

## Alzheimer's Association Report 2016 Alzheimer's disease facts and figures

Alzheimer's Association\*

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### Abstract

This report describes the public health impact of Alzheimer's disease, including incidence and prevalence, mortality rates, costs of care, and the overall impact on caregivers and society. It also examines in detail the financial impact of Alzheimer's on families, including annual costs to families and the difficult decisions families must often make to pay those costs. An estimated 5.4 million Americans have Alzheimer's disease. By mid-century, the number of people living with Alzheimer's disease in the United States is projected to grow to 13.8 million, fueled in large part by the aging baby boom generation. Today, someone in the country develops Alzheimer's disease every 66 seconds. By 2050, one new case of Alzheimer's is expected to develop every 33 seconds, resulting in nearly 1 million new cases per year. In 2013, official death certificates recorded 84,767 deaths from Alzheimer's disease, making it the sixth leading cause of death in the United States and the fifth leading cause of death in Americans age  $\geq 65$  years. Between 2000 and 2013, deaths resulting from stroke, heart disease, and prostate cancer decreased 23%, 14%, and 11%, respectively, whereas deaths from Alzheimer's disease increased 71%. The actual number of deaths to which Alzheimer's disease contributes is likely much larger than the number of deaths from Alzheimer's disease recorded on death certificates. In 2016, an estimated 700,000 Americans age  $\geq 65$  years will die with Alzheimer's disease, and many of them will die because of the complications caused by Alzheimer's disease. In 2015, more than 15 million family members and other unpaid caregivers provided an estimated 18.1 billion hours of care to people with Alzheimer's and other dementias, a contribution valued at more than \$221 billion. Average per-person Medicare payments for services to beneficiaries age  $\geq 65$  years with Alzheimer's disease and other dementias are more than two and a half times as great as payments for all beneficiaries without these conditions, and Medicaid payments are 19 times as great. Total payments in 2016 for health care, long-term care and hospice services for people age  $\geq 65$  years with dementia are estimated to be \$236 billion. The costs of Alzheimer's care may place a substantial financial burden on families, who often have to take money out of their retirement savings, cut back on buying food, and reduce their own trips to the doctor. In addition, many family members incorrectly believe that Medicare pays for nursing home care and other types of long-term care. Such findings highlight the need for solutions to prevent dementia-related costs from jeopardizing the health and financial security of the families of people with Alzheimer's and other dementias.

### Keywords:

Alzheimer's disease; Dementia; Diagnostic criteria; Prevalence; Incidence; Mortality; Morbidity; Caregivers; Family caregiver; Spouse caregiver; Sandwich generation caregiver; Health care costs; Health care expenditures; Long-term care costs; Medicare spending; Medicaid spending; Long-term care insurance; Care contributor; Out-of-pocket expenses; Food security; Financial security; Families; Income

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### 1. About this report

*2016 Alzheimer's Disease Facts and Figures* is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia, as well as other dementias.

Background and context for interpretation of the data are contained in the Overview. This information includes descriptions of the various causes of dementia and a summary of current knowledge about Alzheimer's disease. Additional sections address prevalence, mortality and morbidity, caregiving, and use and costs of health care and services. The Special Report discusses the personal financial impact of Alzheimer's disease on families.

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

- Revised criteria and guidelines for diagnosing Alzheimer's disease from the National Institute on Aging and the Alzheimer's Association.
- Overall number of Americans with Alzheimer's disease nationally and for each state.
- Proportion of women and men with Alzheimer's and other dementias.
- Estimates of lifetime risk for developing Alzheimer's disease.
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age.
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state, and the impact of caregiving on caregivers.
- Use and costs of health care, long-term care and hospice care for people with Alzheimer's disease and other dementias.
- The personal financial impact of Alzheimer's on families, including annual costs and the effect on family income.

The [Appendices](#) detail sources and methods used to derive statistics in this report.

This report frequently cites statistics that apply to individuals with all types of dementia. When possible, specific information about Alzheimer's disease is provided; in other cases, the reference may be a more general one of "Alzheimer's disease and other dementias."

## 2. Overview of Alzheimer's disease

Alzheimer's disease is a degenerative brain disease and the most common cause of dementia [1,2]. Dementia is characterized by a decline in memory, language, problem-solving and other cognitive skills that affects a person's ability to perform everyday activities. This decline occurs because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed. In Alzheimer's disease, the damage and destruction of neurons eventually affects other parts of the brain, including those that enable a person to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease are bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

### 2.1. Dementia

Physicians may refer to the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* to guide them in determining if an individual has dementia, and, if so, what may be the cause. Based on the latest *DSM* criteria [3], dementia is classified as a major neurocognitive disorder because it interferes with both cognitive function and performing everyday activities. Cognitive function refers to memory,

speech, language, judgment, reasoning, planning and other thinking abilities. Examples of everyday activities are making a meal, paying bills, and traveling to a store to make a purchase.

When an individual has symptoms of dementia, such as memory or language problems, a physician will conduct tests to identify the cause. Different causes of dementia are associated with distinct symptom patterns and brain abnormalities, as described in [Table 1](#). Studies indicate that many people with dementia, especially those in the older age groups, have brain abnormalities associated with more than one cause of dementia [4–8]. This condition is called mixed dementia.

In some cases, individuals with symptoms of dementia do not have dementia, but instead have a condition whose symptoms mimic those of dementia. Common causes of dementia-like symptoms are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. Unlike dementia, these conditions often may be reversed with treatment. One meta-analysis, a method of analysis in which results of multiple studies are examined, reported that 9 percent of people with dementia-like symptoms did not in fact have dementia, but had other conditions that were potentially reversible [9].

### 2.2. Alzheimer's disease

Alzheimer's disease was first identified more than 100 years ago, but 70 years passed before it was recognized as the most common cause of dementia, as well as a major cause of death [12]. Not until then did Alzheimer's disease become a significant area of research. Although the research that followed has revealed a great deal about Alzheimer's, much is yet to be discovered about the precise biological changes that cause Alzheimer's, why it progresses more quickly in some than in others, and how the disease can be prevented, slowed or stopped.

Researchers believe that early detection of Alzheimer's will be key to preventing, slowing and stopping the disease. The last 10 years have seen tremendous growth in research on early detection. This research spurred the 2011 publication of new diagnostic criteria and guidelines for Alzheimer's disease [13–16]. According to the criteria, the brain changes of Alzheimer's begin before symptoms such as memory loss appear, whereas earlier criteria require memory loss and a decline in thinking abilities for an Alzheimer's diagnosis to be made. Because scientific evaluation of some components of the new criteria is ongoing, "Alzheimer's disease" in this report refers to the disease as defined by the earlier criteria [17].

#### 2.2.1. Symptoms

Alzheimer's disease symptoms vary among individuals. The most common initial symptom is a gradually worsening ability to remember new information. This occurs because the first neurons to be damaged and destroyed are usually in brain regions involved in forming new memories. As

Table 1  
Causes of dementia and associated characteristics\*

Cause	Characteristics
Alzheimer's disease	<p>Most common cause of dementia; accounts for an estimated 60 percent to 80 percent of cases. About half of these cases involve solely Alzheimer's pathology; many of the remaining cases have evidence of pathologic changes related to other dementias. This is called mixed dementia (see mixed dementia in this table).</p> <p>Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing and walking.</p> <p>Revised criteria and guidelines for diagnosing Alzheimer's were proposed and published in 2011. They recommend that Alzheimer's be considered a slowly progressive brain disease that begins well before clinical symptoms emerge.</p> <p>The hallmark pathologies of Alzheimer's are the progressive accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons.</p>
Vascular dementia	<p>Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. However, it is very common in older individuals with dementia, with about 50 percent having pathologic evidence of vascular dementia (infarcts). In most cases, the infarcts coexist with Alzheimer's pathology (see mixed dementia in this table) [10].</p> <p>Impaired judgment or impaired ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. In addition to changes in cognition, people with vascular dementia can have difficulty with motor function, especially slow gait and poor balance.</p> <p>Vascular dementia occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer's (and vice versa). That practice is no longer considered consistent with the pathologic evidence, which shows that the brain changes of Alzheimer's and vascular dementia commonly coexist. When evidence of two or more causes of dementia are present at the same time, the individual is considered to have mixed dementia (see mixed dementia in this table).</p>
Dementia with Lewy bodies (DLB)	<p>People with DLB have some of the symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and slowness, gait imbalance or other parkinsonian movement features. These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment.</p> <p>Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease (PD), in which it is accompanied by severe neuronal loss in a part of the brain called the substantia nigra. While people with DLB and PD both have Lewy bodies, the onset of the disease is marked by motor impairment in PD and cognitive impairment in DLB.</p> <p>The brain changes of DLB alone can cause dementia, but very commonly brains with DLB have coexisting Alzheimer's pathology. In people with both DLB and Alzheimer's pathology, symptoms of both diseases may emerge and lead to some confusion in diagnosis. Vascular dementia can also coexist and contribute to the dementia. When evidence of more than one dementia is present, the individual is said to have mixed dementia (see mixed dementia in this table).</p>
Mixed dementia	<p>Characterized by the hallmark abnormalities of more than one cause of dementia — most commonly Alzheimer's combined with vascular dementia, followed by Alzheimer's with DLB, and Alzheimer's with vascular dementia and DLB. Vascular dementia with DLB is much less common [5,6].</p> <p>Recent studies suggest that mixed dementia is more common than previously recognized, with about half of older people with dementia having pathologic evidence of more than one cause of dementia [5,6]. Recent studies also show that the likelihood of having mixed dementia increases with age and is highest in the oldest-old, people age 85 or older.</p>
Frontotemporal lobar degeneration (FTLD)	<p>Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.</p> <p>Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease. Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have protein inclusions (usually tau protein or the transactive response DNA-binding protein).</p> <p>The brain changes of FTLD may occur in those age 65 years and older, similar to Alzheimer's disease, but most people with this form of dementia develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60. FTLD accounts for about 10 percent of dementia cases.</p>

(Continued)

Table 1  
Causes of dementia and associated characteristics\* (Continued)

Cause	Characteristics
Parkinson's disease (PD) dementia	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine. The incidence of PD is about one-tenth that of Alzheimer's. As PD progresses, it often results in dementia secondary to the accumulation of Lewy bodies in the cortex (similar to DLB) or the accumulation of beta-amyloid clumps and tau tangles (similar to Alzheimer's disease).
Creutzfeldt-Jakob disease	This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes. Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction. May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection. A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.
Normal pressure hydrocephalus	Symptoms include difficulty walking, memory loss and inability to control urination. Accounts for less than 5 percent of dementia cases [11]. Caused by impaired reabsorption of cerebrospinal fluid and the consequent build-up of fluid in the brain, increasing pressure in the brain. People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

\*For more information on these and other causes of dementia, visit [alz.org/dementia](http://alz.org/dementia).

neurons in other parts of the brain are damaged and destroyed, 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 when 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, including apathy and depression.
- Increased anxiety, agitation and sleep disturbances.

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

The pace at which symptoms advance from mild to moderate to severe varies from person to person. As the disease progresses, cognitive and functional abilities decline. In the more advanced stages, people need help with basic activities of daily living, such as bathing, dressing, eating and using the bathroom; lose their ability to communicate; fail to recognize loved ones; and become bed-bound and reliant on around-the-clock care. When individuals have difficulty moving, 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.

## 2.2.2. Diagnosis

No single, simple test exists to diagnose Alzheimer's disease. Instead, one's physician, often with the help of a neurologist, will use a variety of approaches and tools to help make a diagnosis. They include the following:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member or other person close to the individual to provide input about changes in thinking skills or behavior.
- Conducting cognitive tests and physical and neurologic examinations.
- Having the individual undergo blood tests and brain imaging to rule out other potential causes of dementia symptoms, such as a tumor or certain vitamin deficiencies.

Diagnosing Alzheimer's requires a careful and comprehensive medical evaluation. Although physicians can almost always determine if a person has dementia, it may be difficult to identify the exact cause. Several days or weeks may be needed for the patient to complete the required tests and examinations and for the physician to interpret the results and make a diagnosis.

## 2.2.3. Brain changes associated with Alzheimer's disease

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form connections with other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by a receiving neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly

through the brain's neuronal circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

The accumulation of the protein beta-amyloid (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes believed to contribute to the damage and destruction of neurons that result in memory loss and other symptoms of Alzheimer's. As brain changes advance, 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 inside neurons and are also believed to contribute to cell death. The brains of people with advanced Alzheimer's disease show inflammation, dramatic shrinkage from cell loss, and widespread debris from dead and dying neurons.

The brain changes associated with Alzheimer's may begin 20 or more years [18–21] before symptoms appear. When the initial changes occur, the brain compensates for them, enabling individuals to continue to function normally. As neuronal damage increases, the brain can no longer compensate for the changes and individuals show subtle cognitive decline. Later, neuronal damage is so significant that individuals show obvious cognitive decline, including symptoms such as memory loss or confusion as to time or place. Later still, basic bodily functions such as swallowing are impaired.

#### 2.2.4. Mild cognitive impairment (MCI): A potential precursor to Alzheimer's disease

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 do not affect the individual's ability to carry out everyday activities. Approximately 15 percent to 20 percent of people age 65 or older have MCI [22]. People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's and other dementias than people without MCI [23,24]. A recent systematic review of 32 studies found that an average of 32 percent of individuals with MCI developed Alzheimer's disease in 5 years [25]. This is similar to an earlier meta-analysis of 41 studies that found that among individuals with MCI who were tracked for 5 years or longer, an average of 38 percent developed dementia [24]. Identifying which individuals with MCI are more likely to develop Alzheimer's and other dementias is a major goal of current research.

The revised criteria and guidelines for Alzheimer's diagnosis [13–16] suggest that in some cases MCI is actually an early stage of Alzheimer's (called MCI due to Alzheimer's disease) or another form of dementia. However, MCI can develop for reasons other than Alzheimer's, and MCI

does not always lead to dementia. In some individuals, MCI reverts to normal cognition 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.

#### 2.2.5. Genetic abnormalities that cause Alzheimer's disease

##### 2.2.5.1. Genetic mutations

A small percentage of Alzheimer's cases (an estimated 1 percent or less) [26] develop as a result of mutations to any of three specific genes. A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes. These mutations involve the gene for the amyloid precursor protein (APP) and the genes for the presenilin 1 and presenilin 2 proteins. Those inheriting a mutation to the APP or presenilin 1 genes are guaranteed to develop Alzheimer's. Those inheriting a mutation to the presenilin 2 gene have a 95 percent chance of developing the disease [27]. Individuals with mutations in any of these three genes tend to develop Alzheimer's symptoms before age 65, sometimes as early as age 30, while the vast majority of individuals with Alzheimer's have late-onset disease, occurring at age 65 or later.

##### 2.2.5.2. Down syndrome

About 400,000 Americans have Down syndrome [28]. People with Down syndrome are born with an additional full or partial copy of chromosome 21, one of the 23 human chromosomes. People with Down syndrome are at high risk of developing a type of dementia that is either the same as or similar to that caused by Alzheimer's disease. Scientists are not certain why people with Down syndrome are at higher risk, but it may be related to the additional full or partial copy of chromosome 21. This chromosome includes a gene that encodes for the production of APP, which in people with Alzheimer's is cut into beta-amyloid fragments that go on to accumulate into the hallmark amyloid plaques of Alzheimer's.

By age 40, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brains [29]. As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. Studies suggest that many people with Down syndrome will begin showing symptoms of dementia in their early to mid-50s and that more than 75 percent of adults with Down syndrome over age 65 have Alzheimer's disease [30,31].

#### 2.2.6. Risk factors for Alzheimer's disease

With the exception of cases of Alzheimer's caused by genetic abnormalities, experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause.



### 2.2.6.1. Age, family history and the apolipoprotein E (APOE) $\epsilon 4$ gene

The greatest risk factors for late-onset “sporadic” Alzheimer's are older age [32,33], having a family history of Alzheimer's [34–37] and carrying the *APOE*  $\epsilon 4$  gene [38,39].

#### 2.2.6.1.1. Age

Age is the greatest of these three risk factors. Most people with Alzheimer's disease are age 65 or older. People younger than 65 can have Alzheimer's, but they are much less likely to develop the disease than older individuals. As age increases, so does the likelihood of having Alzheimer's. For example, 15 percent of those with Alzheimer's are ages 65–74, while 44 percent are ages 75–84. Although older age is a risk factor, Alzheimer's is not a normal part of aging, and older age alone is not sufficient to cause the disease.

#### 2.2.6.1.2. Family history of Alzheimer's disease

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, 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 [34,40]. Those who have more than one first-degree relative with Alzheimer's are at even higher risk [37]. 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 *APOE*  $\epsilon 4$  risk gene.

#### 2.2.6.1.3. APOE $\epsilon 4$ gene

The *APOE* gene provides the blueprint for a protein that transports cholesterol in the bloodstream. Everyone inherits one of three forms of the *APOE*  $\epsilon 4$  gene— $\epsilon 2$ ,  $\epsilon 3$ , or  $\epsilon 4$ —from each parent. The  $\epsilon 3$  form is the most common, and the  $\epsilon 2$  form the least common. The  $\epsilon 4$  form is somewhat more common than the  $\epsilon 2$  form. The estimated distribution of the  $\epsilon 2$ ,  $\epsilon 3$  and  $\epsilon 4$  forms of *APOE* is shown in Table 2.

Having the  $\epsilon 4$  form increases one's risk of developing Alzheimer's compared with having the  $\epsilon 3$  form, while having the  $\epsilon 2$  form may decrease one's risk compared with

having the  $\epsilon 3$  form. Those who inherit one copy of the  $\epsilon 4$  form have a three-fold higher risk of developing Alzheimer's than those without the  $\epsilon 4$  form, while those who inherit two copies of the  $\epsilon 4$  form have an 8- to 12-fold higher risk [40,42,43]. In addition, those with the  $\epsilon 4$  form are more likely to develop Alzheimer's at a younger age than those with the  $\epsilon 2$  or  $\epsilon 3$  forms of the *APOE* gene [44]. Researchers estimate that 40 percent to 65 percent of people diagnosed with Alzheimer's have one or two copies of the *APOE*  $\epsilon 4$  gene [38,39].

Unlike inheriting a genetic mutation that causes Alzheimer's, inheriting the  $\epsilon 4$  form of the *APOE* gene does not guarantee that an individual will develop Alzheimer's. This is also true for more than 20 recently identified genes that appear to affect the risk of Alzheimer's. These recently identified genes are believed to have a limited effect on the overall prevalence of Alzheimer's because they are rare or only slightly increase risk [45].

#### 2.2.6.2. Modifiable risk factors

Although risk factors such as age and family history cannot be changed, other risk factors can be changed, or modified, to reduce risk of cognitive decline and dementia. A recent report [46] evaluating the state of the evidence on the effects of modifiable risk factors on cognitive decline and dementia concluded that there is sufficiently strong evidence, from a population-based perspective, that regular physical activity and management of cardiovascular risk factors (especially diabetes, obesity, smoking and hypertension) reduce the risk of cognitive decline and may reduce the risk of dementia. It also concluded that there is sufficiently strong evidence that a healthy diet and lifelong learning/cognitive training may reduce the risk of cognitive decline. A second report examining the evidence regarding modifiable risk factors for cognitive decline reached similar conclusions [47].

##### 2.2.6.2.1. 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, 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 dementia. These factors include smoking [48–50], obesity in midlife [51–53], and diabetes [54–57]. Some studies propose that impaired glucose processing (a precursor to diabetes) may also result in an increased risk for dementia [51,58,59]. Midlife hypertension [51,60–62] and midlife high cholesterol [63,64] are also implicated as risk factors for dementia.

Conversely, factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer's and other dementias. Physical activity [57,65,66] appears to be

Table 2

Estimated percentages of the U.S. population with the  $\epsilon 2$ ,  $\epsilon 3$  and  $\epsilon 4$  forms of the apolipoprotein E (*APOE*) gene\*

<i>APOE</i> form	Percentage
$\epsilon 2/\epsilon 2$	0.5
$\epsilon 2/\epsilon 3$	11
$\epsilon 2/\epsilon 4$	2
$\epsilon 3/\epsilon 3$	61
$\epsilon 3/\epsilon 4$	23
$\epsilon 4/\epsilon 4$	2

NOTE. Created from data from Raber and colleagues [41].

\*One form of the *APOE* gene is inherited from each parent. People with one or two copies of  $\epsilon 4$  are at higher risk of developing Alzheimer's than individuals who do not have a copy of  $\epsilon 4$ .

one of these factors. In addition, emerging evidence suggests that consuming a diet that benefits the heart, such as one that is lower in saturated fats, may be associated with reduced Alzheimer's and dementia risk [57,67–71].

Researchers have begun studying combinations of health factors (hypertension, for instance) and lifestyle behaviors (physical activity being an example) to learn whether combinations of risk factors better identify Alzheimer's and dementia risk than individual risk factors [72].

#### 2.2.6.2.2. Education

People with fewer years of formal education are at higher risk for Alzheimer's and other dementias than those with more years of formal education [73–77]. 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 [76,78,79]. 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 changes of Alzheimer's by using alternate routes of neuron-to-neuron communication to complete a cognitive task.

Some scientists believe other factors may contribute to or explain the increased risk of dementia among those with lower educational attainment. These factors include an increased likelihood of having occupations that are less mentally stimulating [80]. In addition, lower educational attainment may reflect lower socioeconomic status [80], which may increase one's likelihood of poor nutrition and decrease one's ability to afford health care or obtain treatments, such as treatments for cardiovascular risk factors.

#### 2.2.6.2.3. Social and cognitive engagement

Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias [81–93]. Remaining socially and mentally active may help build cognitive reserve, but the exact mechanism by which this may occur is unknown. More research is needed to better understand how social and cognitive engagement may affect biological processes to reduce risk.

#### 2.2.6.2.4. Traumatic brain injury (TBI)

TBI is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. According to the Centers for Disease Control and Prevention (CDC) [94], an estimated 1.7 million Americans will sustain a TBI in any given year. Falls and motor vehicle accidents are the leading causes of TBIs [94,95]. About 75 percent of TBIs are mild, meaning that the resulting confusion, disorientation or lack of consciousness lasts 30 minutes or less. Moderate TBIs result in a loss of consciousness or post-traumatic amnesia that lasts more than 30 minutes but less than 24 hours. If loss of consciousness or post-traumatic amnesia lasts 24 hours or more, the TBI is considered severe. Moderate and severe TBIs increase

the risk of developing Alzheimer's disease and other dementias. Compared with no TBI, moderate TBI is associated with twice the risk of developing Alzheimer's and other dementias, and severe TBI with 4.5 times the risk [96].

Individuals who have experienced repeated TBIs are at higher risk of dementia, cognitive impairment and neurodegenerative disease than individuals who have not experienced TBI [97–105]. Some of these conditions, such as chronic traumatic encephalopathy (CTE), can only be definitively diagnosed upon autopsy. CTE is associated with repeated blows to the head, such as those that may occur while playing contact sports. CTE causes the brain to deteriorate over time. Physicians and researchers are only beginning to understand many aspects of CTE. For that reason, there is not yet consensus on the symptoms of CTE. Other than repeated brain trauma, the causes and risk factors for CTE remain unknown. Currently, there is no test to determine if someone has CTE and no treatment or cure. The only known way to prevent it is to avoid repeated head injuries.

Individuals can decrease their risk of TBI by wearing seatbelts while traveling, avoiding repeated blows to the head in contact sports, wearing helmets during activities such as bicycling, and ensuring one's living environment is well lit and free of tripping hazards.

### 2.2.7. Treatment of Alzheimer's disease

#### 2.2.7.1. Pharmacologic treatment

None of the pharmacologic treatments (medications) available today for Alzheimer's disease slows or stops the damage and destruction of neurons that cause Alzheimer's symptoms and makes the disease fatal. The six drugs approved by the U.S. Food and Drug Administration (FDA) for the treatment of Alzheimer's temporarily improve symptoms by increasing the amount of chemicals called neurotransmitters in the brain.<sup>A1</sup> The effectiveness of these drugs varies from person to person.

In the decade of 2002–2012, 244 drugs for Alzheimer's were tested in clinical trials registered with [clinicaltrials.gov](http://clinicaltrials.gov), a National Institutes of Health registry of publicly and privately funded clinical studies [106]. Only one of the 244 drugs successfully completed clinical trials and went on to receive approval from the FDA. Many factors contribute to the difficulty of developing effective treatments for Alzheimer's. These factors include the high cost of drug development, the relatively long time needed to observe whether an investigational treatment affects disease progression, and the structure of the brain, which is protected by the blood-brain barrier, through which only very specialized small-molecule drugs can cross.

#### 2.2.7.2. Non-pharmacologic therapy

Non-pharmacologic therapies are those that do not involve medication. Non-pharmacologic therapies are often used with the goal of maintaining or improving cognitive function, the ability to perform activities of daily living, or

overall quality of life. They also may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression. Examples include art therapy, activity-based therapy and memory training. As with current pharmacologic therapies, non-pharmacologic therapies have not been shown to alter the course of Alzheimer's disease.

Systematic reviews of published research on non-pharmacologic therapies have found that some, such as exercise and cognitive activity (for example, gardening, word games, listening to music and cooking) show promise [107]. However, compared with pharmacologic treatments, relatively few non-pharmacologic therapies have been tested in multiple large randomized controlled studies and shown consistent results. In randomized controlled studies, participants are randomly assigned to receive a therapy or not receive a therapy, and results from the two groups are compared. Additional research on non-pharmacologic therapies is needed to better evaluate their effectiveness.

#### 2.2.8. *Living with Alzheimer's disease*

Despite the lack of disease-modifying therapies for Alzheimer's, studies have consistently shown that active 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 [108–110]. Active management includes:

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.
- Coordination of care among physicians, other health care professionals and lay caregivers.
- Participation in activities and/or adult day care programs.
- Taking part in support groups and supportive services.

To learn more about each of these ways of helping to manage Alzheimer's, as well as practical information for living with the disease and being a caregiver for an individual with Alzheimer's, visit [alz.org](http://alz.org).

### 2.3. *A modern diagnosis of Alzheimer's disease: Revised criteria and guidelines*

In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association proposed revised criteria and guidelines for diagnosing Alzheimer's disease [13–16]. These criteria and guidelines update diagnostic criteria and guidelines published in 1984 by the National Institute of Neurological Disorders and Stroke and the Alzheimer's Association, then known as the Alzheimer's Disease and Related Disorders Association (ADDA) [17]. In 2012, the NIA and the Alzheimer's Association also developed new guidelines to help pathologists describe and categorize the brain changes associated with Alzheimer's disease and other dementias on autopsy [111].

#### 2.3.1. *Differences between the original and revised 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 three notable changes:

- (1) They identify two stages of Alzheimer's disease: mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease. In contrast, for Alzheimer's disease to be diagnosed using the 1984 criteria, clear dementia must have already become apparent.
- (2) They propose—for research purposes—criteria for a preclinical phase of Alzheimer's occurring before symptoms such as memory loss develop.
- (3) 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 the presence of particular groups of proteins in blood) are among several factors being studied as possible biomarkers for Alzheimer's. Finding a simple and inexpensive test, such as a blood test, would be ideal for patients, physicians and scientists. Research is underway to develop such a test, but no test to date has shown the accuracy and reliability needed to diagnose Alzheimer's.

#### 2.3.2. *The stages of Alzheimer's disease identified by the 2011 criteria and guidelines*

The stages of Alzheimer's disease identified by the 2011 criteria and guidelines are MCI due to Alzheimer's disease and dementia due to Alzheimer's disease. In addition, preclinical Alzheimer's disease is identified as a possible stage for research purposes.

##### 2.3.2.1. *Dementia due to Alzheimer's disease*

This stage is characterized by noticeable memory, thinking and behavioral symptoms that impair a person's ability to function in daily life.

##### 2.3.2.2. *MCI due to Alzheimer's disease*

People with MCI show cognitive decline greater than expected for their age and education level, but this decline does not significantly interfere with everyday activities. Approximately 15 percent to 20 percent of people age 65 or older have MCI [22]. Further cognitive decline is more likely among individuals whose MCI involves memory problems (called amnesic MCI) than among those whose MCI does not involve memory problems. Approximately



two-thirds of those with MCI have amnesic MCI [112]. About one-third of people with MCI develop dementia, most commonly Alzheimer's, in 5 years [25]. However, some people with MCI, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status [113]. It is unclear why some people with MCI develop dementia and others do not.

### 2.3.2.3. Proposed for research: Preclinical Alzheimer's disease

Although the 2011 criteria and guidelines propose preclinical disease as a potential stage of Alzheimer's disease, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional research is needed before this stage can be identified. In this proposed stage, individuals may have measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, but they may have not yet developed noticeable symptoms such as memory loss. This proposed preclinical or presymptomatic stage reflects current thinking that Alzheimer's-related brain changes may begin 20 years or more before symptoms occur [18-20]. Ongoing research continues to explore this possible stage of the disease.

### 2.3.3. Biomarker tests

Dementia and MCI due to Alzheimer's disease can be accurately diagnosed by a physician based on symptoms, family interviews and current diagnostic tests, but the 2011 criteria and guidelines recommend biomarker tests if a physician is unsure of the cause of cognitive decline. The criteria 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 early in the disease, either at the MCI stage or during the proposed preclinical stage. 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. Furthermore, biomarkers will play an important role in developing treatments because they will enable researchers to identify which individuals to enroll in clinical trials of potential new therapies. By using biomarkers, researchers can enroll only those individuals with the brain changes that treatments target [114].

The most effective biomarker test or combination of tests may differ depending on the stage of the disease and other factors [115].

## 3. Prevalence

Millions of Americans have Alzheimer's disease and other dementias. As the size and proportion of the U.S. population age 65 and older continue to increase, the number of

Americans with Alzheimer's disease and other dementias will grow. This number will escalate rapidly in coming years, as the baby boom generation has begun to reach age 65 and beyond, the age range of greatest risk of Alzheimer's. In fact, the first members of the baby boom generation turn 70 in 2016.

The prevalence of Alzheimer's disease refers to the proportion of people in a population who have Alzheimer's at a given point in time. This section reports on the number and proportion of people with Alzheimer's disease to describe the magnitude of the burden of Alzheimer's on the community and health care system. Incidence, the number of new cases per year, is also provided as an estimate of the risk of developing Alzheimer's disease and other dementias for different age groups. Estimates from selected studies on the number and proportion 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.

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

An estimated 5.4 million Americans of all ages have Alzheimer's disease in 2016. This number includes an estimated 5.2 million people age 65 and older [33]<sup>A2</sup> and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's [116].

- One in nine people age 65 and older (11 percent) has Alzheimer's disease [33].<sup>A3</sup>
- About one-third of people age 85 and older (32 percent) have Alzheimer's disease.
- Eighty-one percent of people who have Alzheimer's disease are age 75 or older (Fig. 1) [33].<sup>A4</sup>

The estimated number of individuals age 65 and older with Alzheimer's disease comes from a study using the latest data from the 2010 U.S. Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people [33].

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from

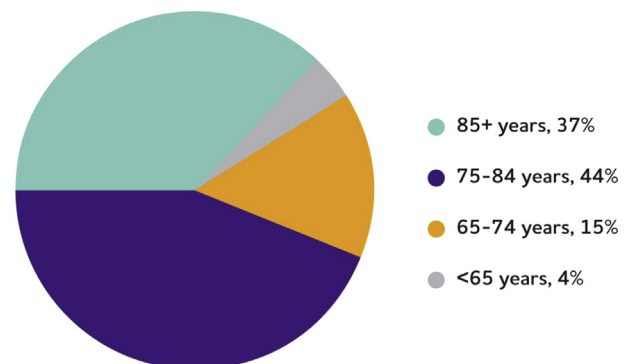


Fig. 1. Ages of people with Alzheimer's disease in the United States, 2016. Created from data from Hebert and colleagues [33].<sup>A4</sup>

other population-based studies including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults [117,118].<sup>A5</sup> Based on estimates from ADAMS, 14 percent of people age 71 and older in the United States have dementia [117].

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study is tested for dementia. But in the community, only about half of those who would meet the diagnostic criteria for Alzheimer's disease and other dementias are diagnosed with dementia by a physician [119–121]. Furthermore, as discussed in the 2015 *Alzheimer's Disease Facts and Figures Special Report*, fewer than half of those who have a diagnosis of Alzheimer's or another dementia in their medical records or their caregivers report being told of the diagnosis [122–124]. Because Alzheimer's disease is underdiagnosed and underreported, a large portion of Americans with Alzheimer's may not know they have it.

The estimates of the number and proportion of people who have Alzheimer's are based on commonly accepted criteria for diagnosing Alzheimer's disease that have been used since 1984. These criteria are applicable only after the onset of symptoms. But as described in the Overview, revised criteria and guidelines by the National Institute on Aging and the Alzheimer's Association published in 2011 [13–16] propose that Alzheimer's begins before the onset of symptoms, which is consistent with what most researchers now believe. More study is needed to estimate how many people may have MCI due to Alzheimer's disease – and how many people may be in the stage of preclinical Alzheimer's that has been proposed for research purposes. However, if Alzheimer's disease could be accurately detected before symptoms developed, the number of people reported to have Alzheimer's disease would be much larger than what is presented in this report.

### 3.1.1. Subjective cognitive decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's and other dementias as well as MCI [125–127]. Subjective cognitive decline does not refer to someone occasionally forgetting their keys or the name of someone they recently met; it refers to more serious issues such as having trouble remembering how to do things they have always done or forgetting things that they would normally know. Not all of those who experience subjective cognitive decline go on to develop MCI or Alzheimer's disease and other dementias, but many do [128,129]. Data from the 2013 Behavioral Risk Factor Surveillance System (BRFSS) survey, which included questions on self-perceived confusion and memory loss for people in 17 U.S. states, showed that

11 percent of Americans age 45 and older reported experiencing worsening confusion or memory loss, but 76 percent had not consulted a health care professional about it [130]. Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

### 3.1.2. Differences between women and men in the prevalence of Alzheimer's disease and other dementias

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women [33].<sup>A6</sup> Of the 5.2 million people age 65 and older with Alzheimer's in the United States, 3.3 million are women and 1.9 million are men [33].<sup>A6</sup> Based on estimates from ADAMS, among people age 71 and older, 16 percent of women have Alzheimer's disease and other dementias compared with 11 percent of men [117,131].

There are a number of potential reasons why more women than men have Alzheimer's disease and other dementias. The prevailing view has been that this discrepancy is due to the fact that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's [131–133]. Many studies of incidence (which indicates risk of developing disease) of Alzheimer's [74,75,132,134–137] or any dementia [73,74,133–135,138] have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age. However, limited new research suggests that risk could be higher for women, potentially due to biological or genetic variations or even different life experiences (for example, type and amount of education, or occupational choices) [133,139]. Data from the Framingham Heart Study suggest that because men have a higher rate of death from cardiovascular disease than women in middle age, men who survive beyond age 65 may have a healthier cardiovascular risk profile and thus a lower risk for dementia than women of the same age, though more research is needed to support this finding [133]. Another large study showed that the *APOE*  $\epsilon$ 4 genotype, the best known genetic risk factor for Alzheimer's disease, may have a stronger association with Alzheimer's disease in women than men [140,141]. It is unknown why this may be the case, but some evidence suggests an interaction between the *APOE*  $\epsilon$ 4 genotype and the sex hormone estrogen [142,143]. Nonetheless, evidence does not support the use of supplemental estrogen after menopause to prevent Alzheimer's [144,145], although some research suggests possible benefits for women who have had their ovaries removed [146,147]. Finally, because low education is a risk factor for dementia [73–80], it is possible that lower educational attainment in women than in men born in the first half of the 20th century could account for a higher risk of Alzheimer's and other dementias in women; however, this possibility has not been thoroughly investigated scientifically.

### 3.1.3. Racial and ethnic differences in the prevalence of Alzheimer's disease and other dementias

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older African-Americans and Hispanics are more likely than older whites to have Alzheimer's disease and other dementias [148–152]. A review of many studies by an expert panel concluded that older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites [153,154], and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites [154–156].<sup>A7</sup> Currently, there is not enough evidence to estimate the prevalence of Alzheimer's disease and other dementias in other racial and ethnic groups.

Variations in health, lifestyle and socioeconomic risk factors across racial groups likely account for most of the differences in risk of Alzheimer's disease and other dementias by race [157]. Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race [158,159], genetic factors do not appear to account for the large prevalence differences among racial groups [157,160]. Instead, health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for Alzheimer's disease and other dementias, are believed to account for these differences as they are more prevalent in African-American and Hispanic people [161,162]. Indeed, vascular dementia accounts for a larger proportion of dementia in African-Americans than in whites [159]. Socioeconomic characteristics, including lower levels of education, higher rates of poverty and greater exposure to discrimination, may also increase risk in African-American and Hispanic communities [161,162]. Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such factors [74,117,157].

There is evidence that missed diagnoses of Alzheimer's disease and other dementias are more common among older African-Americans and Hispanics than among older whites [163,164]. Based on data for Medicare beneficiaries age 65 and older, Alzheimer's disease or another dementia had been diagnosed in 6.9 percent of white older adults, 9.4 percent of African-Americans and 11.5 percent of Hispanics [165]. Although rates of diagnosis were higher among African-Americans than among whites, according to prevalence studies that detect all people who have dementia irrespective of their use of the health care system, the rates should be twice as high as those for whites (approximately 13.8 percent instead of 9.4 percent).

### 3.2. Estimates of the number of people with Alzheimer's disease by state

Table 3 lists the estimated number of people age 65 and older with Alzheimer's disease by state for 2016, the projected number for 2025, and the projected percentage change

Table 3

Projections of total numbers of Americans age 65 and older with Alzheimer's by state

State	Projected number with Alzheimer's (in thousands)		Percentage change 2016–2025
	2016	2025	
Alabama	89	110	23.6
Alaska	6.8	11	61.8
Arizona	130	200	53.8
Arkansas	54	67	24.1
California	610	840	37.7
Colorado	67	92	37.3
Connecticut	74	91	23.0
Delaware	17	23	35.3
District of Columbia	9.0	9.0	0.0
Florida	510	720	41.2
Georgia	130	190	46.2
Hawaii	26	35	34.6
Idaho	23	33	43.5
Illinois	220	260	18.2
Indiana	110	130	18.2
Iowa	63	73	15.9
Kansas	51	62	21.6
Kentucky	69	86	24.6
Louisiana	84	110	31.0
Maine	26	35	34.6
Maryland	100	130	30.0
Massachusetts	120	150	25.0
Michigan	180	220	22.2
Minnesota	91	120	31.9
Mississippi	52	65	25.0
Missouri	110	130	18.2
Montana	19	27	42.1
Nebraska	33	40	21.2
Nevada	41	64	56.1
New Hampshire	23	32	39.1
New Jersey	170	210	23.5
New Mexico	37	53	43.2
New York	390	460	17.9
North Carolina	160	210	31.3
North Dakota	14	16	14.3
Ohio	210	250	19.0
Oklahoma	62	76	22.6
Oregon	62	84	35.5
Pennsylvania	270	320	18.5
Rhode Island	23	27	17.4
South Carolina	84	120	42.9
South Dakota	17	20	17.6
Tennessee	110	140	27.3
Texas	350	490	40.0
Utah	30	42	40.0
Vermont	12	17	41.7
Virginia	140	190	35.7
Washington	100	140	40.0
West Virginia	37	44	18.9
Wisconsin	110	130	18.2
Wyoming	9.1	13	42.9

NOTE. Created from data provided to the Alzheimer's Association by Weuve and colleagues [166].<sup>A8</sup>

in the number of people with Alzheimer's between 2016 and 2025 [166].<sup>A8</sup> Comparable estimates and projections for other types of dementia are not available.

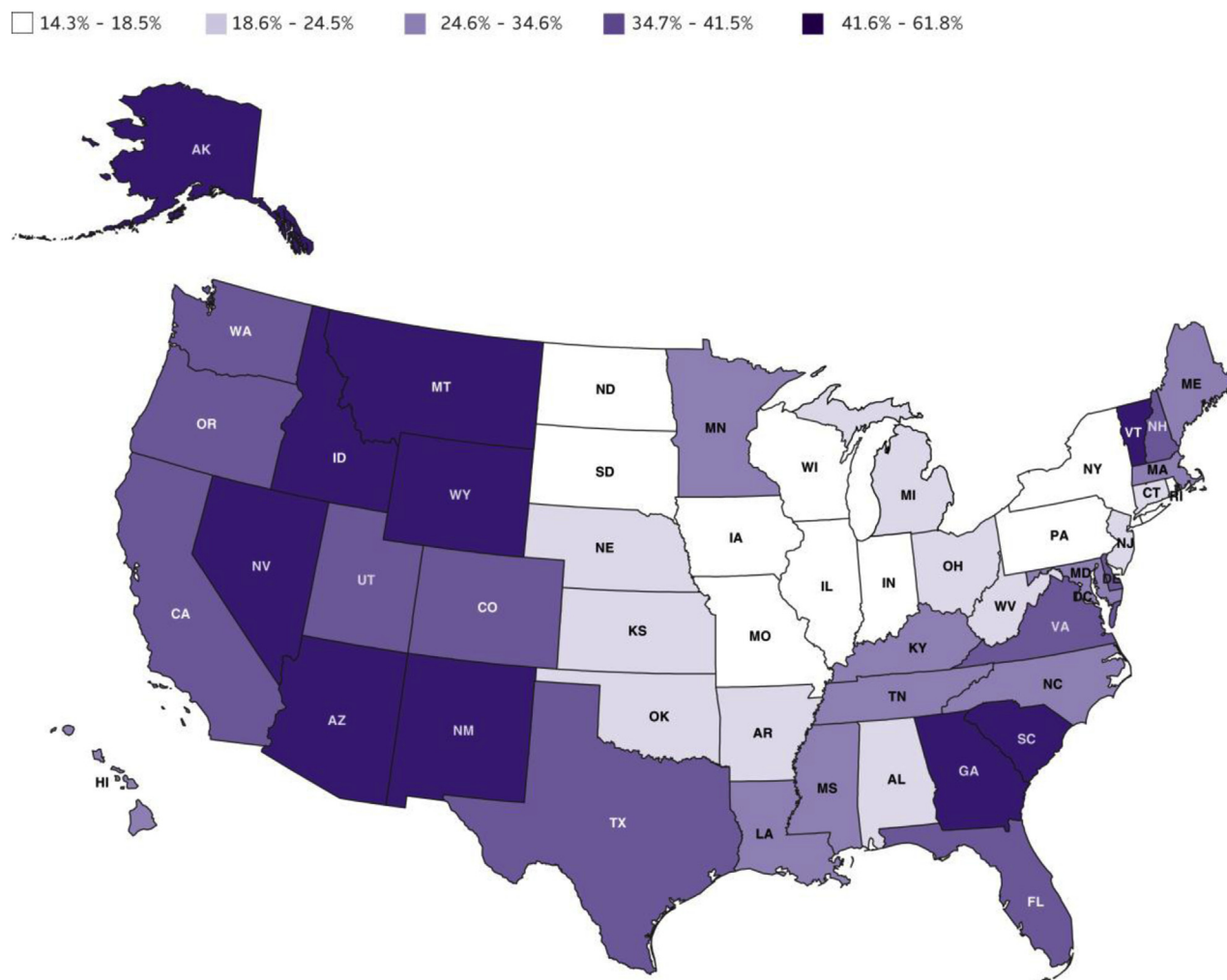


Fig. 2. Projected increases between 2016 and 2025 in Alzheimer's disease prevalence by state. Change from 2016 to 2025 for Washington, D.C.: 0.0%. Created from data provided to the Alzheimer's Association by Weuve and colleagues [166].<sup>A8</sup>

As shown in [Fig. 2](#), between 2016 and 2025 every state and region across the country is expected to experience an increase of at least 14 percent in the number of people with Alzheimer's due to increases in the population age 65 and older. The West and Southeast are expected to experience the largest percentage increases in people with Alzheimer's between 2016 and 2025. These increases will have a marked impact on states' health care systems; reliance on Medicaid, to which states contribute funds; and families and caregivers.

### 3.3. Incidence of Alzheimer's disease

While prevalence refers to *existing* cases of a disease in a population at a given time, incidence refers to *new* cases of a disease that develop in a given period of time in a defined population—in this case, the U.S. population age 65 or older. Incidence provides a measure of *risk* for developing a disease. Approximately 476,000 people age 65 or older will develop Alzheimer’s disease in the United States in 2016.<sup>A9</sup> The number of new cases of Alzheimer’s increases

dramatically with age: in 2016, there will be approximately 63,000 new cases among people age 65 to 74, 172,000 new cases among people age 75 to 84, and 241,000 new cases among people age 85 and older (the “oldest-old”) [167].<sup>A9</sup> This translates to approximately two new cases per 1000 people age 65 to 74, 13 new cases per 1000 people age 75 to 84, and 37 new cases per 1000 people age 85 and older.<sup>A9</sup> Because of the increasing number of people age 65 and older in the United States, particularly the oldest-old, the annual number of new cases of Alzheimer’s and other dementias is projected to double by 2050 [167].

- Every 66 seconds, someone in the United States develops Alzheimer's.<sup>A10</sup>
- By mid-century, someone in the United States will develop the disease every 33 seconds.<sup>A10</sup>

### 3.4. Lifetime risk of Alzheimer's disease

Lifetime risk is the probability that someone of a given age will develop a condition during his or her remaining



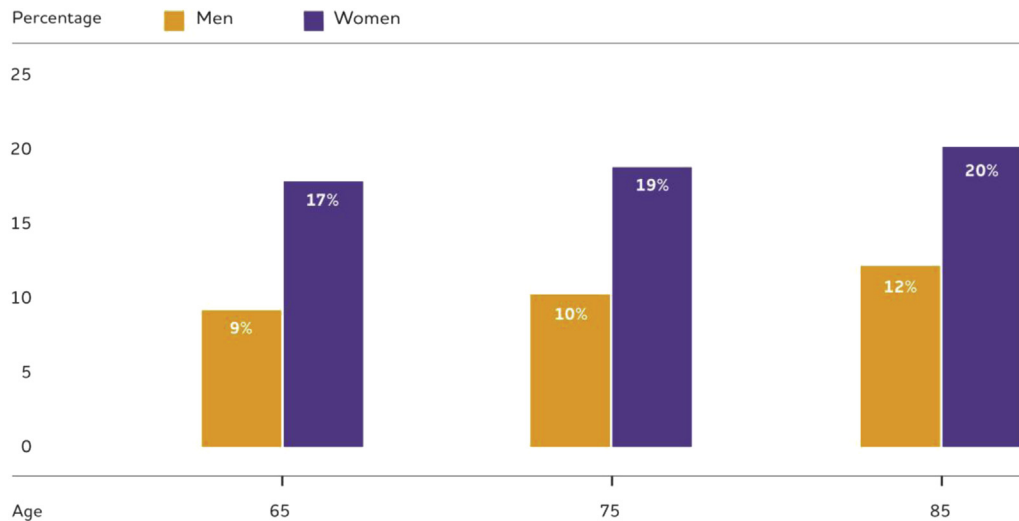


Fig. 3. Estimated lifetime risk for Alzheimer's, by age and sex, from the Framingham Study. Created from data from Seshadri and colleagues [168].

life span. Data from the Framingham Study were used to estimate lifetime risks of Alzheimer's disease by age and sex [168].<sup>A11</sup> As shown in Fig. 3, the study found that the estimated lifetime risk for Alzheimer's specifically at age 65 was one in six (17 percent) for women and one in 11 (9 percent) for men [168].

### 3.5. Trends in the prevalence and incidence of Alzheimer's disease

A growing number of studies indicate that the age-specific risk of Alzheimer's and other dementias in the United States and other higher-income Western countries may have declined in the past 25 years [169–176], though results are mixed [32]. These declines have largely been attributed to increasing levels of education and improved control of cardiovascular risk factors [171,177]. Such findings are promising and suggest that identifying and reducing risk factors for Alzheimer's and other dementias may be effective. Although these findings indicate that a person's risk of dementia at any given age may be decreasing slightly, it should be noted that the total number of Americans with Alzheimer's and other dementias is expected to continue to increase dramatically because of the population's shift to older ages (see Looking to the future). Thus, while these findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow.

### 3.6. Looking to the future

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to medical advances, as well as social and environmental conditions [178]. Additionally, a large segment of the American population—the baby boom generation—has begun to reach age 65 and older, when the risk for Alzheimer's and other

dementias is elevated. By 2030, the segment of the U.S. population age 65 and older will increase substantially, and the projected 74 million older Americans will make up over 20 percent of the total population (up from 14 percent in 2012) [178].

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 Fig. 4 [33].<sup>A12</sup>

- In 2010, there were an estimated 454,000 new cases of Alzheimer's disease. By 2030, that number is projected to be 615,000 (a 35 percent increase), and by 2050, 959,000 (a 110 percent increase from 2010) [167].
- By 2025, the number of people age 65 and older with Alzheimer's disease is estimated to reach 7.1 million—almost a 40 percent increase from the 5.2 million age 65 and older affected in 2016 [33].<sup>A13</sup>
- By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5.2 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent or cure the disease [33].<sup>A12</sup> Previous estimates based on high range projections of population growth provided by the U.S. Census suggest that this number may be as high as 16 million [179].<sup>A14</sup>

### 3.7. Growth of the oldest-old population

Longer life expectancies and aging baby boomers will also increase the number and percentage of Americans who will be among the oldest-old. Between 2012 and 2050, the oldest-old are expected to increase from 14 percent of all people age 65 and older in the United States to 22 percent of all people age 65 and older [178]. This will result in an additional 12 million oldest-old people—individuals at the highest risk for developing Alzheimer's [178].

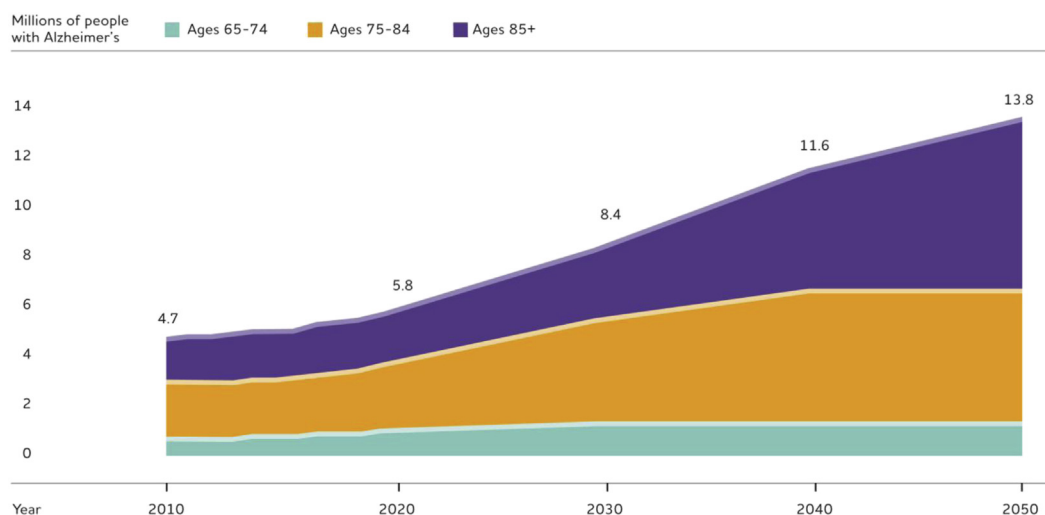


Fig. 4. Projected number of people age 65 and older (total and by age group) in the U.S. population with Alzheimer's disease, 2010 to 2050. Created from data from Hebert and colleagues [33].<sup>A12</sup>

- In 2016, about 2 million people who have Alzheimer's disease are age 85 or older, accounting for 37 percent of all people with Alzheimer's [33].
- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's [33].
- By 2050, as many as 7 million people age 85 and older may have Alzheimer's disease, accounting for half (51 percent) of all people 65 and older with Alzheimer's [33].

#### 4. Mortality and morbidity

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States [180]. It is the fifth-leading cause of death for those age 65 and older [180]. However, it may cause even more deaths than official sources recognize. Alzheimer's is also a leading cause of disability and poor health (morbidity). Before a person with Alzheimer's dies, he or she lives through years of morbidity as the disease progresses.

##### 4.1. Deaths from Alzheimer's disease

It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to data from the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), 84,767 people died from Alzheimer's disease in 2013 [180]. 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" [181]. 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, and Alzheimer's and other dementias are underreported as the underlying cause of death [182–184]. 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 is the most commonly identified cause of death among elderly people with Alzheimer's disease and other dementias [185,186]. The number of people with Alzheimer's disease who die while experiencing these other 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. A recent study using data from the Rush Memory and Aging Project and the Religious Orders Study supports this concept: researchers estimated that 500,000 deaths among people age 75 and older could be attributed to Alzheimer's disease in the United States in 2010 (estimates for people age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if those individuals did not have Alzheimer's [187].

The situation has been described as a "blurred distinction between death *with* dementia and death *from* dementia" [188]. According to data from the Chicago Health and Aging Project (CHAP), an estimated 600,000 people age 65 and older in the United States had Alzheimer's when they died in 2010, meaning they died *with* Alzheimer's disease [189]. Of these, an estimated 400,000 were age 85 and older, and an estimated 200,000 were age 65 to 84. Furthermore, according to Medicare data, about one-third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia [165,190]. Although some seniors who have Alzheimer's disease at the time of

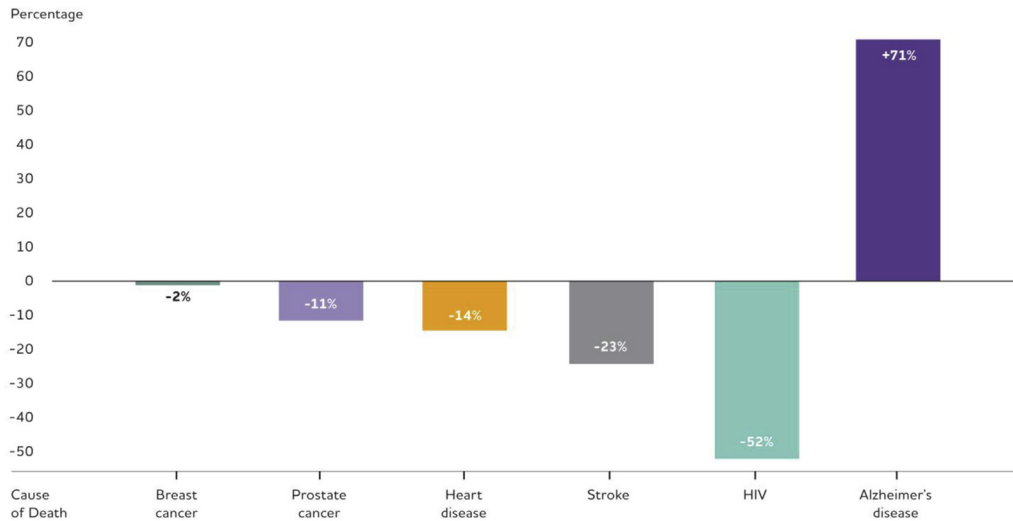


Fig. 5. Percentage changes in selected causes of death (all ages) between 2000 and 2013. Created from data from the National Center for Health Statistics [180].

death die from causes that are unrelated to Alzheimer's, many of them die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia. A recent study evaluating the contribution of individual common diseases to death using a nationally representative sample of older adults found that dementia was the second largest contributor to death behind heart failure [191]. Thus, for people who have Alzheimer's when they die, the disease is expected to significantly and directly contribute to their deaths.

In 2016, an estimated 700,000 people in the United States age 65 and older will have Alzheimer's disease when they die, based on CHAP data [189]. The true number of deaths caused by Alzheimer's is likely to be somewhere between the official number of deaths from Alzheimer's (as indicated by death certificates) and the estimated number of people who have Alzheimer's disease when they die. 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 [192].

#### 4.2. 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. Although deaths from other major causes have decreased significantly, official records indicate that deaths from Alzheimer's disease have increased significantly. Between 2000 and 2013, deaths attributed to Alzheimer's disease increased 71 percent, while those attributed to the number one cause of death (heart disease) decreased 14 percent (Fig. 5) [180]. 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.

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

Table 4 provides information on the number of deaths due to Alzheimer's by state in 2013, 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 2013, the mortality rate for Alzheimer's disease was 27 deaths per 100,000 people [180].

#### 4.4. Alzheimer's disease death rates

As shown in Fig. 6, the rate of deaths attributed to Alzheimer's has risen substantially since 2000 [180]. Table 5 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65 [180]. The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old [193]. Between 2000 and 2013, the death rate from Alzheimer's did not increase for people age 65 to 74, but increased 23 percent for people age 75 to 84, and 39 percent for people age 85 and older.

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

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's [194–199]. This reflects the slow, insidious progression of Alzheimer's. On average, a person with Alzheimer's disease will spend 40 percent of their total number of years living with dementia in its most severe stage [192]. Much of this

Table 4  
Number of deaths and annual mortality rate (per 100,000) due to Alzheimer's disease by state, 2013

State	Number of deaths	Mortality rate
Alabama	1398	28.9
Alaska	72	9.8
Arizona	2383	36.0
Arkansas	918	31.0
California	11,891	31.0
Colorado	1316	25.0
Connecticut	824	22.9
Delaware	192	20.7
District of Columbia	130	20.1
Florida	5093	26.0
Georgia	2048	20.5
Hawaii	260	18.5
Idaho	347	21.5
Illinois	2919	22.7
Indiana	2104	32.0
Iowa	1252	40.5
Kansas	742	25.6
Kentucky	1462	33.3
Louisiana	1505	32.5
Maine	401	30.2
Maryland	919	15.5
Massachusetts	1699	25.4
Michigan	3220	32.5
Minnesota	1427	26.3
Mississippi	925	30.9
Missouri	2026	33.5
Montana	267	26.3
Nebraska	557	29.8
Nevada	448	16.1
New Hampshire	351	26.5
New Jersey	1812	20.4
New Mexico	339	16.3
New York	2556	13.0
North Carolina	2872	29.2
North Dakota	363	50.2
Ohio	3798	32.8
Oklahoma	1145	29.7
Oregon	1312	33.4
Pennsylvania	3271	25.6
Rhode Island	346	32.9
South Carolina	1623	34.0
South Dakota	418	49.5
Tennessee	2536	39.0
Texas	5293	20.0
Utah	412	14.2
Vermont	269	42.9
Virginia	1642	19.9
Washington	3277	47.0
West Virginia	590	31.8
Wisconsin	1671	29.1
Wyoming	126	21.6
<b>U.S. Total</b>	<b>84,767</b>	<b>26.8</b>

NOTE. Created from data from the National Center for Health Statistics [180].<sup>A15</sup>

time will be spent in a nursing home. Exemplifying this, 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 [192]. In all, an estimated two-thirds of those who die of dementia do so in nursing homes,

compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions [200].

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

The long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease because much of that time is spent in a state of disability and dependence. Scientists have developed methods to measure and compare the burden of different diseases on a population in a way that takes into account not only the number of people with the condition, but also both the number of years of life lost due to that disease as well as the number of healthy years of life lost by virtue of being in a state of disability. These measures indicate that Alzheimer's is a very burdensome disease and that the burden of Alzheimer's has increased more dramatically in the United States than other diseases in recent years. The primary measure of disease burden is called disability-adjusted life years (DALYs), which is the sum of the number of years of life lost due to premature mortality and the number of years lived with disability, totaled across all those with the disease. Using this measure, Alzheimer's rose from the 25th most burdensome disease in the United States in 1990 to the 12th in 2010. No other disease or condition increased as much [201]. In terms of years of life lost, Alzheimer's disease rose from 32nd to 9th, the largest increase for any disease. In terms of years lived with disability, Alzheimer's disease went from ranking 17th to 12th; only kidney disease equaled Alzheimer's in as high a jump in rank.

Taken together, the numbers in this section indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, the disease is also contributing to more and more cases of poor health and disability in the United States.

### 5. Caregiving

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, as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and transportation [202,203]. More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias.<sup>A16</sup>

#### 5.1. Unpaid caregivers

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers [204]. In 2015, caregivers of people with Alzheimer's and other dementias provided an estimated 18.1 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at \$221.3 billion. This is approximately 47 percent of the net value of Walmart sales in 2014 (\$473.1 billion) [205] and eight times the total



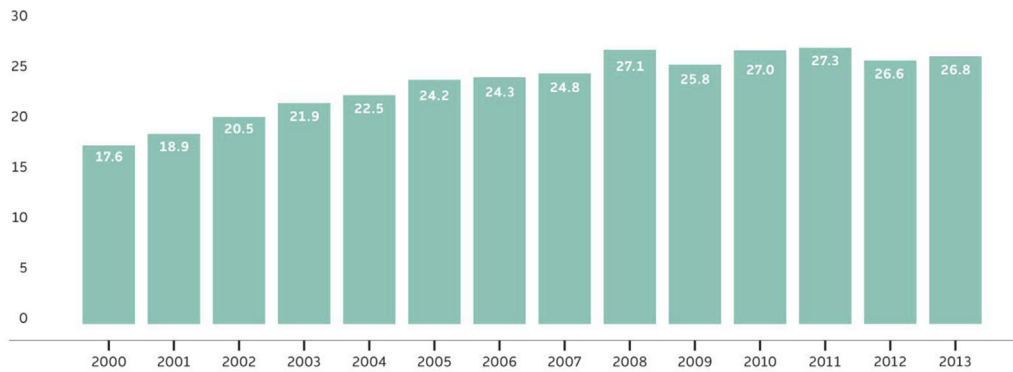


Fig. 6. U.S. annual Alzheimer's death rate (per 100,000) by year. Created from data from the National Center for Health Statistics [180].

Table 5

U.S. annual Alzheimer's death rates (per 100,000) by age

Age	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
45–54	0.2	0.2	0.1	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.3	0.2	0.2	0.2
55–64	2.0	2.1	1.9	2.0	1.8	2.1	2.1	2.2	2.2	2.0	2.1	2.2	2.2	2.2
65–74	18.7	18.6	19.6	20.7	19.5	20.2	19.9	20.2	21.1	19.4	19.8	19.2	17.9	18.1
75–84	139.6	147.2	157.7	164.1	168.5	177.0	175.0	175.8	192.5	179.1	184.5	183.9	175.4	171.6
85+	667.7	725.4	790.9	846.8	875.3	935.5	923.4	928.7	1002.2	945.3	987.1	967.1	936.1	929.5

NOTE. Created from data from the National Center for Health Statistics [180].

revenue of McDonald's in 2014 (\$27.4 billion) [206]. The value of informal care (not including caregivers' out-of-pocket costs) was nearly equal to the costs of direct medical and long-term care of dementia in 2010 [207].

The three primary reasons caregivers decide to provide care and assistance to a person with Alzheimer's disease are (1) the desire to keep a family member/friend at home (65 percent), (2) proximity to the person with dementia (48 percent) and (3) the caregiver's perceived obligation as a spouse or partner (38 percent).<sup>A17</sup> Individuals with dementia living in the community are more likely than those without dementia to rely on multiple unpaid caregivers; 30 percent of people with dementia rely on three or more caregivers, whereas 23 percent of people without dementia rely on three or more unpaid caregivers [208]. Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8 percent). Of these individuals, more than 40 percent live alone, perhaps making it more difficult to ask for and receive informal care [208].

#### 5.1.1. Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's disease and other dementias in the United States [209–212].<sup>A17</sup> About one in three caregivers (34 percent) is age 65 or older.<sup>A17</sup> Over two-thirds of caregivers are married, living with a partner or in a long-term relationship [210].<sup>A17</sup> More than two-thirds of caregivers are non-Hispanic white [209,210],<sup>A17</sup> while 10 percent are African-American, 8 percent are Hispanic, and 5 percent are Asian.<sup>A17</sup> Over

40 percent of dementia caregivers have a college degree or greater education [210].<sup>A17</sup> Forty-one percent of caregivers have a household income of \$50,000 or less.<sup>A17</sup> Among primary caregivers of people with dementia (individuals who indicate having the most responsibility for helping their relatives), over half (55 percent) take care of parents [212]. Most caregivers (66 percent) live with the care recipient in the community [208]. It is estimated that 250,000 children and young adults between ages 8 and 18 provide help to someone with Alzheimer's disease or another dementia [213]. National surveys have found that 23 percent of Alzheimer's disease and dementia caregivers were "sandwich generation" caregivers—meaning that they care not only for an aging parent, but also for children under age 18.<sup>A17</sup>

#### 5.1.2. Caregiving and women

The responsibilities of caring for someone with dementia often fall to women. Approximately two-thirds of caregivers are women [209,210].<sup>A17</sup> More specifically, over one-third of dementia caregivers are daughters [208]. It is more common for wives to provide informal care for a husband than vice versa [214]. On average, female caregivers spend more time caregiving than male caregivers. For example, daughters provide, on average, 102 hours per month whereas sons provide 80 hours per month [208]. According to the 2014 Alzheimer's Association Women and Alzheimer's Poll, more than twice as many women caregivers as men caregivers reported spending 21 to 60 hours per week providing care, and two and a half times as many reported living with the person with dementia full time [215]. Caregivers who are women may experience slightly higher levels

Table 6  
Dementia caregiving tasks

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

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of burden, depression and impaired health than men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, take on more caregiving tasks, and are more likely to care for someone with a greater number of behavioral problems.

### 5.1.3. Caregiving tasks

The care provided to people with Alzheimer's disease and other dementias is wide-ranging and in some instances all-encompassing. Table 6 summarizes some of the most common types of dementia care provided.

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 conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia help with an average of two ADLs and five IADLs and are more likely to monitor the health of their care recipients than are caregivers of people without dementia (79 percent versus 66 percent) [216]. Data from the 2011 National Health and Aging Trends Study [209,217] indicated that caregivers of people with dementia are more likely than caregivers of people without dementia to provide help with self-care and mobility (85 percent versus 71 percent) and health or medical care (63 percent versus 52 percent). Yet half of caregivers of people with Alzheimer's disease or another dementia indicate having no experience performing medical/nursing tasks (51 percent) [216].

Among all older adults with dementia, 77 percent receive assistance with ADLs or household activities in contrast to only 20 percent of older adults without dementia [208]. Over half of individuals with dementia (53 percent) receive assistance from family members or other informal caregivers for ADLs compared with 11 percent of older adults without dementia [208]. Among older adults who receive help, nearly 40 percent of people with dementia receive help with three or more ADLs compared with 14 percent of people without dementia [208].

In addition to assisting with ADLs, almost two-thirds of caregivers of people with Alzheimer's disease and other dementias advocate for their care recipient with government agencies and service providers (61 percent) and manage finances (65 percent). Close to half arrange for outside services (45 percent), and nearly four of five communicate with health care professionals (79 percent) [216]. Caregivers of people with dementia are more likely to coordinate health care for the care recipient than caregivers of people without dementia (86 percent versus 72 percent) [209]. Caring for a person with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms (for example, anxiety, apathy and lack of inhibition) and severe behavioral problems. Family caregivers often lack the information or resources necessary to manage the increasingly complex medication regimens for people with dementia [218].

When a person with Alzheimer's or another dementia moves to an assisted living residence or nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 6 to providing emotional support, interacting with facility staff and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing and other ADLs [219–221]. Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility, but other studies have found that distress declines significantly following admission [221–223].

### 5.1.4. Duration of caregiving

Eighty-six percent of dementia caregivers have provided care and assistance for at least the past year, according to the national 2014 Alzheimer's Association Women and Alzheimer's Poll (which included both men and women).<sup>A17</sup>

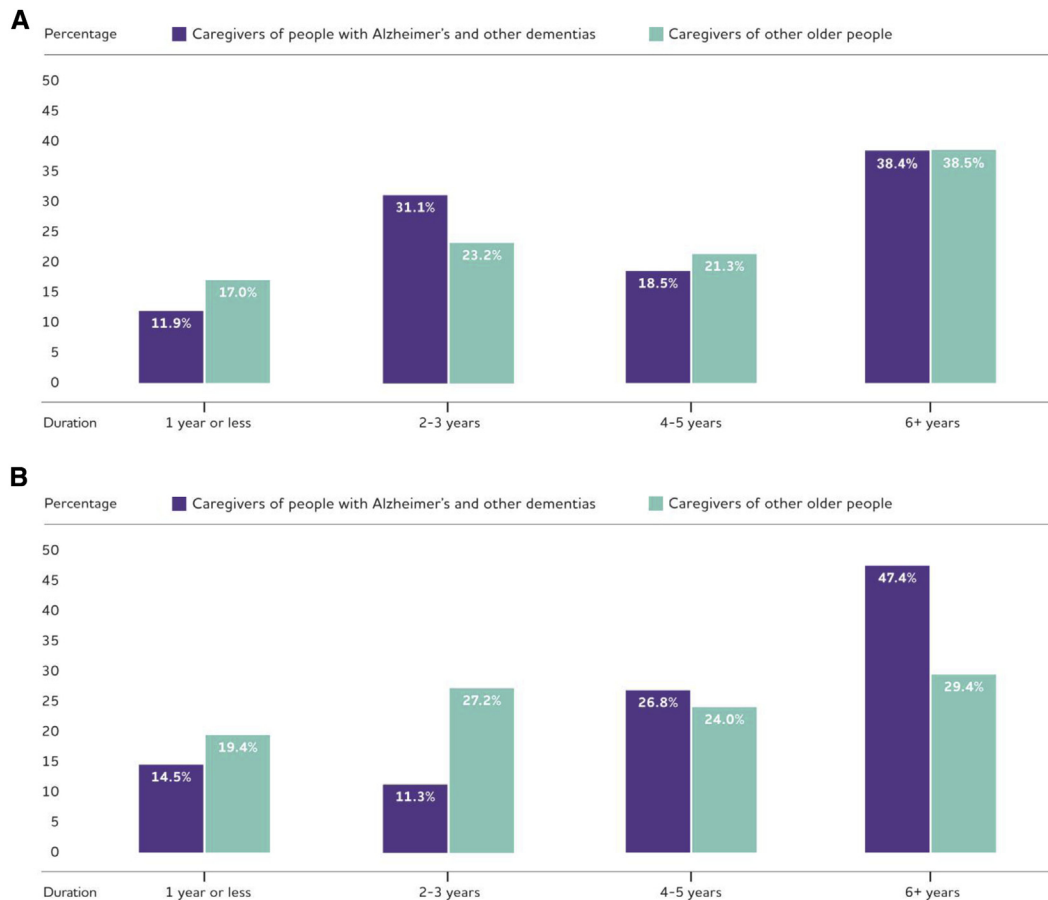


Fig. 7. (A) Proportion of Alzheimer's and dementia caregivers versus caregivers of other older people in the community by duration of caregiving, United States, 2011. Created from data from the National Health and Aging Trends Study [209]. (B) Proportion of Alzheimer's and dementia caregivers versus caregivers of other older people in residential care settings by duration of caregiving, United States, 2011. Created from data from the National Health and Aging Trends Study [209].

Caregivers of people with Alzheimer's and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions. As shown in Fig. 7A, 38 percent of all family caregivers of care recipients living in the community had provided care for 6 or more years. As shown in Fig. 7B, this increases to 47 percent for family caregivers of people with dementia living in residential care settings, compared with 29 percent for family caregivers of older adults without dementia who live in residential care settings [209].

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

In 2015, the 15.9 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 18.1 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1139 hours of care per caregiver per year.<sup>A18</sup> With this care valued at \$12.25 per hour,<sup>A19</sup> the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was \$221.3 billion in 2015. Table 7 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 provided care valued at more than \$4 billion in each of 21 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. Additional research is needed to estimate the future value of family care for people with Alzheimer's disease as the U.S. population continues to age. A longitudinal study of the monetary value of family caregiving for individuals with dementia found that the overall value of daily family care increased 18 percent with each additional year of providing care, and that value of daily care increased as the care recipient's cognitive abilities declined [224].

Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia, with over half providing more than 21 hours of care per week [209,216]. Considering all sources of unpaid care (for example, help from multiple family members) among people who receive such care, individuals with dementia receive

Table 7

Number of Alzheimer's and dementia (AD/D) caregivers, hours of unpaid care, economic value of unpaid care and higher health care costs of caregivers by state, 2015\*

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) <sup>†</sup>
Alabama	302	344	\$4209	\$177
Alaska	33	38	\$463	\$28
Arizona	319	364	\$4456	\$163
Arkansas	175	199	\$2440	\$101
California	1592	1814	\$22,215	\$936
Colorado	239	272	\$3336	\$135
Connecticut	177	202	\$2471	\$144
Delaware	53	60	\$740	\$42
District of Columbia	28	32	\$388	\$27
Florida	1080	1230	\$15,069	\$726
Georgia	513	584	\$7160	\$263
Hawaii	66	75	\$915	\$42
Idaho	79	90	\$1108	\$42
Illinois	590	671	\$8224	\$375
Indiana	334	381	\$4662	\$209
Iowa	135	153	\$1876	\$88
Kansas	150	171	\$2099	\$96
Kentucky	270	307	\$3764	\$166
Louisiana	231	263	\$3224	\$147
Maine	68	78	\$953	\$55
Maryland	291	331	\$4055	\$205
Massachusetts	332	378	\$4629	\$289
Michigan	510	580	\$7108	\$317
Minnesota	249	284	\$3478	\$174
Mississippi	206	234	\$2868	\$126
Missouri	314	357	\$4374	\$205
Montana	49	55	\$679	\$30
Nebraska	81	92	\$1133	\$54
Nevada	143	162	\$1990	\$77
New Hampshire	66	75	\$917	\$48
New Jersey	449	511	\$6260	\$320
New Mexico	106	121	\$1480	\$66
New York	1021	1163	\$14,245	\$800
North Carolina	454	516	\$6327	\$275
North Dakota	30	35	\$425	\$22
Ohio	596	678	\$8310	\$396
Oklahoma	222	252	\$3092	\$136
Oregon	178	202	\$2480	\$110
Pennsylvania	673	766	\$9390	\$488
Rhode Island	53	60	\$739	\$41
South Carolina	300	341	\$4181	\$177
South Dakota	37	43	\$521	\$25
Tennessee	426	485	\$5941	\$255
Texas	1359	1547	\$18,957	\$756
Utah	145	165	\$2025	\$68
Vermont	30	34	\$417	\$21
Virginia	455	519	\$6354	\$268
Washington	330	375	\$4597	\$210
West Virginia	108	123	\$1503	\$77
Wisconsin	192	219	\$2679	\$131
Wyoming	28	32	\$388	\$18
<b>U.S. Total</b>	<b>15,864</b>	<b>18,066</b>	<b>\$221,312</b>	<b>\$10,151</b>

NOTE. 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>A16,A18,A19,A20</sup>

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

<sup>†</sup>Higher health care costs are the dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state.<sup>A20</sup>



an average of 171 hours of care per month, which is over 100 hours more care per month than those without dementia (66 hours per month, on average) [204].

#### 5.1.6. Impact of Alzheimer's disease caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the middle to later stages of Alzheimer's 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 [225]. Individuals with Alzheimer's also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen, the care required of family members can result in increased emotional stress and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment and paying for health care or other services for themselves and their care recipients (see [Special Report](#)) [226–231].<sup>A17</sup> The intimacy, shared 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 disease.

##### 5.1.6.1. Caregiver emotional well-being

Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others [232],<sup>A17</sup> they also report high levels of stress when providing care:

- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial financial, emotional and physical difficulties [209].
- Fifty-nine percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high ([Fig. 8](#)).<sup>A17</sup>

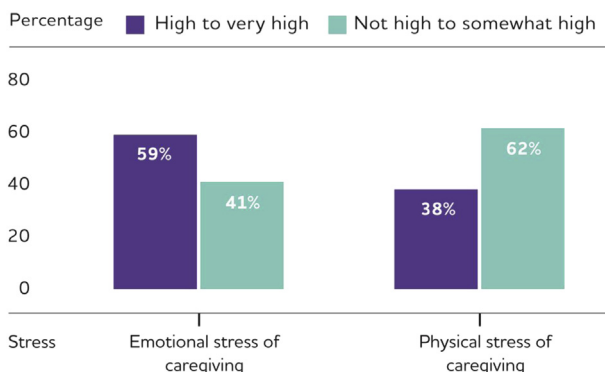


Fig. 8. Proportion of Alzheimer's and dementia caregivers who report high or very high emotional and physical stress due to caregiving. Created from data from the Alzheimer's Association.<sup>A17</sup>

- Approximately 40 percent of family caregivers of people with dementia suffer from depression, compared with 5 to 17 percent of non-caregivers of similar ages [230,233–236]. Rates of depression increase with the severity of cognitive impairment of the person with dementia [237,238].
- One in five (22 percent) caregivers of people with Alzheimer's disease or another dementia has difficulty with medical/nursing tasks, compared with 11 percent of caregivers of individuals without dementia [216].
- According to the 2014 Alzheimer's Association poll, respondents often believed they had no choice in taking on the role of caregiver.<sup>A17</sup>
- The 2014 Alzheimer's Association poll also found that women with children under age 18 felt that caregiving for someone with Alzheimer's disease was more challenging than caring for children (53 percent).<sup>A17</sup>
- The demands of caregiving may intensify as people with dementia approach the end of life [239]. 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 [240]. One study of end-of-life care found that 72 percent of family caregivers experienced relief when the person with Alzheimer's disease or another dementia died [240].
- Many caregivers of people with Alzheimer's disease and other dementias provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.<sup>A17</sup>
- Sandwich generation caregivers indicate lower quality of life and diminished health and health behaviors (for example, less likely to choose healthful foods and less likely to exercise) compared with non-sandwich generation caregivers or non-caregivers [241–243].

##### 5.1.6.2. Caregiver physical health

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of dementia care provision increases caregivers' susceptibility to disease and health complications [244]. As shown in [Fig. 8](#), 38 percent of Alzheimer's and dementia caregivers indicate that the physical impact of caregiving was high to very high.<sup>A17</sup> Sleep disturbances, which can occur frequently when caring for a relative with Alzheimer's disease or another dementia, have also been shown to negatively influence family caregivers' health [245,246]. Caregivers of people with Alzheimer's disease and other dementias were also more likely to indicate a high degree of physical strain related to care provision than other caregivers (28 percent versus 17 percent, respectively) [216].

##### 5.1.6.2.1. General health

Seventy-four percent of caregivers of people with Alzheimer's disease and other dementias reported that

they were “somewhat concerned” to “very concerned” about maintaining their own health since becoming a caregiver.<sup>A17</sup> Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor [228]. Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse [247]. According to the 2009 and 2010 Behavioral Risk Factor Surveillance System (BRFSS) surveys, 7 percent of dementia caregivers indicate that the greatest difficulty of caregiving is that it creates or aggravates their own health problems compared with 2 percent of other caregivers [210]. According to 1998–2010 biannual data from the Health and Retirement Survey, dementia caregivers were much more likely (41 percent increased odds) than other caregivers to become increasingly frail from the period prior to the death of a spouse receiving care to the time of the spouse's death, accounting for differences in age and additional factors [248]. Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers [249].

#### 5.1.6.2.2. Physiological changes

The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions. For example, several studies found that under certain circumstances 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 [250–255].

Caregivers of a spouse with Alzheimer's or another dementia are more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones [256], reduced immune function [226,257], slow wound healing [258], increased incidence of hypertension [259], coronary heart disease [260] and impaired function of the endothelium

(the inner lining of the blood vessels). Some of these changes may be associated with an increased risk of cardiovascular disease [261].

#### 5.1.6.2.3. Health care

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$10.2 billion in health care costs in the United States in 2015.<sup>A20</sup> Table 7 shows the estimated higher health care costs for Alzheimer's and dementia caregivers in each state. In separate studies, hospitalization and emergency department visits were more likely for dementia caregivers who helped care recipients who were depressed, had low functional status or had behavioral disturbances [262,263]. Increased depressive symptoms among caregivers over time are also linked to more frequent doctor visits, a higher number of outpatient tests and procedures, and greater use of over-the-counter and prescription medications [263].

#### 5.1.6.2.4. 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 dementia in their medical records 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 [264]. Studies of other dementias have found that caregivers who perceive higher strain due to care responsibilities are at significantly higher risk for death than caregivers who perceive little or no strain [265].

#### 5.1.6.3. Caregiver employment

Among people who were employed at any time since they became caregivers of someone with Alzheimer's or another dementia, 9 percent ultimately quit their jobs to continue providing care. Fifty-four percent had to go in late or leave early, and 15 percent had to take a leave of absence. Other

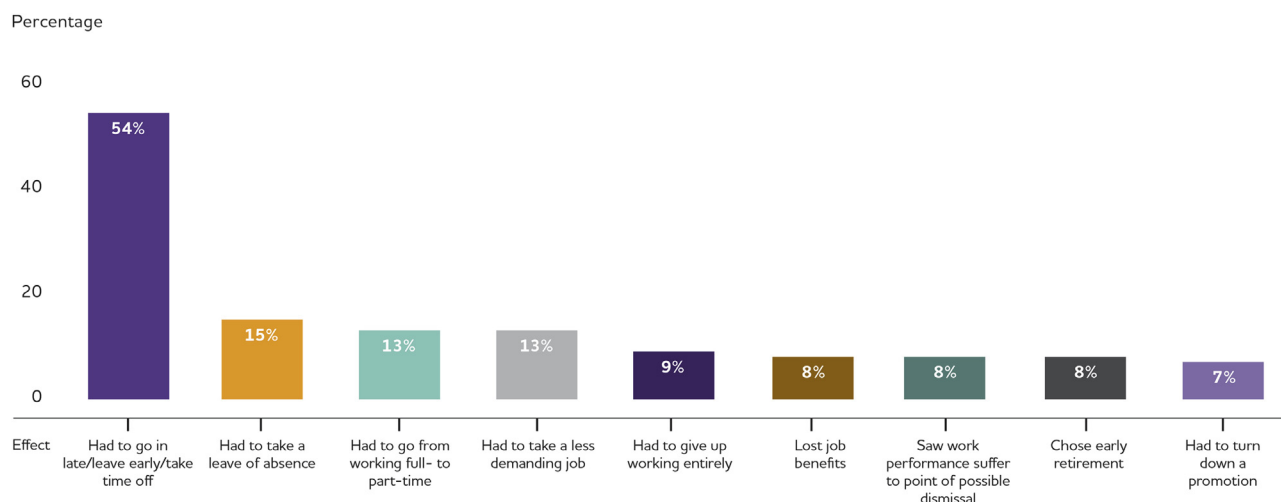


Fig. 9. Work-related changes among caregivers of people with Alzheimer's disease and other dementias who had been employed at any time since they began caregiving. Created from data from the Alzheimer's Association.<sup>A18</sup>

Table 8  
Type and focus of caregiver interventions

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

NOTE. Created from data from Pinquart and colleagues and Sörensen and colleagues [230,231].

work-related challenges for dementia caregivers who had been employed at any time since they began caregiving are summarized in Fig. 9.<sup>A18</sup>

#### 5.1.7. Interventions designed to assist caregivers

For more than 30 years, strategies to support family caregivers of people with Alzheimer's disease have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 8 [230,231].

In general, interventions aim to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia. Specific approaches used in various interventions include providing education to caregivers, helping caregivers manage dementia-related symptoms, improving social support for caregivers, and providing caregivers with respite from caregiving duties.

According to a recent publication that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention meets the needs not only of caregivers, but of care recipients as well [266]. A 2012 report identified 44 interventions that have been shown by randomized controlled trials conducted in the United States to have benefits for individuals with Alzheimer's disease and other dementias as well as their family caregivers, and more evaluations are emerging each year [267,268].

Interventions for dementia caregivers that have demonstrated efficacy in scientific evaluations have been gradually implemented in the community [269–278]. These imple-

mentation efforts are generally successful at improving how caregiver services are delivered, and they have the potential to reach a large number of families while also helping caregivers cope with their responsibilities. Similar efforts have attempted to broaden the reach and accessibility of interventions for dementia caregivers through the use of technologies (for instance, video-phone delivery and online training) and have shown some success [279,280]. However, more work is needed to ensure that interventions for dementia caregivers are available and accessible to those who need them. Because caregivers and the settings in which they provide care are diverse, more studies are required to define which interventions are most effective for specific situations [281–283]. Improved tools to "personalize" services for caregivers to maximize their benefits is an emerging area of research [284,285]. More studies are also needed to explore the effectiveness of interventions in different racial, ethnic and socioeconomic groups and in different geographic settings [280,286–290].

#### 5.2. Paid caregivers

##### 5.2.1. 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, provide most of the paid long-term care to older adults living at home or in residential settings. In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents [291–293]. Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and international backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care

[292,294]. One review found that direct-care workers received, on average, 75 hours of training and that this training included little focus on issues specific or pertinent to dementia care [292]. Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges [295]. Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments [296]. Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest benefits [294,297].

### 5.2.2. Shortage of geriatric health care professionals in the United States

Professionals who may receive special training in caring for older adults include physicians, nurse practitioners, registered nurses, social workers, pharmacists, physician assistants and case workers [295]. It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs [298]. There are currently 7428 certified geriatricians and 1629 geriatric psychiatrists in the United States, or one geriatrician and one geriatric psychiatrist for every 2526 and 11,526 Americans 75 years of age and over, respectively [299]. The American Geriatrics Society estimates that due to the increase in older Americans and the stagnation of the number of new geriatric professionals trained in the past decade, these ratios will drop to one geriatrician and one geriatric psychiatrist for every 4484 and 20,448 older Americans, respectively, by 2030 [299]. According to the Institute of Medicine, less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics [295]. Similarly, although 73 percent of social workers serve clients age 55 and older, only 4 percent have formal certification in geriatric social work [295]. Further affecting the number of paid caregivers is the overall aging of the long-term care workforce [296].

Recognizing that the complex care challenges of people with dementia require interprofessional collaboration and education, ongoing efforts have attempted to integrate innovative care management practices with traditional primary care for people with dementia [300–302]. One example involves a skilled professional who serves as the care “manager” of the person with dementia. The care manager collaborates with primary care physicians and nurse practitioners to develop personalized care plans. These plans can provide support to family caregivers, help people with dementia manage care transitions (for example, a change in care provider or site of care), and ensure the person with dementia has access to appropriate community-based services. Other models include addressing the needs of family caregivers simultaneously with comprehensive disease management of the care recipient to improve the quality of life of both family caregivers and people with dementia in the community [303]. Several evaluations have suggested that such approaches have considerable potential for

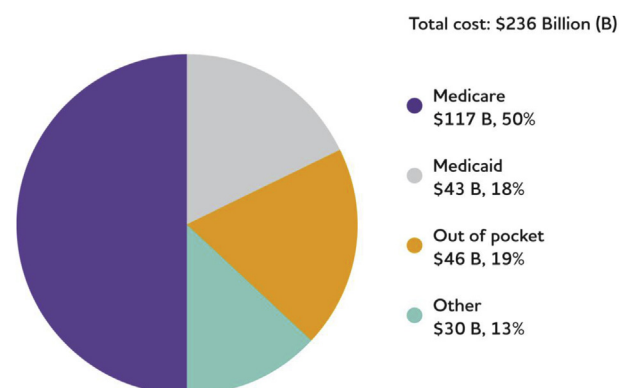


Fig. 10. Aggregate cost of care by payment source for Americans age 65 and older with Alzheimer's disease and other dementias, 2016. Data are in 2016 dollars. Created from The Lewin Model.<sup>A21</sup> “Other” payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care. Totals for payment sources may not add to total cost due to rounding.

improving outcomes for people with dementia and their family caregivers (for example, delayed nursing home admission and reductions in caregiver distress) [304–308]. Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate [309,310].

## 6. Use and costs of health care, long-term care and hospice

The costs of health care, long-term care and hospice for individuals with Alzheimer's disease and other dementias are substantial, and Alzheimer's disease is one of the costliest chronic diseases to society [207]. Total payments in 2016 (in 2016 dollars) for all individuals with Alzheimer's disease and other dementias are estimated at \$236 billion (Fig. 10). Medicare and Medicaid are expected to cover \$160 billion, or 68 percent, of the total health care and long-term care payments for people with Alzheimer's disease and other dementias. Out-of-pocket spending is expected to be \$46 billion, or 19 percent of total payments.<sup>A21</sup>

### 6.1. Total cost of health care, long-term care and hospice

Table 9 reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's disease and other dementias. Unless otherwise indicated, all costs in this section are reported in 2015 dollars.<sup>A22</sup> Total per-person health care and long-term care payments in 2015 from all sources 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 (\$49,126 per person for those with dementia compared with \$15,550 per person for those without dementia) [190].<sup>A23</sup>



Table 9

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 2015 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	\$22,206	\$19,776	\$25,600	\$8427
Medicaid	11,338	249	26,837	590
Uncompensated	306	439	120	345
HMO	1114	1729	254	1625
Private insurance	2534	2784	2183	1704
Other payer	1015	183	2176	161
Out of pocket	10,495	3548	20,207	2559
<b>Total*</b>	<b>49,126</b>	<b>28,911</b>	<b>77,381</b>	<b>15,550</b>

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [190].

\*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.

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 [190]. 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. Average Medicaid payments per person for Medicare beneficiaries with Alzheimer's disease and other dementias (\$11,338) were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's disease and other dementias (\$590) (Table 9) [190].

Despite these and 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. Medicare beneficiaries age 65 and older with Alzheimer's and other dementias paid \$10,495 out of pocket, on average, for health care and long-term care services not covered by other sources (Table 9) [190]. Average per-person out-of-pocket payments were highest (\$20,207 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 [190].

Recently, researchers evaluated the additional or "incremental" health care and caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics) [207,311]. One group of researchers found that the incremental health care and nursing home costs for those with dementia was \$28,501 per year in 2010 dollars (\$32,781 in 2015 dollars) [207].<sup>A22,A24</sup> Another group of researchers found that the incremental lifetime cost of Alzheimer's disease was substantially higher for women

compared with men, due to a greater risk of developing Alzheimer's disease. Additionally, because women are more likely to be widowed and living in poverty, the incremental Medicaid costs associated with Alzheimer's disease were 70 percent higher for women compared with men [312].

Other researchers compared end-of-life costs for individuals with and without dementia and found that the total cost in the last 5 years of life was \$287,038 in 2010 dollars for people with dementia and \$183,001 for people with other conditions (\$330,143 and \$210,483, respectively, in 2015 dollars), a difference of 57 percent [313]. Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for people with dementia (32 percent versus 11 percent).

## 6.2. Use and costs of health care services

People with Alzheimer's disease and other dementias have twice as many hospital stays per year as other older people [165]. 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 artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke 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.

### 6.2.1. 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.** There are 538 hospital stays per 1000 Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias compared with 266 hospital stays per 1000 Medicare beneficiaries age 65 and older without these conditions [165]. The

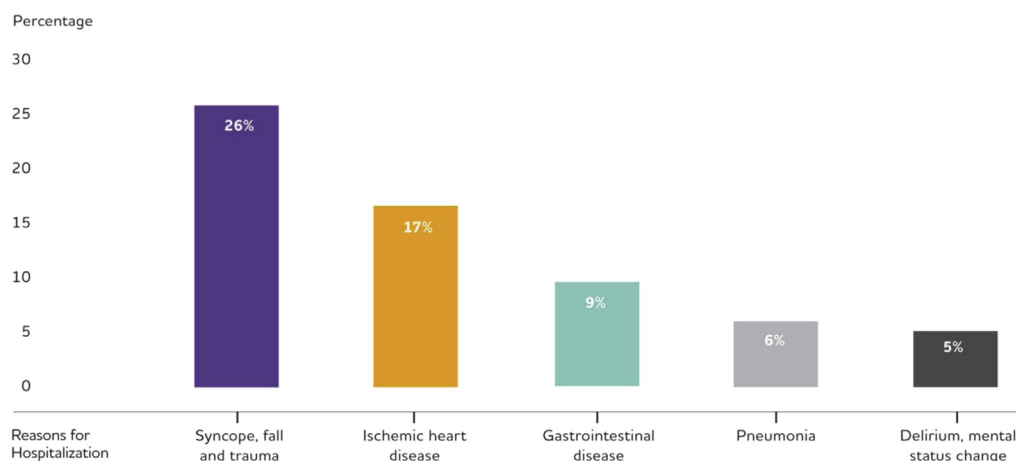


Fig. 11. Reasons for hospitalization of individuals with Alzheimer's disease: Percentage of hospitalized individuals by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's disease were used to calculate percentages. The remaining 37 percent of hospitalizations were due to other reasons. Created from data from Rudolph and colleagues [314].

most common reasons for hospitalization of people with Alzheimer's disease are syncope (fainting), fall and trauma (26 percent); ischemic heart disease (17 percent); and gastrointestinal disease (9 percent) (Fig. 11) [314].

- *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 [315]. There are 283 skilled nursing facility stays per 1000 beneficiaries with Alzheimer's and other dementias compared with 73 stays per 1000 beneficiaries for people without these conditions [165].
- *Home health care.* Twenty-five percent of Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias have at least one home health care visit during the year, compared with 10 percent of Medicare beneficiaries age 65 and older without Alzheimer's and other dementias [165].

Differences in health care use between individuals with and without dementia are most prominent for those residing in the community. Based on data from the Health and Retirement Study, community-residing individuals with dementia were more likely to have a potentially preventable hospitalization, an emergency department visit that was potentially avoidable, and/or an emergency department visit that resulted in a hospitalization [316]. For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to or quality of preventive and primary care. Based on data from the 2006 to 2008 Health and Retirement Study and Medicare, preventable hospitalizations represented 25 percent of the total hospitalizations for individuals with

Alzheimer's disease and other dementias [317]. The proportion was substantially higher, however, for African-Americans, Hispanics and individuals with low incomes. Hispanic older adults had the highest proportion of preventable hospitalizations (34 percent). Based on data from the 1998 to 2008 Health and Retirement Study and Medicare, after controlling for demographic characteristics, clinical characteristics and health risk factors, individuals with dementia had a 1.33 times greater risk and individuals with depression and dementia had a 1.66 times greater risk of having a preventable hospitalization than those without dementia, cognitive impairment without dementia or depression [318]. Healthy People 2020, the U.S. Department of Health and Human Services' initiative to achieve 10-year goals for health promotion and disease prevention, has set a target to reduce preventable hospitalizations for people with Alzheimer's disease and other dementias by 10 percent by 2020 [317].

#### 6.2.2. Costs of health care services

With the exception of prescription medications, average per-person payments for health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice 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 10) [190]. The fact that only payments for prescription drugs were lower for those with Alzheimer's and other dementias underscores the lack of effective pharmacologic treatments available to those with dementia.

#### 6.2.3. Use and costs of health care services across the spectrum of cognitive impairment

Health care costs increase with the presence of dementia. In a population-based study of adults ages 70 to 89 in Olmsted County, Minnesota, annual health care costs were

Table 10

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, in 2015 dollars

Service	Beneficiaries with Alzheimer's disease and other dementias	Beneficiaries without Alzheimer's disease and other dementias
Inpatient hospital	\$11,834	\$4758
Medical provider*	6440	4269
Skilled nursing facility	4334	504
Nursing home	20,114	894
Hospice	1976	193
Home health	1583	511
Prescription medications†	3037	3095

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [190].

\*"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.

significantly higher for individuals with newly diagnosed dementia and prevalent dementia than for those with normal cognition, and annual health care costs were also significantly higher for individuals with prevalent dementia compared with those with mild cognitive impairment [319]. Annual health care costs for individuals with mild cognitive impairment were not significantly different, however, from costs for individuals with normal cognition.

Individuals newly diagnosed with Alzheimer's disease have higher health care use and costs in the year prior to diagnosis and in the 2 years after diagnosis than those who do not receive this diagnosis, according to a study of Medicare Advantage enrollees (that is, Medicare beneficiaries enrolled in a private Medicare health insurance plan) [320]. Enrollees with a new diagnosis of Alzheimer's disease had \$2331 in 2011 dollars (\$2602 in 2015 dollars) more in health care costs (medical and prescriptions) in the year prior to diagnosis, \$9333 (\$10,418 in 2015 dollars) more in costs in the year following diagnosis, and \$5761 (\$6430 in 2015 dollars) more in costs in the second year following diagnosis. In another study of pre-diagnosis health care costs, Medicaid enrollees with Alzheimer's disease had \$5549 in 2010 dollars (\$6382 in 2015 dollars) more in health care costs in the year prior to diagnosis, with \$3321 (\$3820 in 2015 dollars) due to additional outpatient medical care and \$1442 (\$1681 in 2015 dollars) in additional home care and adult day care services [321].

While more work is needed to understand the underlying causes of increased use of health care services immediately prior to and after receiving a diagnosis of Alzheimer's disease, it may be attributed to care for disability and injuries, such as falls, that might result from the early stage of the disease [322]; treatments related to cognitive impairment or coexisting medical conditions; and costs of diagnostic procedures.

Table 11

Specific coexisting medical conditions among Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias, 2013

Coexisting condition	Percentage of beneficiaries with Alzheimer's disease and other dementias who also had a coexisting medical condition
Coronary artery disease	38
Diabetes	37
Chronic kidney disease	29
Congestive heart failure	28
Chronic obstructive pulmonary disease	25
Stroke	22
Cancer	13

NOTE. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2013 [165].

#### 6.2.4. Impact of Alzheimer's disease and other dementias on use and costs of health care in people with coexisting medical conditions

Medicare beneficiaries with Alzheimer's disease and other dementias are more likely than those without dementia to have other chronic conditions [165]. While 12 percent of Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias have five or more chronic conditions (including Alzheimer's and other dementias), only 2.5 percent of Medicare beneficiaries without Alzheimer's disease and other dementias have five or more chronic conditions [165]. Table 11 reports the proportion of people with Alzheimer's disease and other dementias who have certain coexisting medical conditions. In 2013, 38 percent of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 37 percent also had diabetes, 29 percent also had chronic kidney disease, 28 percent also had congestive heart failure and 25 percent also had COPD [165].

People with Alzheimer's or another dementia and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Fig. 12) [165]. Research has demonstrated that Medicare beneficiaries with Alzheimer's disease and other dementias have more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting [323]. Another research team found that individuals hospitalized with heart failure are more likely to be readmitted or die after hospital discharge if they also have cognitive impairment [324].

Similarly, Medicare beneficiaries who have Alzheimer's and other dementias and a serious coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries who have the same medical condition without dementia. Table 12 shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have

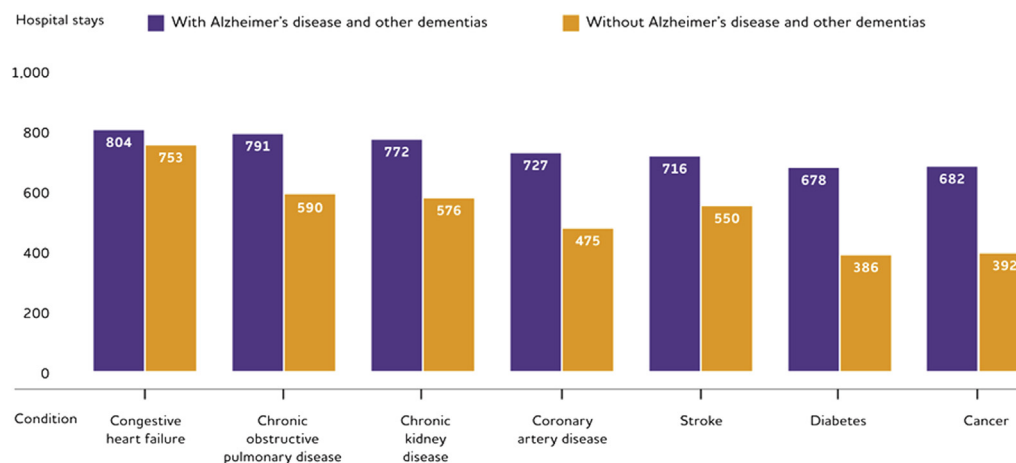


Fig. 12. Hospital stays per 1,000 beneficiaries age 65 and older with specified coexisting medical conditions, with and without Alzheimer's disease and other dementias, 2014. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [165].

Alzheimer's disease and other dementias and beneficiaries who do not have dementia [165]. Medicare beneficiaries with dementia had higher average per-person payments in all categories except hospital care payments for individuals with congestive heart failure.

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

An estimated 58 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 [190]. Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone [190]. As their disease progresses, people with Alzheimer's and other dementias generally receive more care from family members and other unpaid caregivers. Many people with dementia also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times during

Table 12

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, 2014, in 2015 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
Coronary artery disease						
With AD/D	\$25,339	\$7498	\$2137	4249	\$2262	\$2775
Without AD/D	15,815	5400	1521	1365	938	361
Diabetes						
With AD/D	24,529	7134	2093	4109	2188	2499
Without AD/D	13,542	4469	1341	1187	814	246
Congestive heart failure						
With AD/D	27,804	8427	2244	4644	2369	3322
Without AD/D	23,589	8555	2016	2514	1682	779
Chronic kidney disease						
With AD/D	27,058	8075	2191	4520	2238	2968
Without AD/D	19,400	6647	1728	1824	1159	457
Chronic obstructive pulmonary disease						
With AD/D	26,860	8098	2219	4479	2315	3078
Without AD/D	18,323	6485	1676	1694	1151	581
Stroke						
With AD/D	25,711	7401	2116	4421	2175	3088
Without AD/D	18,523	6020	1704	2222	1404	583
Cancer						
With AD/D	24,358	7020	2049	3811	2001	2762
Without AD/D	15,449	4615	1406	1017	668	467

NOTE. Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014 [165].

\*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.



the often long course of the disease. The average costs of these services are high (assisted living, \$43,200 per year [325], and nursing home care, \$80,300 to \$91,250 per year) [325], and Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illnesses.

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

Most people with Alzheimer's 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 [326]. 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 [326].

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

- **Adult day services.** Thirty-two percent of individuals using adult day services have Alzheimer's disease or other dementias [327], and 73 percent of adult day service programs offer specific programs for individuals with Alzheimer's disease and other dementias [328].
- **Assisted living.** Forty-two percent of residents in assisted living facilities (that is, housing that includes services to assist with everyday activities, such as medication management and meals) had Alzheimer's disease and other dementias in 2010 [329]. Forty percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's disease and other dementias [330]. Small residential care facilities (4 to 25 beds) have a larger proportion of residents with Alzheimer's and other dementias than larger facilities (47 percent versus 42 percent in facilities with 26 to 50 beds and 37 percent in facilities with more than 50 beds) [330]. Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's disease and other dementias [331].
- **Nursing home care.** Of all Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias, 31 percent live in a nursing home [190]. Of all Medicare beneficiaries residing in a nursing home, 64 percent have Alzheimer's disease and other dementias [190].
- **Alzheimer's special care units.** An Alzheimer's special care unit is a dedicated unit in a nursing home that has tailored services for individuals with Alzheimer's and other dementias. Nursing homes had a total of 73,742 beds in Alzheimer's special care units in 2014,

a decrease of 3 percent from the previous year [332,333]. These Alzheimer's special care unit beds accounted for 71 percent of all special care unit beds and 4 percent of all nursing home beds.

A recent research study demonstrates that individuals with dementia often move between a nursing facility, hospital and home, rather than remaining in a nursing facility [334]. In this longitudinal study of primary care patients with dementia, researchers found that those discharged from a nursing facility were nearly equally as likely to be discharged home (39 percent) as discharged to a hospital (44 percent). Individuals with dementia may also transition between a nursing facility and hospital or between a nursing facility, home and hospital, creating challenges for caregivers and providers to ensure that care is coordinated across settings. Other research has shown that nursing home residents frequently have burdensome transitions at the end of life, including admission to an intensive care unit in the last month of life, late enrollment in hospice and receipt of a feeding tube [335]. The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States [336].

Researchers also found that both the number of transitions between health care settings and the odds of having a feeding tube inserted at the end of life varied across the country. Furthermore, individuals with frequent transitions between health care settings were more likely to have feeding tubes at the end of life, even though feeding tube placement has little or no benefit. These differences across geographic regions were not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. They may reflect differences in the quality of care, although more research is needed. Additionally, researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. Feeding tube use was lower among people with dementia whose care was managed by a general practitioner [337].

Research has also demonstrated a decrease in the proportion of individuals with Alzheimer's disease who die in an acute care hospital, with end-of-life care shifting to home and nursing homes [338]. Additionally, more than twice as many individuals with the disease were receiving hospice care at the time of death in 2009 than in 2000 (48 percent in 2009 versus 20 percent in 2000). With the expansion of hospice care, the use of feeding tubes in the last 90 days of life has decreased for individuals with Alzheimer's disease and other dementias [339]. Similarly, expansion of hospice care is also associated with a reduction in the proportion of individuals with Alzheimer's disease and other dementias who have more than two hospitalizations for any reason or more than one hospitalization for pneumonia, urinary tract infection, dehydration or sepsis in the last 90 days of life [339].

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home



and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. The federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs. In 2013, home and community-based services represented the majority (51 percent) of Medicaid spending on long-term services and supports, with the remaining 49 percent for institutional care [340]. More work is needed, however, to understand the extent to which home and community-based services meet the needs of individuals with Alzheimer's disease and other dementias.

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

Costs are high for care provided at home or in an adult day center, an assisted living facility or a nursing home. The following estimates are for all users of these services.

- *Home care.* The median cost for a paid non-medical home health aide is \$20 per hour, or \$160 for an 8-hour day [325].
- *Adult day centers.* The median cost of adult day services is \$69 per day [325]. Ninety-five percent of adult day centers provide care for people with Alzheimer's disease and other dementias, and 2 percent of these centers charged an additional fee for these clients in 2012 [341].
- *Assisted living facilities.* The median cost for basic services in an assisted living facility is \$3600 per month, or \$43,200 per year [325].
- *Nursing homes.* The average cost for a private room in a nursing home is \$250 per day, or \$91,250 per year. The average cost of a semi-private room in a nursing home is \$220 per day, or \$80,300 per year [325].

### 6.3.3. 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 \$24,150 or less, and 25 percent had incomes of \$14,350 or less [342].
- Fifty percent of Medicare beneficiaries had total savings of \$63,350 or less, 25 percent had savings of \$11,900 or less, and 8 percent had no savings or were in debt. Median savings were substantially lower for African-American and Hispanic Medicare beneficiaries than for white Medicare beneficiaries [342].

### 6.3.4. Long-term care insurance

Enrollment in private long-term care insurance is more common for older adults with higher-than-average incomes. While only 3 percent of adults age 55 and older had

long-term care insurance in 2008, 19 percent with incomes greater than \$100,000 had long-term care insurance [343]. The average annual long-term care insurance premium was \$2283 in 2010 (\$2586 in 2015 dollars) [343]. Private health [344] and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2011, representing \$28 billion of the \$404 billion total in 2015 dollars [345]. The private long-term care insurance market has consolidated since 2010. Five major insurance carriers either exited the market or substantially increased premiums since then, making policies unaffordable for many individuals [346]. The Patient Protection and Affordable Care Act passed in 2010 included a provision to create a federal long-term care insurance program, the Community Living Assistance Services and Support (CLASS) Act. The provision was repealed in 2013.

### 6.3.5. 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.

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be \$43 billion in 2016 (in 2016 dollars).<sup>A21</sup> Estimated state-by-state Medicaid spending on people with Alzheimer's and other dementias in 2016 (in 2016 dollars) is included on Table 13. 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 an average of \$26,837 per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility, compared with \$249 for those with the diagnosis living in the community and an average of \$590 for older adults without the diagnosis living in the community and long-term care facilities (Table 9) [190].

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's disease, researchers found significant differences in the costs of care by race/ethnicity [347]. These results demonstrated that African-Americans had significantly higher costs of care than whites or Hispanics, primarily due to more inpatient care and greater severity of illness. These differences may be attributable to later-stage diagnosis, which may lead to higher levels of disability while

Table 13  
Total Medicaid costs for Americans age 65 and older living with  
Alzheimer's disease and other dementias by state, 2016 (in millions)

State	2016
Alabama	\$808
Alaska	56
Arizona	304
Arkansas	317
California	3336
Colorado	508
Connecticut	883
Delaware	210
District of Columbia	116
Florida	2336
Georgia	1055
Hawaii	197
Idaho	133
Illinois	1531
Indiana	935
Iowa	602
Kansas	420
Kentucky	664
Louisiana	657
Maine	180
Maryland	1061
Massachusetts	1569
Michigan	1326
Minnesota	767
Mississippi	529
Missouri	801
Montana	150
Nebraska	302
Nevada	177
New Hampshire	225
New Jersey	1929
New Mexico	192
New York	4178
North Carolina	1094
North Dakota	179
Ohio	2320
Oklahoma	457
Oregon	225
Pennsylvania	3209
Rhode Island	415
South Carolina	561
South Dakota	156
Tennessee	971
Texas	2278
Utah	147
Vermont	96
Virginia	866
Washington	453
West Virginia	368
Wisconsin	706
Wyoming	75
<b>U.S.</b>	<b>43,035</b>

NOTE. Created from data from the Lewin Model.<sup>A21</sup>

All cost figures are reported in 2016 dollars. State totals may not add to the U.S. total due to rounding.

receiving care; delays in accessing timely primary care; lack of care coordination; and duplication of services across providers. However, more research is needed to understand the reasons for this health care disparity.

### 6.3.6. Programs to reduce avoidable health care and nursing home use

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other on the care delivery team.

Studies of the effectiveness of caregiver support programs suggest that these programs have promise for reducing unnecessary emergency department visits and hospitalizations and reducing transitions to residential care for individuals with Alzheimer's disease and other dementias. For example, in an evaluation of the Dementia Care Services Program in North Dakota, researchers found that hospitalizations, ambulance use, emergency department visits and 911 calls decreased significantly after caregivers began working with the program, which offered them care consultations, resources and referrals [348]. In another study, researchers estimated the effects of applying the New York University Caregiver Intervention on health care costs and utilization in Minnesota over 15 years. They determined that this intervention, which includes spouse and family caregiver counseling sessions, a weekly caregiver support group and telephone counseling, would increase by 5 percent the number of individuals with dementia who would be able to continue residing in the community. They also predicted that nearly 20 percent fewer individuals with dementia would die in residential care [349], and that the reduced number of transitions to residential care would lower health care costs in Minnesota by \$996 million in 2011 dollars (\$1.1 billion in 2015 dollars) over the 15-year period. More research is needed to determine the extent to which these results apply to the broader population of individuals with Alzheimer's disease and other dementias and their caregivers.

Additionally, collaborative care models—models that include not only geriatricians, but also social workers, nurses and medical assistants—can improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits [306]. For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by \$3474 in 2012 dollars (\$3741 in 2015 dollars) over a year for individuals with memory problems compared with others whose care was overseen by a primary care provider only [306]. More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of \$618 (\$665 in 2015 dollars).

### 6.4. Use and costs of hospice care

Hospice care provides medical care, pain management and emotional and spiritual support for people who are dying, including people with Alzheimer's disease and other dementias. Hospice care also provides emotional and spiritual support and bereavement services for families of people

who are dying. The main purpose of hospice is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. 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 people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (61,146 people) [350]. An additional 11 percent of those admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (119,872 people) [350]. 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 [350]. 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 [350]. Average per-person hospice care payments for beneficiaries with Alzheimer's disease and other dementias were 10 times as great as for all other Medicare beneficiaries (\$1976 per person compared with \$193 per person) [190].

#### 6.5. Projections for the future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's disease and other dementias are projected to increase from \$236 billion in 2016 to more than \$1 trillion in 2050 (in 2016 dollars). This dramatic rise includes a nearly five-fold increase in government spending under Medicare and Medicaid and a nearly five-fold increase in out-of-pocket spending.<sup>A21</sup>

### 7. Special Report: The personal financial impact of Alzheimer's disease on families

Alzheimer's is, by its nature, a very personal disease. Individuals living with the disease must grapple with changes in their ability to think and function that threaten their identity and their role within their families. Families are personally affected by Alzheimer's too. Their everyday lives often become busier as they take on responsibilities that the individual with Alzheimer's can no longer perform. And, very often, family members become caregivers.

These and other aspects of the effects of Alzheimer's disease on families are well studied. In contrast, little is known about the personal financial impact of Alzheimer's on families. How much of their own money do families spend to provide for the needs of the person with Alzheimer's? Does this affect everyday and long-term purchasing decisions? Do they have to cut back on work or work more because of the expense of caring for someone with

Alzheimer's disease? Are families prepared to handle the financial impact of Alzheimer's disease?

Because studies on this important topic are scarce, the Alzheimer's Association commissioned a nationwide scientific survey of more than 3500 Americans who were asked these questions and more.<sup>A25</sup> The results reveal that many families, as well as friends, of people with Alzheimer's disease and other dementias are making great sacrifices to help care for them. It was common for survey respondents to spend money from their savings and retirement accounts, jeopardizing their own financial security.

Alarming, the Alzheimer's Association survey also revealed that many respondents had to cut back on basic necessities—such as food and medical care—for themselves and their families. At the same time, many respondents did not know or had misconceptions about what expenses Medicare and Medicaid cover, leaving them unprepared to handle the tremendous costs associated with the disease.

Taken together, the results of the survey point to the significant financial burden placed on families because their friend or family member with Alzheimer's disease or another dementia can no longer afford to take care of themselves.

#### 7.1. Alzheimer's Association Survey

A total of 3524 Americans (respondents) were interviewed for the Alzheimer's Association Family Impact of Alzheimer's Survey. They were first asked if they had a relative or friend with Alzheimer's disease or another dementia. If they did, they were next asked if they had paid for expenses at least once per month during the preceding 12 months for their relative or friend. Those who said "Yes" were then asked a series of questions about the amount and personal financial impact of contributions. Those who did not pay expenses for their friend or family member with dementia were next asked if they had taken care of that person at least once a month during the preceding 12 months. If they did, they were then asked a series of questions about the personal financial impact of caregiving, including questions about employment and spending, that were also asked of those who provided financial assistance. A total of 502 respondents provided financial assistance and/or caregiving. These 502 respondents are referred to as care contributors in this Special Report.

Care contributors could be frequent caregivers, occasional caregivers, people who provided financial assistance alone, or people who provided both financial assistance and caregiving. Fig. 13 shows the relationship between care contributors and their relative or friend with dementia. Ninety-three percent of care contributors were family members, and 7 percent were friends.

In addition to questions about the personal financial impact of caregiving, care contributors and survey

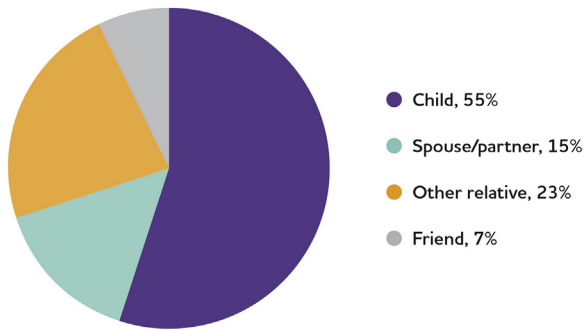


Fig. 13. Relationship of care contributors to their relative or friend with Alzheimer's or another dementia. Created from data from the Alzheimer's Association Family Impact of Alzheimer's Survey.<sup>A25</sup>

respondents who were not care contributors were asked about the availability of food in their households, the roles of Medicare and Medicaid, and the cost and coverage provided by long-term care insurance.

## 7.2. Impact on families

### 7.2.1. Out-of-pocket expenses incurred by care contributors

The results of the Alzheimer's Association survey showed that care contributors spent an average of \$5155 of their own money (out of pocket) per year to take care of their relative or friend with Alzheimer's or another dementia. However, amounts varied (Fig. 14). Annual out-of-pocket costs ranged from less than \$1000 to more than \$100,000. Those who personally incurred the highest expenses were spouses/partners, who spent an average of over \$12,000 per year, and adult children, who spent an average of about \$4800 per year. Some children (16 percent) spent \$10,000 or more.

The most commonly reported expenses were food (63 percent) and other groceries (56 percent). The next most commonly reported expenses were travel (49 percent), medical supplies (for example, adult diapers, 48 percent),

medications (39 percent), non-medical in-home care (18 percent), and in-home healthcare (14 percent).

While the Alzheimer's Association survey asked about a variety of expenses incurred by care contributors, other research has examined total out-of-pocket expenses for health care specifically, irrespective of whether the expenses were paid by the person with dementia or care contributors. One example is a recent study using data from the Aging, Demographics, and Memory Study (ADAMS, a nationally representative sample of older adults and a subset of the Health and Retirement Study [HRS]). Researchers found that total out-of-pocket spending for health care for people with dementia was more than three times the out-of-pocket expenses for people of the same age without dementia [351]. Another study using HRS data explored out-of-pocket spending during the last 5 years of life for people with various chronic diseases [313]. The researchers found that people with Alzheimer's disease and other dementias had the highest out-of-pocket spending of those with the other chronic conditions studied. Out-of-pocket costs for those with Alzheimer's and other dementias were more than twice those of people with cancer and 74 percent higher than people with cardiovascular disease.

Data in the Use and Costs of Health Care, Long-term Care, and Hospice section of *2016 Alzheimer's Disease Facts and Figures* confirm this discrepancy in out-of-pocket spending. Based on data from the Medicare Current Beneficiary Survey, people living with Alzheimer's disease and other dementias incur an average of nearly \$10,500 per year in out-of-pocket expenses for health care and long-term care services, even when receiving support from Medicare, Medicaid, and private insurance. In contrast, people of similar age who do not have dementia incur about \$2500 in out-of-pocket expenses annually. The high out-of-pocket costs paid by people with dementia may result in the quick depletion of savings and other assets, leaving not only the affected individuals, but also their families and friends, vulnerable.

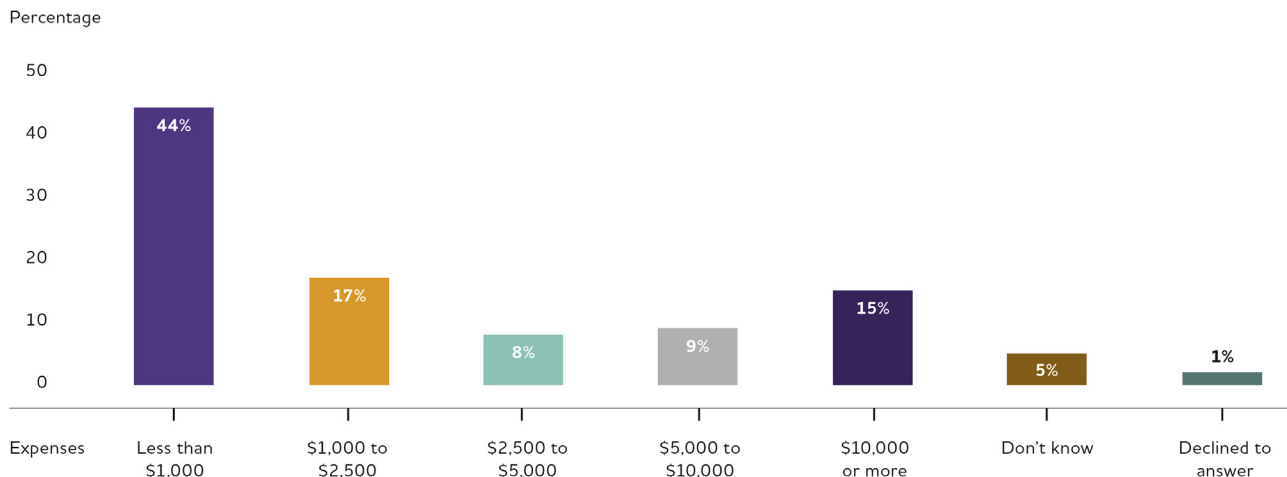


Fig. 14. Annual out-of-pocket expenses incurred by care contributors. Created from data from the Alzheimer's Association Family Impact of Alzheimer's Survey.<sup>A25</sup>



### 7.2.2. Impact on financial security and household expenses

Forty-eight percent of care contributors reported that paying expenses for their friend or family member with dementia had caused them to cut back on spending in the preceding 12 months, and 43 percent reported that paying these expenses had caused them to cut back on saving money (Fig. 15).

Twenty percent reported spending money from their own retirement savings to help pay for dementia-related expenses, including 45 percent of spouses/partners and 17 percent of children. The finding that care contributors are spending money from their own savings and retirement accounts suggests that these individuals may be jeopardizing their own financial security to care for those who no longer have the financial ability to pay for their own personal health care needs. In addition, by spending savings and retirement funds, care contributors may unknowingly be decreasing the financial security of their children and succeeding generations.

Alarming, 20 percent of care contributors cut back on going to the doctor themselves, 11 percent cut back on buying medicine for themselves, and an additional 11 percent cut back on their children's educational expenses.

These statistics support the idea that some care contributors may be jeopardizing their own health, as well as their own financial well-being, to support the individual with dementia. They also support the idea that the financial impact of dementia on the affected individual may decrease the educational opportunities afforded their children and grandchildren.

Thirteen percent of care contributors sold assets to help pay expenses for their friend or family member with dementia. Among the assets sold were vehicles (42 percent), jewelry and other collectibles (22 percent), furniture (15 percent), electronics (14 percent), and a dwelling (12 percent).

### 7.2.3. Impact on food security

One of the ways the Alzheimer's Association survey explored the impact of dementia-related costs on families was by asking respondents questions about their ability to feed their families. The questions were from an established and validated survey developed by the U.S. Department of Agriculture (USDA) to measure the concept of "household food security" [352]. The survey asked respondents how often they could not afford to buy enough food for their household in the past 12 months, how often they could not afford balanced meals, how often they had to skip meals because they could not afford food, whether they ate less because they could not afford food, and whether they had been hungry because there was not enough food. As shown in Fig. 16, care contributors for a person with Alzheimer's disease or another dementia were more likely to struggle with having sufficient quantities of food than were other survey respondents. Care contributors were 28 percent more likely than non-care contributors to report that they ate less or were hungry because they didn't have enough money to afford proper meals. These data suggest that the high costs associated with providing for a person with Alzheimer's or another dementia may be contributing to food insecurity in many families.

### 7.2.4. Impact on care contributor employment

Similarly, many care contributors for people with Alzheimer's disease and other dementias experience disruptions in employment as a result of the demands of caregiving.

Many care contributors in the Alzheimer's Association survey reported that they had to work fewer hours or stop working entirely to support the person with dementia (Fig. 17). Thirty-five percent of care contributors reported household income losses as a result of these employment

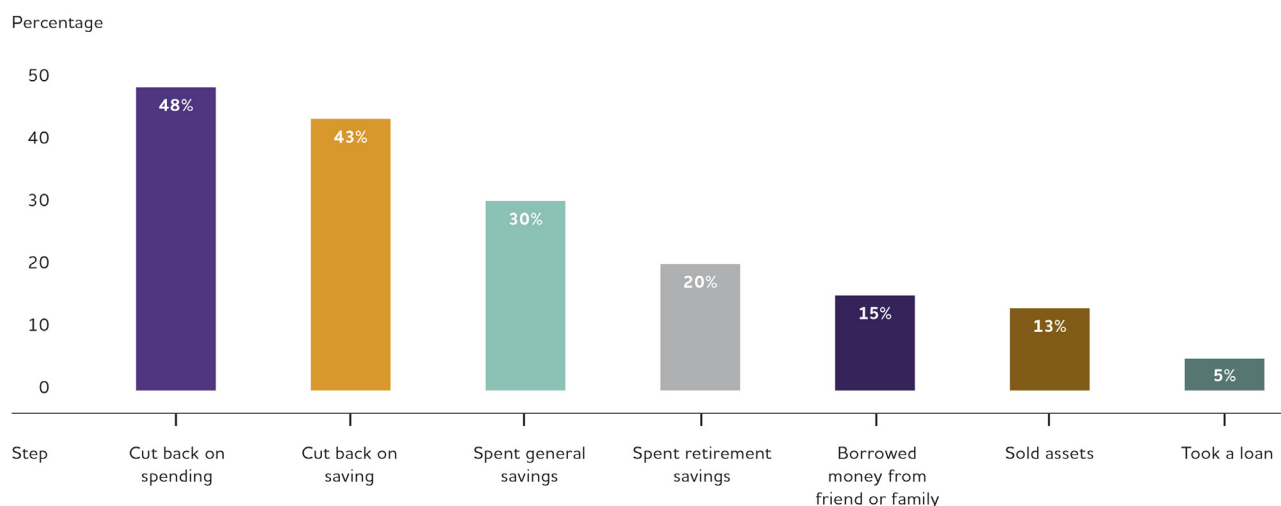


Fig. 15. Percentage of care contributors who took the indicated steps to help pay for the needs of their relative or friend with Alzheimer's or another dementia. Created from data from the Alzheimer's Association Family Impact of Alzheimer's Survey.<sup>A25</sup>

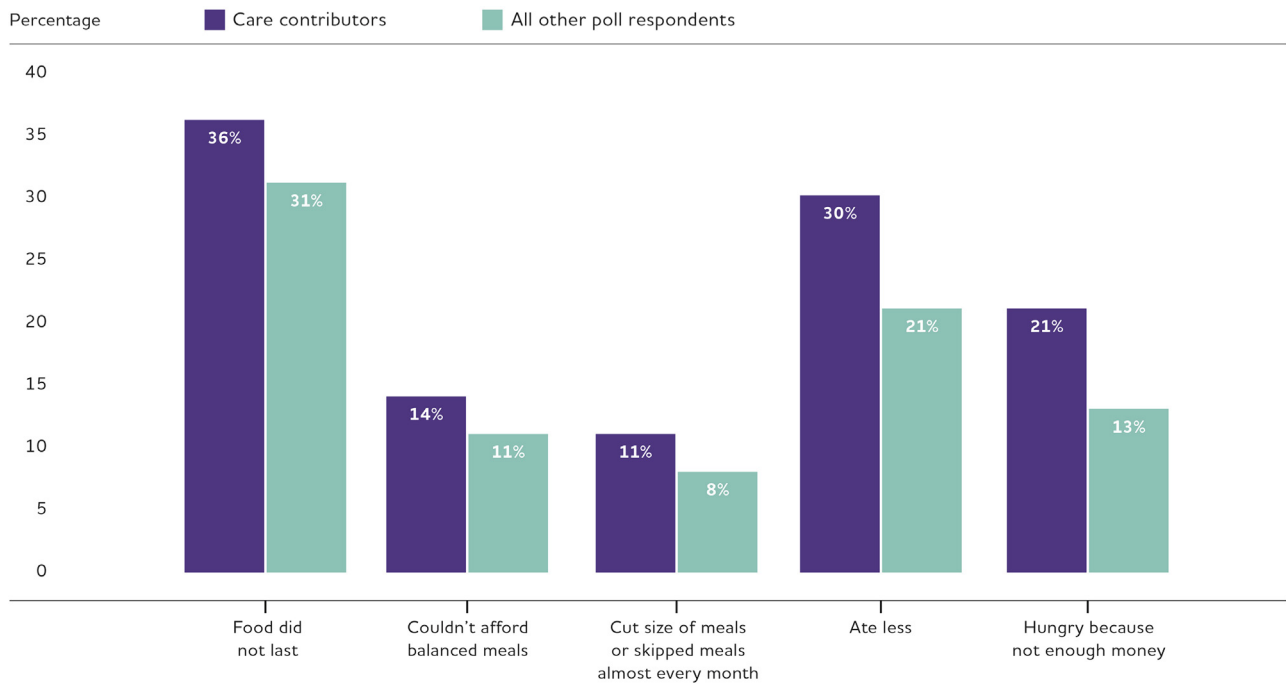


Fig. 16. Percentages of care contributors and other survey respondents who said “Yes,” “Sometimes,” or “Often” to questions about food security. Created from data from the Alzheimer’s Association Family Impact of Alzheimer’s Survey.<sup>A25</sup>

changes. Care contributors and their families who experienced income losses lost an average of \$15,194 compared with their income the year before employment changes. Among those who reported income losses, 41 percent lost 20 percent or more of their household income. An additional 23 percent lost 10 percent to nearly 20 percent of their household income.

In contrast to most studies and surveys on how caregiving affects one’s employment, the Alzheimer’s Association sur-

vey found that some care contributors had to *increase* work—*increase* the number of hours worked, take an additional job, go back to work, or postpone retirement—to help pay expenses for their relative or friend with dementia (Fig. 18).

#### 7.2.5. Impact on saving and spending by household income

Many families struggle with the high cost of providing for the expenses of both themselves and their friend or relative with dementia. Because people of different income levels may cut back on saving and spending in different ways, respondents were asked their annual household income. Among care contributors with annual household incomes of \$35,000 or less, 35 percent reported having to cut back on buying groceries such as bread, fruit, vegetables, and meat compared with 15 percent of those with household incomes of \$35,000 to \$75,000 and 10 percent of those with household incomes of more than \$75,000 (Fig. 19).

Thirty percent of lower income care contributors and 24 percent of middle-income care contributors reported cutting back on going to the doctor themselves. In addition, 19 percent of lower income care contributors and 9 percent of middle-income care contributors reported cutting back on buying medicine for themselves. Although fewer in number, many respondents reported that they had to cut back on filling prescriptions or providing needed dental or vision care for their relative or friend with dementia.

In a recent study [351], researchers tested the idea that high out-of-pocket expenses related to dementia care were causing people with dementia to spend less on other

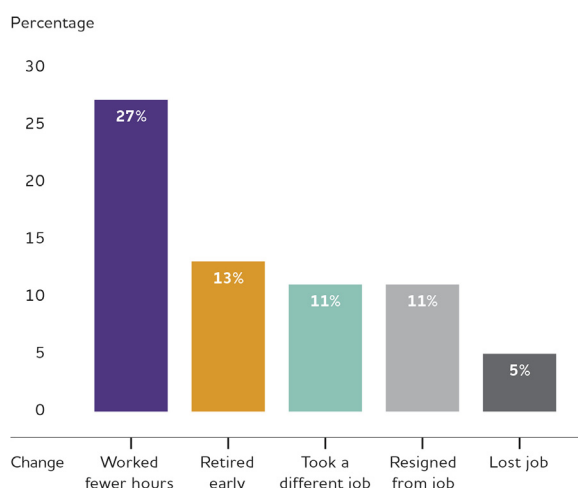


Fig. 17. Employment changes among care contributors who cut back work hours to support a family member or friend with dementia. Created from data from the Alzheimer’s Association Family Impact of Alzheimer’s Survey.<sup>A25</sup>

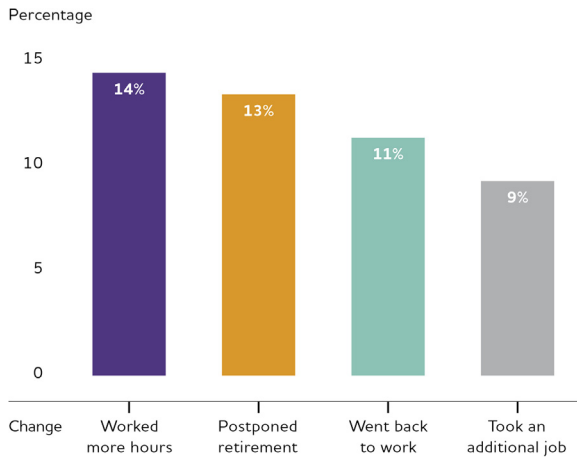


Fig. 18. Employment changes among care contributors who increased work hours to support a family member or friend with dementia. Created from data from the Alzheimer's Association Family Impact of Alzheimer's Survey.<sup>A25</sup>

health-related needs. Even though out-of-pocket health care expenses for people with dementia were three times higher than for people without dementia, the researchers found no evidence that people with dementia were more likely than other people to forego dental or other medical expenses. The Alzheimer's Association survey asked a different but related question: Did care contributors cut back on paying for those expenses for their relative or friend with dementia? The survey found that it was relatively uncommon for care contributors to cut back on purchasing prescription medications or dental or eye care for the person with dementia. However, as already described, the survey found that 30 percent of people in the lowest income group and 24 percent

in the middle-income group were foregoing doctor visits for themselves to provide financial support for their relative or friend with dementia.

Altogether, these findings suggest that dementia-related expenses may contribute to household financial stress that has direct implications for household members, including less access to food, health care, and medications and decreased financial stability. The impact is especially strong on those having the least financial security at the outset.

#### 7.2.6. Out-of-pocket expenses as a percentage of household income

In a 2015 study using HRS data [313], researchers concluded that people with dementia had out-of-pocket expenses during the last 5 years of life that placed a large financial burden on families. Furthermore, those expenses placed a disproportionately high financial burden on people who were already financially stressed. In particular, the researchers showed that out-of-pocket spending during the last 5 years of life among people with dementia represented an average of 32 percent of their household wealth measured 5 years before death. However, that percentage was much higher among people with limited financial assets, particularly certain racial or ethnic groups, people with less education, and unmarried or widowed women. For dementia-related expenses during the last 5 years of life, African-Americans spent an average of about one-third the amount spent by other racial/ethnic groups (\$23,425 versus \$64,819). However, the expenses incurred by African-Americans represented an average of 84 percent of their household wealth, compared with 32 percent for people from other racial/ethnic backgrounds. Unmarried women

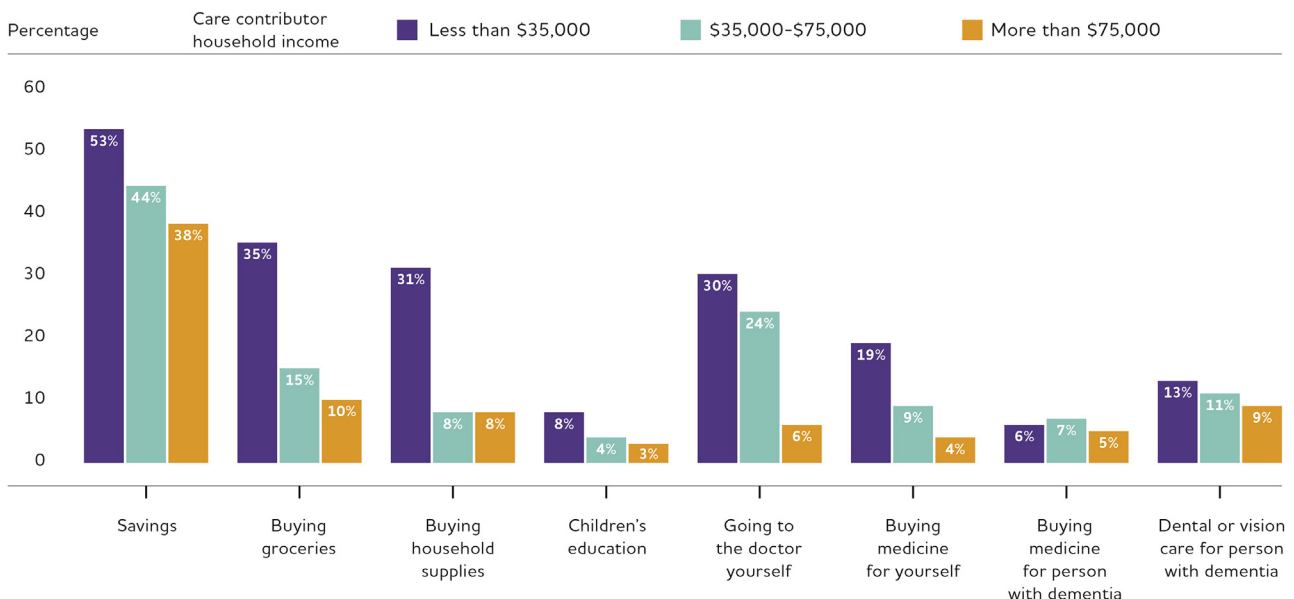


Fig. 19. Reductions in savings or spending by household income. Created from data from the Alzheimer's Association Family Impact of Alzheimer's Survey.<sup>A25</sup>

with dementia (never married or widowed) spent 58 percent of their wealth on out-of-pocket expenses related to dementia during their last 5 years of life, compared with 7 percent for married women with dementia.

This HRS study clearly illustrates that the amount of money spent per year on dementia-related expenses has very different financial implications for different individuals and families. The Alzheimer's Association survey found that about 25 percent of care contributors spent more than 10 percent of their annual household income for dementia-related expenses, and a small group of care contributors (about 1 in 30) spent more than 90 percent of their annual income.

### 7.3. Lack of knowledge about the roles of Medicare and Medicaid

The Alzheimer's Association survey also asked all 3524 respondents—regardless of whether they were care contributors—specific questions to assess the general public's knowledge about the roles of Medicare and Medicaid in helping to pay for nursing home care and other forms of long-term care.

The results indicated widespread lack of knowledge about the roles of these programs. Twenty-eight percent of respondents believed incorrectly that Medicare pays for nursing home care, and 37 percent did not know whether it did. Medicare pays for inpatient hospital care, physician-certified inpatient rehabilitation in a skilled nursing facility after a hospital stay and various other costs, but custodial care in nursing homes is not covered. Lack of knowledge about the role of Medicaid was also common, with 36 percent of respondents incorrectly believing that Medicaid was long-term care insurance and 25 percent not knowing if that was true. Medicaid helps pay for some medical and long-term care costs for people with limited income and resources and, in most instances, individuals must have depleted nearly all of their assets to be eligible for Medicaid.

In addition, many people believe that their medical insurance will cover long-term care, even when it doesn't. About 30 percent of respondents believed they had insurance coverage for long-term care, but national statistics indicate that only about 3 percent of all U.S. adults, and about 10 percent of adults older than 55, actually have long-term care insurance [353]. As noted in the Use and Costs of Health Care, Long-term Care, and Hospice section, long-term care insurance is expensive and becoming more difficult to obtain. The lack of knowledge about Medicare, Medicaid, and long-term care insurance may leave many individuals and families unprepared for the high costs of long-term care for someone with Alzheimer's disease or another dementia.

### 7.4. Toward solutions

This Special Report highlights the fact that many care contributors for people with Alzheimer's and other

dementias must cut back on basic necessities for themselves and their families—necessities such as food and their own medical care—to support their relative or friend. Furthermore, the Use and Costs of Health Care, Long-term Care, and Hospice section notes that 50 percent of Medicare beneficiaries have less than \$63,350 in savings and 50 percent have incomes of \$24,150 or less. Thus, it is clear that many people find it difficult to save money for retirement, suggesting that other solutions are needed to prepare families for the high out-of-pocket costs associated with Alzheimer's disease and other dementias. Furthermore, there is clearly a need for better education of Americans about the roles of Medicare, Medicaid, and private insurance.

Numerous organizations recommend that people plan and save for the possibility of needing long-term care insurance in later life, as it has the potential to alleviate much of the financial burden that would otherwise be placed on families.

In addition, individuals and families benefit from becoming educated about the financial resources available to them and using that information to plan for the future. Even if a family has limited financial resources, planning ahead and knowing what is possible (and what is not) enables families to make the best choices possible. Other tips:

- When planning for retirement, remember to think about how to prepare for the need for long-term medical care. After an Alzheimer's diagnosis, your options may be more limited.
- Check with your employer to see what types of programs and benefits may be available to you.
- Conduct an inventory of your financial resources (savings, insurance, retirement benefits, government assistance, VA benefits, etc.). A financial planner or elder care attorney can help with this.
- Learn about Medicare and the expenses it covers.
- Learn about Medicaid and who is eligible.
- Investigate long-term care services (for example, home care, assisted living residences, and nursing homes) in your area. Ask what types of insurance they accept and if they accept Medicaid in case you run out of money.
- Call the local Agency on Aging to determine what community services and support programs are available (For example, respite care, home maker services, and Meals on Wheels can help alleviate financial burdens).
- Once you understand what you have for financial resources and what you can afford, make a plan for how to access care.

Additional information is available at [alzheimers.gov](http://alzheimers.gov), [eldercare.gov](http://eldercare.gov) and [alz.org/care](http://alz.org/care).

### 7.5. Conclusion

The costs of caring for a relative or friend with Alzheimer's disease or another dementia can have striking effects on a household. These costs can jeopardize the ability



to buy food, leading to food insecurity and increasing the risks of poor nutrition and hunger. In addition, the costs can make it more difficult for individuals and families to maintain their own health and financial security. Lack of knowledge about the roles of government assistance programs for older people and those with low income is common, leaving many families vulnerable to unexpected expenses associated with chronic conditions such as Alzheimer's and other dementias. Better solutions are needed to ensure that relatives and friends of people with dementia are not jeopardizing their own health and financial security to help pay for dementia-related costs.

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## Appendices: End Notes

<sup>A1</sup>*Six drugs approved by the U.S. Food and Drug Administration (FDA):* The FDA has approved six drugs to alleviate symptoms of Alzheimer's disease: tacrine (discontinued in the United States due to potentially severe side effects), galantamine, rivastigmine, donepezil, memantine, and a drug that combines memantine and donepezil. None of these drugs slows or stops the progression of Alzheimer's disease.

<sup>A2</sup>*Number of Americans age 65 and older with Alzheimer's disease for 2016 (prevalence of Alzheimer's in 2016):* The number 5.2 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 [33].

<sup>A3</sup>*Proportion of Americans age 65 and older with Alzheimer's disease:* The 11 percent for the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer's disease (5.2 million) by the U.S. population age 65 and older in 2016, as projected by the U.S. Census Bureau (49.4 million) = 11 percent. Eleven percent is the same as one in nine (see 2014 National Population Projections: Downloadable Files located at [https://www.census.gov/population/projections/data/national/2014/downloadable\\_files.html](https://www.census.gov/population/projections/data/national/2014/downloadable_files.html)).

<sup>A4</sup>*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 (0.8), 75 to 84 (2.4), and 85+ (2.0) based on prevalence estimates for each age group and incidence data from the Chicago Health and Aging Project (CHAP) [33].

<sup>A5</sup>*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 [117]. (Note that the CHAP estimates referred to in this end note are from an earlier study using 2000 U.S. Census data [179].) 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 [118]. 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 [6], 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.

<sup>A6</sup>*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 (3.3 million) and men (1.9 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 et al. [33]

<sup>A7</sup>*Prevalence of Alzheimer's disease and other dementias in older whites, African-Americans and Hispanics:* The statement that African-Americans are twice as likely and Hispanics one and one-half times as likely as whites to have Alzheimer's disease and other dementias is the conclusion of an expert review of a number of multiracial and multi-ethnic data sources, as reported in detail in the Special Report of the Alzheimer's Association's 2010 *Alzheimer's Disease Facts and Figures*.

<sup>A8</sup>*State-by-state prevalence of Alzheimer's disease:* These state-by-state prevalence numbers are based on an analysis of incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality [166]. Specific prevalence numbers projected for each year from 2016 to 2025 derived from this analysis were provided to the Alzheimer's Association by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

<sup>A9</sup>*Number of new cases of Alzheimer's disease this year (incidence of Alzheimer's in 2016):* The East Boston Established Populations for Epidemiologic Study of the Elderly (EPESE) estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020. See Hebert et al. [167] The Alzheimer's Association calculated the incidence of new cases in 2016 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.6 (for the number of years from 2010 to 2016 divided by the number of years from 2010 to 2020), adding that result (22,200) to the Hebert et al. estimate for 2010 (454,000) = 476,200 [167]. Rounded to the nearest thousand, this is 476,000 new cases of Alzheimer's disease in 2016. The same technique for linear interpolation from 2000 to 2010 projections was used to calculate the number of new cases in 2016 for ages 65–74, 75–84 and 85 and older. The age group-specific Alzheimer's disease incident rate is the number of new people with Alzheimer's per population at risk (the total number of people in the age group in question). These incidence rates are expressed as number of new cases per 1000 people using the total number of people per age group (e.g., 65–74, 75–84, 85+) for 2016 from population projections from the 2000 U.S. Census as the denominator (see National Population Projections for 2016 to 2020: Summary Tables located at <http://www.census.gov/population/projections/files/natproj/summary/np-t4-e.pdf>).

<sup>A10</sup>*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 66 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 (476,200)<sup>A9</sup> = 66.2 seconds, rounded to 66 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al. [167]) = 32.8 seconds, rounded to 33 seconds.

<sup>A11</sup>*Criteria for identifying subjects with Alzheimer's disease and other dementias in the Framingham Study:* Starting in 1975, nearly 2800 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 et al. [131] The definition of Alzheimer's disease and other dementias used in the Framingham Study was thus very strict; using a definition that 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.

<sup>A12</sup>*Projected number of people with Alzheimer's disease:* This figure comes from the CHAP study [33]. Other projections are somewhat lower (see, for example, Brookmeyer et al. [354]) because they relied on more conservative methods for counting people who currently have Alzheimer's disease.<sup>A9</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.

<sup>A13</sup>*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 [33].

<sup>A14</sup>*Previous high and low projections of Alzheimer's disease prevalence in 2050:* High and low prevalence projections for 2050 from the U.S. Census were not available for the most recent analysis of CHAP data [33]. 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 [179].

<sup>A15</sup>*Annual mortality rate due to Alzheimer's disease by state:* Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the true burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to Alzheimer's.

<sup>A16</sup>*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, we applied 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) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2015. Available at: [www.census.gov/popest/data/datasets.html](http://www.census.gov/popest/data/datasets.html). Accessed on Jan. 22, 2016. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP [355]. 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 another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26 percent figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 15.864 million Alzheimer's and dementia caregivers.

<sup>A17</sup>*The 2014 Alzheimer's Association Women and Alzheimer's Poll:* This poll questioned a nationally-representative sample of 3102 American adults about their attitudes, knowledge and experiences related to Alzheimer's disease and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's disease or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "over-sampled" Hispanics, selected from U.S. Census tracts with higher than an 8 percent concentration of this group. A list sample of Asian-Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews



comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

<sup>A18</sup>*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 1139 hours per year. The number of family and other unpaid caregivers (15.864 million)<sup>A16</sup> was multiplied by the average hours of care per year, which totals 18.066 billion hours of care.

<sup>A19</sup>*Value of unpaid caregiving:* To calculate this number, the Alzheimer's Association used the method of Amo et al. [356]. This method uses the average of the federal minimum hourly wage (\$7.25 in 2015) and the mean hourly wage of home health aides (\$17.24 in July 2015) [357]. The average is \$12.25, which was multiplied by the number of hours of unpaid care (18.066 billion) to derive the total value of unpaid care (\$221.312 billion; this is slightly higher than the total resulting from multiplying \$12.25 by 18.066 billion because 18.066 is a rounded number for the hours of unpaid care).

<sup>A20</sup>*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*. 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' [358]. 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 (BRFSS)<sup>A16</sup> were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009 [359], inflated to 2015 dollars. 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 \$640. The amount of the additional cost in each state, which varied by state from a low of \$472 in Utah to a high of \$976 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state<sup>A16</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 \$10.151 billion. 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" [360].

<sup>A21</sup>*Lewin Model on Alzheimer's and dementia costs:* These numbers come from a model created for the Alzheimer's Association by the Lewin Group and updated in January 2015. The model estimates total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias. The model originally used cost data from the 2008 Medicare Current Beneficiary Survey (MCBS); for the 2016 cost estimates, the cost data were updated using the 2011 MCBS. A comprehensive report on the model, *Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars*, was published by the Alzheimer's Association in February 2015. In June 2015, the Lewin Group added to the model estimates of state-by-state Medicaid spending on people with Alzheimer's and other dementias, which were initially published in the Alzheimer's Association's November 2015 report, *The Impact of Alzheimer's Disease on Medicaid Costs: A Growing Burden for States*. Both reports and additional information on the model, its long-term projections and its methodology are available at [www.alz.org/trajectory](http://www.alz.org/trajectory).

<sup>A22</sup>*All cost estimates were inflated to year 2015 dollars using the Consumer Price Index (CPI):* All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

<sup>A23</sup>*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 [190]. 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 *2016 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 and 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.

Costs from the MCBS analysis are based on responses from 2008 and reported in 2015 dollars.

<sup>A24</sup>*Differences in estimated costs reported by Hurd and colleagues:* Hurd et al. [207] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2016 Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS). One reason that the per-person costs estimated by Hurd et al. are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that Hurd et al.'s estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's disease and other dementias (those costs attributed only to dementia), while the per-person costs in *2016 Alzheimer's Disease Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

<sup>A25</sup>*Alzheimer's Association Family Impact of Alzheimer's Survey:* The survey was conducted by Abt SRBI between December 10 and 28, 2015. Potential respondents were contacted by telephone using randomly dialed phone numbers for both landline and cell phones in the United States. Cell phone respondents were offered \$10 reimbursement to cover the cost of the call. The survey was conducted in both English and Spanish, and telephone exchanges in regions with a high Hispanic population were oversampled to obtain a representative sample in the final tally. In addition, a list of people known to be Asian-American and a list of known caregivers were used to increase the number of those respondents. The respondents were selected if they were age 18 or older. A subset of respondents were identified as care con-

tributors as described in the text. Care contributors were not required to be living with the person who had dementia. The overall response rate to the survey was 11.4 percent, which was determined using the Response Rate 3 method of the American Association for Public Opinion Research.

Responses to the Alzheimer's Association Family Impact of Alzheimer's Survey are presented after population weighting procedures were performed in several stages. The first stage of weighting corrected for probability of selection of a respondent associated with the number of adults in the household and the respondent's telephone usage, overlapping landline and cell phone sample frames, and the relative sizes of each frame and each sample. The correction for the number of adults in the household is because respondents in households with more adults were less likely to be selected; the weight ensures that we don't over-represent adults from smaller households and under-represent adults from larger households. The correction for overlapping landline and cell phone frames is needed because households with landlines and cell phones were more likely to be selected than households with only cell phones or a landline; without this correction, households with landlines and cell phones would be over-represented. The weighting step for the relative sizes of each frame and each sample refers to the basic probability of selection of each phone number. Landline numbers had a higher probability of selection than did cell phone numbers. The adjustment for the probability of selection ensures that we did not over-represent landline numbers or under-represent cell phone numbers.

The second stage of weighting balanced the sample demographics to estimated population parameters for age x gender, education x gender, age x education, race and Hispanic ethnicity, and telephone usage.

This step ensures that the survey sample matches the U.S. population with respect to age, gender, education, race/ethnicity, and telephone usage (landline only, cell phone only, and landline + cell phone). A separate weighting was performed for care contributors. Because no official demographic benchmarks exist for this population, benchmark estimates were derived from characteristics of the care contributors reached in the landline and randomly dialed digit sample, which are probability based and nationally representative. The weight for the care contributor sample balances all ( $n = 502$ ) care contributor cases to the weighted estimates for gender and race/ethnicity derived from the landline and cell random-digit dialed care contributors. This weighting adjusted for the fact that the care contributors reached through the list sample were somewhat more likely to be female and white compared with those reached in the probability-based component of the study.

Margins of error originating from random sampling for the cohort of care contributors are  $\pm 4.54$  percentage points. Corresponding margins of error for the overall survey sample are  $\pm 2.04$  percentage points. Additional error may derive from the wording of questions, inaccuracy of respondent reports, or other potential sources.