



# Alzheimer's Disease Facts 2013



Alzheimer's disease is the most common type of dementia. "Dementia" is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain (called neurons) die or no longer function normally. The death or malfunction of neurons causes changes in one's memory, behavior and ability to think clearly. In Alzheimer's disease, these brain changes eventually impair an individual's ability to carry out such basic bodily functions as walking and swallowing. Alzheimer's disease is ultimately fatal.

### DEMENTIA: DEFINITION AND SPECIFIC TYPES

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.<sup>(1)</sup> To meet *DSM-IV* criteria for dementia, the following are required:

- Symptoms must include decline in memory *and* in at least one of the following cognitive abilities:
  - 1) Ability to speak coherently or understand spoken or written language.
  - 2) Ability to recognize or identify objects, assuming intact sensory function.
  - 3) Ability to perform motor activities, assuming intact motor abilities and sensory function and comprehension of the required task.
  - 4) Ability to think abstractly, make sound judgments and plan and carry out complex tasks.
- The decline in cognitive abilities must be severe enough to interfere with daily life.

In May 2013, the American Psychiatric Association is expected to release *DSM-5*. This new version of *DSM* is expected to incorporate dementia into the diagnostic category of major neurocognitive disorder.

To establish a diagnosis of dementia using *DSM-IV*, a physician must determine the cause of the individual's symptoms. Some conditions have symptoms that mimic dementia but that, unlike dementia, may be reversed with treatment. An analysis of 39 articles describing 5,620 people with dementia-like symptoms reported that 9 percent had potentially reversible dementia.<sup>(2)</sup> Common causes of potentially reversible dementia are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. In contrast, Alzheimer's disease and other dementias are caused by damage to neurons that cannot be reversed with current treatments.

When an individual has dementia, a physician must conduct tests (see Diagnosis of Alzheimer's Disease, page 6) to identify the form of dementia that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and brain abnormalities, as described in Table 1. However, increasing evidence from long-term observational and autopsy studies indicates that many people with dementia have brain abnormalities associated with more than one type of dementia.<sup>(3-7)</sup> This is called mixed dementia and is most often found in individuals of advanced age.

### ALZHEIMER'S DISEASE

Alzheimer's disease was first identified more than 100 years ago, but research into its symptoms, causes, risk factors and treatment has gained momentum only in the last 30 years. Although research has revealed a great deal about Alzheimer's, the precise changes in the brain that trigger the development of Alzheimer's, and the order in which they occur, largely remain unknown. The only exceptions are certain rare, inherited forms of the disease caused by known genetic mutations.

#### Symptoms of Alzheimer's Disease

Alzheimer's disease affects people in different ways. The most common symptom pattern begins with a gradually worsening ability to remember new information. This occurs because the first neurons to die and malfunction are usually neurons in brain regions involved in forming new memories. As neurons in other parts of the brain malfunction and die, individuals experience other difficulties. The following are common symptoms of Alzheimer's:

- Memory loss that disrupts daily life.
- Challenges in planning or solving problems.

- Difficulty completing familiar tasks at home, at work or at leisure.
- Confusion with time or place.
- Trouble understanding visual images and spatial relationships.
- New problems with words in speaking or writing.
- Misplacing things and losing the ability to retrace steps.
- Decreased or poor judgment.
- Withdrawal from work or social activities.
- Changes in mood and personality.

For more information about the warning signs of Alzheimer’s, visit [www.alz.org/10signs](http://www.alz.org/10signs).

Individuals progress from mild Alzheimer’s disease to moderate and severe disease at different rates. As the disease progresses, the individual’s cognitive and functional abilities decline. In advanced Alzheimer’s, people need help with basic activities of daily living (ADLs), such as bathing, dressing, eating and using the bathroom. Those in the final stages of the disease lose

their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on around-the-clock care. When an individual has difficulty moving because of Alzheimer’s disease, they are more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer’s-related pneumonia is often a contributing factor to the death of people with Alzheimer’s disease.

### Diagnosis of Alzheimer’s Disease

A diagnosis of Alzheimer’s disease is most commonly made by an individual’s primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. The physician also asks a family member or other person close to the individual to provide input. In addition, the physician conducts cognitive tests and physical and neurologic examinations and may request that the individual undergo magnetic resonance imaging (MRI) scans. MRI scans can help identify brain changes, such as the presence of a tumor or evidence of a stroke, that could explain the individual’s symptoms.

**TABLE 1** COMMON TYPES OF DEMENTIA AND THEIR TYPICAL CHARACTERISTICS

Type of Dementia	Characteristics
<b>Alzheimer’s disease</b>	<p>Most common type of dementia; accounts for an estimated 60 to 80 percent of cases.</p> <p>Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.</p> <p>New criteria and guidelines for diagnosing Alzheimer’s were proposed in 2011. They recommend that Alzheimer’s disease be considered a disease that begins well before the development of symptoms (pages 8–9).</p> <p>Hallmark brain abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain.</p>
<b>Vascular dementia</b>	<p>Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than is Alzheimer’s disease.</p> <p>Impaired judgment or ability to make plans is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer’s.</p> <p>Vascular dementia occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location of the brain injury determines how the individual’s thinking and physical functioning are affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer’s disease (and vice versa). That practice is no longer considered consistent with pathologic evidence, which shows that the brain changes of both types of dementia can be present simultaneously. When any two or more types of dementia are present at the same time, the individual is considered to have “mixed dementia.”</p>

TABLE 1 (cont.)

## COMMON TYPES OF DEMENTIA AND THEIR TYPICAL CHARACTERISTICS

Type of Dementia	Characteristics
<b>Dementia with Lewy bodies (DLB)</b>	<p>People with DLB have some of the symptoms common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.</p> <p>Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease, but the aggregates may appear in a pattern that is different from DLB.</p> <p>The brain changes of DLB alone can cause dementia, or they can be present at the same time as the brain changes of Alzheimer's disease and/or vascular dementia, with each entity contributing to the development of dementia. When this happens, the individual is said to have "mixed dementia."</p>
<b>Frontotemporal lobar degeneration (FTLD)</b>	<p>Includes dementias such as behavioral variant FTLD, primary progressive aphasia, Pick's disease and progressive supranuclear palsy.</p> <p>Typical symptoms include changes in personality and behavior and difficulty with language.</p> <p>Nerve cells in the front and side regions of the brain are especially affected. No distinguishing microscopic abnormality is linked to all cases.</p> <p>The brain changes of behavioral variant FTLD may be present at the same time as the brain changes of Alzheimer's, but people with behavioral variant FTLD generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with Alzheimer's.</p>
<b>Mixed dementia</b>	<p>Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia — most commonly, vascular dementia, but also other types, such as DLB.</p> <p>Recent studies suggest that mixed dementia is more common than previously thought.</p>
<b>Parkinson's disease</b>	<p>As Parkinson's disease progresses, it often results in a severe dementia similar to DLB or Alzheimer's.</p> <p>Problems with movement are a common symptom early in the disease.</p> <p>Alpha-synuclein aggregates are likely to begin 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.</p> <p>The incidence of Parkinson's disease is about one-tenth that of Alzheimer's disease.</p>
<b>Creutzfeldt-Jakob disease</b>	<p>Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.</p> <p>Results from an infectious misfolded protein (prion) that causes other proteins throughout the brain to misfold and thus malfunction.</p> <p>Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p>
<b>Normal pressure hydrocephalus</b>	<p>Symptoms include difficulty walking, memory loss and inability to control urination.</p> <p>Caused by the buildup of fluid in the brain.</p> <p>Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</p>

# A MODERN DIAGNOSIS OF ALZHEIMER'S DISEASE: PROPOSED NEW CRITERIA AND GUIDELINES

## IN 2011, THE NATIONAL INSTITUTE ON AGING (NIA) AND THE ALZHEIMER'S ASSOCIATION PROPOSED NEW CRITERIA AND GUIDELINES FOR DIAGNOSING ALZHEIMER'S DISEASE.<sup>(8-11)</sup>

These criteria and guidelines updated diagnostic criteria and guidelines published in 1984 by the Alzheimer's Association and the National Institute of Neurological Disorders and Stroke. In 2012, the NIA and the Alzheimer's Association also proposed new guidelines to help pathologists describe and categorize the brain changes associated with Alzheimer's disease and other dementias.<sup>(12)</sup>

It is important to note that these are proposed criteria and guidelines. More research is needed, especially research about biomarkers, before the criteria and guidelines can be used in clinical settings, such as in a doctor's office.

### **DIFFERENCES BETWEEN THE ORIGINAL AND NEW CRITERIA**

The 1984 diagnostic criteria and guidelines were based chiefly on a doctor's clinical judgment about the cause of an individual's symptoms, taking into account reports from the individual, family members and friends; results of cognitive tests; and general neurological assessment. The new criteria and guidelines incorporate two notable changes:

(1) They identify three stages of Alzheimer's disease, with the first occurring before symptoms such as memory loss develop. In contrast, for Alzheimer's disease to be diagnosed using the 1984 criteria, memory loss and a decline in thinking abilities severe enough to affect daily life must have already occurred.

(2) They incorporate biomarker tests. A biomarker is a biological factor that can be measured to indicate the presence or absence of disease, or the risk of developing a disease. For example, blood glucose level is a biomarker of diabetes, and cholesterol level is a biomarker of heart disease risk. Levels of certain proteins in fluid (for example, levels of beta-amyloid and tau in the cerebrospinal fluid and blood) are among several factors being studied as possible biomarkers for Alzheimer's.

### **THE THREE STAGES OF ALZHEIMER'S DISEASE PROPOSED BY THE NEW CRITERIA AND GUIDELINES**

The three stages of Alzheimer's disease proposed by the new criteria and guidelines are preclinical

Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease, and dementia due to Alzheimer's disease. These stages are different from the stages now used to describe Alzheimer's. The 2011 criteria propose that Alzheimer's disease begins before the development of symptoms, and that new technologies have the potential to identify brain changes that precede the development of symptoms. Using the new criteria, an individual with these early brain changes would be said to have preclinical Alzheimer's disease or MCI due to Alzheimer's, and those with symptoms would be said to have dementia due to Alzheimer's disease. Dementia due to Alzheimer's would encompass all stages of Alzheimer's disease commonly described today, from mild to moderate to severe.

*Preclinical Alzheimer's disease* — In this stage, individuals have measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, but they have not yet developed symptoms such as memory loss. This preclinical or presymptomatic stage reflects current thinking that Alzheimer's-related brain changes may begin 20 years or more before symptoms occur. Although the new criteria and guidelines identify

preclinical disease as a stage of Alzheimer's, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional research on biomarker tests is needed before this stage of Alzheimer's can be diagnosed.

*MCI due to Alzheimer's disease* — Individuals with MCI have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities. Studies indicate that as many as 10 to 20 percent of people age 65 or older have MCI.<sup>(13-15)</sup> As many as 15 percent of people whose MCI symptoms cause them enough concern to contact their doctor's office for an exam go on to develop dementia each year. Nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in three or four years.<sup>(16)</sup>

When MCI is identified through community sampling, in which individuals in a community who meet certain criteria are assessed regardless of whether they have memory or cognitive complaints, the estimated rate of progression to Alzheimer's is slightly lower — up to 10 percent per year.<sup>(17)</sup> Further cognitive decline is

more likely among individuals whose MCI involves memory problems than among those whose MCI does not involve memory problems. Over one year, most individuals with MCI who are identified through community sampling remain cognitively stable. Some, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status.<sup>(18)</sup> It is unclear why some people with MCI develop dementia and others do not. When an individual with MCI goes on to develop dementia, many scientists believe the MCI is actually an early stage of the particular form of dementia, rather than a separate condition.

Once accurate biomarker tests for Alzheimer's have been identified, the new criteria and guidelines recommend biomarker testing for people with MCI to learn whether they have brain changes that put them at high risk of developing Alzheimer's disease and other dementias. If it can be shown that changes in the brain, cerebrospinal fluid and/or blood are caused by physiologic processes associated with Alzheimer's, the new criteria and guidelines recommend a diagnosis of MCI due to Alzheimer's disease.

*Dementia due to Alzheimer's disease* — This stage is characterized by memory, thinking and behavioral

symptoms that impair a person's ability to function in daily life and that are caused by Alzheimer's disease-related brain changes.

#### **BIOMARKER TESTS**

The new criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of beta-amyloid accumulation in the brain and (2) biomarkers showing that neurons in the brain are injured or actually degenerating.

Many researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function (called "disease-modifying" treatments) will be most effective when administered during the preclinical and MCI stages of the disease. Biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment. They also will be critical for monitoring the effects of treatment. At this time, however, more research is needed to validate the accuracy of biomarkers and better understand which biomarker test or combination of tests is most effective in diagnosing Alzheimer's disease. The most effective test or combination of tests may differ depending on the stage of the disease and the type of dementia.<sup>(19)</sup>

## Changes in the Brain That Are Associated with Alzheimer's Disease

Many experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. In Alzheimer's, these multiple factors are a variety of brain changes that may begin 20 or more years before symptoms appear. Increasingly, the time between the initial brain changes of Alzheimer's and the symptoms of advanced Alzheimer's is considered by scientists to represent the "continuum" of Alzheimer's. At the start of the continuum, the individual is able to function normally despite these brain changes. Further along the continuum, the brain can no longer compensate for the neuronal damage that has occurred, and the individual shows subtle decline in cognitive function. In some cases, physicians identify this point in the continuum as MCI. Toward the end of the continuum, the damage to and death of neurons is so significant that the individual shows obvious cognitive decline, including symptoms such as memory loss or confusion as to time or place. At this point, physicians following the 1984 criteria and guidelines for Alzheimer's would diagnose the individual as having Alzheimer's disease. The 2011 criteria and guidelines propose that the entire continuum, not just the symptomatic points on the continuum, represents Alzheimer's. Researchers continue to explore why some individuals who have brain changes associated with the earlier points of the continuum do not go on to develop the overt symptoms of the later points of the continuum.

These and other questions reflect the complexity of the brain. A healthy adult brain has 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form specialized connections with other neurons. At such connections, called synapses, information flows in tiny chemical pulses released by one neuron and detected by the receiving neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions,

movements and skills. Alzheimer's disease interferes with the proper functioning of neurons and synapses.

Among the brain changes believed to contribute to the development of Alzheimer's are the accumulation of the protein beta-amyloid *outside* neurons in the brain (called beta-amyloid plaques) and the accumulation of an abnormal form of the protein tau *inside* neurons (called tau tangles). In Alzheimer's disease, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of beta-amyloid is believed to interfere with the neuron-to-neuron communication at synapses and to contribute to cell death. Tau tangles block the transport of nutrients and other essential molecules in the neuron and are also believed to contribute to cell death. The brains of people with advanced Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

## Genetic Mutations That Cause Alzheimer's Disease

The only known cause of Alzheimer's is genetic mutation — an abnormal change in the sequence of chemical pairs inside genes. A small percentage of Alzheimer's disease cases, probably fewer than 1 percent, are caused by three known genetic mutations. These mutations involve the gene for the amyloid precursor protein and the genes for the presenilin 1 and presenilin 2 proteins. Inheriting any of these genetic mutations guarantees that an individual will develop Alzheimer's disease. In such individuals, disease symptoms tend to develop before age 65, sometimes as early as age 30. People with these genetic mutations are said to have "dominantly inherited" Alzheimer's.

The development and progression of Alzheimer's in these individuals is of great interest to researchers, as the changes occurring in their brains also occur in individuals with the more common late-onset Alzheimer's disease (in which symptoms develop at age 65 or older). Future treatments that are effective in people with dominantly inherited Alzheimer's may

provide clues to effective treatments for people with late-onset disease.

The Dominantly Inherited Alzheimer Network (DIAN) is a worldwide network of research centers investigating disease progression in people with a gene for dominantly inherited Alzheimer's who have not yet developed symptoms. DIAN researchers have found a pattern of brain changes in these individuals. The pattern begins with decreased levels of beta-amyloid in the cerebrospinal fluid (CSF, the fluid surrounding the brain and spinal cord). This is followed by increased levels of the protein tau in CSF and increased levels of beta-amyloid in the brain. As the disease progresses, the brain's ability to use glucose, its main fuel source, decreases. This decreased glucose metabolism is followed by impairment of a type of memory called episodic memory, and then a worsening of cognitive skills that is called global cognitive impairment.<sup>(20)</sup> Whether this pattern of changes will also hold true for individuals at high risk for late-onset Alzheimer's disease or younger-onset Alzheimer's (in which symptoms develop before age 65) that is not dominantly inherited requires further study.

### Risk Factors for Alzheimer's Disease

Many factors contribute to one's likelihood of developing Alzheimer's. The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a typical part of aging. Most people with Alzheimer's disease are diagnosed at age 65 or older. However, people younger than 65 can also develop the disease, although this is much more rare. Advancing age is not the only risk factor for Alzheimer's disease. The following sections describe other risk factors.

#### Family History

Individuals who have a parent, brother or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.<sup>(21-23)</sup> Those who have more than one first-degree relative with Alzheimer's are at even higher risk of developing the disease.<sup>(24)</sup> When diseases run in families, heredity (genetics), shared environmental

and lifestyle factors, or both, may play a role. The increased risk associated with having a family history of Alzheimer's is not entirely explained by whether the individual has inherited the *apolipoprotein E-ε4* risk gene.

#### Apolipoprotein E-ε4 (APOE-ε4) Gene

The *APOE* gene provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the *APOE* gene — ε2, ε3 or ε4 — from each parent. The ε3 form is the most common,<sup>(25)</sup> with about 60 percent of the U.S. population inheriting ε3 from both parents.<sup>(26)</sup> The ε2 and ε4 forms are much less common. An estimated 20 to 30 percent of individuals in the United States have one or two copies of the ε4 form<sup>(25-26)</sup>; approximately 2 percent of the U.S. population has two copies of ε4.<sup>(26)</sup> The remaining 10 to 20 percent have one or two copies of ε2.

Having the ε3 form is believed to neither increase nor decrease one's risk of Alzheimer's, while having the ε2 form may decrease one's risk. The ε4 form, however, increases the risk of developing Alzheimer's disease and of developing it at a younger age. Those who inherit two ε4 genes have an even higher risk. Researchers estimate that between 40 and 65 percent of people diagnosed with Alzheimer's have one or two copies of the *APOE-ε4* gene.<sup>(25, 27-28)</sup>

Inheriting the *APOE-ε4* gene does not guarantee that an individual will develop Alzheimer's. This is also true for several genes that appear to increase risk of Alzheimer's, but have a limited overall effect in the population because they are rare or only slightly increase risk. Many factors other than genetics are believed to contribute to the development of Alzheimer's disease.

#### Mild Cognitive Impairment (MCI)

MCI is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities.

People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's and other dementias than people without MCI. However, MCI does not always lead to dementia. For some individuals, MCI reverts to normal cognition on its own or remains stable. In other cases, such as when a medication causes cognitive impairment, MCI is mistakenly diagnosed. Therefore, it's important that people experiencing cognitive impairment seek help as soon as possible for diagnosis and possible treatment.

The 2011 proposed criteria and guidelines for diagnosis of Alzheimer's disease<sup>(8-11)</sup> suggest that in some cases MCI is actually an early stage of Alzheimer's or another dementia. (For more information on MCI, see *A Modern Diagnosis of Alzheimer's Disease: Proposed New Criteria and Guidelines*, pages 8-9.)

#### ***Cardiovascular Disease Risk Factors***

Growing evidence suggests that the health of the brain is closely linked to the overall health of the heart and blood vessels. The brain is nourished by one of the body's richest networks of blood vessels. A healthy heart helps ensure that enough blood is pumped through these blood vessels to the brain, and healthy blood vessels help ensure that the brain is supplied with the oxygen- and nutrient-rich blood it needs to function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of developing Alzheimer's and other dementias. These factors include smoking,<sup>(29-31)</sup> obesity (especially in midlife),<sup>(32-37)</sup> diabetes,<sup>(31, 38-41)</sup> high cholesterol in midlife<sup>(34, 42)</sup> and hypertension in midlife.<sup>(34, 37, 43-45)</sup>

A pattern that has emerged from these findings, taken together, is that dementia risk may increase with the presence of the "metabolic syndrome," a collection of conditions occurring together — specifically, three or more of the following: hypertension, high blood glucose, central obesity (obesity in which excess weight is predominantly carried at the waist) and abnormal blood cholesterol levels.<sup>(40)</sup>

Conversely, factors that protect the heart may protect the brain and reduce the risk of developing Alzheimer's and other dementias. Physical activity<sup>(40, 46-48)</sup> appears to be one of these factors. In addition, emerging evidence suggests that consuming a diet that benefits the heart, such as one that is low in saturated fats and rich in vegetables and vegetable-based oils, may be associated with reduced Alzheimer's and dementia risk.<sup>(40)</sup>

Unlike genetic risk factors, many of these cardiovascular disease risk factors are *modifiable* — that is, they can be changed to decrease the likelihood of developing cardiovascular disease and, possibly, the cognitive decline associated with Alzheimer's and other forms of dementia.

#### ***Education***

People with fewer years of education are at higher risk for Alzheimer's and other dementias than those with more years of formal education.<sup>(49-53)</sup> Some researchers believe that having more years of education builds a "cognitive reserve" that enables individuals to better compensate for changes in the brain that could result in symptoms of Alzheimer's or another dementia.<sup>(52, 54-56)</sup> According to the cognitive reserve hypothesis, having more years of education increases the connections between neurons in the brain and enables the brain to compensate for the early brain changes of Alzheimer's by using alternate routes of neuron-to-neuron communication to complete a cognitive task. However, some scientists believe that the increased risk of dementia among those with lower educational attainment may be explained by other factors common to people in lower socioeconomic groups, such as increased risk for disease in general and less access to medical care.<sup>(57)</sup>

#### ***Social and Cognitive Engagement***

Additional studies suggest that other modifiable factors, such as remaining mentally<sup>(58-60)</sup> and socially active, may support brain health and possibly reduce the risk of Alzheimer's and other dementias.<sup>(61-68)</sup> Remaining socially and cognitively active may help build cognitive reserve (see Education, above), but the exact mechanism by which this may occur is unknown. Compared with cardiovascular disease risk factors, there are fewer studies of the

association between social and cognitive engagement and the likelihood of developing Alzheimer's disease and other dementias. More research is needed to better understand how social and cognitive engagement may affect biological processes to reduce risk.

### ***Traumatic Brain Injury (TBI)***

Moderate and severe TBI increase the risk of developing Alzheimer's disease and other dementias.<sup>(69)</sup> 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. Not all blows or jolts to the head disrupt brain function. Moderate TBI is defined as a head injury resulting in loss of consciousness or post-traumatic amnesia that lasts more than 30 minutes. If loss of consciousness or post-traumatic amnesia lasts more than 24 hours, the injury is considered severe. Half of all moderate or severe TBIs are caused by motor vehicle accidents.<sup>(70)</sup> Moderate TBI is associated with twice the risk of developing Alzheimer's and other dementias compared with no head injuries, and severe TBI is associated with 4.5 times the risk.<sup>(71)</sup> These increased risks have not been studied for individuals experiencing occasional mild head injury or any number of common minor mishaps such as bumping one's head against a shelf or an open cabinet door.

Groups that experience repeated head injuries, such as boxers, football players<sup>(72)</sup> and combat veterans, are at higher risk of dementia, cognitive impairment and neurodegenerative disease than individuals who experience no head injury.<sup>(73-78)</sup> Emerging evidence suggests that even repeated mild TBI might promote neurodegenerative disease.<sup>(79)</sup> Some of these neurodegenerative diseases, such as chronic traumatic encephalopathy, can only be distinguished from Alzheimer's upon autopsy.

## **Treatment of Alzheimer's Disease**

### ***Pharmacologic Treatment***

Pharmacologic treatments are treatments in which medication is administered to stop an illness or treat its symptoms. None of the treatments available today for Alzheimer's disease slows or stops the death and

malfunction of neurons in the brain that cause Alzheimer's symptoms and make the disease fatal. However, dozens of drugs and therapies aimed at slowing or stopping brain cell death and malfunction are being studied worldwide. Five drugs have been approved by the U.S. Food and Drug Administration that temporarily improve symptoms of Alzheimer's disease by increasing the amount of chemicals called neurotransmitters in the brain. The effectiveness of these drugs varies across the population.

Despite the lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can improve quality of life through all stages of the disease for individuals with dementia and their caregivers.<sup>(79-81)</sup> Active management includes (1) appropriate use of available treatment options; (2) effective management of coexisting conditions; (3) coordination of care among physicians, other health care professionals and lay caregivers; (4) participation in activities and/or adult day care programs; and (5) taking part in support groups and supportive services.

### ***Nonpharmacologic Therapy***

Nonpharmacologic therapies are those that employ approaches other than medication, such as cognitive training and behavioral interventions. As with pharmacologic therapies, no nonpharmacologic therapies have been shown to alter the course of Alzheimer's disease, although some are used with the goal of maintaining cognitive function or helping the brain compensate for impairments. Other nonpharmacologic therapies are intended to improve quality of life or reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. A wide range of nonpharmacologic interventions have been proposed or studied, although few have sufficient evidence supporting their effectiveness. There is some evidence that specific nonpharmacologic therapies may improve or stabilize cognitive function, performance of daily activities, behavior, mood and quality of life.<sup>(82)</sup>

Millions of Americans have Alzheimer's disease and other dementias. The number of Americans with Alzheimer's disease and other dementias will grow each year as the number and proportion of the U.S. population age 65 and older continue to increase. The number will escalate rapidly in coming years as the baby boom generation ages.

Estimates from selected studies on the prevalence and characteristics of people with Alzheimer's and other dementias vary depending on how each study was conducted. Data from several studies are used in this section (for data sources and study methods, see the Appendices). Most estimates are from a new study using the same methods as the study that provided estimates in previous years' *Facts and Figures* reports, but with updated data.<sup>(83), A1</sup> Although some of the estimates are slightly different than estimates in previous *Facts and Figures* reports, researchers consider them to be statistically indistinguishable from previous estimates when accounting for margins of error.

### PREVALENCE OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

An estimated 5.2 million Americans of all ages have Alzheimer's disease in 2013. This includes an estimated 5 million people age 65 and older<sup>(83), A1</sup> and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.<sup>(84)</sup>

- One in nine people age 65 and older (11 percent) has Alzheimer's disease.<sup>A2</sup>
- About one-third of people age 85 and older (32 percent) have Alzheimer's disease.<sup>(83)</sup>
- Of those with Alzheimer's disease, an estimated 4 percent are under age 65, 13 percent are 65 to 74, 44 percent are 75 to 84, and 38 percent are 85 or older.<sup>(83), A3</sup>

The estimated prevalence for people age 65 and older comes from a new 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 diseases of older people. Although this estimate is slightly lower than the estimate presented in previous *Facts and Figures* reports, it does not represent a real change in prevalence. According to the lead author of both the original and the new studies on the prevalence of Alzheimer's, "Statistically, [the estimates] are comparable, and, more importantly, both old and new estimates continue to show that the burden [Alzheimer's disease] places on the population, short of any effective preventive interventions, is going to continue to increase substantially."<sup>(83)</sup>

In addition to estimates from CHAP, the national prevalence of Alzheimer's disease and all forms of dementia have been estimated from other population-based studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.<sup>(85-86), A4</sup> National estimates of the prevalence of all forms of dementia are not available from CHAP, but based on estimates from ADAMS, 13.9 percent of people age 71 and older in the United States have dementia.<sup>(85)</sup>

Prevalence studies such as CHAP and ADAMS are designed so that all individuals with dementia are detected. But in the community, only about half of those who would meet the diagnostic criteria for Alzheimer's disease and other dementias have received a diagnosis of dementia from a physician.<sup>(87)</sup> Because Alzheimer's disease is under-diagnosed, half of the estimated 5.2 million Americans with Alzheimer's may not know they have it.

The estimates from CHAP and ADAMS are based on commonly accepted criteria for diagnosing Alzheimer's disease that have been used since 1984. In 2009, an expert workgroup was convened by the Alzheimer's Association and the NIA to recommend updated diagnostic criteria and guidelines, as described in the Overview (pages 8-9). These proposed new criteria and guidelines were published in 2011.<sup>(8-11)</sup> If Alzheimer's disease can be detected earlier, in the stages of preclinical Alzheimer's and/or MCI due to Alzheimer's as defined by the 2011 criteria, the number of people reported to have Alzheimer's disease would be much larger than what is presented in this report.

### **Prevalence of Alzheimer's Disease and Other Dementias in Women and Men**

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women.<sup>(83), A5</sup> Of the 5 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.8 million are men.<sup>(83), A5</sup> Based on estimates from ADAMS, 16 percent of women age 71 and older have Alzheimer's disease and other dementias compared with 11 percent of men.<sup>(85, 88)</sup>

The larger proportion of older women who have Alzheimer's disease and other dementias is primarily explained by the fact that women live longer, on average, than men.<sup>(88-89)</sup> Many studies of the age-specific incidence (development of new cases) of Alzheimer's disease<sup>(89-95)</sup> or any dementia<sup>(90-92, 96-97)</sup> have found no significant difference by sex. Thus, women are not more likely than men to develop dementia at any given age.

### **Prevalence of Alzheimer's Disease and Other Dementias by Years of Education**

People with fewer years of education appear to be at higher risk for Alzheimer's and other dementias than those with more years of education.<sup>(91, 94, 97-99)</sup> Some of the possible reasons are explained in the Risk Factors for Alzheimer's Disease section of the Overview (page 12).

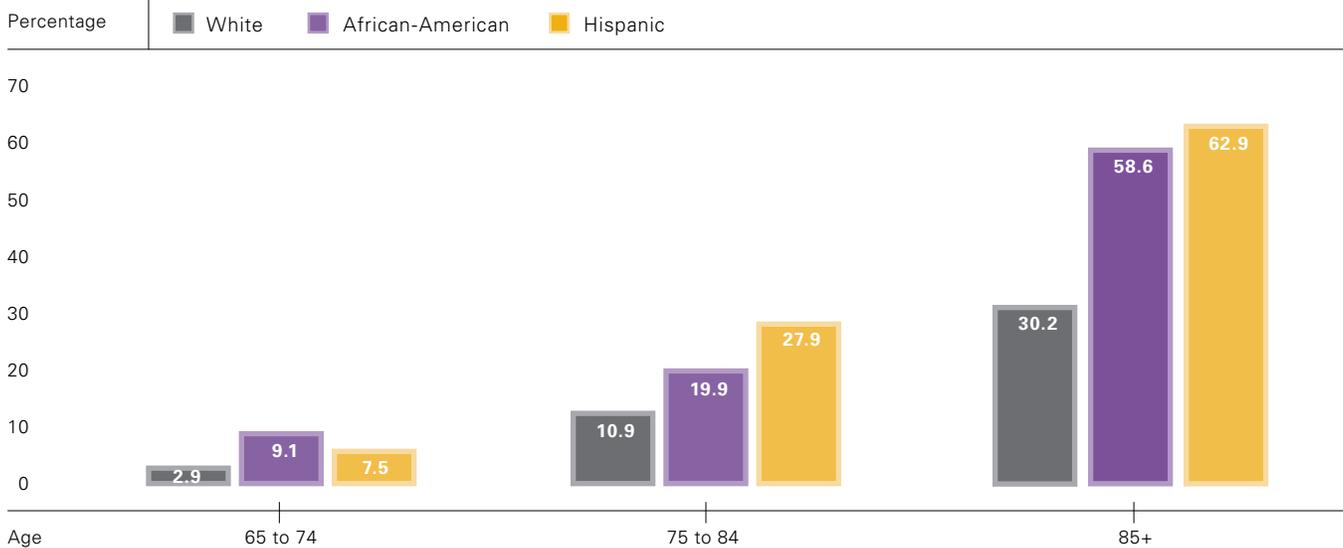
### **Prevalence of Alzheimer's Disease and Other Dementias in Older Whites, African-Americans and Hispanics**

While most people in the United States living with Alzheimer's and other dementias are non-Hispanic whites, older African-Americans and Hispanics are proportionately more likely than older whites to have Alzheimer's disease and other dementias.<sup>(100-101)</sup> Data indicate that in the United States, older African-Americans are probably about twice as likely to have Alzheimer's and other dementias as older whites,<sup>(102)</sup> and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites.<sup>(103)</sup> Figure 1 shows the estimated prevalence for each group, by age.

Despite some evidence of racial differences in the influence of genetic risk factors on Alzheimer's and other dementias, genetic factors do not appear to account for these large prevalence differences across racial groups.<sup>(104)</sup> Instead, health conditions such as high blood pressure and diabetes that may increase one's risk for Alzheimer's disease and other dementias are believed to account for these differences because they are more prevalent in African-American and Hispanic people. Lower levels of education and other socioeconomic characteristics in these communities may also increase risk. Some studies suggest that differences based on race and ethnicity do not persist in detailed analyses that account for these factors.<sup>(85, 91)</sup>

There is evidence that missed diagnoses are more common among older African-Americans and Hispanics than among older whites.<sup>(105-106)</sup> A recent study of Medicare beneficiaries found that Alzheimer's disease and other dementias had been diagnosed in 8.2 percent of white beneficiaries, 11.3 percent of African-American beneficiaries and 12.3 percent of Hispanic beneficiaries.<sup>(107)</sup> Although rates of diagnosis were higher among African-Americans than among whites, this difference was not as great as would be expected based on the estimated differences found in prevalence studies, which are designed to detect all people who have dementia.

**FIGURE 1** PROPORTION OF PEOPLE AGE 65 AND OLDER WITH ALZHEIMER’S DISEASE AND OTHER DEMENTIAS



Created from data from Gurland et al. <sup>(103)</sup>

### INCIDENCE AND LIFETIME RISK OF ALZHEIMER’S DISEASE

While prevalence is the number of *existing* cases of a disease in a population at a given time, incidence is the number of *new* cases of a disease that develop in a given time period. The estimated annual incidence (rate of developing disease in one year) of Alzheimer’s disease appears to increase dramatically with age, from approximately 53 new cases per 1,000 people age 65 to 74, to 170 new cases per 1,000 people age 75 to 84, to 231 new cases per 1,000 people age 85 and older (the “oldest-old”).<sup>(108)</sup> Some studies have found that incidence rates drop off after age 90, but these findings are controversial. One analysis indicates that dementia incidence may continue to increase and that previous observations of a leveling off of incidence rates among the oldest-old may be due to sparse data for this group.<sup>(109)</sup> Because of the increasing number of people age 65 and older in the United States, the annual number of new cases of Alzheimer’s and other dementias is projected to double by 2050.<sup>(108)</sup>

- Every 68 seconds, someone in the United States develops Alzheimer’s.<sup>A6</sup>
- By mid-century, someone in the United States will develop the disease every 33 seconds.<sup>A6</sup>

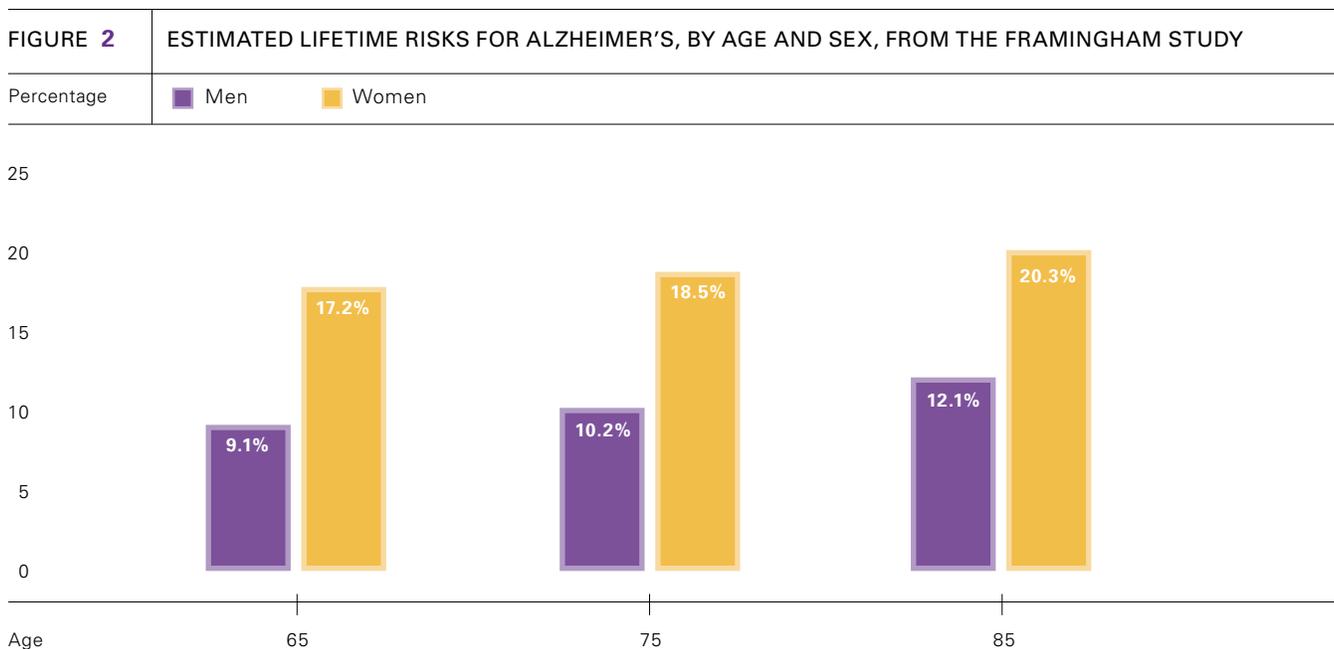
Lifetime risk is the probability that someone of a given age develops a condition during their remaining lifespan. Data from the Framingham Study were used to estimate lifetime risks of Alzheimer’s disease and of any dementia.<sup>(110), A7</sup> The study found that 65-year-old women without dementia had a 20 percent chance of developing dementia during the remainder of their lives (estimated lifetime risk), compared with a 17 percent chance for men. As shown in Figure 2 (page 18), for Alzheimer’s disease specifically, the estimated lifetime risk at age 65 was nearly one in five (17.2 percent) for women compared with one in 11 (9.1 percent) for men.<sup>(110), A8</sup> As previously noted, these differences in lifetime risks between women and men are largely due to women’s longer life expectancy.

The definition of Alzheimer’s disease and other dementias used in the Framingham Study required documentation of moderate to severe disease as well as symptoms lasting a minimum of six months. Using a definition that also includes milder disease and disease of less than six months’ duration, lifetime risks of Alzheimer’s disease and other dementias would be much higher than those estimated by this study.

**ESTIMATES OF THE NUMBER OF PEOPLE WITH ALZHEIMER’S DISEASE, BY STATE**

Table 2 (pages 21–22) summarizes the projected total number of people age 65 and older with Alzheimer’s disease by state for 2000, 2010 and 2025.<sup>A9</sup> The percentage changes in the number of people with Alzheimer’s between 2000 and 2010 and between 2000 and 2025 are also shown. Note that the total number of people with Alzheimer’s is larger for states with larger populations, such as California and New York. Comparable estimates and projections for other types of dementia are not available.

As shown in Figure 3, between 2000 and 2025 some states and regions across the country are expected to experience double-digit percentage increases in the numbers of people with Alzheimer’s due to increases in the proportion of the population age 65 and older. The South and West are expected to experience 50 percent and greater increases in numbers of people with Alzheimer’s between 2000 and 2025. Some states (Alaska, Colorado, Idaho, Nevada, Utah and Wyoming) are projected to experience a doubling (or more) of the number of people with Alzheimer’s. Although the projected increases in the Northeast are not nearly as marked as those in other regions of the United States, it should be noted that this region of the country currently has a large proportion of people with Alzheimer’s relative to other regions because this region already has a high proportion of people age 65 and older. The increasing number of individuals with Alzheimer’s will have a marked impact on states’ health care systems, as well as on families and caregivers.

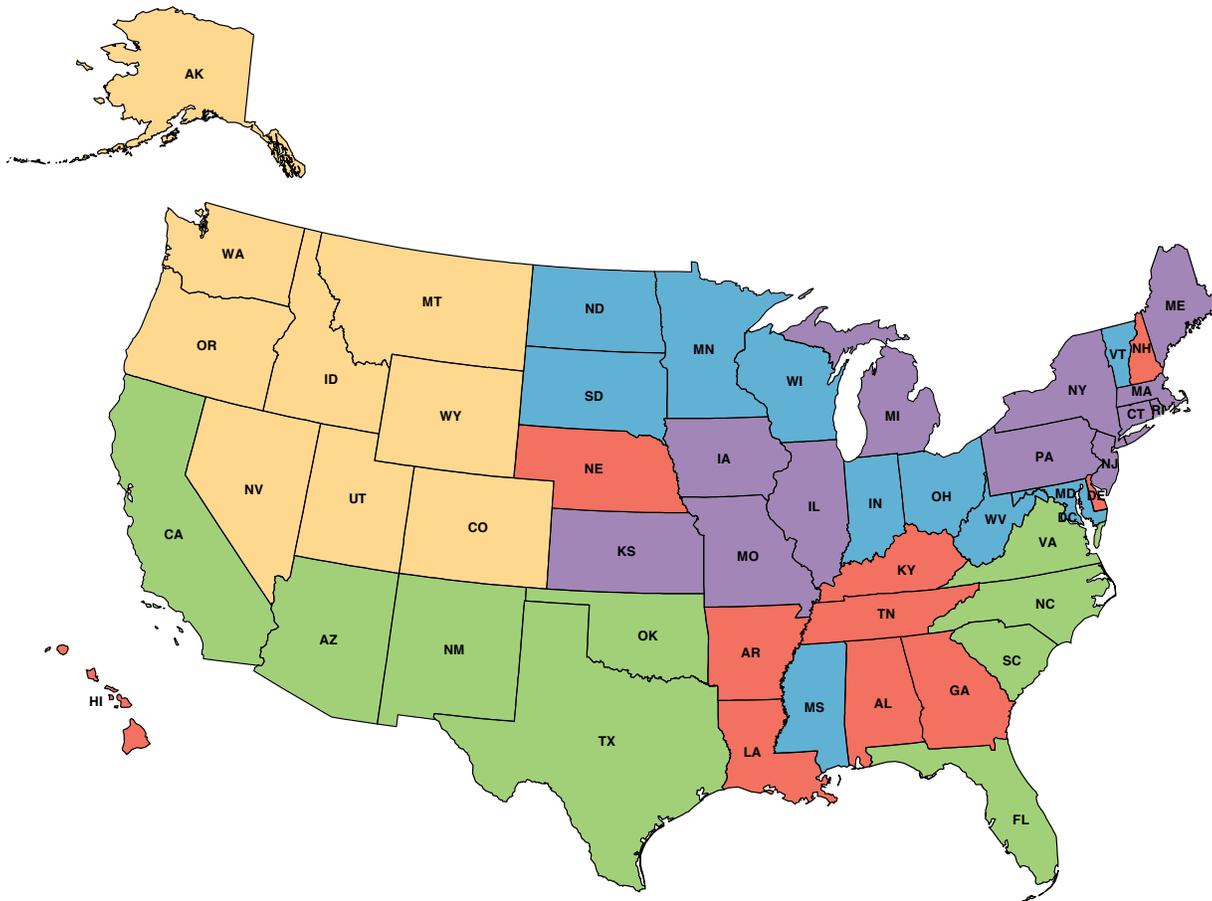


Created from data from Seshadri et al.<sup>(110)</sup>

FIGURE 3

PROJECTED CHANGES BETWEEN 2000 AND 2025 IN ALZHEIMER'S PREVALENCE BY STATE

0 – 24.0%    
  24.1% – 31.0%    
  31.1% – 49.0%    
  49.1% – 81.0%    
  81.1% – 127.0%



Created from data from Hebert et al.<sup>A9</sup>

### LOOKING TO THE FUTURE

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions.<sup>(111)</sup> Additionally, a large segment of the American population — the baby boom generation — has begun to reach the age

range of elevated risk for Alzheimer's and other dementias, with the first baby boomers having reached age 65 in 2011. By 2030, the segment of the U.S. population age 65 and older is expected to grow dramatically, and the estimated 72 million older Americans will make up approximately 20 percent of the total population (up from 13 percent in 2010).<sup>(111)</sup>

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer’s disease, as shown in Figure 4.<sup>(83), A10</sup>

- In 2000, there were an estimated 411,000 new cases of Alzheimer’s disease. For 2010, that number was estimated to be 454,000 (a 10 percent increase); by 2030, it is projected to be 615,000 (a 50 percent increase from 2000); and by 2050, 959,000 (a 130 percent increase from 2000).<sup>(108)</sup>
- By 2025, the number of people age 65 and older with Alzheimer’s disease is estimated to reach 7.1 million — a 40 percent increase from the 5 million age 65 and older currently affected.<sup>(83), A11</sup>
- By 2050, the number of people age 65 and older with Alzheimer’s disease may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow or stop the disease.<sup>(83), A10</sup> Previous estimates suggest that this number may be as high as 16 million.<sup>(112), A12</sup>

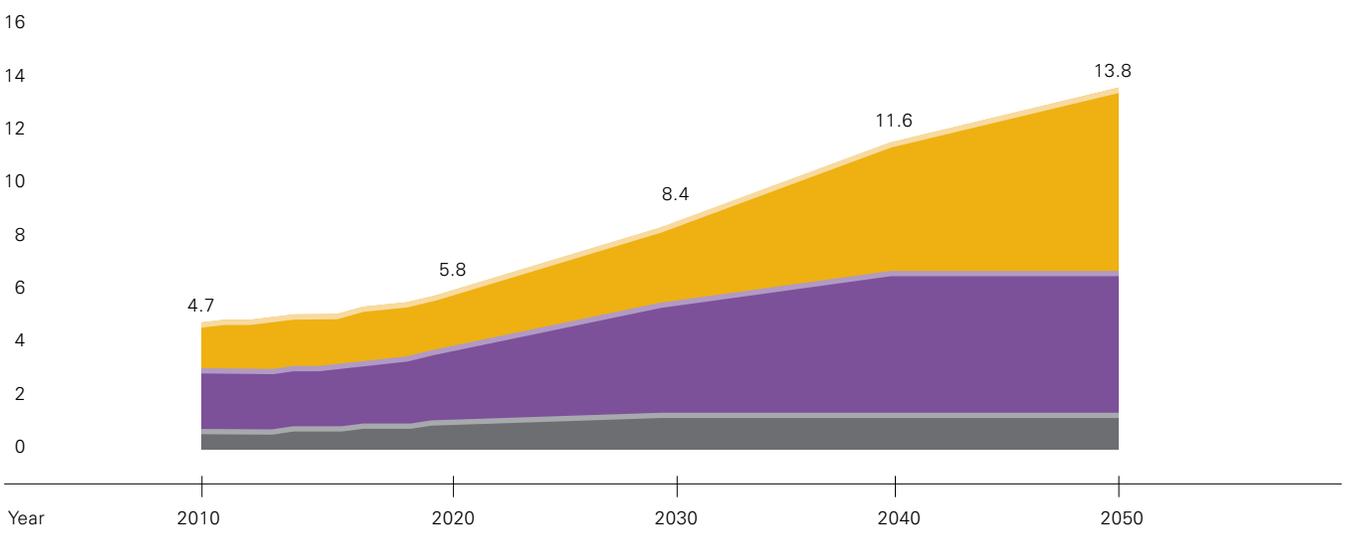
Longer life expectancies and aging baby boomers will also increase the number and percentage of Americans who will be among the oldest-old. Between 2010 and 2050, the oldest-old are expected to increase from 14 percent of all people age 65 and older in the United States to 20 percent of all people age 65 and older.<sup>(111)</sup> This will result in an additional 13 million oldest-old people — individuals at the highest risk for developing Alzheimer’s.<sup>(111)</sup>

- By 2050, the number of Americans age 85 years and older will nearly quadruple to 21 million.<sup>(111)</sup>
- In 2013, the 85-years-and-older population includes about 2 million people with Alzheimer’s disease, or 40 percent of all people with Alzheimer’s age 65 and older.<sup>(83)</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 are likely to have Alzheimer’s.<sup>(83)</sup>

**FIGURE 4** PROJECTED NUMBER OF PEOPLE AGE 65 AND OLDER (TOTAL AND BY AGE GROUP) IN THE U.S. POPULATION WITH ALZHEIMER’S DISEASE, 2010 TO 2050

Millions of people with Alzheimer’s

■ Ages 65-74   ■ Ages 75-84   ■ Ages 85+



Created from data from Hebert et al.<sup>(83), A10</sup>

TABLE 2

## PROJECTIONS OF TOTAL NUMBERS OF AMERICANS AGE 65 AND OLDER WITH ALZHEIMER'S, BY STATE

State	Projected Total Numbers (in 1,000s) with Alzheimer's			Percentage Change in Alzheimer's (Compared with 2000)	
	2000	2010	2025	2010	2025
Alabama	84.0	91.0	110.0	8	31
Alaska	3.4	5.0	7.7	47	126
Arizona	78.0	97.0	130.0	24	67
Arkansas	56.0	60.0	76.0	7	36
California	440.0	480.0	660.0	9	50
Colorado	49.0	72.0	110.0	47	124
Connecticut	68.0	70.0	76.0	3	12
Delaware	12.0	14.0	16.0	17	33
District of Columbia	10.0	9.1	10.0	-9	0
Florida	360.0	450.0	590.0	25	64
Georgia	110.0	120.0	160.0	9	45
Hawaii	23.0	27.0	34.0	17	48
Idaho	19.0	26.0	38.0	37	100
Illinois	210.0	210.0	240.0	0	14
Indiana	100.0	120.0	130.0	20	30
Iowa	65.0	69.0	77.0	6	18
Kansas	50.0	53.0	62.0	6	24
Kentucky	74.0	80.0	97.0	8	31
Louisiana	73.0	83.0	100.0	14	37
Maine	25.0	25.0	28.0	0	12
Maryland	78.0	86.0	100.0	10	28
Massachusetts	120.0	120.0	140.0	0	17
Michigan	170.0	180.0	190.0	6	12
Minnesota	88.0	94.0	110.0	7	25
Mississippi	51.0	53.0	65.0	4	27
Missouri	110.0	110.0	130.0	0	18
Montana	16.0	21.0	29.0	31	81
Nebraska	33.0	37.0	44.0	12	33
Nevada	21.0	29.0	42.0	38	100
New Hampshire	19.0	22.0	26.0	16	37
New Jersey	150.0	150.0	170.0	0	13

TABLE 2 (cont.)

## PROJECTIONS OF TOTAL NUMBERS OF AMERICANS AGE 65 AND OLDER WITH ALZHEIMER'S, BY STATE

State	Projected Total Numbers (in 1,000s) with Alzheimer's			Percentage Change in Alzheimer's (Compared with 2000)	
	2000	2010	2025	2010	2025
New Mexico	27.0	31.0	43.0	15	59
New York	330.0	320.0	350.0	-3	6
North Carolina	130.0	170.0	210.0	31	62
North Dakota	16.0	18.0	20.0	13	25
Ohio	200.0	230.0	250.0	15	25
Oklahoma	62.0	74.0	96.0	19	55
Oregon	57.0	76.0	110.0	33	93
Pennsylvania	280.0	280.0	280.0	0	0
Rhode Island	24.0	24.0	24.0	0	0
South Carolina	67.0	80.0	100.0	19	49
South Dakota	17.0	19.0	21.0	12	24
Tennessee	100.0	120.0	140.0	20	40
Texas	270.0	340.0	470.0	26	74
Utah	22.0	32.0	50.0	45	127
Vermont	10.0	11.0	13.0	10	30
Virginia	100.0	130.0	160.0	30	60
Washington	83.0	110.0	150.0	33	81
West Virginia	40.0	44.0	50.0	10	25
Wisconsin	100.0	110.0	130.0	10	30
Wyoming	7.0	10.0	15.0	43	114

Created from data from Hebert et al.<sup>A9</sup>

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States.<sup>(113)</sup> It is the fifth-leading cause of death for those age 65 and older.<sup>(113)</sup> However, it may cause even more deaths than official sources recognize.

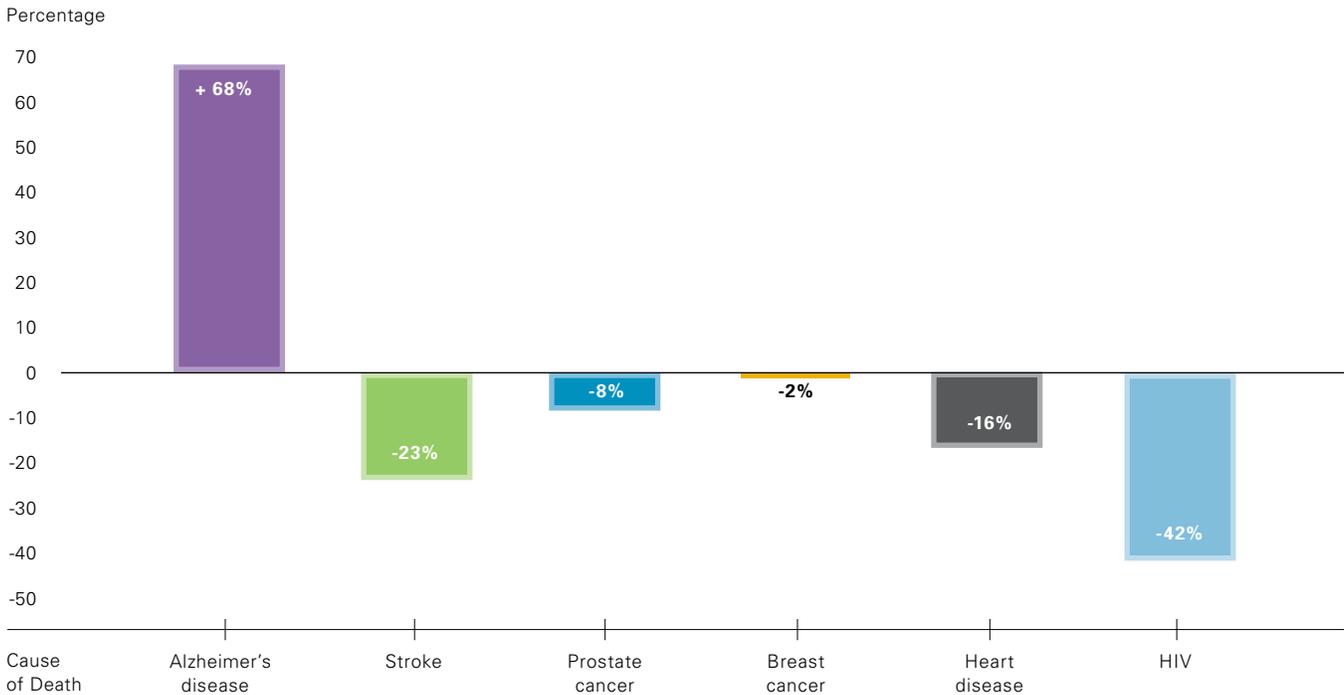
### DEATHS FROM ALZHEIMER'S DISEASE

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 final data from the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), 83,494 people died from Alzheimer's disease in 2010 (the most recent year for which final data are available).<sup>(113)</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 by the World Health Organization as "the disease or injury which initiated the train of events leading directly to death."<sup>(114)</sup> However, death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.<sup>(115-117)</sup> Severe dementia frequently causes complications such as immobility, swallowing disorders and malnutrition that can significantly increase the risk of other serious conditions that can cause death. One such condition is pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with Alzheimer's disease and other dementias.<sup>(118-119)</sup> The number of people with Alzheimer's and other dementias who die while experiencing these conditions may not be counted among the number of people who died *from* Alzheimer's disease according to the CDC definition, even though Alzheimer's disease is likely a contributing cause of death. Thus, it is likely that Alzheimer's disease is a contributing cause of death for more Americans than is indicated by CDC data.

The situation has been described as a "blurred distinction between death *with* dementia and death *from* dementia."<sup>(120)</sup> According to CHAP data, an estimated 400,000 people died *with* Alzheimer's in 2010, meaning they died after developing Alzheimer's disease.<sup>A13</sup> Furthermore, according to Medicare data, one-third of all seniors who die in a given year have been previously diagnosed with Alzheimer's or another dementia.<sup>(107, 121)</sup> Although some seniors who die with Alzheimer's disease die from causes that were 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. A recent study evaluated the contribution of individual common diseases to death using a nationally representative sample of older adults, and it found that dementia was the second largest contributor to death behind heart failure.<sup>(122)</sup> Thus, for people who die with Alzheimer's disease and other dementias, dementia is expected to be a significant direct contributor to their deaths.

In 2013, an estimated 450,000 people in the United States will die *with* Alzheimer's.<sup>A13</sup> The true number of deaths caused by Alzheimer's is likely to be somewhere between the official estimated numbers of those dying from Alzheimer's (as indicated by death certificates) and those dying with Alzheimer's (that is, dying after developing Alzheimer's). Regardless of the cause of death, among people age 70, 61 percent of those with Alzheimer's are expected to die before age 80 compared with 30 percent of people without Alzheimer's.<sup>(123)</sup>

**FIGURE 5** | PERCENTAGE CHANGES IN SELECTED CAUSES OF DEATH (ALL AGES) BETWEEN 2000 AND 2010



Created from data from the National Center for Health Statistics.<sup>(113,124)</sup>

### **PUBLIC HEALTH IMPACT OF DEATHS FROM ALZHEIMER'S DISEASE**

As the population of the United States ages, Alzheimer's is becoming a more common cause of death. While deaths from other major causes have decreased significantly, deaths from Alzheimer's disease have increased significantly. Between 2000 and 2010, deaths attributed to Alzheimer's disease increased 68 percent, while those attributed to the number one cause of death, heart disease, decreased 16 percent (Figure 5).<sup>(113, 124)</sup> The increase in the number and proportion of death certificates listing Alzheimer's as the underlying cause of death reflects both changes in patterns of reporting deaths on death certificates

over time as well as an increase in the actual number of deaths attributable to Alzheimer's.

Another way to describe the impact of Alzheimer's disease on mortality is through a statistic known as population attributable risk. It represents the proportion of deaths (in a specified amount of time) in a population that may be preventable if a disease were eliminated. The population attributable risk of Alzheimer's disease on mortality over five years in people age 65 and older is estimated to be between 5 percent and 15 percent.<sup>(125-126)</sup> This means that over the next five years, 5 percent to 15 percent of all deaths in older people can be attributed to Alzheimer's disease.

**TABLE 3** NUMBER OF DEATHS AND ANNUAL MORTALITY RATE (PER 100,000) DUE TO ALZHEIMER'S DISEASE, BY STATE, 2010

State	Number of Deaths	Rate	State	Number of Deaths	Rate
Alabama	1,523	31.9	Montana	302	30.5
Alaska	85	12.0	Nebraska	565	30.9
Arizona	2,327	36.4	Nevada	296	11.0
Arkansas	955	32.8	New Hampshire	396	30.1
California	10,856	29.1	New Jersey	1,878	21.4
Colorado	1,334	26.5	New Mexico	343	16.7
Connecticut	820	22.9	New York	2,616	13.5
Delaware	215	23.9	North Carolina	2,817	29.5
District of Columbia	114	18.9	North Dakota	361	53.7
Florida	4,831	25.7	Ohio	4,109	35.6
Georgia	2,080	21.5	Oklahoma	1,015	27.1
Hawaii	189	13.9	Oregon	1,300	33.9
Idaho	410	26.2	Pennsylvania	3,591	28.3
Illinois	2,927	22.8	Rhode Island	338	32.1
Indiana	1,940	29.9	South Carolina	1,570	33.9
Iowa	1,411	46.3	South Dakota	398	48.9
Kansas	825	28.9	Tennessee	2,440	38.4
Kentucky	1,464	33.7	Texas	5,209	20.7
Louisiana	1,295	28.6	Utah	375	13.6
Maine	502	37.8	Vermont	238	38.0
Maryland	986	17.1	Virginia	1,848	23.1
Massachusetts	1,773	27.1	Washington	3,025	45.0
Michigan	2,736	27.7	West Virginia	594	32.1
Minnesota	1,451	27.4	Wisconsin	1,762	31.0
Mississippi	927	31.2	Wyoming	146	25.9
Missouri	1,986	33.2	<b>U.S. Total</b>	<b>83,494</b>	<b>27.0</b>

Created from data from the National Center for Health Statistics.<sup>(113)</sup>

## STATE-BY-STATE DEATHS FROM ALZHEIMER'S DISEASE

Table 3 provides information on the number of deaths due to Alzheimer's by state in 2010, 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 2010, the mortality rate for Alzheimer's disease was 27 deaths per 100,000 people.<sup>(113)</sup>

## DEATH RATES BY AGE

Although people younger than 65 can develop and die from Alzheimer's disease, the highest risk of death from Alzheimer's is in people age 65 or older. As seen in Table 4, death rates for Alzheimer's increase dramatically with age. Compared with the rate of death due to any cause among people age 65 to 74, death rates were 2.6 times as high for those age 75 to 84 and 7.4 times as high for those age 85 and older. For diseases of the heart, mortality rates were 2.9 times and 10.5 times as high, respectively. For all cancers, mortality rates were 1.8 times as high and 2.6 times as high, respectively. In contrast, Alzheimer's disease death rates were 9.3 times as high for people age 75 to 84 and 49.9 times as high for people 85 and older compared with the Alzheimer's disease death rate among people age 65 to 74.<sup>(113)</sup> The high death rate at older ages for Alzheimer's underscores the lack of a cure or effective treatments for the disease.

Age	2000	2002	2004	2006	2008	2010
45-54	0.2	0.1	0.2	0.2	0.2	0.3
55-64	2.0	1.9	1.8	2.1	2.2	2.1
65-74	18.7	19.6	19.5	19.9	21.1	19.8
75-84	139.6	157.7	168.5	175.0	192.5	184.5
85+	667.7	790.9	875.3	923.4	1,002.2	987.1
<b>Rate*</b>	<b>18.1</b>	<b>20.8</b>	<b>22.6</b>	<b>23.7</b>	<b>25.8</b>	<b>25.1</b>

\*Reflects average death rate for ages 45 and older.

Created from data from the National Center for Health Statistics.<sup>(113)</sup>

## DURATION OF ILLNESS FROM DIAGNOSIS TO DEATH

Studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's.<sup>(126-131)</sup> This indicates the slow, insidious nature of the progression of Alzheimer's. On average, a person with Alzheimer's disease will spend more years (40 percent of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stage.<sup>(123)</sup> Much of this time will be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's compared with only 4 percent of the general population.<sup>(123)</sup> In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20 percent of cancer patients and 28 percent of people dying from all other conditions.<sup>(132)</sup> Thus, the long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease.

**Caregiving** refers to attending to another individual's health needs. Caregiving often includes assistance with one or more activities of daily living (ADLs; such as bathing and dressing).<sup>(133-134)</sup> More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias.<sup>A14</sup>

## UNPAID CAREGIVERS

Unpaid caregivers are primarily immediate family members, but they also may be other relatives and friends. In 2012, these people provided an estimated 17.5 billion hours of unpaid care, a contribution to the nation valued at over \$216 billion, which is approximately half of the net value of Wal-Mart sales in 2011 (\$419 billion)<sup>(135)</sup> and more than eight times the total sales of McDonald's in 2011 (\$27 billion).<sup>(136)</sup> Eighty percent of care provided in the community is provided by unpaid caregivers (most often family members), while fewer than 10 percent of older adults receive all of their care from paid caregivers.<sup>(137)</sup>

### Who Are the Caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's disease and other dementias.<sup>(138), A15</sup> Data from the 2010 Behavioral Risk Factor Surveillance System (BRFSS) survey conducted in Connecticut, New Hampshire, New Jersey, New York and Tennessee<sup>(138)</sup> found that 62 percent of caregivers of people with Alzheimer's disease and other dementias were women; 23 percent were 65 years of age and older; 50 percent had some college education or beyond; 59 percent were currently employed, a student or homemaker; and 70 percent were married or in a long-term relationship.<sup>(138)</sup>

The Aging, Demographics, and Memory Study (ADAMS), based on a nationally representative subsample of older adults from the Health and Retirement Survey,<sup>(139)</sup> compared two types of caregivers: those caring for people with dementia and those caring for people with cognitive problems that did not reach the threshold of dementia. The caregiver groups did not differ significantly by age (60 versus 61, respectively), gender (71 percent versus 81 percent female), race

(66 percent versus 71 percent non-Hispanic white) or marital status (70 percent versus 71 percent married). Almost half of caregivers took care of parents.<sup>(140)</sup>

The National Alliance for Caregiving (NAC)/AARP found that 30 percent of caregivers had children under 18 years old living with them; such caregivers are sometimes called "sandwich caregivers" because they simultaneously provide care for two generations.<sup>(141)</sup>

### Ethnic and Racial Diversity in Caregiving

Among caregivers of people with Alzheimer's disease and other dementias, the NAC/AARP found the following:<sup>(141)</sup>

- A greater proportion of white caregivers assist a parent than caregivers of individuals from other racial/ethnic groups (54 percent versus 38 percent).
- On average, Hispanic and African-American caregivers spend more time caregiving (approximately 30 hours per week) than non-Hispanic white caregivers (20 hours per week) and Asian-American caregivers (16 hours per week).
- Hispanic (45 percent) and African-American caregivers (57 percent) are more likely to experience high burden from caregiving than whites and Asian-Americans (about one-third and one-third, respectively).

As noted in the Prevalence section of this report, the racial/ethnic distribution of people with Alzheimer's disease will change dramatically by 2050. Given the greater likelihood of acquiring Alzheimer's disease among African-Americans and Hispanics coupled with the increasing number of African-American and Hispanic older adults by 2050, it can be assumed that family caregivers will be more ethnically and racially diverse over the next 35 years.

## Caregiving Tasks

The care provided to people with Alzheimer’s disease and other dementias is wide-ranging and in some instances all-encompassing. The types of dementia care provided are shown in Table 5.

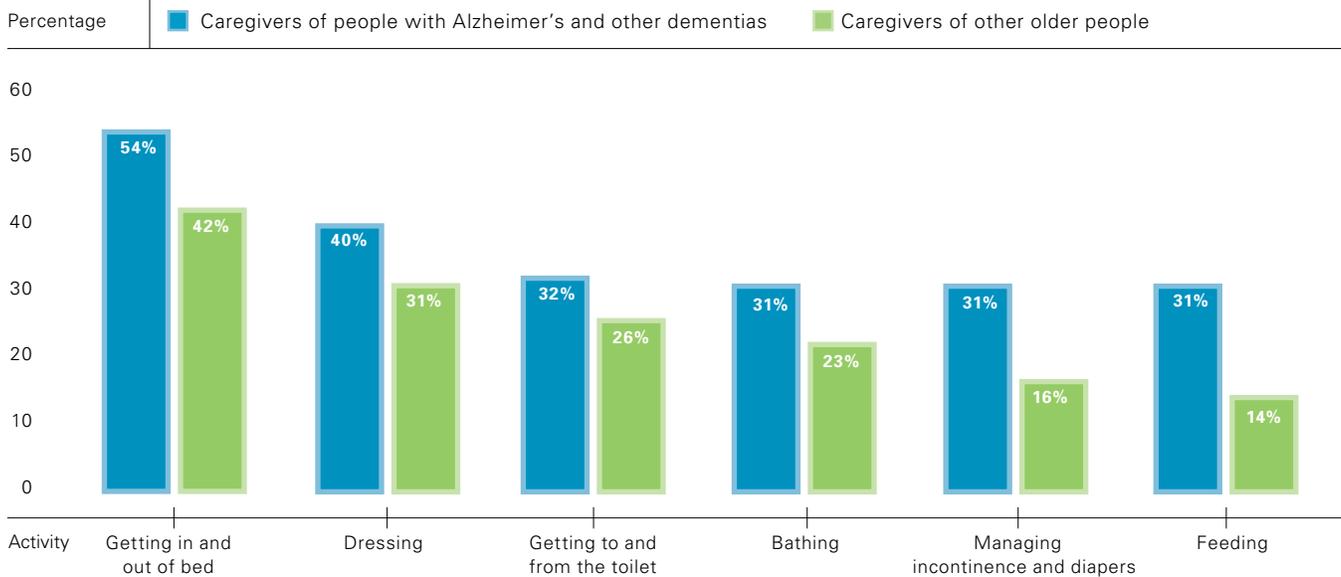
Though the care provided by family members of people with Alzheimer’s disease and other dementias is somewhat similar to the help provided by caregivers of people with other diseases, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely than caregivers of other older people to assist with any ADL (Figure 6). More than half of dementia caregivers report providing help with getting in and out of bed, and about one-third of family caregivers provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence and feeding (Figure 6). These findings suggest the heightened degree of

dependency experienced by some people with Alzheimer’s disease and other dementias. Fewer caregivers of other older people report providing help with each of these types of care.<sup>(141)</sup>

In addition to assisting with ADLs, almost two-thirds of caregivers of people with Alzheimer’s and other dementias advocate for their care recipient with government agencies and service providers (64 percent), and nearly half arrange and supervise paid caregivers from community agencies (46 percent). By contrast, caregivers of other older adults are less likely to advocate for their family member (50 percent) and supervise community-based care (33 percent).<sup>(141)</sup> Caring for a person with dementia also means managing symptoms that family caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems.

	Help 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, 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. <sup>(142)</sup>
	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: <ul style="list-style-type: none"> <li>• Providing overall management of getting through the day.</li> <li>• 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.</li> </ul>

**FIGURE 6** PROPORTION OF CAREGIVERS OF PEOPLE WITH ALZHEIMER’S AND OTHER DEMENTIAS VS. CAREGIVERS OF OTHER OLDER PEOPLE WHO PROVIDE HELP WITH SPECIFIC ACTIVITIES OF DAILY LIVING, UNITED STATES, 2009



Created from data from the National Alliance for Caregiving and AARP.<sup>(141)</sup>

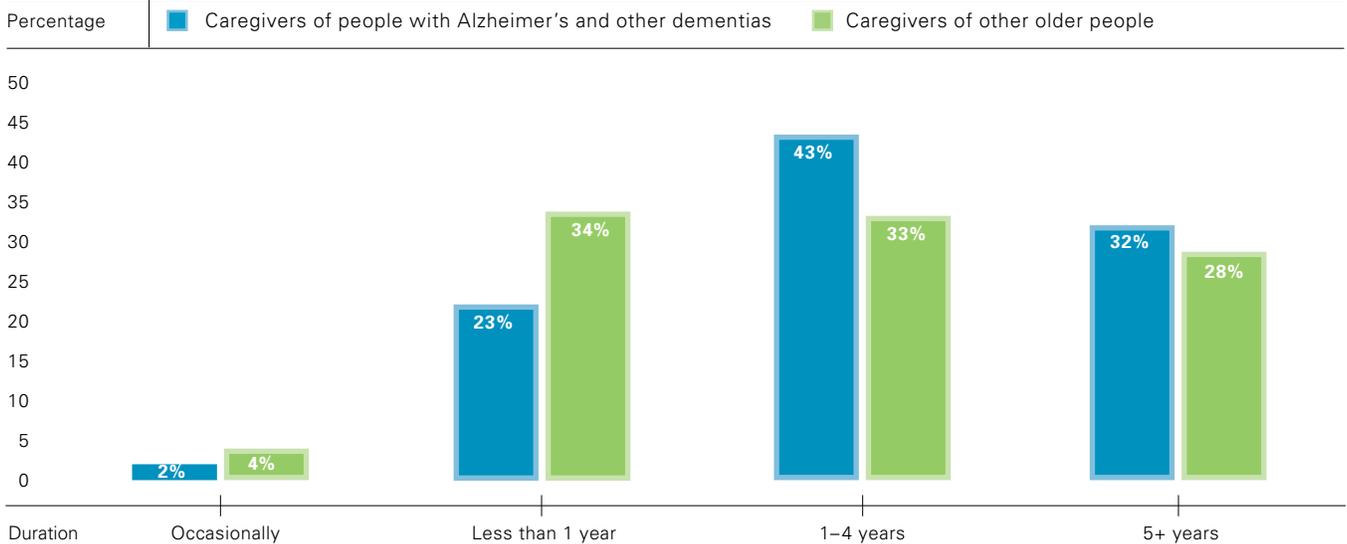
When a person with Alzheimer’s or other dementia moves to an assisted living residence or nursing home, the help provided by his or her family caregiver usually changes from hands-on, ADL types of care to visiting, providing emotional support to the relative in residential care, interacting with facility staff and advocating for appropriate care for their relative. However, some family caregivers continue to help with bathing, dressing and other ADLs.<sup>(143-145)</sup> Admitting a relative to a residential care setting (such as a nursing home) 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 significantly after admission.<sup>(145-146)</sup> The relationship between the caregiver and person with dementia may explain these discrepancies. For example, husbands,

wives and daughters were significantly more likely to indicate persistent burden up to 12 months following placement than other family caregivers, while husbands were more likely than other family caregivers to indicate persistent depression up to a year following a relative’s admission to a residential care facility.<sup>(146)</sup>

#### Duration of Caregiving

Caregivers of people with Alzheimer’s and other dementias provide care for a longer time, on average, than do caregivers of older adults with other conditions. As shown in Figure 7 (page 32), 43 percent of caregivers of people with Alzheimer’s and other dementias provide care for one to four years compared with 33 percent of caregivers of people without dementia. Similarly, 32 percent of dementia caregivers provide care for over five years compared with 28 percent of caregivers of people without dementia.<sup>(141)</sup>

**FIGURE 7** PROPORTION OF ALZHEIMER'S AND DEMENTIA CAREGIVERS VS. CAREGIVERS OF OTHER OLDER PEOPLE BY DURATION OF CAREGIVING, UNITED STATES, 2009



Created from data from the National Alliance for Caregiving and AARP.<sup>(141)</sup>

### Hours of Unpaid Care and Economic Value of Caregiving

In 2012, the 15.4 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 17.5 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>A16</sup> With this care valued at \$12.33 per hour,<sup>A17</sup> the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was \$216.4 billion in 2012. Table 6 (pages 34-35) 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 and other dementias provide care valued at more than \$1 billion in each of 39 states. Unpaid caregivers in each of the four most populous states — California, Florida, New York and Texas — provided care valued at more than \$14 billion.

Some studies suggest that family caregivers provide even more intensive daily support to people who reach a

clinical threshold of dementia. For example, a recent report from ADAMS found that family caregivers of people who were categorized as having dementia spent nine hours per day providing help to their relatives.<sup>(140)</sup>

### Impact of Alzheimer's Disease Caregiving

Caring for a person with Alzheimer's and other dementias poses special challenges. For example, people with Alzheimer's disease 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>(142)</sup> Individuals with dementia may also require increasing levels of supervision and personal care as the disease progresses. As these symptoms worsen with the progression of a relative's dementia, the care required of family members can result in family caregivers' experiencing increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, and

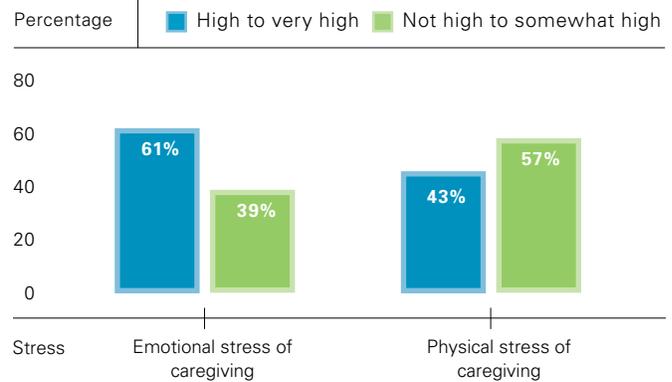
depleted income and finances.<sup>(147-152), A15</sup> The intimacy and history of experiences and memories that are often part of the relationship between a caregiver and care recipient may also be threatened due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's.

### Caregiver Emotional Well-Being

Although caregivers report some positive feelings about caregiving, including family togetherness and the satisfaction of helping others,<sup>A15</sup> they also report high levels of stress over the course of providing care:

- Based on a Level of Care Index that combined the number of hours of care and the number of ADL tasks performed by the caregiver, fewer dementia caregivers in the 2009 NAC/AARP survey were classified in the lowest level of burden compared with caregivers of people without dementia (17 percent versus 31 percent, respectively).<sup>(141)</sup>
- Sixty-one percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high (Figure 8).<sup>A15</sup>
- Most family caregivers report "a good amount" to "a great deal" of caregiving strain concerning financial issues (56 percent) and family relationships (53 percent).<sup>A15</sup>
- Earlier research in smaller samples found that over one-third (39 percent) of caregivers of people with dementia suffered from depression compared with 17 percent of non-caregivers.<sup>(153-154)</sup> A meta-analysis of research comparing caregivers affirmed this gulf in the prevalence of depression between caregivers of people with dementia and non-caregivers.<sup>(151)</sup> In the ADAMS sample, 44 percent of caregivers of people with dementia indicated depressive symptoms, compared with 27 percent of caregivers of people who had cognitive impairment but no dementia.<sup>(140)</sup>
- In the 2009 NAC/AARP survey, caregivers most likely to indicate stress were women, older, residing with the care recipient, white or Hispanic, and believed there was no choice in taking on the role of caregiver.<sup>(141)</sup>

**FIGURE 8** PROPORTION OF ALZHEIMER'S AND DEMENTIA CAREGIVERS WHO REPORT HIGH OR VERY HIGH EMOTIONAL AND PHYSICAL STRESS DUE TO CAREGIVING



Created from data from the Alzheimer's Association.<sup>A15</sup>

- When caregivers report being stressed because of the impaired person's behavioral symptoms, it increases the chance that they will place the care recipient in a nursing home.<sup>(138, 141, 155)</sup>
- Seventy-seven percent of family caregivers of people with Alzheimer's disease and other dementias said that they somewhat agree to strongly agree that there is no "right or wrong" when families decide to place their family member in a nursing home. Yet many such caregivers experience feelings of guilt, emotional upheaval and difficulties in adapting to the admission transition (for example, interacting with care staff to determine an appropriate care role for the family member).<sup>(143, 145, 156-157), A15</sup>
- Demands of caregiving may intensify as people with dementia near the end of life. In the year before the person's death, 59 percent of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful. One study of end-of-life care found that 72 percent of family caregivers said they experienced relief when the person with Alzheimer's disease or other dementia died.<sup>(145, 158-159)</sup>

TABLE 6

NUMBER OF ALZHEIMER'S AND DEMENTIA (AD/D) CAREGIVERS, HOURS OF UNPAID CARE, ECONOMIC VALUE OF THE CARE AND HIGHER HEALTH CARE COSTS OF CAREGIVERS, BY STATE, 2012\*

State	AD/D Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	Higher Health Care Costs of Caregivers (in millions of dollars)
Alabama	297	338	\$4,171	\$161
Alaska	33	37	\$459	\$26
Arizona	303	345	\$4,250	\$143
Arkansas	172	196	\$2,419	\$92
California	1,528	1,740	\$21,450	\$830
Colorado	231	264	\$3,250	\$121
Connecticut	175	200	\$2,461	\$132
Delaware	51	58	\$715	\$37
District of Columbia	26	30	\$368	\$24
Florida	1,015	1,156	\$14,258	\$630
Georgia	495	563	\$6,944	\$235
Hawaii	64	73	\$895	\$38
Idaho	76	87	\$1,067	\$37
Illinois	584	665	\$8,202	\$343
Indiana	328	373	\$4,604	\$190
Iowa	135	154	\$1,897	\$81
Kansas	149	170	\$2,099	\$88
Kentucky	266	303	\$3,731	\$152
Louisiana	226	258	\$3,180	\$134
Maine	68	77	\$951	\$50
Maryland	282	321	\$3,962	\$184
Massachusetts	325	370	\$4,557	\$262
Michigan	507	577	\$7,118	\$291
Minnesota	243	277	\$3,415	\$157
Mississippi	203	231	\$2,854	\$115

TABLE 6 (cont.)

State	AD/D Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	Higher Health Care Costs of Caregivers (in millions of dollars)
Missouri	309	351	\$4,333	\$187
Montana	47	54	\$663	\$27
Nebraska	80	92	\$1,128	\$49
Nevada	135	153	\$1,889	\$67
New Hampshire	64	73	\$905	\$44
New Jersey	439	500	\$6,166	\$289
New Mexico	105	120	\$1,480	\$61
New York	1,003	1,142	\$14,082	\$726
North Carolina	437	497	\$6,132	\$245
North Dakota	28	32	\$400	\$19
Ohio	589	671	\$8,267	\$361
Oklahoma	214	244	\$3,004	\$121
Oregon	167	191	\$2,352	\$96
Pennsylvania	667	760	\$9,369	\$447
Rhode Island	53	60	\$746	\$38
South Carolina	287	327	\$4,031	\$157
South Dakota	36	41	\$510	\$22
Tennessee	414	472	\$5,815	\$229
Texas	1,294	1,474	\$18,174	\$665
Utah	137	156	\$1,918	\$60
Vermont	30	34	\$416	\$20
Virginia	443	504	\$6,216	\$241
Washington	323	368	\$4,538	\$190
West Virginia	108	123	\$1,520	\$72
Wisconsin	189	215	\$2,656	\$120
Wyoming	27	31	\$385	\$17
<b>U.S. Totals</b>	<b>15,410</b>	<b>17,548</b>	<b>\$216,373</b>	<b>\$9,121</b>

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

Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.<sup>A14, A16, A17, A18</sup>

### ***Caregiver Physical Health***

For some caregivers, the demands of caregiving may cause declines in their own health. Specifically, family caregivers of people with dementia may experience greater risk of chronic disease, physiological impairments, increased health care utilization and mortality than those who are not caregivers.<sup>(149)</sup>

Forty-three percent of caregivers of people with Alzheimer's disease and other dementias reported that the physical impact of caregiving was high to very high (Figure 8).<sup>A15</sup>

### ***General Health***

Seventy-five percent of caregivers of people with Alzheimer's disease and other dementias reported that they were "somewhat" to "very concerned" about maintaining their own health since becoming a caregiver.<sup>A15</sup> Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor.<sup>(149)</sup> Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse.<sup>(141,160)</sup> Data from the 2010 BRFSS caregiver survey found that 7 percent of dementia caregivers say the greatest difficulty of caregiving is that it creates or aggravates their own health problems compared with 2 percent of other caregivers.<sup>(138)</sup> Other studies suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.<sup>(161)</sup>

### ***Physiological Changes***

The chronic stress of caregiving is associated with physiological changes that indicate risk of developing chronic conditions. For example, a series of recent studies found that under certain conditions some Alzheimer's caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers.<sup>(162-167)</sup> Overall, the literature remains fairly consistent in suggesting that the chronic stress of dementia care can have potentially negative influences on caregiver health.

Caregivers of a spouse with Alzheimer's or other dementias are more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones,<sup>(168)</sup> reduced immune function,<sup>(147, 169)</sup> slow wound healing,<sup>(170)</sup> increased incidence of hypertension,<sup>(171)</sup> coronary heart disease<sup>(172)</sup> and impaired endothelial function (the endothelium is the inner lining of the blood vessels). Some of these changes may be associated with an increased risk of cardiovascular disease.<sup>(173)</sup>

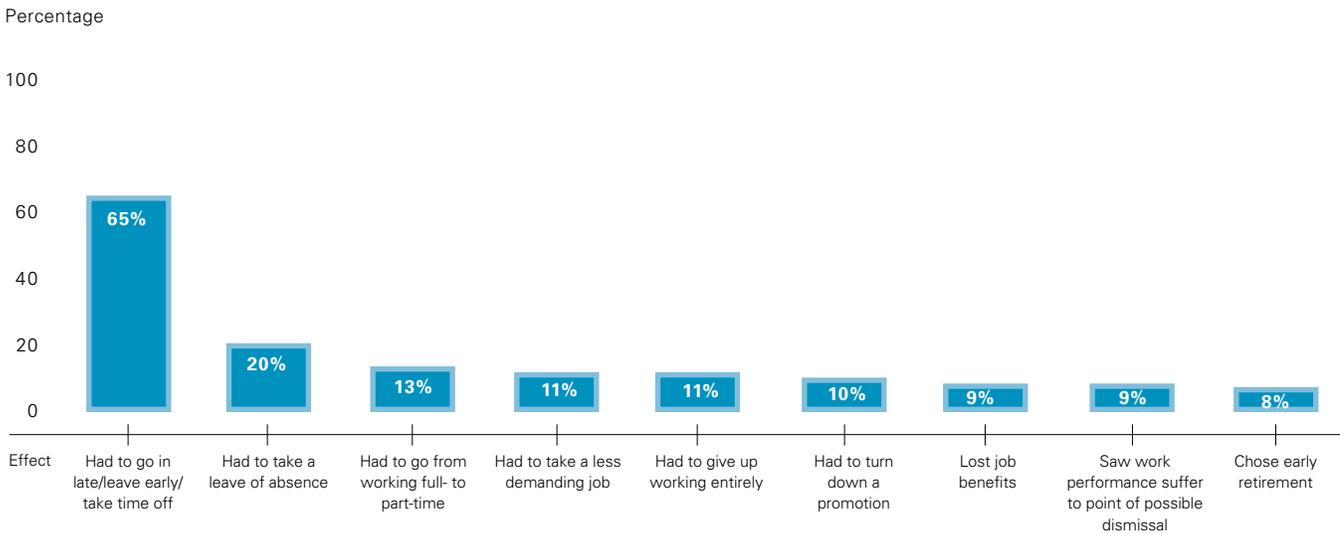
### ***Health Care Utilization***

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$9.1 billion in health care costs in the United States in 2012.<sup>A18</sup> Table 6 shows the estimated higher health care costs for Alzheimer's and dementia caregivers in each state. Dementia caregivers were more likely to visit the emergency department or be hospitalized in the preceding six months if the care recipient was depressed, had low functional status or had behavioral disturbances than if the care recipient did not exhibit these symptoms.<sup>(174)</sup>

### ***Mortality***

The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings on this issue. In one study, caregivers of spouses who were hospitalized and had medical records of dementia were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers.<sup>(175)</sup> However, other studies have found that caregivers have lower mortality rates than non-caregivers.<sup>(176-177)</sup> One study reported that higher levels of stress were associated with higher rates of mortality in both caregivers and non-caregivers.<sup>(177)</sup> These findings suggest that it is high stress, not caregiving per se, that increases the risk of mortality. Such results emphasize that dementia caregiving is a complex undertaking; simply providing care to someone with Alzheimer's disease or other dementia may not consistently result in stress or negative health problems

**FIGURE 9** EFFECT OF CAREGIVING ON WORK: WORK-RELATED CHANGES AMONG CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS



Created from data from the Alzheimer's Association.<sup>A15</sup>

for caregivers. Instead, the stress of dementia caregiving is influenced by a number of other factors, such as dementia severity, how challenging the caregivers perceive certain aspects of care to be, available social support and caregiver personality. All of these factors are important to consider when understanding the health impact of caring for a person with dementia.<sup>(178)</sup>

#### **Caregiver Employment**

Among caregivers of people with Alzheimer's disease and other dementias, about 60 percent reported being employed full- or part-time.<sup>(141)</sup> Employed dementia caregivers indicate having to make major changes to their work schedules because of their caregiving responsibilities. Sixty-five percent said they had to go in late, leave early or take time off, and 20 percent had to take a leave of absence. Other work-related changes pertaining to caregiving are summarized in Figure 9.<sup>A15</sup>

#### **Interventions that May Improve Caregiver Outcomes**

Intervention strategies to support family caregivers of people with Alzheimer's disease have been developed and evaluated. The types and focus of these interventions are summarized in Table 7 (page 38).<sup>(179)</sup>

In general, these interventions aim to lessen negative aspects of caregiving with the goal of improving health outcomes of dementia caregivers. Methods used to accomplish this objective include enhancing caregiver strategies to manage dementia-related symptoms, bolstering resources through enhanced social support and providing relief/respite from daily care demands. Desired outcomes of these interventions include decreased caregiver stress and depression and delayed nursing home admission of the person with dementia.

**TABLE 7** | TYPE AND FOCUS OF CAREGIVER INTERVENTIONS

Type of Intervention	Description
<b>Psychoeducational</b>	Includes 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 (i.e., cognitive impairment, behavioral symptoms and care-related needs). Includes lectures, discussions and written materials and is led by professionals with specialized training.
<b>Supportive</b>	Focuses on building support among participants and creating a setting in which to discuss problems, successes and feelings regarding caregiving. Group members recognize that others have similar concerns. Interventions provide opportunities to exchange ideas and strategies that are most effective. These groups may be professionally or peer-led.
<b>Psychotherapy</b>	Involves a relationship between the caregiver and a trained therapy professional. Therapists may teach such skills as self-monitoring; challenge negative thoughts and assumptions; help develop problem-solving abilities; and focus on time management, overload, management of emotions and re-engagement in pleasant activities and positive experiences.
<b>Multicomponent</b>	Includes various combinations of interventions such as psychoeducational, supportive, psychotherapy and technological approaches. These interventions are led by skilled professionals.

Created from data from Sørensen et al.<sup>(179)</sup>

Characteristics of effective caregiver interventions include programs that are administered over long periods of time, interventions that approach dementia care as an issue for the entire family, and interventions that train dementia caregivers in the management of behavioral problems.<sup>(180-182)</sup> Multidimensional interventions appear particularly effective. These approaches combine individual consultation, family sessions and support, and ongoing assistance to help dementia caregivers manage changes that occur as the disease progresses. Two examples of successful multidimensional interventions are the New York University Caregiver Intervention<sup>(183-184)</sup> and the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) II programs.<sup>(152, 179, 185-187)</sup>

Although less consistent in their demonstrated benefits, support group strategies and respite services such as adult day programs may offer encouragement or relief to enhance caregiver outcomes. The effects of pharmacological therapies for treating symptoms of dementia (for example, acetylcholinesterase inhibitors, memantine, antipsychotics and antidepressants) also appear to modestly reduce caregiver stress.<sup>(188)</sup>

Several sources<sup>(179, 182, 189-195)</sup> recommend that caregiver services identify “the risk factors and outcomes unique to each caregiver”<sup>(182)</sup> when selecting caregiver interventions. More work is needed, however, in testing the efficacy of these support programs among different caregiver groups in order to ensure their benefits for caregivers across diverse clinical, racial, ethnic, socioeconomic and geographic contexts.<sup>(196)</sup>

## PAID CAREGIVERS

### Direct-Care Workers for People with Alzheimer's Disease and Other Dementias

Direct-care workers, such as nurse aides, home health aides and personal- and home-care aides, comprise the majority of the formal health care delivery system for older adults (including those with Alzheimer's disease and other dementias). In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents.<sup>(197-198)</sup> Most nursing assistants are women, an increasing number of whom are diverse in terms of ethnic or racial background. Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.<sup>(197, 199)</sup> One review found that direct-care workers received, on average, 75 hours of training that included little focus on issues specific or pertinent to dementia care.<sup>(197)</sup> Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.<sup>(137)</sup> An additional challenge is that while direct-care workers are often at the forefront of dementia care delivery in nursing homes, these staff are unlikely to receive adequate dementia training due to insufficient administrative support. Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest, positive benefits.<sup>(200)</sup>

### Shortage of Geriatric Health Care Professionals in the United States

Professionals who may receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers and others.<sup>(137)</sup> It is projected that the United States will need an additional 3.5 million health care professionals by 2030 just to maintain the current ratio of health care professionals to the older population.<sup>(137)</sup> The need for health care professionals trained in geriatrics is escalating, but few providers choose this career path. It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs.<sup>(201)</sup> In 2010, there were 4,278 physicians practicing geriatric medicine in the United States. An estimated 36,000 geriatricians will be needed to adequately meet the needs of older adults in the United States by 2030.<sup>(137)</sup> Other health-related professions also have low numbers of geriatric specialists relative to the population's needs. According to the Institute of Medicine, less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.<sup>(137)</sup> Similarly, while 73 percent of social workers have clients age 55 and older and between 7.6 and 9.4 percent of social workers are employed in long-term care settings, only 4 percent have formal certification in geriatric social work.<sup>(137)</sup>

As the number of people with Alzheimer’s disease and other dementias grows, spending for their care will increase dramatically. For people with these conditions, aggregate payments for health care, long-term care and hospice are projected to increase from \$203 billion in 2013 to \$1.2 trillion in 2050 (in 2013 dollars).<sup>A19</sup> Medicare and Medicaid cover about 70 percent of the costs of care.

**TOTAL PAYMENTS FOR HEALTH CARE, LONG-TERM CARE AND HOSPICE**

In addition to Medicare and Medicaid, several other sources contribute to payments for costs of care. (All costs that follow are reported in 2012 dollars,<sup>A20</sup> unless otherwise indicated.) Table 8 reports the average per-person payments for health care and long-term care services for Medicare beneficiaries with Alzheimer’s disease and other dementias. In 2008, total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer’s and other dementias were three times as great as payments for other Medicare beneficiaries in the same age group (\$45,657 per person for those with dementia compared with \$14,452 per person for those without dementia).<sup>(121), A21</sup>

Twenty-nine percent of older individuals with Alzheimer’s disease and other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia.<sup>(121)</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 for the Medicaid program. In 2008, average Medicaid payments per person for Medicare beneficiaries age 65 and older with Alzheimer’s disease and other dementias were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer’s disease and other dementias (\$10,538 per person for individuals with dementia compared with \$549 for individuals without dementia; Table 8).<sup>(121)</sup>

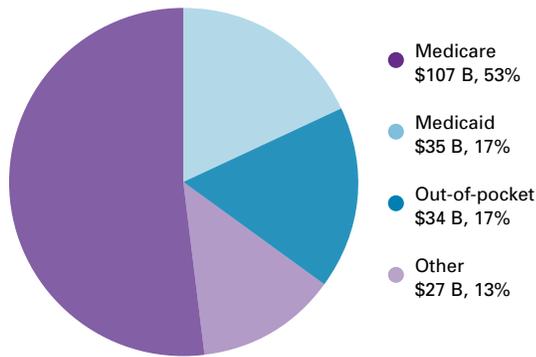
**TABLE 8** AVERAGE ANNUAL PER-PERSON PAYMENTS FOR HEALTH CARE AND LONG-TERM CARE SERVICES, MEDICARE BENEFICIARIES AGE 65 AND OLDER, WITH AND WITHOUT ALZHEIMER’S DISEASE AND OTHER DEMENTIAS AND BY PLACE OF RESIDENCE, IN 2012 DOLLARS

Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer’s Disease and Other Dementias
	Overall	Community-Dwelling	Residential Facility	
Medicare	\$20,638	\$18,380	\$23,792	\$7,832
Medicaid	10,538	232	24,942	549
Uncompensated	284	408	112	320
HMO	1,036	1,607	236	1,510
Private insurance	2,355	2,588	2,029	1,584
Other payer	943	171	2,029	149
Out-of-pocket	9,754	3,297	18,780	2,378
<b>Total*</b>	<b>45,657</b>	<b>26,869</b>	<b>71,917</b>	<b>14,452</b>

\*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.<sup>(121)</sup>

**FIGURE 10** AGGREGATE COSTS OF CARE BY PAYER FOR AMERICANS AGE 65 AND OLDER WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS, 2013\*

Total cost: \$203 Billion (B)



\*Data are in 2013 dollars.

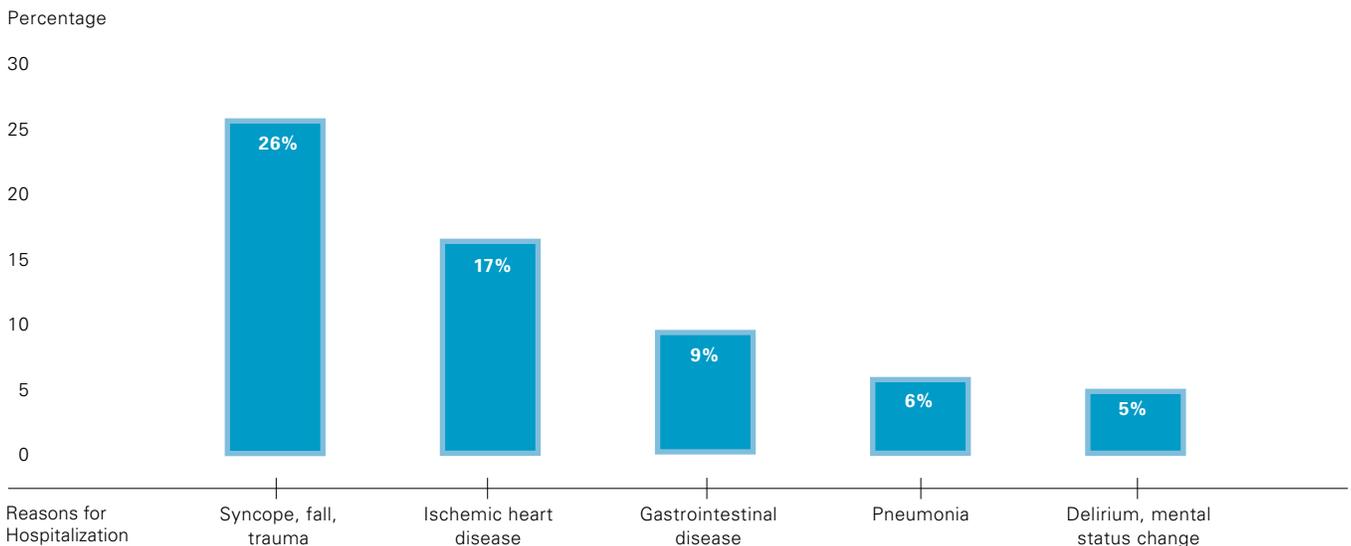
Created from data from the application of The Lewin Model<sup>A19</sup> to data from the Medicare Current Beneficiary Survey for 2008.<sup>(121)</sup> "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Total payments for 2013 are estimated at \$203 billion, including \$142 billion for Medicare and Medicaid combined in 2013 dollars (Figure 10). These figures are derived from a model developed by The Lewin Group using data from the Medicare Current Beneficiary Survey and The Lewin Group's Long-Term Care Financing Model.<sup>A19</sup>

### USE AND COSTS OF HEALTH CARE SERVICES

People with Alzheimer's disease and other dementias have more than three times as many hospital stays per year as other older people.<sup>(121)</sup> Moreover, the use of health care services for people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke

**FIGURE 11** REASONS FOR HOSPITALIZATION OF PEOPLE WITH ALZHEIMER'S DISEASE: PERCENTAGE OF HOSPITALIZED PEOPLE BY ADMITTING DIAGNOSIS\*



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

Created from data from Rudolph et al.<sup>(202)</sup>

or cancer who *also* have Alzheimer’s and other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

### Use of Health Care Services

Older people with Alzheimer’s disease and other dementias have more hospital stays, skilled nursing facility stays and home health care visits than other older people.

- *Hospital.* In 2008, there were 780 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer’s disease or other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries without these conditions.<sup>(121)</sup> The most common reasons for hospitalization of people with Alzheimer’s disease include syncope, fall and trauma (26 percent), ischemic heart disease (17 percent) and gastrointestinal disease (9 percent) (Figure 11).<sup>(202)</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>(203)</sup> In 2008, there were 349 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer’s and other dementias compared with 39 stays per 1,000 beneficiaries for people without these conditions.<sup>(121)</sup>
- *Home health care.* In 2008, 23 percent of Medicare beneficiaries age 65 and older with Alzheimer’s disease and other dementias had at least one home health visit during the year, compared with 10 percent of Medicare beneficiaries without Alzheimer’s and other dementias.<sup>(107)</sup>

**TABLE 9** AVERAGE ANNUAL PER-PERSON PAYMENTS FOR HEALTH CARE SERVICES PROVIDED TO MEDICARE BENEFICIARIES AGE 65 AND OLDER WITH AND WITHOUT ALZHEIMER’S DISEASE AND OTHER DEMENTIAS

	Beneficiaries with Alzheimer’s Disease and Other Dementias	Beneficiaries without Alzheimer’s Disease and Other Dementias
Inpatient hospital	\$10,293	\$4,138
Medical provider*	6,095	4,041
Skilled nursing facility	3,955	460
Nursing home	18,353	816
Hospice	1,821	178
Home health	1,460	471
Prescription medications**	2,787	2,840

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

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.<sup>(121)</sup>

### Costs of Health Care Services

With the exception of prescription medications, average per-person payments for all other health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility and home health care) were higher for Medicare beneficiaries with Alzheimer’s disease and other dementias than for other Medicare beneficiaries in the same age group (Table 9).<sup>(121)</sup> The fact that only payments for prescription drugs are lower for those with Alzheimer’s and other dementias underscores the lack of effective treatments available to those with dementia.

### Impact of Coexisting Medical Conditions on Use and Costs of Health Care Services

Medicare beneficiaries with Alzheimer’s disease and other dementias are more likely than those without dementia to have other chronic conditions.<sup>(107)</sup>

Table 10 reports the proportion of people with Alzheimer’s disease and other dementias who have certain coexisting medical conditions. In 2009, 30 percent of Medicare beneficiaries age 65 and older with dementia also had coronary heart disease, 29 percent also had diabetes, 22 percent also had congestive heart failure, 17 percent also had chronic kidney disease and 17 percent also had chronic obstructive pulmonary disease.<sup>(107)</sup>

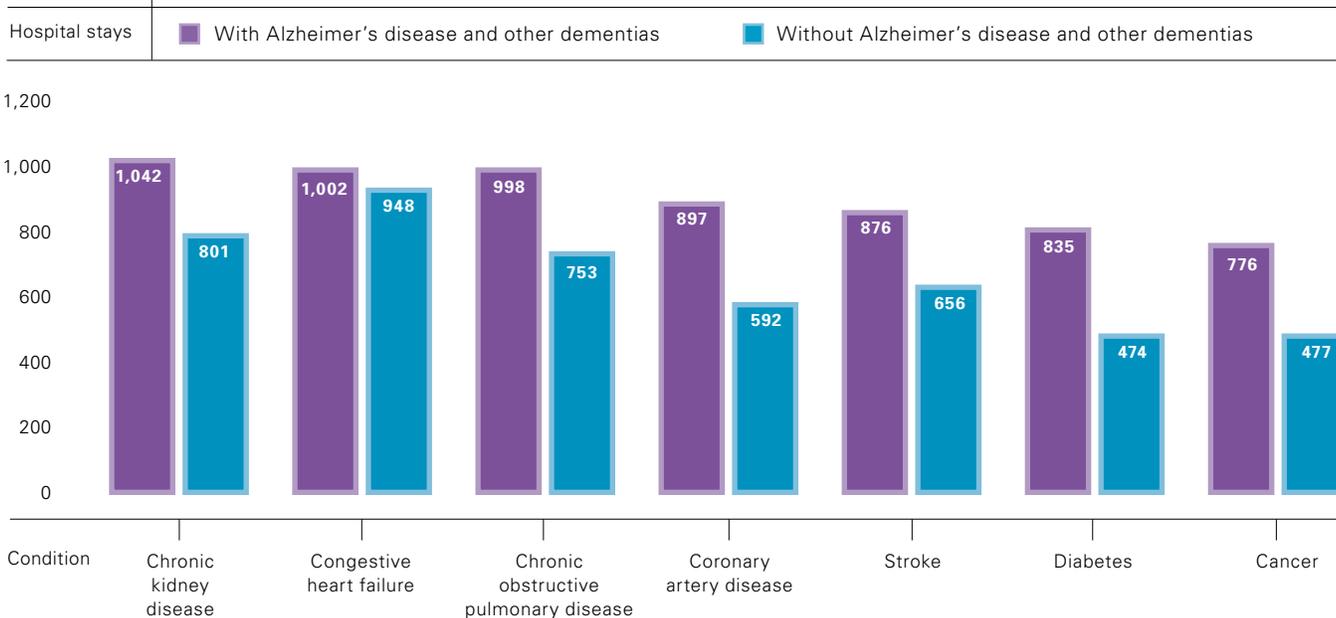
People with Alzheimer’s and other dementias in addition to other serious coexisting medical conditions are more likely to be hospitalized than people with the same coexisting medical conditions but without dementia (Figure 12).<sup>(107)</sup>

**TABLE 10** SPECIFIC COEXISTING MEDICAL CONDITIONS AMONG MEDICARE BENEFICIARIES AGE 65 AND OLDER WITH ALZHEIMER’S DISEASE AND OTHER DEMENTIAS, 2009

Coexisting Condition	Percentage of People with Alzheimer’s Disease and Other Dementias Who Also Had Coexisting Medical Condition
Coronary heart disease	30%
Diabetes	29%
Congestive heart failure	22%
Chronic kidney disease	17%
Chronic obstructive pulmonary disease	17%
Stroke	14%
Cancer	9%

Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.<sup>(107)</sup>

**FIGURE 12** HOSPITAL STAYS PER 1,000 BENEFICIARIES AGE 65 AND OLDER WITH SPECIFIED COEXISTING MEDICAL CONDITIONS, WITH AND WITHOUT ALZHEIMER’S DISEASE AND OTHER DEMENTIAS, 2009



Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.<sup>(107)</sup>

TABLE 11

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 DISEASE AND OTHER DEMENTIAS, 2009, IN 2012 DOLLARS\*

Medical Condition by Alzheimer's Disease/Dementia (AD/D) Status	Average Per-Person Medicare Payment					
	Total Medicare Payments	Hospital Care	Physician Care	Skilled Nursing Facility Care	Home Health Care	Hospice Care
<b>Coronary heart disease</b>						
With AD/D	27,286	10,312	1,718	4,344	2,721	2,347
Without AD/D	16,924	7,410	1,314	1,324	1,171	342
<b>Diabetes</b>						
With AD/D	26,627	9,813	1,608	4,211	2,802	2,121
Without AD/D	14,718	6,048	1,132	1,203	1,110	240
<b>Congestive heart failure</b>						
With AD/D	26,149	11,712	1,773	4,816	2,848	2,943
Without AD/D	30,034	11,991	1,772	2,610	2,244	833
<b>Chronic kidney disease</b>						
With AD/D	32,190	12,927	1,902	4,845	2,658	2,560
Without AD/D	24,767	10,834	1,665	1,999	1,646	530
<b>Chronic obstructive pulmonary disease</b>						
With AD/D	29,660	11,521	1,811	4,748	2,821	2,650
Without AD/D	20,260	9,029	1,488	1,730	1,516	665
<b>Stroke</b>						
With AD/D	27,774	10,160	1,669	4,557	2,578	2,758
Without AD/D	19,940	7,875	1,419	2,336	1,891	652
<b>Cancer</b>						
With AD/D	25,559	9,135	1,567	3,653	2,221	2,890
Without AD/D	16,727	6,198	1,202	989	788	592

\*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 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.<sup>(107)</sup>

Similarly, Medicare beneficiaries who have Alzheimer's and other dementias in addition to another serious coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries who have the same medical conditions without dementia. Table 11 shows the average per-person total Medicare payments and average per-person Medicare payments for hospital, physician, skilled nursing facility, home health and

hospice care for beneficiaries with other serious medical conditions who either do or do not have Alzheimer's and other dementias.<sup>(107)</sup> Medicare beneficiaries with a serious medical condition and dementia had higher average per-person payments than Medicare beneficiaries with the same medical condition but without dementia, with the exceptions of hospital care and total Medicare payments for beneficiaries with congestive heart failure.

## USE AND COSTS OF LONG-TERM CARE SERVICES

An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias.<sup>(121, 204)</sup> Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone.<sup>(121)</sup> People with Alzheimer's disease and other dementias generally receive more care from family members and other unpaid caregivers as their disease progresses. 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 in the often long course of their illness. Given the high average costs of these services (adult day services, \$70 per day;<sup>(204)</sup> assisted living, \$42,600 per year;<sup>(204)</sup> and nursing home care, \$81,030 to \$90,520 per year),<sup>(204)</sup> individuals often spend down their income and assets and eventually qualify for Medicaid. 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.

### Use of Long-Term Care Services by Setting

Most people with Alzheimer's disease and 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. A study of older people who needed help to perform daily activities — such as dressing, bathing, shopping and managing money — found that those who also had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care.<sup>(205)</sup> In addition, those who had cognitive impairment and received paid services used almost twice as many hours of care monthly as those who did not have cognitive impairment.<sup>(205)</sup>

People with Alzheimer's and other dementias make up a large proportion of all elderly people who receive nonmedical home care, adult day services and nursing home care.

- *Home care.* According to state home care programs in Connecticut, Florida and Michigan, more than one-third (about 37 percent) of older people who receive primarily nonmedical home care services, such as personal care and homemaker services, have cognitive impairment consistent with dementia.<sup>(206-208)</sup>
- *Adult day services.* At least half of elderly attendees at adult day centers have dementia.<sup>(209-210)</sup>
- *Assisted living and residential care.* Forty-two percent of residents in assisted living and residential care facilities had Alzheimer's disease and other dementias in 2010.<sup>(211)</sup>
- *Nursing home care.* Of all nursing home residents, 68 percent have some degree of cognitive impairment. Twenty-seven percent have very mild to mild cognitive impairment, and 41 percent have moderate to severe cognitive impairment (Table 12).<sup>(212)</sup> Of all Medicare beneficiaries age 65 and older living in a nursing home, 64 percent have Alzheimer's disease and other dementias.<sup>(121)</sup>
- *Alzheimer's special care units.* An Alzheimer's special care unit is a separate unit in a nursing home that has special services for individuals with Alzheimer's and other dementias. Nursing homes had a total of 79,937 beds in Alzheimer's special care units in June 2012.<sup>(213)</sup> These Alzheimer's special care unit beds accounted for 72 percent of all special care unit beds and 5 percent of all nursing home beds at that time. The number of nursing home beds in Alzheimer's special care units increased in the 1980s but has decreased since 2004, when there were 93,763 beds in such units.<sup>(214)</sup>

**TABLE 12** COGNITIVE IMPAIRMENT IN NURSING HOME RESIDENTS, BY STATE, 2009

State	Total Nursing Home Residents*	Percentage of Residents at Each Stage of Cognitive Impairment**		
		None	Very Mild/Mild	Moderate/Severe
Alabama	52,312	29	27	44
Alaska	1,328	32	29	39
Arizona	41,703	48	24	28
Arkansas	33,723	23	29	48
California	259,778	36	26	38
Colorado	40,681	33	29	39
Connecticut	63,252	39	25	36
Delaware	9,842	35	28	37
District of Columbia	5,448	36	26	38
Florida	212,553	41	23	36
Georgia	68,186	16	23	61
Hawaii	8,574	25	22	53
Idaho	12,558	34	26	40
Illinois	169,385	29	32	39
Indiana	84,063	37	29	34
Iowa	48,471	22	31	47
Kansas	35,871	24	31	45
Kentucky	50,942	32	24	44
Louisiana	43,523	25	26	49
Maine	18,802	37	25	38
Maryland	65,917	40	23	37
Massachusetts	103,135	36	23	41
Michigan	104,790	33	26	41
Minnesota	70,474	30	30	40
Mississippi	29,306	23	29	48
Missouri	78,350	31	31	39
Montana	10,795	24	30	46
Nebraska	27,007	28	30	42
Nevada	13,630	43	26	31
New Hampshire	15,831	34	24	42
New Jersey	120,300	42	24	34
New Mexico	13,423	32	28	40

TABLE 12 (cont.)

## COGNITIVE IMPAIRMENT IN NURSING HOME RESIDENTS, BY STATE, 2009

State	Total Nursing Home Residents*	Percentage of Residents at Each Stage of Cognitive Impairment**		
		None	Very Mild/Mild	Moderate/Severe
New York	232,754	35	25	40
North Carolina	89,429	35	24	42
North Dakota	10,609	22	31	47
Ohio	190,576	30	27	42
Oklahoma	37,263	29	31	40
Oregon	27,099	37	29	34
Pennsylvania	189,524	33	28	40
Rhode Island	17,388	32	28	40
South Carolina	39,616	29	23	48
South Dakota	11,347	20	31	49
Tennessee	71,723	26	27	48
Texas	192,450	19	30	51
Utah	17,933	38	27	34
Vermont	7,106	31	24	45
Virginia	73,685	34	26	39
Washington	57,335	33	28	39
West Virginia	21,815	37	21	42
Wisconsin	73,272	35	27	38
Wyoming	4,792	19	28	54
<b>U.S. Total</b>	<b>3,279,669</b>	<b>32</b>	<b>27</b>	<b>41</b>

\*These figures include all individuals who spent any time in a nursing home in 2009.

\*\*Percentages for each state may not sum to 100 because of rounding.

Created from data from the U.S. Department of Health and Human Services.<sup>(212)</sup>

Despite increasing demand for nursing home and long-term acute hospital care services, there have been a number of restrictions on adding new facilities and increasing the number of beds in existing facilities. In addition, the Medicare, Medicaid and SCHIP (State Children's Health Insurance Program) Extension Act of 2007 issued a three-year moratorium on the designation of new long-term care hospitals and increases in Medicare-certified beds for existing long-term care hospitals.<sup>(215)</sup> Long-term care hospitals are acute care hospitals that serve patients who have long-term acute medical care needs, with average lengths of hospital stay of more than 25 days.<sup>(216)</sup> Patients are often transferred from the intensive care units of acute care hospitals to long-term care hospitals for medical care related to rehabilitation services, respiratory therapy and pain management. This moratorium was in response to the need for Medicare to develop criteria for patients admitted to long-term care hospitals with Medicare coverage, due to continued growth in the number of long-term care facilities and beds. The moratorium expired on December 28, 2012.<sup>(215, 217)</sup> In 2011, certificate-of-need programs were in place to regulate nursing home beds in 37 states, and a number of these states had implemented a certificate-of-need moratorium on the number of beds and/or facilities.<sup>(218)</sup>

### Costs of Long-Term Care Services

Costs are high for care provided at home or in an adult day center, assisted living facility or nursing home. The following estimates are for all users of these services. The only exception is the cost of Alzheimer's special care units in nursing homes, which only applies to the people with Alzheimer's disease and other dementias who are in these units.

- *Home care.* In 2011, the average cost for a paid nonmedical home health aide was \$21 per hour, or \$168 for an eight-hour day.<sup>(204)</sup>
- *Adult day centers.* In 2011, the average cost of adult day services was \$70 per day. Ninety-five percent of adult day centers provided care for people with Alzheimer's disease and other dementias, and 2 percent of these centers charged an additional fee for these clients.<sup>(204)</sup>
- *Assisted living.* In 2011, the average cost for basic services in an assisted living facility was \$3,550 per month, or \$42,600 per year. Seventy-two percent of assisted living facilities provided care to people with Alzheimer's disease and other dementias, and 52 percent had a specific unit for people with Alzheimer's and other dementias. In facilities that charged a different rate for individuals with dementia, the average rate was \$4,807 per month, or \$57,684 per year, for this care.<sup>(204)</sup>
- *Nursing homes.* In 2011, the average cost for a private room in a nursing home was \$248 per day, or \$90,520 per year. The average cost of a semi-private room in a nursing home was \$222 per day, or \$81,030 per year. Approximately 80 percent of nursing homes that provide care for people with Alzheimer's disease charge the same rate regardless of whether the individual has Alzheimer's. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with Alzheimer's disease was \$13 higher (\$261 per day, or \$95,265 per year) and the average cost for a semi-private room was \$8 higher (\$230 per day, or \$83,950 per year).<sup>(204)</sup> Fifty-five percent of nursing homes that provide care for people with Alzheimer's disease and other dementias had separate Alzheimer's special care units.<sup>(204)</sup>

### Affordability of Long-Term Care Services

Few individuals with Alzheimer's disease and 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 and other dementias specifically, but 50 percent of Medicare beneficiaries had incomes of \$22,276 or less, and 25 percent had incomes of \$13,418 or less in 2010 (in 2012 dollars). Two hundred percent of the U.S. Census Bureau's poverty threshold was \$21,576 for one person age 65 and older and \$27,192 for a family of two, with the head of household age 65 and older.<sup>(219-220)</sup>
- Fifty percent of Medicare beneficiaries had retirement accounts of \$2,203 or less, 50 percent had financial assets of \$31,849 or less, and 50 percent had total savings of \$55,516 or less, equivalent to less than one year of nursing home care in 2010 (in 2012 dollars).<sup>(219)</sup>

### Long-Term Care Insurance

In 2010, about 7.3 million people had long-term care insurance policies.<sup>(221)</sup> Private health and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2009, representing \$18.4 billion of the \$263 billion (in 2012 dollars) in long-term care spending.<sup>(222)</sup> The private long-term care insurance market has decreased substantially since 2010, however, with five major insurance carriers either exiting the market or substantially increasing premiums, making policies unaffordable for many individuals.<sup>(223)</sup>

### 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.

The federal and state governments share in managing and funding the program, and states differ greatly in the services covered by their Medicaid programs. Medicaid plays a critical role for people with dementia who can no longer afford to pay for long-term care expenses on their own. In 2008, 58 percent of Medicaid spending on long-term care was allocated to institutional care, and the remaining 42 percent was allocated to home and community-based services.<sup>(222)</sup>

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be \$35 billion in 2013.<sup>A19</sup> About half of all Medicaid beneficiaries with Alzheimer's disease and other dementias are nursing home residents, and the rest live in the community.<sup>(224)</sup> Among nursing home residents with Alzheimer's disease and other dementias, 51 percent rely on Medicaid to help pay for their nursing home care.<sup>(224)</sup>

In 2008, total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with Alzheimer's and other dementias 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. Medicaid paid \$24,942 per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility compared with \$232 for those with the diagnosis living in the community and \$549 for those without the diagnosis (Table 8, page 41).<sup>(121)</sup>

## **OUT-OF-POCKET COSTS FOR HEALTH CARE AND LONG-TERM CARE SERVICES**

Despite other sources of financial assistance, individuals with Alzheimer's disease and other dementias still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments and services not covered by Medicare, Medicaid or additional sources of support.

In 2008, Medicare beneficiaries age 65 and older with Alzheimer's and other dementias paid \$9,754 out of pocket, on average, for health care and long-term care services not covered by other sources (Table 8, page 41).<sup>(121)</sup> Average per-person out-of-pocket payments were highest (\$3,297 per person) for individuals living in nursing homes and assisted living facilities and were almost six times as great as the average per-person payments for individuals with Alzheimer's disease and other dementias living in the community.<sup>(121)</sup> In 2013, out-of-pocket spending for individuals with Alzheimer's and other dementias is expected to total an estimated \$34 billion (Figure 10, page 42).<sup>A19</sup>

Before implementation of the Medicare Part D Prescription Drug Benefit in 2006, out-of-pocket expenses were increasing annually for Medicare beneficiaries.<sup>(225)</sup> In 2003, out-of-pocket costs for prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries age 65 and older.<sup>(226)</sup> The Medicare Part D Prescription Drug Benefit has helped to reduce out-of-pocket costs for prescription drugs for many Medicare beneficiaries, including beneficiaries with Alzheimer's and other dementias.<sup>(227)</sup> Sixty percent of all Medicare beneficiaries were enrolled in a Medicare Part D plan in 2011, and the average monthly premium for Medicare Part D was \$39 (range: \$15 to \$132).<sup>(227)</sup> As noted earlier, however, the most expensive component of out-of-pocket costs for people with Alzheimer's and other dementias is nursing home and other residential care.

## **USE AND COSTS OF HOSPICE CARE**

Hospices provide medical care, pain management and emotional and spiritual support for people who are dying, including people with Alzheimer's disease and other dementias. Hospices also provide emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice care is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Individuals can receive hospice care in their homes, assisted living residences or nursing homes. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid and other sources also pay for hospice care.

In 2009, 6 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (61,146 people).<sup>(228)</sup> An additional 11 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (119,872 people).<sup>(228)</sup> Hospice length of stay has increased over the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of Alzheimer's disease increased from 67 days in 1998 to 106 days in 2009.<sup>(228)</sup> The average length of stay for hospice beneficiaries with a primary diagnosis of non-Alzheimer's dementia increased from 57 days in 1998 to 92 days in 2009.<sup>(228)</sup> Average per-person hospice care payments across all beneficiaries with Alzheimer's disease and other dementias were 10 times as great as average per-person payments for all other Medicare beneficiaries (\$1,821 per person compared with \$178 per person).<sup>(121)</sup>

## **PROJECTIONS FOR THE FUTURE**

Total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias are projected to increase from \$203 billion in 2013 to \$1.2 trillion in 2050 (in 2013 dollars). This dramatic rise includes a six-fold increase in government spending under Medicare and Medicaid and a five-fold increase in out-of-pocket spending.<sup>A19</sup>

This Special Report describes the experiences and needs of a specific type of caregiver: long-distance caregivers — those who care for a loved one who lives far away. It describes the characteristics of long-distance caregivers, their needs, the barriers they encounter, how the caregiving situation affects them and efforts that have been made to alleviate the caregiving burden they experience. These issues have received little attention but are the source of increasing concern.

Much of what is known about long-distance caregivers comes from studies in which the care recipient was an older person who needed assistance to perform daily activities because of cognitive or physical impairments. Most studies were not exclusive to caregivers for someone with dementia. Nevertheless, in key studies about 30 percent of caregivers reported that the care recipient had Alzheimer’s disease or a related condition.<sup>(229)</sup> Therefore, it is reasonable to expect that the results of those key studies apply to caregivers for people with dementia. In some cases, findings specific to caregivers of people with Alzheimer’s disease and other dementias are available, and the findings have been included in this Special Report.

### DEFINITION AND PREVALENCE

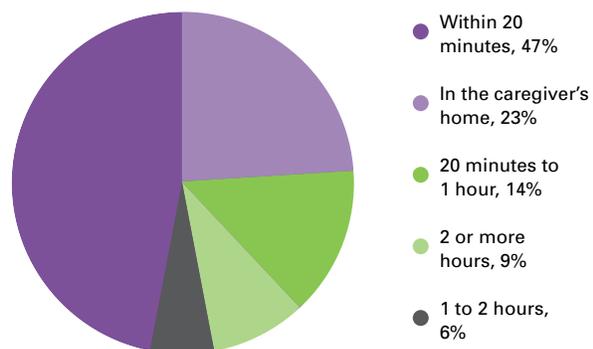
Studies of long-distance caregivers have differed with respect to how they define “long-distance,” but a common definition is one in which the caregiver lives at least one or two hours away from the care recipient. A 2009 report from the National Alliance for Caregiving and AARP (NAC/AARP)<sup>(229)</sup> compiled information from 1,480 caregivers of adults age 18 or older who needed assistance with self-care in the United States. In that report, 9 percent of caregivers lived two or more hours away from the care recipient and 4 percent lived one to two hours away. The remainder lived less than one hour away.

A subanalysis of the NAC/AARP study was performed in which caregivers were included only if they provided care for someone 50 or older who had Alzheimer’s

disease or a related condition. Travel times between those 404 caregivers and their care recipients are shown in Figure 13. Nine percent of caregivers lived two or more hours away from the care recipient, and 6 percent lived one to two hours away.<sup>(141)</sup>

On the basis of these findings and the estimate that more than 15.4 million people in the United States are caregivers for someone who has Alzheimer’s disease or other dementia (see Caregiving section), we estimate that about 2.3 million of those caregivers live at least one hour away from the care recipient. As discussed below, the types and amount of care these individuals provide vary greatly.

**FIGURE 13** TRAVEL TIMES BETWEEN CAREGIVERS AND CARE RECIPIENTS FOR CAREGIVERS OF PEOPLE WHO HAVE ALZHEIMER’S DISEASE OR A RELATED CONDITION



Created from data from the National Alliance for Caregiving and AARP.<sup>(141)</sup>

## FACTORS INFLUENCING GEOGRAPHIC SEPARATION

As noted in the Caregiving section, most caregivers for people with dementia are relatives of the care recipient. In the subanalysis of the 2009 NAC/AARP survey, 79 percent of caregivers for people with dementia were caring for their parent, parent-in-law, grandparent or grandparent-in-law.<sup>(141)</sup>

Because so many caregivers are a descendant (or descendant-in-law) of the care recipient, it is worthwhile exploring the factors that influence geographic separation between the places of residence of children and their parents. Several studies have done so.<sup>(230-232)</sup> The two strongest factors affecting geographic separation are:<sup>(230-232)</sup>

- *Education levels of parents and children.* When parents or their adult children have many years of formal education, they tend to live farther apart than those who have fewer years of formal education.
- *Number of children.* Parents who have many adult children are more likely to have one child who lives nearby than parents who have fewer children.

Other factors affecting geographic separation of parents and children include:<sup>(230-232)</sup>

- *Age.* Young adult children tend to live closer to their parents than middle-age children. Parents older than 80 tend to live closer to their children than parents younger than 80.
- *Income.* Children with higher incomes tend to live farther from their parents than children with lower incomes.
- *Children's family size.* Children with large families of their own tend to live farther from their parents than children who have small families.

- *Geography.* Parents who live in rural areas tend to live farther from their children than parents who live in urban areas. Children or parents who live in the western United States tend to live farther from each other than those who live in the eastern part of the country.
- *Geographic mobility.* Parents or children who have an extensive history of geographic mobility tend to live farther from each other than those who have less history of geographic mobility.

The gender of adult children does not strongly influence geographic separation from their parents, even though daughters are more likely to be caregivers than sons.

The cited studies were not restricted to children who were caregivers. However, in at least one study the health and disability levels of parents did not strongly influence geographic separation between them and their adult children.<sup>(231)</sup> Therefore, it is reasonable to expect that these same factors influence geographic separation when adult children are caregivers for their parents. Indeed, small studies specific to caregivers have found that long-distance caregivers, on average, are more educated, more affluent and more likely to be married than local caregivers.<sup>(141, 233-236)</sup>

## ROLES

Caregivers for people with dementia perform a variety of caregiving tasks, and each caregiving situation is unique. In some studies, unpaid caregivers are categorized into two groups: primary caregivers and secondary caregivers. In most of the studies cited here, secondary caregivers were those who identified themselves as such; that is, they recognized that another person was the primary caregiver.

Primary caregivers of people who have dementia are more likely than secondary caregivers to help with essential activities such as dressing, personal hygiene, feeding, movement and toileting (activities of daily

living; ADLs). Primary caregivers may also help with tasks that are less essential for basic functioning but that help the care recipient live independently — such tasks include housework, managing medications, shopping, managing money and providing transportation (instrumental activities of daily living; IADLs). Secondary caregivers are more likely to help with IADLs than ADLs.

In a nationwide survey conducted in 2004 by the MetLife Mature Market Institute, 23 percent of long-distance caregivers reported that they were the primary or only caregiver for their care recipient.<sup>(233)</sup> In the NAC/AARP surveys, the percentage of long-distance caregivers who identified themselves as the primary caregiver has varied from 11 percent (2004) to 35 percent (2009).<sup>(141, 235)</sup> Another study of caregivers for people with dementia in the Los Angeles area found that 19 percent of long-distance caregivers considered themselves the primary caregiver, whereas 65 percent of local caregivers did so.<sup>(237)</sup> From these studies, we estimate that, among long-distance caregivers for people with dementia, about one in five is a primary caregiver.

Despite the fact that most long-distance caregivers consider themselves secondary caregivers, the MetLife study found that:<sup>(238)</sup>

- 72 percent of long-distance caregivers helped the care recipient perform IADLs.
- Long-distance caregivers spent an average of 3.4 hours per week arranging services for the care recipient and another four hours per week checking on the care recipient or monitoring care.
- Almost 40 percent of long-distance caregivers reported that they helped the care recipient perform ADLs.
- On average, long-distance caregivers spent about 22 hours per month helping with IADLs and about 12 hours per month helping with ADLs.

## UNIQUE CHALLENGES

Long-distance caregivers who are the primary caregiver have the same needs as local primary caregivers, but long-distance caregivers have the added burden of having to travel more than an hour to perform most of their caregiving tasks.<sup>(237)</sup> Predictably, long-distance caregivers are more likely than local caregivers to report distance as a barrier to performing their caregiving tasks.<sup>(236, 238)</sup>

### Coordinating Care

Long-distance caregivers, especially those who are secondary caregivers, frequently assume the role of coordinators of care — working to assist the primary caregiver by finding, coordinating and monitoring the recipient's formal care and social services.<sup>(237, 239)</sup>

Long-distance caregivers who are primary caregivers may have to take on multiple roles — providing direct care by helping with ADLs and IADLs as well as coordinating formal health care and social services. While performing these tasks, long-distance caregivers often report difficulties in finding services available in the care recipient's community and in monitoring service providers.<sup>(236)</sup> These tasks can be especially difficult when the care recipient lives in a rural area.

### Assessing the Care Recipient's Condition and Needs

Long-distance caregivers also reported greater difficulty than local caregivers in obtaining information about the care recipient.<sup>(236-237)</sup> Specifically, many long-distance caregivers report that care recipients either downplay or exaggerate their condition and needs. As a consequence, long-distance caregivers may be less able to gauge the care recipient's needs.<sup>(240)</sup> Similarly, long-distance caregivers have difficulty obtaining accurate information about the recipient's condition from local caregivers or neighbors.

### Communicating with Health Care Providers

Long-distance caregivers may not be available to accompany the care recipient to health care visits, especially when those visits are unexpected.

Furthermore, long-distance caregivers often find it more difficult than local caregivers to communicate with health care providers, who may assume that the long-distance caregiver is not an important contact or is less involved in caregiving. These barriers make it difficult for long-distance caregivers to acquire accurate information about the care recipient's health status, in turn making it difficult for these caregivers to assist in making health care decisions.<sup>(237, 239)</sup>

### Family Strain and Disagreements with Siblings

Although many of the effects of caregiving are common to long-distance caregivers and local caregivers, long-distance caregivers report higher rates of family disagreement.<sup>(237)</sup> Sources of these problems can vary, but often include disagreements with siblings about caregiving decisions and resentment from local caregivers that the long-distance caregivers are not more helpful.<sup>(236-237, 241)</sup>

### Psychological Distress

In some studies, long-distance caregivers reported higher rates of psychological distress than local caregivers, even though local caregivers were more likely to feel overwhelmed by their caregiving responsibilities.<sup>(237)</sup> Psychological distress among long-distance caregivers may arise from difficulties in ascertaining the care recipient's condition and needs, and the fact that long-distance caregivers are frequently asked to help during acute crises.<sup>(240)</sup> Some long-distance caregivers may also experience feelings of regret or remorse owing to self-assessments that distance has restricted their caregiving capacity.<sup>(242)</sup>

### Employment

About 60 percent of caregivers for people with dementia are employed either part-time or full-time,<sup>(141)</sup> and long-distance caregivers have similar rates of employment.<sup>(233, 242)</sup> Many caregivers miss work and use vacation or sick days for caregiving. Long-distance caregivers experience even greater disruptions in their employment because of the time required to travel to where the care recipient lives.<sup>(233, 237-238)</sup>

### Financial Burden

Given that local caregivers are much more likely to be primary caregivers than long-distance caregivers,<sup>(141)</sup> it is not surprising that local caregivers provide significantly more hours of care on average than long-distance caregivers.<sup>(237)</sup> Thus the uncompensated economic value of care provided by local caregivers is likely to greatly exceed that of long-distance caregivers. Nevertheless, long-distance caregivers have significantly higher annual out-of-pocket expenses for care-related costs than local caregivers.<sup>(233, 243)</sup> In one nationwide survey published in 2007, long-distance caregivers had annual out-of-pocket expenses of \$9,654 compared with \$5,055 for local caregivers (in 2012 dollars).<sup>(243), A20</sup> These expenses included the costs of travel as well as telephone bills, paying for hired help and other expenses associated with long-distance caregiving.<sup>(243)</sup>

## INTERVENTIONS

### Support for Long-Distance Caregivers

With the growth of the Web, an increasing number of online and computer-aided programs have been developed to provide assistance to long-distance caregivers. Whether a program is implemented online, via telephone or in person, it should reflect the range of support and information needed by long-distance caregivers, such as:

- Access to a professional family consultant who can act as a liaison between care recipients and long-distance care providers, and who can help alleviate family disagreements.
- Access to print or Web-based elder-care resource guides for the area in which the care recipient lives.
- Access to information about elder-care attorneys and financial planners in the area in which the care recipient lives.
- For both long-distance and other caregivers, assistance in developing a comprehensive safety plan for the care recipient that can be accessed and implemented by both local and long-distance caregivers.
- Help with caring for an individual who lives alone.

## Technology

Several caregiving advocacy organizations have issued calls to use technology to assist long-distance caregivers. The National Research Council of the U.S. National Academies convened the Workshop on Technology for Adaptive Aging in 2003 and outlined research priorities for the development of technological devices to assist older adults, including those with cognitive or physical impairments.<sup>(244)</sup>

The Workshop report identified core technologies in various stages of development and how they could help aging people remain independent, as well as help their caregivers monitor the care recipient and provide care and assistance when needed. Such technologies include wireless broadband networks to connect care recipients and caregivers, biosensors and diagnostic tools, activity sensors, information processing systems to detect changes in health status based on sensor input, displays and actuators to assist in using appliances and home controls, artificial intelligence devices and systems that act as personal assistants and coaches, adaptive interfaces that allow impaired people to perform household tasks, and other devices and tools. Technological innovations may offer the potential to increase the connectedness of caregivers and care recipients and alleviate some of the burden of caregiving, including the burden of long-distance caregiving.<sup>(238, 245-248)</sup> Additional research is needed on the use of technologies to assist long-distance caregivers.

## TRENDS

As described in the Prevalence section, the number and percentage of Americans who have Alzheimer's disease and other dementias are expected to increase dramatically in coming decades. Commensurate with this increase in prevalence are expected increases in the number and percentage of Americans who are caregivers for older people who have dementia or other disabilities.<sup>(137)</sup>

Some have predicted that increases in geographic mobility in the United States will lead to even greater increases in the percentage of caregivers who live far away from their care recipient.<sup>(236)</sup> However, there is not widespread agreement that geographic mobility has been increasing. An extensive analysis of long-term trends in geographic mobility in the United States concluded that geographic mobility rates actually declined between the 1950s and early 2000s among all age groups.<sup>(249)</sup>

Studies attempting to determine the percentage of caregivers who are long-distance caregivers have not shown a consistent increase. Two studies showed modest increases during the 1980s and 1990s,<sup>(250-251)</sup> but another study found a modest decrease in recent years (2004 to 2009).<sup>(229)</sup> However, even if the percentage of long-distance caregivers is not increasing, their absolute number is likely to increase along with the number of all caregivers required to care for increasing numbers of older people who have disabilities, including Alzheimer's disease and other dementias.

## CONCLUSIONS

About 2.3 million people in the United States are caregivers for a person with Alzheimer's disease or other dementia who lives at least one hour away. Although most of those long-distance caregivers are secondary caregivers, about 1 in 5 is a primary caregiver, about 7 in 10 help the care recipient with IADLs and about 4 in 10 help with ADLs. While long-distance caregivers may spend less time helping the care recipient than local caregivers, long-distance caregivers have higher out-of-pocket expenses on average, experience greater challenges assessing the care recipient's condition and needs, report more difficulty communicating with health care providers, and often experience higher levels of psychological distress and family discord arising from their caregiving roles. Thus, support programs tailored to the needs of long-distance caregivers are needed to address the particular challenges they encounter.

## END NOTES

A1. Number of Americans age 65 and older with Alzheimer's disease for 2013: The number 5 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. See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013. The estimates of Alzheimer's prevalence in the United States reported in previous *Facts and Figures* reports come from an older analysis using the same methods but older data from CHAP and data from the 2000 U.S. Census. See Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census. *Arch Neurol* 2003;60:1119–22.

A2. Proportion of Americans age 65 and older with Alzheimer's disease: The 11 percent is calculated by dividing the estimated number of people age 65 and older with Alzheimer's disease (5 million) by the U.S. population age 65 and older in 2013, as projected by the U.S. Census Bureau (44.2 million) = 11 percent. Eleven percent is the same as one in nine.

A3. Percentage of total Alzheimer's disease cases by age groups: Percentages for each age group are based on the estimated 200,000 under 65, plus the estimated numbers (in millions) for people 65 to 74 (0.7), 75 to 84 (2.3), and 85+ (2.0) based on prevalence estimates for each age group and incidence data from the Chicago Health and Aging Project (CHAP). See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013. Percentages do not total 100 due to rounding.

A4. Differences between CHAP and ADAMS estimates for Alzheimer's disease prevalence: The Aging, Demographics, and Memory Study (ADAMS) estimates the prevalence of Alzheimer's disease to be lower than does the Chicago Health and Aging Project (CHAP), at 2.3 million Americans age 71 and older in 2002. See Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(1–2):125–32. [Note that the CHAP estimates referred to in this end note are from an earlier study using 2000 U.S. Census data. See Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census. *Arch Neurol* 2003;60:1119–22.] 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. See Wilson RS, Weir DR, Leurgans SE, Evans DA, Hebert LE, Langa KM, et al. Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States. *Alzheimers Dement* 2011;7(1):74–9. Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's disease and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common (see Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer's disease and mild cognitive impairment. *Ann Neurol* 2009;66(2):200–8), the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's disease in the United States.

A5. Number of women and men age 65 and older with Alzheimer's disease in the United States: The estimates for the number of U.S. women (3.2 million) and men (1.8 million) age 65 and older with Alzheimer's in 2013 is from unpublished data from the Chicago Health and Aging Project (CHAP). For analytic methods, see Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013.

A6. Number of seconds for the development of a new case of Alzheimer's disease: Although Alzheimer's does not present suddenly like stroke or heart attack, the rate at which new cases occur can be computed in a similar way. The 68 seconds number is calculated by dividing the number of seconds in a year (31,536,000) by the number of new cases in a year. One study estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020. See Hebert LE, Beckett LA, Scherr PA, Evans DA. Annual incidence of Alzheimer disease in the United States projected to the years 2000 through 2050. *Alzheimer Dis Assoc Disord* 2001;15:169–73. The Alzheimer's Association calculated that the incidence of new cases in 2012 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.2 (for the number of years from 2010 to 2012 divided by the number of years from 2010 to 2020), adding that result (7,400) to the Hebert et al. (2001) estimate for 2010 (454,000) = 461,400. The number of seconds in a year (31,536,000) divided by 461,400 = 68.3 seconds, rounded to 68 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al., 2001) = 32.8 seconds, rounded to 33 seconds.

A7. Criteria for identifying subjects with Alzheimer's disease and other dementias in the Framingham Study: Starting in 1975, nearly 2,800 people from the Framingham Study who were age 65 and free of dementia were followed for up to 29 years. Standard diagnostic criteria (DSM-IV criteria) were used to diagnose dementia in the Framingham Study, but, in addition, the subjects had to have at least "moderate" dementia according to the Framingham Study criteria, which is equivalent to a score of 1 or more on the Clinical Dementia Rating (CDR) Scale, and they had to have symptoms for six months or more. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's disease. The examination for dementia and Alzheimer's disease is described in detail in Seshadri S, Wolf PA, Beiser A, Au R, McNulty K, White R, et al. Lifetime risk of dementia and Alzheimer's disease: The impact of mortality on risk estimates in the Framingham Study. *Neurology* 1997;49:1498–504.

A8. Number of baby boomers who will develop Alzheimer's disease and other dementias: The numbers for remaining lifetime risk of Alzheimer's disease and other dementias for baby boomers were developed by the Alzheimer's Association by applying the data provided to the Association on remaining lifetime risk by Alexa Beiser, Ph.D.; Sudha Seshadri, M.D.; Rhoda Au, Ph.D.; and Philip A. Wolf, M.D., from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, to U.S. Census data.

A9. State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific gender, years of education, race and mortality. See Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. State-specific projections through 2025 of Alzheimer's disease prevalence. *Neurology* 2004;62:1645. The numbers in Table 2 are found in online material related to this article, available at <http://www.neurology.org/content/62/9/1645.extract>. These numbers do not add up exactly to the reported estimate of the total number of Americans with Alzheimer's disease (see End Note A1) because they come from slightly different data sources; the state-by-state data uses 2000 U.S. Census data.

A10. The projected number of people with Alzheimer's disease comes from the CHAP study: See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013. Other projections are somewhat lower (see Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health* 1998;88(9):1337-42) because they relied on more conservative methods for counting people who currently have Alzheimer's disease.<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 disease over the coming decades.

A11. Projected number of people age 65 and older with Alzheimer's disease 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. See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013.

A12. Previous high and low projections of Alzheimer's disease prevalence in 2050: The latest projections provided by the U.S. Census do not include high and low series based on different predictions about future changes to the population. Therefore, a high and low range for the projection to the year 2050 was not available for the most recent analysis of CHAP data. See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013. The previous high and low projections indicate that the projected number of Americans with Alzheimer's in 2050 age 65 and older will range from 11 to 16 million. See Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census. *Arch Neurol* 2003;60:1119-22.

A13. Deaths with Alzheimer's disease: The estimates for the number of Americans dying with Alzheimer's disease, 400,000 in 2010 and 450,000 in 2013, were provided to the Alzheimer's Association by Liesi Hebert as unpublished results from her study. See Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer's disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology*. Available at [www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract](http://www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5.abstract). Published online before print, Feb. 6, 2013.

A14. Number of family and other unpaid caregivers of people with Alzheimer's and other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS). 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, the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the Centers for Disease Control and Prevention, Healthy Aging Program, unpublished data) was applied to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2012. Available at [www.census.gov/popest/data/datasets.html](http://www.census.gov/popest/data/datasets.html). Accessed on Jan. 7, 2013. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or other dementias, the Alzheimer's Association used data from the results of a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP (National Alliance for Caregiving, Caregiving in the U.S., November 2009. Available at [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf)). 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 percent of caregivers said that: (1) Alzheimer's or other dementias 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 percent figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 15,409,609 Alzheimer's and dementia caregivers.

A15. Alzheimer's Association 2010 Women and Alzheimer's Poll: This poll contacted 3,118 adults nationwide by telephone from Aug. 25 to Sept. 3, 2010. Telephone numbers were randomly chosen in separate samples of landline and cell phone exchanges across the nation, allowing listed and unlisted numbers to be contacted, and multiple attempts were made to contact each number. Within households, individuals were randomly selected. Interviews were conducted in English and Spanish. The survey "oversampled" African-Americans and Hispanics, selected from U.S. Census tracts with higher than 8 percent concentration of each group. It also included an oversample of Asian-Americans using a listed sample of Asian-American households. The combined samples include: 2,295 white, non-Hispanic; 326 African-American; 309 Hispanic; 305 Asian-American; and 135 respondents of another race. Cases were weighted to account for differential probabilities of selection and to account for overlap in the landline and cell phone sampling frames. The sample was adjusted to match U.S. Census demographic benchmarks for gender, age, education, race/ethnicity, region and telephone service. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. This national survey included 202 caregivers of people with Alzheimer's and other dementias. This was supplemented with 300 interviews from a listed sample of caregivers of people with Alzheimer's for a total of 502 caregiver interviews. 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 other dementias. The weight of the caregiver sample adjusted all 502 caregiver cases to the weighted estimates for gender and race/ethnicity derived from the base survey of caregivers. Questionnaire design and interviewing were conducted by Abt SRBI of New York. Susan Pinkus of S.H. Pinkus Research and Associates coordinated the polling and helped in the analysis of the poll data.

A16. 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 and 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 (15,409,609)<sup>A14</sup> was multiplied by the average hours of care per year, which totals 17,548,462,657 hours of care.

A17. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Amo et al. See Amo PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff* 1999;18:182-8. This method uses the average of the federal minimum hourly wage (\$7.25 in 2012) and the mean hourly wage of home health aides (\$17.40 in July 2012) [see U.S. Department of Labor, Bureau of Labor Statistics. Employment, hours, and earnings from the Current Employment Statistics Survey. Series 10-CEU 6562160008, Home Health Care Services (NAICS code 6216), Average Hourly Earnings, July 2012. Available at [www.bls.gov/ces](http://www.bls.gov/ces). Accessed on Dec. 7, 2012]. The average is \$12.33, which was multiplied by the number of hours of unpaid care (17,548,462,657)<sup>A16</sup> to derive the total value of unpaid care (\$216,372,544,560).

A18. Higher health care costs of Alzheimer's caregivers: This figure is based on a methodology originally developed by Brent Fulton, Ph.D., for The Shriver Report: A Woman's Nation Takes on Alzheimer's.<sup>(252)</sup> A survey of 17,000 employees of a multinational firm based in the United States estimated that caregivers' health care costs were 8 percent higher than non-caregivers'. See Albert SM, Schulz R. The MetLife Study of Working Caregivers and Employer Health Care Costs, New York, N.Y.: MetLife Mature Market Institute, 2010. To determine the dollar amount represented by that 8 percent figure nationally and in each state, the 8 percent figure and the proportion of caregivers from the 2009 Behavioral Risk Factor Surveillance System<sup>A14</sup> were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009, inflated to 2012 dollars. See Centers for Medicare and Medicaid Services, Center for Strategic Planning, Health Expenditures by State of Residence 1991-2009. Available at <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsStateHealthAccountsResidence.html>. The dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state (reflecting the 8 percent higher costs for caregivers) produced the average additional health care costs for caregivers in each state. Nationally, this translated into an average of \$592. The amount of the additional cost in each state, which varied by state from a low of \$436 in Utah to a high of \$902 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state<sup>A14</sup> to arrive at that state's total additional health care costs of Alzheimer's and other dementia caregivers as a result of being a caregiver. The combined total for all states was \$9,121,120,080. Fulton concluded that this is "likely to be a conservative estimate because caregiving for people with Alzheimer's is more stressful than caregiving for most people who don't have the disease."<sup>(252)</sup>

A19. Lewin Model on Alzheimer's and dementia and costs: These numbers come from a model created for the Alzheimer's Association by The Lewin Group, modified to reflect more recent estimates and projections of the prevalence of Alzheimer's disease.<sup>(83)</sup> The model estimates total payments for community-based health care services using data from the Medicare Current Beneficiary Survey (MCBS). The model was constructed based on 2004 MCBS data; those data have been replaced with the more recent 2008 MCBS data.<sup>A21</sup> Nursing facility care costs in the model are based on The Lewin Group's Long-Term Care Financing Model. More information on the model, its long-term projections and its methodology is available at [www.alz.org/trajectory](http://www.alz.org/trajectory).

A20. All cost estimates were inflated to year 2012 dollars using the Consumer Price Index (CPI): All Urban Consumers seasonally adjusted average prices for medical care services. The relevant item within medical care services was used for each cost element (e.g., the medical care services 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; the nursing home and adult day services item within the CPI was used to inflate nursing home payments).

A21. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2008 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The MCBS, a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries, is linked to Medicare Part B claims. The survey is supported by the U.S. Centers for Medicare and 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 nurse who is familiar with the survey participant and his or her medical record. Data from the MCBS analysis that are included in *2013 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 disease 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 disease and 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.

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