.<sup>568</sup> Additionally, those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life<sup>569</sup> and more likely to receive regular treatment for pain.<sup>570,571</sup> Nearly half of individuals with dementia die while receiving hospice care.<sup>547</sup> 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.<sup>572</sup>

#### Feeding tube use at the end of life

Individuals with frequent transitions between health care settings are more likely to have feeding tubes at the end of life, even though feeding tube placement does not prolong life or improve outcomes.<sup>529</sup> The odds of having a feeding tube inserted at the end of life vary across the country and are not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. Researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. By contrast, feeding tube use



**FIGURE 15** Place of death due to Alzheimer's disease, 1999 to 2017. Created from data from the National Center for Health Statistics.<sup>575</sup>

**TABLE 17** Average Annual Per-Person Payments by Type of Service and Race/Ethnicity for Medicare Beneficiaries Age 65 and Older, with Alzheimer's or Other Dementias, in 2019 Dollars

Race/Ethnicity	Total Medicare Payments Per Person	Hospital Care	Physician Care	Skilled Nursing Facility Care	Home Health Care	Hospice Care
White	\$21,174	\$5,683	\$1,637	\$3,710	\$1,832	\$3,382
Black/African American	28,633	9,566	2,219	4,599	2,239	2,503
Hispanic/Latino	22,694	7,690	1,930	3,535	1,932	1,864
Other	27,548	8,649	2,171	3,703	3,969	2,756

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.<sup>291</sup>

was lower among people with dementia whose care was managed by a general practitioner.<sup>573,574</sup> With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last 90 days of life has decreased for individuals with Alzheimer's or other dementias.<sup>563</sup> 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 prior to death decreased from nearly 12% in 2000 to less than 6% in 2014.<sup>574</sup>

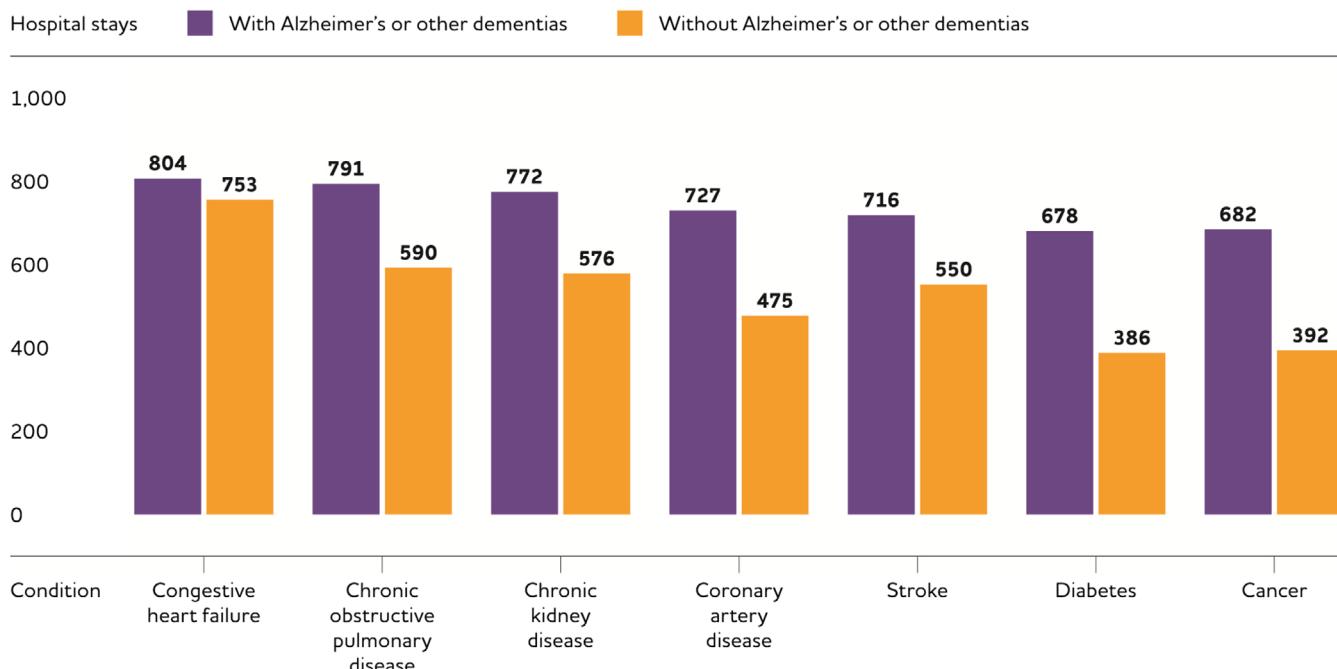
#### Place of death for individuals with Alzheimer's or other dementias

Between 1999 and 2017, the proportion of individuals with Alzheimer's who died in a nursing home decreased from 68% to 51%, and the proportion who died in a medical facility decreased from 15% to 5%.<sup>575</sup> During the same period, the proportion of individuals who died at home increased from 14% to 28% (Figure 15).<sup>575</sup>

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

Among Medicare beneficiaries with Alzheimer's or other dementias, black/African Americans had the highest Medicare payments per person per year, while whites had the lowest payments (\$28,633 versus \$21,174, respectively) (Table 17). The largest difference in payments was for hospital care, with black/African Americans incurring 1.7 times as much in hospital care costs as whites (\$9,566 versus \$5,683).<sup>291</sup>

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's dementia that included both Medicaid and Medicare claims data, researchers found significant differences in the costs of care by race/ethnicity.<sup>576</sup> These results demonstrated that black/African Americans had significantly higher costs of care than whites or Hispanics/Latinos, primarily due to more inpatient care and more



**FIGURE 16** Hospital stays per 1,000 Medicare beneficiaries age 65 and older with specified coexisting medical conditions, with and without Alzheimer's or other dementias, 2014. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.<sup>291</sup>

comorbidities. These differences may be attributable to later-stage diagnosis, which may lead to higher levels of disability while receiving care; delays in accessing timely primary care; lack of care coordination; duplication of services across providers; or inequities in access to care. However, more research is needed to understand the reasons for this health care disparity.

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

### 6.5.1 | Preventable hospitalizations

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to, or quality of, preventive and primary care. Unplanned hospital readmissions within 30 days are another type of hospitalization that potentially could have been avoided with appropriate post-discharge care. In 2013, 21% of hospitalizations for fee-for-service Medicare enrollees with Alzheimer's or other dementias were either for unplanned readmissions within 30 days or for an ambulatory care sensitive condition (that is, a condition that was potentially avoidable with timely and effective ambulatory care). The total cost to Medicare of these potentially preventable hospitalizations was \$4.7 billion (in 2013 dollars; \$5.4 billion in 2019 dollars).<sup>577</sup> Of people with dementia who had at least one hospitalization, 18% were readmitted within 30 days. Of those who were readmitted within 30 days, 27% were read-

mitted two or more times. Ten percent of Medicare enrollees had at least one hospitalization for an ambulatory care-sensitive condition, and 14% of total hospitalizations for Medicare enrollees with Alzheimer's or other dementias were for ambulatory care sensitive conditions.

Based on Medicare administrative data from 2010 to 2015, preventable hospitalizations represented 23.5% of the total hospitalizations for individuals with Alzheimer's or other dementias.<sup>578</sup> Black/African American older adults had a substantially higher proportion of preventable hospitalizations (32%) compared with Hispanic/Latino and white older adults (22%).

Based on data from the Health and Retirement Study and from Medicare, after controlling for demographic, clinical and health risk factors, individuals with dementia had a 30% greater risk of having a preventable hospitalization than those without a neuropsychiatric disorder (that is, dementia, depression or cognitive impairment without dementia). Moreover, individuals with both dementia and depression had a 70% greater risk of preventable hospitalization than those without a neuropsychiatric disorder.<sup>579</sup> Another group of researchers found that individuals with dementia and a caregiver with depression had 73% higher rates of emergency department use over 6 months than individuals with dementia and a caregiver who did not have depression.<sup>580</sup>

Medicare beneficiaries who have Alzheimer's or other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Figure 16).<sup>291</sup> One research team found that individuals

hospitalized with heart failure are more likely to be readmitted or die after hospital discharge if they also have cognitive impairment.<sup>581</sup> Another research team found that Medicare beneficiaries with Alzheimer's or other dementias have more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting.<sup>582</sup> A third research team found that having depression, rheumatoid arthritis or osteoarthritis was associated with higher emergency department use in Medicare beneficiaries with possible or probable dementia and two more chronic conditions.<sup>583</sup>

Differences in health care use between individuals with and without dementia are most prominent for those residing in the community. Based on data from the Health and Retirement Study, community-residing individuals with dementia were more likely to have a potentially preventable hospitalization, an emergency department visit that was potentially avoidable, and/or an emergency department visit that resulted in a hospitalization.<sup>584</sup> For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

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

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other focusing on the care delivery team. The Caregiving section describes a number of caregiver support programs, and some of these also hold promise for reducing transitions to residential care for individuals with Alzheimer's or other dementias. Additionally, collaborative care models — models that include not only geriatricians, but also social workers, nurses and medical assistants, for example — can improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits.<sup>502</sup> For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by \$3,474 in 2012 dollars (\$4,153 in 2019 dollars) over a year for individuals with memory problems compared with others with memory problems whose care was overseen by a primary care provider only.<sup>502</sup> More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of \$618 (\$739 in 2019 dollars) — a nearly 6-to-1 return on investment. Another group of researchers, however, found that a dementia care program that used nurse practitioners and physicians to co-manage patients was cost neutral after taking into account the costs of the program and cost savings due to fewer long-term care nursing home admissions.<sup>585</sup> However, in a recent systematic review and meta-analysis of 17 randomized controlled trials from seven different countries aimed at reducing avoidable acute hospital care by persons with dementia, none of the interventions reduced acute hospital use, such as emergency department visits, hospital admissions, or hospital days.<sup>586</sup>

A group of researchers found that individuals with dementia whose care was concentrated within a smaller number of clinicians had fewer hospitalizations and emergency department visits and lower health care spending overall compared with individuals whose care was dispersed across a larger number of clinicians.<sup>587</sup> More research is needed to understand whether continuity of care is a strategy for decreasing unnecessary health care use for people with Alzheimer's or other dementias.

## 6.6 | Projections for the future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's or other dementias are projected to increase from \$305 billion in 2020 to more than \$1.1 trillion in 2050 (in 2020 dollars). This dramatic rise includes nearly four-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.<sup>A16</sup>

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

While there are currently no FDA-approved pharmacologic treatments that prevent or cure Alzheimer's disease or slow its progression, several groups of researchers have estimated the cost savings of future interventions that either slow the onset of dementia or reduce the symptoms.<sup>312,588,590</sup> One group of researchers estimated that a treatment introduced in 2025 that delays the onset of Alzheimer's by 5 years would reduce total health care payments by 33% and out-of-pocket payments by 44% in 2050.<sup>588</sup> A second group of researchers estimated the cost savings of delaying the onset of Alzheimer's disease by 1 to 5 years. For individuals age 70 and older, they projected a 1-year delay would reduce total health care payments by 14% in 2050, a 3-year delay would reduce total health care payments by 27%, and a 5-year delay would reduce health care payments by 39%.<sup>589</sup> They also projected that a delay in onset may increase per capita health care payments through the end of life due to longer life, although the additional health care costs may be offset by lower informal care costs. A third group of researchers estimated that a treatment that slows the rate of functional decline by 10% would reduce average per-person lifetime costs by \$3,880 in 2015 dollars (\$4,308 in 2019 dollars), while a treatment that reduces the number of behavioral and psychological symptoms by 10% would reduce average per-person lifetime costs by \$680 (\$755 in 2019 dollars).<sup>312</sup>

The Alzheimer's Association commissioned a study of the potential cost savings of early diagnosis,<sup>590</sup> assuming that 88% of individuals who will develop Alzheimer's disease would be diagnosed in the MCI phase rather than the dementia phase or not at all. Approximately \$7 trillion could be saved in medical and long-term care costs for individuals who were alive in 2018 and will develop Alzheimer's disease. Cost savings were due to a smaller spike in costs immediately before and after diagnosis due to 1) the diagnosis being made during the MCI

phase rather than the dementia phase, which has higher costs, and 2) lower medical and long-term care costs for individuals who have diagnosed and managed MCI and dementia compared with individuals with unmanaged MCI and dementia.

A treatment that prevents, cures or slows the progression of the disease could result in substantial savings to the U.S. health care system. Without changes to the structure of the U.S. health care system, however, access to new treatments for Alzheimer's may be severely restricted by capacity constraints. For example, one group of researchers developed a model of capacity constraints that estimated that individuals would wait an average of 19 months for treatment in 2020 if a new treatment is introduced by then.<sup>591</sup> Under this model, approximately 2.1 million individuals with MCI due to Alzheimer's disease would develop Alzheimer's dementia between 2020 and 2040 while on waiting lists for treatment. This model assumed both that the hypothetical treatment would require infusions at infusion centers and that it would depend on people being evaluated with amyloid PET scans. While the introduction of new treatments that prevent, cure or slow the progress of Alzheimer's could have a dramatic effect on the incidence and severity of Alzheimer's, it is clear that their effectiveness could be limited by constraints on both health care system capacity and health insurance reimbursement.

## 7 | SPECIAL REPORT: ON THE FRONT LINES: PRIMARY CARE PHYSICIANS AND ALZHEIMER'S CARE IN AMERICA

Alzheimer's and other dementias represent a growing crisis in America. As reported in the Prevalence section of this year's *Alzheimer's Disease Facts and Figures*, there are currently more than 5 million Americans living with Alzheimer's dementia, a number which is projected to increase to nearly 14 million by the year 2050. Meanwhile is a shortage of specialty physicians to provide care for the large and increasing numbers of people with Alzheimer's dementia in the United States. As a result, the responsibility for their medical care rests mainly with primary care physicians. This Special Report examines the current gaps and projected future shortages in specialty care for Alzheimer's and other dementias. It also explores the challenges primary care physicians face in caring for those currently living with Alzheimer's dementia in meeting the future care needs of an aging U.S. population. This report concludes with recommendations to address these shortages and challenges so more Americans have access to dementia care.

### 7.1 | Who diagnoses and provides medical care?

Medical care for people with Alzheimer's and other dementias involves a broad array of practitioners, including physicians, neuropsychologists, and allied health care professionals such as occupational and physical therapists and home health aides. In this report, we focus on primary care physicians (family medicine, internal medicine, general practice) and specialists such as geriatricians, neurologists, geriatric

psychiatrists, and neuropsychologists. Given the complexity of diagnosing and managing treatment for people living with dementia, there is general agreement that a having a robust workforce of specialists would be ideal to optimize their care. However, the reality is that the shortage of such specialists means that the major responsibility for diagnosing and treating people living with dementia lies with primary care physicians.

For example, one recent study<sup>597</sup> found that the vast majority of older Americans diagnosed with dementia never see a dementia care specialist and are overwhelmingly diagnosed and cared for by non-specialists. Specifically, the study found that 85% of people first diagnosed with dementia were diagnosed by a non-dementia specialist, specialist usually a primary care physician. The same study found that one year after diagnosis, less than a quarter of patients had seen a dementia specialist. After five years, the percent of patients who had seen a dementia specialist had only increased to 36%. Specialty care was particularly low for Hispanic and Asian people.

### 7.2 | Growing need, projected shortages in specialists

As noted in the Prevalence section, between 2020 and 2050 the size of America's older population (those 65 and over) is expected to increase dramatically. As the size of the older population grows, the number of living with Alzheimer's dementia will also increase. Today approximately one in 10 people age 65 and older has Alzheimer's dementia. At the same time, however, the workforce to care for the older population is currently, and is likely to continue to be, inadequate.

According to the National Center for Health Workforce Analysis,<sup>598</sup> there was already a shortage of geriatricians in 2013, and although a modest increase in supply was projected by 2025, it was not expected to meet demand. Trends in medical training also point to a growing shortage of geriatricians into the future. For example, geriatrics-related graduate medical education programs grew by only 1.1% from the 2001-2002 academic year to the 2017-2018 academic year.<sup>599</sup> Similarly, a study of the current and future U.S. neurology workforce projected a 19% shortage of neurologists by 2025.<sup>600</sup>

We project large increases in the need for specialists to care for people living with Alzheimer's dementia in 2050. Table 18 shows state-by-state projections for the number of geriatricians needed in the year 2050. As a nation, we need to triple the number of geriatricians who were practicing in 2019 to have enough geriatricians to care for those 65 and older who are projected to have Alzheimer's dementia in 2050 (approximately 10% of the population age 65 and older). However, the number must increase nine times to have enough geriatricians to care for the 30% of the population age 65 and older estimated by the National Center for Health Workforce Analysis to need geriatrician care. Similar analyses also showed large projected needs for neurologists, geriatric psychiatrists, and neuropsychologists, specialists who provide critical expertise in dementia diagnosis and care.

These shortages will affect states differently. The gaps are small in some states. For example, New York, Hawaii and Washington, D.C.,

**TABLE 18** Projected Geriatrician Needs in 2050 by State

State	Number of Geriatricians in 2019	Number of Geriatricians Needed in 2050 to Serve 10% of Those Age 65 and Older	Number of Geriatricians Needed in 2050 to Serve 30% of Those Age 65 and Older
Alabama	44	228	684
Alaska	6	31	92
Arizona	89	363	1,089
Arkansas	51	134	402
California	590	1,676	5,029
Colorado	89	289	867
Connecticut	99	166	497
Delaware	17	55	165
District of Columbia	37	28	83
Florida	348	1,365	4,096
Georgia	96	492	1,476
Hawaii	61	64	192
Idaho	10	87	261
Illinois	218	517	1,551
Indiana	65	299	897
Iowa	24	142	426
Kansas	23	121	364
Kentucky	34	207	622
Louisiana	31	198	595
Maine	37	71	213
Maryland	150	288	865
Massachusetts	206	347	1,042
Michigan	169	465	1,394
Minnesota	93	270	811
Mississippi	25	124	373
Missouri	103	283	849
Montana	8	59	177
North Carolina	159	535	1,606
North Dakota	15	34	103
Nebraska	23	84	253
Nevada	40	158	474
New Hampshire	30	72	217
New Jersey	205	398	1,193
New Mexico	29	93	279
New York	605	818	2,454
Ohio	163	537	1,611
Oklahoma	28	171	512
Oregon	62	232	695
Pennsylvania	278	601	1,803
Rhode Island	32	49	147
South Carolina	66	288	865
South Dakota	10	44	131
Tennessee	40	343	1,029
Texas	342	1,255	3,766

(Continues)

**TABLE 18** (Continued)

State	Number of Geriatricians in 2019	Number of Geriatricians Needed in 2050 to Serve 10% of Those Age 65 and Older	Number of Geriatricians Needed in 2050 to Serve 30% of Those Age 65 and Older
Utah	21	114	341
Vermont	5	32	95
Virginia	103	406	1,218
Washington	132	399	1,198
West Virginia	19	83	250
Wisconsin	84	273	820
Wyoming	4	26	79
<b>U.S. TOTAL</b>	<b>5,218</b>	<b>15,417</b>	<b>46,252</b>

**Notes:** The 10% column is how many geriatricians will be needed to serve *only* those 65 and older projected to have Alzheimer's dementia in 2050, assuming that the percentage of people age 65 and older with Alzheimer's dementia remains at 10%. The 30% column is how many geriatricians will be needed to serve the 30% of people age 65 and older who need geriatrician care, regardless of whether they have dementia, according to the National Center for Health Workforce Analysis.<sup>598</sup> The number of practicing geriatricians in 2019 was provided by IQVIA and includes physicians with geriatrics as either their primary or secondary specialty. Calculations assume that each geriatrician can care for up to 700 patients.<sup>598</sup> The underlying state-by-state estimates of the 2050 population age 65 and older were provided by Claritas Pop-Facts 2020.

appear well-positioned to achieve the relatively modest increases they need. In contrast, 14 states need to at least quintuple the number of practicing geriatricians by 2050 to care for those 65 and older projected to have Alzheimer's dementia, or increase the number by 15 times to care for the 30% of the population age 65 and older projected to need geriatrician care. Two states, Tennessee and Idaho, will need to increase the number of geriatricians by nine times just to meet the care needs of those projected to have Alzheimer's dementia, or by 26 times to meet the needs of all those projected to need geriatrician care.

### 7.3 | Primary care physicians

With a shortage of medical specialists to meet the current and future needs for Alzheimer's dementia care in the United States, primary care physicians will play an increasingly important role in caring for individuals across the disease continuum – from identifying warning signs, to providing competent diagnoses, and to meeting the ongoing care and support needs for patients living with a complex, progressive, and ultimately fatal disease.

While PCPs are clearly on the front lines, little is known about the extent of PCPs' preparedness to meet the growing demands for dementia care in the clinical setting. In order to learn more about PCPs' experiences, exposure and attitudes about their medical education and training in dementia care, the Alzheimer's Association commissioned Versta Research to conduct surveys of 1) PCPs,<sup>A20</sup> 2) recent medical school graduates currently completing a residency in primary care<sup>A21</sup> and 3) recent primary care residency graduates.<sup>A22</sup> All surveys were conducted from December 11 to December 26, 2019.

The Alzheimer's Association surveys revealed that

- PCPs recognize they are on the front lines of diagnosing and providing care for Alzheimer's and other dementias.
- Half of PCPs believe that the medical profession is not prepared to meet the expected increase in demand.

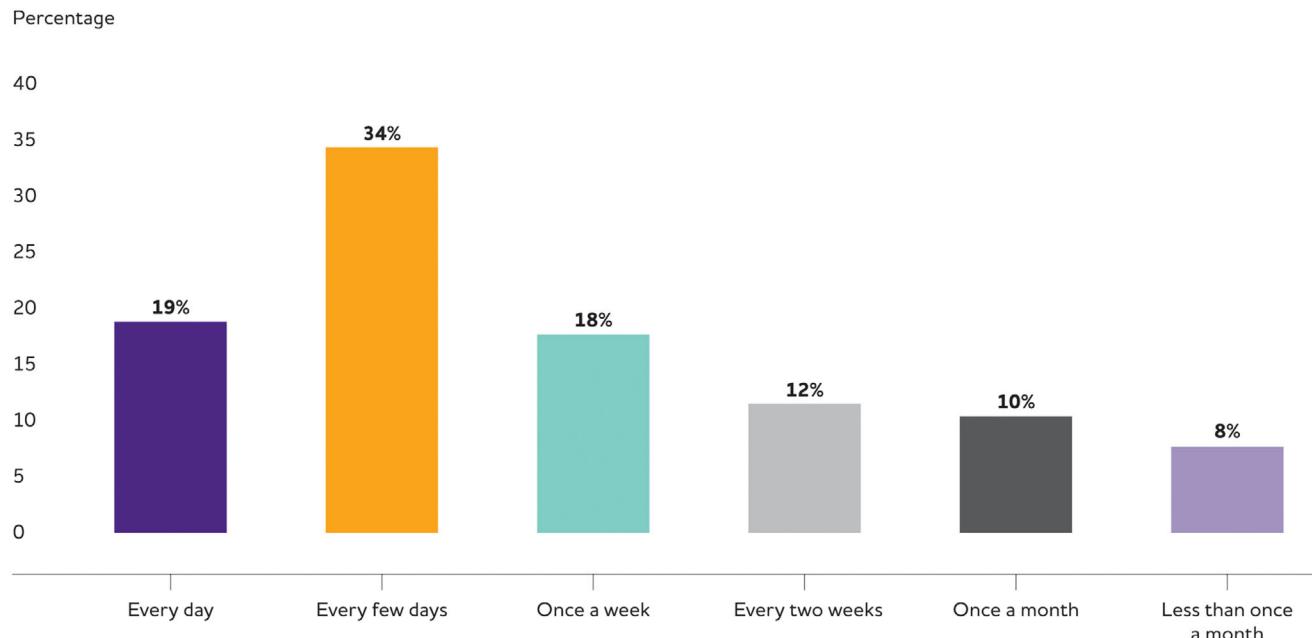
#### Alzheimer's Association Surveys

Physicians included in the Alzheimer's Association Primary Care Physician Dementia Training Survey<sup>A20</sup> were recruited via WebMD's Medscape Physician Panel, which includes 68% of all practicing PCPs in the United States. To qualify for the survey, PCPs had to have been in practice for at least two years, spend at least 50% of their time in direct patient care, and have a practice in which at least 10% of their patients were age 65 or older. A total of 1000 PCPs, balanced by age, gender, years in practice, type of practice, specialty, and region to match the total U.S. population of PCPs, were included in the survey.<sup>A20</sup>

A total of 202 current PCP residents in general, family or internal medicine who completed their medical school training within the last two years were recruited to participate in the Alzheimer's Association Recent Medical School Graduate Dementia Training Survey<sup>A21</sup> through WebMD's Medscape Healthcare Professional Panel.

PCPs who had completed their residency within the last two years were recruited to participate in the Alzheimer's Association Recent Primary Care Resident Dementia Training Survey<sup>A22</sup> through WebMD's Medscape Physician Panel. The sample included 200 PCPs and was matched to the full population of PCPs who are in their first two years of practice based on age, gender, specialty, and region.<sup>A22</sup>

- More than half of PCPs state that there are not enough specialists to receive patient referrals.
- Medical school and residency programs in primary care offer very limited coursework and patient contact related to Alzheimer's and other dementias.



**FIGURE 17** Frequency of Primary Care Physicians Receiving Questions about Alzheimer's or Other Dementias from Patients Age 65 and Older. Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.<sup>A20</sup>

- PCPs feel a duty and are committed to staying current on the latest information about the care of patients with Alzheimer's and other dementias, particularly disease management and treatment, screening and testing, and diagnosis.
- Despite this, fewer than half have pursued additional training in dementia care since medical school and residency, noting challenges associated with obtaining such training.
- Nearly two in five PCPs say their own experience in treating patients has been one of the most important teachers, second only to continuing medical education (CME) courses.

Overall, the results of the Alzheimer's Association surveys underscore the important role PCPs play in providing critical dementia care. Findings also highlight the need for additional dementia care training opportunities for PCPs, both during medical school and residency and in subsequent clinical practice.

### 7.3.1 | Survey results

#### Patient population

The Alzheimer's Association Primary Care Physician Dementia Care Training Survey revealed that more than four in five PCPs (82%) believe they are on the front lines of providing critical elements of dementia care for their patients. PCPs reported that, on average, 40% of their patients are age 65 and older and, of these, 13% have been diagnosed with Alzheimer's or other dementias. The survey also demonstrated that the topic of dementia is one that comes up frequently during patient visits. The majority (53%) of PCPs receive questions related to Alzheimer's or other dementias from their patients age 65 and older,

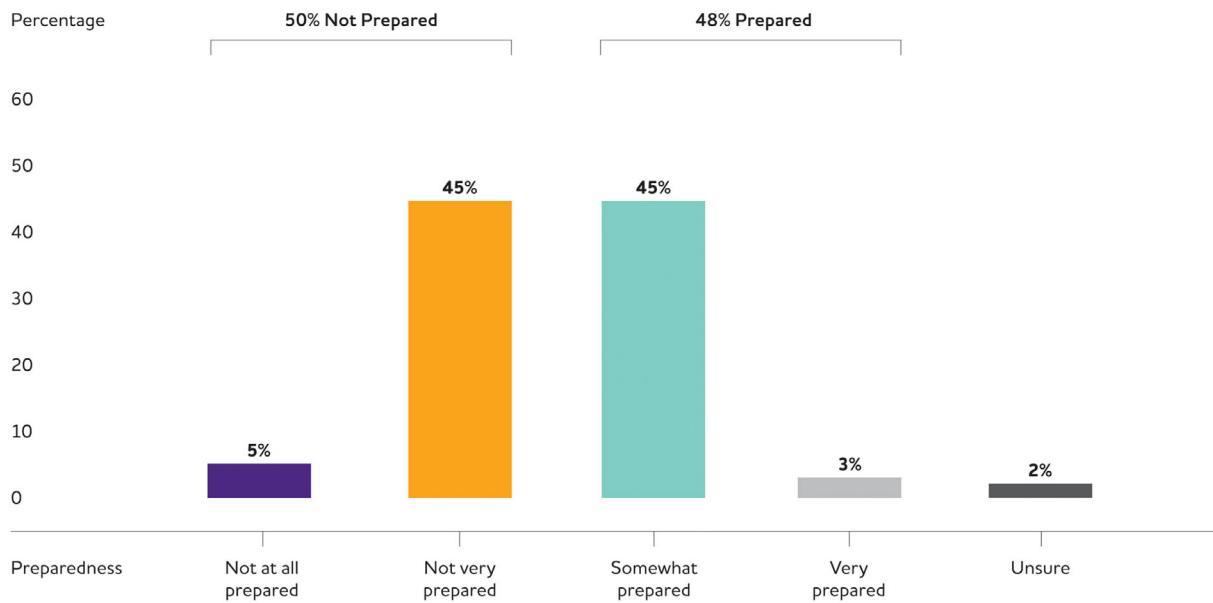
or their families, every few days or more with nearly one in five (19%) receiving these questions on a daily basis (Figure 17).

PCPs report that the number of patients with Alzheimer's disease is growing. Almost nine of ten PCPs (87%) expect the number of patients they see with dementia to increase over the next five years, and one-third (33%) expect the number of diagnosed patients to increase "a lot".

#### Management of patients

Despite knowing that they are on the front lines of dementia care, a significant number of PCPs surveyed reported that they do not feel adequately prepared to care for patients with Alzheimer's and other dementias. More than one-quarter (27%) report being only sometimes or never comfortable answering patient questions about Alzheimer's or other dementias. Moreover, even though the vast majority of diagnoses are made by PCPs, nearly four in 10 PCPs (39%) report never or only sometimes or never being comfortable personally making a diagnosis of Alzheimer's or other dementias. In addition, half of PCPs say that the medical profession is either "not very prepared" or "not at all prepared" to care for the growing number of people living with Alzheimer's or other dementias (Figure 18).

To care for their patients optimally, nearly one-third (32%) of PCPs make specialist referrals for their dementia patients at least once a month. However, most PCPs (55%) report that there are not enough specialists in their area to meet patient demand (Figure 19). There was a substantial difference in PCPs' report of specialist availability depending on whether their practice was located in an urban or rural setting. While 44% of PCPs in a large city and 54% of those located in a suburb near a large city reported that there are not enough specialists in their area, 63% of PCPs in a small city or town and 71% of those in a rural area said the same.



**FIGURE 18** Medical Profession's Preparedness to Care for People Living with Alzheimer's and Other Dementias. Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.<sup>A20</sup>

#### *Medical school and residency training in dementia care*

The vast majority of PCPs (91%) had at least some training in the diagnosis and care of Alzheimer's and other dementias in medical school, but most of those (66%) describe it as being "very little." Almost one-quarter (22%) of all PCPs had no residency training in dementia diagnosis and care. Of the 78% who did undergo training, 65% reported that the amount was "very little."

Encouragingly, this trend seems to be changing. A greater proportion of recently trained PCPs report medical school and residency training in dementia care compared with PCPs with a greater number of years in practice. Ninety-eight percent of PCPs in practice for 2–9 years report at least some dementia training in medical school, compared with 81% of those with 30 or more years in practice. Similarly, 85% of PCPs in practice for 2–9 years report receiving dementia training during their residency, compared to 65% of PCPs with 30 years or more of practice. However, regardless of how much training they had, most PCPs (78%) said that medical school and residency can never fully prepare a physician for dementia care.

To better understand the dementia training new PCPs are undergoing, the Alzheimer's Association surveyed recent medical school and residency graduates. The survey of first- and second-year PCP residents revealed an average of 41 hours of medical school coursework that specifically focused on dementia, including Alzheimer's. However more than one in five (21%) reported having fewer than 20 hours of dementia coursework in medical school. During their clinical training in medical school, they reported seeing an average of just 20 dementia patients.

The survey of recent residents (currently in their first or second year of practice) revealed that residents had an average of eight hours of formal curricular training focused specifically on Alzheimer's or other dementias, and one-quarter (26%) reported fewer than two hours. On average, recent residents saw and helped 50 patients with demen-

tia during their residency training. However, they were only involved in diagnostic workup for 10 people with dementia who undiagnosed when initially seen. Only 18% of recent residents feel "very prepared" to provide dementia care in practice, compared with 72% who feel "somewhat," "not very" or "not at all" prepared.

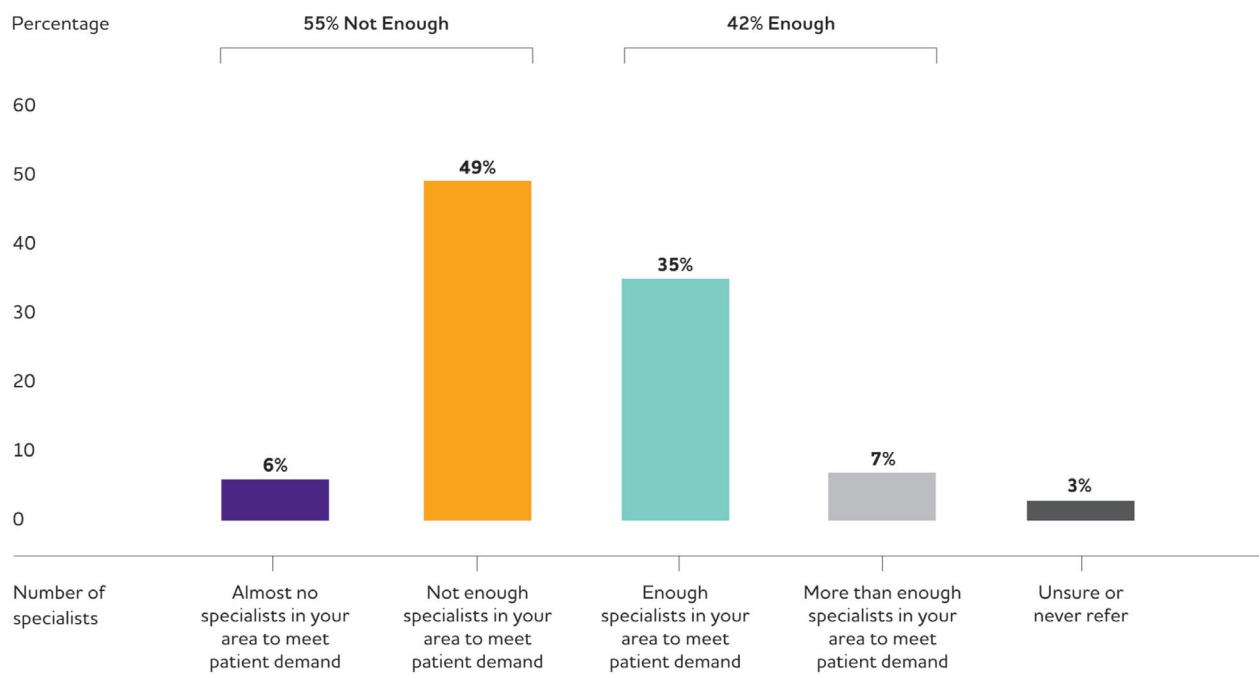
#### *Keeping current*

**Finding New Developments.** The Alzheimer's Association surveys revealed that virtually all PCPs (99%) believe it is important to stay current on new developments in dementia care. Similar responses were found among recent medical school graduates (99%) and recent residents (100%).

- 93% feel a duty to patients to keep up with new developments in diagnosis and care.
- 92% believe patients and caregivers expect them to know the latest thinking and best practices around dementia care.
- 92% believe dementia care is a rapidly evolving area of medicine that requires ongoing learning and training.

In addition, the surveys found that more than two-thirds of PCPs (69%) say they are always learning about the diagnosis and care of Alzheimer's and other dementias, and half (50%) say they put in a lot of time and effort keeping up with new developments. However, more than three in five (63%) feel they don't have enough time to keep up with all of the new developments and half (53%) say the extent to which they are keeping up with the new developments in dementia care is "only a little" or "not at all." PCPs have enormous demands on their time and energy, across all health-related domains, so ensuring that PCPs have readily accessible, high quality training opportunities is an important challenge for the field.

The most important areas where PCPs want to stay current on Alzheimer's and other dementias include management and treatment



**FIGURE 19** Availability of Dementia Specialists for Patient Referral. Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.<sup>A20</sup>

(83%), screening and testing (69%) and diagnosis (64%). These same three areas also ranked as most important in the surveys of recent medical school graduates and recent residents. Additional areas where PCPs want to stay current include prevention (49%), family support (49%), managing dementia alongside other conditions (46%), signs and symptoms (44%), reducing risk (41%), patient support (40%), end-of-life care (31%), palliative care and hospice (28%), coordinating care with other health care providers (24%), quality improvement measures (20%), pathophysiology (19%), and clinical trials (16%).

**Additional training opportunities.** To keep up to date, PCPs are following new developments in dementia care mainly by scanning journals or content summaries for newly published research (77%) or scanning CME offerings for new training opportunities (66%).<sup>A23</sup> However, only two of five PCPs (42%) have completed additional training specifically on dementia care since their residency. The most common formats for additional training are CME courses (91%), medical conferences (68%), reading professional journals (67%) and UpToDate® (53%).<sup>A24</sup> The vast majority (89%) of PCPs feel that staying current with dementia diagnosis and care developments requires more than just fulfilling CME requirements, and when learning, the majority (55%) try to go deeper than what most CME offers.

When asked specifically about additional training opportunities, 58% of PCPs feel that the quality of existing training options is either good or excellent, though challenges in obtaining the training were noted. Nearly a third (31%) say the current options are difficult to access and half (49%) say that there are too few options for continuing education and training on dementia care. In fact, 37% reported that they learned the most about dementia care from their own experiences treating patients, second only to the 40% who reported learning the

most from CME courses (Figure 20). This finding highlights a need for better dementia training programs for PCPs. Additional sources where PCPs have learned the most about dementia diagnosis and care include UpToDate® (32%), professional journals (32%), medical conferences (31%) and in residency (29%).<sup>A25</sup>

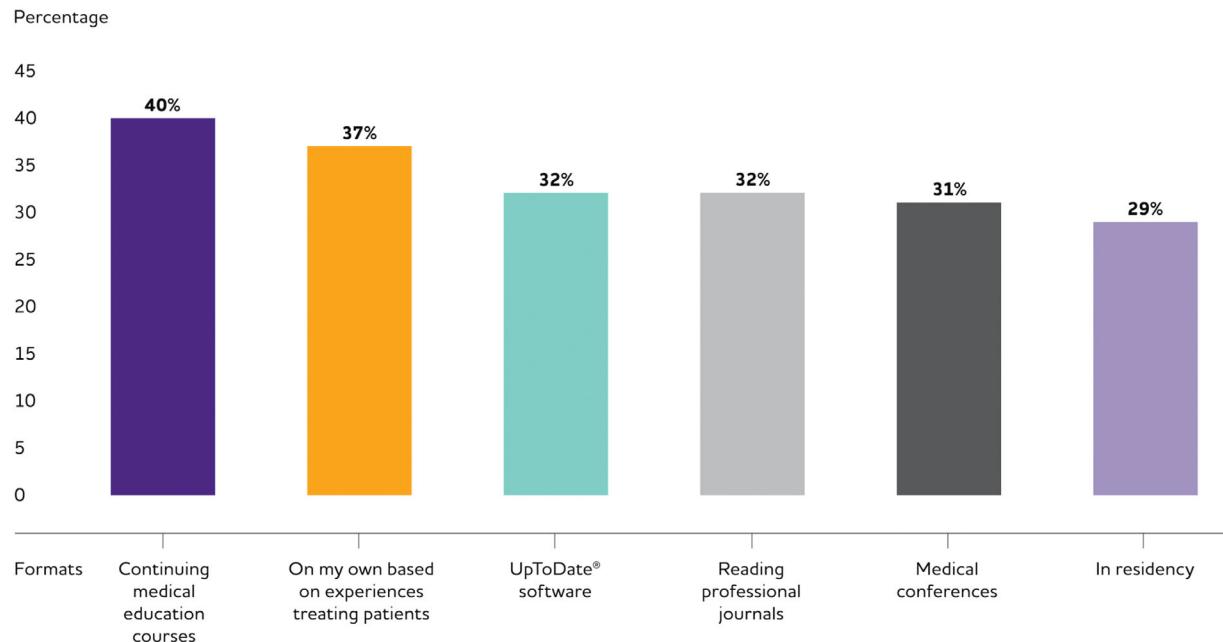
The reasons provided by PCPs for pursuing additional dementia care training include general ongoing patient needs given their patient population (70%), specific patient problems or needs they are trying to solve (64%), a professional obligation to stay current (60%), or their own personal or professional interest in the topic (53%). Few PCPs have pursued additional training due to requirements for medical licensing (11%), health insurance companies or other payers (3%), or their employer (1%).

PCPs who haven't pursued additional training say it's because they don't have time (38%) and because they typically refer Alzheimer's and other dementia patients to other physicians (35%). Just 19% of those who haven't pursued additional training say it's because they feel confident in how their dementia patients are being managed.<sup>A26</sup>

#### 7.4 | Meeting future demand

This Alzheimer's Association dementia care analysis and survey should sound an alarm regarding the future of dementia care in America. This report indicates a shortage of dementia care specialists and a PCP community committed, but not always adequately prepared, to meet the increased demands of an aging population.

One way to address shortages in the workforce is through scholarship and loan forgiveness programs offered by federal and state



**FIGURE 20** Where Primary Care Physicians Learned the Most about Dementia Diagnosis and Care. Created from data from the Alzheimer's Association Primary Care Physician Dementia Training Survey.<sup>A20</sup>

governments. Studies have found that loan repayment programs are correlated with increasing the number of physicians practicing in rural areas<sup>601</sup> and directly influence the decision of osteopathic medical graduates to become primary care physicians.<sup>602</sup> A large increase between 2002 and 2009 in the number of young people choosing nursing as a career followed the large increase in federal funding for nursing workforce development, which includes loan repayment and scholarships.<sup>603</sup> A report on the geriatric workforce by the Institute of Medicine (now known as the National Academy of Medicine) concluded that “programs that link financial support to service have been effective in increasing the numbers of health care professionals that serve in underserved areas of the country” and that such programs “serve as good models for the development of similar programs to address shortages of geriatric providers.”<sup>476</sup>

Another approach that may increase the number of providers available to diagnose and treat those with Alzheimer's and other dementias is through educational funding. For example, federal funding of departments of family medicine at U.S. medical schools is associated with an expansion of the primary care workforce.<sup>604</sup> In addition, a recent demonstration project by the Centers for Medicare & Medicaid Services (CMS) found that funding for clinical education of Advanced Practice Registered Nurses (APRN) resulted in a 54% increase in APRN student enrollment, with graduations increasing 67%.<sup>605</sup>

In addition to policies that strengthen the specialty workforce, federal and state support is needed for programs that build capacity in primary care. One example is Project ECHO® (Extension for Community Healthcare Outcomes), a highly successful tele-mentoring program for health care providers developed by the University of New Mexico. Project ECHO has been shown to improve primary care for multiple diseases, including hepatitis C<sup>606</sup> and complex diabetes.<sup>607</sup> The Alzheimer's Association is launching a global initiative to build

primary care capacity for dementia care through expanded use of this model.

Another approach to bridging the gap is to expand collaborative and coordinated care programs, which rely heavily on non-specialists. Pilot programs for individuals with dementia have reduced hospital and emergency room visits<sup>502,608</sup> and nursing home placement.<sup>585</sup> In the UCLA Alzheimer's and Dementia Care Program, dementia care management is provided by a nurse practitioner supervised by a primary care physician. After one year in the program, 58% of people living with dementia and 63% of their caregivers showed clinical benefit on validated instruments,<sup>508</sup> and the gross savings to Medicare on an annual basis totaled \$2,404 per patient per year.<sup>585</sup> A similar collaborative care model in Indiana, the Healthy Aging Brain Center (HABC), resulted in gross savings of \$3,474 per patient per year.<sup>502</sup> While the HABC included a specialist (either a geriatrician or behavioral neurologist) as part of the care team, the bulk of the team were not physicians, and included a registered nurse, a medical assistant, a technician and a social worker. And among 780 individuals with dementia who participated in the Care Ecosystem, which uses a trained navigator, an advanced practice nurse, a social worker and a pharmacist, there were 120 fewer emergency room visits, 16 fewer ambulance use events, and 13 fewer hospitalizations than would otherwise be expected over a 12-month period.<sup>608</sup> Individuals in these care models still sometimes received care from specialists, but the improvement in quality care can be attributed to the well-trained, largely primary care teams.

The Alzheimer's Association also offers a variety of resources to support health systems and clinicians throughout the disease continuum, including early detection and diagnosis of Alzheimer's and other dementias, management of these conditions, and care planning and support services following a diagnosis.

For a complete listing of available Alzheimer's Association resources to support health systems and clinicians, visit [alz.org/professionals/health-systems-clinicians](http://alz.org/professionals/health-systems-clinicians).

## 7.5 | Conclusion

This Special Report underscores the urgent need to develop the medical workforce to meet current and future demands for quality diagnosis and care of people living with Alzheimer's and other dementias. Current and projected future shortages in specialist care—geriatricians, neurologists, geriatric psychiatrists and neuropsychologists—place the burden of the vast majority of patient care on PCPs. However, while PCPs recognize that they are on the front lines of this crisis and feel a duty to provide the highest quality care, they report that the medical profession is not prepared to adequately face the problem, acknowledge that there is a shortage of specialists to receive patient referrals, and note that training opportunities are lacking or difficult to access. The severity of these needs requires solutions that develop the specialty workforce while also improving capacity in primary care.

## ACKNOWLEDGMENTS

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## ENDNOTES

- A1. Estimated number (prevalence) of Americans age 65 and older with Alzheimer's dementia for 2020 (prevalence of Alzheimer's in 2020): The number 5.8 million is from published prevalence estimates based on incidence data from the Chicago Health and Aging Project (CHAP) and population estimates from the 2010 U.S. Census.<sup>62</sup>
- A2. Percentage of total Alzheimer's dementia cases by age groups: Percentages for each age group are based on the estimated 200,000 people under 65,<sup>62</sup> plus the estimated numbers for people age 65 to 74 (1 million), 75 to 84 (2.7 million), and 85+ (2.1 million) based on prevalence estimates for each age group and incidence data from the CHAP study.
- A3. Proportion of Americans age 65 and older with Alzheimer's dementia: The 10% of the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer's dementia (5.8 million) by the U.S. population age 65 and older in 2020, as projected by the U.S. Census Bureau (56.4 million) = approximately 10%.<sup>184</sup>
- A4. Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence: ADAMS estimated the prevalence of Alzheimer's dementia to be lower than CHAP, at 2.3 million Americans age 71 and older in 2002,<sup>187</sup> while the CHAP estimate for 2000 was 4.5 million.<sup>592</sup> At a 2009 conference convened by the National Institute on Aging and the Alzheimer's Association, researchers determined that this discrepancy was mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's.<sup>188</sup> Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,<sup>37</sup> 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.
- A5. State-by-state prevalence of Alzheimer's dementia: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality.<sup>206</sup> Specific prevalence numbers for 2020 were derived from this analysis and provided to the Alzheimer's Association by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.
- A6. Criteria for identifying people with Alzheimer's or other dementias in the Framingham 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.<sup>211</sup> 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 6 months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.
- A7. Number of women and men age 65 and older with Alzheimer's dementia in the United States: The estimates for the number of U.S. women (3.6 million) and men (2.2 million) age 65 and older with Alzheimer's in 2020 is from unpublished data from CHAP. For analytic methods, see Hebert et al.<sup>62</sup>
- A8. Prevalence of Alzheimer's and other dementias in older whites, black/African Americans and Hispanics/Latinos: The statement that black/African Americans are twice as likely and Hispanics/Latinos one and one-half times as likely as whites to have Alzheimer's or other dementias is the conclusion of an expert review of a number of multiracial and multiethnic data sources, as reported in detail in the Special Report of the Alzheimer's Association's 2010 *Alzheimer's Disease Facts and Figures*.
- A9. Projected number of people with Alzheimer's dementia: This figure comes from the CHAP study.<sup>62</sup> Other projections are

- somewhat lower (see, for example, Brookmeyer et al.<sup>593</sup>) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.<sup>A4</sup> 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.
- A10. Projected number of people age 65 and older with Alzheimer's dementia in 2025: The number 7.1 million is based on a linear extrapolation from the projections of prevalence of Alzheimer's for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP.<sup>62</sup>
- A11. 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 true 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.
- A12. 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 BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over whether they 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. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2019. Available at: <https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html>. Accessed on January 6, 2020. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP.<sup>594</sup> 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. In response, 26% of caregivers said that: (1) Alzheimer's or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26% figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 16.343 million Alzheimer's and dementia caregivers.
- A13. 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.
- A14. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's or other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. The number of family and other unpaid caregivers (16.343 million)<sup>A12</sup> was multiplied by the average hours of care per year, which totals 18.611 billion hours of care. This is slightly lower than the product of multiplying 1,139 by 16.343 million because of rounding.
- A15. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Amo and colleagues.<sup>595</sup> This method uses the average of the federal minimum hourly wage (\$7.25 in 2019) and the mean hourly wage of home health aides (\$18.97 in July 2019).<sup>596</sup> The average is \$13.11, which was multiplied by the number of hours of unpaid care (18.611 billion) to derive the total value of unpaid care (\$243.994 billion; this is slightly higher than the product of multiplying \$13.11 by 18.611 billion because 18.611 billion is a rounded number for the hours of unpaid care).
- A16. Lewin Model on Alzheimer's and dementia costs: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice – as well as state-by-state Medicaid spending – for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in

January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Hebert and colleagues<sup>62</sup> and included in this report (5.8 million in 2020),<sup>A2</sup> rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

A17. All cost estimates were inflated to year 2019 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.

A18. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2011 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health.<sup>207</sup> The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in 2020 *Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

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

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

Costs from the MCBS analysis are based on responses from 2011 and reported in 2019 dollars.

A19. Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues<sup>520</sup> estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. 2020 *Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS) to be \$50,201. 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 2020 *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).

A20. Alzheimer's Association Primary Care Physician Dementia Training Survey: In sampling from the Medscape physician panel, data from the American Medical Association (AMA) master file of all practicing physicians in the United States were used to stratify sampling and weight final data, ensuring a representative sample based on age, gender, years in practice, type of practice, specialty, and region. Of the 1,000 respondents of the survey, 18% spent less than 90% of their professional time in direct patient care, while 82% spent between 90 and 100% of their time in direct patient care. On average, 50% of their patients were age 18-64 and 40% were age 65 and older. Sixty percent of respondents were male and 39% were female. Twenty-nine percent of respondents had been in practice for 10-19 years, 28% for 20-29 years, 24% for 35 years or more, and 19% for fewer than 10 years. Eighty-three percent had office-based practices, and 14% had hospital-based practices. Fifty percent had a primary medical specialty of family medicine, 47% specialized in internal

medicine, and three percent were general practitioners. Thirty-four percent of respondents practiced in the South, 25% in the West, 22% in the Midwest, and 19% in the Northeast.

- A21. Alzheimer's Association Recent Medical School Graduate Dementia Training Survey: Of the 202 respondents of the survey, 55% were in their first year of residency and 45% were in their second year. Ninety-seven percent of respondents were under age 40 and three percent were age 40-49. Sixty-nine percent of respondents were male, and 31% were female. Sixty-eight percent had a primary medical specialty of internal medicine, 31% specialized in family medicine, and less than one percent were general practitioners. Thirty-two percent of respondents were in residency in the South, 25% in the Northeast, 23% in the Midwest, and 20% in the West. In estimating total hours of training from the survey data, 48 work weeks were assumed per year, with 5 hours of formal curriculum training each week, over the course of a three-year PCP residency.
- A22. Alzheimer's Association Recent Primary Care Resident Dementia Training Survey: Data from the AMA master file were used to weight final data to ensure a sample that closely matches the full population of PCPs who are in their first two years of practice based on age, gender, specialty and region. Of the 200 respondents of the survey, 43% spent less than 90% of their professional time in direct patient care, while 57 percent spent between 90 and 100% of their time in direct patient care. Fifty-eight percent had finished residency and begun an independent practice within the last year, and 42% had done so within the last two years. Fifty-two percent of respondents were male and 48% were female. Sixty-one percent had office-based practices, and 34% had hospital-based practices. Fifty-seven percent had a primary medical specialty of family medicine, 42% specialized in internal medicine, and one percent were general practitioners. Thirty-one percent of respondents practiced in the South, 27% in the West, 25% in the Midwest, and 16% in the Northeast. To estimate total hours of training from the survey data, it was assumed that each one-week block of coursework involved 45 hours of classroom and study time.
- A23. Other ways PCPs follow new developments in the diagnosis and care of Alzheimer's and other dementias: Additional responses, ranked by the percentage of participants who selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Email or social media alerts that track new developments or offerings (31%); Listening to podcasts hosted by medical professionals that focus on Alzheimer's and dementia (25%); Subscribing to publications focused on disorders of the nervous system (17%); Participating in online groups of physicians who discuss Alzheimer's and dementia (13%); Subscribing to an online community focused on Alzheimer's and dementia (9%); Other ways (12%).
- A24. Other formats for additional training in dementia: Additional responses, ranked by the percentage of participants who

selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Lectures (including grand rounds, noon conferences, etc.) (38%); Other online resources (such as AAN, NIH, CDC, etc.) (20%); Workshops (11%); YouTube videos or other resources found on social media platforms (4%); Geriatric fellowship (2%); Another format (4%).

- A25. Other sources where PCPs have learned the most about dementia diagnosis and care: Additional responses, ranked by the percentage of participants who selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Own research to learn about the topic (17%); In medical school (15%); Lectures (including grand rounds, noon conferences, etc.) (13%); Professional discussion groups (8%); Other online resources (such as AAN, NIH, CDC, etc.) (6%); Workshops (5%); YouTube videos or other resources found on social media platforms (1%); Another format (1%); Geriatric fellowship (less than 1%).
- A26. Other reasons for not pursuing additional training in dementia diagnosis and care: Additional responses, ranked by the percentage of participants who selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Decided to focus practice on another area of medicine (17%); Dementia care is less relevant than other topics (15%); Do not have good access to resources for additional training (14%); Do not see much Alzheimer's or other dementia among patients (7%); Medical school and residency training was sufficient (5%); Not much has changed in dementia care so there is no need (5%); Other reasons (1%).

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