

# 2011 Alzheimer's Disease Facts and Figures

INCLUDES A SPECIAL REPORT ON  
EARLY DETECTION AND DIAGNOSIS

AN ESTIMATED **5.4** MILLION PEOPLE HAVE ALZHEIMER'S DISEASE

**14.9**  
MILLION UNPAID CAREGIVERS

**183** BILLION DOLLARS IN ANNUAL COSTS

## **ABOUT THIS REPORT**

*2011 Alzheimer's Disease Facts and Figures* provides a statistical resource for U.S. data related to Alzheimer's disease, the most common type of dementia, as well as other dementias. Background and context for interpretation of the data are contained in the Overview. This information includes definitions of the types of dementia and a summary of current knowledge about Alzheimer's disease. Additional sections address prevalence, mortality, caregiving and use and costs of care and services. The Special Report focuses on the benefits and challenges of early detection and diagnosis of Alzheimer's disease.

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

- Overall number of Americans with Alzheimer's disease nationally and for each state
- Proportion of women and men with Alzheimer's and other dementias
- Estimates of lifetime risk for developing Alzheimer's disease
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state, and the impact of caregiving on caregivers
- Use and costs of health care, long-term care and hospice care for people with Alzheimer's disease and other dementias
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age

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

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

The conclusions in this report reflect currently available data on Alzheimer's disease. They are the interpretations of the Alzheimer's Association.

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## OVERVIEW OF ALZHEIMER'S DISEASE

This section begins with a definition of dementia and the characteristics of specific types of dementia, followed by information on Alzheimer's disease, including symptoms, diagnosis, causes, risk factors and treatment. More detailed information on these topics is available at [www.alz.org](http://www.alz.org).

#1

ALZHEIMER'S DISEASE IS THE MOST COMMON TYPE OF DEMENTIA.

## Dementia: Definition and Specific Types

Dementia is caused by various diseases and conditions that result in damaged brain cells or connections between brain cells. When making a diagnosis of dementia, physicians commonly refer to the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.<sup>(1)</sup> To meet *DSM-IV* criteria for dementia, the following are required:

- Symptoms must include decline in memory *and* in at least one of the following cognitive abilities:
  - 1) Ability to generate coherent speech or understand spoken or written language;
  - 2) Ability to recognize or identify objects, assuming intact sensory function;
  - 3) Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and

4) Ability to think abstractly, make sound judgments and plan and carry out complex tasks.

- The decline in cognitive abilities must be severe enough to interfere with daily life.

It is important for a physician to determine the cause of memory loss or other dementia-like symptoms. Some symptoms can be reversed if they are caused by treatable conditions, such as depression, delirium, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies.

When dementia is not caused by treatable conditions, a physician must conduct further assessments to identify the form of dementia that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Table 1 provides information about the most common types of dementia.

**table 1:** Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Alzheimer's disease	<p>Most common type of dementia; accounts for an estimated 60 to 80 percent of cases.</p> <p>Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.</p> <p>Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).</p>
Vascular dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	<p>Considered the second most common type of dementia.</p> <p>Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries.</p> <p>Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.</p>
Mixed dementia	<p>Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia — most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.</p> <p>Recent studies suggest that mixed dementia is more common than previously thought.</p>

**table 1 (continued):** Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Dementia with Lewy bodies	<p>Pattern of decline may be similar to Alzheimer’s, including problems with memory and judgment as well as behavior changes.</p> <p>Alertness and severity of cognitive symptoms may fluctuate daily.</p> <p>Visual hallucinations, muscle rigidity and tremors are common.</p> <p>Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</p>
Parkinson’s disease	<p>Many people who have Parkinson’s disease (a disorder that usually involves movement problems) also develop dementia in the later stages of the disease.</p> <p>The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.</p>
Frontotemporal dementia	<p>Nerve cells in the front and side regions of the brain are especially affected.</p> <p>Typical symptoms include changes in personality and behavior and difficulty with language.</p> <p>No distinguishing microscopic abnormality is linked to all cases.</p> <p>Pick’s disease, characterized by Pick’s bodies (nerve cells containing an abnormal accumulation of fibers made of the protein tau), is one type of frontotemporal dementia.</p>
Creutzfeldt-Jakob disease	<p>Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.</p> <p>Caused by the misfolding of prion protein throughout the brain.</p> <p>Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p>
Normal pressure hydrocephalus	<p>Caused by the buildup of fluid in the brain.</p> <p>Symptoms include difficulty walking, memory loss and inability to control urination.</p> <p>Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</p>



Although Alzheimer's disease is the most common type of dementia, increasing evidence from long-term observational and autopsy studies indicates that many people with dementia have brain abnormalities associated with more than one type of dementia.<sup>(2-6)</sup>

## Alzheimer's Disease

Alzheimer's disease was first identified more than 100 years ago, but research into its symptoms, causes, risk factors and treatment has only gained momentum in the last 30 years. While research has revealed a great deal about Alzheimer's, with the exception of certain inherited forms of the disease, the cause or causes of Alzheimer's disease remain unknown.

### Symptoms of Alzheimer's Disease

Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty in remembering new information. This is because disruption of brain cell function usually begins in regions involved in forming new memories. As damage spreads, individuals experience other difficulties. The following are warning signs of Alzheimer's:

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

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

Individuals progress from mild Alzheimer's disease to moderate and severe disease at different rates. As the disease progresses, the individual's cognitive and functional abilities decline. In advanced Alzheimer's, people need help with basic activities of daily living, such as bathing, dressing, using the bathroom and eating. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on around-the-clock care. The inability in late-stage Alzheimer's disease to move around can make a person more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer's disease is ultimately fatal, and Alzheimer-related pneumonia is often the cause.

Although families generally prefer to keep the person with Alzheimer's at home as long as possible, most people with the disease eventually move into a nursing home or another residence where around-the-clock professional care is available.

### Diagnosis of Alzheimer's Disease

A diagnosis of Alzheimer's disease is most commonly made by an individual's primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. Ideally, a family member or other individual close to the patient is available to provide input. The physician also conducts cognitive tests and physical and neurologic examinations. In addition, the patient may undergo magnetic resonance imaging (MRI) scans to identify brain changes that have occurred so the physician can rule out other possible causes of cognitive decline. For more information about the diagnosis of Alzheimer's disease, see the Special Report.

### Causes of Alzheimer's Disease

The cause or causes of Alzheimer's disease are not yet known. However, most experts agree that Alzheimer's, like other common chronic diseases, probably develops as a result of multiple factors rather than a single cause.

Among the brain changes believed to contribute to the development of Alzheimer's are the accumulation of the protein beta-amyloid *outside* nerve cells (neurons) in the brain and the accumulation of the protein tau *inside* neurons. A healthy adult brain has 100 billion neurons, each with long, branching extensions. These long, branching extensions enable individual neurons to form specialized connections with other neurons. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and detected by the receiving neuron. The brain contains 100 trillion synapses. They allow signals to travel rapidly and constantly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

In Alzheimer's disease, information transfer at synapses begins to fail, the number of synapses declines and neurons eventually die. The accumulation of beta-amyloid outside these synapses is believed to interfere with neuron-to-neuron communication and contribute to cell death. Inside the neuron, abnormally high levels of tau form tangles that block the transport of nutrients and other essential molecules throughout the cell. This is also believed to contribute to cell death. Brains with advanced Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

One known cause of Alzheimer's is genetic mutation. A small percentage of Alzheimer's disease cases, probably less than 1 percent, are caused by rare genetic mutations. These mutations involve the gene for the amyloid precursor protein on chromosome 21, the gene for the presenilin 1 protein on chromosome 14 and the gene for the presenilin 2 protein on chromosome 1. Inheriting any of these genetic mutations guarantees that an individual will develop Alzheimer's disease. In such individuals, the disease tends to develop before age 65, sometimes in individuals as young as 30. These people are said to have "familial" Alzheimer's disease.

### **Risk Factors for Alzheimer's Disease**

The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most Americans with Alzheimer's disease are aged 65 or older. These individuals are said to have late-onset Alzheimer's disease. However, people younger than age 65 can also develop the disease. When Alzheimer's occurs in a person younger than 65 who does not have familial Alzheimer's disease, it is referred to as "younger-onset" or "early-onset" Alzheimer's.

Advancing age is not the only risk factor for Alzheimer's disease. The following sections describe other prominent risk factors.

#### ***Family History***

Family history is another risk factor for Alzheimer's disease. Individuals with a parent, brother or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.<sup>(7-9)</sup> Those with more than one first-degree relative with Alzheimer's are at even higher risk of developing the disease.<sup>(10)</sup> When diseases run in families, heredity (genetics), environmental factors or both may play a role.

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

A genetic factor in late-onset Alzheimer's disease is APOE-ε4. APOE-ε4 is one of three common forms (ε2, ε3 and ε4) of the APOE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the APOE gene from each parent. Those who inherit one APOE-ε4 gene have increased risk of developing Alzheimer's disease and of developing it at an earlier age than those who inherit the ε2 or ε3 forms of the APOE gene. Those who inherit two APOE-ε4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's.

### ***Mild Cognitive Impairment (MCI)***

Another established risk factor for Alzheimer's disease is MCI, a condition in which a person has problems with memory, language or another essential cognitive ability that are severe enough to be noticeable to others and show up on cognitive tests, but not severe enough to interfere with daily life. Studies indicate that as many as 10 to 20 percent of people aged 65 and older have MCI.<sup>(11-13)</sup> People whose MCI symptoms cause them enough concern to visit a physician appear to have a higher risk of developing dementia. It's estimated that as many as 15 percent of these individuals progress from MCI to dementia each year. From this estimate, nearly half of all people who have visited a physician about MCI symptoms will develop dementia in three or four years.<sup>(14)</sup> It is unclear why some people with MCI develop dementia while others do not. MCI may in some cases represent a transitional state between normal aging and the earliest symptoms of Alzheimer's.

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

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

Some data indicate that cardiovascular disease risk factors, such as high cholesterol (especially in midlife), Type 2 diabetes, high blood pressure (especially in midlife), physical inactivity, smoking and obesity, are associated with a higher risk of developing Alzheimer's and other dementias.<sup>(15-25)</sup> Unlike genetic risk factors, many of these cardiovascular disease risk factors are *modifiable* — that is, they can be changed to decrease the likelihood of developing cardiovascular disease and, possibly, the cognitive decline associated with Alzheimer's and other forms of dementia. More limited

data suggest that other modifiable factors, such as remaining mentally active and consuming a diet low in saturated fats and rich in vegetables, may support brain health.<sup>(26-27)</sup>

### ***Head Trauma and Traumatic Brain Injury***

Moderate and severe head trauma, head injury and traumatic brain injury are associated with an increased risk of Alzheimer's disease and dementia. If the head injury results in loss of consciousness or post-traumatic amnesia lasting more than 30 minutes, the injury is considered moderate; if either of these lasts more than 24 hours, the injury is considered severe. Data indicate that moderate head injuries are associated with twice the risk of developing Alzheimer's compared with no head injuries, and severe head injuries are associated with 4.5 times the risk.<sup>(28-29)</sup> These increased risks have not been shown for individuals experiencing mild head injury or any number of common mishaps such as bumping one's head while exiting a car. Groups that experience repeated head injuries, such as boxers, football players and combat veterans, may be at increased risk of dementia, late-life cognitive impairment and evidence of tau tangles (a hallmark of Alzheimer's) at autopsy.<sup>(30-35)</sup> Some studies suggest that APOE-ε4 carriers who experience moderate or severe head injury are at increased risk of developing Alzheimer's compared with APOE-ε4 carriers who do not have a history of moderate or severe head injury.<sup>(28, 36-37)</sup>

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

No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration has approved five drugs that temporarily slow worsening of symptoms for about six to 12 months. They are effective for only about half of the individuals who take them. However, researchers around the world are studying numerous treatment strategies that may have the potential to change the course of the disease. Approximately 75 to 100 experimental therapies aimed at slowing or stopping the progression of Alzheimer's are in clinical testing in human volunteers.

Researchers believe that treatments to slow or stop the progression of Alzheimer's disease and preserve brain function will be most effective when administered early in the course of the disease. The brain changes in individuals with Alzheimer's are thought to begin 10 years or more before such symptoms as memory loss appear, and this may be the period during which future Alzheimer drugs will first be given. Much research in recent years has focused on identifying biomarkers that will aid in early detection and tell physicians which patients should receive treatment during these very beginning stages of Alzheimer's. (A biomarker is a naturally occurring, measurable substance or condition that reliably indicates the presence or absence of disease or the risk of later developing a disease; for example, blood glucose levels are a biomarker of diabetes, and cholesterol levels are a biomarker of cardiovascular disease risk.)

To aid in early detection and in diagnosis of Alzheimer's disease from its earliest signs to its eventual impact on mental and physical function, in 2009 the National Institute on Aging and the Alzheimer's Association convened three workgroups to explore the need for new diagnostic criteria that better reflect the full continuum of the disease. In 2010, these workgroups proposed recommendations to update the diagnostic criteria for Alzheimer's dementia and MCI. The workgroup recommendations also include criteria for "preclinical Alzheimer's disease," a new diagnostic category representing the earliest changes that occur even before symptoms such as memory loss or the symptoms associated with MCI. All of the recommendations incorporate the use of biomarkers for diagnosis. Among the biomarkers being considered are brain volume, level of glucose metabolism in the brain, presence of beta-amyloid in the brain and levels of beta-amyloid and tau in cerebrospinal fluid.

These recommendations would currently be used *only* in research settings. Their accuracy must be confirmed in research studies before they can be used in clinical practice, such as during a visit to a physician.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for individuals with Alzheimer's and their caregivers.<sup>(38-40)</sup> Active management includes (1) appropriate use of available treatment options, (2) effective integration of coexisting conditions into the treatment plan, (3) coordination of care among physicians, other healthcare professionals and lay caregivers and (4) use of activity and support groups, adult day care programs and supportive services such as counseling.

**PREVALENCE**

Millions of Americans have Alzheimer's disease or other dementia.

1 in 8

OLDER AMERICANS HAS ALZHEIMER'S DISEASE.

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

Estimates from selected studies on the prevalence and characteristics of people with Alzheimer's and other dementias vary depending on how each study was conducted. Data from several studies are used in this section to describe the prevalence of these conditions and the proportion of people with the conditions by gender, race and ethnicity, and years of education. Data sources and study methods are described in the Appendices.

## Prevalence of Alzheimer's Disease and Other Dementias

An estimated 5.4 million Americans of all ages have Alzheimer's disease in 2011. This figure includes 5.2 million people aged 65 and older<sup>(41)</sup>, A1 and 200,000 individuals under age 65 who have younger-onset Alzheimer's.<sup>(42)</sup>

- One in eight people aged 65 and older (13 percent) has Alzheimer's disease.<sup>A2</sup>
- Nearly half of people aged 85 and older (43 percent) have Alzheimer's disease.<sup>A3</sup>
- Of those with Alzheimer's disease, an estimated 4 percent are under age 65, 6 percent are 65 to 74, 45 percent are 75 to 84, and 45 percent are 85 or older.<sup>(41)</sup>, A4

The estimated numbers for people over 65 come from the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people. Recently, the National Institute on Aging and the Alzheimer's Association convened a

conference to examine certain discrepancies among estimates from CHAP and other studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.<sup>(43)</sup> A panel of experts concluded that the discrepancies in the published estimates arose from differences in how those studies counted who had Alzheimer's disease. When the same diagnostic criteria were applied across studies, the estimates were very similar.<sup>(44)</sup>, A5

National estimates of the prevalence of all forms of dementia are not available from CHAP. Based on estimates from ADAMS, 13.9 percent of people aged 71 and older in the United States have dementia.<sup>(43)</sup> This number would be higher using the broader diagnostic criteria of CHAP.

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

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of all Americans living with Alzheimer's are women.<sup>A6</sup> Of the 5.2 million people over age 65 with Alzheimer's in the United States, 3.4 million are women and 1.8 million are men.<sup>A6</sup> Based on estimates from ADAMS, 16 percent of women aged 71 and older have Alzheimer's disease or other dementia compared with 11 percent of men.<sup>(43)</sup>, 45)

Further analyses show that the larger proportion of older women than men who have Alzheimer's disease or other dementia is primarily explained by the fact that women live longer on average than men.<sup>(45-46)</sup> Moreover, many studies of the age-specific incidence (development of new cases) of Alzheimer's disease<sup>(46-52)</sup> or any dementia<sup>(47-49, 53-54)</sup> have found no significant difference by gender. Thus, women are *not* more likely than men to develop dementia at any given age.

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

People with fewer years of education appear to be at higher risk for Alzheimer’s and other dementias than those with more years of education. Prevalence and incidence studies show that having fewer years of education is associated with a greater likelihood of having dementia<sup>(43, 55)</sup> and a greater risk of developing dementia.<sup>(48, 51, 54, 56-57)</sup>

Some researchers believe that a higher level of education provides a “cognitive reserve” that enables individuals to better compensate for changes in the brain that could result in Alzheimer’s or another dementia.<sup>(58-59)</sup> However, others believe that these differences in educational attainment and dementia risk reflect such factors as increased risk for disease in general and less access to medical care in lower socioeconomic groups.<sup>(60)</sup>

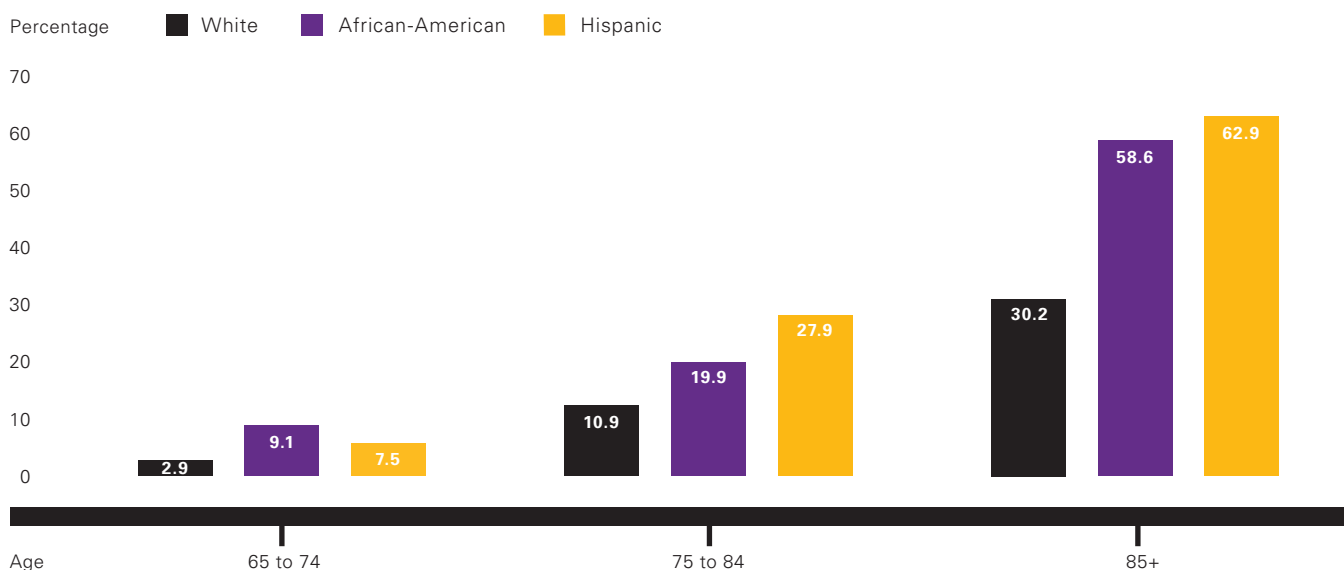
### **Prevalence of Alzheimer’s Disease and Other Dementias in Older Whites, African-Americans and Hispanics**

While most people in the United States living with Alzheimer’s and other dementias are non-Hispanic whites, older African-Americans and Hispanics are proportionately more likely than older whites to have Alzheimer’s disease and other dementias.<sup>(61-62)</sup> Data indicate that in the United States, older African-Americans are probably about twice as likely to have Alzheimer’s and other dementias as older whites,<sup>(63)</sup> and Hispanics are about one and one-half times as likely to have Alzheimer’s and other dementias as older whites.<sup>(55)</sup> Figure 1 shows the estimated prevalence for each group, by age, from the Washington Heights-Inwood Columbia Aging Project (WHICAP).

No known genetic factors can account for these prevalence differences across racial groups. Instead, health conditions such as high blood pressure and diabetes, lower levels of education and other differences in socioeconomic characteristics that are risk factors for Alzheimer’s disease and other dementias are more common in older African-Americans and Hispanics than in older whites. Some studies suggest that differences based on race and ethnicity do not persist in detailed analyses that account for these factors.<sup>(43, 48)</sup>

Prevalence studies such as WHICAP are designed so that all individuals with dementia are detected. But in the community, only about half of those with Alzheimer’s disease or other dementia receive a diagnosis.<sup>(64)</sup> There is evidence that missed diagnoses are more common among older African-Americans and Hispanics than among older whites.<sup>(65-66)</sup> For example, a 2006 study of Medicare beneficiaries found that Alzheimer’s disease or another dementia had been diagnosed in 9.6 percent of white beneficiaries, 12.7 percent of African-American beneficiaries and 14 percent of Hispanic beneficiaries.<sup>(67)</sup> Although rates of diagnosis were higher among African-Americans and Hispanics compared with whites, the difference was not as great as would be expected based on the estimated differences found in prevalence studies. This disparity is of increasing concern because the proportion of older Americans who are African-American and Hispanic is projected to grow in coming years.<sup>(68)</sup> If the current racial and ethnic disparities in diagnostic rates continue, the proportion of individuals with undiagnosed dementia will increase.

**figure 1:** Proportion of People Aged 65 and Older with Alzheimer’s Disease and Other Dementias, by Race/Ethnicity, Washington Heights-Inwood Columbia Aging Project, 2006



Created from data from Gurland et al. <sup>(65)</sup>

### Incidence and Lifetime Risk of Alzheimer’s Disease

Prevalence is the number of *existing* cases of a disease in a population at a given time. Incidence is the number of *new* cases of a disease in a given time period. The estimated annual incidence (rate of developing disease in a one-year period) of Alzheimer’s disease appears to increase dramatically with age, from approximately 53 new cases per 1,000 people aged 65 to 74, to 170 new cases per 1,000 people aged 75 to 84, to 231 new cases per 1,000 people over age 85 (the “oldest-old”).<sup>(69)</sup> Some studies have found that incidence levels off after age 90, but these findings are controversial. A recent analysis indicates that dementia incidence may continue to increase and that previous observations of an incidence plateau may be due to sparse data for the oldest-old.<sup>(70)</sup> Because of the increase in the number of people over 65 in the United States, the annual total number of new cases of Alzheimer’s and other dementias is projected to double by 2050.<sup>(69)</sup>

- Every 69 seconds, someone in America develops Alzheimer’s.<sup>A7</sup>
- By mid-century, someone in America will develop the disease every 33 seconds.<sup>A7</sup>

Lifetime risk is the probability that someone of a given age develops a condition during their remaining lifespan. Data from the original Framingham Study population was used to estimate lifetime risks of Alzheimer’s disease and of any dementia.<sup>(71), A8</sup> Starting in 1975, nearly 2,800 people from the Framingham Study who were age 65 and free of dementia were followed for up to 29 years. The study found that 65-year-old women without dementia had a 20 percent chance of developing dementia during the remainder of their lives (estimated lifetime risk), compared with a 17 percent chance for men. For Alzheimer’s, the estimated lifetime risk was nearly one in five (17.2 percent) for women compared with one in 10 (9.1 percent) for men.<sup>(71), A9</sup> Figure 2 presents lifetime risks of Alzheimer’s for men and women of specific



ages. As previously noted, these differences in lifetime risks between women and men are largely due to the longer life expectancy for women.

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

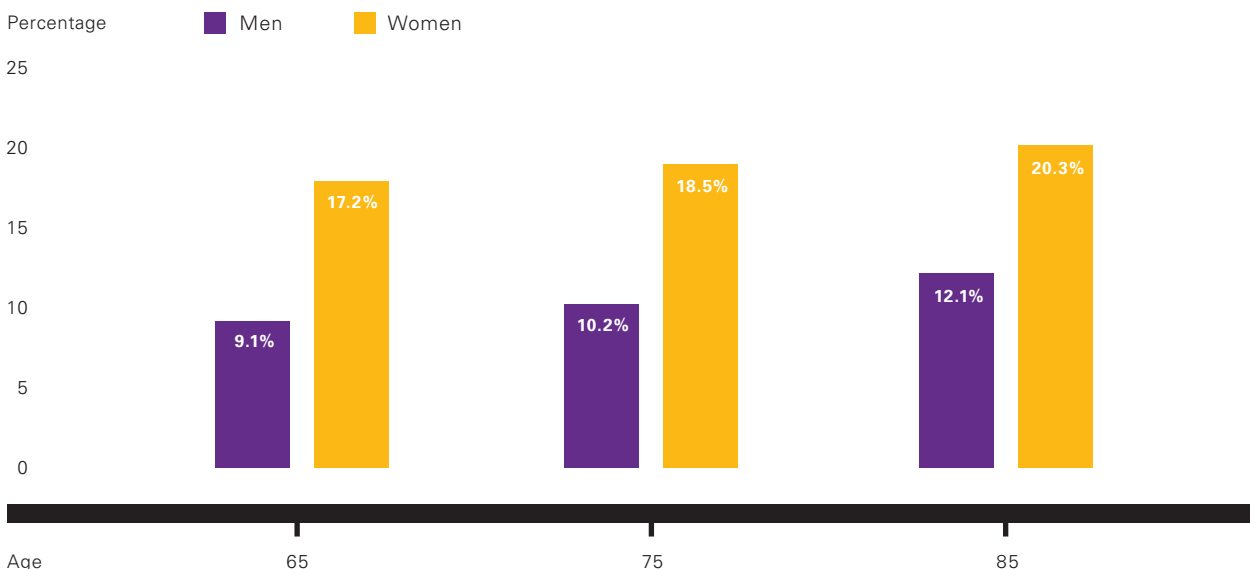
### Estimates of the Number of People with Alzheimer’s Disease, by State

Table 2 (pages 18 to 19) summarizes the projected total number of people aged 65 and older with Alzheimer’s disease by state for the years 2000, 2010 and 2025.<sup>A10</sup>

The percentage changes in the number of people with Alzheimer’s between 2000 and 2010 and between 2000 and 2025 are also shown. Note that the total number of people with Alzheimer’s will be larger for states with larger populations, such as California and New York. Comparable projections for other types of dementia are not available.

As shown in Figure 3, between 2000 and 2025 some states and regions across the country are expected to experience double-digit percentage increases in the overall numbers of people with Alzheimer’s, due to increases in the proportion of the population over age 65. The South and West are expected to experience 50 percent and greater increases in numbers of people with Alzheimer’s between 2000 and 2025. Some states (Alaska, Colorado, Idaho, Nevada, Utah and Wyoming) are projected to experience a doubling (or more) in number of people with Alzheimer’s.

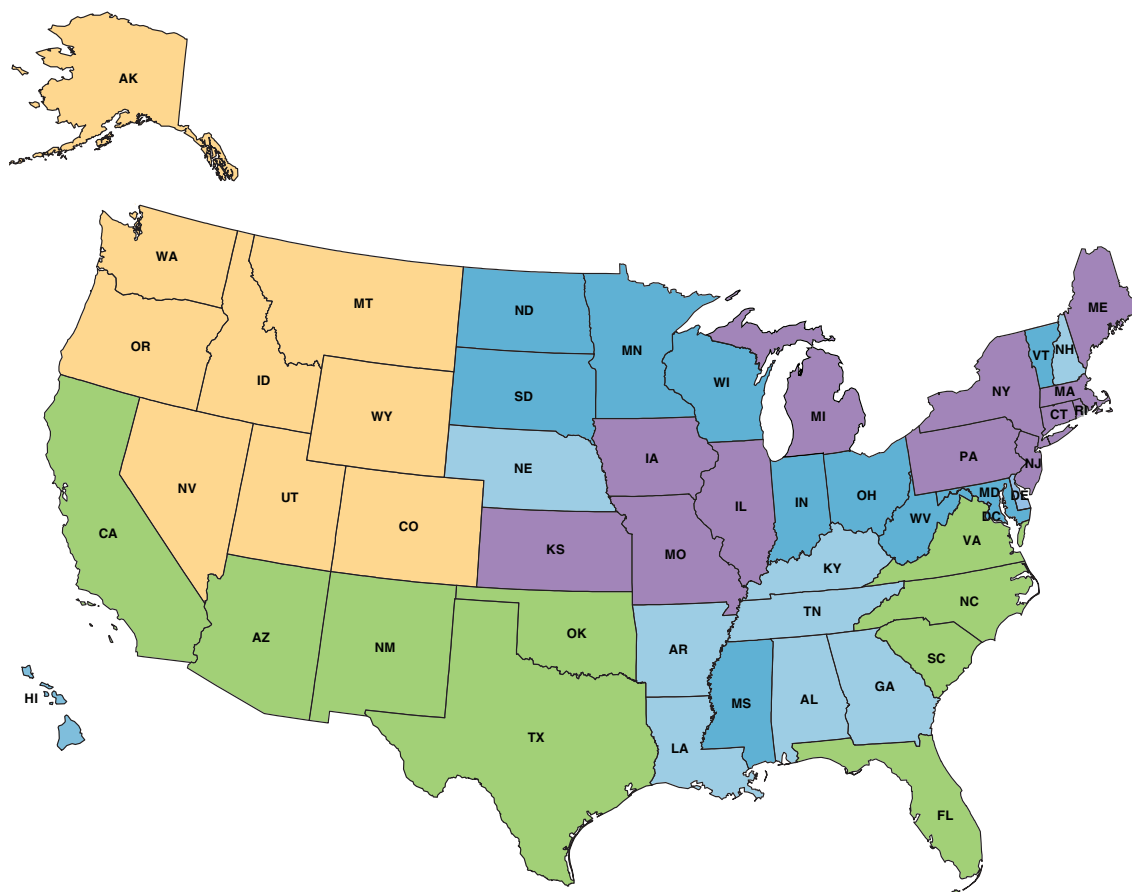
**figure 2:** Framingham Estimated Lifetime Risks for Alzheimer’s by Age and Sex



Created from data from Seshadri et al. (71)

**figure 3:** Projected Changes Between 2000 and 2025 in Alzheimer Prevalence by State

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



Created from data from Hebert et al.<sup>(72), A10</sup>

Although the projected increases in the Northeast are not nearly as marked as those in other regions of the United States, it should be noted that this section of the country currently has a large proportion of people with Alzheimer’s relative to other regions because this region already has a high proportion of people over age 65. The increasing number of people with Alzheimer’s will have a marked impact on states’ healthcare systems, not to mention families and caregivers.

### Looking to the Future

The number of Americans surviving into their 80s and 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions.<sup>(73)</sup> Additionally, a very large segment of the American population — the baby boom generation — is reaching retirement age. In fact, the first baby boomers are reaching age 65 this year.

By 2030, the segment of the U.S. population aged 65 years and older is expected to double, and the estimated 71 million older Americans will make up approximately 20 percent of the total population.<sup>(74)</sup>

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer’s disease and other dementias, as shown in Figure 4.<sup>A11</sup>

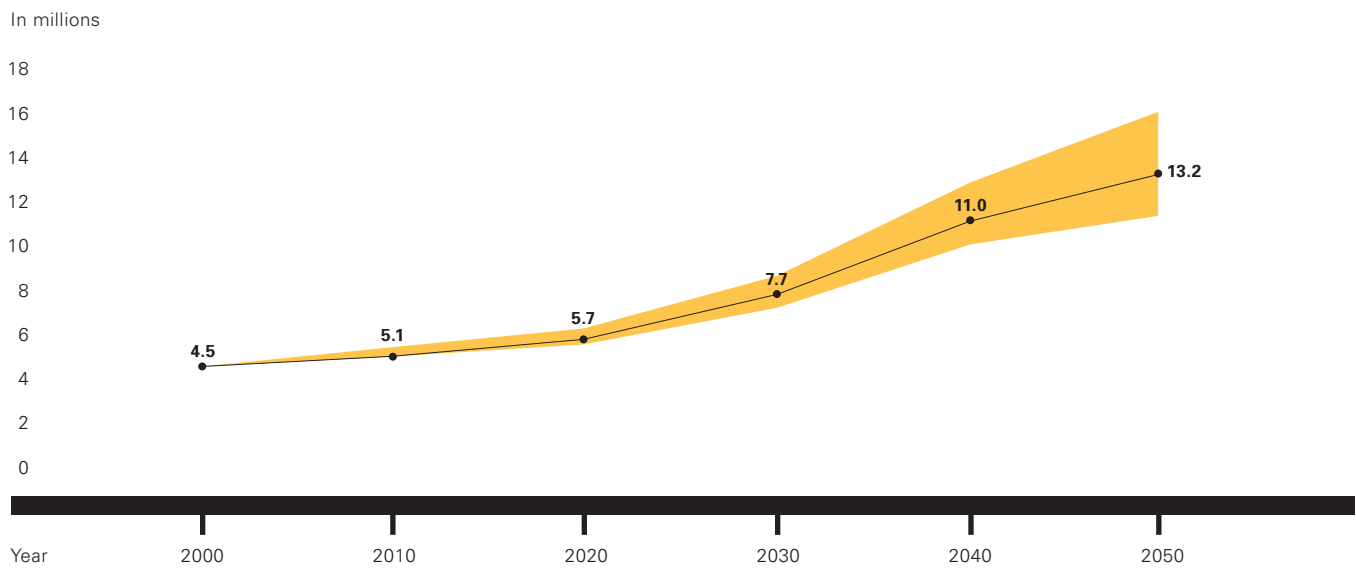
- In 2000, there were an estimated 411,000 new (incident) cases of Alzheimer’s disease. For 2010, that number was estimated to be 454,000 (a 10 percent increase); by 2030, it is projected to be 615,000 (50 percent increase from 2000); and by 2050, 959,000 (130 percent increase from 2000).<sup>(69)</sup>
- By 2030, the number of people aged 65 and older with Alzheimer’s disease is estimated to reach 7.7 million — a 50 percent increase from the 5.2 million aged 65 and older currently affected.<sup>(41)</sup>
- By 2050, the number of people aged 65 and older with Alzheimer’s disease may triple, from 5.2 million to a projected 11 to 16 million, barring the development of

medical breakthroughs to prevent or more effectively treat the disease.<sup>(41), A11</sup>

Longer life expectancies and aging baby boomers will also increase the numbers and percentages of Americans who will be among the oldest-old. Between 2010 and 2050, the oldest-old are expected to increase from 15 percent of all older people in the United States to one in every four older Americans (24 percent).<sup>(73)</sup> This will result in an additional 15 million oldest-old people — individuals at high risk for developing Alzheimer’s.<sup>(73)</sup>

- In 2010, an estimated 6 million Americans were 85 years and older; by 2050, that number will nearly quadruple to 21 million.<sup>(73)</sup>
- In 2010, the 85-years-and-older population included about 2.4 million people with Alzheimer’s disease, or 47 percent of the Alzheimer population aged 65 and older.<sup>(41)</sup>
- When the first wave of baby boomers reaches age 85 years (2031), an estimated 3.5 million people aged 85 and older will have Alzheimer’s.<sup>(41)</sup>

**figure 4:** Projected Numbers of People Aged 65 and Over in the U.S. Population with Alzheimer’s Disease (in Millions) Using the U.S. Census Bureau Estimates of Population Growth\*



\*Numbers indicate middle estimates per decade. Colored areas indicate low and high estimates per decade.

Created from data from Hebert et al 2003.<sup>(41), A11</sup>

**table 2:** Projections by State for Total Numbers of Americans Aged 65 and Older with Alzheimer's

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

**table 2 (continued)**

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

Created from data from Hebert et al.<sup>(72), A10</sup>

## MORTALITY

Alzheimer's disease is the sixth-leading cause of death across all ages in the United States.<sup>(75)</sup> It is the fifth-leading cause of death for those aged 65 and older.<sup>(75)</sup>

5th

LEADING CAUSE OF DEATH FOR THOSE 65 AND OLDER.

In 2008, based on preliminary data from the National Center for Health Statistics, Alzheimer’s was reported as the underlying cause of death for 82,476 people.<sup>(75)</sup> However, as discussed in the Special Report, Alzheimer’s disease was often not listed as an underlying cause of death in those who had the condition.<sup>(76-79)</sup> Thus, Alzheimer’s disease may be the cause of death or a contributing cause of death for even more Americans than indicated by official government data.

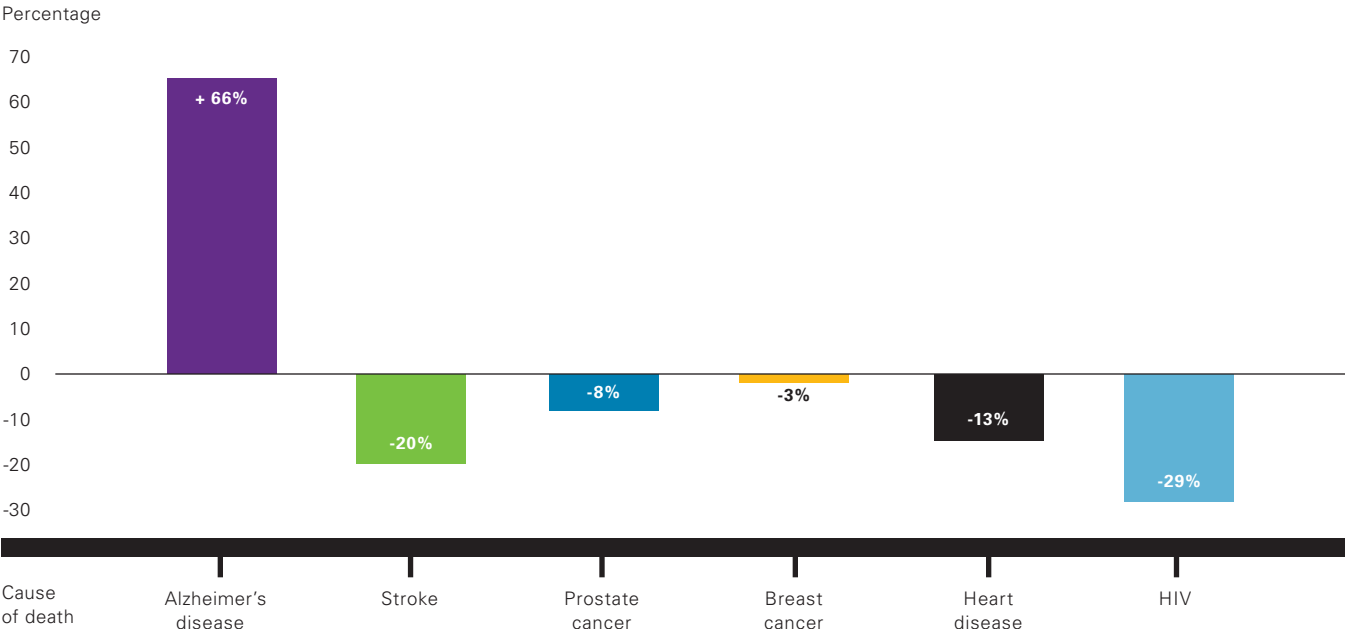
**Deaths from Alzheimer’s Disease**

Alzheimer’s is becoming a more common cause of death as the populations of the United States and other countries age. While other major causes of death continue to experience significant declines, those from Alzheimer’s disease have continued to rise. Between 2000 and 2008 (preliminary data), deaths attributed to Alzheimer’s disease increased 66 percent, while those attributed to the number one cause of death, heart disease, decreased 13 percent (Figure 5).<sup>(75,80)</sup>

The increase in the number and proportion of death certificates listing Alzheimer’s 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.

The different ways in which dementia eventually ends in death can create ambiguity about the underlying cause of death. Severe dementia frequently causes such complications as immobility, swallowing disorders and malnutrition. These complications can significantly increase the risk of developing pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with Alzheimer’s disease and other dementias. The situation has been described as a “blurred distinction between death *with* dementia and death *from* dementia.”<sup>(81)</sup> Regardless of the cause of death, 61 percent of people with Alzheimer’s at age 70 are expected to die before age 80 compared with 30 percent of people at age 70 without Alzheimer’s.<sup>(82)</sup>

**figure 5:** Percentage Changes in Selected Causes of Death (All Ages) Between 2000<sup>a</sup> and 2008<sup>b</sup>



a National Center for Health Statistics. *Deaths: Final Data for 2000*.<sup>(80)</sup>  
 b National Center for Health Statistics. *Deaths: Preliminary Data for 2008*.<sup>(75)</sup>

**table 3:** Number of Deaths and Annual Mortality Rate (per 100,000) Due to Alzheimer’s Disease by State, 2007

State	Number of Deaths	Rate	State	Number of Deaths	Rate
Alabama	1,517	32.8	Montana	260	27.1
Alaska	65	9.5	Nebraska	512	28.9
Arizona	2,051	32.4	Nevada	248	9.7
Arkansas	824	29.1	New Hampshire	418	31.8
California	8,497	23.2	New Jersey	1,823	21.0
Colorado	1,109	22.8	New Mexico	322	16.3
Connecticut	764	21.8	New York	1,999	10.4
Delaware	201	23.2	North Carolina	2,460	27.1
District of Columbia	140	23.8	North Dakota	395	61.7
Florida	4,644	25.4	Ohio	3,671	32.0
Georgia	1,849	19.4	Oklahoma	927	25.6
Hawaii	247	19.2	Oregon	1,200	32.0
Idaho	416	27.7	Pennsylvania	3,505	28.2
Illinois	2,734	21.3	Rhode Island	328	31.0
Indiana	1,663	26.2	South Carolina	1,396	31.7
Iowa	1,202	40.2	South Dakota	346	43.5
Kansas	860	31.0	Tennessee	2,276	37.0
Kentucky	1,198	28.2	Texas	4,814	20.1
Louisiana	1,324	30.8	Utah	393	14.9
Maine	470	35.7	Vermont	205	33.0
Maryland	881	15.7	Virginia	1,703	22.1
Massachusetts	1,695	26.3	Washington	2,689	41.6
Michigan	2,432	24.1	West Virginia	534	29.5
Minnesota	1,179	22.7	Wisconsin	1,658	29.6
Mississippi	797	27.3	Wyoming	110	21.0
Missouri	1,681	28.6	<b>U.S. Total</b>	<b>74,632</b>	<b>24.7</b>

Created from data from Xu et al.<sup>(63)</sup>



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

Table 3 provides information on the number of deaths due to Alzheimer’s by state in 2007. (State-by-state death data by specific cause of death were not included in the preliminary data for 2008.) The information was obtained from death certificates and reflects the underlying cause of death, as defined by the World Health Organization: “the disease or injury which initiated the train of events leading directly to death.”<sup>(83)</sup> The table also provides annual mortality rates by state in order 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 2007, the mortality rate for Alzheimer’s disease was 24.7 deaths per 100,000 people. Based on the preliminary data for 2008, the U.S. rate increased to 27.1 per 100,000.

## Death Rates by Age

Although people younger than 65 can develop and die from Alzheimer’s disease, the highest risk of death from Alzheimer’s is in people aged 65 or older. As seen in Table 4, death rates for Alzheimer’s increase dramatically with age. To put these age-related differences into perspective, in the United States in 2007 (the most recent data available), compared with people aged 65 to 74, the total mortality rates from all causes of death was 2.5 times as high for those aged 75 to 84 and 6.4 times as high for those aged 85 and older. For diseases of the heart, mortality rates were 2.8 times and 9.2 times as high, respectively. For all cancers, mortality rates were 1.8 times as high and 2.2 times as high, respectively. In contrast, Alzheimer’s disease death rates were 8.6 times as high for people aged 75 to 84 and 41.2 times as high for people 85 and older compared with people aged 65 to 74.<sup>(83)</sup> This large age-related increase in death rates due to Alzheimer’s underscores the lack of a cure or effective treatments for the disease.

**table 4:** U.S. Alzheimer Death Rates (per 100,000) by Age, 2000, 2004 and 2007

Age	2000	2004	2007
45–54	0.2	0.2	0.2
55–64	2.0	1.9	2.2
65–74	18.7	19.7	20.6
75–84	139.6	168.7	176.7
85+	667.7	818.8	849.1
Total*	17.6	22.5	24.7

\*Reflects average death rate for ages 45 and older.  
Created from data from Xu et al.<sup>(83)</sup>

## Duration of Illness from Diagnosis to Death

Studies indicate that people 65 and older survive an average of four to eight years after a diagnosis of Alzheimer’s disease, yet some live as long as 20 years with Alzheimer’s.<sup>(84-88)</sup> This indicates the slow, insidious nature of the progression of Alzheimer’s, with loss of memory and thinking abilities, as well as loss of independence over the duration of the illness. On average, a person with Alzheimer’s will spend more years (40 percent of the total number of years with Alzheimer’s) in the most severe stage of the disease than in any other stage.<sup>(82)</sup> And much of this time will be spent in a nursing home, as nursing home admission by the age of 80 is expected for 75 percent of people with Alzheimer’s compared with only 4 percent of the general population.<sup>(82)</sup> In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20 percent of cancer patients and 28 percent of people dying from all other conditions.<sup>(89)</sup> Thus, in addition to Alzheimer’s being the sixth-leading cause of death, the long duration of illness may be an equally telling statistic of the public health impact of Alzheimer’s disease.

## CAREGIVING

Nearly 15 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia.<sup>A12, A13</sup>

80%

OF CARE PROVIDED AT HOME IS DELIVERED BY FAMILY CAREGIVERS.

## Unpaid Caregivers

Unpaid caregivers are primarily family members, but they also include other relatives and friends. In 2010, they provided 17 billion hours of unpaid care, a contribution to the nation valued at over \$202 billion.

Eighty percent of care provided at home is delivered by family caregivers; fewer than 10 percent of older adults receive all of their care from paid workers.<sup>(90)</sup> Caring for a person with Alzheimer's or another dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving may also have a negative impact on the health, employment, income and financial security of caregivers.<sup>A14</sup> However, a variety of interventions have been developed that may assist individuals with the challenges of caregiving. (Table 5, page 31).

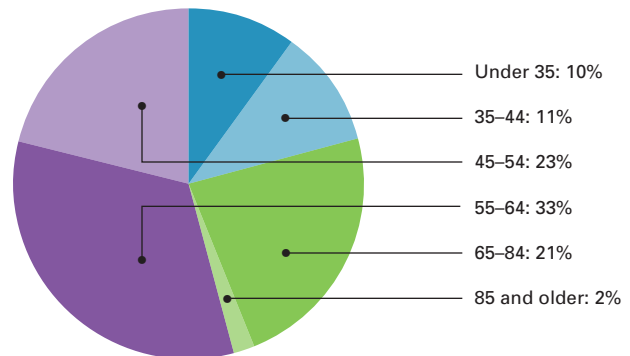
### Who are the Caregivers?

Sixty percent of family caregivers and other unpaid caregivers of people with Alzheimer's disease and other dementias are women. Most caregivers are aged 55 or older (56 percent) (Figure 6), are married (66 percent), have obtained less than a college degree (67 percent) and are white (70 percent). Over half are the primary breadwinners of the household (55 percent), and nearly half are employed full or part time (44 percent). Fifty percent of unpaid caregivers of people with Alzheimer's and other dementias live in the same household as the person for whom they provide care. Twenty-six percent of family caregivers have children under 18 years old living with them.<sup>A14</sup> These caregivers are sometimes referred to as the "sandwich generation" because they simultaneously provide care for two generations.<sup>(91-92)</sup>

### Care Provided by Ethnic Communities

In a 2010 poll conducted on behalf of the Alzheimer's Association, 70 percent of caregivers were white, 15 percent were African-American, 12 percent were Hispanic, 1 percent were Asian-American and 2 percent were from other ethnic groups.<sup>A14</sup>

**figure 6:** Ages of Alzheimer and Other Dementia Caregivers, 2010



Created from data from the Alzheimer's Association 2010 Women and Alzheimer's Poll, October 2010.<sup>A14</sup>

Other characteristics of multi-ethnic caregivers were described in a National Alliance for Caregiving (NAC)/AARP 2009 study. These African-American, Asian-American and Hispanic caregivers were 18 years of age and over and provided assistance to someone 50 years of age or older.<sup>(91)</sup>

African-American caregivers were on average older than those in other groups (48 years old). They were more likely to be single or never married (28 percent) than were caregivers overall (15 percent) or white caregivers (12 percent). Most African-American caregivers (59 percent) and Hispanic caregivers (56 percent) had an annual household income of less than \$50,000, and they were more likely to be in this income group than were caregivers overall (39 percent), white caregivers (34 percent) or Asian-American caregivers (31 percent). African-American caregivers (41 percent) were more likely to provide assistance with three or more activities of daily living (ADLs) than were white caregivers (28 percent) and Asian-American caregivers (23 percent).<sup>(91)</sup> ADLs include getting in and out of bed, bathing, dressing, feeding, getting to and from the toilet and managing incontinence.

Asian-American family caregivers were almost equally likely to be male or female. While most were married (58 percent), more Asian-American caregivers were single or never married (29 percent versus 15 percent of all caregivers and 12 percent of white caregivers). Asian-Americans were highly educated and more likely to be college graduates than were other caregiving groups (40 percent versus 26 percent of caregivers overall, 26 percent of white caregivers and 22 percent of Hispanic caregivers). Asian-Americans also had a relatively high annual income.<sup>(91)</sup>

Hispanic caregivers were an average of 43 years old and were younger than white and African-American caregivers. They were less likely to be married than were white caregivers (48 percent versus 63 percent) and more likely to have children or grandchildren under age 18 living in their household (47 percent versus 32 percent of all caregivers, 30 percent of white caregivers and 30 percent of African-American caregivers). Hispanic caregivers were more likely to be a primary caregiver (61 percent versus 48 percent of white caregivers and 43 percent of Asian-American caregivers) and more likely to report an annual income of under \$50,000 (56 percent versus 39 percent of caregivers overall, 34 percent of white caregivers and 31 percent of Asian-American caregivers). They were more likely to feel they needed help balancing their work and family responsibilities (39 percent versus 27 percent of caregivers overall and 25 percent of white caregivers) and finding time for themselves (41 percent versus 29 percent of white caregivers).<sup>(91)</sup>

### Caregiving Tasks

The type of help provided by family and other unpaid caregivers depends on the needs of the older person or person with Alzheimer's or other dementia and the stage of disease. Caregiving tasks can include:<sup>(91-92)</sup>

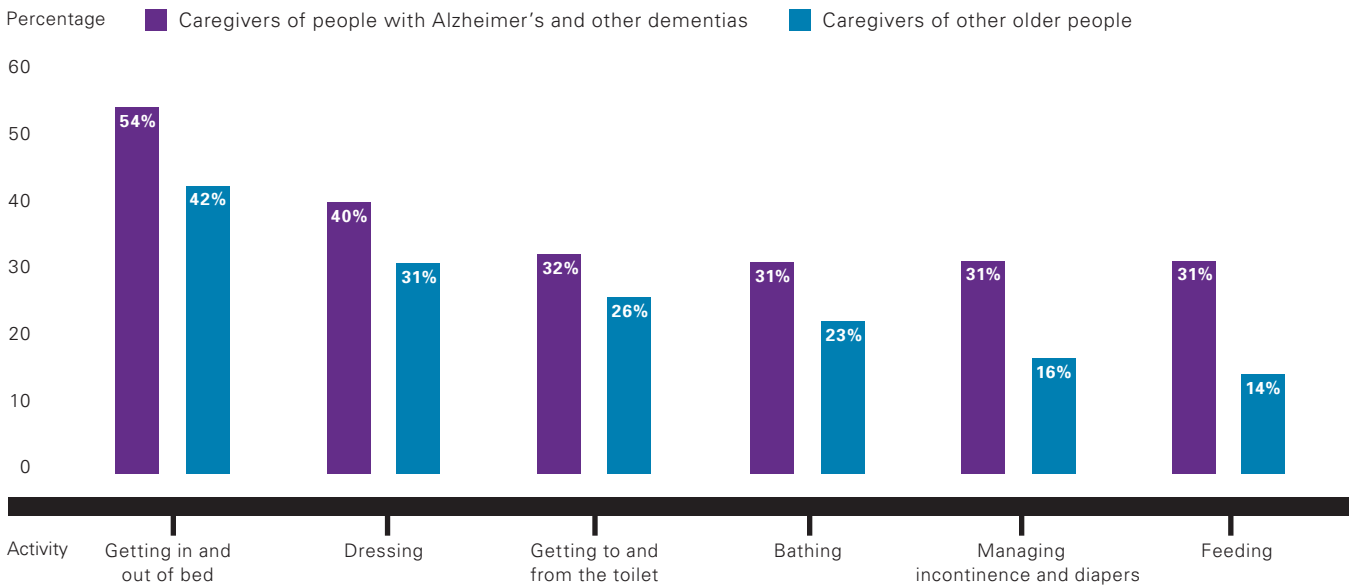
- Instrumental ADLs:
  - Shopping for groceries, preparing meals and providing transportation

- Helping the person take medications correctly and following treatment recommendations for dementia and other medical conditions
- Managing finances and legal affairs
- Personal ADLs:
  - Bathing, dressing, grooming, feeding and helping the person use the toilet or manage incontinence
- Managing safety issues and behavioral symptoms of the disease:
  - Assisting with mobility needs and transferring from bed to chair
  - Supervising the person to avoid unsafe activities such as wandering and getting lost
- Finding and using supportive services:
  - Making arrangements for medical care and paid in-home, assisted living or nursing home care
- Hiring and supervising others who provide care
- Performing household chores

Family and other unpaid caregivers of people with Alzheimer's and other dementias are more likely than caregivers of other older people to assist with all ADLs. Over half the caregivers of people with Alzheimer's and other dementias report providing help with getting in and out of bed. About one-third also provided help getting to and from the toilet, bathing, managing incontinence and feeding (Figure 7). Fewer caregivers of other older people report providing help with each of these types of care.<sup>(91)</sup>

In addition to assisting with ADLs, almost two-thirds of caregivers of people with Alzheimer's and other dementias advocate for their care recipient with government agencies and service providers (64 percent), and nearly half arrange and supervise paid caregivers from outside community agencies (46 percent). In contrast, caregivers of other older adults are less likely to advocate for their family member (50 percent) and supervise community-based care (33 percent).<sup>(91)</sup>

**figure 7:** Proportion of Caregivers of People with Alzheimer’s or Other Dementia vs. Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer’s Association by Matthew Greenwald and Associates, Nov. 11, 2009.<sup>(91)</sup>

When a person with Alzheimer’s or another dementia moves to an assisted living facility or nursing home, the help provided by his or her family caregiver usually changes. Yet many caregivers continue to assist with financial and legal affairs, make arrangements for medical care and provide emotional support. Some also continue to help with bathing, dressing and other ADLs.<sup>(93-95)</sup>

**Duration of Caregiving**

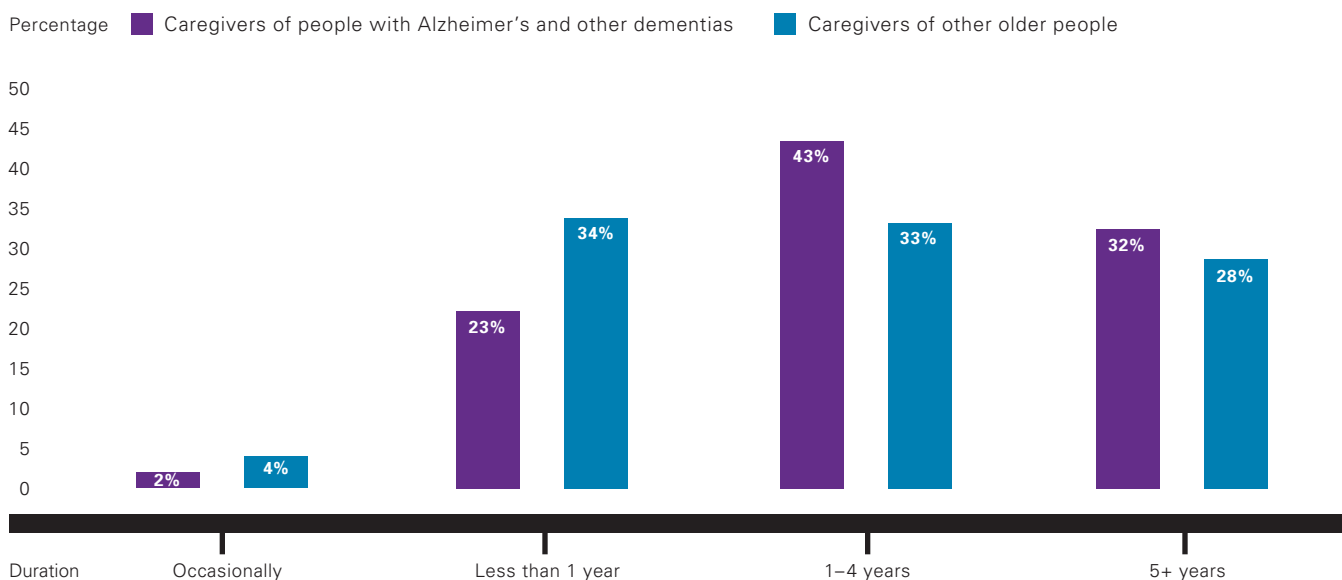
Caregivers of people with Alzheimer’s and other dementias are more likely than caregivers of other older people to provide care for a longer amount of time. They are more likely to have provided care for 1 to 4 years than are their other caregiver counterparts (43 percent versus 33 percent), and somewhat more likely to be providing care for five or more years (32 percent versus 28 percent) (Figure 8).<sup>(91)</sup>

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

In 2010, the 14.9 million family and other unpaid caregivers of people with Alzheimer’s and other dementias provided an estimated 17 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.<sup>A15</sup> With this care valued at \$11.93 per hour,<sup>A16</sup> the estimated economic value of the care provided by family and other unpaid caregivers of people with Alzheimer’s and other dementias was \$202.6 billion in 2010. Table 6 (pages 32 to 33) shows the total hours of unpaid care as well as the value of the care provided by family and other unpaid caregivers for the United States and each state.

Unpaid caregivers of people with Alzheimer’s and other dementias provided care valued at more than

**figure 8:** Proportion of Alzheimer and Dementia Caregivers vs. Caregivers of Other Older People by Duration of Caregiving, United States, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, Nov. 11, 2009.<sup>(91)</sup>

\$1 billion in each of 38 states. Unpaid caregivers in each of the nine most populous states — California, Florida, Georgia, Illinois, Michigan, New York, Ohio, Pennsylvania and Texas — provided care valued at more than \$6 billion.

Average hours per week of unpaid care provided for people with Alzheimer's and other dementias increase if the caregiver lives with the person, as the person's disease worsens and if there are coexisting medical conditions.<sup>(91, 96-98)</sup>

#### Impact of Caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. Although memory loss is the best-known symptom, these diseases also cause loss of judgment, orientation and the ability to understand and communicate effectively. Personality and behavior are affected as well. Individuals require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income

and financial security. The close relationship between the caregiver and the impaired person — a relationship involving shared emotions, experiences and memories — may particularly place caregivers at risk for psychological and physical illness.<sup>(99)</sup>

#### Caregiver Emotional Well-Being

Although caregivers report positive feelings about caregiving, including family togetherness and the satisfaction of helping others,<sup>A14</sup> they also report high levels of stress over the course of providing care, such as:

- *Emotional stress.* Sixty-one percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high (Figure 9).<sup>A14</sup> In addition, about 33 percent of family caregivers of people with Alzheimer's and other dementias report symptoms of depression.<sup>(100-101)</sup> Family caregivers of people with Alzheimer's and other dementias reported a good amount to a great deal of caregiving strain concerning financial issues (56 percent) and family relationships (53 percent).<sup>A14</sup>

- *Stress related to nursing home placement.* Caregiver stress related to the impaired person’s behavioral symptoms is often associated with nursing home placement.<sup>(100-101)</sup> However, even after caregivers place their family member in a nursing home, many still report high levels of emotional and physical stress (Figure 9).<sup>A14, (93, 95)</sup> Seventy-seven percent of family caregivers of people with Alzheimer’s disease and other dementias said that they somewhat agree to strongly agree that there is no right or wrong when families decide to place their family member in a nursing home.

- *Stress related to end-of-life care.* Care may intensify as people with dementia near the end of life. In the year before the person’s death, 59 percent of caregivers felt they were “on duty” 24 hours a day, and many felt that caregiving during this time was extremely stressful. A total of 72 percent of family caregivers said they experienced relief when the person died.<sup>(98, 102-103)</sup>

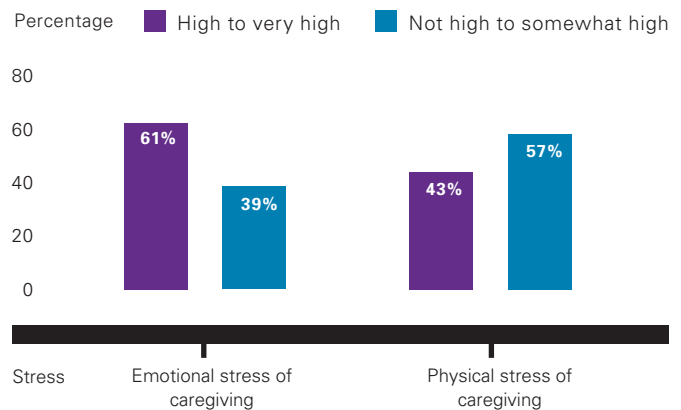
**Caregiver Physical Health**

Caregivers may become potential “secondary patients” because of the negative impact that providing care may have on their general health and risk for chronic disease, health-related physiological changes, healthcare utilization and even death.<sup>(104)</sup> Forty-three percent of caregivers for people with Alzheimer’s disease or other dementia reported that the physical and emotional stress of caregiving was high to very high (Figure 9).<sup>A14</sup> The physical and emotional impact of caregiving on Alzheimer and other dementia caregivers is estimated to result in \$7.9 billion in increased healthcare costs in the United States.<sup>A17</sup>

General Health and Risk for Chronic Disease

Caregivers of people with Alzheimer’s and other dementias said they were somewhat to very concerned about maintaining their own health since becoming a caregiver (75 percent).<sup>A14</sup> Dementia caregivers were more likely than noncaregivers to report that their health was fair or poor, and they were more likely than caregivers of other older people to say that caregiving made their health worse.<sup>(91-92)</sup>

**figure 9: Proportion of Alzheimer and Dementia Caregivers Who Report High or Very High Emotional and Physical Stress Due to Caregiving**



Created from data from the Alzheimer’s Association 2010 Women and Alzheimer’s Poll, October 2010.<sup>A14</sup>

Caregivers of people with Alzheimer’s and other dementias may also have difficulty maintaining healthy behaviors, as only 3 percent reported using physical activity as a way of getting relief from their caregiving responsibilities.<sup>A12</sup> High body mass index (BMI), known to be associated with chronic illnesses, was noted in approximately 66 percent of family caregivers, who were either overweight or obese.<sup>(105-106)</sup> Functional status (as assessed by walking speed) was found to decrease in older women caregivers who had the most stressful caregiving situations and had more indicators of metabolic syndrome (i.e., hypertension, diabetes, high cholesterol and high BMI), suggesting that these caregivers may experience greater decline in health.<sup>(107)</sup>

Physiological Changes

Caregivers of people with Alzheimer’s or another dementia are also more likely than noncaregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones,<sup>(108)</sup> reduced immune function,<sup>(109-110)</sup> slow wound healing,<sup>(111)</sup> new hypertension,<sup>(112)</sup> new coronary heart disease<sup>(113)</sup> and impaired endothelial function, which may be associated with increased risk of cardiovascular disease.<sup>(114)</sup>

Healthcare Utilization

In one study, caregivers of people with dementia were more likely to have an emergency department visit or hospitalization in the previous six months if they were depressed or were taking care of individuals who needed more help with ADLs and had more behavioral symptoms.<sup>(115)</sup>

Death

The health of the person with dementia may also affect caregiver mortality. Spouse caregivers of people who were hospitalized for dementia were more likely than spouse caregivers of people who were hospitalized for other diseases to die in the following year, even after accounting for the age of the spouse caregiver.<sup>(116)</sup>

**Caregiver Employment**

Although 44 percent of caregivers reported being employed full or part time, many caregivers of people with Alzheimer’s and other dementias reported making major changes to their work schedules because of their caregiving responsibilities: 61 percent of women and 70 percent of men said they had to go in late,

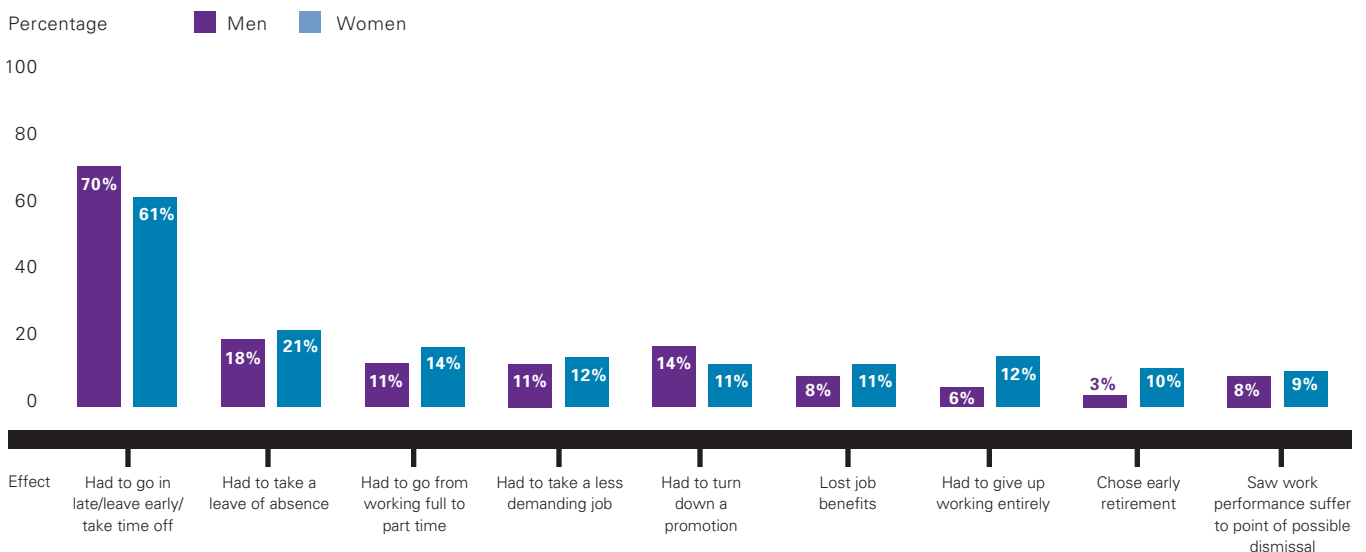
leave early or take time off and 21 percent of women and 18 percent of men had to take a leave of absence. Other work-related changes pertaining to caregiving are summarized in Figure 10.<sup>A14</sup>

**Interventions that May Improve Caregiver Outcomes**

A variety of interventions have been tested with family caregivers of people with Alzheimer’s disease or other forms of dementia. The type and focus of these interventions are briefly summarized in Table 5.<sup>(117)</sup> These interventions involve a variety of approaches, including individual and/or group educational and support sessions, home-based visits, and technology-based interventions involving telephone calls, the Internet, video or audiotapes, computers and interactive television.<sup>(118)</sup>

Overall, family caregivers give these interventions positive evaluations and, depending on how the interventions are delivered, they have been effective in improving outcomes such as caregiver knowledge, skill and well-being; decreasing caregiver burden and depressive symptoms;<sup>(117-122)</sup> and delaying time to nursing home placement.<sup>(123-124)</sup>

**figure 10:** Effect of Caregiving on Work: Caregiver Work-Related Changes



Created from data from the Alzheimer’s Association 2010 Women and Alzheimer’s Poll, October 2010.<sup>A14</sup>



**table 5:** Types and Focus of Caregiver Interventions

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

Created from data from Sørensen et al.<sup>(17)</sup>

## Paid Caregivers

Paid caregivers who provide care to older adults, many of whom have Alzheimer’s or another dementia, include direct-care workers and professionals. Direct-care workers comprise the majority of the formal healthcare delivery system for older adults and include nurse aides, home health aides and personal- and home-care aides. Professionals who receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers and others.<sup>(90)</sup>

Direct-care workers provide most of the paid care to older adults, including assistance with bathing, dressing, housekeeping and food preparation. Their jobs may be rewarding and their performance may have direct effects on the quality of care provided, but their work is difficult, and they typically are poorly paid and receive little or no training to assume these responsibilities. Turnover rates are high, and recruitment and retention are persistent challenges.<sup>(90)</sup>

It is projected that the United States will need an additional 3.5 million healthcare providers by 2030 just to maintain the current ratio of healthcare workers to the population.<sup>(90)</sup> The need for healthcare professionals trained in geriatrics is escalating, but few providers choose this career path. In 2007, the number of physicians certified in geriatric medicine totaled 7,128; those certified in geriatric psychiatry equaled 1,596. By 2030, an estimated 36,000 geriatricians will be needed. Some have estimated that the increase from current levels will amount to less than 10 percent, while others believe there will be a net loss of physicians for geriatric patients.<sup>(90)</sup>

Other professions also have low numbers of geriatric specialists: 4 percent of social workers and less than 1 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.<sup>(90)</sup>

**table 6:** Number of Alzheimer and Dementia Caregivers, Hours of Unpaid Care and Economic Value of the Care by State, 2010\*

State	Number of Alzheimer/ Dementia Caregivers	Hours of Unpaid Care per Year	Value of Unpaid Care
Alabama	287,605	327,524,195	\$3,907,363,643
Alaska	30,927	35,219,116	\$420,164,054
Arizona	298,440	339,863,759	\$4,054,574,648
Arkansas	167,733	191,014,266	\$2,278,800,194
California	1,459,978	1,662,623,044	\$19,835,092,909
Colorado	222,124	252,954,381	\$3,017,745,769
Connecticut	169,828	193,399,655	\$2,307,257,883
Delaware	48,486	55,216,111	\$658,728,208
District of Columbia	24,368	27,750,804	\$331,067,095
Florida	960,037	1,093,290,130	\$13,042,951,247
Georgia	482,255	549,192,095	\$6,551,861,693
Hawaii	58,782	66,940,708	\$798,602,641
Idaho	73,230	83,393,999	\$994,890,413
Illinois	579,505	659,939,981	\$7,873,083,975
Indiana	320,477	364,959,768	\$4,353,970,036
Iowa	131,854	150,154,788	\$1,791,346,620
Kansas	146,190	166,481,322	\$1,986,122,167
Kentucky	260,815	297,016,579	\$3,543,407,792
Louisiana	218,965	249,357,171	\$2,974,831,052
Maine	66,702	75,960,081	\$906,203,767
Maryland	270,156	307,654,020	\$3,670,312,453
Massachusetts	319,337	363,660,975	\$4,338,475,436
Michigan	507,176	577,572,277	\$6,890,437,260
Minnesota	237,441	270,397,947	\$3,225,847,510
Mississippi	198,199	225,709,258	\$2,692,711,448

**table 6 (continued)**

State	Number of Alzheimer/ Dementia Caregivers	Hours of Unpaid Care per Year	Value of Unpaid Care
Missouri	304,448	346,705,485	\$4,136,196,441
Montana	45,551	51,873,834	\$618,854,834
Nebraska	77,632	88,407,470	\$1,054,701,115
Nevada	126,003	143,492,193	\$1,711,861,862
New Hampshire	63,808	72,664,273	\$866,884,778
New Jersey	427,827	487,208,978	\$5,812,403,103
New Mexico	100,582	114,542,742	\$1,366,494,918
New York	990,490	1,127,970,106	\$13,456,683,363
North Carolina	415,521	473,194,910	\$5,645,215,276
North Dakota	26,280	29,927,827	\$357,038,974
Ohio	585,317	666,558,493	\$7,952,042,822
Oklahoma	205,843	234,414,494	\$2,796,564,913
Oregon	162,761	185,352,080	\$2,211,250,320
Pennsylvania	654,261	745,071,864	\$8,888,707,335
Rhode Island	52,641	59,947,185	\$715,169,911
South Carolina	274,195	312,252,785	\$3,725,175,727
South Dakota	35,369	40,278,116	\$480,517,925
Tennessee	400,859	456,497,713	\$5,446,017,719
Texas	1,213,767	1,382,237,356	\$16,490,091,652
Utah	132,991	151,450,408	\$1,806,803,372
Vermont	29,244	33,302,526	\$397,299,134
Virginia	422,116	480,706,197	\$5,734,824,927
Washington	309,956	352,977,490	\$4,211,021,459
West Virginia	105,464	120,102,716	\$1,432,825,396
Wisconsin	186,380	212,249,635	\$2,532,138,141
Wyoming	25,617	29,172,531	\$348,028,290
<b>U.S. Totals</b>	<b>14,915,530</b>	<b>16,985,805,836</b>	<b>\$202,640,663,621</b>

\*Differences between U.S. totals and summing the state numbers are the result of rounding.

Created from data from the 2009 BRFSS, U.S. Census Bureau, National Alliance for Caregiving, AARP and U.S. Department of Labor.<sup>A12, A14, A15</sup>

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

As the number of people with Alzheimer's disease and other dementias grows in the future, aggregate payments for their care will increase dramatically.

1.1 TRILLION

PROJECTED COST OF CARE BY 2050: \$1.1 TRILLION.

For people with Alzheimer’s disease and other dementias, aggregate payments for health care, long-term care and hospice are projected to increase from \$183 billion in 2011 to \$1.1 trillion in 2050 (in 2011 dollars). Medicare and Medicaid cover about 70 percent of the costs of care. This section describes the use and costs of health care, long-term care and hospice by people with Alzheimer’s disease and other dementias. All costs are reported in 2010 dollars,<sup>A18</sup> unless otherwise indicated.

### Total Payments for Health Care, Long-Term Care and Hospice

Table 7 reports the average per person payments for healthcare and long-term care services for Medicare beneficiaries with Alzheimer’s disease or other dementia. In 2004, total per person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer’s disease or other dementia were three times as great as payments for other Medicare beneficiaries in the same age group

(\$42,072 per person for those with Alzheimer’s disease or other dementia compared with \$13,515 per person for those without these conditions, in 2010 dollars).<sup>(125), A19</sup>

Most older people with Alzheimer’s disease and other dementias have Medicare,<sup>A20</sup> and their high use of hospital and other healthcare services translates into high costs for Medicare. In 2004, Medicare payments per person for beneficiaries aged 65 and older with Alzheimer’s and other dementias were almost three times as high as average Medicare payments for other Medicare beneficiaries in the same age group.<sup>(125)</sup>

Twenty-two percent of older people with Alzheimer’s disease and other dementias who have Medicare also have Medicaid coverage.<sup>(125)</sup> Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets,<sup>A21</sup> and the high use of these services by people with Alzheimer’s and other dementias translates into high

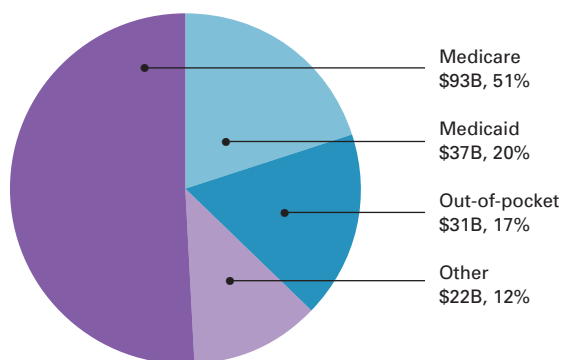
**table 7: Average per Person Payments for Healthcare and Long-Term Care Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimer’s Disease or Other Dementia and by Place of Residence, 2004 Medicare Current Beneficiary Survey, 2010 Dollars**

	Beneficiaries with Alzheimer’s or Other Dementia by Place of Residence			Beneficiaries without Alzheimer’s Disease or Other Dementia
	All	Community-Dwelling Beneficiaries	Facility-Dwelling Beneficiaries	
Medicare	\$19,304	\$16,189	\$24,005	\$6,720
Medicaid	8,419	895	19,772	915
Uncompensated	333	426	191	256
HMO	523	679	286	897
Private insurance	2,354	2,562	2,041	1,869
Other payer	662	237	1,301	269
Out-of-pocket	3,141	2,929	21,272	2,442
Total*	42,072	24,250	68,964	13,515

\*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease or other dementia include payments for community-dwelling and facility-dwelling beneficiaries. Created from data from Alzheimer’s Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009*.<sup>(125)</sup>

**figure 11: Aggregate Costs of Care by Payer for Americans Aged 65 and Older with Alzheimer’s Disease and Other Dementias, 2011\***

Total cost: \$183 Billion



\*Data are in 2011 dollars.

Source: Model developed by The Lewin Group for the Alzheimer’s Association;<sup>A22</sup> B = billions. “Other” payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

costs for Medicaid. In 2004, Medicaid payments per person for Medicare beneficiaries aged 65 and older with Alzheimer’s and other dementias were more than nine times as great as average Medicaid payments for other Medicare beneficiaries in the same age group (\$8,419 per person for people with Alzheimer’s disease and other dementias compared with \$915 for people without these conditions, in 2010 dollars; Table 7).<sup>(125)</sup>

Based on a model developed for the Alzheimer’s Association by The Lewin Group using the average per person payments from all sources for health care for people aged 65 and older with Alzheimer’s disease and other dementias and The Lewin Group’s Long-Term Care Financing Model, total payments for 2011 are estimated at \$183 billion, including \$130 billion for Medicare and Medicaid combined (in 2011 dollars, Figure 11).<sup>A22</sup>

## Use and Costs of Healthcare Services

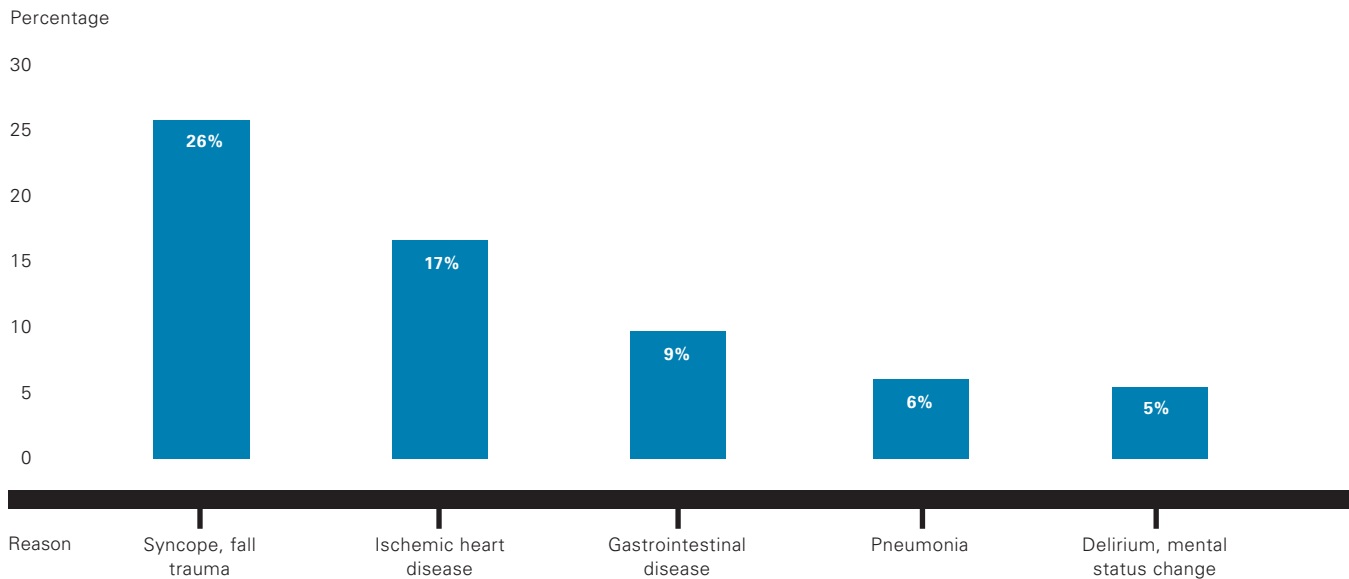
People with Alzheimer’s disease and other dementias have three times as many hospital stays as other older people.<sup>(125)</sup> Moreover, use of healthcare services for people with other serious medical conditions is strongly affected by the presence or absence of Alzheimer’s and other dementias. In particular, people with coronary heart disease, diabetes, congestive heart failure and cancer who *also* have Alzheimer’s and other dementias have higher use and costs of healthcare services than do people with these medical conditions but no coexisting Alzheimer’s or other dementia.

### Use of Healthcare Services by Setting

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

- **Hospital.** In 2004, there were 828 hospital stays per 1,000 Medicare beneficiaries aged 65 and older with Alzheimer’s disease or other dementia compared with 266 hospital stays per 1,000 Medicare beneficiaries without these conditions.<sup>(125)</sup> At any point in time, about one-quarter of all hospital patients aged 65 and older are people with Alzheimer’s and other dementias.<sup>(126)</sup> The most common reasons for hospitalization of people with Alzheimer’s disease include syncope, fall and trauma (26 percent), ischemic heart disease (17 percent) and gastrointestinal disease (9 percent) (Figure 12).<sup>(127)</sup>
- **Skilled nursing facility.** In 2004, there were 319 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer’s and other dementias compared with 39 stays per 1,000 beneficiaries for people without these conditions.<sup>(125)</sup>
- **Home health care.** In 2004, one-quarter of Medicare beneficiaries aged 65 and older who received Medicare-covered home healthcare services were people with Alzheimer’s and other dementias.<sup>(128)</sup>

**figure 12: Reasons for Hospitalization by People with Alzheimer’s Disease: Percentage of Hospitalized People by Admitting Diagnosis**



Created from data from Rudolph et al.<sup>(127)</sup>

**Costs of Healthcare Services by Setting**

In 2004, average per person payments from all sources for healthcare services, including hospital, physician and other medical provider, skilled nursing facility, home health care and prescription medications, were higher for Medicare beneficiaries aged 65 and older with Alzheimer’s and other dementias than for other Medicare beneficiaries in the same age group (Table 8).

**Impact of Coexisting Medical Conditions on Use and Costs of Healthcare Services**

Ninety-five percent of all Medicare beneficiaries have at least one coexisting medical condition.<sup>(129)</sup> Table 9 reports the proportion of people with Alzheimer’s disease or other dementia with certain coexisting medical conditions. In 2004, 26 percent of Medicare beneficiaries aged 65 and older with Alzheimer’s disease and other dementias also had coronary heart disease; 23 percent also had diabetes; 16 percent also had congestive heart failure; 13 percent also had cancer; and 8 percent also had Parkinson’s disease.<sup>(125)</sup>

People with serious medical conditions and Alzheimer’s or other dementia are more likely to be hospitalized than people with the same serious medical conditions but no Alzheimer’s or other dementia (Figure 13). They also have longer hospital stays.

Similarly, average per person payments for many healthcare services are also higher for people who have other serious medical conditions and Alzheimer’s or other dementia than for people who have the other serious medical conditions but no dementia. Table 10 shows the average per person total Medicare payments and average per person Medicare payments for hospital, physician, skilled nursing facility and home health care for beneficiaries with other serious medical conditions who either do or do not have Alzheimer’s or other dementia.<sup>(130)</sup> Medicare beneficiaries with a serious medical condition and Alzheimer’s or other dementia had higher average per person payments

**table 8:** Average per Person Payments, from All Sources, for Healthcare Services Provided to Medicare Beneficiaries Aged 65 and Older with or without Alzheimer’s Disease or Other Dementia, 2004 Medicare Beneficiary Survey, in 2010 Dollars

	Beneficiaries with Alzheimer’s Disease or Other Dementia	Beneficiaries without Alzheimer’s Disease or Other Dementia
Hospital	\$9,768	\$3,503
Medical provider*	5,551	3,948
Skilled nursing facility	3,862	424
Home health care	1,601	359
Prescription medications**	3,198	2,203

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

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

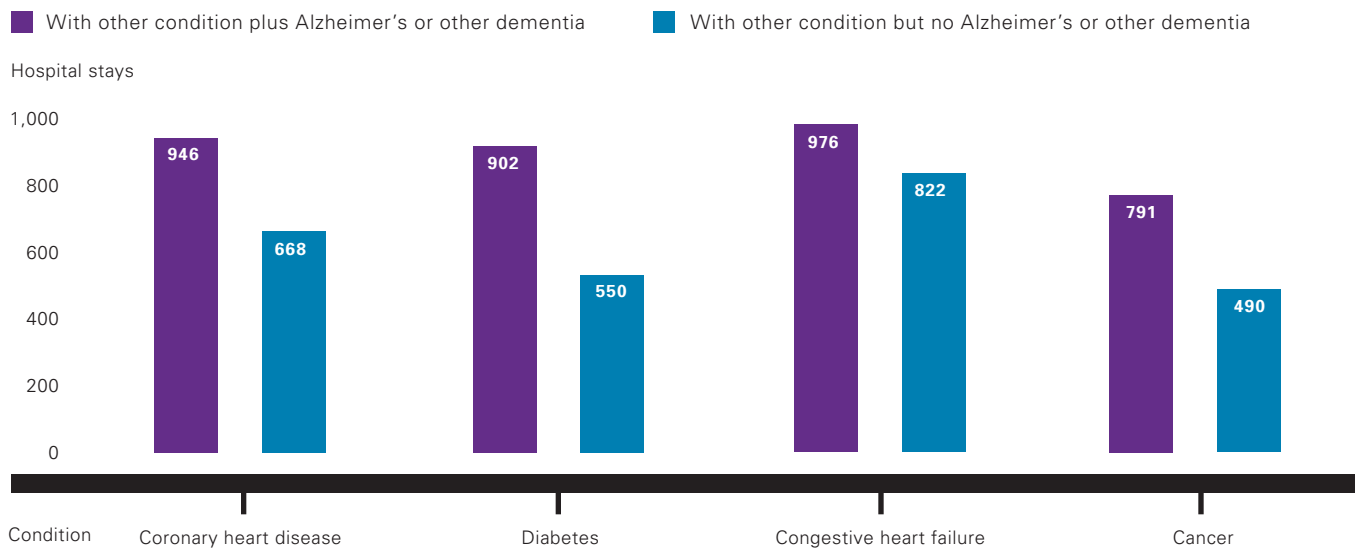
Created from data from Alzheimer’s Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009.*<sup>(125)</sup>

**table 9:** Percentages of Medicare Beneficiaries Aged 65 and Older with Alzheimer’s Disease and Other Dementias by Specified Coexisting Medical Conditions, 2004 Medicare Current Beneficiary Survey

Coexisting Condition	Percentage with Alzheimer’s or Other Dementia and the Coexisting Condition
Hypertension	60%
Coronary heart disease	26%
Stroke — late effects	25%
Diabetes	23%
Osteoporosis	18%
Congestive heart failure	16%
Chronic obstructive pulmonary disease	15%
Cancer	13%
Parkinson’s disease	8%

Created from data from Alzheimer’s Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009.*<sup>(125)</sup>

**figure 13:** Hospital Stays per 1,000 Medicare Beneficiaries Aged 65 and Older with Selected Medical Conditions by Presence or Absence of Alzheimer’s Disease and Other Dementias, 2006



Created from data from Alzheimer’s Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries, 2009.*<sup>(130)</sup>



**table 10: Average per Person Payments by Type of Service and Medical Condition for Medicare Beneficiaries with or without Alzheimer’s Disease and Other Dementias, 2006 Medicare Claims, in 2010 Dollars\***

Selected Medical Condition by Alzheimer’s Disease/ Dementia (AD/D) Status	Average per Person Medicare Payment				
	Total Payment	Payment for Hospital Care	Payment for Physician Care	Payment for Skilled Nursing Facility Care	Payment for Home Health Care
<b>Coronary Heart Disease</b>					
With AD/D	\$24,275	\$9,752	\$1,690	\$3,587	\$1,748
Without AD/D	17,102	7,601	1,462	1,124	868
<b>Diabetes</b>					
With AD/D	24,129	9,417	1,598	3,586	1,928
Without AD/D	15,162	6,279	1,277	1,078	884
<b>Congestive Heart Failure</b>					
With AD/D	24,900	9,999	1,663	3,740	1,756
Without AD/D	20,722	9,384	1,696	1,663	1,198
<b>Cancer</b>					
With AD/D	21,933	8,110	1,503	2,905	1,498
Without AD/D	15,887	5,637	1,293	822	583

\*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 data from Alzheimer’s Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries, 2009*.<sup>(130), A23</sup>

than Medicare beneficiaries with the same medical condition but no Alzheimer’s or other dementia, with one exception (payments for physician care for people with congestive heart failure).

### Use and Costs of Long-Term Care Services

Seventy percent of people with Alzheimer’s disease and other dementias live at home, usually with help from family and friends.<sup>(131)</sup> As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers.<sup>(78)</sup> Many people with Alzheimer’s and other dementias also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times in the

often long course of their illness. Given the high average costs of these services (e.g., adult day center services, \$69 per day;<sup>(132)</sup> assisted living, \$38,596 per year;<sup>(132)</sup> and nursing home care, \$74,239–\$82,113 per year,<sup>(132)</sup> in 2010 dollars), most people with Alzheimer’s and other dementias and their families cannot afford them for long. Medicaid is the only federal program that will cover the long nursing home stays that most people with dementia require in the late stages of their illness, but Medicaid requires beneficiaries to be poor to receive coverage. The Affordable Care Act (the national healthcare reform law enacted in 2010) includes a new voluntary insurance program, known as the CLASS Act, to help pay for long-term care and support services, including some nursing home costs. Benefits will not be payable until 2018, however, and

like private long-term care insurance, the program requires individuals to sign up for the insurance with their employer before they develop dementia.

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

Most people with Alzheimer's disease and other dementias who live at home receive unpaid help from family members and friends, but some also receive paid home and community-based services, such as personal care and adult day center care. A study of older people who needed help to perform daily activities, such as dressing, bathing, shopping and managing money, found that those who also had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care.<sup>(133)</sup> In addition, those who had cognitive impairment and received paid services used almost twice as many hours of care monthly as those who did not have cognitive impairment.<sup>(133)</sup>

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

- *Home care.* More than one-third (about 37 percent) of older people who receive primarily nonmedical home care services, such as personal care and homemaker services, through state home care programs in Connecticut, Florida and Michigan have cognitive impairment consistent with dementia.<sup>(134-136)</sup>
- *Adult day center services.* At least half of elderly adult day center participants have Alzheimer's disease or other dementia.<sup>(137-138)</sup>
- *Assisted living care.* Estimates from various studies indicate that 45 to 67 percent of residents of assisted living facilities have Alzheimer's disease or other dementia.<sup>(125, 139)</sup>

- *Nursing home care.* In 2008, 68 percent of all nursing home residents had some degree of cognitive impairment, including 27 percent who had mild cognitive impairment and 41 percent who had moderate to severe cognitive impairment (Table 11).<sup>(140)</sup> In June 2010, 47 percent of all nursing home residents had a diagnosis of Alzheimer's or other dementia in their nursing home record.<sup>(141)</sup>
- *Alzheimer special care unit.* Nursing homes had a total of 82,586 beds in Alzheimer special care units in June 2010.<sup>(142-143)</sup> These Alzheimer special care unit beds accounted for 73 percent of all special care unit beds and 5 percent of all nursing home beds at that time. The number of nursing home beds in Alzheimer special care units increased in the 1980s but has decreased since 2004, when there were 93,763 beds in such units.<sup>(144)</sup> Since almost half of nursing home residents have Alzheimer's or other dementia, and only 5 percent of nursing home beds are in Alzheimer special care units, it is clear that the great majority of nursing home residents with Alzheimer's and other dementias are not in Alzheimer special care units.

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

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

- *Home care.* In 2009, the average cost for nonmedical home care, including personal care and homemaker services, was \$20 per hour or \$160 for an eight-hour day.<sup>(132)</sup>

**table 11: Cognitive Impairment in Nursing Home Residents by State, 2008\***

State	Total Nursing Home Residents*	Percentage of Residents at Each Level of Cognitive Impairment**		
		None	Very Mild/ Mild	Moderate/ Severe
Alabama	51,482	28	27	45
Alaska	1,291	31	28	41
Arizona	41,443	46	25	29
Arkansas	34,114	24	29	47
California	258,863	35	26	39
Colorado	40,195	31	30	39
Connecticut	63,283	38	26	36
Delaware	9,716	35	27	38
District of Columbia	5,176	37	23	40
Florida	208,486	40	23	37
Georgia	66,743	16	23	61
Hawaii	8,631	27	23	51
Idaho	12,296	31	28	41
Illinois	170,454	29	32	39
Indiana	85,600	36	27	37
Iowa	49,620	22	30	47
Kansas	36,106	23	31	46
Kentucky	51,147	31	24	45
Louisiana	43,506	24	27	49
Maine	18,434	35	25	40
Maryland	65,573	40	23	37
Massachusetts	103,502	35	24	42
Michigan	102,649	32	26	42
Minnesota	71,003	30	30	40
Mississippi	28,567	23	28	49
Missouri	79,422	30	31	39
Montana	11,283	25	30	45
Nebraska	27,381	27	30	43
Nevada	13,072	41	26	33
New Hampshire	15,867	33	24	43
New Jersey	119,505	42	24	34
New Mexico	13,116	30	28	43

**table 11 (continued): Cognitive Impairment in Nursing Home Residents by State, 2008\***

State	Total Nursing Home Residents*	Percentage of Residents at Each Level of Cognitive Impairment**		
		None	Very Mild/ Mild	Moderate/ Severe
New York	229,599	35	26	40
North Carolina	89,223	34	24	42
North Dakota	10,594	21	31	48
Ohio	191,179	30	27	43
Oklahoma	37,668	30	30	40
Oregon	27,336	35	29	36
Pennsylvania	185,933	32	27	41
Rhode Island	17,242	32	28	40
South Carolina	38,530	29	23	49
South Dakota	11,372	20	30	49
Tennessee	70,494	25	27	48
Texas	189,553	24	32	45
Utah	17,743	38	28	34
Vermont	6,912	29	25	46
Virginia	72,214	33	26	41
Washington	56,775	32	29	39
West Virginia	22,104	36	22	42
Wisconsin	74,358	35	28	38
Wyoming	4,828	20	29	52
<b>U.S. Total</b>	<b>3,261,183</b>	<b>32</b>	<b>27</b>	<b>41</b>

\*These figures include all individuals who spent any time in a nursing home in 2008.

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

Created from data from U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. *Nursing Home Data Compendium*, 2009 Edition.<sup>1140</sup>

- *Adult day center services.* In 2009, the average cost of adult day services was \$69 per day.<sup>(132)</sup> Ninety-five percent of adult day centers provided care for people with Alzheimer's and other dementias, and 2 percent of these centers charged an additional fee for these clients.
- *Assisted living facility.* In 2009, the average cost for basic services in an assisted living facility was \$3,216 per month, or \$38,596 per year.<sup>(132)</sup> Fifty-nine percent of assisted living facilities provided specialized Alzheimer and dementia care and charged an average of \$4,556 per month, or \$54,670 per year, for this care. (Differences between the per year totals and the multiplying of per month figures by 12 are the result of rounding.)
- *Nursing home.* In 2009, the average cost for a private room in a nursing home was \$225 per day, or \$82,113 per year. The average cost of a semi-private room in a nursing home was \$203 per day, or \$74,239 per year.<sup>(132)</sup> Twenty-nine percent of nursing homes had separate Alzheimer special care units. The average cost for a private room in an Alzheimer special care unit was \$239 per day, or \$87,362 per year, and the average cost for a semi-private room was \$214 per day, or \$77,998 per year.<sup>(132)</sup> (Differences between the per year totals and the multiplying of per day figures by 365 are the result of rounding.)

#### Affordability of Long-Term Care Services

Few individuals with Alzheimer's disease or other dementia and their families either 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 dementia specifically, but 47 percent of people aged 65 and older had incomes less than 200 percent of the federal poverty level in 2009 (200 percent of the federal poverty level was \$21,660 for a household of one in 2010).<sup>(145)</sup> Even for older people with higher incomes, the costs of home care, adult day center services, assisted living care or nursing home care can quickly exceed their income.
- In 2005, 65 percent of older people living in the community, and 84 percent of those at high risk of needing nursing home care, had assets that would pay for less than a year in a nursing home.<sup>(146)</sup> Fifty-seven percent of older people in the community and 75 percent of those at high risk of needing nursing home care did not have enough assets to cover even a month in a nursing home.<sup>(146)</sup>

#### Long-Term Care Insurance

In 2007, about 8 million people had long-term care insurance policies, which paid out \$3.9 billion (in 2010 dollars) for services for those who filed claims in that year.<sup>(147)</sup> Private health and long-term care insurance policies funded only about 9 percent of total long-term care spending in 2006, representing \$18.7 billion of the \$207.5 billion (in 2010 dollars) in long-term care spending.<sup>(148)</sup> However, long-term care insurance plays a significant role in paying for the care of people with dementia who purchase policies before developing the disease.

### Medicaid Costs

Medicaid covers nursing home care and other long-term care services in the community for individuals who meet program requirements for level of care, income and assets. To receive coverage, beneficiaries must have low incomes or be poor due to their expenditures on these services. Most nursing home residents who qualify for Medicaid must spend all of their Social Security checks and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse.

The federal government and the states share in managing and funding the program, and states differ greatly in the services covered by their Medicaid programs. Medicaid plays a critical role for people with dementia who can no longer afford to pay for their long-term care expenses on their own. In 2008, Medicaid spending on institutional care accounted for 58 percent of its long-term care expenditures, and spending on home and community-based services accounted for the remaining 42 percent of expenditures.<sup>(148)</sup>

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be \$37 billion in 2011.<sup>A22</sup> About half of all Medicaid beneficiaries with Alzheimer's disease and other dementias are nursing home residents, and the rest live in the community.<sup>(131)</sup> Among nursing home residents with Alzheimer's disease and other dementias, 51 percent relied on Medicaid to help pay for their nursing home care.<sup>(131)</sup>

In 2004, total per person Medicaid payments for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were nine times as high as Medicaid payments for other Medicare beneficiaries aged 65 and older without the disease.

Much of the difference in Medicaid payments for beneficiaries with Alzheimer's and other dementias is due to the costs associated with long-term care (i.e., nursing homes and other residential care facilities, such as assisted living facilities). Medicaid paid \$19,772 (in 2010 dollars) per person for Medicare beneficiaries with a diagnosis of Alzheimer's disease and other dementias living in a long-term care facility compared with \$895 for those with the diagnosis living in the community (Table 7, page 35).<sup>(125)</sup>

### Out-of-Pocket Costs for Healthcare and Long-Term Care Services

Although Medicare, Medicaid and other sources such as the Veterans Health Administration and private insurance pay for most hospital and other healthcare services and some long-term care services for older people with Alzheimer's and other dementias, individuals and their families still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums, deductibles and copayments and for healthcare and long-term care services that are not covered by Medicare, Medicaid or other sources.

In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's disease and other dementias had average annual per person out-of-pocket costs totaling \$3,141 for healthcare and long-term care services that were not covered by other sources (Table 7, page 35).<sup>(125)</sup> Average per person out-of-pocket costs were highest for people with Alzheimer's and other dementias who were living in nursing homes and assisted living facilities (\$21,272 per person). Out-of-pocket costs for people aged 65 and older with Alzheimer's and other dementias who were living in the community were 20 percent higher (\$2,929 per person) than the average costs for all other Medicare beneficiaries in that age group (\$2,442 per person).<sup>(125)</sup>

Before the implementation of the Medicare Part D Prescription Drug Benefit in 2006, out-of-pocket expenses were increasing annually for Medicare beneficiaries.<sup>(149)</sup> In 2003, out-of-pocket costs for prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries aged 65 and older.<sup>(150)</sup> Other important components of out-of-pocket costs were premiums for Medicare and private insurance (45 percent) and payments for hospital, physician and other healthcare services that were not covered by other sources (31 percent). The Medicare Part D Prescription Drug Benefit has helped to reduce out-of-pocket costs for prescription drugs for many Medicare beneficiaries, including beneficiaries with Alzheimer's and other dementias.<sup>(151)</sup> Sixty percent of all Medicare beneficiaries were enrolled in a Medicare Part D plan in 2010, and the average monthly premium for Medicare Part D is \$40.72 in 2011 (range: \$14.80 to \$133.40).<sup>(152)</sup> Clearly, however, the biggest component of out-of-pocket costs for people with Alzheimer's and other dementias is nursing home and other residential care, and out-of-pocket costs for these services are likely to continue to grow over time.

## Use and Costs of Hospice Care

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

### Use of Hospice Services

In 2008, 6 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (60,488 people).<sup>(153)</sup> An additional 11 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (113,204 people). Hospice length of stay has increased over the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of Alzheimer's disease increased from 67 days in 1998 to 105 days in 2008.<sup>(153)</sup> The average length of stay for hospice beneficiaries with a primary diagnosis of non-Alzheimer dementia increased from 57 days in 1998 to 89 days in 2008.

### Costs of Hospice Services

In 2004, hospice care payments from all sources for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias totaled \$3.6 billion (in 2010 dollars).<sup>(125)</sup> Average per person hospice care payments for these beneficiaries were eight times as much as payments for other Medicare beneficiaries in the same age group (\$1,244 per person compared with \$153 per person).<sup>(125)</sup>

## Projections for the Future

Total payments for healthcare, long-term care and hospice for people with Alzheimer's disease and other dementias are projected to increase from \$183 billion in 2011 to \$1.1 trillion in 2050 (in 2011 dollars). This dramatic rise includes a 7-fold increase in Medicare payments and a 5-fold increase in payments from Medicaid and out-of-pocket and other sources (i.e., private insurance, health maintenance organizations, other managed care organizations and uncompensated care).<sup>(154)</sup>

SPECIAL REPORT

## **EARLY DETECTION AND DIAGNOSIS: BENEFITS AND CHALLENGES**

Individuals with Alzheimer's disease and other forms of dementia require and benefit from a variety of medical and support services.

**50%**

**AS MANY AS HALF OF PEOPLE SATISFYING DIAGNOSTIC CRITERIA  
FOR DEMENTIA HAVE NEVER RECEIVED A DIAGNOSIS.**



This Special Report aims to document current knowledge about the benefits of early detection and diagnosis and about the prevalence and causes of undiagnosed dementia. Another key objective is to highlight causes of delayed or missed diagnosis that can be corrected by changes in practice or policy. In the absence of a formal diagnosis, medical and support services are difficult to obtain, depriving affected individuals of treatments and services that could improve their symptoms and help them maintain their independence for as long as possible.

**Benefits of Early Detection and Diagnosis**

Early detection and diagnosis of cognitive impairment confers many benefits (Table 12). In some individuals, cognitive impairment may be caused by a treatable or

reversible condition (for example, depression or vitamin B12 deficiency); early detection and diagnosis of such a condition prevents needless impairment.

For people affected by irreversible cognitive decline or dementia, a formal and documented diagnosis helps them and their relatives understand what is happening and opens access to valuable support services. In this way, diagnosis might reduce the anxiety and emotional burden experienced by affected individuals and their families. Diagnosis also could allow affected people, relatives and caregivers to plan for the future, help affected people obtain medical care to manage symptoms and optimize function, and assist affected people and caregivers alike to take steps to reduce the risk of accidents requiring medical care.

**table 12:** Possible Benefits of Early Detection and Diagnosis

<p><b>ALLOWS</b> prompt evaluation and treatment of reversible or treatable causes of cognitive impairment</p>	<p>healthcare facilities — often free of cost — while participating in important medical research; and opportunities to learn in-depth about Alzheimer’s disease through regular contact with trained clinical staff</p>	<p><b>ALLOWS</b> physicians and caregivers to be aware of patients who may have difficulty managing their own health care, such as when and how to take other prescription medications<sup>(155)</sup></p>	<p><b>PROVIDES</b> caregivers and family members with access to training, education and support services</p>
<p><b>ALLOWS</b> potential management of symptoms with medication or other interventions</p>	<p><b>HELPS</b> prevent prescription of medications for coexisting conditions that worsen cognitive function</p>	<p><b>AIDS</b> management of possible behavioral symptoms</p>	<p><b>REDUCES</b> the burden on caregivers<sup>(157)</sup></p>
<p><b>ENABLES</b> potential inclusion in Alzheimer clinical trials. Benefits of participating in clinical trials include possible slowing of disease progression, if pharmacologic or nonpharmacologic therapies being studied in clinical trials prove effective; receipt of expert medical care at leading</p>	<p><b>HELPS</b> facilitate treatment or management of coexisting medical conditions that worsen cognitive function</p>	<p><b>HELPS</b> reduce anxiety on the part of the affected person and his or her family about the cause of symptoms<sup>(156)</sup></p>	<p><b>MAY REDUCE</b> the incidence of falls and accidents by alerting caregivers to potential risks<sup>(158)</sup></p>
			<p><b>ALLOWS</b> family members and caregivers to be alert to potential financial mismanagement and scams<sup>(159)</sup></p>
			<p><b>ALLOWS</b> planning for the future</p>

## Detection and Diagnosis

Current medical guidelines do not recommend that primary care physicians perform routine assessment for cognitive impairment or dementia in their patients, unless a patient exhibits obvious signs or symptoms of cognitive impairment.<sup>(160)</sup> In the past, such medical assessment was time-consuming, complex and expensive, and there was insufficient evidence that it improved health outcomes or was free from harm.<sup>(64, 160-161)</sup> The lack of an efficient and inexpensive way to assess cognitive function has been a barrier to the early detection of cognitive decline and to the delivery of medical care to those needing it. In 2003, for example, the U.S. Preventive Services Task Force noted that, “For dementia screening to lead to improved health outcomes, primary care providers would need a brief, accurate screening test that could be applied during routine office visits,” leading to more comprehensive diagnostic evaluation.<sup>(64)</sup>

### Advances in Detection

Recently, simple and inexpensive tests have been developed that can be used by primary care physicians for routine assessment of patients in the clinic.<sup>(162)</sup> Examples of such tests include the Mini-Cog test, the General Practitioner Assessment of Cognition (GPCOG) and others. It must be noted, however, that such assessment is valuable only for identifying people requiring more complete testing; it is not sufficient to establish a diagnosis of dementia. The medical community has not yet developed a consensus regarding which single test is best for routine assessment.

Medicare’s new Annual Wellness Visit includes assessment for possible cognitive impairment.<sup>(163)</sup> Because of this change, it is hoped that earlier detection will be more common, prompting complete diagnostic evaluation in appropriate people. Nevertheless, physicians still rely primarily on the patient, a relative or a caregiver to raise concerns

about cognitive decline or to accurately respond to physicians’ questions about cognitive function.<sup>(157, 161)</sup> As discussed in detail in subsequent sections of this report, many existing barriers affect the ability or willingness of individuals and their caregivers to recognize cognitive impairment and to discuss it with their physician.

### Diagnostic Challenges

Once a physician suspects that a patient may have cognitive decline or dementia, it is recommended that the patient participate in a full diagnostic evaluation. The diagnosis of any form of dementia can present significant challenges to the physicians involved. Although Alzheimer’s disease is recognized as the most common form of dementia,<sup>(164)</sup> there are several different forms of dementia, each with a unique set of diagnostic criteria. Many of the diagnostic challenges associated with Alzheimer’s disease also apply to the diagnosis of other forms of dementia.

### Diagnostic Criteria

The criteria for diagnosis of Alzheimer’s disease are considered reliable and valid, as more than 90 percent of patients diagnosed with the condition are found to have it on autopsy.<sup>(165)</sup> Nevertheless, the diagnostic criteria are based on a variety of imperfect tests, as well as the experience and subjective assessment of the physician performing the evaluation.<sup>(43)</sup> Furthermore, it is rare for a diagnosis to be completed in one clinic visit; rather, patients must be observed over time to document changes in cognitive function.<sup>(164)</sup>

Strictly speaking, a definitive diagnosis of Alzheimer’s disease can occur only by pathologic examination of brain tissue after death.<sup>(165)</sup> Therefore, the clinical diagnosis using criteria such as those mentioned in the Overview represents a compromise, allowing for diagnosis of probable disease and subsequent management during life. Indeed, one study examining the medical records of people who had definitive Alzheimer’s disease at autopsy showed that, among

the 463 medical records investigated, about 20 percent did not include a diagnosis of probable Alzheimer’s disease.<sup>(166)</sup> This finding illustrates the challenges of diagnosing Alzheimer’s disease even in severely affected people. Other forms of dementia are even more challenging to diagnose because the currently available diagnostic criteria are not considered valid or reliable.<sup>(165)</sup>

**Diagnostic Methods**

Intensive research efforts are focused on discovering and validating reliable tests for diagnosing Alzheimer’s disease and other dementias in living people. These tests include brain imaging and tests of cerebrospinal fluid and blood to identify changes that signal

Alzheimer’s disease or other forms of dementia. Despite promising results from recent research (Table 13), such tests require significant additional research before they are ready for use in the clinic.<sup>(165)</sup> Certain routine laboratory tests are recommended, but these are to rule out other conditions that can cause cognitive dysfunction, such as vitamin B12 deficiency or hypothyroidism. Routine brain imaging using computed tomography (CT) or magnetic resonance imaging (MRI) is also recommended for patients with suspected dementia,<sup>(165)</sup> but neither of these can be used for definitive diagnosis. Rather, their primary role is to investigate or exclude other potential causes of cognitive dysfunction.<sup>(164)</sup>

**table 13:** Recent Advances in the Use of Biomarkers\* and Brain Imaging for Diagnosing Dementia in Living People

<p><b>SCIENTISTS</b> around the world are focused on developing and validating reliable ways to detect and diagnose Alzheimer’s disease and other forms of dementia. Recent reports in the medical literature and the lay press have revealed promising advances toward these goals.</p> <p>Two recent reports indicate that biomarkers in the cerebrospinal fluid or blood<sup>(167)</sup> may be useful for detecting Alzheimer’s disease, even in people who have no noticeable symptoms. Significant advances are also being made in the ability to detect accumulation of beta-amyloid plaques in the</p>	<p>brain, which are a characteristic feature of Alzheimer’s disease.</p> <p>A number of approaches are being studied and developed for the use of brain imaging for early detection of dementia. These approaches include imaging of structural changes in the brain as well as the use of dyes and molecular markers to identify abnormal brain changes related to dementia.<sup>(168)</sup></p> <p>In light of these advances, the International Working Group for New Research Criteria for Diagnosis of Alzheimer’s Disease has recently recommended that the diagnostic criteria for Alzheimer’s disease be changed to include the presence of a</p>	<p>biomarker or imaging evidence of disease.<sup>(169)</sup> This recommendation was echoed in 2010 by workgroups convened by the National Institute on Aging and the Alzheimer’s Association (see Overview). Biomarkers would currently be used <i>only</i> in research settings. Their accuracy must be validated in research studies before they can be used in clinical practice.</p> <p>At this time, the use of biomarkers or imaging for diagnosing Alzheimer’s disease has not been established in large-scale trials. Thus, further study is essential to ensure that testing is safe, accurate and reliable.</p>
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\*A biomarker is a naturally occurring, measurable substance or condition that reliably indicates the presence or absence of disease or the risk of later developing a disease; for example, blood glucose levels are a biomarker of diabetes, and cholesterol levels are a biomarker of cardiovascular disease risk.

### *Additional Diagnostic Challenges*

Several other factors contribute to the challenge of diagnosing dementia. One hindrance is the presence of symptoms resembling dementia that are caused by other conditions or drugs.<sup>(170-171)</sup> In many cases, patients present to their physician with a mix of true chronic cognitive impairment, drug-induced declines in cognitive function, and illnesses that can cause treatable cognitive impairment. In one study of 1,000 patients presenting to a clinic for memory problems, for example, 23 percent were found to have a condition that was potentially reversible with treatment and that either caused or contributed to their memory problem.<sup>(171)</sup> Hence, before a diagnosis of dementia can be made, physicians must often try discontinuing or adding certain medications in an attempt to discern treatable or reversible causes of cognitive impairment and to spare patients from unnecessary disability.<sup>(164, 171)</sup>

Another hindrance to diagnosis is insufficient information about how cognitive function changes during healthy aging.<sup>(160)</sup> Thus, it can be difficult to discern when an individual's cognitive function declines to a degree that signals the presence of disease in a person of that age. Furthermore, the trajectory of cognitive function during healthy aging is affected by numerous factors, including education, family history or genetic susceptibility and the presence of other disorders such as depression.<sup>(160)</sup> Many of these factors affect how the signs and symptoms of dementia are expressed in different individuals.

## Frequency of Delayed or Missed Diagnosis

Because of the importance of diagnosis to affected individuals and their caregivers, and the importance of understanding the true prevalence of dementia for purposes of policymaking and public health planning, several studies have attempted to quantify how many people with dementia remain undiagnosed. These studies have used several different methods, each with strengths and weaknesses. Thus, the results of individual studies must be interpreted cautiously. Nevertheless, when considered together the studies provide at least a framework from which to gauge the magnitude of the problem, and from which to begin understanding its causes and potential solutions.

### **Studies Comparing Medical Records to Patient Symptoms**

In 2003, a review of four studies concluded that fewer than half of patients who met standard diagnostic criteria for dementia had a diagnosis of dementia in their medical record or noted on an independent physician questionnaire.<sup>(64)</sup> More recent studies have found similar results.

For example, a 2009 article re-examined eight studies that estimated the frequency of missed, delayed or incorrect diagnoses of dementia in the primary care setting. Estimated frequencies were calculated by comparing actual diagnoses (diagnoses disclosed to the researchers or noted in an existing medical record) with standardized reference diagnostic methods

(administered by a panel of trained raters). Of 791 people who met standard diagnostic criteria for dementia, 384 had the diagnosis recorded in their medical record or reported by the examining physician, representing a diagnostic sensitivity of 49 percent. Looking at it another way, about half of patients with dementia had no record of being diagnosed.<sup>(157)</sup> In this same study, the likelihood that a patient had received a diagnosis of dementia depended on the severity of dementia: 60 to 100 percent of patients with severe dementia had been diagnosed, compared with only 9 to 41 percent of patients with few or mild symptoms.<sup>(157)</sup>

Like other types of studies trying to estimate rates of missed diagnosis, this review has shortcomings, as noted by its authors. For example, some cases attributed to missed diagnosis may have arisen from documentation errors or even a deliberate decision to not document the diagnosis. Furthermore, it is not possible to estimate the delay between onset of symptoms and documentation of a diagnosis.<sup>(157)</sup>

#### **Studies Using Medicare Claims Data, Death Certificates and Other Records**

Other studies have tried to quantify the frequency of missed diagnosis by comparing data from numerous sources.<sup>(172-174)</sup> These sources used different criteria to determine whether a diagnosis was made, including the patient's primary and specialist medical records; surveys; Medicare claims; use of an FDA-approved medication for Alzheimer's disease; whether the individual or their family member was aware of the diagnosis; and whether the diagnosis appeared on a

death certificate. In one study, for example, 13 percent of elderly participants had a dementia-related diagnosis, and 3.6 percent had a diagnosis of Alzheimer's disease according to Medicare claims data.<sup>(173)</sup>

In the same group of elderly individuals, however, only 6.3 percent had a dementia-related diagnosis noted on their death certificate, and only 2.4 percent had an Alzheimer's disease diagnosis noted on their death certificate.<sup>(173)</sup>

The most recent study compared three criteria for an established diagnosis in people at least 65 years old: (1) affirmative responses on the Medicare Current Beneficiary Survey (MCBS), (2) use of an Alzheimer medication and (3) evidence of an Alzheimer diagnosis in Medicare claims data.<sup>(172)</sup> Among the more than 57,669 individuals in the study, 3,198 (5.5 percent) had evidence of a diagnosis from at least one of those sources. However, only 366 (0.63 percent) had evidence from all three sources, and only about 1 percent had evidence from two sources.<sup>(172)</sup>

Several explanations for low agreement between estimates have been offered, including documentation errors, unwillingness of patients or their proxies to report a diagnosis on surveys or in Medicare claims, differences in coding practices among physicians, and death certificates that report only the immediate cause of death without noting underlying dementia.<sup>(172-174)</sup>

These findings suggest the presence of problems in the healthcare system that could be addressed to improve both the reliability of data collection and the frequency of diagnosis.

## Causes of Low Rates of Detection and Diagnosis

Some of the inherent challenges faced by physicians charged with detecting and diagnosing dementia have already been discussed. A number of additional factors contribute to the problem of delayed or missed diagnosis of dementia. An extensive analysis of these factors, identified in multiple studies, was described in a recent report.<sup>(157)</sup> This section focuses on selected factors analyzed in that report, particularly those identified in more recent studies and those amenable to improvement or correction.

### Physician-Related Factors

In primary care settings, physicians report insufficient time and insufficient reimbursement as important causes of missed diagnosis of dementia.<sup>(175)</sup> In many cases, physicians feel that there is a more pressing need to diagnose and treat a patient's other medical conditions, and some doubt the value of diagnosing a condition for which they believe there are no effective treatments.<sup>(176)</sup> Several studies have also concluded that many physicians lack sufficient training or experience in assessing dementia.<sup>(157, 177)</sup> In addition, most primary care clinics do not have routine procedures for assessment of possible dementia, in part because simple, reliable and inexpensive tests to help detect dementia have become available only recently and are not yet incorporated into guidelines. As already discussed, without such an assessment, it is difficult for physicians to detect signs or symptoms of dementia in a short clinic visit, especially in cases of mild dementia.<sup>(157, 175, 178-179)</sup>

Another major barrier to timely diagnosis is the attitude among some physicians that a formal diagnosis may be more harmful than helpful.<sup>(157)</sup> However, research suggests that most patients and their families prefer full disclosure of a dementia diagnosis,<sup>(156-157, 180-182)</sup> and many, but not all, patients prefer to discuss memory problems with their physician rather than keep them hidden.<sup>(180-181)</sup> Finally, communication barriers, including language barriers and difficulties discussing or explaining a dementia diagnosis, are likely to be contributing factors in the low rates of diagnosis.<sup>(157, 177, 183)</sup>

### Patient- and Caregiver-Related Factors

As already noted, physicians must often rely on patients or their caregivers to alert them to changes in a patient's cognitive status. One study showed that caregivers waited as long as seven years after noticing symptoms before seeking medical evaluation for the affected person.<sup>(97)</sup> In another study, almost half of patients who had evidence of dementia on an initial assessment refused further evaluation to confirm a diagnosis.<sup>(184)</sup> Such findings suggest a lack of knowledge among the general public about dementia,<sup>(185)</sup> about the benefits of accurate diagnosis and about available support resources. Such delays may also indicate the presence of other real or perceived barriers, such as poor access to care or concerns about the cost of care.<sup>(157)</sup> The ability of patients or their caregivers to recognize symptoms of dementia is also influenced by the patient's age,<sup>(185)</sup> as many individuals from a variety of cultural backgrounds view memory loss as a sign of normal aging rather than part of a disease process.<sup>(186-187)</sup>

As mentioned in the section on Prevalence, an individual's ethnicity may affect the odds that they will develop dementia, as well as the odds that they will be diagnosed. Furthermore, elderly individuals from ethnic minority groups are less likely to have access to educational and diagnostic services.<sup>(65, 185, 187-188)</sup> The degree to which a diagnosis of dementia is viewed as a stigma also varies across different ethnic groups,<sup>(188)</sup> and this phenomenon likely affects the chances that an affected person will seek evaluation or be encouraged to do so by family members. Finally, ethnicity and related language barriers have been shown to affect the reliability of some tests used to assess cognitive function.<sup>(189)</sup>

#### **System-Related Factors**

Several factors related to the healthcare system have already been mentioned because they intersect with physician- or patient-related factors. These factors include real or perceived constraints related to clinic time, cost and reimbursement; access to care and educational services; and barriers related to ethnic and language differences. Other system-related factors include lack of access to community services on the part of both physicians and patients; problems with the coordination of care;<sup>(190-191)</sup> lack of specialists available for consultation, especially in rural areas; imposed limits on the use of diagnostic tests; and the fact that dementia care has not been a public health priority.<sup>(175, 178, 192)</sup>

## **Conclusion**

Although available data do not permit definitive estimates of how many individuals have undiagnosed dementia, the convergence of evidence from numerous sources indicates that as many as half of people satisfying diagnostic criteria for dementia have never received a diagnosis. Some lines of evidence suggest that as many as 80 percent or more of affected individuals have never been diagnosed. Delayed detection of Alzheimer's disease or other dementia, or delayed or missed diagnosis, deprives affected people of numerous potential benefits and imposes unnecessary physical and emotional burdens on their caregivers. Numerous factors have been identified that contribute to these challenges, and many of those factors can be improved or corrected using existing knowledge and technologies. Such solutions, however, may require cooperation among various stakeholders and a forward-looking allocation of resources. Remedies for other factors affecting the detection and diagnosis of dementia are under intensive research.

## End Notes

A1. Number of Americans over age 65 with Alzheimer's disease for 2011: The number 5.2 million is based on linear extrapolation from published prevalence estimates for 2010 (5.1 million) and 2020 (5.7 million). See Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census." *Archives of Neurology* 2003;60:1119–1122. These prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP).

A2. Proportion of Americans over age 65 with Alzheimer's disease: The 13 percent is calculated by dividing the estimated number of people aged 65 and older with Alzheimer's disease (5.2 million) by the U.S. population aged 65 and older in 2009, the latest available data from the U.S. Census Bureau (39.6 million) = 13 percent. Thirteen percent is the same as 1 in 8.

A3. Proportion of Americans over age 85 with Alzheimer's disease: The 43 percent is calculated by dividing the number of people aged 85 and older with Alzheimer's disease (2.4 million) by the U.S. population aged 85 and older in 2009, the latest available data from the U.S. Census Bureau (5.6 million) = 43 percent. Forty-three percent is nearly half.

A4. Percentage of total Alzheimer's disease cases by age groups: Percentages for each age group are based on the estimated 200,000 for people under 65, plus the estimated numbers for people 65 to 74 (0.3), 75 to 84 (2.4), and 85+ (2.4) based on linear extrapolation from published prevalence estimates for each age group for 2010 and 2020. See Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census." *Archives of Neurology* 2003;60:1119–1122. These prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP).

A5. Differences between CHAP and ADAMS estimates for Alzheimer's disease prevalence: The Aging, Demographics, and Memory Study (ADAMS) estimates the prevalence of Alzheimer's disease to be lower than does the Chicago Health and Aging Project (CHAP), at 2.3 million Americans aged 71 and older in 2002. See Plassman, BL; Langa, KM; Fisher, GG; et al. "Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study." *Neuroepidemiology* 2007;29(1-2):125–132. At a recent conference convened by the National Institute on Aging and the Alzheimer's Association, researchers determined that this discrepancy was mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's. (See Wilson, RS; Weir, DR; Leurgans, SE; Evans, DA; Hebert, LE; Langa, KM; et al. "Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States." *Alzheimer's & Dementia* 2011;7(1):74–79.) Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's disease and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common (see Schneider, JA; Arvanitakis, Z; Leurgans, SE; Bennett DA. "The neuropathology of probable Alzheimer's disease and mild cognitive impairment." *Annals of Neurology* 2009;66(2):200–208), the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's disease in the United States.

A6. Number of men and women over age 65 with Alzheimer's disease in the United States: The estimates for number of U.S. women (3.3 million) and men (1.8 million) aged 65 and older with Alzheimer's in 2010 was provided to the Alzheimer's Association by Denis Evans, M.D., on July 21, 2010, and first published in Shriver, M. *The Shriver Report: A Woman's Nation Takes on Alzheimer's*. Alzheimer's Association; October 2010. The figure is derived from data from CHAP published in Hebert, LE; et al., "Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census," *Archives of Neurology* 2003;60:1119–1122. For 2011, we took the proportion of U.S. women and men aged 65 and older with Alzheimer's in 2010 (65 percent and 35 percent, respectively) and applied these proportions to the new estimate for total number of Americans aged 65 and older with Alzheimer's (5.2 million) to obtain the 3.4 million and 1.8 million figures.

A7. Number of seconds for development of a new case of Alzheimer's disease: Although Alzheimer's does not present suddenly like stroke or heart attack, the rate at which new cases occur can be computed in a similar way. The 69 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. Hebert et al. (2001) estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020. See Hebert, LE; Beckett, LA; Scherr, PA; Evans, DA. "Annual incidence of Alzheimer disease in the United States projected to the years 2000 through 2050." *Alzheimer Disease & Associated Disorders* 2001;15:169–173. The Alzheimer's Association calculated that the incidence of new cases in 2011 would be 449,700 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.1 (for the number of years from 2010 to 2011 divided by the number of years from 2010 to 2020), adding that result (3,700) to the Hebert et al. (2001) estimate for 2010 (454,000) = 457,700. 31,536,000 divided by 457,700 = 68.9 seconds, rounded to 69 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al., 2001) = 32.8 seconds, rounded to 33 seconds.

A8. Criteria for identifying subjects with Alzheimer's disease and other dementias in the Framingham Study: Standard diagnostic criteria (DSM-IV criteria) were used to diagnose dementia in the Framingham Study, but, in addition, the subjects had to have at least "moderate" dementia according to the Framingham criteria, which is equivalent to a score of 1 or more on the Clinical Dementia Rating (CDR) Scale, and they had to have symptoms for six months or more. Standard diagnostic criteria (the NINCDS-ADRDA criteria) were used to diagnose Alzheimer's disease. The examination for dementia and Alzheimer's disease is described in detail in Seshadri, S; Wolf, PA; Beiser, A; Au, R; McNulty, K; White, R; et al. "Lifetime risk of dementia and Alzheimer's disease: The impact of mortality on risk estimates in the Framingham Study." *Neurology* 1997;49:1498–1504.

A9. Number of baby boomers who will develop Alzheimer's disease and other dementias: The numbers for remaining lifetime risk of Alzheimer's disease and other dementias for baby boomers were developed by the Alzheimer's Association by applying the data provided to the Association on remaining lifetime risk by Alexa Beiser, Ph.D.; Sudha Seshadri, M.D.; Rhoda Au, Ph.D.; and Philip A. Wolf, M.D., from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, to U.S. Census data for the number of women and men aged 43 to 61 in November 2007, used here to estimate the number of women and men aged 44 to 62 in 2008.



A10. State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific gender, years of education, race and mortality. See Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans DA. "State-specific projections through 2025 of Alzheimer's disease prevalence." *Neurology* 2004;62:1645. The numbers in Table 2 are found in online material related to this article, available at [www.neurology.org](http://www.neurology.org).

A11. The projected number of people with Alzheimer's disease comes from the CHAP study: See Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census." *Archives of Neurology* 2003;60:1119–1122. Other projections are somewhat lower (see Brookmeyer, R; Gray, S; Kawas, C. "Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset." *American Journal of Public Health* 1998;88(9):1337–1342) because they relied on more conservative methods for counting people who currently have Alzheimer's disease, as outlined in Appendix End Note A5. Nonetheless, these estimates are statistically consistent with each other, and *all* projections suggest substantial growth in the number of people with Alzheimer's disease over the coming decades.

A12. Number of family and other unpaid caregivers of people with Alzheimer's and other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS). In 2009, the BRFSS survey asked respondents aged 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the Centers for Disease Control, Healthy Aging Program, unpublished data) to the number of people aged 18 and older nationally and in each state from the U.S. Census Bureau report for July 2009. Available at [www.census.gov/popest/states/asrh/files/SCPRC-EST2009-18+POP-RES.csv](http://www.census.gov/popest/states/asrh/files/SCPRC-EST2009-18+POP-RES.csv). Accessed on Nov. 22, 2010. (July 2009 state-by-state population data were used because 2010 data will not be released until April 2011.) To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, we used data from the results of a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP (National Alliance for Caregiving, *Caregiving in the U.S.: Executive Summary*, November 2009. Available at [www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf](http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf)). The NAC/AARP survey asked respondents aged 18 and over whether they were providing unpaid care for a relative or friend aged 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 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. We applied the 26 percent figure to the total number of caregivers nationally and in each state.

A13. Comparison to previous numbers: The total number of Alzheimer and dementia caregivers is significantly higher than reported in previous editions of *Facts and Figures*. The baseline for the calculation to determine the number of total Alzheimer and dementia caregivers, as noted in the previous Appendix note, is the Behavioral Risk Factor Surveillance System (BRFSS) system question on caregiving. That question was asked by every state in the 2000 BRFSS, but not asked again in every state until 2009. As a result, previous editions of *Facts and Figures*, using the 2000 data as the baseline, did not account for the annual increases in the number of total caregivers from 2001 to 2008 and thus under-reported the number of Alzheimer and other dementia caregivers.

A14. Alzheimer's Association 2010 Women and Alzheimer's Poll: This poll contacted 3,118 adults nationwide by telephone from Aug. 25 to Sept. 3, 2010. Telephone numbers were randomly chosen in separate samples of landline and cell phone exchanges across the nation, allowing listed and unlisted numbers to be contacted, and multiple attempts were made to contact each number. Within households, individuals were randomly selected and interviews were conducted in English and Spanish. The survey "oversampled" African-American and Hispanics, selected from Census tracts with higher than 8 percent concentration of each respective group. It also included an oversample of Asian-Americans using a listed sample of Asian-American households. The combined samples include: 2,295 white, non-Hispanic; 326 African-American; 309 Hispanic; 305 Asian-American; and 135 respondents of another race. Cases were weighted to account for differential probabilities of selection and to account for overlap in the landline and cell phone sampling frames. The sample was adjusted to match Census demographic benchmarks for gender, age, education, race/ethnicity, region and telephone service. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. This national survey included 202 caregivers of people with Alzheimer's or other dementia. This was supplemented with 300 interviews from a listed sample of caregivers of people with Alzheimer's for a total of 502 caregiver interviews. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend aged 50 or older who suffered from Alzheimer's or other dementia. The weight of the caregiver sample adjusted all 502 caregiver cases to the weighted estimates for gender and race/ethnicity derived from the base survey of caregivers. Questionnaire design and interviewing was conducted by Abt SRBI of New York. Susan Pinkus of S.H. Pinkus Research and Associates coordinated the polling and helped in the analysis of the poll.

A15. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's and other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. We multiplied the number of family and other unpaid caregivers (14,915,530) by the average hours of care per year (1,139), which equals 16,985,805,836 hours of care.

A16. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Amo et al. (see Amo, PS; Levine, C; Memmott, MM. "The economic value of informal caregiving." *Health Affairs* 1999;18:182–188). This method uses the average of the minimum hourly wage (\$7.25 in 2010) and the mean hourly wage of home health aides (\$16.60 in July 2010) [see U.S. Department of Labor, Bureau of Labor Statistics. *Employment, Hours, and Earnings from Current Employment Statistics Survey*. Series 10-CEU 6562160008, Home Health Care Services (NAICS code 6216), Average Hourly Earnings, July 2010. Available at data.bls.gov/ces. Accessed on Nov. 22, 2010]. The average is \$11.93. We multiplied the number of hours of unpaid care by \$11.93, which equals \$202,640,663,621.

A17. Higher healthcare costs of Alzheimer caregivers: This figure is based on a methodology 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' healthcare costs were 8 percent higher than noncaregivers' (Albert, SM; Schulz, R. *The MetLife Study of Working Caregivers and Employer Health Care Costs*, New York, N.Y.: MetLife Mature Market Institute, 2010). This translates into an additional \$530 per year (Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, *Total Personal Health Care Per Capita Spending, by Age Group, Calendar Years, 1987, 1996, 1999, 2002, 2004 and Personal Health Care Spending by Age Group and Source of Payment, Calendar Year 2004, Total Payer (in millions)*. Available at [www.cms.gov/NationalHealthExpendData/downloads2004-agetables.pdf](http://www.cms.gov/NationalHealthExpendData/downloads2004-agetables.pdf). Accessed on Aug. 18, 2010). The total number of unpaid Alzheimer and dementia caregivers — 14.9 million — is multiplied by \$530 to get the total additional health care costs of Alzheimer and other dementia caregivers as a result of being a caregiver (\$7.9 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."<sup>(193)</sup>

A18. All cost estimates were inflated to year 2010 dollars using the Consumer Price Index (CPI): All Urban Consumers seasonally adjusted average prices for medical care services. The relevant item within medical care services was used for each cost element (e.g., the medical care services item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; the nursing home and adult day services item within the CPI was used to inflate nursing home payments).

A19. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2004 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The MCBS, a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries, is linked to Medicare Part B claims. The survey is supported by the U.S. Centers for Medicare and Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a nurse who is familiar with the survey participant and his or her medical record. Data from the MCBS analysis that are included in *2011 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries aged 65 and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of Alzheimer's disease or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's disease or other dementia in 2004: The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician or other healthcare provider visit. The diagnostic codes used to identify survey participants with Alzheimer's disease and other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11.

A20. Medicare: Medicare is a medical insurance program available to all Americans aged 65 and older and to a limited number of younger individuals who meet the requirements for Social Security Disability Insurance (SSDI). In 2007, 95 percent of people aged 65 and older had Medicare (U.S. Department of Health and Human Services, *Health Care Financing Review: Medicare and Medicaid Statistical Supplement, Brief Summaries of Medicare and Medicaid*, Nov. 1, 2008). Original, fee-for-service Medicare covers hospital care; physician services; home health care; laboratory and imaging tests; physical, occupational and speech therapy; hospice and other medical services. Medicare beneficiaries can choose to enroll in a Medicare health maintenance organization (HMO) as an alternative to the original, fee-for-service Medicare. Medicare does not cover long-term care in a nursing home, but it does cover short stays in "skilled nursing facilities" when the stay follows within 30 days of a hospitalization of three days or more for an acute illness such as a heart attack or broken hip. Medicare beneficiaries pay premiums for coverage and generally pay deductibles and co-payments for particular services. Medicare premiums, deductibles and co-payments do not cover the full cost of services to beneficiaries. The program is tax-supported.

A21. Medicaid: Medicaid is a publicly funded health services program for low-income Americans. It is jointly funded by the federal government and the states according to a complex formula. In addition to basic health services, Medicaid covers nursing home care and various home- and community-based long-term care services for individuals who meet program requirements for level of care, income and assets. States have considerable flexibility about which services are covered in their Medicaid programs, and covered services vary greatly in different states.

A22. Lewin Model on Alzheimer's and Dementia and Costs: These numbers come from a model created for the Alzheimer's Association by The Lewin Group. The model estimates total payments for community-based health care services based on findings from the previous analysis of data from the 2004 Medicare Current Beneficiary Survey (MCBS)<sup>(125)</sup>, A19 and for nursing facility care based on The Lewin Group's Long-Term Care Financing Model. More information on the model, its long-term projections, and its methodology is available at [www.alz.org/trajjectory](http://www.alz.org/trajjectory).

A23. National 20% Sample Medicare Fee-for-Service Beneficiaries Report: These numbers come from an analysis of Medicare claims data for 2005–2006. The analysis was conducted by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The data come from Medpar files (hospital and skilled nursing facility services), outpatient files (outpatient hospital services), carrier files (physician and supplier services), hospice files (hospice services), DME (durable medical equipment) files and home health files (home health services). Data from the analysis that are included in *2011 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries aged 65 and older. For this analysis, people with dementia are defined as those who have at least one claim with a diagnostic code for Alzheimer's disease or other dementia in Medpar, Medicare Part B, hospice or home health files in 2005. The diagnostic codes used to identify survey participants with Alzheimer's disease and other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11. People with other chronic conditions are defined as those who had at least one Medicare Part A claim or two Part B claims occurring at least seven days apart with a diagnostic code for the condition. Medicare beneficiaries with Alzheimer's disease, other dementias and other chronic conditions were identified in 2005 Medicare claims, and outcomes (use and costs of services) were taken from 2006 Medicare claims. This prospective method decreases the influence of people with a new diagnosis, which is usually associated with higher use and costs of services compared with ongoing management of the condition.

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The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.

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