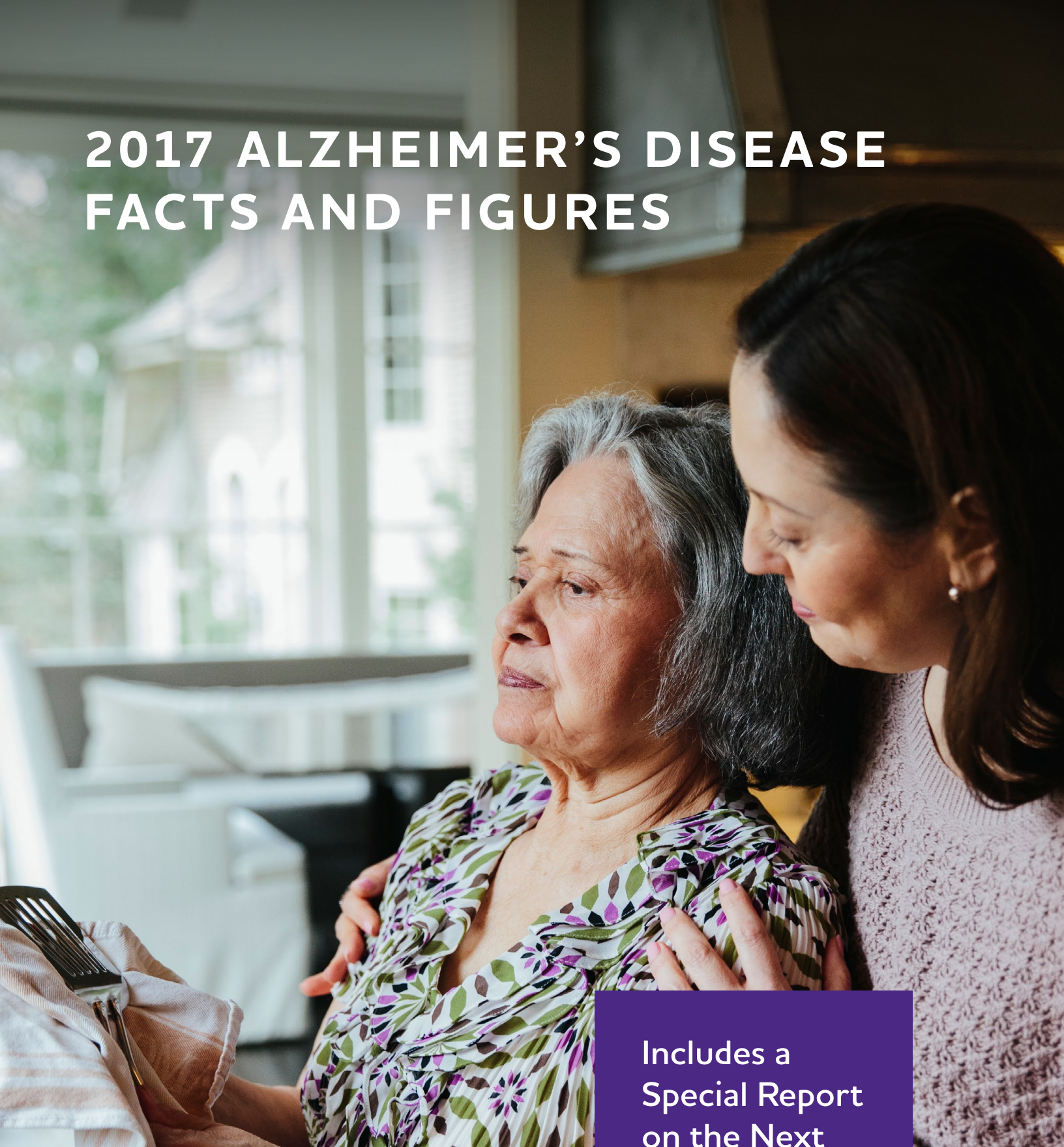# 2017 ALZHEIMER'S DISEASE FACTS AND FIGURES

**alzheimer's ꝏ association®**

THE BRAINS BEHIND SAVING YOURS.®

Includes a Special Report on the Next Frontier of Alzheimer's Research

# About this report

*2017 Alzheimer's Disease Facts and Figures* is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia. Background and context for interpretation of the data are contained in the overview. Additional sections address prevalence, mortality and morbidity, caregiving, and use and costs of health care, long-term care and hospice. The Special Report examines what we have learned about the diagnosis of Alzheimer's disease through research, and how we could identify and count the number of people with the disease in the future.

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

- Proposed guidelines for diagnosing Alzheimer's disease from the National Institute on Aging and the Alzheimer's Association (pages 15-16).
- How the diagnosis of Alzheimer's disease has evolved from 1984 to today (pages 64-65).
- Overall number of Americans with Alzheimer's dementia nationally (page 18) and for each state (pages 20-22).
- Proportion of women and men with Alzheimer's or other dementias (page 19).
- Lifetime risk for developing Alzheimer's dementia (page 23).
- Number of deaths due to Alzheimer's disease nationally (page 27) and for each state (pages 28-29), and death rates by age (page 31).
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state (pages 38 and 39), and the impact of caregiving on caregivers (pages 37 and 40-43).
- Cost of care for individuals with Alzheimer's or other dementias in the United States in 2017, including costs paid by Medicare and Medicaid and costs paid out of pocket (page 47).
- Health care and long-term care payments for Medicare beneficiaries with Alzheimer's or other dementias compared with beneficiaries without dementia (page 48).
- Medicaid costs for people with Alzheimer's and other dementias, by state (page 55).

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

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

## What is "Alzheimer's Dementia"?
### A Note About Terminology

As discussed in the overview (see pages 4-16), under the 1984 diagnostic guidelines, an individual with Alzheimer's disease must have symptoms of dementia. In contrast, under the proposed revised guidelines of 2011, Alzheimer's disease encompasses an entire continuum from the initial pathologic changes in the brain before symptoms appear through the dementia caused by the accumulation of brain changes. This means that Alzheimer's disease includes not only those with dementia due to the disease, but also those with mild cognitive impairment due to Alzheimer's and asymptomatic individuals who have verified biomarkers of Alzheimer's. As a result, what was "Alzheimer's disease" under the 1984 guidelines is now more accurately labeled, under the 2011 guidelines, as "dementia due to Alzheimer's" or "Alzheimer's dementia" — one stage in the continuum of the disease.

This edition of *Alzheimer's Disease Facts and Figures* reflects this change in understanding and terminology. That is, the term "Alzheimer's disease" is now used only in those instances that refer to the underlying disease and/or the entire continuum of the disease. The term "Alzheimer's dementia" is used to describe those in the dementia stage of the continuum. Thus, in most instances where past editions of the report used "Alzheimer's disease," the current edition now uses "Alzheimer's dementia." The data examined are the same and are comparable across years — only the way of describing the affected population has changed. For example, *2016 Alzheimer's Disease Facts and Figures* reported that 5.4 million individuals in the United States had "Alzheimer's disease." The 2017 edition reports that 5.5 million individuals have "Alzheimer's dementia." These prevalence estimates are comparable: they both identify the number of individuals who are in the dementia stage of Alzheimer's disease. The only thing that has changed is the term used to describe their condition.

# CONTENTS

# 1

Number of diseases in the 10 leading causes of deaths in the United States that cannot be prevented, slowed or cured.

**Alzheimer's disease stands alone.**

Alzheimer's disease is a degenerative brain disease and the most common cause of dementia.[1-2] Dementia is a syndrome — a group of symptoms — that has a number of causes. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities. These difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed. In Alzheimer's disease, neurons in other parts of the brain are eventually damaged or destroyed as well, 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.

## Dementia

When an individual has symptoms of dementia, 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 (see pages 6-7). Studies show that many people with dementia symptoms, especially those in the older age groups, have brain abnormalities associated with more than one cause of dementia.[3-7]

In some cases, individuals with symptoms of dementia do not actually 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.[8]

## Alzheimer's Disease

Alzheimer's disease was first described in 1906, but about 70 years passed before it was recognized as a common cause of dementia and a major cause of death.[9] 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 the disease, why it progresses more quickly in some than in others, and how the disease can be prevented, slowed or stopped.

### Symptoms

The differences between typical age-related cognitive changes and signs of Alzheimer's can be subtle (see Table 2, page 9). Just as individuals are different, so are the Alzheimer's symptoms they may experience. The most common initial symptom is a gradually worsening ability to remember new information. This occurs

**TABLE 1**

Causes of Dementia and Associated Characteristics*

| Cause | Characteristics |
|---|---|
| Alzheimer's disease | Most common cause of dementia; accounts for an estimated 60 percent to 80 percent of cases. Autopsy studies show that about half of these cases involve solely Alzheimer's pathology; many of the remaining cases have evidence of additional pathologic changes related to other dementias. This is called mixed pathology, and if recognized during life is called mixed dementia. |
| | 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. |
| | Revised guidelines for diagnosing Alzheimer's were proposed and published in 2011 (see pages 15-16). They recommend that Alzheimer's be considered a slowly progressive brain disease that begins well before clinical symptoms emerge. |
| | 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. |
| Vascular dementia | 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 as a mixed pathology in older individuals with Alzheimer's dementia, about 50 percent of whom have pathologic evidence of infarcts (silent strokes).[10] |
| | 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. |
| | 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. |
| | 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 there is clinical evidence of two or more causes of dementia, the individual is considered to have mixed dementia. |
| Dementia with Lewy bodies (DLB) | 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. |
| | 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. |
| | The brain changes of DLB alone can cause dementia, but very commonly people 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 recognized during life, the individual is said to have mixed dementia. |

**TABLE 1 (cont.)**

**Causes of Dementia and Associated Characteristics***

| Cause | Characteristics |
|---|---|
| Mixed dementia | 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.[4-5]<br><br>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.[4-5] 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). |
| Fronto-temporal lobar degeneration (FTLD) | Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.<br><br>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.<br><br>Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein).<br><br>The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer's, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60. FTLD accounts for about 10 percent of dementia cases. |
| Parkinson's disease (PD) | Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD.<br><br>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.<br><br>The incidence of PD is about one-tenth that of Alzheimer's.<br><br>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). |
| Creutzfeldt–Jakob disease | This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes.<br><br>Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction.<br><br>May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection.<br><br>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.<br><br>Accounts for less than 5 percent of dementia cases.[11]<br><br>Caused by impaired reabsorption of cerebrospinal fluid and the consequent buildup of fluid in the brain, increasing pressure in the brain.<br><br>People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk.<br><br>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.

because the first neurons to be damaged and destroyed are usually in brain regions involved in forming new memories. As neurons in other parts of the brain are damaged and destroyed, individuals experience other difficulties, including neurobehavioral symptoms such as agitation, sleeplessness and delusions.

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; 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 often contributes to the death of people with Alzheimer's disease. When Alzheimer's destroys cells in the areas of the brain that control swallowing, an individual becomes vulnerable to death by Alzheimer's-related malnutrition and dehydration.

## Diagnosis

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

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member to provide input about changes in thinking skills and behavior.
- Conducting 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 individual to complete the required tests and examinations and for the physician to interpret the results and make a diagnosis.

## 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 fragment beta-amyloid (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes associated with Alzheimer's. Beta-amyloid plaques are believed to contribute to cell death by interfering with neuron-to-neuron communication at synapses, while tau tangles block the transport of nutrients and other essential molecules inside neurons. The brains of people with advanced Alzheimer's disease show inflammation, dramatic shrinkage from cell loss, and widespread debris from dead and dying neurons.

Research suggests that the brain changes associated with Alzheimer's may begin 20 or more years before symptoms appear.[12-15] 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.

While research settings have the tools and expertise to identify some of the early brain changes of Alzheimer's, additional research is needed to fine-tune the tools'

TABLE 2

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

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

\* For more information about the symptoms of Alzheimer's, visit alz.org/10signs.

accuracy before they become available for clinical use. In addition, treatments to prevent, slow or stop these changes are not yet available, although many are being tested in clinical trials.

### Mild Cognitive Impairment (MCI): A Potential Precursor to Alzheimer's and Other Dementias

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.[16] People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's or other dementias than people without MCI.[17-18] A systematic review of 32 studies found that an average of 32 percent of individuals with MCI developed Alzheimer's dementia in 5 years.[19] This is similar to a 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.[18] Identifying which individuals with MCI are more likely to develop Alzheimer's or other dementias is a major goal of current research.

Revised guidelines for diagnosing Alzheimer's disease that were published in 2011[20-23] (see pages 15-16) 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.

### Genetic Abnormalities Associated with Alzheimer's

Certain genetic mutations and the extra copy of chromosome 21 that characterizes Down syndrome are uncommon genetic changes that affect the risk of Alzheimer's. There are also common variations in genes that affect the risk of Alzheimer's (see APOE-e4, page 11).

*Genetic Mutations*

A small percentage of Alzheimer's cases (an estimated 1 percent or less)[24] 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.[25] 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, in which symptoms become apparent at age 65 or later.

*Down Syndrome*

About 400,000 Americans have Down syndrome.[26] In Down syndrome, an individual is born with an additional copy of chromosome 21, one of the 23 human chromosomes. Scientists are not certain why people with Down syndrome are at higher risk of developing Alzheimer's, but it may be related to the additional 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 accumulate into plaques. Having an extra copy of chromosome 21 may increase the amount of beta-amyloid fragments in the brain.

By age 40, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brains.[27] As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of Alzheimer's. According to the National Down Syndrome Society, about 30 percent of people with Down syndrome who are in their 50s have Alzheimer's dementia.[28] Fifty percent or more of people with Down syndrome will develop Alzheimer's dementia as they age.[29]

### Risk Factors for Alzheimer's

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.

#### *Age, Family History and the Apolipoprotein E (APOE)-e4 Gene*

The greatest risk factors for late-onset Alzheimer's are older age,[30-31] having a family history of Alzheimer's[32-35] and carrying the APOE-e4 gene.[36-37]

##### *Age*

Age is the greatest of these three risk factors, with the vast majority of people with Alzheimer's dementia being age 65 or older. As noted in the Prevalence section (see pages 17-25), the percentage of people with Alzheimer's dementia increases dramatically with age: 3 percent of people age 65-74, 17 percent of people age 75-84, and 32 percent of people age 85 or older have Alzheimer's dementia.[31] It is important to note that Alzheimer's is not a normal part of aging, and older age alone is not sufficient to cause Alzheimer's dementia.

##### *Family History*

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.[32,38] Those who have more than one first-degree relative with Alzheimer's are at even higher risk.[35] When diseases run in families, heredity (genetics), shared environmental and lifestyle factors (for example, access to healthy foods and level of physical activity), 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-e4 risk gene.

##### *APOE-e4 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 gene — e2, e3 or e4 — from each parent. The e3 form is the most common, with 50 percent to 90 percent of individuals having one or two copies.[39] The e4 form is the next most common, with 5 percent to 35 percent having one or two copies, and the e2 form is the least common, with 1 percent to 5 percent having one or two copies.[39] The estimated distribution of the six possible e2, e3 and e4 pairs is shown in Table 3.

Having the e4 form increases one's risk of developing Alzheimer's compared with having the e3 form, while having the e2 form may decrease one's risk compared with having the e3 form. Those who inherit one copy of the e4 form have three times the risk of developing Alzheimer's compared with those with the e3 form, while those who inherit two copies of the e4 form have an eight- to 12-fold risk.[38,41-42] In addition, those with the e4 form are more likely to develop Alzheimer's at a younger age than those with the e2 or e3 forms of the APOE gene.[43] A meta-analysis including 20 published articles describing the frequency of the e4 form among people in the United States who had been diagnosed with Alzheimer's found that 56 percent had one copy of the APOE-e4 gene, and 11 percent had two copies of the APOE-e4 gene.[44] Another study found that among 1,770 diagnosed individuals from 26 Alzheimer's disease centers, 65 percent had at least one copy of the APOE-e4 gene.[45]

**Estimated Percentages of the U.S. Population with the Six Possible e2, e3 and e4 Pairs of the Apolipoprotein E (APOE) Gene**

| APOE Pair | Percentage |
| --- | --- |
| e2/e2 | 0.5 |
| e2/e3 | 11 |
| e2/e4 | 2 |
| e3/e3 | 61 |
| e3/e4 | 23 |
| e4/e4 | 2 |

Created from data from Raber et al.[40]
Percentages do not total 100 due to rounding.

Unlike inheriting a genetic mutation that causes Alzheimer's, inheriting the APOE-e4 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 genes are believed to have a limited effect on the overall prevalence of Alzheimer's because they are rare or only slightly increase risk.[46]

**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 report[47] 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 report from the Institute of Medicine examined the evidence regarding modifiable risk factors for cognitive decline and reached similar conclusions.[48]

*Cardiovascular Disease Risk Factors*
Brain health is affected by the health of the heart and blood vessels. Although it makes up just 2 percent of body weight, the brain consumes 20 percent of the body's oxygen and energy supplies.[49] A healthy heart ensures that enough blood is pumped to the brain, while healthy blood vessels enable the oxygen- and nutrient-rich blood to reach the brain so it can function normally.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of dementia. These factors include smoking,[50-52] obesity in midlife[53-55] and diabetes.[56-59] Some studies propose that impaired glucose processing (a precursor to diabetes) may also result in an increased risk for dementia.[53,60-61] Hypertension[53,62-64] and high cholesterol[65-66] in midlife 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 or other dementias. Physical activity[59,67-70] appears to be one of these factors. In addition, emerging evidence suggests that consuming a diet that benefits the heart, such as one that is lower in saturated fats, may be associated with reduced Alzheimer's and dementia risk.[59,71-75]

Researchers have begun studying combinations of health factors and lifestyle behaviors (for example, blood pressure and physical activity) to learn whether combinations of risk factors better identify Alzheimer's and dementia risk than individual risk factors, as well as whether intervening on multiple risk factors simultaneously has a greater chance of reducing risk than addressing a single risk factor.[76]

*Education*
People with more years of formal education are at lower risk for Alzheimer's and other dementias than those with fewer years of formal education.[77-81] Some researchers believe that having more years of education builds a "cognitive reserve" that enables individuals to better compensate for brain changes that could result in symptoms of Alzheimer's or other dementias.[80,82-83] According to the cognitive reserve hypothesis, having more years of education increases the connections between neurons, enabling the brain to use alternate routes of neuron-to-neuron communication to complete cognitive tasks when the usual routes have neuronal gaps because of Alzheimer's.

Some scientists believe other factors may contribute to or explain the increased risk of dementia among those with fewer years of formal education. These factors include an increased likelihood of having occupations that are less mentally stimulating.[84-87] In addition, having fewer years of formal education is associated with lower socioeconomic status,[88] which in turn may increase one's likelihood of experiencing poor nutrition and decrease one's ability to afford health care or medical treatments, such as treatments for cardiovascular risk factors. Finally, in the United States, people with fewer years of education tend to

have more cardiovascular risk factors for Alzheimer's, including being less physically active[89] and having a higher risk of diabetes[90-92] and cardiovascular disease.[93]

*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.[94-104] 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.

*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), an estimated 1.7 million Americans will sustain a TBI in any given year.[105] Falls and motor vehicle accidents are the leading causes of TBI.[105-106]

Two ways to classify the severity of TBI are by the duration of loss of consciousness or post-traumatic amnesia[107] and the individual's initial score on the 15-point Glasgow Coma Scale.[108] Based on these classification approaches,

- *Mild TBI* (also known as a concussion) is characterized by loss of consciousness or post-traumatic amnesia lasting 30 minutes or less, or an initial Glasgow score of 13-15; about 75 percent of TBIs are mild.[106]
- *Moderate TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting more than 30 minutes but less than 24 hours, or an initial Glasgow score of 9-12.
- *Severe TBI* is characterized by loss of consciousness or post-traumatic amnesia lasting 24 hours or more, or an initial Glasgow score of 8 or less.

Solid evidence indicates that moderate and severe TBI increase the risk of developing certain forms of dementia.[107,109-112] Those who experience repeated head injuries (such as boxers, football players and combat veterans) may be at an even higher risk of dementia, cognitive impairment and neurodegenerative disease.[113-122]

Chronic traumatic encephalopathy (CTE) is a neuropathologic diagnosis (meaning it is characterized by brain changes that can only be identified at autopsy) associated with repeated blows to the head, such as those that may occur while playing contact sports. It is also associated with the development of dementia. Currently, there is no test to determine if someone has CTE-related brain changes during life. Other than repeated brain trauma, such as TBI, the causes and risk factors for CTE remain unknown. Like Alzheimer's dementia, at autopsy, CTE is characterized by tangles of an abnormal form of the protein tau in the brain. Unlike Alzheimer's, these tangles typically appear around small blood vessels, and beta-amyloid plaques are only present in certain circumstances.[123] How the brain changes associated with CTE are linked to cognitive or behavioral dysfunction is unclear. It is thought to be caused by repetitive TBI.

Individuals can decrease their risk of TBI by ensuring their living environments are well lit and free of tripping hazards, wearing seatbelts while traveling, and wearing helmets when on a bicycle, snowmobile or other open, unrestrained vehicle. Athletes and members of the military who have experienced repeated concussions may be able to prevent injury before recovery by following clinical guidelines for return to play or military duty.

### Treatment of Alzheimer's Dementia

*Pharmacologic Treatment*
None of the pharmacologic treatments (medications) available today for Alzheimer's dementia slows or stops the damage and destruction of neurons that cause Alzheimer's symptoms and make 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.[A1] The effectiveness of these drugs varies from person to person and is limited in duration.

In the decade of 2002-2012, 244 drugs for Alzheimer's were tested in clinical trials registered with clinicaltrials.gov, a National Institutes of Health registry of publicly and privately funded clinical studies.[124] 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.

*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 computerized memory training, listening to favorite music as a way to stir recall, and incorporating special lighting to lessen sleep disorders. As with current pharmacologic therapies, non-pharmacologic therapies have not been shown to alter the course of Alzheimer's disease.

Reviews and meta-analyses of non-pharmacologic therapies tested in randomized controlled trials (in which participants are randomly assigned to either receive or not receive a therapy, and the results of the two groups are compared) have found that some are beneficial to people with Alzheimer's dementia. Among these are exercise[125-126] and cognitive stimulation.[127] Specifically, a meta-analysis[125] found that aerobic exercise and a combination of aerobic and non-aerobic exercise can improve cognitive function, while a systematic review[126] found that exercise has a positive effect on overall cognitive function and is associated with a slower rate of cognitive decline in people with Alzheimer's. However, researchers caution that additional randomized controlled trials involving larger numbers of participants are needed to understand to what extent exercise may slow cognitive decline. A second systematic review[127] found that cognitive stimulation had beneficial effects on cognitive function and some aspects of well-being.

### Living with Alzheimer's

Despite the lack of therapies that slow or stop Alzheimer's, studies have consistently shown that active management of Alzheimer's and other dementias can improve quality of life for affected individuals and their caregivers.[128-130] 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 that are meaningful and bring purpose to one's life.
- Having opportunities to connect with others living with dementia; support groups and supportive services are examples of such opportunities.

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

# A Modern Diagnosis of Alzheimer's Disease: Revised Guidelines

In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association proposed revised guidelines for diagnosing Alzheimer's disease.[20-23] These guidelines updated diagnostic criteria and guidelines published in 1984 by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Association, then known as the Alzheimer's Disease and Related Disorders Association (ADRDA).[131] 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 and other dementias on autopsy.[132]

## Differences Between the Original and Revised Guidelines

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 revised guidelines incorporate the same steps for diagnosis, but also 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. Among several factors being studied as possible biomarkers for Alzheimer's are the amount of beta-amyloid in the brain as shown on positron emission tomography (PET) imaging and levels of certain proteins in fluid (for example, levels of beta-amyloid and tau in the cerebrospinal fluid and levels of particular groups of proteins in blood). Finding a simple and inexpensive test, such as a blood test, to diagnose Alzheimer's would be ideal for patients, physicians and scientists. Research is underway to develop such a test, but to date, no test has shown the accuracy and reliability needed to diagnose Alzheimer's.

Another difference is that the revised guidelines identify two stages of Alzheimer's disease: mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease. In addition, the revised guidelines propose — for research purposes — a preclinical phase of Alzheimer's that occurs before symptoms such as memory loss develop.

*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.

*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.[16]

*Proposed for Research – Preclinical Alzheimer's Disease*: 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.[12-14] Ongoing research continues to explore this possible stage of the disease.

In contrast, the 1984 criteria identify Alzheimer's as a disease that begins when symptoms of dementia such as memory loss are already present and have impaired an individual's ability to carry out daily tasks.

### Looking to the Future

Many researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function 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 treatments that slow or stop the disease when such treatments are available. They also will be critical for monitoring the effects of treatment. Furthermore, biomarkers play an important role in developing treatments because they 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.[133]

It's important to note that the most effective biomarker test or combination of tests may differ depending on the stage of the disease and other factors.[134]

For more information on the revised guidelines and their potential impact, see the Special Report (pages 61-68).

# 1 in 10

people age 65 and older
has Alzheimer's dementia.

Millions of Americans have Alzheimer's or 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 or other dementias will grow. This number will escalate rapidly in coming years, as the population of Americans age 65 and older is projected to nearly double from 48 million to 88 million by 2050.[135] The baby boom generation has already begun to reach age 65 and beyond,[136] the age range of greatest risk of Alzheimer's; in fact, the first members of the baby boom generation turned 70 in 2016.

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

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

An estimated 5.5 million Americans of all ages are living with Alzheimer's dementia in 2017. This number includes an estimated 5.3 million people age 65 and older[A2,31] and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's, though there is greater uncertainty about the younger-onset estimate.[137]

- One in 10 people age 65 and older (10 percent) has Alzheimer's dementia.[A3,31]
- The percentage of people with Alzheimer's dementia increases with age: 3 percent of people age 65-74, 17 percent of people age 75-84, and 32 percent of people age 85 and older have Alzheimer's dementia.[31]
- Of people who have Alzheimer's dementia, 82 percent are age 75 or older (Figure 1).[A4,31]
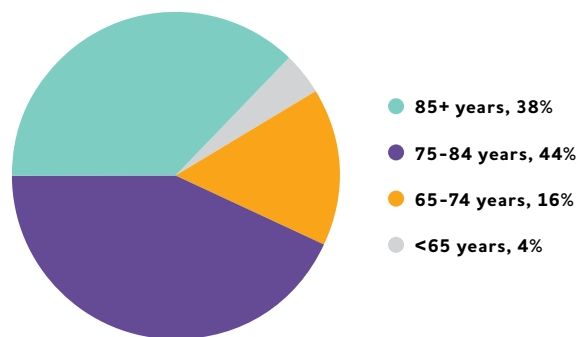
The estimated number of people age 65 and older with Alzheimer's dementia comes from a study using the latest data from the 2010 U.S. Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health conditions of older people.[31]

National estimates of the prevalence of all dementias are not available from CHAP, but they are available from other population-based studies including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.[A5,138-139] Based on estimates from ADAMS, 14 percent of people age 71 and older in the United States have dementia.[138]

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study is tested for dementia. But outside of research settings, only about half of those who would meet the diagnostic criteria for Alzheimer's and other dementias are diagnosed with dementia by a physician.[140-142] Furthermore, as discussed in *2015 Alzheimer's Disease Facts and Figures*, fewer than half of those who have a diagnosis of Alzheimer's or another dementia in their Medicare records (or their caregiver, if the person was too impaired to respond to the survey) report being told of the diagnosis.[143-146] Because Alzheimer's dementia 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 in this section refer to people who have Alzheimer's dementia. But as described in the Overview section (see pages 4-16) and Special Report (see pages 61-68), revised diagnostic guidelines[20-23] propose that Alzheimer's disease begins many years before the onset of dementia. More research is needed to estimate how many people may have MCI due to Alzheimer's disease and how many people may be in the preclinical stage of Alzheimer's disease. However, if Alzheimer's disease could be accurately detected before dementia develops, the number of people reported to have Alzheimer's disease would change to include more than just people who have been diagnosed with Alzheimer's dementia.

## Subjective Cognitive Decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's or other dementias as well as MCI.[147-151] 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 one has always done or forgetting things that one would normally know. Not all of those who experience subjective cognitive decline go on to develop MCI or dementia, but many do.[152-154] According to a recent study, only those who over time consistently reported subjective cognitive decline that they found worrisome were at higher risk for developing Alzheimer's dementia.[155] Data from the 2015 Behavioral Risk Factor Surveillance System (BRFSS) survey, which included questions on self-perceived confusion and memory loss for people in 33 U.S. states and the District of Columbia, showed that 12 percent of Americans age 45 and older reported subjective cognitive decline, but 56 percent of those who reported it had not consulted a health care professional about it.[156] Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

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

More women than men have Alzheimer's or other dementias. Almost two-thirds of Americans with Alzheimer's are women.[A6,31] Of the 5.3 million people age 65 and older with Alzheimer's in the United States, 3.3 million are women and 2.0 million are men.[A6,31] Based on estimates from ADAMS, among people age 71 and older, 16 percent of women have Alzheimer's or other dementias compared with 11 percent of men.[138,157]

There are a number of potential biological and social reasons why more women than men have Alzheimer's or other dementias.[158] 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.[157,159-160] Many studies of incidence (which indicates risk of developing disease) of Alzheimer's or any dementia[161] have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age. A recent study using data from the Framingham Heart Study suggests that because men in middle age 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 an apparent lower risk for dementia than women of the same age.[160] Epidemiologists call this "survival bias" because the men who survive to older ages and are included in studies tend to be the healthiest men; as a result, they may have a lower risk of developing Alzheimer's and other dementia than the men who died at an earlier age from cardiovascular disease. More research is needed to support this finding.

However, researchers have recently begun to revisit the question of whether the risk of Alzheimer's could actually be higher for women at any given age due to biological or genetic variations or differences in life experiences.[162] A large study showed that the APOE-e4 genotype, the best known genetic risk factor for Alzheimer's dementia, may have a stronger association with Alzheimer's dementia in women than

in men.[163-164] It is unknown why this may be the case, but some evidence suggests that it may be due to an interaction between the APOE-e4 genotype and the sex hormone estrogen.[165-166] Finally, because low education is a risk factor for dementia,[80-83,88,161] 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.[167]

### Racial and Ethnic Differences in the Prevalence of Alzheimer's and Other Dementias

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older African-Americans and Hispanics are more likely, on a per-capita basis, than older whites to have Alzheimer's or other dementias.[168-173] A review of many studies by an expert panel concluded that older African-Americans are about twice as likely to have Alzheimer's or other dementias as older whites,[174-175] and Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older whites.[A7,175-177] Currently, there is not enough evidence from population-based cohort studies in which everyone is tested for dementia to estimate the national prevalence of Alzheimer's and other dementias in other racial and ethnic groups. However, a study examining electronic medical records for members of a large health plan in California indicated that dementia incidence — determined by the presence of a dementia diagnosis in one's medical record — was highest in African-Americans, intermediate for Latinos (the term used in the study for those who self-reported as Latino or Hispanic) and whites, and lowest for Asian-Americans.[178]

Variations in health, lifestyle and socioeconomic risk factors across racial groups likely account for most of the differences in risk of Alzheimer's and other dementias by race.[179] Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race,[180-181] genetic factors do not appear to account for the large prevalence differences among racial groups.[179,182]

Instead, health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for Alzheimer's and other dementias, are believed to account for these differences as they are more prevalent in African-American and Hispanic people.[183-184] Indeed, vascular dementia accounts for a larger proportion of dementia in African-Americans than in whites.[181] Socioeconomic characteristics, including lower levels of education, higher rates of poverty, and greater exposure to early life adversity and discrimination, may also increase risk in African-American and Hispanic communities.[183-185] Some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such factors.[78,138,179]

There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among older African-Americans and Hispanics than among older whites.[186-187] Based on data for Medicare beneficiaries age 65 and older, Alzheimer's or another dementia had been diagnosed in 6.9 percent of whites, 9.4 percent of African-Americans and 11.5 percent of Hispanics.[188] 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 higher (i.e., twice as high as 6.9 percent, which is approximately 13.8 percent).

### Estimates of the Number of People with Alzheimer's Dementia by State

Table 4 lists the estimated number of people age 65 and older with Alzheimer's dementia by state for 2017, the projected number for 2025, and the projected percentage change in the number of people with Alzheimer's between 2017 and 2025.[A8,189] Comparable estimates and projections for other types of dementia are not available.

TABLE 4

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

| State | Projected Number with Alzheimer's (in thousands) | | Percentage Change | State | Projected Number with Alzheimer's (in thousands) | | Percentage Change |
|---|---|---|---|---|---|---|---|
| | 2017 | 2025 | 2017–2025 | | 2017 | 2025 | 2017–2025 |
| Alabama | 90 | 110 | 22.2 | Montana | 20 | 27 | 35.0 |
| Alaska | 7.1 | 11 | 54.9 | Nebraska | 33 | 40 | 21.2 |
| Arizona | 130 | 200 | 53.8 | Nevada | 43 | 64 | 48.8 |
| Arkansas | 55 | 67 | 21.8 | New Hampshire | 24 | 32 | 33.3 |
| California | 630 | 840 | 33.3 | New Jersey | 170 | 210 | 23.5 |
| Colorado | 69 | 92 | 33.3 | New Mexico | 38 | 53 | 39.5 |
| Connecticut | 75 | 91 | 21.3 | New York | 390 | 460 | 17.9 |
| Delaware | 18 | 23 | 27.8 | North Carolina | 160 | 210 | 31.3 |
| District of Columbia | 9 | 9 | 0.0 | North Dakota | 14 | 16 | 14.3 |
| Florida | 520 | 720 | 38.5 | Ohio | 210 | 250 | 19.0 |
| Georgia | 140 | 190 | 35.7 | Oklahoma | 63 | 76 | 20.6 |
| Hawaii | 27 | 35 | 29.6 | Oregon | 63 | 84 | 33.3 |
| Idaho | 24 | 33 | 37.5 | Pennsylvania | 270 | 320 | 18.5 |
| Illinois | 220 | 260 | 18.2 | Rhode Island | 23 | 27 | 17.4 |
| Indiana | 110 | 130 | 18.2 | South Carolina | 86 | 120 | 39.5 |
| Iowa | 64 | 73 | 14.1 | South Dakota | 17 | 20 | 17.6 |
| Kansas | 52 | 62 | 19.2 | Tennessee | 110 | 140 | 27.3 |
| Kentucky | 70 | 86 | 22.9 | Texas | 360 | 490 | 36.1 |
| Louisiana | 85 | 110 | 29.4 | Utah | 30 | 42 | 40.0 |
| Maine | 27 | 35 | 29.6 | Vermont | 12 | 17 | 41.7 |
| Maryland | 100 | 130 | 30.0 | Virginia | 140 | 190 | 35.7 |
| Massachusetts | 120 | 150 | 25.0 | Washington | 110 | 140 | 27.3 |
| Michigan | 180 | 220 | 22.2 | West Virginia | 37 | 44 | 18.9 |
| Minnesota | 92 | 120 | 30.4 | Wisconsin | 110 | 130 | 18.2 |
| Mississippi | 53 | 65 | 22.6 | Wyoming | 9.4 | 13 | 38.3 |
| Missouri | 110 | 130 | 18.2 | | | | |

Created from data provided to the Alzheimer's Association by Weuve et al.[A8, 189]

**Projected Increases Between 2017 and 2025 in Alzheimer's Dementia Prevalence by State**

| | | | | |
|---|---|---|---|---|
| ☐ 14.1% – 18.5% | ☐ 18.6% – 22.6% | ☐ 22.7% – 30.0% | ☐ 30.1% – 36.1% | ☐ 36.2% – 54.9% |
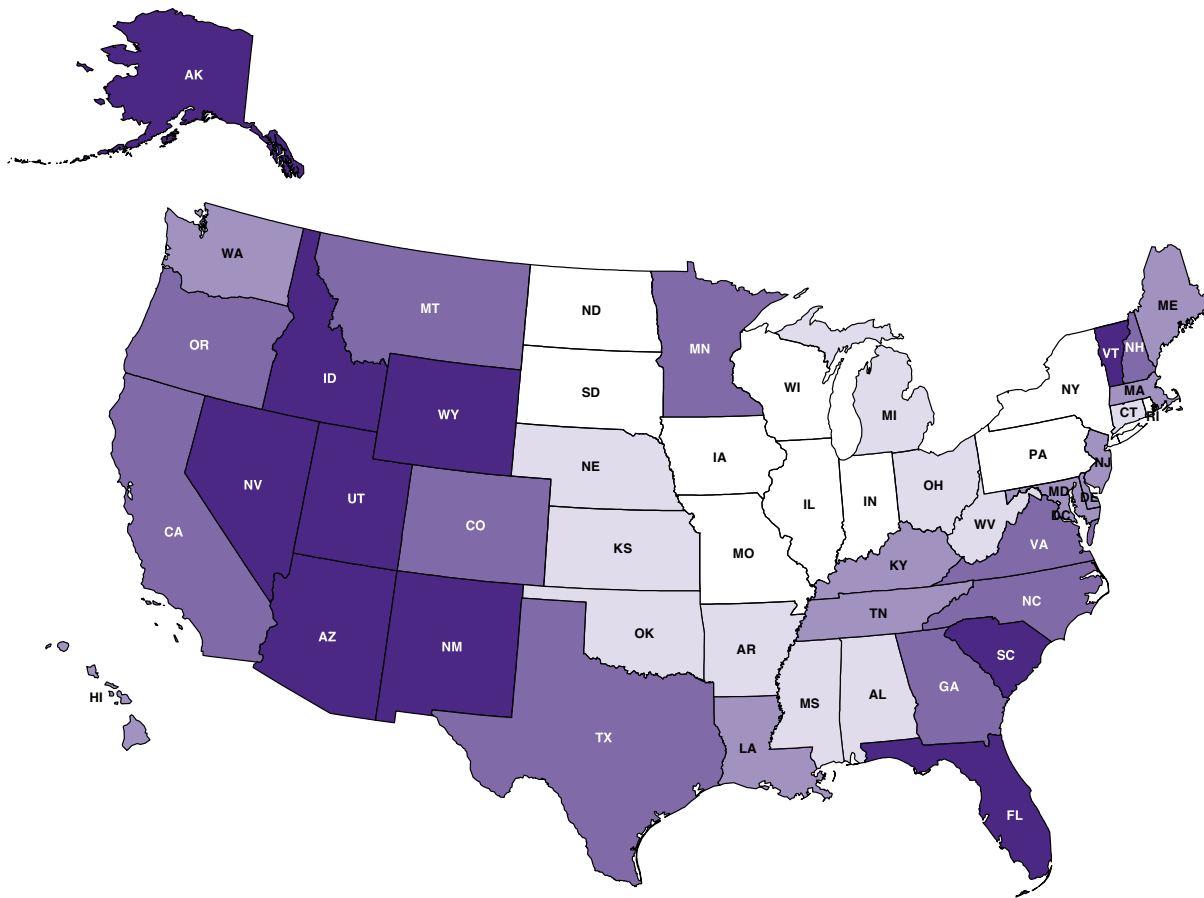


Change from 2017 to 2025 for Washington, D.C.: 0.0%

Created from data provided to the Alzheimer's Association by Weuve et al.[A8, 189]

As shown in Figure 2, between 2017 and 2025 every state 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 2017 and 2025. These increases will have a marked impact on states' health care systems, as well as the Medicaid program, which covers the costs of long-term care and support for some older residents with dementia.

## Incidence of Alzheimer's Dementia

While prevalence refers to *existing* cases of a disease in a population at a given time, incidence refers to *new* cases of a disease that develop in a given period of time in a defined population — in this case, the U.S. population age 65 or older. Incidence provides a measure of *risk* for developing a disease. According to one study using data from the Established Populations for Epidemiologic Study of the Elderly (EPESE), approximately 480,000 people age 65 or older will

develop Alzheimer's dementia in the United States in 2017.[A9] The number of new cases of Alzheimer's increases dramatically with age: in 2017, there will be approximately 64,000 new cases among people age 65 to 74, 173,000 new cases among people age 75 to 84, and 243,000 new cases among people age 85 and older (the "oldest-old").[A9,190] This translates to approximately two new cases per 1,000 people age 65 to 74, 12 new cases per 1,000 people age 75 to 84, and 37 new cases per 1,000 people age 85 and older.[A9] A more recent study using data from the Adult Changes in Thought (ACT) study, a cohort of members of the Group Health health care delivery system in the Northwest United States, reported even higher incidence rates for Alzheimer's dementia.[161] 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.[190]

- Every 66 seconds, someone in the United States develops Alzheimer's dementia.[A10]
- By 2050, someone in the United States will develop Alzheimer's dementia every 33 seconds.[A10]

## Lifetime Risk of Alzheimer's Dementia

Lifetime risk is the probability that someone of a given age will develop a condition during his or her remaining life span. Data from the Framingham Heart Study were used to estimate lifetime risks of Alzheimer's dementia by age and sex.[A11,160] As shown in Figure 3, the study found that the estimated lifetime risk for Alzheimer's dementia at age 45 was approximately one in five (20 percent) for women and one in 10 (10 percent) for men. The risks for both sexes were slightly higher at age 65.[160]

## Trends in the Prevalence and Incidence of Alzheimer's Dementia

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,[191-202] though results are mixed.[30] These declines have been

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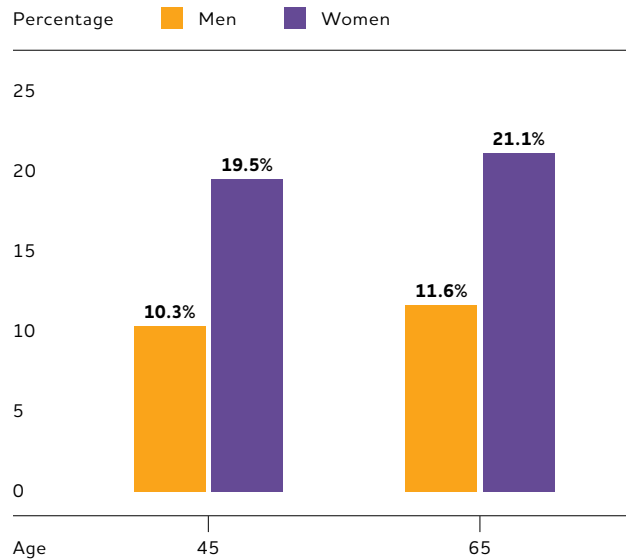


Created from data from Chene et al.[160]

attributed to increasing levels of education and improved control of cardiovascular risk factors.[193,199,202] 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 or other dementias is expected to continue to increase dramatically because of the population's shift to older ages. Furthermore, it is unclear whether these positive trends will continue into the future given worldwide trends showing increasing mid-life diabetes and obesity — potential risk factors for Alzheimer's dementia — which may lead to a rebound in dementia risk in coming years.[200,203-204] Thus, while recent findings are promising, the social and economic burden of Alzheimer's and other dementias will continue to grow. Moreover, 68 percent of the projected increase in the global prevalence and burden of dementia by 2050 will take place in low- and middle-income countries, where there is no evidence for a decline in the risk of Alzheimer's and other dementias.[205]

## 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.[206] Additionally, a large segment of the American population — the baby boom generation — has begun to reach age 65 and older, ages 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).[206] As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's dementia, as shown in Figure 4.[A12,31]

- In 2010, there were an estimated 454,000 new cases of Alzheimer's dementia. 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).[190]
- By 2025, the number of people age 65 and older with Alzheimer's dementia is estimated to reach 7.1 million — almost a 35 percent increase from the 5.3 million age 65 and older affected in 2017.[A13,31]
- By 2050, the number of people age 65 and older with Alzheimer's dementia may nearly triple, from 5.3 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent or cure Alzheimer's disease.[A12,31] 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.[A14,207]

**FIGURE 4**

**Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population with Alzheimer's Dementia, 2010 to 2050**
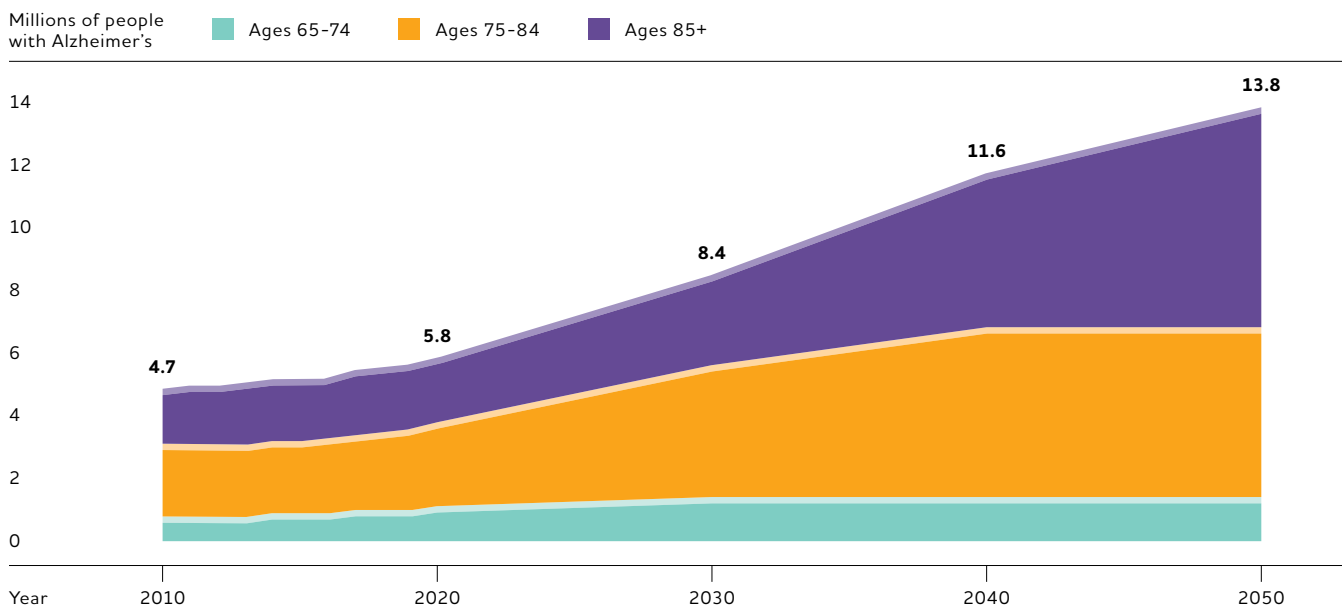


Created from data from Hebert et al.[A12, 31]

### 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 85 and older. 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.[206] This will result in an additional 12 million oldest-old people — individuals at the highest risk for developing Alzheimer's dementia.[206]

- In 2017, about 2.1 million people who have Alzheimer's dementia are age 85 or older, accounting for 38 percent of all people with Alzheimer's dementia.[31]
- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's dementia.[31]
- By 2050, as many as 7 million people age 85 and older may have Alzheimer's dementia, accounting for half (51 percent) of all people 65 and older with Alzheimer's dementia.[31]

# 89 percent

Increase in deaths due to Alzheimer's between 2000 and 2014. Deaths from Alzheimer's have nearly doubled during this period while those from heart disease — the leading cause of death — have declined.

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States.[208] It is the fifth-leading cause of death for those age 65 and older.[198] 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.

## 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), 93,541 people died from Alzheimer's disease in 2014.[208] 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."[209]

Severe dementia frequently causes complications such as immobility, swallowing disorders and malnutrition that significantly increase the risk of serious acute conditions that can cause death. One such condition is pneumonia, which is the most commonly identified cause of death among elderly people with Alzheimer's or other dementias.[210-211] Death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[212-214] As a result, people with Alzheimer's disease who die due to these acute conditions may not be counted among the number of people who died from Alzheimer's disease according to the World Health Organization definition, even though Alzheimer's disease may well have caused the acute condition listed on the death certificate. This difficulty in using death certificates to accurately determine the number of deaths from Alzheimer's has been referred to as a "blurred distinction between death with dementia and death from dementia."[215]

Another way to determine the number of deaths from Alzheimer's disease is through calculations that compare the estimated risk of death in those who have Alzheimer's with the estimated risk of death in those who do not have Alzheimer's. A study using data from the Rush Memory and Aging Project and the Religious Orders Study estimated that 500,000 deaths among people age 75 and older in the United States in 2010 could be attributed to Alzheimer's (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.[216]

The true number of deaths caused by Alzheimer's is somewhere between the number of deaths from Alzheimer's recorded on death certificates and the number of people who have Alzheimer's disease when they die. According to 2014 Medicare claims data, about one-third of all Medicare beneficiaries who die in a given year have been diagnosed with Alzheimer's or another dementia.[188] Based on data from the Chicago Health and Aging Project (CHAP) study, in 2017 an estimated 700,000 people age 65 and older in the United States will have Alzheimer's when they die.[217] Although some seniors who have Alzheimer's disease at the time of death die from causes that are unrelated to Alzheimer's, many of them die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia.

Irrespective of the cause of death, among people age 70, 61 percent of those with Alzheimer's are expected to die before age 80 compared with 30 percent of people without Alzheimer's.[218]

## 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, and it is the only top 10 cause of death that cannot be prevented, cured or even slowed. Although deaths from other major causes have decreased significantly, official records indicate that deaths from Alzheimer's disease have increased significantly.

FIGURE 5

**Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2014**
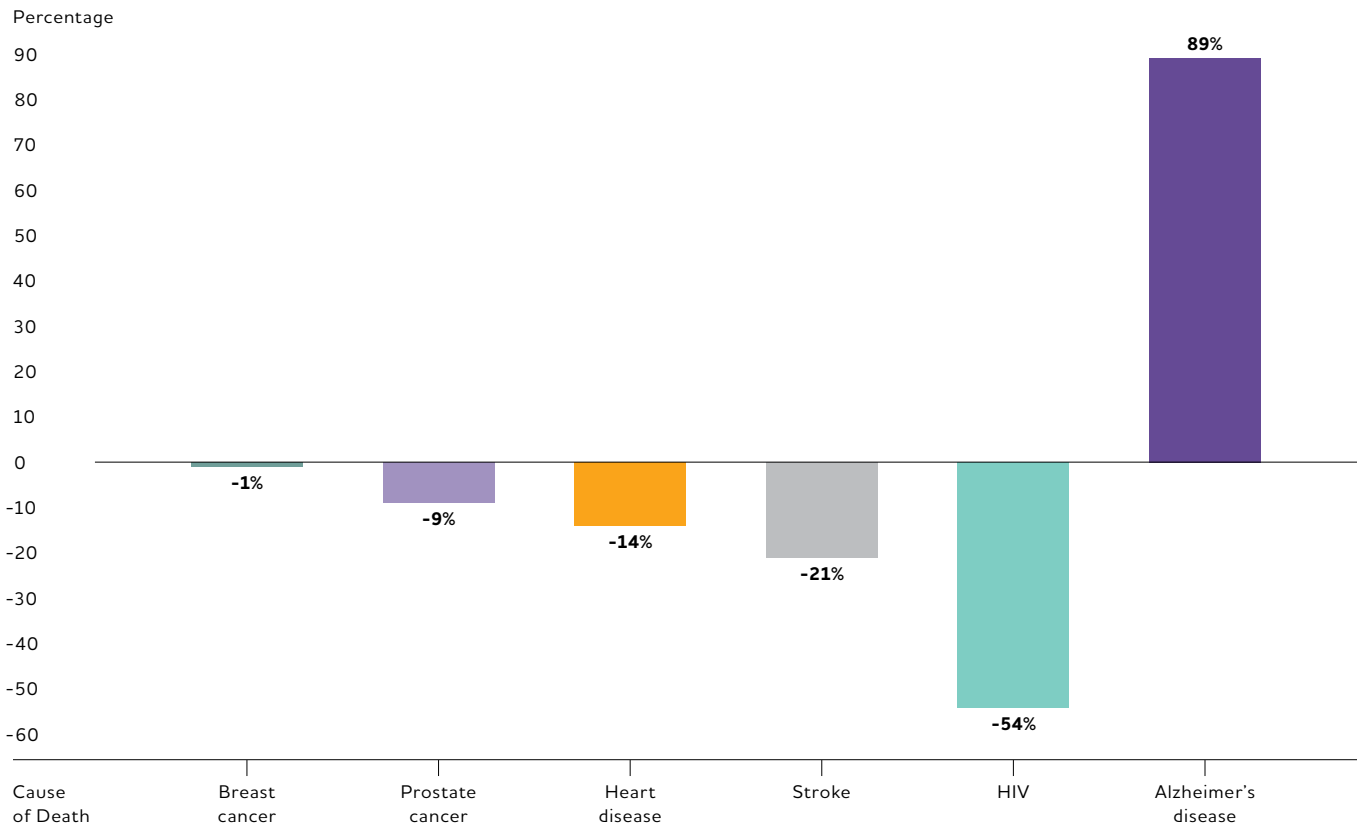


Created from data from the National Center for Health Statistics.[208, 219]

Between 2000 and 2014, deaths from Alzheimer's disease as recorded on death certificates increased 89 percent, while deaths from the number one cause of death (heart disease) decreased 14 percent (Figure 5).[208] The increase in the number 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.

## State-by-State Deaths from Alzheimer's Disease

Table 5 provides information on the number of deaths due to Alzheimer's by state in 2014, 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 2014, the mortality rate for Alzheimer's disease was 29 deaths per 100,000 people.[A15,208]

TABLE 5

**Number of Deaths and Annual Mortality Rate (per 100,000 People) Due to Alzheimer's Disease, by State, 2014**

| State | Number of Deaths | Mortality Rate | State | Number of Deaths | Mortality Rate |
|---|---|---|---|---|---|
| Alabama | 1,885 | 38.9 | Montana | 253 | 24.7 |
| Alaska | 68 | 9.2 | Nebraska | 515 | 27.4 |
| Arizona | 2,485 | 36.9 | Nevada | 606 | 21.3 |
| Arkansas | 1,193 | 40.2 | New Hampshire | 396 | 29.8 |
| California | 12,644 | 32.6 | New Jersey | 1,962 | 22.0 |
| Colorado | 1,364 | 25.5 | New Mexico | 442 | 21.2 |
| Connecticut | 923 | 25.7 | New York | 2,639 | 13.4 |
| Delaware | 188 | 20.1 | North Carolina | 3,246 | 32.6 |
| District of Columbia | 119 | 18.1 | North Dakota | 364 | 49.2 |
| Florida | 5,874 | 29.5 | Ohio | 4,083 | 35.2 |
| Georgia | 2,670 | 26.4 | Oklahoma | 1,227 | 31.6 |
| Hawaii | 326 | 23.0 | Oregon | 1,411 | 35.5 |
| Idaho | 376 | 23.0 | Pennsylvania | 3,486 | 27.3 |
| Illinois | 3,266 | 25.4 | Rhode Island | 403 | 38.2 |
| Indiana | 2,204 | 33.4 | South Carolina | 1,938 | 40.1 |
| Iowa | 1,313 | 42.3 | South Dakota | 434 | 50.9 |
| Kansas | 790 | 27.2 | Tennessee | 2,672 | 40.8 |
| Kentucky | 1,523 | 34.5 | Texas | 6,772 | 25.1 |
| Louisiana | 1,670 | 35.9 | Utah | 584 | 19.8 |
| Maine | 434 | 32.6 | Vermont | 266 | 42.5 |
| Maryland | 934 | 15.6 | Virginia | 1,775 | 21.3 |
| Massachusetts | 1,688 | 25.0 | Washington | 3,344 | 47.4 |
| Michigan | 3,349 | 33.8 | West Virginia | 620 | 33.5 |
| Minnesota | 1,628 | 29.8 | Wisconsin | 1,876 | 32.6 |
| Mississippi | 1,098 | 36.7 | Wyoming | 162 | 27.7 |
| Missouri | 2,053 | 33.9 | **U.S. Total** | **93,541** | **29.3** |

Created from data from the National Center for Health Statistics.[A15, 208]

FIGURE 6

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

Rate

30 •

25 •

20 •

15 •

10 •

5 •

0 •

17.6   18.9   20.5   21.9   22.5   24.2   24.3   24.8   27.1   25.8   27.0   27.3   26.6   26.8   29.3

Year   2000   2001   2002   2003   2004   2005   2006   2007   2008   2009   2010   2011   2012   2013   2014
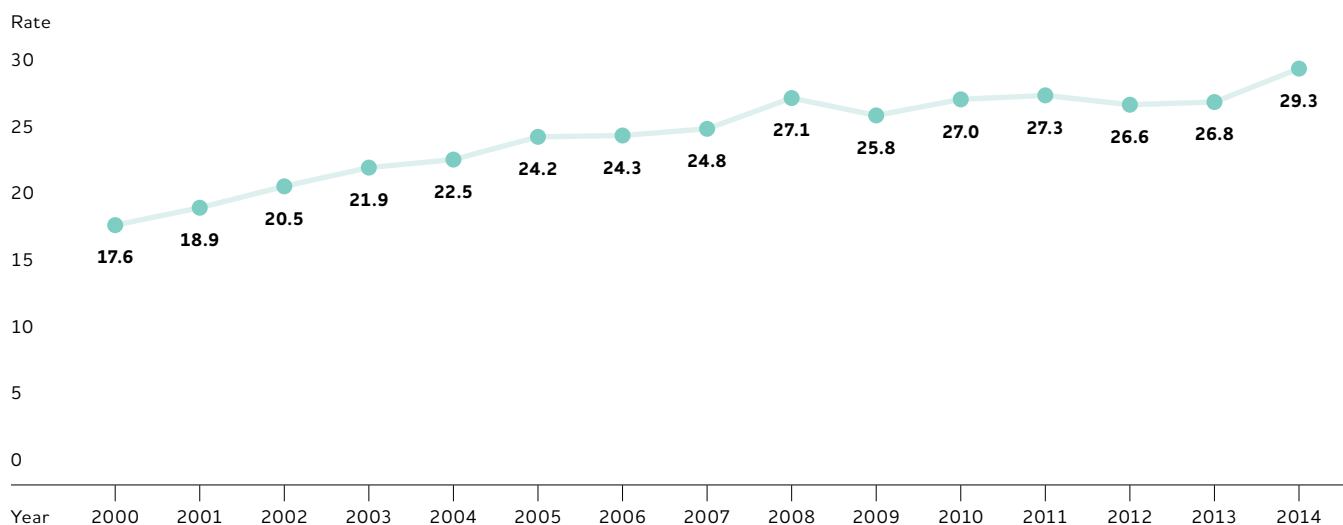
Created from data from the National Center for Health Statistics.[208]

## Alzheimer's Disease Death Rates

As shown in Figure 6, the rate of deaths attributed to Alzheimer's has risen substantially since 2000.[208] Table 6 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65.[208] The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old.[220] Between 2000 and 2014, the death rate from Alzheimer's increased only slightly for people age 65 to 74, but increased 33 percent for people age 75 to 84, and 51 percent for people age 85 and older.

## Duration of Illness from Diagnosis to Death

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's dementia, yet some live as long as 20 years with Alzheimer's.[161,221-228] This reflects the slow, insidious progression of Alzheimer's. Of the total number of years that they live with Alzheimer's dementia, individuals will spend an average of 40 percent of this time in dementia's most severe stage.[218] Much of the time will be spent in a nursing home. At age 80, approximately 75 percent of people living with

Alzheimer's dementia are expected to be in a nursing home compared with only 4 percent of the general population at age 80.[218] 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.[229]

## 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

TABLE 6

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

| Age | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **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 | 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 | 2.1 |
| **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 | 19.6 |
| **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 | 185.6 |
| **85+** | 667.7 | 725.4 | 790.9 | 846.8 | 875.3 | 935.5 | 923.4 | 928.7 | 1,002.2 | 945.3 | 987.1 | 967.1 | 936.1 | 929.5 | 1,006.8 |

Created from data from the National Center for Health Statistics.[208]

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.[230] 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, these statistics indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, but also that the disease is contributing to more and more cases of poor health and disability in the United States.

**CAREGIVING**

More than

**15** million

Americans provide unpaid care
for people with Alzheimer's
or other dementias.

**Caregiving refers to attending to another person'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.[231-232] Caregivers also provide emotional support to people with Alzheimer's. More than 15 million Americans provide unpaid care for people with Alzheimer's or other dementias.[A16] In addition to providing descriptive information, this section compares caregivers of people with dementia to either caregivers of people with other medical conditions, or if that comparison is not available, to non-caregivers of similar ages and other characteristics.**

## 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.[233] Nearly half of all caregivers (46 percent) who provide help to older adults do so for someone with Alzheimer's or another dementia.[234] In 2016, caregivers of people with Alzheimer's or other dementias provided an estimated 18.2 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at $230.1 billion. This is approximately 48 percent of the revenue of Walmart in 2016 ($482 billion)[235] and nine times the total revenue of McDonald's in 2015 ($25.4 billion).[236] 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.[237]

The three primary reasons caregivers provide care and assistance to a person with Alzheimer's are (1) the desire to keep a family member or 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).[A17] Individuals with dementia living in the community are more likely than older adults without dementia to rely on multiple unpaid caregivers; 30 percent of older adults with dementia rely on three or more caregivers, whereas 23 percent of older adults without dementia rely on three or more unpaid caregivers.[238] 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.[238]

### Who are the Caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's or other dementias in the United States.[A17,239-242] About one in three caregivers (34 percent) is age 65 or older.[A17] Over two-thirds of caregivers are married, living with a partner or in a long-term relationship.[A17,240] More than two-thirds of caregivers are non-Hispanic white,[A17,239-240,243] while 10 percent are African-American, 8 percent are Hispanic, and 5 percent are Asian.[A17] Approximately 40 percent of dementia caregivers have a college degree or greater education.[A17,240,243] Forty-one percent of caregivers have a household income of $50,000 or less.[A17] Among primary caregivers (individuals who indicate having the most responsibility for helping their relatives) of people with dementia, over half take care of their parents.[156,242-243] Most caregivers (66 percent) live with the care recipient in the community.[238] It is estimated that 250,000 children and young adults between ages 8 and 18 provide help to someone with Alzheimer's or another dementia.[244] National surveys have found that approximately one quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children under age 18.[A17,156,243]

### Caregiving and Women

The responsibilities of caring for someone with dementia often fall to women. Approximately two-thirds of caregivers are women.[A17,239-240] More specifically, over one-third of dementia caregivers

TABLE 7

**Dementia Caregiving Tasks**

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

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

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

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

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

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

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

Hiring and supervising others who provide care.

Assuming additional responsibilities that are not necessarily specific tasks, such as:
- Providing overall management of getting through the day.
- Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver.

Managing other health conditions (i.e., "comorbidities"), such as arthritis, diabetes or cancer.

Providing emotional support and a sense of security.

are daughters.[233,238] It is more common for wives to provide informal care for a husband than vice versa.[245] On average, female caregivers spend more time caregiving than male caregivers.[238] According to the 2014 Alzheimer's Association Women and Alzheimer's Poll, of those providing care for 21 to more than 60 hours per week, 67 percent were women and 33 percent were men.[246] The 2015 Behavioral Risk Factor Surveillance System (BRFSS) survey found that of all dementia caregivers who spend more than 40 hours per week providing care, 69 percent were women.[156] Two and a half times as many women as men reported living with the person with dementia full time.[246] Of those providing care to someone with dementia for more than 5 years, 63 percent are women and 37 percent are men.[156] Similarly, caregivers who are women may experience higher levels of burden, depression and impaired health than men, with evidence suggesting that these differences arise because female caregivers tend to spend more time caregiving, to take on more caregiving tasks, and to care for someone with more cognitive, functional and/or behavior problems.[247] Women caregivers are also more likely than men to indicate a need for individual counseling, respite care and support groups.[156]

### Caregiving Tasks

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

Though the care provided by family members of people with Alzheimer's or other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely to monitor the health of their care recipients than are caregivers of people without dementia (79 percent versus 66 percent).[248] Data from the 2011 National Health and Aging Trends Study[239,249] 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). Seventy-seven percent of older adults with dementia receive informal assistance with at least one ADL or household activity in contrast to only 20 percent of older adults without dementia; nearly 40 percent of people with dementia receive informal help with three or more ADLs compared with 14 percent of people without dementia.[238] Figure 7 illustrates how family caregivers of people with dementia are more likely than caregivers of other older people to assist with ADLs. 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.[238]

In addition to assisting with ADLs, more caregivers of people with Alzheimer's or other dementias advocate for their care recipient with community agencies and care providers (65 percent) and manage finances (68 percent) compared with caregivers of people without dementia (46 percent and 50 percent).[243] More caregivers of people with Alzheimer's or other dementias arrange for outside services (46 percent) and communicate with health care professionals (80 percent) compared with caregivers of people without dementia (27 percent and 59 percent).[243] 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).[234,239] One in five caregivers of people with Alzheimer's or other dementias (22 percent) report problems dealing with a bank or credit union when helping with the care recipient's

**Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015**

Percentage ■ Caregivers of people with Alzheimer's and other dementias ■ Caregivers of other older people
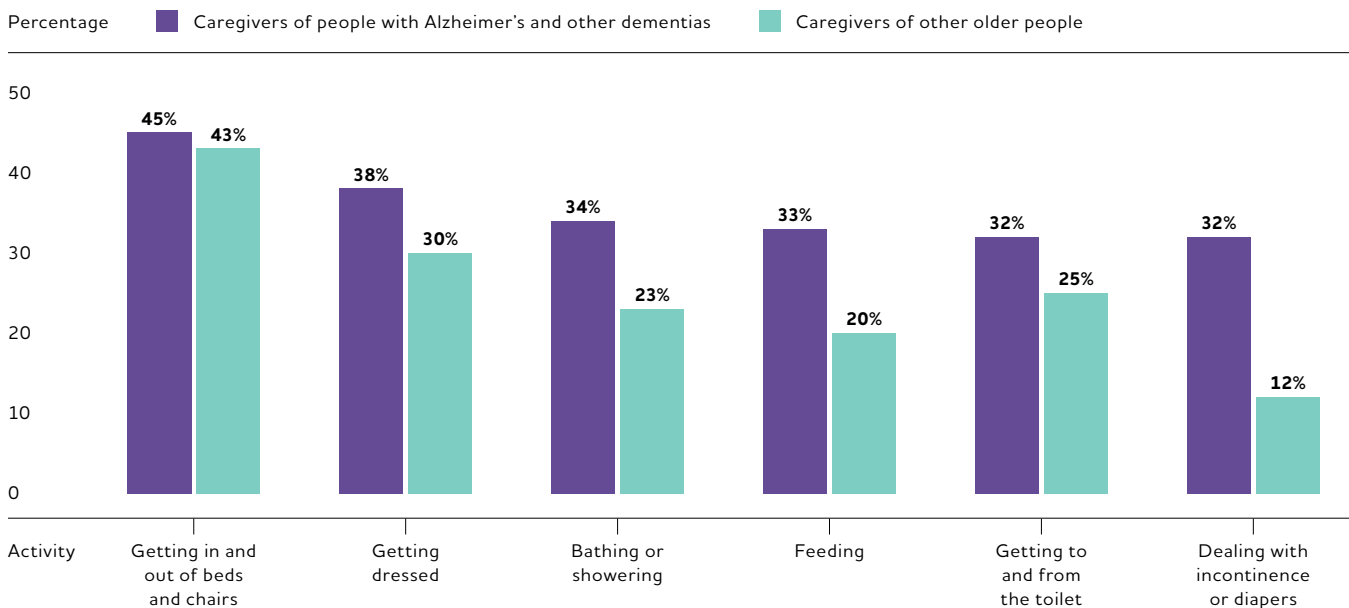


Created from data from National Alliance for Caregiving and AARP.[243]

**FIGURE 8**

**Proportion of Alzheimer's and Dementia Caregivers Versus Caregivers of Other Older People in Residential Care Settings by Duration of Caregiving, United States, 2011**

Percentage ■ Caregivers of people with Alzheimer's and other dementias ■ Caregivers of other older people
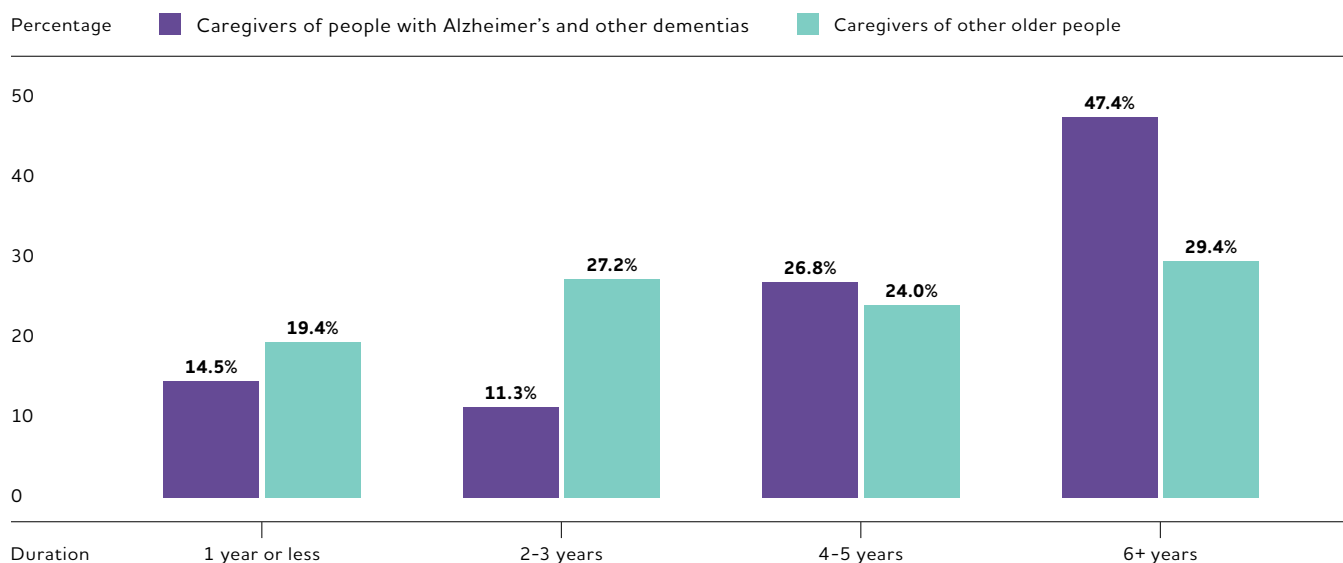


Created from data from the National Health and Aging Trends Study.[238]

finances, compared with 9 percent of caregivers of people without dementia.[243] 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. For example, family caregivers of people with Alzheimer's or other dementias are more likely than family caregivers of people without dementia to help with emotional or mental health problems (41 percent versus 16 percent) and behavioral issues (15 percent versus 4 percent).[243]

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 7 (see page 34) 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.[250-252]

### 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 surveyed both men and women).[A17] Fifty-four percent of caregivers of people with Alzheimer's or other dementias have provided care for two years or more, compared with 50 percent of caregivers of older adults with other conditions.[156] Caregivers of people with Alzheimer's or other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions. Well over half (57 percent) of family caregivers of people with Alzheimer's or other dementias in the community had provided care for 4 or more years. As shown in Figure 8, this percentage increases to 74 percent for family caregivers of people with dementia living in residential care settings compared with 53 percent for family caregivers of people with other conditions.[238]

More than six in 10 (63 percent) Alzheimer's caregivers expect to continue having care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia (49 percent).[243]

## Hours of Unpaid Care and Economic Value of Caregiving

In 2016, the 15.9 million family and other unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 18.2 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.[A18] With this care valued at $12.65 per hour,[A19] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia across the United States was $230.1 billion in 2016. Table 8 (see pages 38-39) shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's or other dementias provided care valued at more than $4 billion in each of 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. A longitudinal study of the monetary value of family caregiving for people with dementia found that the overall value of daily family care increased 18 percent with each additional year of providing care, and that the value of this care increased as the care recipient's cognitive abilities declined.[253] A study based on the same data source found that the estimated economic value of daily family caregiving costs were lower in situations in which caregivers felt closer in their relationship with the person with dementia.[254] Additional research is needed to estimate the future value of family care for people with Alzheimer's as the U.S. population continues to age.

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 26 percent providing 41 or more hours

of care per week.[239,248] Considering all sources of unpaid care (for example, help from multiple family members), individuals with dementia receive 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).[233]

## Impact of Alzheimer's Caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people in the middle to later stages of Alzheimer's experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are affected as well, and these changes are often among the most challenging for family caregivers.[255-257] 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.[A17,258-265] Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey reported in *2016 Alzheimer's Disease Facts and Figures* indicated that among care contributors (a friend or relative who paid for dementia expenses and/or provided care for someone with dementia at least once a month in the prior year), 48 percent cut back on spending and 43 percent cut back on saving due to the out-of-pocket cost of providing help to someone with dementia.[265] Due to care responsibilities in the year prior to the survey, close to four in 10 care contributors indicated that the "food they bought just didn't last, and they didn't have money to get more" and three in 10 ate less because of care-related costs.[265]

TABLE 8

Number of Alzheimer's and Dementia (A/D) Caregivers, Hours of Unpaid Care, Economic
Value of Unpaid Care and Higher Health Care Costs of Caregivers by State, 2016*

| State | A/D Caregivers (in thousands) | Hours of Unpaid Care (in millions) | Value of Unpaid Care (in millions of dollars) | Higher Health Care Costs of Caregivers (in millions of dollars)[†] |
|---|---|---|---|---|
| Alabama | 303 | 345 | $4,359 | $188 |
| Alaska | 33 | 38 | 480 | 30 |
| Arizona | 325 | 370 | 4,685 | 176 |
| Arkansas | 176 | 200 | 2,531 | 108 |
| California | 1,600 | 1,822 | 23,043 | 999 |
| Colorado | 244 | 277 | 3,510 | 146 |
| Connecticut | 177 | 201 | 2,548 | 153 |
| Delaware | 53 | 61 | 770 | 45 |
| District of Columbia | 28 | 32 | 405 | 29 |
| Florida | 1,100 | 1,253 | 15,850 | 785 |
| Georgia | 519 | 591 | 7,478 | 283 |
| Hawaii | 66 | 75 | 944 | 45 |
| Idaho | 81 | 92 | 1,167 | 46 |
| Illinois | 588 | 670 | 8,470 | 397 |
| Indiana | 335 | 382 | 4,831 | 223 |
| Iowa | 135 | 154 | 1,945 | 93 |
| Kansas | 150 | 171 | 2,168 | 102 |
| Kentucky | 271 | 308 | 3,901 | 177 |
| Louisiana | 232 | 264 | 3,341 | 157 |
| Maine | 69 | 78 | 988 | 58 |
| Maryland | 291 | 332 | 4,196 | 218 |
| Massachusetts | 333 | 380 | 4,803 | 309 |
| Michigan | 511 | 582 | 7,361 | 337 |
| Minnesota | 251 | 286 | 3,614 | 186 |
| Mississippi | 206 | 234 | 2,964 | 134 |
| Missouri | 314 | 358 | 4,530 | 218 |

TABLE 8 (cont.)

**Number of Alzheimer's and Dementia (A/D) Caregivers, Hours of Unpaid Care, Economic Value of Unpaid Care and Higher Health Care Costs of Caregivers by State, 2016\***

| State | A/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)† |
|---|---|---|---|---|
| Montana | 49 | 56 | $708 | $33 |
| Nebraska | 82 | 93 | 1,176 | 58 |
| Nevada | 145 | 165 | 2,093 | 83 |
| New Hampshire | 66 | 75 | 954 | 52 |
| New Jersey | 449 | 511 | 6,465 | 340 |
| New Mexico | 106 | 121 | 1,531 | 70 |
| New York | 1,020 | 1,161 | 14,691 | 848 |
| North Carolina | 459 | 523 | 6,614 | 296 |
| North Dakota | 30 | 35 | 438 | 24 |
| Ohio | 597 | 680 | 8,598 | 421 |
| Oklahoma | 223 | 253 | 3,206 | 145 |
| Oregon | 181 | 206 | 2,609 | 119 |
| Pennsylvania | 673 | 766 | 9,693 | 519 |
| Rhode Island | 53 | 61 | 766 | 44 |
| South Carolina | 304 | 347 | 4,385 | 191 |
| South Dakota | 38 | 43 | 542 | 27 |
| Tennessee | 430 | 489 | 6,191 | 273 |
| Texas | 1,380 | 1,571 | 19,876 | 815 |
| Utah | 148 | 169 | 2,138 | 74 |
| Vermont | 30 | 34 | 430 | 23 |
| Virginia | 458 | 521 | 6,591 | 286 |
| Washington | 335 | 382 | 4,832 | 227 |
| West Virginia | 107 | 122 | 1,543 | 82 |
| Wisconsin | 193 | 219 | 2,775 | 140 |
| Wyoming | 28 | 32 | 400 | 20 |
| **U.S. Total** | **15,975** | **18,192** | **$230,127** | **$10,852** |

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

†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.[A20]

Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare & Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.[A16, A18, A19, A20]

### Caregiver Emotional and Social Well-Being

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. Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others,[A17,266-269] they also report high levels of stress when providing care:

- Based on the Level of Care Index that combined the number of hours of care and the number of ADL tasks performed by the caregiver, more dementia caregivers in the 2015 NAC/AARP survey were classified as having a high level of burden than caregivers of people without dementia (46 percent versus 38 percent).[243]
- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.[239]
- Fifty-nine percent of family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high to very high (Figure 9).[A17] Nearly half of dementia caregivers indicate that providing help is highly stressful (49 percent) compared with 35 percent of caregivers of people without dementia.[243]
- Many caregivers of people with Alzheimer's or other dementias provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.[A17]

### Depression and Mental Health

- Approximately 30 percent to 40 percent of family caregivers of people with dementia suffer from depression, compared with 5 percent to 17 percent of non-caregivers of similar ages.[270-274]
- The prevalence of depression is higher among dementia caregivers than other caregivers such as those who provide help to individuals with schizophrenia (20 percent) or stroke (19 percent).[274-276]

- Depression risk increases alongside the worsening cognitive symptoms of the person with dementia.[274,277-278]
- In a recent meta-analysis, kin relationship was the strongest predictor of caregiver depression; caregivers of spouses had two and a half times higher odds of having depression as caregivers of people who were not spouses.[274]
- The prevalence of anxiety among dementia caregivers is 44 percent, which is higher than among caregivers of people with stroke (31 percent).[274,276]
- Caregivers of individuals with Alzheimer's report more subjective cognitive problems (e.g., memory complaints) and experience greater declines in cognition over time than non-caregivers matched for age and other characteristics.[279-280]

### Strain

- Twice as many caregivers of people with Alzheimer's or other dementias have difficulty with medical/nursing-related tasks (e.g., injections, tube feedings, catheter/colostomy care) as caregivers of individuals without dementia (22 percent compared with 11 percent).[248]
- Half of caregivers (51 percent) of people with Alzheimer's or other dementias indicate having no experience performing medical/nursing-related tasks,[248] and they often lack the information or resources necessary to manage complex medication regimens.[281-282]
- According to the 2014 Alzheimer's Association poll of caregivers, respondents often believed they had no choice in taking on the role of caregiver.[A17]
- The poll also found that women with children under age 18 felt that caregiving for someone with Alzheimer's was more challenging than caring for children (53 percent).[A17]
- 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.[264,283-285]

## Stress of Care Transitions

- Admitting a relative to a residential care facility has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility, but other studies have found that distress declines following admission.[252,286-287]

- The demands of caregiving may intensify as people with dementia approach the end of life.[288] In the year before a care recipient'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.[289] One study of end-of-life care found that 72 percent of family caregivers experienced relief when the person with Alzheimer's or another dementia died.[289]

### Caregiver Physical Health

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of providing dementia care increases caregivers' susceptibility to disease and health complications.[290] As shown in Figure 9, 38 percent of Alzheimer's and dementia caregivers indicate that the physical stress of caregiving is high to very high.[A17] Nearly three in 10 caregivers of people with Alzheimer's or other dementias report that providing care results in high physical strain (29 percent) compared with 17 percent of caregivers of people without dementia.[243] Sleep disturbances, which can occur frequently when caring for a relative with Alzheimer's or another dementia, have also been shown to negatively influence family caregivers' health.[291-292]

## General Health

Seventy-four percent of caregivers of people with Alzheimer's or other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.[A17] Forty-two percent of caregivers of people with Alzheimer's or another dementia report that their health is excellent or very good, which is lower than caregivers of people without dementia (50 percent).[243]

**Proportion of Alzheimer's and Dementia Caregivers Who Report High to Very High Emotional and Physical Stress Due to Caregiving**
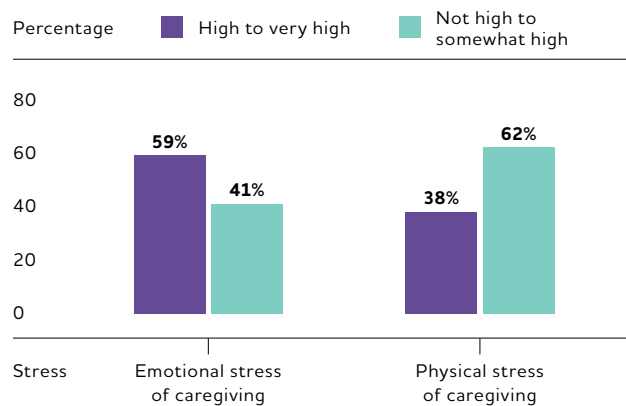


Created from data from the Alzheimer's Association.[A17]

In addition, over 1 in 3 caregivers of people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities (35 percent) compared with 19 percent of caregivers of people without dementia.[243] Dementia caregivers indicated lower health-related quality of life than non-caregivers and were more likely than non-caregivers to report that their health was fair or poor.[260,264,293-294] Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse.[295] Data from the Health and Retirement Study showed that dementia caregivers who provided care to spouses were much more likely (41 percent increased odds) than other spousal caregivers to become increasingly frail during the time between becoming a caregiver and their spouse's death, accounting for differences in age and additional factors.[296] Other studies, however, suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.[297]

## 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.[298-303]

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,[304] reduced immune function,[258,305] slow wound healing,[306] coronary heart disease,[307] impaired function of the endothelium (the inner lining of blood vessels) and increased incidence of hypertension.[308] Some of these changes may be associated with an increased risk of cardiovascular disease.[309]

*Health Care*
The physical and emotional impact of dementia caregiving is estimated to have resulted in $10.9 billion in health care costs in the United States in 2016.[A20] Table 8 (see pages 38-39) shows the estimated higher health care costs for caregivers of people with Alzheimer's or other dementias 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.[264,310-311] 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.[311]

*Mortality*
The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings. 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.[312] One study found that caregivers who perceive higher strain due to care responsibilities are at higher risk for death than caregivers who perceive little or no strain.[313]

*Caregiver Employment*
Six in 10 caregivers of people with Alzheimer's or another dementia were employed in the past year while providing help.[243] These individuals worked an average of 35 hours per week while caregiving.[243] Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 15 percent quit their jobs or retired early due to their care responsibilities. Fifty-seven percent reported sometimes needing to go in late or leave early, and 16 percent had to take a leave of absence. Other work-related challenges for dementia and non-dementia caregivers who had been employed in the past year are summarized in Figure 10.[243]

### Interventions Designed to Assist Caregivers
For more than 30 years, strategies to support family caregivers of people with Alzheimer's have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 9 (see page 44).[262-263]

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

According to a recent publication on dementia caregiver interventions that reviewed seven meta-analyses and 17 systematic reviews of randomized controlled trials, the following characteristics distinguish interventions that are effective: family caregivers are actively involved in the intervention, in contrast to passively receiving information; the intervention is tailored and flexible to meet the changing needs of family caregivers during the course of a relative's dementia; and the intervention

FIGURE 10

**Work-Related Changes Among Caregivers of People with Alzheimer's and Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving**

Percentage    ■ Caregivers of people with Alzheimer's and other dementias    ■ Caregivers of other people
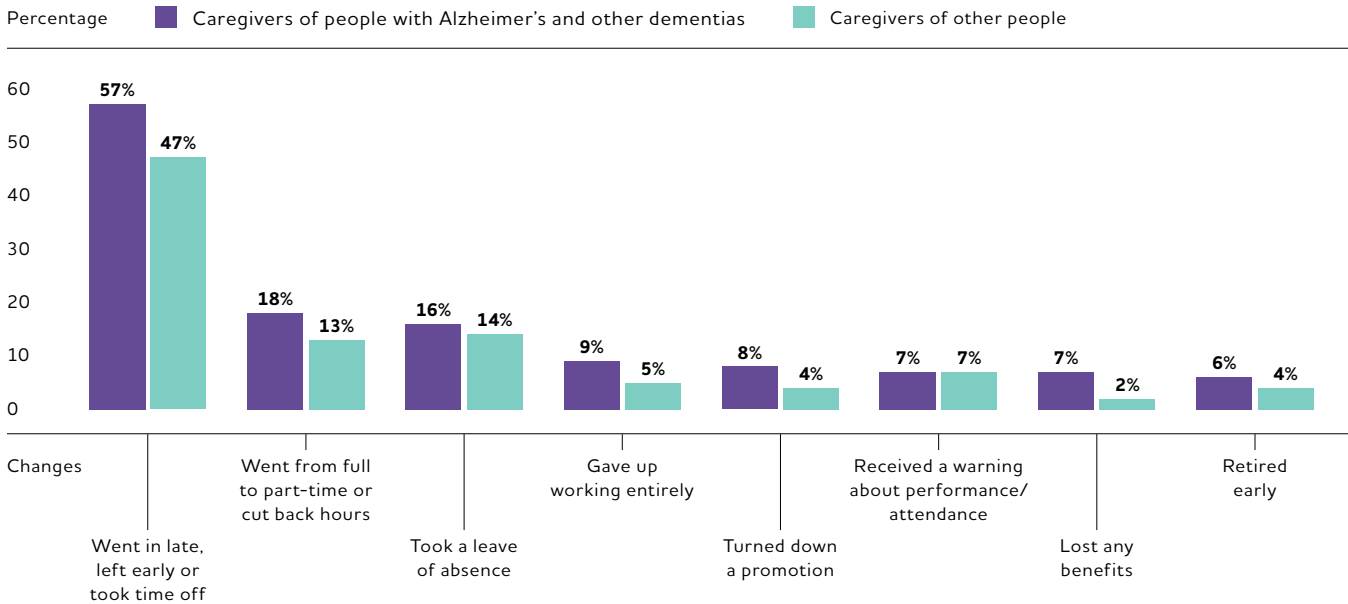


Created from data from the National Alliance for Caregiving and AARP.[243]

meets the needs not only of caregivers, but of care recipients as well.[314] 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 or other dementias as well as their family caregivers, and more evaluations are emerging each year.[315-316]

Interventions for dementia caregivers that have demonstrated efficacy in scientific evaluations have been gradually implemented in the community.[317-328] These implementation 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.[329-331] 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.[332-334] Improved tools to "personalize" services for caregivers to maximize their benefits represent an emerging area of research.[335-338] More studies are also needed to explore the effectiveness of interventions in different racial, ethnic and socioeconomic groups and in various geographic settings.[330,339-345]

## Paid Caregivers

### Direct Care Workers for People with Alzheimer's or Other Dementias

Direct-care workers, such as nurse aides, home health aides and personal and home care aides, provide most of the paid long-term care to older adults living at home or in residential settings.[346] In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents.[347-349] Nursing assistants help with bathing,

**TABLE 9**

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 approaches | Include a structured program that provides information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (that is, cognitive impairment, behavioral symptoms and care-related needs). Include 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 psychotherapeutic 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). |

Created from data from Pinquart et al. and Sörensen et al.[262-263]

dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and geographic backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.[348,350] 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.[348] Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.[351] Inadequate education and challenging work environments have also contributed to higher turnover rates among nursing staff across care environments.[352] Studies have shown

that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits.[350,353-357]

### 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.[351] It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs.[358] As of 2014, there were 7,428 certified geriatricians and 1,629 geriatric psychiatrists in the United States, or one geriatrician and one geriatric psychiatrist for every 2,526 and 11,526 Americans age

75 or older, respectively.[359] The American Geriatrics Society estimates that, due to the increase in older Americans and the stagnation in the number of new geriatric professionals trained in the past decade, this differential will increase to one geriatrician and one geriatric psychiatrist for every 4,484 and 20,448 older Americans, respectively, by 2030.[359] Less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.[351] Similarly, although 73 percent of social workers serve clients age 55 and older, only 4 percent have formal certification in geriatric social work.[351] Furthermore, the overall aging of the long-term care workforce may affect the number of paid caregivers.[352]

### Enhancing Health Care for Family Caregivers

There is a growing consensus that primary care providers of people with Alzheimer's should acknowledge the presence of caregivers and assess their well-being to improve the overall management of the person with dementia.[360-363] Recognizing that the complex care challenges of people with dementia also require interprofessional collaboration and education,[363-365] ongoing efforts have attempted to integrate innovative care management practices with traditional primary care for people with dementia.[366-369] 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.[370] Several evaluations have suggested that such approaches have considerable potential for improving outcomes for people with dementia and their family caregivers (for example, delayed nursing home admission and reduction in caregiver distress).[371-375] Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate.[376-377]

In 2016, the National Academies of Sciences, Engineering, and Medicine released *Families Caring for an Aging America*, a seminal report that includes a number of recommendations to refocus national health care reform efforts from models of care that center on the patient (person-centered care) to models of care that also explicitly engage and support the patient's family (person- and family-centered care).[378] These service models recognize the important role family members play in providing care and incorporate family caregivers during the delivery of health care to relatives with dementia. Furthermore, these models encourage health care providers to deliver evidence-based services and support to both caregivers and care recipients.[378-379]

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

# $259 billion

2017 marks the first year total
annual payments for caring for
individuals living with Alzheimer's
or other dementias will surpass a
quarter of a trillion dollars.

The costs of health care and long-term care for individuals with Alzheimer's or other dementias are substantial, and dementia is one of the costliest conditions to society.[237] Total payments in 2017 (in 2017 dollars) for all individuals with Alzheimer's or other dementias are estimated at $259 billion (Figure 11). Medicare and Medicaid are expected to cover $175 billion, or 67 percent, of the total health care and long-term care payments for people with Alzheimer's or other dementias. Out-of-pocket spending is expected to be $56 billion, or 22 percent of total payments.[A21] Throughout the rest of this section, all costs are reported in 2016 dollars unless otherwise indicated.[A22]

## Total Cost of Health Care and Long-Term Care

Table 10 (see page 48) reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias. Total per-person health care and long-term care payments in 2016 from all sources for Medicare beneficiaries with Alzheimer's or other dementias were over three times as great as payments for other Medicare beneficiaries in the same age group ($46,786 per person for those with dementia compared with $13,351 per person for those without dementia).[A23,380]

Twenty-seven percent of older individuals with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia.[380] 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 annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias ($8,182) were 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias ($349) (Table 10).[380]

FIGURE 11

Aggregate Cost of Care by Payment Source for Americans Age 65 and Older with Alzheimer's and Other Dementias, 2017*



Total cost:
$259 Billion (B)

● Medicare
$131 B, 51%

● Medicaid
$44 B, 17%

● Out of pocket
$56 B, 22%
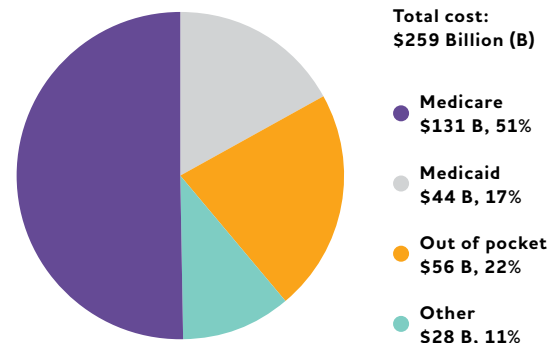
● Other
$28 B, 11%

*Data are in 2017 dollars.
Created from data from the Lewin Model.[A21] "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Despite these and other sources of financial assistance, individuals with Alzheimer's or other dementias still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments and services not covered by Medicare, Medicaid or additional sources of support. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid $10,315 out of pocket annually for health care and long-term care services not covered by other sources (Table 10).[380]

Researchers have evaluated the additional or "incremental" health care, long-term 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).[237,381] One group of researchers found that the incremental health care and nursing home costs for those with dementia were $28,501 per person per year in 2010 dollars ($32,924 in 2016 dollars).[A22,A24,237] Another group of researchers found that the incremental lifetime cost of

TABLE 10

**Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars**

| Payment Source | Beneficiaries with Alzheimer's or Other Dementias | Beneficiaries without Alzheimer's or Other Dementias |
|---|---|---|
| Medicare | $23,497 | $7,223 |
| Medicaid | 8,182 | 349 |
| Uncompensated | 364 | 365 |
| Health maintenance organization | 1,205 | 1,475 |
| Private insurance | 2,152 | 1,358 |
| Other payer | 895 | 231 |
| Out of pocket | 10,315 | 2,232 |
| Total* | $46,786 | $13,351 |

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.[380]

Alzheimer's dementia was substantially higher for women than men, due to a greater lifetime risk of developing Alzheimer's dementia.[382] Additionally, because women are more likely to be widowed and living in poverty, the incremental Medicaid costs associated with Alzheimer's dementia were 70 percent higher for women than men.

Other researchers compared end-of-life costs for individuals with and without dementia and found that the total cost in the last 5 years of life was $287,038 per person in 2010 dollars for people with dementia and $183,001 per person without dementia but with other conditions ($341,651 and $217,820 respectively, in 2016 dollars), a difference of 57 percent.[383] Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia than for people without dementia (32 percent versus 11 percent).

## Use and Costs of Health Care Services

### Use of Health Care Services

People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people.[188] Moreover, the use of health care services by people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's or other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

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

FIGURE 12

**Reasons for Hospitalization of Individuals with Alzheimer's Dementia:
Percentage of Hospitalized Individuals by Admitting Diagnosis***
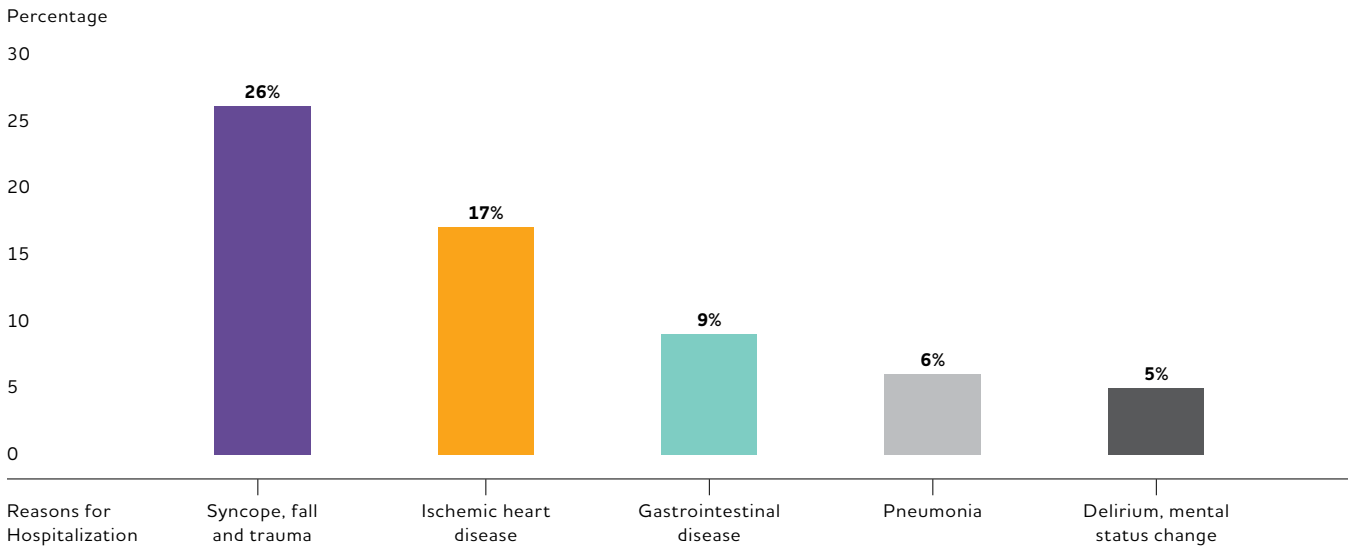
Percentage



*All hospitalizations for individuals with a clinical diagnosis of probable or possible Alzheimer's were
used to calculate percentages. The remaining 37 percent of hospitalizations were due to other reasons.
Created from data from Rudolph et al.[385]

- Hospital. There are 538 hospital stays per 1,000
  Medicare beneficiaries age 65 and older with
  Alzheimer's or other dementias compared with
  266 hospital stays per 1,000 Medicare beneficiaries
  age 65 and older without these conditions.[188]
  A person with dementia in 2012 had, on average,
  22.5 inpatient days — defined as days in a hospital
  or skilled nursing facility — compared with 4.6 days
  for the Medicare population as a whole.[384] The most
  common reasons for hospitalization of people with
  Alzheimer's dementia are syncope (fainting), fall
  and trauma (26 percent); ischemic heart disease
  (17 percent); and gastrointestinal disease (9 percent)
  (Figure 12).[385] In a study of inpatient hospitalizations
  of adults age 60 and older, those with Alzheimer's
  were at 7 percent greater risk of dying during the
  hospital stay and stayed nearly a day longer than
  individuals without Alzheimer's dementia.[386]
- 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.[387] There are 283 skilled nursing facility
stays per 1,000 beneficiaries with Alzheimer's or
other dementias compared with 73 stays per 1,000
beneficiaries for people without these conditions —
a rate nearly four times as great.[188]

- Home health care. Twenty-five percent of Medicare
  beneficiaries age 65 and older with Alzheimer's or
  other dementias have at least one home health care
  visit during the year, compared with 10 percent of
  Medicare beneficiaries age 65 and older without
  Alzheimer's or other dementias.[188]

### Costs of Health Care Services

Average per-person payments for health care services
(hospital, physician and other medical provider, nursing
home, skilled nursing facility, hospice and home health
care) and prescription medications were higher for
Medicare beneficiaries with Alzheimer's or other
dementias than for other Medicare beneficiaries in
the same age group (Table 11, see page 50).[380]

Average Annual Per-Person Payments for Health Care and Long-Term Care Services Provided to Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars

| Service | Beneficiaries with Alzheimer's or Other Dementias | Beneficiaries without Alzheimer's or Other Dementias |
|---|---|---|
| Inpatient hospital | $10,415 | $3,364 |
| Medical provider* | 6,031 | 3,757 |
| Skilled nursing facility | 6,547 | 448 |
| Nursing home | 14,999 | 726 |
| Hospice | 1,966 | 149 |
| Home health care | 2,461 | 357 |
| Prescription medications† | 3,318 | 2,846 |

*"Medical provider" includes physician, other medical provider and laboratory services, and medical equipment and supplies.

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.[380]

## 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 significantly higher for individuals with newly diagnosed dementia and existing dementia than for those with normal cognition, and significantly higher for individuals with existing dementia than those with mild cognitive impairment (MCI).[388] Annual health care costs for individuals with MCI were not significantly different, however, from costs for individuals with normal cognition.

Several groups of researchers have found that health care and prescription drug spending is significantly higher in the year prior to diagnosis[389-391] and two years prior to diagnosis[392] compared with otherwise similar individuals not diagnosed with Alzheimer's or another dementia, although there is less agreement about the sources of increased spending. In one study, the largest differences were in inpatient and post-acute care,[390] while in another study the differences in spending were primarily due to outpatient care, home care and medical day services.[391] In a third study, the differences were due to home health care, skilled nursing care and durable medical equipment.[392] Two groups of researchers have found that spending in the year after diagnosis continued to be higher than for individuals not diagnosed with the disease, ranging from $9,333 in 2011 dollars ($10,781 in 2016 dollars)[389] to $17,852 in 2014 dollars ($18,961 in 2016 dollars).[390] One group of researchers found no difference in health care spending in the two years after diagnosis.[392] Researchers have found that time to Alzheimer's dementia diagnosis after the earliest diagnosis of cognitive decline was shorter for individuals whose cognitive impairment was diagnosed by a specialist (that is, neurologist, psychiatrist or geriatrician) than those diagnosed by a non-specialist. Additionally, individuals diagnosed with cognitive impairment by a specialist had lower Medicare costs in the year after receiving a diagnosis of Alzheimer's dementia than those diagnosed by a non-specialist.[393] While more research 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 dementia, it may be attributed to care for disability and injuries, such as falls, that might result from the early stage of the disease;[394] treatments related to cognitive impairment or coexisting medical conditions; the timing of receiving an Alzheimer's diagnosis; and costs of diagnostic procedures.

## Impact of Alzheimer's and Other Dementias on Use and Costs of Health Care in People with Coexisting Medical Conditions

Medicare beneficiaries with Alzheimer's or other dementias are more likely than those without dementia to have other chronic conditions.[188] While 26 percent of Medicare beneficiaries age 65 and older with Alzheimer's or other dementias have five

TABLE 12

Specific Coexisting Medical Conditions Among Medicare Beneficiaries Age 65 and Older with Alzheimer's or Other Dementias, 2013

| Coexisting Condition | Percentage of Beneficiaries with Alzheimer's or 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 |

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2013.[188]

or more chronic conditions (including Alzheimer's or other dementias), only 3.8 percent of Medicare beneficiaries without Alzheimer's or other dementias have five or more chronic conditions.[188] Table 12 reports the proportion of people with Alzheimer's or 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 chronic obstructive pulmonary disease.[188]

Medicare beneficiaries who have Alzheimer's or 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 13 (see page 52) shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have Alzheimer's or other dementias and beneficiaries who do not have Alzheimer's.[188] Medicare beneficiaries with Alzheimer's

or other dementias had higher average per-person payments in all categories except hospital care payments for individuals with congestive heart failure.

## Use and Costs of Long-Term Care Services

An estimated 58 percent of older adults with Alzheimer's or other dementias live in the community, compared with 98 percent of older adults without Alzheimer's or other dementias.[380] Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone.[380] As their disease progresses, people with Alzheimer's or other dementias generally receive more care from family members and other unpaid caregivers. Many people with dementia also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times during the often long course of the disease. The average costs of these services are high (assisted living: $43,539 per year[395] and nursing home care: $82,125 to $92,378 per year),[395] 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.

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

Most people with Alzheimer's or other dementias who live at home receive unpaid help from family members and friends, but some also receive paid home- and community-based services, such as personal care and adult day care. 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.[396] 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.[396]

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

**TABLE 13**

Average Annual Per-Person Payments by Type of Service and Coexisting Medical Condition for Medicare
Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars*

| Medical Condition by Alzheimer's/Dementia (A/D) Status | Average Per-Person Medicare Payment | | | | | |
|---|---|---|---|---|---|---|
| | Total Medicare Payments | Hospital Care | Physician Care | Skilled Nursing Facility Care | Home Health Care | Hospice Care |
| **Coronary artery disease** | | | | | | |
| With A/D | **$26,223** | $7,853 | $2,199 | $4,386 | $2,343 | $3,092 |
| Without A/D | **16,366** | 5,656 | 1,565 | 1,410 | 971 | 374 |
| **Diabetes** | | | | | | |
| With A/D | **25,385** | 7,472 | 2,154 | 4,242 | 2,267 | 2,590 |
| Without A/D | **14,014** | 4,681 | 1,380 | 1,225 | 844 | 255 |
| **Congestive heart failure** | | | | | | |
| With A/D | **28,773** | 8,825 | 2,310 | 4,794 | 2,455 | 3,452 |
| Without A/D | **24,412** | 8,960 | 2,075 | 2,596 | 1,742 | 807 |
| **Chronic kidney disease** | | | | | | |
| With A/D | **28,002** | 8,457 | 2,255 | 4,666 | 2,319 | 3,075 |
| Without A/D | **20,077** | 6,989 | 1,779 | 1,883 | 1,201 | 473 |
| **Chronic obstructive pulmonary disease** | | | | | | |
| With A/D | **27,797** | 8,481 | 2,283 | 4,624 | 2,399 | 3,189 |
| Without A/D | **18,962** | 6,792 | 1,725 | 1,749 | 1,201 | 602 |
| **Stroke** | | | | | | |
| With A/D | **26,608** | 7,751 | 2,177 | 4,564 | 2,254 | 3,199 |
| Without A/D | **19,169** | 6,305 | 1,753 | 2,294 | 1,455 | 605 |
| **Cancer** | | | | | | |
| With A/D | **25,207** | 7,352 | 2,109 | 3,934 | 2,074 | 2,862 |
| Without A/D | **15,987** | 4,833 | 1,447 | 1,050 | 692 | 484 |

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

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.[188]

- Adult day services. Thirty-two percent of individuals using adult day services have Alzheimer's or other dementias,[397] and 73 percent of adult day service programs offer specific programs for individuals with Alzheimer's or other dementias.[398]
- 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 or other dementias in 2010.[399] Forty percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias.[400] Small residential care facilities (4 to 25 beds) have a larger proportion of residents with Alzheimer's or other dementias than larger facilities (47 percent in facilities with 4 to 25 beds compared with 42 percent in facilities with 26 to 50 beds and 37 percent in facilities with more than 50 beds).[400] Fifty-eight percent of residential care facilities offer programs for residents with Alzheimer's or other dementias.[401]
- Nursing home care. Sixty-one percent of nursing home residents in 2014 had moderate or severe cognitive impairment.[402] Nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's dementia compared with only 4 percent of the general population.[218]
- 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 or 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.[403-404] These Alzheimer's special care unit beds accounted for just 4 percent of all nursing home beds, despite 61 percent of nursing home residents having moderate or severe cognitive impairment.

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

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home- and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. The federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs. Spending on home care for Medicare beneficiaries with Alzheimer's or other dementias nearly doubled between 2004 and 2011, although increases in spending may be due to a variety of factors, including more people being diagnosed with Alzheimer's dementia, more people using home care, more intensive use of home care service and an increase in Medicaid coverage by older adults.[380,405] In 2014, home- and community-based services represented the majority (53 percent) of Medicaid spending on long-term services and supports, with the remaining 47 percent for institutional care.[406] More research is needed, however, to understand the extent to which home- and community-based services meet the needs of individuals with Alzheimer's or other dementias.

### Transitions Between Care Settings

A recent research study demonstrated that individuals with dementia often move between a nursing facility, hospital and home, rather than remaining solely in a nursing facility.[407] 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.[408] The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.[409]

### Costs of Long-Term Care Services

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

- Home care. The median cost for a paid non-medical home health aide is $20 per hour and $127 per day.[395] Home care costs have increased by 1.3 percent annually over the past 5 years.
- Adult day centers. The median cost of adult day services is $68 per day.[395] The cost of adult day services has increased by 2.5 percent annually over the past 5 years. Ninety-five percent of adult day centers provide care for people with Alzheimer's or other dementias, and 2 percent of these centers charged an additional fee for these clients in 2012.[410]
- Assisted living facilities. The median cost for care in an assisted living facility is $3,628 per month, or $43,539 per year.[395] The cost of assisted living has increased 2.2 percent annually over the past 5 years.
- Nursing homes. The average cost for a private room in a nursing home is $253 per day, or $92,378 per year. The average cost of a semi-private room in a nursing home is $225 per day, or $82,125 per year.[395] The cost of nursing home care has increased by 3.5 percent and 3.1 percent annually over the past 5 years for a private and semi-private room, respectively.

*Affordability of Long-Term Care Services*

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

- Income and asset data are not available for people with Alzheimer's or other dementias specifically, but 50 percent of Medicare beneficiaries have incomes of $24,150 or less and 25 percent have incomes of $14,350 or less (in 2014 dollars).[411]
- Fifty percent of Medicare beneficiaries had total savings of $63,350 or less (in 2014 dollars), 25 percent have 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 beneficiaries than for white Medicare beneficiaries.[411]

*Long-Term Care Insurance*

Long-term care insurance covers costs of long-term care services and supports in the home, in the community and in residential facilities. Long-term care insurance typically covers care provided in a nursing home, assisted living facility, and Alzheimer's special care facility, as well as community-based services such as adult day care and services provided in the home, including nursing care and help with personal care.[412] The 2016 Alzheimer's Association Family Impact of Alzheimer's Survey reported in *2016 Alzheimer's Disease Facts and Figures* found that among the more than 3,500 respondents, 28 percent believed that Medicare covered the cost of nursing home care for people with Alzheimer's and 37 percent did not know whether it covered the cost of nursing home care.[265] While Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing facility and hospice care, it does not cover long-term care in a nursing home.[413]

Industry reports estimate that approximately 7.3 to 7.5 million Americans have long-term care insurance.[414-415] Enrollment in private long-term care insurance is more common for older adults with higher-than-average incomes. While only 8.8 percent of adults age 55 and older had long-term care insurance in 2008, 19 percent of those with incomes greater than $100,000 had coverage.[416] Private health and long-term care insurance policies funded only about 8 percent of total long-term care spending in 2013, representing $24.8 billion of the $310 billion total in 2013 dollars.[417] The private long-term care insurance market has consolidated since 2010. Five major insurance carriers either exited the market or substantially increased premiums, making policies unaffordable for many individuals.[418]

*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

TABLE 14

**Total Medicaid Costs for Americans Age 65 and Older Living with Alzheimer's or Other Dementias by State**

| State | 2017 (in millions of dollars) | 2025 (in millions of dollars) | Percentage Increase | State | 2017 (in millions of dollars) | 2025 (in millions of dollars) | Percentage Increase |
|---|---|---|---|---|---|---|---|
| Alabama | $797 | $1,092 | 37.0 | Montana | $139 | $197 | 41.8 |
| Alaska | 59 | 107 | 82.5 | Nebraska | 310 | 398 | 28.5 |
| Arizona | 332 | 530 | 59.7 | Nevada | 158 | 269 | 70.6 |
| Arkansas | 335 | 440 | 31.2 | New Hampshire | 225 | 325 | 44.6 |
| California | 3,464 | 5,085 | 46.8 | New Jersey | 1,887 | 2,534 | 34.3 |
| Colorado | 526 | 765 | 45.3 | New Mexico | 177 | 270 | 52.4 |
| Connecticut | 880 | 1,151 | 30.8 | New York | 4,598 | 6,128 | 33.3 |
| Delaware | 212 | 303 | 43.1 | North Carolina | 1,112 | 1,580 | 42.1 |
| District of Columbia | 115 | 131 | 13.7 | North Dakota | 166 | 209 | 25.7 |
| Florida | 2,279 | 3,347 | 46.9 | Ohio | 2,242 | 2,851 | 27.2 |
| Georgia | 1,038 | 1,544 | 48.7 | Oklahoma | 440 | 592 | 34.6 |
| Hawaii | 196 | 276 | 40.6 | Oregon | 222 | 308 | 38.6 |
| Idaho | 129 | 190 | 47.8 | Pennsylvania | 3,236 | 3,907 | 20.7 |
| Illinois | 1,565 | 2,134 | 36.4 | Rhode Island | 416 | 548 | 31.5 |
| Indiana | 913 | 1,196 | 30.9 | South Carolina | 544 | 793 | 45.8 |
| Iowa | 598 | 768 | 28.4 | South Dakota | 157 | 205 | 30.6 |
| Kansas | 403 | 526 | 30.7 | Tennessee | 939 | 1,335 | 42.1 |
| Kentucky | 685 | 920 | 34.3 | Texas | 2,493 | 3,832 | 53.7 |
| Louisiana | 658 | 905 | 37.6 | Utah | 152 | 228 | 50.5 |
| Maine | 187 | 266 | 42.1 | Vermont | 98 | 142 | 44.3 |
| Maryland | 1,042 | 1,488 | 42.8 | Virginia | 826 | 1,228 | 48.7 |
| Massachusetts | 1,550 | 1,970 | 27.1 | Washington | 461 | 669 | 45.0 |
| Michigan | 1,299 | 1,685 | 29.7 | West Virginia | 394 | 505 | 28.3 |
| Minnesota | 781 | 1,055 | 35.1 | Wisconsin | 687 | 897 | 30.6 |
| Mississippi | 536 | 707 | 31.8 | Wyoming | 71 | 108 | 52.1 |
| Missouri | 843 | 1,102 | 30.7 | **U.S. Total** | **$43,570** | **$59,739** | **37.1** |

All cost figures are reported in 2017 dollars. State totals may not add to the U.S. total due to rounding.
Created from data from the Lewin Model.[A21]

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. There is a general lack of knowledge about Medicaid coverage and long-term care. In a survey about the financial impact of Alzheimer's and other dementias on families, 36 percent of respondents mistakenly believed that Medicaid was long-term care insurance.[265] While Medicaid covers the cost of nursing home care, its coverage of many long-term care and support services, such as assisted living care, home-based skilled nursing care and help with personal care, varies by state.

Total Medicaid spending for people with Alzheimer's or other dementias is projected to be $44 billion in 2017 (in 2017 dollars).[A21] Estimated state-by-state Medicaid spending on people with Alzheimer's or other dementias in 2017 (in 2017 dollars) is included in Table 14 (see page 55). Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's or other dementias were 23 times as great as Medicaid payments for other Medicare beneficiaries.[380] Much of the difference in payments for beneficiaries with Alzheimer's or other dementias and other beneficiaries is due to the costs associated with long-term care (nursing homes and other residential care facilities, such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid.

### Use and Costs of Care at the End of Life

Hospice care provides medical care, pain management and emotional and spiritual support for people who are dying, including people with Alzheimer's or other dementias. 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 2014, 20 percent of Medicare beneficiaries admitted to hospice had a primary diagnosis of dementia, including Alzheimer's dementia (Table 15)[419], compared with 17 percent in 2009.[420] Dementia was the second most common primary diagnosis for Medicare beneficiaries admitted to hospice overall, with cancer being the most common primary diagnosis. For all Medicare beneficiaries admitted to hospice, the average length of stay was 69 days in 2014, with 27 percent having a stay of seven or fewer days in hospice. While average length of stay for hospice beneficiaries by primary diagnosis was not publicly reported for 2014, the average length of stay was 106 days for hospice beneficiaries with a primary diagnosis of Alzheimer's dementia and 92 days for hospice beneficiaries with non-Alzheimer's dementia in 2009.[420] The average per-person hospice payment for Medicare beneficiaries with Alzheimer's dementia was $1,966 compared with $149 for all other Medicare beneficiaries.[380]

For Medicare beneficiaries with advanced dementia who receive skilled nursing facility care in the last 90 days of life, those who are enrolled in hospice are less likely to die in the hospital.[421] Additionally those enrolled in hospice care are less likely to be hospitalized in the last 30 days of life[422] and more likely to receive regular treatment for pain.[423-424] Nearly half of individuals with dementia die in hospice care.[425] Additionally, 19 percent of individuals with dementia receive hospice care in a given year, a higher percentage than for other chronic conditions.[188] Satisfaction with patient care is higher for families of individuals with dementia who are enrolled in hospice care than for those not enrolled in hospice care.[426]

*Feeding Tube Use and Care Transitions at the End of Life*
Individuals with frequent transitions between health care settings are more likely to have feeding tubes at the end of life, even though feeding tube placement has little or no benefit.[384] The odds of having a

TABLE 15

**Number of Medicare Beneficiaries Admitted to Hospice and Percentage with Dementia by State, 2014**

| State | Number of Beneficiaries | Percentage with a Primary Diagnosis of Dementia | State | Number of Beneficiaries | Percentage with a Primary Diagnosis of Dementia |
|---|---|---|---|---|---|
| Alabama | 28,051 | 21 | Montana | 4,069 | 16 |
| Alaska | 732 | 22 | Nebraska | 7,975 | 23 |
| Arizona | 34,540 | 20 | Nevada | 10,081 | 18 |
| Arkansas | 14,679 | 20 | New Hampshire | 5,256 | 21 |
| California | 120,194 | 22 | New Jersey | 32,148 | 22 |
| Colorado | 18,465 | 17 | New Mexico | 8,976 | 19 |
| Connecticut | 13,827 | 20 | New York | 45,817 | 18 |
| Delaware | 5,051 | 13 | North Carolina | 42,538 | 19 |
| District of Columbia | 1,383 | 17 | North Dakota | 2,337 | 20 |
| Florida | 114,869 | 18 | Ohio | 65,314 | 20 |
| Georgia | 42,327 | 22 | Oklahoma | 19,950 | 20 |
| Hawaii | 4,928 | 24 | Oregon | 19,214 | 19 |
| Idaho | 7,759 | 19 | Pennsylvania | 65,878 | 19 |
| Illinois | 47,766 | 20 | Rhode Island | 5,916 | 26 |
| Indiana | 29,262 | 18 | South Carolina | 27,101 | 24 |
| Iowa | 17,735 | 16 | South Dakota | 2,878 | 15 |
| Kansas | 13,655 | 20 | Tennessee | 28,025 | 20 |
| Kentucky | 16,458 | 15 | Texas | 101,161 | 23 |
| Louisiana | 21,787 | 23 | Utah | 11,014 | 18 |
| Maine | 6,442 | 20 | Vermont | 2,270 | 16 |
| Maryland | 19,577 | 18 | Virginia | 28,224 | 21 |
| Massachusetts | 26,544 | 25 | Washington | 23,635 | 21 |
| Michigan | 50,399 | 17 | West Virginia | 9,171 | 18 |
| Minnesota | 21,673 | 21 | Wisconsin | 27,688 | 19 |
| Mississippi | 15,004 | 22 | Wyoming | 1,121 | 9 |
| Missouri | 31,250 | 18 | **U.S. Total** | **1,322,114** | **20** |

Created from data from the U.S. Centers for Medicare & Medicaid Services.[419]

**TABLE 16**

Average Annual Per-Person Payments by Type of Service and Race/Ethnicity for Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, 2014, in 2016 Dollars

| | Total Medicare Payments per Person | Hospital Care | Physician Care | Skilled Nursing Facility Care | Home Health Care | Hospice Care |
|---|---|---|---|---|---|---|
| White | $19,734 | $5,163 | $1,611 | $3,367 | $1,695 | $3,128 |
| African-American | 26,686 | 8,690 | 2,185 | 4,174 | 2,072 | 2,316 |
| Hispanic | 21,151 | 6,986 | 1,900 | 3,209 | 1,787 | 1,724 |
| Other | 25,675 | 7,858 | 2,137 | 3,362 | 3,671 | 2,549 |

Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.[188]

feeding tube inserted at the end of life vary across the country and are not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender. Researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. By contrast, feeding tube use was lower among people with dementia whose care was managed by a general practitioner.[427-428] With the expansion of Medicare-supported hospice care, the use of feeding tubes in the last 90 days of life has decreased for individuals with Alzheimer's or other dementias.[429] Finally, with the increased focus on the lack of evidence supporting feeding tube use for people with advanced dementia, the proportion of nursing home residents receiving a feeding tube in the prior 12 months has decreased from nearly 12 percent in 2000 to less than 6 percent in 2014.[428]

Studies have demonstrated a decrease in the proportion of individuals with Alzheimer's dementia who die in an acute care hospital, with end-of-life care shifting to home and nursing homes.[425] 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). Similarly, expansion of hospice care is also associated with fewer individuals with

dementia having more than two hospitalizations for any reason or more than one hospitalization for pneumonia, urinary tract infection, dehydration or sepsis in the last 90 days of life.[429]
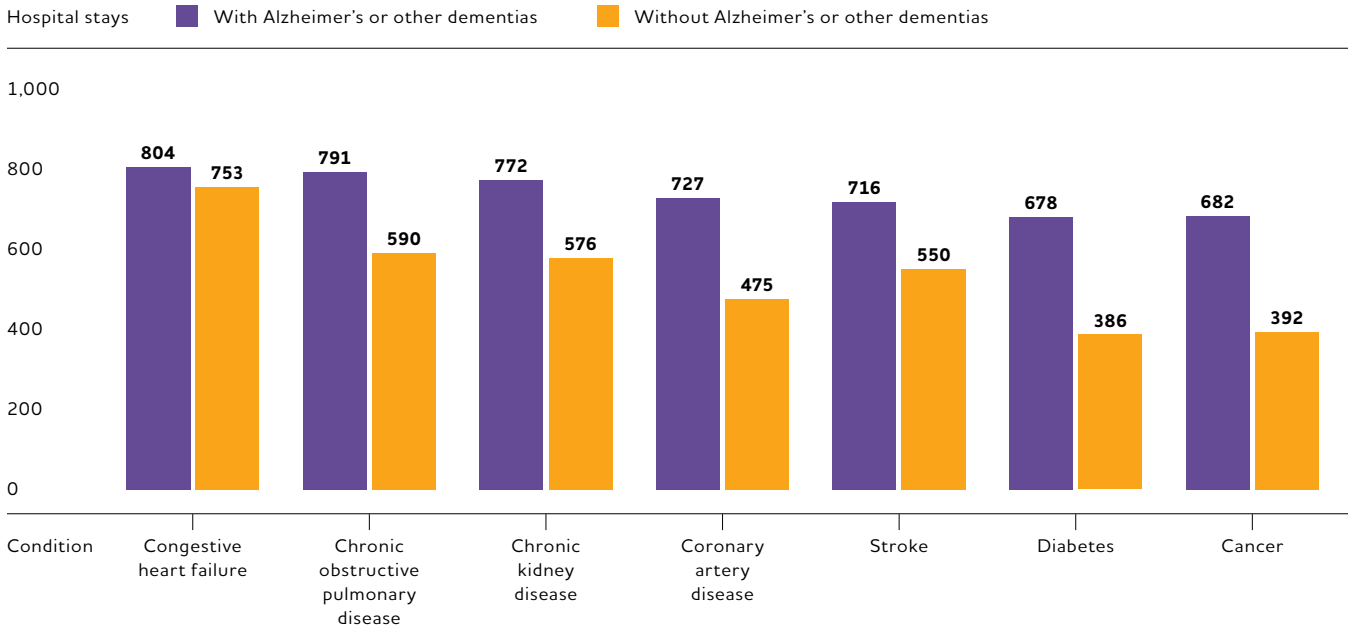
## Use and Costs of Health and Long-Term Care Services by Race/Ethnicity

Among Medicare beneficiaries with Alzheimer's or other dementias, African-Americans had the highest Medicare payments per person, while whites had the lowest spending ($26,686 versus $19,734) (Table 16). The largest difference in spending is for hospital care, for which African-Americans spend 1.7 times more than whites ($8,690 versus $5,163).[188]

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's dementia that included both Medicaid and Medicare claims data, researchers found significant differences in the costs of care by race/ethnicity.[430] These results demonstrated that African-Americans had significantly higher costs of care than whites or Hispanics, primarily due to more inpatient care and more comorbidities. These differences may be attributable to later-stage diagnosis, which may lead to higher levels of disability while receiving care; delays in accessing timely primary care; lack of care coordination; and duplication of services across providers. However, more research is needed to understand the reasons for this health care disparity.

**FIGURE 13**

Hospital Stays per 1,000 Medicare Beneficiaries Age 65 and Older with Specified
Coexisting Medical Conditions, with and without Alzheimer's or Other Dementias, 2014

Hospital stays ■ With Alzheimer's or other dementias ■ Without Alzheimer's or other dementias



Created from unpublished data from the National 5% Sample Medicare Fee-for-Service Beneficiaries for 2014.[188]

## Avoidable Use of Health Care and Long-Term Care Services

### Preventable Hospitalizations

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to or quality of preventive and primary care. Based on data from the 2006 to 2008 Health and Retirement Study and from Medicare, preventable hospitalizations represented 25 percent of the total hospitalizations for individuals with Alzheimer's or other dementias.[431] 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 from Medicare, after controlling for demographic characteristics, clinical characteristics and health risk factors, individuals with dementia had a 1.3 times greater risk and individuals

with depression and dementia had a 1.7 times greater risk of having a preventable hospitalization than those without dementia, cognitive impairment without dementia or depression.[432] 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 or other dementias by 10 percent by 2020.[431]

Medicare beneficiaries who have Alzheimer's or other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Figure 13).[188] One research team found that individuals hospitalized with heart failure are more likely to be readmitted or die after hospital discharge if they also have cognitive impairment.[433] Another research team found that Medicare beneficiaries with Alzheimer's or other dementias have more potentially

avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting.[434]

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.[435] For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

### Initiatives to Reduce Avoidable Health Care and Nursing Home Use

Recent research has demonstrated that two types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other focusing on the care delivery team. The Caregiving section (see pages 32-45) describes caregiver support programs that have promise for reducing unnecessary emergency department visits and hospitalizations and reducing transitions to residential care for individuals with Alzheimer's or other dementias. Additionally, collaborative care models — models that include not only geriatricians, but also social workers, nurses and medical assistants — can improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits.[373] For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by $3,474 in 2012 dollars ($3,871 in 2016 dollars) over a year for individuals with memory problems compared with others whose care was overseen by a primary care provider only.[373] 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 ($689 in 2016 dollars) — a nearly 6-to-1 return on investment.

Another group of researchers found that individuals with dementia whose care was concentrated within a smaller number of clinicians had fewer hospitalizations and emergency department visits and lower health care spending overall, compared with individuals whose care was more dispersed across a larger number of clinicians.[436] More research is needed to understand whether continuity of care is a strategy for decreasing unnecessary health care use for people with Alzheimer's or other dementias.

### Projections for the Future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's or other dementias are projected to increase from $259 billion in 2017 to more than $1.1 trillion in 2050 (in 2017 dollars). This dramatic rise includes more than four-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.[A21]

# SPECIAL REPORT — ALZHEIMER'S DISEASE: THE NEXT FRONTIER

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In the history of medicine, one means to progress is when we make the decision that our assumptions and definitions of disease are no longer consistent with the scientific evidence, and no longer serve our health care needs. The arc of scientific progress is now requiring a change in how we diagnose Alzheimer's disease. Both the National Institute on Aging – Alzheimer's Association (NIA-AA) 2011 workgroup and the International Work Group (IWG) have proposed guidelines that use detectable measures of biological changes in the brain, commonly known as biological markers, or biomarkers, as part of the diagnosis. This Special Report examines how the development and validation of Alzheimer's disease biomarkers — including those detectable in the blood or cerebral spinal fluid, or through neuroimaging — is a top research priority, and how this has the potential to markedly change how we diagnose Alzheimer's disease and, as a result, how we count the number of people with this disease. As research advances a biomarker-based method for diagnosis and treatment at the earliest stages of Alzheimer's disease, we envision a future in which Alzheimer's disease is placed in the same category as other chronic diseases, such as cardiovascular disease or diabetes, which can be readily identified with biomarkers and treated before irrevocable disability occurs.

## Introduction

After Dr. Alois Alzheimer's 1906 case report of the disease that came to bear his name, for much of the 20th century, Alzheimer's disease was defined as an unusual cause of dementia in adults we now consider middle-aged.[1] "Senile dementia" was the diagnosis for the more common cause of dementia in individuals 65 and older. In 1976, Robert Katzman, M.D., made the case that these definitions should change.

Arguing that an age-based distinction between dementia due to Alzheimer's disease and senile dementia was neither scientifically nor medically sensible,[2] he used scientific data to conclude that the two conditions were in fact one and to call them both Alzheimer's disease. "Although further studies are clearly indicated, the fact remains that neither the clinician, the neuropathologist nor the electron microscopist can distinguish between the two disorders (Alzheimer's disease and senile dementia) except by the age of the patient."[2] His rationale was pragmatic — dementia at any age causes substantial personal, medical and economic burden.

Dr. Katzman's contribution that Alzheimer's disease was a cause of dementia across a wide age span was incorporated into diagnostic criteria published in 1984, known as the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (now known as the Alzheimer's Association) Criteria, or NINCDS-ADRDA Criteria.[3] These criteria did not include biomarkers for the diagnosis of Alzheimer's disease.

Since Dr. Katzman's time, Alzheimer's science has made notable discoveries. Using certain biomarkers, we can now distinguish between Alzheimer's disease and other causes of dementia. In this sense, the arc of scientific progress is now requiring another change in how we diagnose Alzheimer's disease. Both the National Institute on Aging – Alzheimer's Association (NIA-AA) 2011 workgroup[4-6] and the International Work Group (IWG)[7-9] have proposed guidelines that use biomarkers as part of the diagnosis. The guidelines use biomarkers

(such as brain imaging of amyloid plaques, changes in brain volume, and measures of tau and amyloid in spinal fluid) and clinical symptoms to define dementia caused by Alzheimer's disease, and also preclinical Alzheimer's and mild cognitive impairment (MCI) due to Alzheimer's.[10-19]

The science of Alzheimer's is the primary driver of this change. Drug interventions in people with Alzheimer's disease dementia have repeatedly reported negative results. Research shows points in the course of the disease when an intervention might effectively slow or even stop the disease. The Dominantly Inherited Alzheimer's Network (DIAN) study findings have shown brain changes starting 10 to 20 years before the onset of dementia symptoms in people genetically destined to get Alzheimer's disease.[20] Ongoing trials in this population are testing interventions at this pre-symptomatic point in an effort to delay or even prevent the onset of dementia symptoms. Other clinical trials (A4 Study, etc.) are testing interventions in people who do not have memory (cognitive) and thinking (functional) changes or these genes but do have measurable Alzheimer's biomarkers.[21]

The development and validation of biomarkers — including those detectable in the blood or cerebrospinal fluid, or through neuroimaging — may significantly change how we identify Alzheimer's disease and, as a result, how we estimate the number of people with this disease. This is important because Alzheimer's disease prevalence and incidence estimates are used to calculate other statistics, which are used to describe the scope of the Alzheimer's problem in the U.S., illustrate the need to combat the disease, and identify and allocate the resources needed to address it.

## Rethinking Our Assumptions About Alzheimer's Disease

The U.S. has, since 2011, charted a national plan to address Alzheimer's disease. The first of the plan's five goals is to effectively treat and prevent the disease by 2025.[22] Researchers and those who translate research into clinical practice have reached a consensus: a core strategy to achieve this goal relies on studies testing

## What are Biomarkers?

A biomarker, or biological marker, is a measurable indicator of some biological state or condition in the human body. Clinicians use biomarkers to diagnose the presence or absence of disease, assess the risk of developing a disease, or understand how a patient has responded to a treatment. For example, a high blood glucose level (blood sugar) may be diagnostic of diabetes and lowering that level can indicate the success of a prescribed diet or medication.

Researchers are investigating several promising biomarkers for Alzheimer's disease. These include, but are not limited to, the amount of accumulation of the proteins beta-amyloid and tau in the brain. These proteins can be measured using brain imaging or the levels in cerebrospinal fluid and blood. Another kind of biomarker is changes in brain size and activity.

Identifying and then validating biomarkers for Alzheimer's is critical. They will facilitate early diagnosis and treatment. Many researchers believe that early intervention — either at the mild cognitive impairment (MCI) stage or even before symptoms appear — offers the best chance of slowing or stopping the progression of Alzheimer's disease and therefore the best chance of preserving brain function.

Biomarkers also have an important role in the discovery of treatments. They enable researchers to identify which individuals to enroll in clinical trials to test new therapies. Biomarkers allow researchers to enroll those individuals with the brain changes that treatments target. (It's important to note that the most effective biomarker test or combination of tests may differ depending on the stage of the disease and other factors.) Biomarkers also allow researchers to monitor the effects of these treatments. The more a change in a biomarker maps onto the health of the patient, the better that biomarker is to assess whether a treatment is effective.

Research on new strategies for earlier diagnosis, including ongoing efforts to identify and validate biomarkers for Alzheimer's disease, is among the most active areas in Alzheimer's science.

drugs in persons who have biomarker confirmation of the presence of Alzheimer's disease.[23] Studies such as the A4 Study discussed above, as well as trials in persons with Alzheimer's disease dementia, are enrolling persons who have these biomarkers.[24,25]

This strategy aligns with approaches taken with other common diseases of aging, such as cardiovascular disease. Clinicians use measures of biological change, such as elevated levels of blood pressure or cholesterol, to diagnose and treat individuals. Their goal is to prevent the person from suffering another heart attack or worsening heart failure, or to prevent these problems from happening in the first place. Someday, clinicians may have a similar strategy to diagnose and treat Alzheimer's disease. They may use biological measures (biomarker-based) to diagnose and then prescribe treatments to these persons, treatments that trials have shown to either slow cognitive and functional decline or even prevent the onset of symptoms of dementia.

Alzheimer's related brain changes — amyloid plaques and tau tangles among others — contribute to the cognitive impairment observed in dementia due to Alzheimer's.[26-29] A clinically effective intervention that targets these brain changes will help to validate the disease as a continuum that begins before cognitive decline. This confirmation will change how we identify (and therefore estimate) individuals with Alzheimer's disease. It will alter the prevalence and incidence of the disease, just as the treatment of vascular disease has altered the prevalence of dementia among individuals with primarily vascular lesions.[30,31] As these events unfold, they compel us to plan for a future when Alzheimer's disease is defined using biomarkers alone, not symptoms. (See pages 67-68, "Determining the Incidence and Prevalence of Alzheimer's Disease.")

## The Evolving Diagnosis of Alzheimer's Disease

Current methods of diagnosis do not conform to what we know about the disease. The 1984 NINCDS-ADRDA criteria for Alzheimer's disease defined it as a clinical disease caused by underlying brain changes.[3] The assumption was that an individual with an amnestic dementia would have Alzheimer's-related brain changes, namely amyloid plaques and tau neurofibrillary tangles, if the individual came to autopsy. Conversely, individuals without amnestic dementia would not have plaques or tangles at autopsy. This definition of Alzheimer's intertwines the signs and symptoms of dementia and the underlying brain changes.[3]

In the years that followed the adoption of those criteria, studies suggested that the clinical symptoms and underlying brain changes do not always align. Autopsy studies found that 10-30 percent of individuals who met NINCDS-ADRDA criteria for Alzheimer's disease did not have significant Alzheimer's-related brain changes (i.e., plaques and/or tangles). Instead, they had other (non-Alzheimer's) brain changes at autopsy.[32] Often Alzheimer's was mixed with non-Alzheimer's brain changes, such as cerebral infarctions or Lewy body disease, particularly in older individuals.[26,27,33] Furthermore, autopsy studies in individuals who were cognitively normal for their age found that roughly 30 percent had Alzheimer's-related brain changes at death.[34-36]

Over the past roughly two decades, biomarkers of Alzheimer's disease-related brain changes continued to be developed. They fit into two classes: (1) brain imaging of amyloid and tau buildup, and of brain volume and brain metabolism changes, and (2) measures of relevant proteins in spinal fluid.[10-19] These biomarkers illustrate or represent the presence of amyloid plaques, tau tangles and brain cell death or injury.[37] Studies have validated that biomarkers are indeed reliable measures of the relevant disease-related changes in the living brain.[38-44] These studies, like autopsy studies, also demonstrated that roughly one-third of individuals who meet NINCDS–ADRDA criteria for Alzheimer's disease do not have the required brain changes (and thus do not have Alzheimer's disease).[43-46] In addition, studies showed that roughly one-third of clinically normal older individuals do have Alzheimer's-related brain changes without the clinical symptoms.[43-45,47,48]

Recognizing the potential for biomarkers, both the NIA-AA and the IWG have proposed that, when used alongside clinical criteria, biomarkers can increase the confidence that a diagnosis of dementia is or is not due to Alzheimer's disease.[4-9,49] Importantly, the NIA-AA also proposed that biomarkers could identify MCI as due either to Alzheimer's (called MCI due to Alzheimer's disease) or to other diseases.[5] The equivalent term for biomarker-positive individuals with MCI is prodromal Alzheimer's disease in the IWG criteria.

Further, the NIA-AA proposed that cognitively normal individuals with abnormal Alzheimer's biomarkers have preclinical Alzheimer's disease. If this is validated, then individuals who have no cognitive impairment but have Alzheimer's biomarkers have Alzheimer's disease.[4]

A biomarker-based diagnosis of Alzheimer's disease — one based on brain changes, not cognitive or functional changes — will change the incidence and prevalence of Alzheimer's.

## The Prevalence and Incidence of Alzheimer's Disease in a New Era of Research

Today, we understand that Alzheimer's disease exists as a continuum beginning with a phase that may only be detectable through biomarkers, moving through the dementia stage. In the future, a biomarker-based diagnosis of Alzheimer's disease will impact the estimates of incidence and prevalence of Alzheimer's. It will add a population of individuals who are currently not included in estimates (people with Alzheimer's biomarkers but no dementia) and remove a population that currently is included (people with dementia but no Alzheimer's biomarkers).

The Alzheimer's Association *2017 Alzheimer's Disease Facts and Figures* reports the prevalence and incidence of Alzheimer's in the U.S. Among individuals age 65 and older, the prevalence in 2017 is estimated to be 5.3 million (one in 10 people age 65 and older or 10 percent have Alzheimer's dementia), and 480,000 people age 65 or older will develop Alzheimer's dementia in the U.S. in 2017 (further information can be found on pages 18-25).

Epidemiologists, demographers and biostatisticians will use these prevalence and incidence estimates to calculate other statistics, such as the numbers of people providing care and support for someone with the disease, the costs of care, and mortality. Clinicians, policy makers and organizations use these statistics to describe the size of the Alzheimer's problem in the U.S., to demonstrate the need to combat the disease, and to identify the resources needed to address it.

Validated Alzheimer's disease biomarkers will transform how study results are interpreted and change the messages and terms professionals and society use to talk about who has Alzheimer's disease and how big of a problem the disease poses.

To accurately answer the question, "What is the true prevalence and incidence of Alzheimer's disease?" we have to identify Alzheimer's disease in a way that is grounded in current science and makes sense to individuals, families, clinicians, researchers and health care policymakers. Looking ahead, a biologically-based Alzheimer's disease diagnosis will yield different prevalence and incidence figures than a diagnosis that uses only the severity of cognitive or functional impairment (either using *DSM* or NINCDS-ADRDA criteria). It will exclude individuals who have dementia but do not have the Alzheimer's biomarkers and thus do not have Alzheimer's disease. On the other hand, it will include individuals with MCI who have Alzheimer's biomarkers and therefore have Alzheimer's disease, a proportion that may, according to existing studies, be as high as 56 percent of persons with a diagnosis of MCI.[50,51] Even further in the future and with more research, it will also include people who do not have cognitive impairment but have Alzheimer's disease biomarkers.

Epidemiologic and related natural history studies that measure cognition in older adults and that want to estimate the prevalence and incidence of Alzheimer's disease will need to gather biomarker data from their participants. We should expect that these study results will further disrupt our understanding of the causes and trajectories of cognitive impairment. Studies that do not use these measures will not be able to accurately

report the prevalence and incidence of Alzheimer's disease. (They can report on the clinical severity of cognitive impairment in a population using constructs such as dementia or mild cognitive impairment.)

It is possible that these biomarker measures will add to the burdens and risks encountered by research participants. This, in turn, may hinder study recruitment, retention and accessibility. Studies to assess why individuals might refuse to undergo biomarker measures, test interventions to change that decision, and discover messaging that motivates the intention to undergo biomarker testing will be essential to address this problem. Studies will likely benefit from collaborations among epidemiologists, bioethicists, clinicians, biomarker scientists and decision-scientists who interpret data and help make public health recommendations.

## Conclusion

Even with scientific progress, a common question from the public has been, "What's the difference between Alzheimer's disease and dementia?" The NINCDS-ADRDA diagnostic criteria of 1984 aimed to help answer that question.[3] Alzheimer's disease is the most frequent cause of the dementia syndrome.

As dementia science has progressed, biomarker-based data have advanced our understanding of who has Alzheimer's disease as well as contributed to a more accurate clinical diagnosis of who has dementia due to Alzheimer's. Biomarker-based clinical criteria and future clinical trial data will continue to change our understanding of who has Alzheimer's disease, as improved diagnostic techniques will provide earlier identification of cognitive impairment, and of the brain changes that lead to it.

As with cardiovascular disease, we must care not just about those who have had a disease manifesting event, such as a heart attack, but everyone who has cardiovascular disease-related biological changes that precede the heart attack. All of these individuals represent the societal burden of cardiovascular disease.

Similarly, although we have known for years about the occurrence of dementia due to Alzheimer's, as a result of the recent use of biomarkers in studies, we have learned that a proportion of people previously thought to have cognitive impairment caused by Alzheimer's disease lack those biomarkers. The diagnosis of Alzheimer's disease will come to include the full spectrum of persons with Alzheimer's biomarkers, those who are symptomatic — with either dementia or MCI — and those who are still asymptomatic but have preclinical Alzheimer's disease. All individuals with biomarkers of Alzheimer's disease, including those with and without dementia symptoms, will represent the full disease burden.

Additional research and development of guidelines for the future use of biomarkers is urgently needed to optimize therapeutic strategies for this potentially much larger population of people with Alzheimer's disease. Successful validation of biomarkers will bring our definition of Alzheimer's disease in line with the remarkable advances we have seen in Alzheimer's research over the past decade. This latest research is now allowing us to envision a future in which Alzheimer's is no longer a disease leading to irrevocable cognitive and functional decline and death, but rather a chronic condition like cardiovascular disease, AIDS or some cancers that can often be managed with early intervention.

# Determining the Incidence and Prevalence of Alzheimer's Disease

Counting the incidence or prevalence of Alzheimer's disease or dementia due to Alzheimer's is complex. In the absence of registries akin to cancer registries or routine disease monitoring systems used to track infectious diseases, investigators must make a series of assumptions. These assumptions mean we are not so much counting as we are estimating the prevalence and incidence of Alzheimer's disease. Below, we review these assumptions, and why studies have arrived at different estimates.

The process begins with identifying a study population, usually a cohort of individuals in a given region. It could also be a representative sample in various regions. Next, investigators select a strategy to identify the cases of dementia due to Alzheimer's disease in that given population. Some studies have used a two-phase strategy that starts with a brief cognitive test administered to the total group of participants to identify potential cases (known as the screening phase of the survey), who are then more fully evaluated using the Alzheimer's disease diagnostic criteria.[52-56] Other studies fully evaluate a random sub-group from the total participants; still others fully evaluate the entire participating group.

A crucial methodological step to identify the individuals with Alzheimer's disease is the choice of diagnostic criteria that will be used in the study. Historically, studies have used a clinical diagnosis of the disease — that is, they counted people who had signs and symptoms of dementia. They have not included biomarkers as part of the criteria for the disease, nor have they excluded people with signs and symptoms of dementia but no biomarkers for Alzheimer's disease.

In most cases, the onset of dementia or dementia caused by Alzheimer's disease is gradual. It is therefore difficult in the early stages of the disease to assign a diagnosis of dementia. Consequently, investigators using brief cognitive tests face the error of mistakenly diagnosing someone as cognitively normal, and therefore without the disease, when in fact, the person is not normal; in other words, the error of false negatives, which can lead to an underestimate of prevalence and incidence. More recent studies, therefore, have abandoned brief screening tests. Instead, they either fully examine all participants in the sample or they fully examine a random sample of the study population.[54-56] Each of the design choices described above creates variability in who is selected for evaluation and, hence, as studies differ in these choices, there is variability in their respective prevalence estimates.

The Alzheimer's Association uses estimates for the prevalence and incidence of Alzheimer's disease modeled by the Chicago Health and Aging Project at Rush University Medical Center, called CHAP.[57,58] CHAP is a longitudinal, population-based study in a geographically defined area of Chicago with significant population diversity. It began in 1993 with a census of individuals age 65 or older using in-home interview and random sampling of participants for clinical evaluation for dementia due to Alzheimer's.[57]

CHAP researchers identify an individual living with Alzheimer's disease by detecting cognitive decline that then triggers a clinical assessment. The clinician uses the 1984 NINCDS-ADRDA criteria for the clinical diagnosis of Alzheimer's disease to determine if the dementia is caused

by Alzheimer's disease.[3] These criteria focus on dementia assessed by an interview with the participant and an informant, usually their partner or child (if available), and cognitive testing.[3]

CHAP uses newly diagnosed cases of Alzheimer's — incidence — to determine the prevalence. This is a notable feature. It minimizes missing cases of the disease whose symptoms are mild or even very mild.[57-59] Evaluation is repeated in 3-year cycles. Calculations of national and state-by-state prevalence figures as well as estimates of future prevalence are extrapolated from the CHAP data and incorporate age, sex and race: (1) risk of developing dementia due to Alzheimer's, (2) increased risk of mortality among those with dementia due to Alzheimer's, (3) U.S. mortality rates, (4) U.S. education levels, and (5) U.S. current and projected total population.[30] Since their first publication in 2003, CHAP produced updated estimates of prevalence in 2013 utilizing 2010 U.S. Bureau of Census population information.[58] The Association's *2017 Alzheimer's Disease Facts and Figures* prevalence estimates are reported from these data for U.S. residents age 65 or over.

Other U.S. based studies have measured either the prevalence or incidence of dementia. Two of note are the Health and Retirement Study-Alzheimer's Disease and Memory Study (HRS-ADAMS) — a nationally representative sample[30,60] — and the Framingham Heart Study (FHS) — a study of all-cause dementia over time in Framingham, Massachusetts.[61] HRS-ADAMS and FHS have consistently reported estimates that are lower than CHAP estimates.[30,60-62]

At a 2009 conference convened by the NIA and the Alzheimer's Association, researchers concluded that these discrepancies were mainly due to differences in diagnostic criteria, differences that reflect the study's different goals.[59] HRS-ADAMS defines a case using the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) criteria for dementia, incorporating impairments in both cognition and function.[59,63] In addition, people exhibiting the symptoms of Alzheimer's disease are not counted as having Alzheimer's if they are determined to have vascular dementia. HRS-ADAMS focuses on the severity of disability, not the precision of the diagnosis of Alzheimer's disease, which is the goal of CHAP.[57, 60, 62] The Framingham Heart Study uses DSM criteria for dementia and the NINCDS-ADRDA criteria, an approach that achieves the goal of determining if a case of dementia is caused by Alzheimer's.[61]

The estimates from each of these studies are often discussed as different numbers measuring the same thing, a conclusion that destabilizes confidence that we can talk coherently about the prevalence of Alzheimer's disease. They are in fact different numbers because they are measuring different things in different populations using different means of identifying individuals with all-cause dementia and/or dementia due to Alzheimer's.[59] None of the studies referenced above used biomarkers in their estimates; inclusion of biomarkers would markedly alter estimates of the prevalence and incidence of Alzheimer's disease.

As research advances a biomarker-based strategy for detection and treatment at the earliest stages of Alzheimer's disease, ever more accurate estimates of the number of persons affected will be needed to understand the full extent of that burden. These estimates will very likely be greater than current estimates and will require appropriate, modernized research and public health strategies.

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# End Notes

A1. Six drugs approved by the U.S. Food and Drug Administration (FDA): The FDA has approved six drugs to alleviate symptoms of Alzheimer's dementia: 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.

A2. Number of Americans age 65 and older with Alzheimer's dementia for 2017 (prevalence of Alzheimer's in 2017): The number 5.3 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.[31]

A3. Proportion of Americans age 65 and older with Alzheimer's dementia: The 10 percent for the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer's dementia (5.3 million) by the U.S. population age 65 and older in 2017, as projected by the U.S. Census Bureau (51.1 million) = approximately 10 percent.[437] Please note that the proportion of Americans age 65 and older with Alzheimer's dementia has gone down slightly in recent years despite the number of Americans with Alzheimer's dementia in this age range going up; this is because of the large number of baby boomers who have started to enter this age range and increased the overall number of seniors, but at the early low risk years in this range.[206]

A4. Percentage of total Alzheimer's dementia cases by age groups: Percentages for each age group are based on the estimated 200,000 people under 65,[31] plus the estimated numbers for people ages 65 to 74 (0.9 million), 75 to 84 (2.4 million), and 85+ (2.1 million) based on prevalence estimates for each age group and incidence data from the CHAP study. Prevalence numbers for age groups do not total 5.5 million due to rounding.

A5. Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence: ADAMS estimated the prevalence of Alzheimer's dementia to be lower than CHAP, at 2.3 million Americans age 71 and older in 2002,[138] while the CHAP estimate for 2000 was 4.5 million.[207] 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.[139] Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,[6] the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's dementia in the United States.

A6. Number of women and men age 65 and older with Alzheimer's dementia in the United States: The estimates for the number of U.S. women (3.3 million) and men (2.0 million) age 65 and older with Alzheimer's in 2013 is from unpublished data from CHAP. For analytic methods, see Hebert et al.[31]

A7. Prevalence of Alzheimer's 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 or 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*.

A8. State-by-state prevalence of Alzheimer's dementia: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality.[189] Specific prevalence numbers projected for each year from 2014 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.

A9. Number of new cases of Alzheimer's dementia this year (incidence of Alzheimer's in 2017): 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[190]). The Alzheimer's Association calculated the incidence of new cases in 2017 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.7 (for the number of years from 2010 to 2017 divided by the number of years from 2010 to 2020), adding that result (25,900) to the Hebert et al. estimate for 2010 (454,000) = 479,900.[190] Rounded to the nearest thousand, this is 480,000 new cases of Alzheimer's dementia in 2017. The same technique for linear interpolation from 2010 to 2020 projections was used to calculate the number of new cases in 2017 for ages 65-74, 75-84 and 85 and older. The age group-specific Alzheimer's dementia 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 1,000 people using the total number of people per age group (e.g., 65-74, 75-84, 85+) for 2017 from population projections from the 2000 U.S. Census as the denominator.[438]

A10. Number of seconds for the development of a new case of Alzheimer's dementia: Although Alzheimer's does not present suddenly like stroke or heart attack, the rate at which new cases develop 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 (479,900)[A9] = 65.7 seconds, rounded to 66 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al.[190]) = 32.8 seconds, rounded to 33 seconds.

A11. Criteria for identifying people with Alzheimer's or other dementias in the Framingham Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.[160] Diagnosis of dementia was made according to Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than six months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.

A12. Projected number of people with Alzheimer's dementia: This figure comes from the CHAP study.[31] Other projections are somewhat lower (see, for example, Brookmeyer et al.[439]) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.[A5] Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's dementia over the coming decades.

A13. <u>Projected number of people age 65 and older with Alzheimer's dementia in 2025</u>: 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.[31]

A14. <u>Previous high and low projections of Alzheimer's dementia prevalence in 2050</u>: High and low prevalence projections for 2050 from the U.S. Census were not available for the most recent analysis of CHAP data.[31] 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.[207]

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

A16. <u>Number of family and other unpaid caregivers of people with Alzheimer's or other dementias</u>: To calculate this number, the Alzheimer's Association started with data from the BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2016. Available at: census.gov/programs-surveys/popest/data/tables.html. Accessed Jan. 4, 2017. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP.[440] 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 15.975 million Alzheimer's and dementia caregivers.

A17. <u>The 2014 Alzheimer's Association Women and Alzheimer's Poll</u>: This poll questioned a nationally representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics, 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.

A18. <u>Number of hours of unpaid care</u>: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's or other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. The number of family and other unpaid caregivers (15.975 million)[A16] was multiplied by the average hours of care per year, which totals 18.191 billion hours of care. This is slightly higher than the total resulting from multiplying 18.191 billion by 15.975 million because 15.975 is a rounded figure for the total number of caregivers.

A19. <u>Value of unpaid caregiving</u>: To calculate this number, the Alzheimer's Association used the method of Amo et al.[441] This method uses the average of the federal minimum hourly wage ($7.25 in 2016) and the mean hourly wage of home health aides ($18.05 in July 2016).[442] The average is $12.65, which was multiplied by the number of hours of unpaid care (18.191 billion) to derive the total value of unpaid care ($230.127 billion; this is slightly higher than the total resulting from multiplying $12.65 by 18.191 billion because 18.191 is a rounded number for the hours of unpaid care).

A20. <u>Higher health care costs of Alzheimer's caregivers</u>: 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'.[443] 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 BRFSS[A16] were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009,[444] inflated to 2016 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 $680. The amount of the additional cost in each state, which varied by state from a low of $501 in Utah to a high of $1,037 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state[A16] 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 $10.852 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."[445]

A21. <u>Lewin Model on Alzheimer's and dementia costs</u>: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid

estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Hebert et al[31] and included in this report (5.3 million in 2017),[A2] rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (the Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

A22. <u>All cost estimates were inflated to year 2016 dollars using the Consumer Price Index (CPI)</u>: 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.

A23. <u>Medicare Current Beneficiary Survey Report</u>: These data come from an analysis of findings from the 2011 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health.[380] The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2017 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

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

Costs from the MCBS analysis are based on responses from 2011 and reported in 2016 dollars.

A24. <u>Differences in estimated costs reported by Hurd and colleagues</u>: Hurd et al.[237] estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2017 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 and other dementias (those costs attributed only to dementia), while the per-person costs in *2017 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).

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