

2012 ALZHEIMER'S DISEASE FACTS AND FIGURES

Includes a Special Report on
People with Alzheimer's Disease and
Other Dementias Who Live Alone

ONE IN EIGHT OLDER AMERICANS HAS ALZHEIMER'S DISEASE. ALZHEIMER'S DISEASE IS THE SIXTH-LEADING CAUSE OF DEATH IN THE UNITED STATES. OVER 15 MILLION AMERICANS PROVIDE UNPAID CARE FOR A PERSON WITH ALZHEIMER'S OR OTHER DEMENTIAS. PAYMENTS FOR CARE ARE ESTIMATED TO BE \$200 BILLION IN 2012.

ABOUT THIS REPORT

2012 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 challenges of people with Alzheimer's disease and other dementias who live alone.

**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

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

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

Dementia: Definition and Specific Types

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.⁽¹⁾ 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 and sensory function and comprehension of the required task.

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

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

To establish a diagnosis of dementia, a physician must determine the cause of the dementia-like symptoms. Some conditions have symptoms that mimic dementia but that, unlike dementia, can be reversed with treatment. These treatable conditions include depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. In contrast, dementia is caused by irreversible damage to brain cells.

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>New criteria and guidelines for diagnosing Alzheimer's were proposed and published in 2011. They recommend that Alzheimer's disease be considered a disease that begins well before the development of symptoms (see pages 8 to 9).</p> <p>Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain.</p>
Vascular dementia	<p>Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than is Alzheimer's disease.</p> <p>Impaired judgment or ability to make plans is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.</p> <p>Occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location of the brain injury determines how the individual's thinking and physical functioning are affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer's disease (and vice versa). That practice is no longer considered consistent with pathologic evidence, which shows that the brain changes of both types of dementia can be present simultaneously. When any two or more types of dementia are present at the same time, the individual is considered to have "mixed dementia."</p>

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

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

When an individual has irreversible dementia, a physician must conduct tests to identify the form of dementia that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and brain abnormalities, as described in Table 1. However, increasing evidence from long-term observational and autopsy studies indicates that many people with dementia, especially elderly individuals, have brain abnormalities associated with more than one type of dementia.⁽²⁻⁶⁾

Alzheimer's Disease

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

Symptoms of Alzheimer's Disease

Alzheimer's disease affects people in different ways, but the most common symptom pattern begins with gradually worsening ability to remember new information. This occurs because disruption of brain cell function usually begins in brain 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.

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, eating and using the bathroom. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on around-the-clock care. When an individual has difficulty moving because of Alzheimer's disease, they are more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer's disease is ultimately fatal, and Alzheimer's-related pneumonia is often a contributing factor.

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, such as the presence of a tumor or evidence of a stroke, that could cause cognitive decline.

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

In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association recommended new diagnostic criteria and guidelines for Alzheimer's disease.⁽⁷⁻¹⁰⁾

The new criteria and guidelines update, refine and broaden guidelines published in 1984 by the Alzheimer's Association and the National Institute of Neurological Disorders and Stroke. The new criteria and guidelines result from work that began in 2009, when more than 40 Alzheimer's researchers and clinicians from around the globe began an in-depth review of the 1984 criteria to decide how they might be improved by incorporating scientific advances from the last three decades.

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

Differences Between the Original and New Criteria

The 1984 criteria were based chiefly on a doctor's clinical judgment about the cause of a patient's symptoms, taking into account reports from the patient, family members and friends; results of

cognitive testing; and general neurological assessment. The new criteria and guidelines incorporate two notable changes:

(1) They identify three stages of Alzheimer's disease, with the first occurring before symptoms such as memory loss develop and before one's ability to carry out everyday activities is affected. In contrast, the 1984 criteria require memory loss and a decline in thinking abilities severe enough to affect daily life before Alzheimer's disease can be diagnosed.

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

The Three Stages of Alzheimer's Disease Proposed by the New Criteria and Guidelines for the Diagnosis of Alzheimer's Disease

The three stages of Alzheimer's disease identified in the new criteria and guidelines are preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease and dementia due to Alzheimer's disease. These stages are different from the stages now used to describe Alzheimer's. Currently, the stages of Alzheimer's are often described as mild/early-stage, moderate/mid-stage or severe/late-stage. The new criteria propose that Alzheimer's disease begins before the mild/early-stage and that new technologies have the potential to identify Alzheimer's-related brain changes that occur before mild/early-stage disease. When these very early changes in the brain are identified, an individual diagnosed using the new criteria would be said to have preclinical Alzheimer's disease or MCI due to Alzheimer's. The third stage of the new criteria, dementia due to Alzheimer's disease, encompasses all stages of Alzheimer's disease as described today, from mild/early-stage to severe/late-stage.

Preclinical Alzheimer's disease — In this stage, individuals have measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, but they

have not yet developed symptoms such as memory loss. This preclinical or pre-symptomatic stage reflects current thinking that Alzheimer's begins creating changes in the brain as many as 20 years before symptoms occur. Although the new criteria and guidelines identify preclinical disease as a stage of Alzheimer's, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional biomarker research is needed before this stage of Alzheimer's can be diagnosed.

MCI due to Alzheimer's disease — Individuals with MCI have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities. Studies indicate that as many as 10 to 20 percent of people age 65 and older have MCI.⁽¹¹⁻¹³⁾ It is estimated that as many as 15 percent of people whose MCI symptoms cause them enough concern to contact their doctor's office for an exam go on to develop dementia each year. From this estimate, nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in three or four years.⁽¹⁴⁾

This estimate is higher than for individuals whose MCI is identified through community sampling (and not as a result of a visit to a doctor because of

cognitive concerns). For these individuals, the rate of progression may reach 10 percent per year.⁽¹⁵⁾ Further cognitive decline is more likely among individuals whose MCI involves memory problems than in those whose MCI does not involve memory problems. Over one year, most individuals with MCI who are identified through community sampling remain cognitively stable. Some, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status.⁽¹⁶⁾ It is unclear why some people with MCI develop dementia and others do not. When an individual with MCI goes on to develop dementia, many scientists believe the MCI is actually an early stage of the particular form of dementia, rather than a separate condition.

The new criteria and guidelines recommend biomarker testing for people with MCI to learn whether they have brain changes that put them at high risk of developing Alzheimer's disease or other dementias. If it can be shown that changes in the brain, cerebrospinal fluid and/or blood are caused by physiologic processes associated with Alzheimer's, the new criteria and guidelines recommend a diagnosis of MCI due to Alzheimer's disease. Before doctors can make such a diagnosis, however, researchers must prove that the biomarker tests accurately indicate risk.

Dementia due to Alzheimer's disease — This stage is characterized by memory, thinking and behavioral symptoms that impair a person's ability to function in daily life and that are caused by Alzheimer's disease-related processes.

Biomarker Tests

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

Researchers believe that future treatments to slow or stop the progression of Alzheimer's disease and preserve brain function (called "disease-modifying" treatments) will be most effective when administered during the preclinical and MCI stages of the disease. In the future, biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment when it becomes available. They also will be critical for monitoring the effects of treatment.

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, develops as a result of multiple factors rather than a single cause.

These factors include a variety of brain changes that begin as many as 20 years before symptoms appear. Increasingly, the time between the initial brain changes of Alzheimer's and the symptoms of advanced Alzheimer's is considered by scientists to represent the "continuum" of Alzheimer's. At the start of the continuum, the individual is able to function normally despite these brain changes. Further along the continuum, the brain can no longer compensate for the increased neuronal damage caused by brain changes, and the individual shows subtle decline in cognitive function. In some cases, physicians identify this point in the continuum as MCI. Toward the end of the continuum, neuronal damage and death is so significant that the individual shows obvious cognitive decline, such as memory changes or confusion as to time or place. At this point, physicians following the 1984 criteria for Alzheimer's would diagnose the individual as having Alzheimer's disease. The new criteria and guidelines propose that the entire continuum, not just the symptomatic points on the continuum, represents Alzheimer's. Researchers continue to explore why some individuals who have the brain changes associated with the earlier points of the continuum do not go on to develop the overt symptoms of the later points of the continuum.

Among the brain changes believed to contribute to the development of Alzheimer's are the accumulation of the protein beta-amyloid *outside* neurons in the brain and the accumulation of the protein tau *inside* neurons. A healthy adult brain has 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form specialized connections with other neurons. At 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 neurons is believed to interfere with the neuron-to-neuron communication of synapses and to 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 process is also believed to contribute to cell death. Brains from people 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, is caused by three known genetic mutations. These mutations involve the gene for the amyloid precursor protein and the genes for the presenilin 1 and presenilin 2 proteins. Inheriting any of these genetic mutations guarantees that an individual will develop Alzheimer's disease. In such individuals, the disease tends to develop before age 65, sometimes in individuals as young as age 30.

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 people with Alzheimer's disease are diagnosed at age 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 develops in a person younger than age 65, 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 risk factors.

Family History

Individuals who have a parent, brother or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.⁽¹⁷⁻¹⁹⁾ Those who have more than one first-degree relative with Alzheimer's are at even higher risk of developing the disease.⁽²⁰⁾ When diseases run in families, heredity (genetics), shared environmental/lifestyle factors or both may play a role.

Apolipoprotein E-ε4 (APOE-ε4)

Individuals with the ε4 form of the gene apolipoprotein E are at increased risk of developing Alzheimer's disease. 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. Unlike inheriting a known genetic mutation for Alzheimer's, inheriting one or two copies of this form of the APOE gene does not guarantee that an individual will develop Alzheimer's.

Mild Cognitive Impairment (MCI)

MCI is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities. People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's and other dementias than people without MCI. In some cases, such as when MCI is caused by certain medications, MCI can be reversed. In other cases, MCI reverts to normal cognition on its own or remains

stable. Therefore, it's important that people experiencing cognitive decline seek help as soon as possible for accurate diagnosis and treatment. The new criteria and guidelines for diagnosis of Alzheimer's disease, published in 2011,⁽⁷⁻¹⁰⁾ suggest that in some cases MCI is actually an early stage of Alzheimer's. For more information, see pages 8 to 9.

Cardiovascular Disease Risk Factors

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

Some data indicate that cardiovascular disease risk factors, such as physical inactivity, high cholesterol (especially in midlife), diabetes, smoking and obesity, are associated with a higher risk of developing Alzheimer's and other dementias.⁽²¹⁻³¹⁾ 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.

Social Engagement and Diet

Additional studies suggest that other modifiable factors, such as remaining mentally and socially active and consuming a diet low in saturated fats and rich in vegetables, may support brain health.⁽³²⁻³³⁾ However, there are fewer of these types of studies than studies of cardiovascular risk factors, and they often involve a smaller number of participants than cardiovascular studies. As a result, their conclusions are generally considered less convincing than those of cardiovascular studies. Thus, compared with other risk factors, relatively little is known about how social engagement or diet may affect Alzheimer's risk.

Head Trauma and Traumatic Brain Injury (TBI)

Head injury, head trauma and TBI are associated with an increased risk of Alzheimer's disease and other dementias. 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.⁽³⁴⁻³⁵⁾ Moderate head injury is defined as a head injury resulting in loss of consciousness or post-traumatic amnesia lasting more than 30 minutes; if either of these lasts more than 24 hours, the injury is considered severe. 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.⁽³⁶⁻⁴¹⁾ Some studies suggest that APOE-ε4 carriers who experience moderate or severe head injury are at higher risk of developing Alzheimer's than APOE-ε4 carriers who do not have a history of moderate or severe head injury.^(34, 42-43) Additional research is needed to better understand the association between brain injury and increased risk of Alzheimer's.

Treatment of Alzheimer's Disease

No treatment is available to slow or stop Alzheimer's disease. The U.S. Food and Drug Administration has approved five drugs that temporarily improve symptoms. The effectiveness of these drugs varies across the population. None of the treatments available today alters the underlying course of this terminal disease. However, researchers around the world are studying dozens of treatment strategies that may have the potential to change the course of the disease.

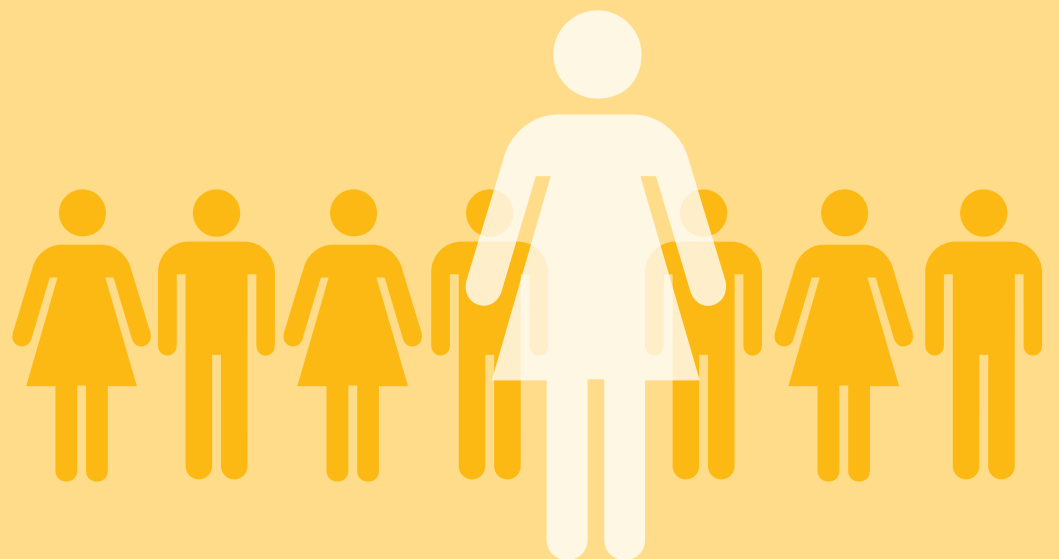
Despite the lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for individuals with dementia and their caregivers.⁽⁴⁴⁻⁴⁶⁾ Active management includes (1) appropriate use of available treatment options, (2) effective management of coexisting conditions, (3) coordination of care among physicians, other health care professionals and lay caregivers, (4) participation in activities and adult day care programs and (5) taking part in support groups and supportive services such as counseling.

PREVALENCE

**MILLIONS OF
AMERICANS HAVE
ALZHEIMER'S
DISEASE AND OTHER
DEMENTIAS.**



One in eight 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 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 2012. This figure includes 5.2 million people age 65 and older⁽⁴⁷⁾, ^{A1} and 200,000 individuals under age 65 who have younger-onset Alzheimer's.⁽⁴⁸⁾

- One in eight people age 65 and older (13 percent) has Alzheimer's disease.^{A2}
- Nearly half of people age 85 and older (45 percent) have Alzheimer's disease.^{A3}
- Of those with Alzheimer's disease, an estimated 4 percent are under age 65, 6 percent are 65 to 74, 44 percent are 75 to 84, and 46 percent are 85 or older.⁽⁴⁷⁾, ^{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. In 2009, the National Institute on Aging (NIA) and the Alzheimer's Association convened a conference to examine discrepancies among estimates from CHAP and other studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.⁽⁴⁹⁾ 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.⁽⁵⁰⁾, ^{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 age 71 and older in the United States have dementia.⁽⁴⁹⁾ This number would be higher using the broader diagnostic criteria of CHAP.

The estimates from CHAP and ADAMS are based on commonly accepted criteria for diagnosing Alzheimer's disease that have been used since 1984. In 2009, an expert workgroup was convened by the Alzheimer's Association and the NIA to recommend updated diagnostic criteria, as described in the Overview (pages 8 to 9). It is unclear exactly how these new criteria, if adopted, could change the estimated prevalence of Alzheimer's. However, if Alzheimer's disease can be detected earlier, in the preclinical stage as defined by the new criteria, the number of people reported to have Alzheimer's disease would be larger than what is presented in this report.

Prevalence studies such as CHAP and ADAMS are designed so that all individuals with dementia are detected. But in the community, only about half of those who would meet the diagnostic criteria for Alzheimer's disease or other dementias have been diagnosed.⁽⁵¹⁾ Because Alzheimer's disease is underdiagnosed, more than half of the 5.4 million Americans with Alzheimer's may not know they have it.

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

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women.^{A6} 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.^{A6} Based on estimates from ADAMS, 16 percent of women age 71 and older have Alzheimer's disease or other dementias compared with 11 percent of men.^(49, 52)

The larger proportion of older women who have Alzheimer's disease or other dementias is primarily explained by the fact that women live longer on average than men.⁽⁵²⁻⁵³⁾ Many studies of the age-specific incidence (development of new cases) of Alzheimer's disease⁽⁵³⁻⁵⁹⁾ or any dementia^(54-56, 60-61) 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^(49, 62) and a greater risk of developing dementia.^(55, 58, 61, 63-64)

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.⁽⁶⁵⁻⁶⁶⁾ However, others believe that the increased risk of dementia among those with lower educational attainment may be explained by other factors common to people in lower socioeconomic groups, such as increased risk for disease in general and less access to medical care.⁽⁶⁷⁾

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.⁽⁶⁸⁻⁶⁹⁾

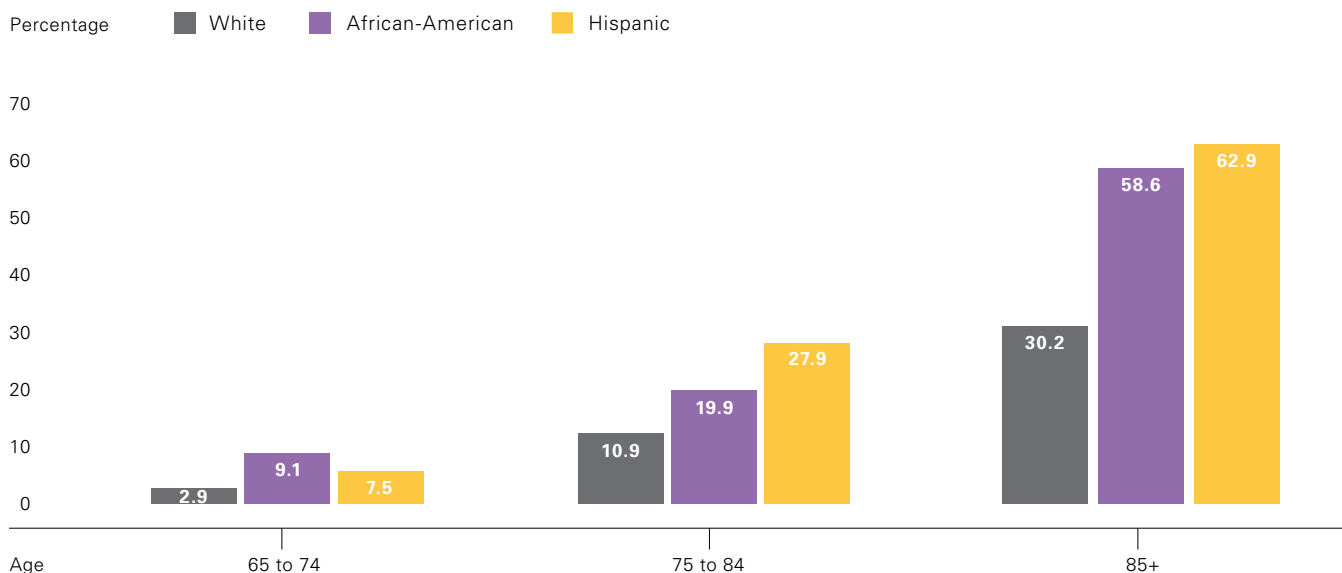
Data indicate that in the United States, older African-Americans are probably about twice as likely to have Alzheimer's and other dementias as older whites,⁽⁷⁰⁾ and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites.⁽⁶²⁾ Figure 1 shows the estimated prevalence for each group, by age, from the Washington Heights-Inwood Columbia Aging Project.

Despite some evidence of racial differences in the influence of genetic risk factors for Alzheimer's and other dementias, genetic factors do not appear to account for these large prevalence differences across racial groups.⁽⁷¹⁾ Instead, health conditions such as high blood pressure and diabetes that increase one's risk for Alzheimer's disease and other dementias are more prevalent in African-American and Hispanic communities. Lower levels of education and other socioeconomic characteristics in these communities may also increase risk. Some studies suggest that differences based on race and ethnicity do not persist in detailed analyses that account for these factors.^(49, 55)

There is evidence that missed diagnoses are more common among older African-Americans and Hispanics than among older whites.⁽⁷²⁻⁷³⁾ For example, a 2006 study of Medicare beneficiaries found that Alzheimer's disease or other dementias had been diagnosed in 9.6 percent of white beneficiaries, 12.7 percent of African-American beneficiaries and 14 percent of Hispanic beneficiaries.⁽⁷⁴⁾ Although rates of diagnosis were higher among African-Americans and Hispanics than among whites, the difference was not as great as would be expected based on the estimated differences found in prevalence studies, which are designed to detect all people who have dementia. 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.⁽⁷⁵⁾ 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 Age 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. ⁽⁶²⁾

Incidence and Lifetime Risk of Alzheimer’s Disease

While prevalence is the number of *existing* cases of a disease in a population at a given time, incidence is the number of *new* cases of a disease 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 age 65 to 74, to 170 new cases per 1,000 people age 75 to 84, to 231 new cases per 1,000 people over age 85 (the “oldest-old”).⁽⁷⁶⁾ 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 a leveling off of incidence among the oldest-old may be due to sparse data for this group.⁽⁷⁷⁾ Because of the increase in the number of people over 65 in the United States, the annual incidence of Alzheimer’s and other dementias is projected to double by 2050.⁽⁷⁶⁾

- Every 68 seconds, someone in America develops Alzheimer’s.^{A7}
- By mid-century, someone in America will develop the disease every 33 seconds.^{A7}

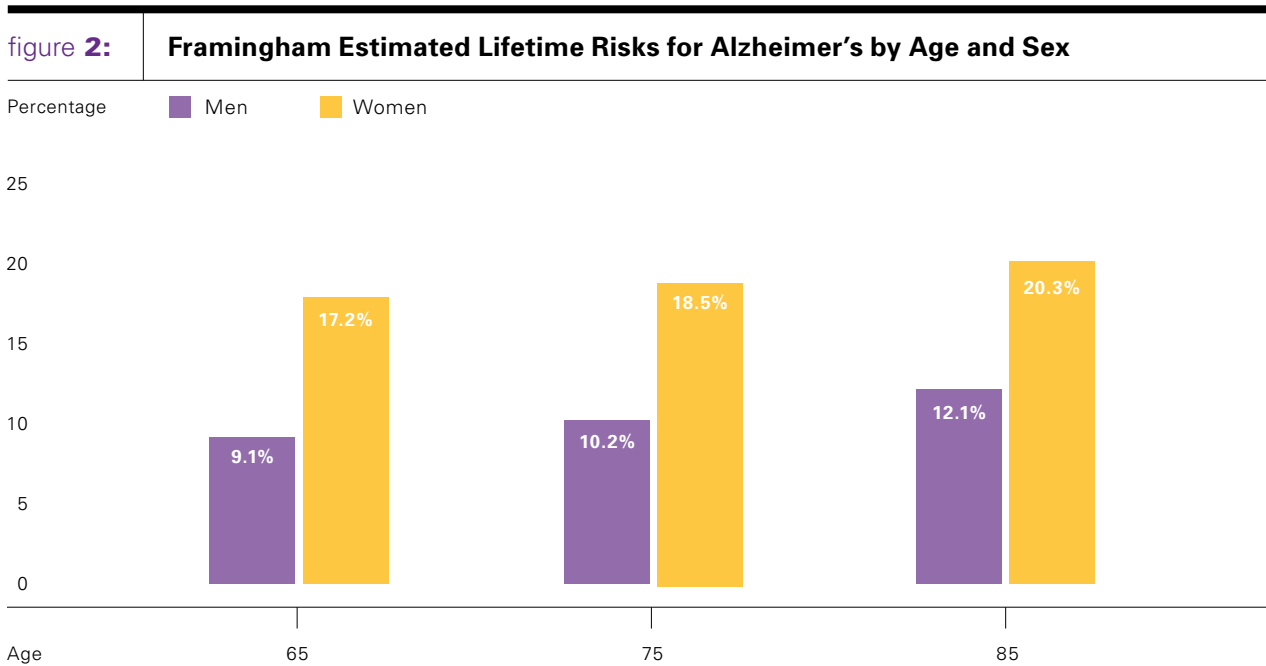
Lifetime risk is the probability that someone of a given age develops a condition during their remaining lifespan. Data from the original Framingham Study population were used to estimate lifetime risks of Alzheimer’s disease and of any dementia.^{(78), A8} Starting in 1975, nearly 2,800 people from 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 nearly one in 10 (9.1 percent) for men.^{(78), A9} 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 women’s longer life expectancy.

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

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

Table 2 (pages 20 to 21) summarizes the projected total number of people age 65 and older with Alzheimer’s disease by state for 2000, 2010 and 2025.^{A10} The percentage changes in the number of people with Alzheimer’s between 2000 and 2010 and between 2000 and 2025 are also shown. Note that the total number of people with Alzheimer’s is larger for states with larger populations, such as California and New York. Comparable projections for other types of dementia are not available.

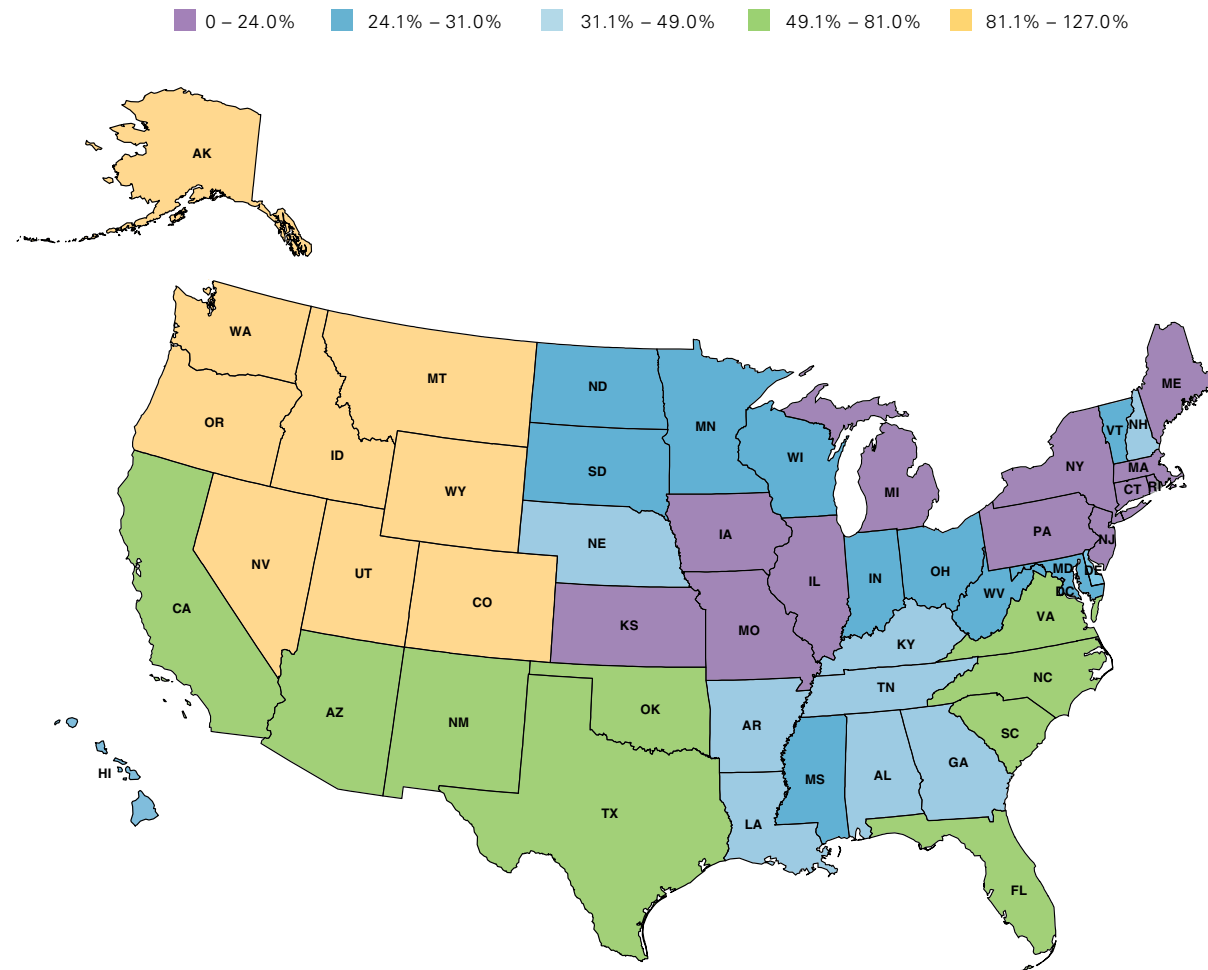
As shown in Figure 3, between 2000 and 2025 some states and regions across the country are expected to experience double-digit percentage increases in the overall numbers of people with Alzheimer’s due to increases in the proportion of the population over age 65. The South and West are expected to experience 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) of the number of people with Alzheimer’s. Although the projected increases in the Northeast are not nearly as marked as those in other regions of the United States, it should be noted that this region of the country currently has a large proportion of people with Alzheimer’s relative to other regions because this region already has a high proportion of people over age 65. The increasing number of people with Alzheimer’s will have a marked impact on states’ health care systems, not to mention families and caregivers.



Created from data from Seshadri et al. (78)

figure 3:

Projected Changes Between 2000 and 2025 in Alzheimer’s Prevalence by State



Created from data from Hebert et al.^{(79), A10}

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.⁽⁸⁰⁾ Additionally, a large segment of the American population — the baby boom generation — is reaching the age of greater risk for Alzheimer’s and other

dementias. In fact, the first baby boomers reached age 65 in 2011. By 2030, the segment of the U.S. population age 65 and older is expected to double, and the estimated 71 million older Americans will make up approximately 20 percent of the total population.⁽⁸¹⁾

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer’s disease, as shown in Figure 4.^{A11}

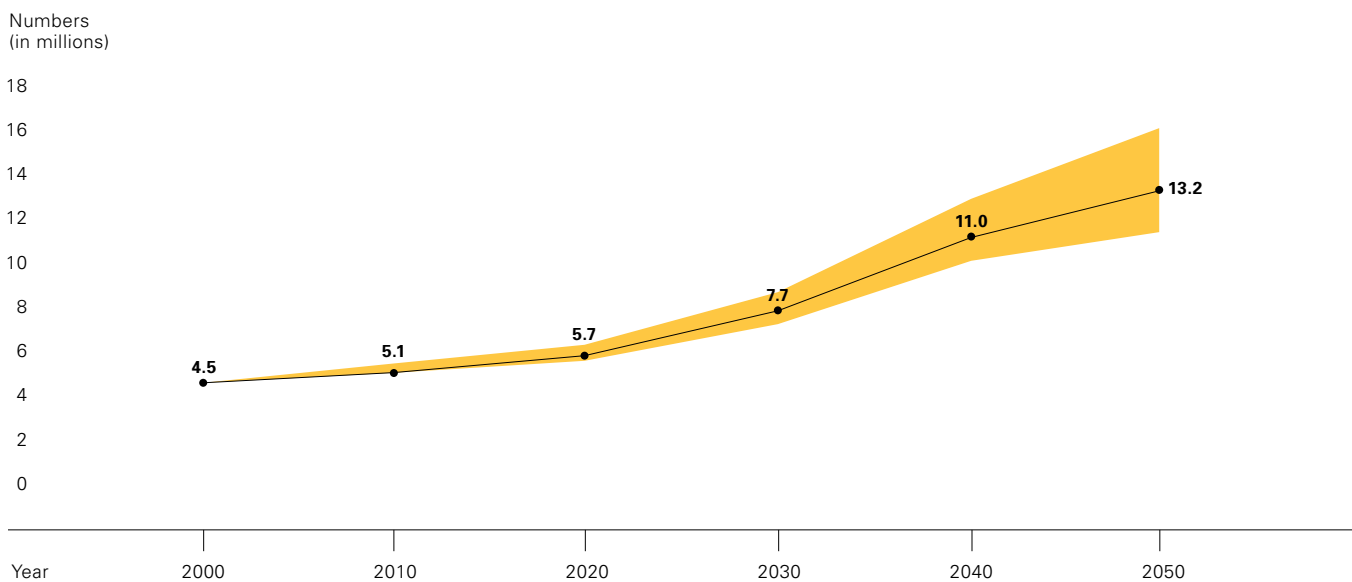
- In 2000, there were an estimated 411,000 new cases of Alzheimer’s disease. For 2010, that number was estimated to be 454,000 (a 10 percent increase); by 2030, it is projected to be 615,000 (a 50 percent increase from 2000); and by 2050, 959,000 (a 130 percent increase from 2000).⁽⁷⁶⁾
- By 2025, the number of people age 65 and older with Alzheimer’s disease is estimated to reach 6.7 million — a 30 percent increase from the 5.2 million age 65 and older currently affected.⁽⁴⁷⁾
- By 2050, the number of people age 65 and older with Alzheimer’s disease may triple, from 5.2 million to a projected 11 million to 16 million, barring the development of medical breakthroughs to prevent, slow or stop the disease.^{(47), A11}

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).⁽⁸⁰⁾ This will result in an additional 15 million oldest-old people — individuals at high risk for developing Alzheimer’s.⁽⁸⁰⁾

- By 2050, the number of Americans age 85 years and older will nearly quadruple to 21 million.⁽⁸⁰⁾
- In 2012, the 85-years-and-older population includes about 2.5 million people with Alzheimer’s disease, or 48 percent of the Alzheimer’s population age 65 and older.⁽⁴⁷⁾
- When the first wave of baby boomers reaches age 85 (in 2031), an estimated 3.5 million people age 85 and older will have Alzheimer’s.⁽⁴⁷⁾

figure 4:

Projected Numbers of People Age 65 and Over in the U.S. Population with Alzheimer’s Disease Using the U.S. Census Bureau Estimates of Population Growth*



*Numbers indicate middle estimates per decade. Colored area indicates low and high estimates per decade.

Created from data from Hebert et al.^{(47), A11}

table 2:

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

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

table 2 (continued)

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

Created from data from Hebert et al.^{(79), A10}

MORTALITY

ALZHEIMER'S DISEASE IS THE **SIXTH-LEADING** CAUSE OF DEATH IN THE UNITED STATES.

Alzheimer's disease is the
fifth-leading cause of death
for those age 65 and older.⁽⁸²⁾

65

Based on 2008 final data from the National Center for Health Statistics, Alzheimer’s was reported as the underlying cause of death for 82,435 people.⁽⁸²⁾ However, death certificates for individuals with Alzheimer’s often list acute conditions as the primary cause of death rather than Alzheimer’s.⁽⁸³⁻⁸⁶⁾ Thus, Alzheimer’s disease is likely a contributing cause of death for even more Americans than indicated by official government data.

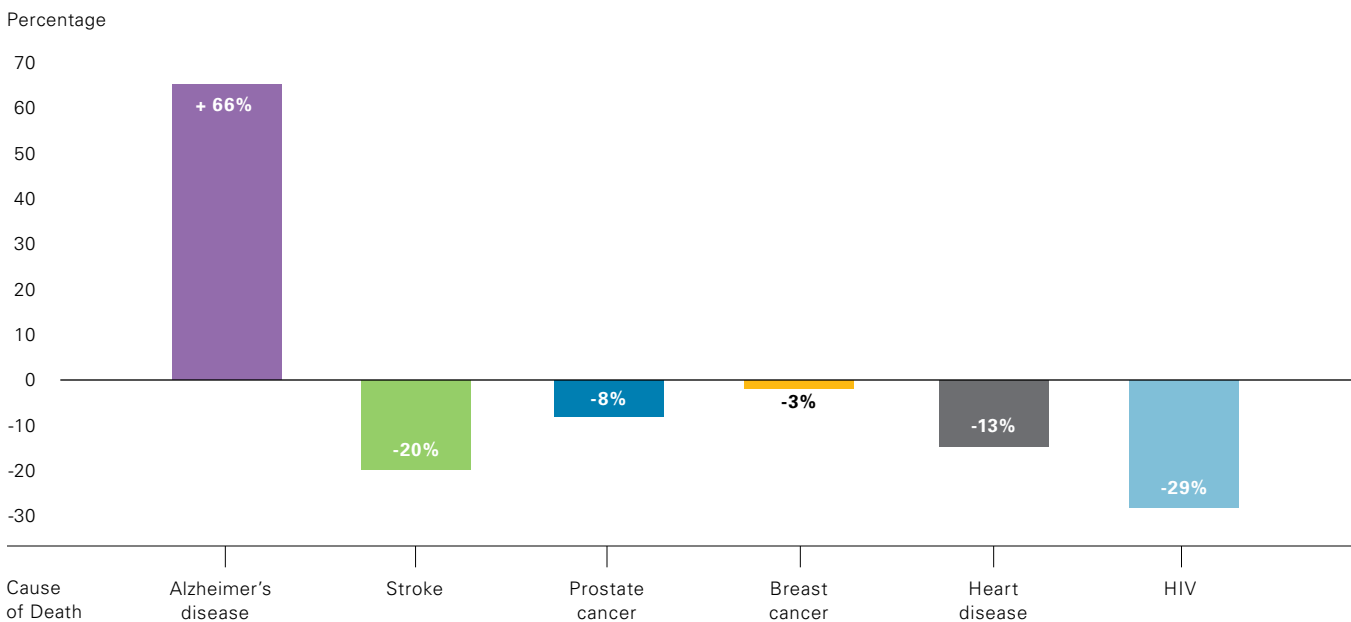
Deaths from Alzheimer’s Disease

Alzheimer’s is becoming a more common cause of death as the populations of the United States and other countries age. While deaths from other major causes continue to experience significant declines, those from Alzheimer’s disease have continued to rise. Between 2000 and 2008, 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).^(82, 87)

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.⁽⁸⁸⁻⁸⁹⁾ The situation has been described as a “blurred distinction between death *with* dementia and death *from* dementia.”⁽⁹⁰⁾ 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.⁽⁹¹⁾

figure 5: Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2008



Created from data from the National Center for Health Statistics⁽⁸⁷⁾ and Miniño et al.⁽⁸²⁾

table 3:

Number of Deaths and Annual Mortality Rate (per 100,000) Due to Alzheimer's Disease, by State, 2008

State	Number of Deaths	Rate	State	Number of Deaths	Rate
Alabama	1,518	32.6	Montana	294	30.4
Alaska	80	11.7	Nebraska	610	34.2
Arizona	2,099	32.3	Nevada	279	10.7
Arkansas	893	31.3	New Hampshire	393	29.9
California	10,098	27.5	New Jersey	1,857	21.4
Colorado	1,353	27.4	New Mexico	366	18.4
Connecticut	839	24.0	New York	2,303	11.8
Delaware	204	23.4	North Carolina	2,624	28.5
District of Columbia	132	22.3	North Dakota	312	48.6
Florida	4,743	25.9	Ohio	4,285	37.3
Georgia	1,929	19.9	Oklahoma	1,061	29.1
Hawaii	218	16.9	Oregon	1,302	34.4
Idaho	393	25.8	Pennsylvania	3,863	31.0
Illinois	3,192	24.7	Rhode Island	359	34.2
Indiana	1,971	30.9	South Carolina	1,492	33.3
Iowa	1,332	44.4	South Dakota	402	50.0
Kansas	961	34.3	Tennessee	2,423	39.0
Kentucky	1,370	32.1	Texas	5,280	21.7
Louisiana	1,361	30.9	Utah	409	14.9
Maine	450	34.2	Vermont	218	35.1
Maryland	1,016	18.0	Virginia	1,763	22.7
Massachusetts	1,832	28.2	Washington	3,105	47.4
Michigan	2,739	27.4	West Virginia	662	36.5
Minnesota	1,344	25.7	Wisconsin	1,655	29.4
Mississippi	916	31.2	Wyoming	125	23.5
Missouri	2,010	34.0	U.S. Total	82,435	27.1

Created from data from Miniño et al.⁽⁹²⁾

Another way to describe the impact of Alzheimer’s disease on mortality is through a statistic known as population attributable risk. It represents the proportion of deaths (in a specified amount of time) in a population that may be preventable if a disease were eliminated. The population attributable risk of Alzheimer’s disease on mortality over five years in people age 65 and older is estimated to be between 5 percent and 15 percent.⁽⁹²⁻⁹³⁾ This means that 5 to 15 percent of all deaths in older people can be attributed to Alzheimer’s disease.

State-by-State Deaths from Alzheimer’s Disease

Table 3 provides information on the number of deaths due to Alzheimer’s by state in 2008. The information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death, defined by the World Health Organization as “the disease or injury which initiated the train of events leading directly to death.”⁽⁸²⁾ The table also provides annual mortality rates by state to compare the risk of death due to Alzheimer’s disease across states with varying population sizes. For the United States as a whole, in 2008, the mortality rate for Alzheimer’s disease was 27.1 deaths per 100,000 people.

Death Rates by Age

Although people younger than 65 can develop and die from Alzheimer’s disease, the highest risk of death from Alzheimer’s is in people age 65 or older. As seen in Table 4, death rates for Alzheimer’s increase dramatically with age. To put these age-related differences into perspective, in the United States in 2008, the total mortality rates from all causes of death were 2.5 times as high for those age 75 to 84 as for people age 65 to 74 and 6.5 times as high for those age 85 and older as for people age 65 to 74. For diseases of the heart, mortality rates were 2.8 times and 9.3 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

table 4: U.S. Alzheimer’s Death Rates (per 100,000) by Age, 2000, 2002, 2004, 2006 and 2008

Age	2000	2002	2004	2006	2008
45–54	0.2	0.1	0.2	0.2	0.2
55–64	2.0	1.9	1.9	2.1	2.2
65–74	18.7	19.7	19.7	20.2	21.5
75–84	139.6	158.1	168.7	175.6	193.3
85+	667.7	752.3	818.8	848.3	910.1
Rate*	17.6	20.4	22.5	24.2	27.1

*Reflects average death rate for ages 45 and older.

Created from data from Miniño et al.⁽⁸²⁾

death rates were 9.0 times as high for people age 75 to 84 and 42.3 times as high for people 85 and older compared with people age 65 to 74.⁽⁸²⁾ This large age-related increase in death rates due to Alzheimer’s underscores the lack of a cure or effective treatments for the disease.

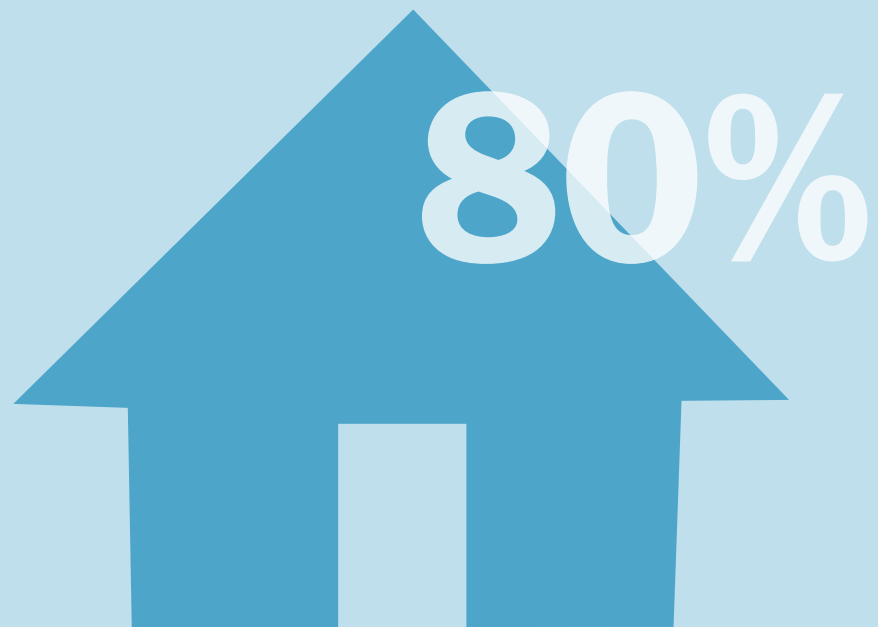
Duration of Illness from Diagnosis to Death

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.⁽⁹³⁻⁹⁷⁾ This indicates the slow, insidious nature of the progression of Alzheimer’s. 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.⁽⁹¹⁾ Much of this time will be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer’s compared with only 4 percent of the general population.⁽⁹¹⁾ 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.⁽⁹⁸⁾ 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

OVER 15 MILLION
AMERICANS PROVIDE
UNPAID CARE FOR A
PERSON WITH ALZHEIMER'S
OR OTHER DEMENTIAS.

Eighty percent of care
provided at home is delivered
by family caregivers.



Unpaid Caregivers

Over 15 million Americans provide unpaid care for a person with Alzheimer’s disease or other dementias.^{A12} Unpaid caregivers are primarily family members, but they also may be other relatives and friends. In 2011, these people provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over \$210 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.⁽⁹⁹⁾ Caring for a person with Alzheimer’s or other dementias 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 health, employment, income and family finances.^{A13} However, a variety of interventions have been developed that may help caregivers with the challenges of caregiving (Table 5, page 35).

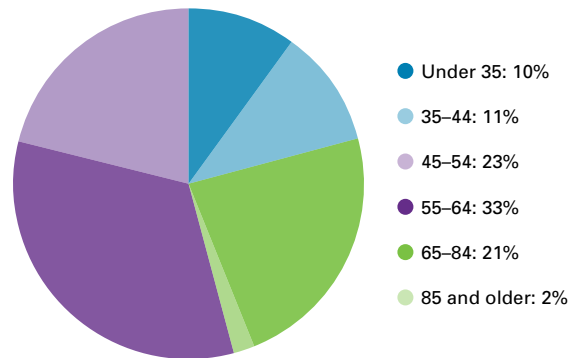
Who are the Caregivers?

Information on caregivers of people with Alzheimer’s disease and other dementias comes from nationally representative surveys that vary in how data are collected. One source is the 2009 Behavioral Risk Factor Surveillance System (BRFSS) survey.⁽¹⁰⁰⁾ The BRFSS survey is an annual public health telephone survey conducted by each state and the District of Columbia in coordination with the U.S. Centers for Disease Control and Prevention.

The 2009 BRFSS surveys conducted in Illinois, Louisiana, Ohio and the District of Columbia included additional questions that enable examination of the differences between caregivers of someone with Alzheimer’s disease or other dementias and other caregivers.⁽¹⁰¹⁾ Over 6,800 caregivers in these states were surveyed. Compared with caregivers of individuals with other conditions, Alzheimer’s and

figure 6:

Ages of Alzheimer’s and Other Dementia Caregivers, 2010



Created from data from the Alzheimer’s Association.^{A13}

dementia caregivers were more likely to be older (52 years versus 46 years), female (70.3 percent versus 59.2 percent), married (72.8 percent versus 63.1 percent) and white (81.0 percent versus 68.6 percent).

Surveys conducted for the Alzheimer’s Association^{A13} and the National Alliance on Caregiving (NAC) and AARP⁽¹⁰²⁾ found no difference in mean age, gender or marital status between caregivers of people with Alzheimer’s and other dementias and caregivers of people without Alzheimer’s and other dementias. This may reflect variations in the surveys’ sampling approach (for example, age and race differences between caregivers and non-caregivers in the BRFSS may have resulted from demographic differences between states that did and did not include the additional caregiver questions), inclusion criteria (the NAC/AARP survey required the care recipient to be at least 50 years old, whereas the BRFSS had no age requirement) or other factors.

The surveys also determined other demographic characteristics of unpaid caregivers of people with Alzheimer’s disease and other dementias. Most (56 percent) were 55 or older (Figure 6, page 27) and had less than a college degree (67 percent).^{A13} They tended to be the primary breadwinners of their household (55 percent), and nearly half were employed full or part time (44 percent).^{A13} Half of these caregivers lived in the same household as the person for whom they provided care. Thirty percent had children under 18 years old living with them; such caregivers are sometimes called the “sandwich generation” because they simultaneously provide care for two generations.⁽¹⁰²⁾ Almost half of caregivers take care of parents.^{(102), A13} Between 6 percent⁽¹⁰²⁾ and 17 percent^{A13} take care of a spouse.

Nine percent of unpaid caregivers of people with Alzheimer’s and other dementias live more than two hours from the person for whom they provide care, and another 6 percent live one to two hours away.⁽¹⁰²⁾ Depending on the definition of “long-distance caregiving,” these numbers indicate that 1.4 million to 2.3 million caregivers of people with Alzheimer’s and other dementias are long-distance caregivers.

Care Provided by Ethnic Communities

Information about the ethnic distribution of caregivers of people with Alzheimer’s disease and other dementias varies by survey. The proportion of caregivers who are non-Hispanic whites ranged from 70 percent^{A13} to 81 percent.⁽¹⁰¹⁻¹⁰²⁾ Non-Hispanic African-Americans comprised between 8 percent⁽¹⁰²⁾ and 15 percent^{A13} of caregivers. Hispanics made up from 1 percent⁽¹⁰¹⁾ to 12 percent of caregivers,^{A13} and Asian-Americans and other ethnic groups made up 1 to 2 percent of caregivers in several surveys.^{A13, (102)}

These surveys contained relatively small numbers of non-white caregivers, making it difficult to compare characteristics of caregivers across racial or ethnic

groups. However, compared with other surveys, the sampling of minorities in the NAC/AARP survey provided more stable estimates of minority caregivers and allowed more stable comparisons across different racial and ethnic groups.

Among caregivers of a person with Alzheimer’s disease or other dementias, specifically, notable differences from the NAC/AARP survey include the following: ⁽¹⁰²⁾

- Non-Hispanic whites are more likely than caregivers of other racial/ethnic groups to care for a parent (54 percent versus 38 percent).
- Non-Hispanic white and Asian-American caregivers are more likely to care for a married person (30 percent and 48 percent, respectively) compared with non-Hispanic African-American caregivers (11 percent).
- Hispanic and non-Hispanic African-American caregivers spend more time caregiving (approximately 30 hours per week) than non-Hispanic white caregivers (19.8 hours per week) and Asian-American caregivers (15.8 hours per week).
- Hispanic and non-Hispanic African-American caregivers are more likely to experience high burden from caregiving (45 percent and 57 percent, respectively), whereas only one-third of non-Hispanic whites and Asian-Americans report high burden.

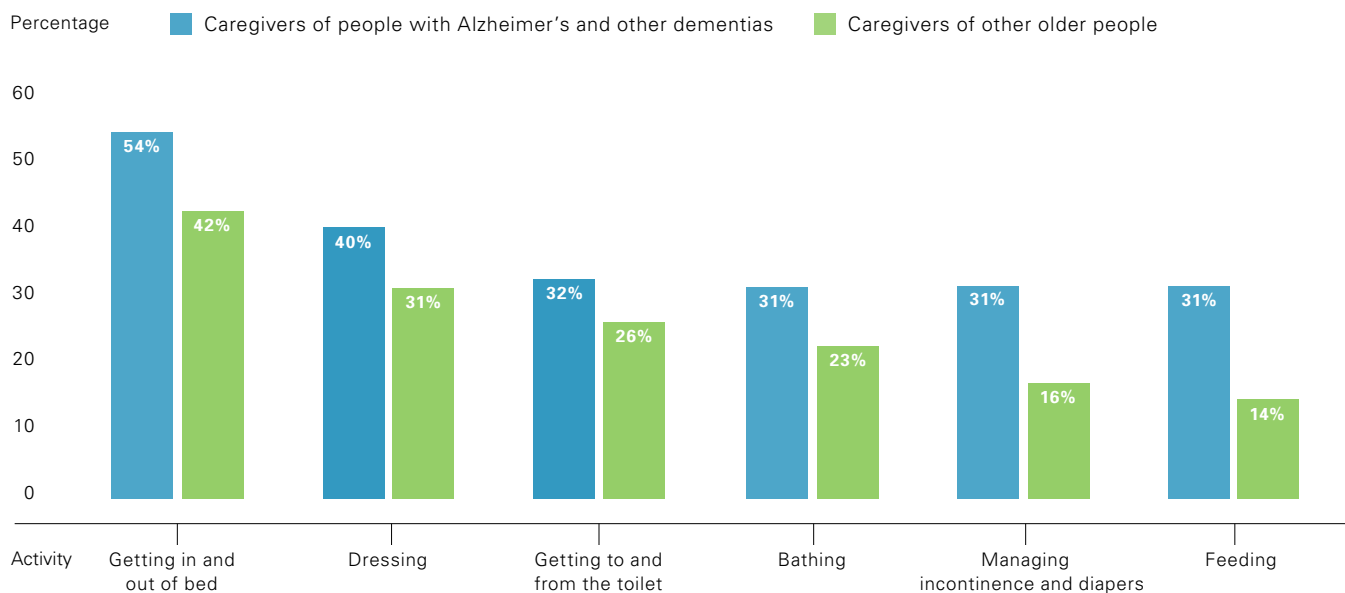
Caregiving Tasks

The type of help provided by family and other unpaid caregivers depends on the needs of the person with Alzheimer’s or other dementias and the stage of disease. Caregiving tasks can include:

- Instrumental activities of daily living (IADLs):
 - Shopping for groceries, preparing meals and providing transportation.

figure 7:

Proportion of Caregivers of People with Alzheimer’s and Other Dementias vs. Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2009

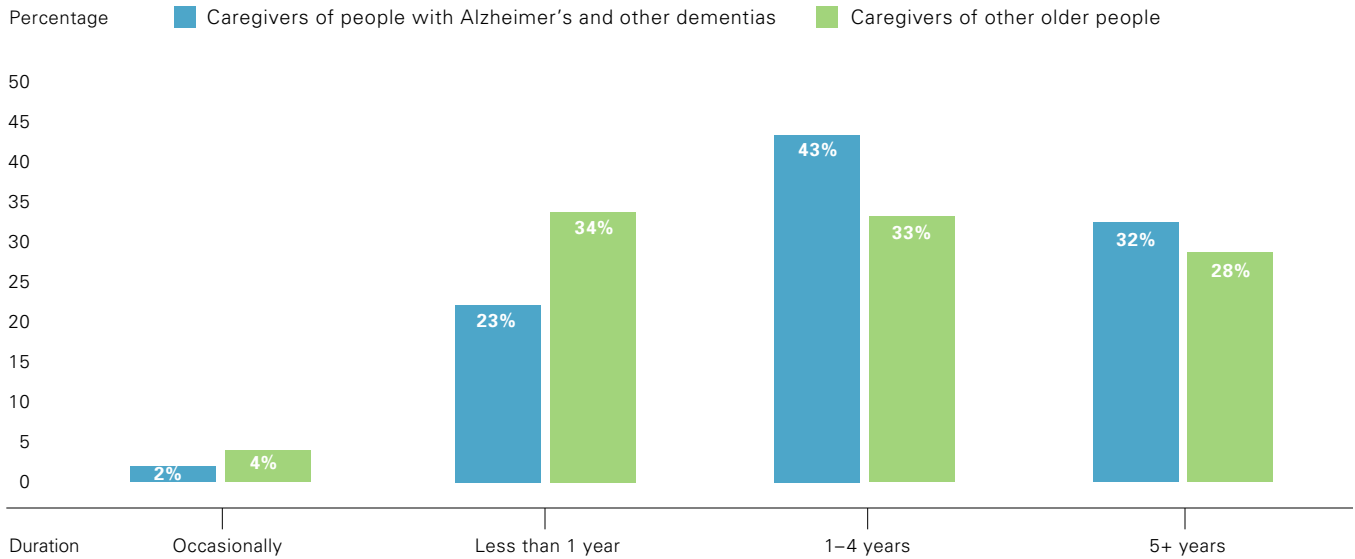


Created from data from the National Alliance for Caregiving and AARP.⁽¹⁰²⁾

- Helping the person take medications correctly and follow treatment recommendations for dementia and other medical conditions.
- Managing finances and legal affairs.
- Personal activities of daily living (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.
 - General additional responsibilities that are not necessarily specific tasks:
 - Overall management of getting through the day.
 - General family issues related to caring for a relative with Alzheimer’s disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver.

figure 8:

Proportion of Alzheimer’s and Dementia Caregivers vs. Caregivers of Other Older People by Duration of Caregiving, United States, 2009



Created from data from the National Alliance for Caregiving and AARP.⁽¹⁰²⁾

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 any given ADL. Over half of the caregivers of people with Alzheimer’s and other dementias report providing help with getting in and out of bed. About one-third also provide help with getting to and from the toilet, bathing, managing incontinence and feeding (Figure 7, page 29). Fewer caregivers of other older people report providing help with each of these types of care.⁽¹⁰²⁾

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). By contrast, caregivers of other older adults are less likely to advocate for their family member (50 percent) and supervise community-based care (33 percent).⁽¹⁰²⁾

When a person with Alzheimer’s or other dementias moves to an assisted living residence 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.⁽¹⁰⁴⁻¹⁰⁶⁾

Duration of Caregiving

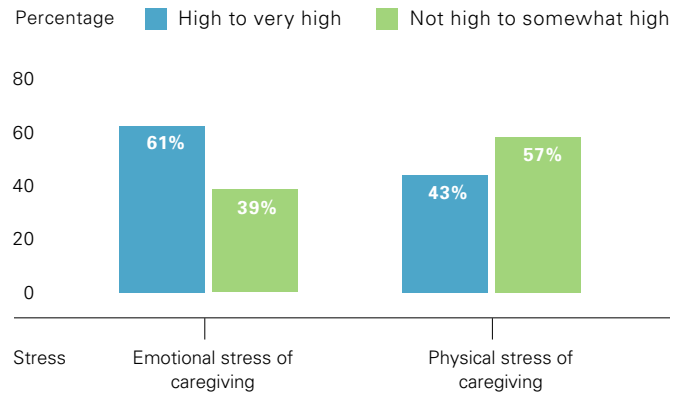
Caregivers of people with Alzheimer’s and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions. For example, among caregivers of people with Alzheimer’s disease, 23 percent had been caregivers for less than one year, 43 percent for one to four years, and 32 percent for five years or more. In contrast, more of their non-Alzheimer’s disease caregiver counterparts had been caregiving for less than one year (34 percent), and fewer of them had been caregiving for one to four years (33 percent) or longer (28 percent) (Figure 8).⁽¹⁰²⁾

Hours of Unpaid Care and Economic Value of Caregiving

In 2011, the 15.2 million family and other unpaid caregivers of people with Alzheimer’s disease and other dementias provided an estimated 17.4 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.^{A14} With this care valued at \$12.12 per hour,^{A15} the estimated economic value of the care provided by family and other unpaid caregivers of people with Alzheimer’s disease and other dementias was \$210.5 billion in 2011. Table 6 (pages 36 to 37) 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.

figure 9:

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



Created from data from the Alzheimer’s Association.^{A13}

Unpaid caregivers of people with Alzheimer’s disease and other dementias provided care valued at more than \$1 billion in each of 39 states. Unpaid caregivers in each of the four most populous states — California, Florida, New York and Texas — provided care valued at more than \$13 billion.

The average hours per week of unpaid care provided for people with Alzheimer’s and other dementias is greater if the caregiver lives with the care recipient, if the care recipient has coexisting medical conditions and as his or her disease progresses.^(102, 107-109)

Impact of Caregiving

Caring for a person with Alzheimer’s or other dementias 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.⁽¹¹⁰⁾

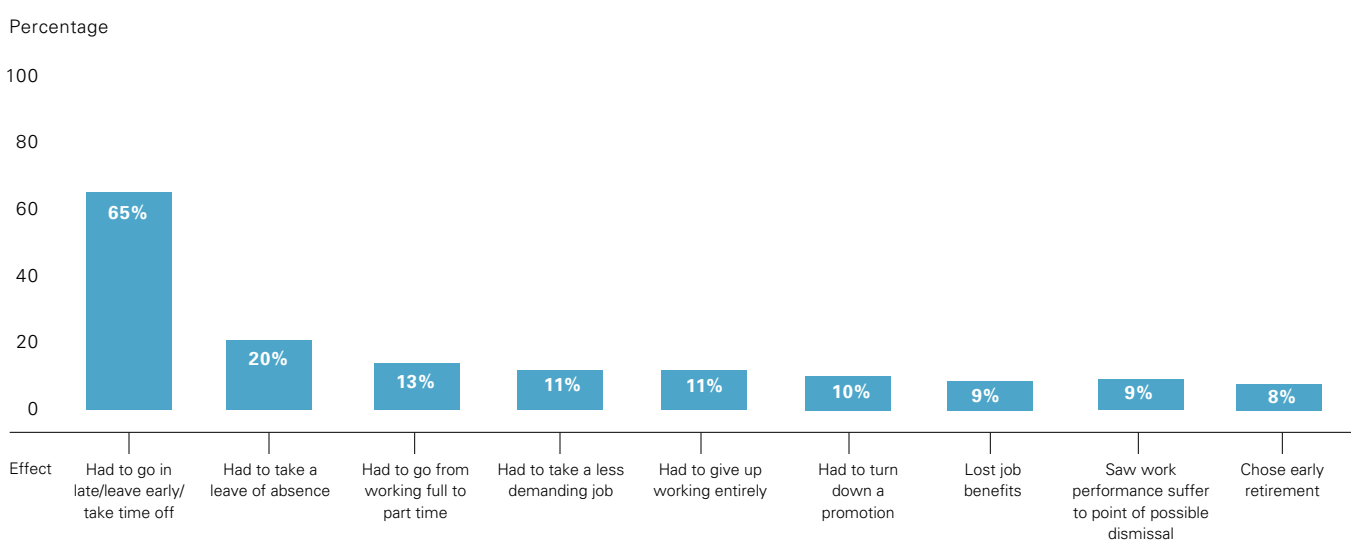
Caregiver Emotional Well-Being

Although caregivers report positive feelings about caregiving, including family togetherness and the

satisfaction of helping others,^{A13} they also report high levels of stress over the course of providing care, such as:

- 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, page 31).^{A13} In addition, about 33 percent of family caregivers of people with Alzheimer’s and other dementias report symptoms of depression.⁽¹¹¹⁻¹¹²⁾ 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).^{A13}
- The BRFSS caregiver survey administered in three states and the District of Columbia found that 36.5 percent of Alzheimer’s and dementia caregivers rated stress as the greatest difficulty they faced, compared with 23.6 percent of non-Alzheimer’s and dementia caregivers.⁽¹⁰¹⁾

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



Created from data from the Alzheimer’s Association.^{A13}

- The NAC/AARP survey found that 40 percent of caregivers reported high emotional stress. This survey found that caregivers who reported high emotional stress tended to be those who were women, the primary caregiver, living with the care recipient and feeling that they had no choice in taking on the role of caregiver.⁽¹⁰²⁾
- Caregivers who report being stressed because of the impaired person's behavioral symptoms are more likely to place their care recipient in a nursing home.⁽¹¹¹⁻¹¹²⁾ However, even after caregivers place their family member in a nursing home, many still report high levels of emotional and physical stress.^(102, 104, 106) 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.^{A13}
- 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.^(109, 113-114)

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, health care utilization and even death.⁽¹¹⁵⁾ Forty-three percent of caregivers of people with Alzheimer's disease or other dementias reported that the physical stress of caregiving was high to very high (Figure 9).^{A13} The physical and emotional impact of dementia caregiving is estimated to result in \$8.7 billion in increased health care costs in the United States.^{A16} Table 6 (pages 36 to 37) shows the estimated higher health care costs for Alzheimer's and dementia caregivers in each state.

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).^{A13} Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor,⁽¹¹⁵⁾ and they were more likely than caregivers of other older people to say that caregiving made their health worse.⁽¹⁰²⁻¹⁰³⁾

Data from the BRFSS caregiver survey found that Alzheimer's and dementia caregivers were more than twice as likely as non-Alzheimer's caregivers to say the greatest difficulty of caregiving is that it creates or exacerbates their own health problems.⁽¹⁰¹⁾

Caregivers of people with Alzheimer's and other dementias may also have difficulty maintaining healthy behaviors, as only 3 percent reported using exercise as a way of getting relief from their caregiving responsibilities.⁽¹¹⁶⁾ However, other studies suggest that caregiving tasks keep older caregivers more physically active than non-caregivers.⁽¹¹⁷⁾

Research suggests that the chronic stress of caregiving may lead to conditions such as metabolic syndrome (a combination of abdominal obesity, high blood pressure, high blood glucose and high cholesterol that is often associated with developing diabetes and heart disease). Metabolic syndrome, in turn, may have detrimental effects on health.⁽¹¹⁸⁾

Physiological Changes

Caregivers of a spouse with Alzheimer's or other dementias are also more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones,⁽¹¹⁹⁾ reduced immune function,⁽¹²⁰⁻¹²¹⁾ slow wound healing⁽¹²²⁾ and increased incidence of hypertension,⁽¹²³⁾ coronary heart disease⁽¹²⁴⁾ and impaired endothelial function, all of which may be associated with increased risk of cardiovascular disease.⁽¹²⁵⁾

Health Care 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.⁽¹²⁶⁾

Mortality

The health of a person with dementia may also affect the caregiver's mortality. In one study, caregivers of a spouse who was hospitalized and had a medical record of dementia were more likely to die in the following year than caregivers whose spouse was hospitalized but did not have dementia, even after accounting for the age of the caregiver.⁽¹²⁷⁾ However, other research has found that this link does not always hold between providing care for a person with dementia and mortality. Some studies have found that caregivers have lower mortality rates than non-caregivers.⁽¹²⁸⁻¹²⁹⁾

One study found that higher stress levels were associated with higher rates of mortality in both caregivers and non-caregivers.⁽¹²⁹⁾ These findings suggest that it is high stress, not caregiving per se, that increases the risk of mortality. Such results underscore the importance of documenting which aspects of caregiving may have adverse health effects on the caregiver, developing programs to help reduce adverse health effects related to caregiving and conducting additional research to better understand the subtleties of the connection between caregiving and mortality.

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: 65 percent said they

had to go in late, leave early or take time off, and 20 percent had to take a leave of absence. Other work-related changes pertaining to caregiving are summarized in Figure 10 (page 32).^{A13}

Interventions that May Improve Caregiver Outcomes

A variety of interventions have been tested with family caregivers of people with Alzheimer's disease and other dementias. The types and focus of these interventions are summarized in Table 5.⁽¹³⁰⁾ 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.⁽¹³¹⁾

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 increasing caregiver knowledge, skill and well-being; decreasing caregiver burden and depressive symptoms;⁽¹³⁰⁻¹³⁵⁾ and delaying time to nursing home placement, which could reduce overall health care costs.⁽¹³⁶⁻¹³⁷⁾

Paid Caregivers

Paid caregivers of people with Alzheimer's disease or other dementias include direct-care workers and professionals. Direct-care workers, such as nurse aides, home health aides and personal- and home-care aides, comprise the majority of the formal health care delivery system for older adults. Professionals who may receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers and others.⁽⁹⁹⁾

Direct-care workers' roles include assistance with bathing, dressing, housekeeping and food preparation. Their jobs may be rewarding and directly influence the

table 5:

Types and Focus of Caregiver Interventions

Type of Intervention	Description
Psychoeducational	Includes a structured program that provides information about the disease, resources and services and about how to expand skills to effectively respond to symptoms of the disease (i.e., cognitive impairment, behavioral symptoms and care-related needs). Includes lectures, discussions and written materials and is led by professionals with specialized training.
Supportive	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.
Psychotherapy	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.
Multicomponent	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.⁽¹³⁰⁾

quality of care provided. However, 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.⁽⁹⁹⁾

It is projected that the United States will need an additional 3.5 million health care providers by 2030 just to maintain the current ratio of health care workers to the population.⁽⁹⁹⁾ The need for health care 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.⁽⁹⁹⁾

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.⁽⁹⁹⁾

table 6:

Number of Alzheimer's and Dementia Caregivers, Hours of Unpaid Care, Economic Value of the Care and Higher Health Care Costs of Caregivers, by State, 2011*

State	Number of Alzheimer's/ Dementia Caregivers	Hours of Unpaid Care	Value of Unpaid Care	Higher Health Care Costs of Caregivers ^{A16}
Alabama	295,297	336,284,751	\$4,075,771,180	\$153,367,534
Alaska	32,089	36,542,585	\$442,896,129	\$24,403,258
Arizona	298,050	339,418,784	\$4,113,755,662	\$134,883,210
Arkansas	171,429	195,223,100	\$2,366,103,974	\$87,632,733
California	1,507,396	1,716,623,053	\$20,805,471,403	\$785,082,435
Colorado	227,372	258,931,710	\$3,138,252,321	\$113,600,337
Connecticut	174,032	198,187,153	\$2,402,028,291	\$125,378,858
Delaware	50,226	57,197,814	\$693,237,500	\$35,363,057
District of Columbia	25,725	29,296,062	\$355,068,269	\$22,247,375
Florida	998,684	1,137,301,634	\$13,784,095,810	\$594,293,482
Georgia	487,575	555,250,899	\$6,729,640,892	\$221,645,679
Hawaii	62,607	71,296,910	\$864,118,545	\$35,778,255
Idaho	75,196	85,633,757	\$1,037,881,136	\$35,394,289
Illinois	581,773	662,523,319	\$8,029,782,630	\$327,515,576
Indiana	326,151	371,420,588	\$4,501,617,522	\$180,794,933
Iowa	134,338	152,984,086	\$1,854,167,121	\$77,522,771
Kansas	148,508	169,121,337	\$2,049,750,604	\$83,682,912
Kentucky	264,658	301,392,092	\$3,652,872,155	\$144,611,313
Louisiana	224,682	255,867,406	\$3,101,112,962	\$127,007,591
Maine	67,456	76,819,336	\$931,050,350	\$47,836,204
Maryland	278,490	317,144,389	\$3,843,789,991	\$173,722,031
Massachusetts	320,694	365,206,782	\$4,426,306,199	\$247,757,832
Michigan	504,550	574,581,267	\$6,963,924,952	\$277,650,941
Minnesota	241,112	274,577,911	\$3,327,884,287	\$148,867,694
Mississippi	202,193	230,257,949	\$2,790,726,338	\$109,676,152

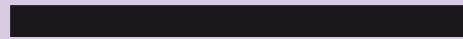
table 6 (continued)

State	Number of Alzheimer's/ Dementia Caregivers	Hours of Unpaid Care	Value of Unpaid Care	Higher Health Care Costs of Caregivers ^{A16}
Missouri	307,276	349,926,190	\$4,241,105,423	\$177,995,547
Montana	46,799	53,294,667	\$645,931,370	\$25,887,532
Nebraska	79,802	90,878,844	\$1,101,451,591	\$46,893,077
Nevada	132,264	150,622,367	\$1,825,543,083	\$63,117,580
New Hampshire	63,975	72,854,161	\$882,992,429	\$41,762,194
New Jersey	435,305	495,725,694	\$6,008,195,408	\$274,669,182
New Mexico	104,833	119,383,774	\$1,446,931,343	\$57,967,569
New York	994,540	1,132,582,680	\$13,726,902,077	\$689,993,768
North Carolina	431,075	490,908,515	\$5,949,811,204	\$231,544,112
North Dakota	27,843	31,707,465	\$384,294,471	\$18,017,922
Ohio	586,878	668,336,953	\$8,100,243,871	\$345,333,151
Oklahoma	212,324	241,794,288	\$2,930,546,775	\$115,051,676
Oregon	165,806	188,819,908	\$2,288,497,287	\$91,032,239
Pennsylvania	664,384	756,600,213	\$9,169,994,588	\$427,038,350
Rhode Island	52,983	60,337,603	\$731,291,751	\$36,638,055
South Carolina	283,504	322,853,918	\$3,912,989,492	\$148,509,055
South Dakota	35,840	40,814,420	\$494,670,767	\$21,083,963
Tennessee	409,890	466,782,927	\$5,657,409,070	\$217,397,364
Texas	1,269,928	1,446,194,202	\$17,527,873,731	\$625,305,707
Utah	134,461	153,123,618	\$1,855,858,249	\$56,200,875
Vermont	29,534	33,633,747	\$407,641,008	\$18,792,895
Virginia	436,639	497,245,036	\$6,026,609,835	\$227,993,981
Washington	319,305	363,625,008	\$4,407,135,094	\$180,377,398
West Virginia	108,205	123,223,331	\$1,493,466,770	\$68,836,860
Wisconsin	188,140	214,254,380	\$2,596,763,084	\$113,966,816
Wyoming	26,920	30,656,898	\$371,561,603	\$15,779,781
U.S. Totals	15,248,740	17,365,265,478	\$210,467,017,597	\$8,652,903,101

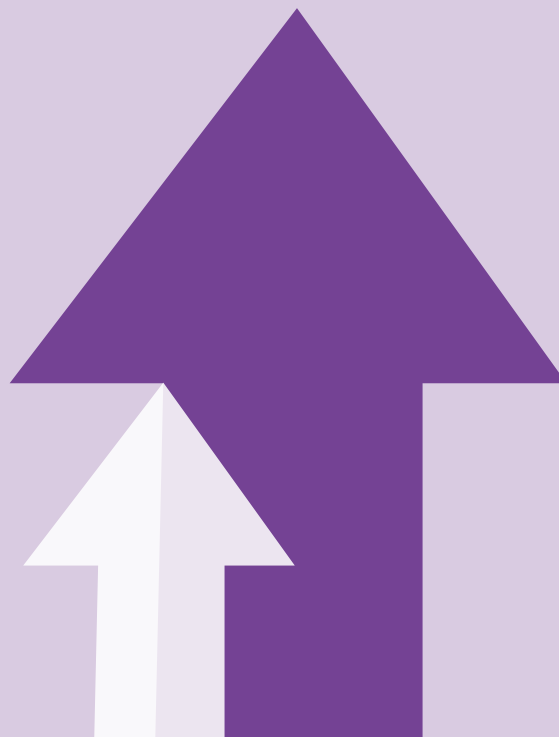
*Differences between U.S. totals and summing the state numbers are the result of rounding.

Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.^{A12, A14, A15, A16}

PAYMENTS FOR CARE FOR 2012 ARE ESTIMATED TO BE **\$200 BILLION.**



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



Aggregate payments for health care, long-term care and hospice for people with Alzheimer’s disease and other dementias are projected to increase from \$200 billion in 2012 to \$1.1 trillion in 2050 (in 2012 dollars).^{A17} Medicare and Medicaid cover about 70 percent of the costs of care. All costs are reported in 2011 dollars,^{A18} unless otherwise indicated.

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

Table 7 reports the average per person payments for health care and long-term care services for Medicare beneficiaries with Alzheimer’s disease and other dementias. In 2008, total per person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer’s and other dementias were three times as great as payments for other Medicare beneficiaries in the same age group (\$43,847 per person for those with Alzheimer’s and

other dementias compared with \$13,879 per person for those without Alzheimer’s and other dementias).^{(138), A19}

Twenty-nine percent of older individuals with Alzheimer’s disease and other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia.⁽¹³⁸⁾ Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people with Alzheimer’s and other dementias translates into high costs for the Medicaid program. In 2008, average Medicaid payments per person for Medicare beneficiaries age 65 and older with Alzheimer’s and other dementias were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer’s and other dementias (\$10,120 per person for individuals with Alzheimer’s and other dementias compared with \$527 for individuals without Alzheimer’s and other dementias; Table 7).⁽¹³⁸⁾

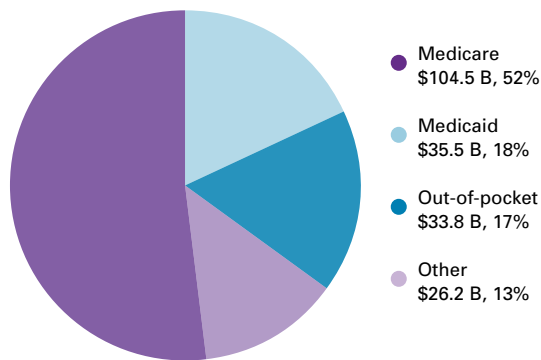
table 7: Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer’s Disease and Other Dementias and By Place of Residence, 2008 Medicare Current Beneficiary Survey, 2011 Dollars

Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer’s Disease and Other Dementias
	Overall	Community-Dwelling	Residential Facility	
Medicare	\$19,820	\$17,651	\$22,849	\$7,521
Medicaid	10,120	222	23,953	527
Uncompensated	273	392	107	308
HMO	994	1,543	227	1,450
Private insurance	2,262	2,485	1,948	1,521
Other payer	906	164	1,942	143
Out-of-pocket	9,368	3,167	18,035	2,284
Total*	\$43,847	\$25,804	\$69,066	\$13,879

*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.⁽¹³⁸⁾

figure 11: **Aggregate Costs of Care by Payer for Americans Age 65 and Older with Alzheimer’s Disease and Other Dementias, 2012***

Total cost: \$200 Billion (B)



*Data are in 2012 dollars.

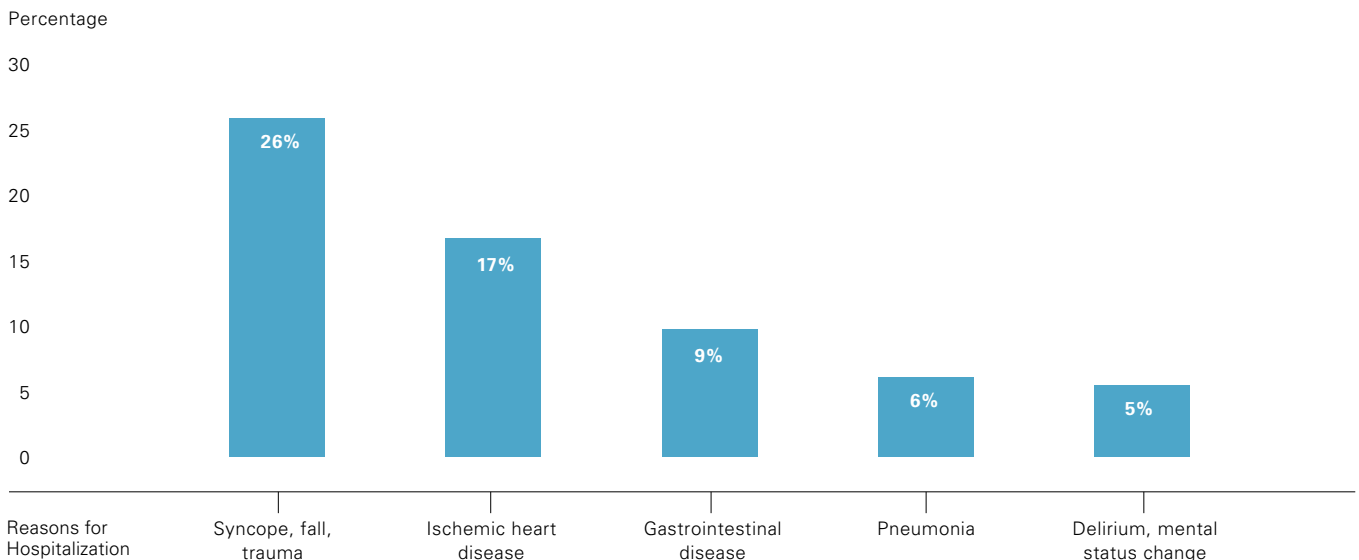
Created from data from the application of The Lewin Model^{A17} to data from the Medicare Current Beneficiary Survey for 2008.⁽¹³⁸⁾ “Other” payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

Total payments for 2012 are estimated at \$200 billion, including \$140 billion for Medicare and Medicaid combined in 2012 dollars (Figure 11). These figures are derived from a model developed by The Lewin Group using data from the Medicare Current Beneficiary Survey and The Lewin Group’s Long-Term Care Financing Model.^{A17}

Use and Costs of Health Care Services

People with Alzheimer’s disease and other dementias have more than three times as many hospital stays as other older people.⁽¹³⁸⁾ Moreover, the use of health care 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, chronic kidney disease, chronic obstructive

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



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

Created from data from Rudolph et al.⁽¹³⁹⁾

pulmonary disease, stroke or cancer who *also* have Alzheimer's and other dementias have higher use and costs of health care services than do people with these medical conditions but no coexisting Alzheimer's and other dementias.

Use of Health Care Services

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

- **Hospital.** In 2008, there were 780 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's disease or other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries without these conditions.⁽¹³⁸⁾ 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).⁽¹³⁹⁾
- **Skilled nursing facility.** In 2008, there were 349 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 39 stays per 1,000 beneficiaries for people without these conditions.⁽¹³⁸⁾
- **Home health care.** In 2008, 23 percent of Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias had at least one home health visit during the year, compared with 10 percent of Medicare beneficiaries without Alzheimer's and other dementias.⁽¹⁴⁰⁾

table 8: Average Annual Per-Person Payments, from All Sources, for Health Care Services Provided to Medicare Beneficiaries Age 65 and Older with and without Alzheimer's Disease and Other Dementias, 2008 Medicare Current Beneficiary Survey, 2011 Dollars

	Beneficiaries with Alzheimer's Disease and Other Dementias	Beneficiaries without Alzheimer's Disease and Other Dementias
Inpatient hospital	\$9,732	\$3,912
Medical provider*	5,967	3,956
Skilled nursing facility	3,812	444
Nursing home	17,693	786
Hospice	1,749	171
Home health care	1,402	452
Prescription medications**	2,681	2,732

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

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.⁽¹³⁸⁾

Costs of Health Care Services

With the exception of prescription medications, average per person payments for all other health care services (i.e., hospital, physician and other medical provider, nursing home, skilled nursing facility and home health care) were higher for Medicare beneficiaries with Alzheimer's disease and other dementias than for other Medicare beneficiaries in the same age group (Table 8).⁽¹³⁸⁾

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

Medicare beneficiaries with Alzheimer’s disease and other dementias are more likely than those without the disease to have other chronic conditions.⁽¹⁴⁰⁾ Table 9 reports the proportion of people with Alzheimer’s disease and other dementias who have certain coexisting medical conditions. In 2009, 30 percent of Medicare beneficiaries age 65 and older with Alzheimer’s and other dementias also had coronary heart disease, 29 percent also had diabetes, 22 percent also had congestive heart failure, 17 percent also had chronic kidney disease and 17 percent also had chronic obstructive pulmonary disease.⁽¹⁴⁰⁾

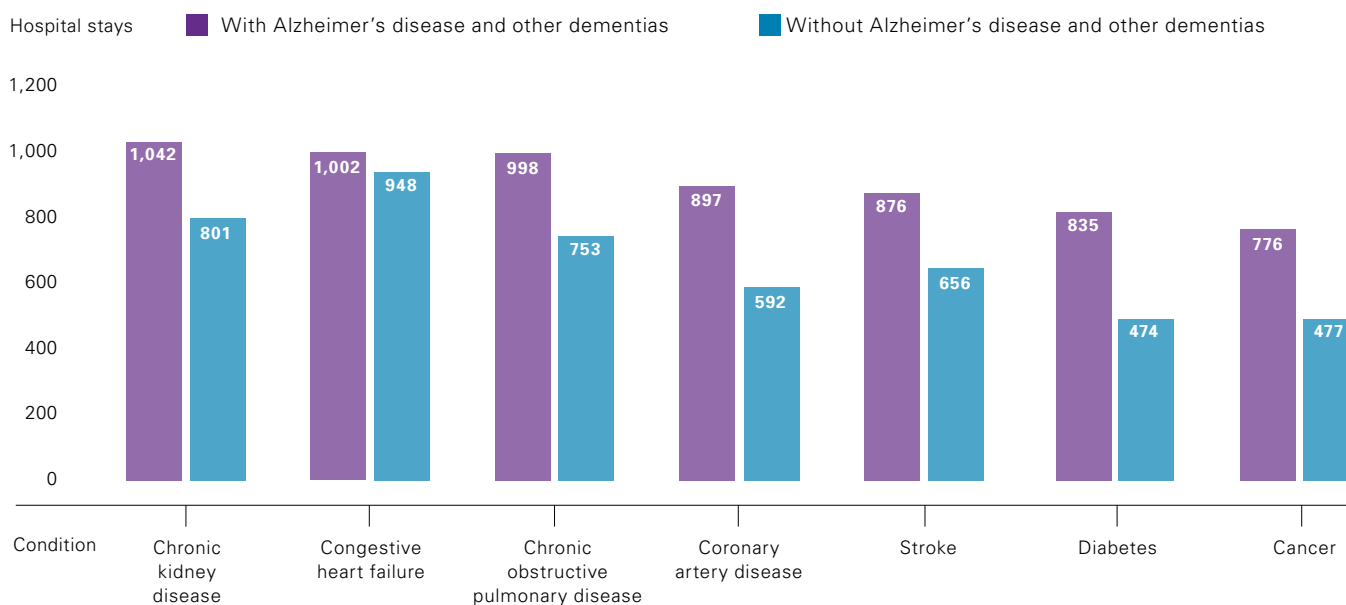
People with serious coexisting medical conditions and Alzheimer’s and other dementias are more likely to be hospitalized than people with the same coexisting medical conditions but without Alzheimer’s and other dementias (Figure 13).⁽¹⁴⁰⁾

table 9: Specific Coexisting Medical Conditions Among Medicare Beneficiaries Age 65 and Older with Alzheimer’s Disease and Other Dementias, 2009

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

Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.⁽¹⁴⁰⁾

figure 13: Hospital Stays per 1,000 Beneficiaries Age 65 and Older with Specified Coexisting Medical Conditions, with and without Alzheimer’s Disease and Other Dementias, 2009



Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.⁽¹⁴⁰⁾

table 10:

Average Annual Per-Person Payments by Type of Service and Coexisting Medical Condition for Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's Disease and Other Dementias, 2009, in 2011 Dollars*

Medical Condition by Alzheimer's Disease/Dementia (AD/D) Status	Average per-Person Medicare Payment					
	Total Medicare Payments	Hospital Care	Physician Care	Skilled Nursing Facility Care	Home Health Care	Hospice Care
Coronary heart disease						
With AD/D	\$25,389	\$9,138	\$1,632	\$4,034	\$2,531	\$2,184
Without AD/D	15,748	6,566	1,248	1,229	1,090	318
Diabetes						
With AD/D	24,776	8,696	1,528	3,911	2,608	1,973
Without AD/D	13,695	5,359	1,075	1,117	1,033	223
Congestive heart failure						
With AD/D	24,331	10,378	1,685	4,472	2,650	2,739
Without AD/D	27,946	10,626	1,683	2,423	2,088	775
Chronic kidney disease						
With AD/D	29,952	11,455	1,807	4,500	2,474	2,382
Without AD/D	23,045	9,601	1,582	1,856	1,532	493
Chronic obstructive pulmonary disease						
With AD/D	27,543	10,209	1,720	4,409	2,625	2,466
Without AD/D	18,851	8,001	1,413	1,607	1,410	619
Stroke						
With AD/D	25,843	9,003	1,585	4,232	2,398	2,567
Without AD/D	18,554	6,979	1,348	2,170	1,760	607
Cancer						
With AD/D	23,782	8,095	1,489	3,392	2,066	2,689
Without AD/D	15,564	5,492	1,142	918	733	551

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

Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.⁽¹⁴⁰⁾

Similarly, average per-person payments for many health care services are higher for people who have other serious coexisting medical conditions in addition to Alzheimer's and other dementias than for people who have the same medical conditions but no Alzheimer's or other dementias. Table 10 shows the average per-person total Medicare payments and average per-person Medicare payments for hospital, physician, skilled nursing facility, home health and

hospice care for beneficiaries with other serious medical conditions who either do or do not have Alzheimer's and other dementias.⁽¹⁴⁰⁾ Medicare beneficiaries with a serious medical condition and Alzheimer's and other dementias had higher average per-person payments than Medicare beneficiaries with the same medical condition but without dementia, with the exceptions of hospital care and total Medicare payments for congestive heart failure.

Use and Costs of Long-Term Care Services

An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias.^(138, 141) Of those with Alzheimer's disease and other dementias who live in the community, 75 percent live with someone and the remaining 25 percent live alone.⁽¹³⁸⁾ As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers.⁽⁷⁸⁾ 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, \$70 per day⁽¹⁴¹⁾; assisted living, \$41,724 per year⁽¹⁴¹⁾; and nursing home care, \$79,110 to \$87,235 per year⁽¹⁴¹⁾), individuals often spend down their assets and eventually qualify for Medicaid. Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illness.

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.⁽¹⁴²⁾ 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.⁽¹⁴²⁾

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 nursing home care.

- *Home care.* According to state home care programs in Connecticut, Florida and Michigan, more than one-third (about 37 percent) of older people who receive primarily nonmedical home care services, such as personal care and homemaker services, have cognitive impairment consistent with dementia.⁽¹⁴³⁻¹⁴⁵⁾
- *Adult day center services.* At least half of elderly attendees at adult day centers have dementia.⁽¹⁴⁶⁻¹⁴⁷⁾
- *Nursing home care.* Sixty-four percent of Medicare beneficiaries age 65 and older living in a nursing home have Alzheimer's disease and other dementias.⁽¹³⁸⁾ In 2009, 68 percent of all nursing home residents had some degree of cognitive impairment, including 27 percent who had very mild to mild cognitive impairment and 41 percent who had moderate to severe cognitive impairment (Table 11).⁽¹⁴⁸⁾ In June 2011, 47 percent of all nursing home residents had a diagnosis of dementia in their nursing home record.⁽¹⁴⁹⁾
- *Alzheimer's special care unit.* Nursing homes had a total of 80,866 beds in Alzheimer's special care units in June 2011.⁽¹⁵⁰⁾ These Alzheimer's special care unit beds accounted for 72 percent of all special care unit beds and 5 percent of all nursing home beds at that time. The number of nursing home beds in Alzheimer's special care units increased in the 1980s but has decreased since 2004, when there were 93,763 beds in such units.⁽¹⁵¹⁾

table 11: Cognitive Impairment in Nursing Home Residents, by State, 2009

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

table 11 (continued): Cognitive Impairment in Nursing Home Residents, by State, 2009

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

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

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

Created from data from the U.S. Department of Health and Human Services.⁽¹⁴⁸⁾

Costs of Long-Term Care Services

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

- *Home care.* In 2011, the average cost for a nonmedical home health aide was \$21 per hour, or \$168 for an eight-hour day.⁽¹⁴¹⁾
- *Adult day centers.* In 2011, the average cost of adult day services was \$70 per day.⁽¹⁴¹⁾ Ninety-five percent of adult day centers provided care for people with Alzheimer's disease and other dementias, and 2 percent of these centers charged an additional fee for these clients.
- *Assisted living.* In 2011, the average cost for basic services in an assisted living facility was \$3,477 per month, or \$41,724 per year.⁽¹⁴¹⁾ Seventy-two percent of assisted living facilities provided care to people with Alzheimer's disease and other dementias, and 52 percent had a specific unit for people with Alzheimer's and other dementias. In facilities that charged a different rate for individuals with Alzheimer's and other dementias, the average rate was \$4,619 per month, or \$55,428 per year, for this care.
- *Nursing homes.* In 2011, the average cost for a private room in a nursing home was \$239 per day, or \$87,235 per year. The average cost of a semi-private room in a nursing home was \$214 per day, or \$78,110 per year.⁽¹⁴¹⁾ Eighty percent of nursing homes that provide care for people with Alzheimer's disease charge the same rate. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with Alzheimer's disease was \$12 higher (\$251 per day, or \$91,615 per year) and the average cost for a semi-private room was \$8

higher (\$222 per day, or \$81,030 per year).⁽¹⁴¹⁾

Thirty-six percent of nursing homes had separate Alzheimer's special care units.⁽¹⁴¹⁾

Affordability of Long-Term Care Services

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

- Income and asset data are not available for people with Alzheimer's or other dementias specifically, but 50 percent of Medicare beneficiaries had incomes of \$21,774 or less, and 25 percent had incomes of \$13,116 or less in 2010 (in 2011 dollars). Two hundred percent of the federal poverty level was \$21,780 for a household of one and \$29,420 for a household of two in 2011.⁽¹⁵²⁻¹⁵³⁾
- Fifty percent of Medicare beneficiaries had retirement accounts of \$2,095 or less, 50 percent had financial assets of \$30,287 or less, and 50 percent had total savings of \$52,793 or less, equivalent to less than one year of nursing home care.⁽¹⁵²⁾

Long-Term Care Insurance

In 2010, about 7.3 million people had long-term care insurance policies.⁽¹⁵⁴⁾ Private health and long-term care insurance policies funded only about 9 percent of total long-term care spending in 2006, representing \$19.0 billion of the \$210.5 billion (in 2011 dollars) in long-term care spending.⁽¹⁵⁵⁾

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. Most nursing home residents who qualify for Medicaid must spend all of their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only

makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse.

The federal and state governments share in managing and funding the program, and states differ greatly in the services covered by their Medicaid programs. Medicaid plays a critical role for people with dementia who can no longer afford to pay for their long-term care expenses on their own. In 2008, 58 percent of Medicaid spending on long-term care was allocated to institutional care, and the remaining 42 percent was allocated to home and community-based services.⁽¹⁵⁵⁾

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be \$35.5 billion in 2012.^{A17} About half of all Medicaid beneficiaries with Alzheimer's disease and other dementias are nursing home residents, and the rest live in the community.⁽¹⁵⁶⁾ Among nursing home residents with Alzheimer's disease and other dementias, 51 percent rely on Medicaid to help pay for their nursing home care.⁽¹⁵⁶⁾

In 2008, total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with Alzheimer's and other dementias is due to the costs associated with long-term care (i.e., nursing homes and other residential care facilities, such as assisted living facilities). Medicaid paid \$23,953 (in 2011 dollars) per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility compared with \$222 for those with the diagnosis living in the community and \$527 for those without the diagnosis (Table 7, page 39).⁽¹³⁸⁾

Out-of-Pocket Costs for Health Care and Long-Term Care Services

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

In 2008, Medicare beneficiaries age 65 and older with Alzheimer's and other dementias paid \$9,368 out-of-pocket on average for health care and long-term care services that were not covered by additional sources (Table 7, page 39).⁽¹³⁸⁾ Average per-person out-of-pocket payments were highest for individuals living in nursing homes and assisted living facilities and were almost six times as great as the average per-person payments for individuals with Alzheimer's disease and other dementias living in the community (\$3,167 per person).⁽¹³⁸⁾ In 2012, total out-of-pocket spending for individuals with Alzheimer's and other dementias is estimated at \$33.8 billion (Figure 11, page 40).^{A17}

Before implementation of the Medicare Part D Prescription Drug Benefit in 2006, out-of-pocket expenses were increasing annually for Medicare beneficiaries.⁽¹⁵⁷⁾ In 2003, out-of-pocket costs for prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries age 65 and older.⁽¹⁵⁸⁾ 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.⁽¹⁵⁹⁾ 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 was \$40.72 in 2011 (range: \$14.80 to \$133.40).⁽¹⁵⁹⁾ As noted earlier,

however, the most expensive component of out-of-pocket costs for people with Alzheimer's and other dementias is nursing home and other residential care. Out-of-pocket costs for these services are likely to continue increasing.

Use and Costs of Hospice Care

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

In 2009, 6 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (61,146 people).⁽¹⁶⁰⁾ An additional 11 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (119,872 people).⁽¹⁶⁰⁾ Hospice length of stay has increased over the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of Alzheimer's disease increased from 67 days in 1998 to 106 days in 2009.⁽¹⁶⁰⁾ The average length of stay for hospice beneficiaries with a primary diagnosis of non-Alzheimer's dementia increased from 57 days in 1998 to 92 days in 2009.⁽¹⁶⁰⁾ Average per-person hospice care payments across all beneficiaries with Alzheimer's disease and other dementias were

10 times as great as average per-person payments for all other Medicare beneficiaries (\$1,749 per person compared with \$171 per person).⁽¹³⁸⁾

Projections for the Future

Total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias are projected to increase from \$200 billion in 2012 to \$1.1 trillion in 2050 (in 2012 dollars). This dramatic rise includes a six-fold increase in government spending under Medicare and Medicaid and a five-fold increase in out-of-pocket spending.^{A17}

SPECIAL REPORT

PEOPLE WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS WHO **LIVE ALONE.**

At least 800,000 Americans
with Alzheimer's disease
live alone.



The right to reside within one’s home is a fundamental human right, recognized by the Universal Declaration of Human Rights of the United Nations. Article 12 of that document states that “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation.”⁽¹⁶¹⁾ And Article 17 states that “No one shall be arbitrarily deprived of his property.”⁽¹⁶¹⁾ As people grow older, reaching age 65 and beyond, they are more likely to live alone, and those with severe cognitive impairment may not be able to care for themselves. Determining the best way to provide a safe environment and adequate care for someone with severe cognitive impairment who chooses to live alone is often difficult and fraught with ethical, societal and emotional dilemmas.^(111, 162) This Special Report attempts to raise awareness of the issues that arise

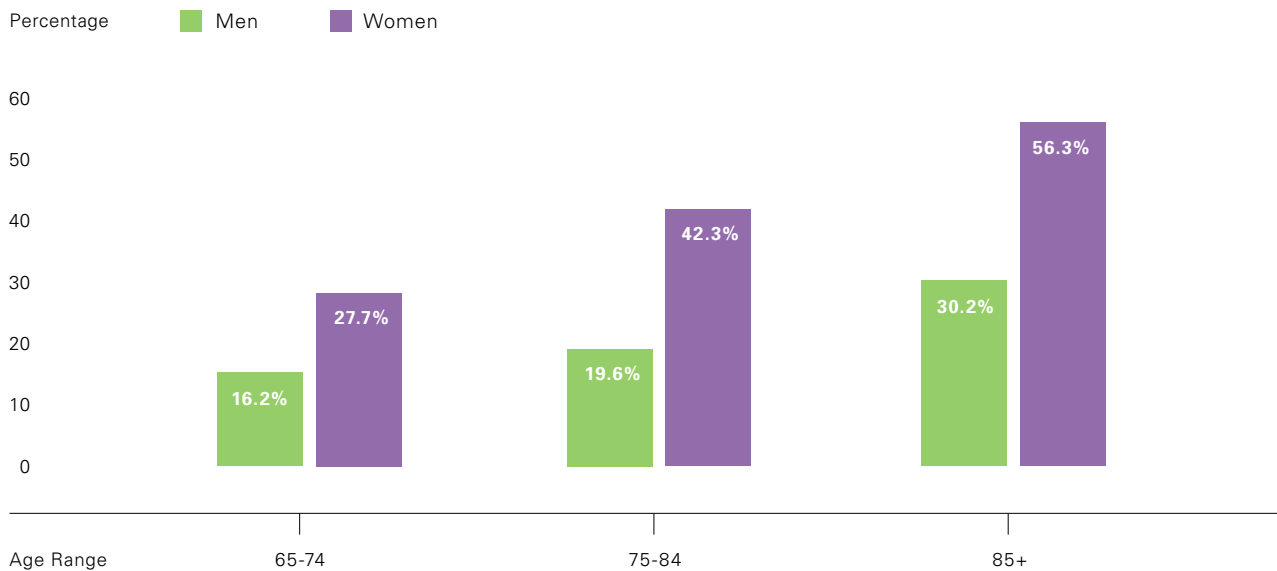
when individuals with Alzheimer’s disease and other dementias live alone, and to stimulate discussion of better ways to meet the unique needs of these individuals.

How Many People in the United States with Alzheimer’s Disease and Other Dementias Live Alone?

Older Americans Living Alone

According to 2011 data from the U.S. Census Bureau,⁽¹⁶³⁾ about 29 percent of Americans age 65 or older — about 11.3 million people — live alone.^{A20} The proportion of people who live alone increases with age and is higher among women than men (Figure 14). Among American women at least 85 years old, more than 56 percent live alone.

figure 14: Percentage of Men and Women Age 65 or Older in the United States Who Live Alone



Created from data from the U.S. Census Bureau.⁽¹⁶³⁾

Living Alone with Dementia

The percentage of Americans with Alzheimer's disease and other dementias who live alone is less straightforward to determine, but several sources of information yield consistent estimates. For the remainder of this report, counts of people who live alone include only those living in the community; that is, it does not include people who live in assisted living facilities, nursing homes, or similar facilities that provide residential support.

Medicare Current Beneficiary Survey

The Medicare Current Beneficiary Survey (MCBS) is an ongoing survey of about 13,000 Medicare beneficiaries chosen to be representative of Medicare beneficiaries nationwide. It provides the largest and most recent estimates of how many Americans who have a diagnosis of dementia live alone. Data are reported for 2008, the most recent year for which data are available.^{(138), A21}

Among Medicare beneficiaries who reported having been diagnosed with Alzheimer's disease or other dementias in the MCBS, 42 percent lived in a nursing home or other facility that provided residential support (e.g., assisted living facility), 44 percent lived in the community with another person, and the remaining 15 percent lived alone in the community. Among those who lived in the community, 25 percent — or one out of four — lived alone.⁽¹³⁸⁾

As reported in the Prevalence section of this report, it is estimated that 5.4 million people in the United States have Alzheimer's disease (page 14). Assuming that the living situations of people who have Alzheimer's disease are similar to the living situations of people who have all types of dementia in the MCBS data, it can be estimated that 800,000 (15 percent of 5.4 million) people in the United States have Alzheimer's disease and live alone in the community.

Aging, Demographics, and Memory Study

Another frequently cited resource for statistical information about people who have Alzheimer's disease and other dementias is the Aging,

Demographics, and Memory Study (ADAMS). The ADAMS data cited here included 1,770 people chosen to represent the characteristics of Americans age 71 or older living in the 48 contiguous states in the years 2000 and 2002.⁽¹⁶⁴⁻¹⁶⁵⁾ Among participants in the study who met the diagnostic criteria for dementia, 32.4 percent lived alone.⁽¹⁶⁵⁻¹⁶⁶⁾ However, this study included people who lived alone in residential care facilities, so this value is probably higher than the percentage who lived alone in the community.

Other Studies

In a study of 1,000 people who provide unpaid care for someone with Alzheimer's disease or other dementias who lived in the community, 21 percent indicated that the care recipient lived alone.⁽¹⁶⁷⁾ This percentage probably underestimates the number of people with dementia who live alone because as many as one-third to one-half of people with dementia who live alone have no identifiable caregiver.⁽¹⁶⁸⁻¹⁷⁰⁾

Another survey asked a nationally representative sample of caregivers about the living situation of their care recipient. Of the 423 care recipients older than 50 who had Alzheimer's disease and who lived in the community, 100 (25 percent) lived alone.⁽¹⁰²⁾ As with the preceding study, this percentage may be an underestimate.

Several smaller studies during the past two decades have found that 20 to 35 percent of people with dementia who lived in the community (not in a nursing home or assisted living facility) lived alone.^(168-169, 171-173)

Summary

The available sources of information consistently indicate that at least 15 percent of Americans (or one out of seven) who have Alzheimer's disease and other dementias live alone in the community. The studies cited in addition to the MCBS data support the conclusion that at least 800,000 people in the United States have Alzheimer's disease and live alone in the community. Adding people who have other dementias would result in an even larger number of individuals with dementia who live alone in the community.

Racial and Geographic Disparities

Studies of the demographic characteristics of people with Alzheimer's disease who live alone are sparse, but there is some evidence of substantial ethnic, geographic and cultural differences.⁽¹⁷⁰⁾ Among all Americans age 65 and older living in the community, non-Hispanic white women and African-American women are more likely than women of other races to live alone.⁽¹⁷³⁾ Also, African-American men older than 65 are more likely than Asian or non-Hispanic white men in the same age range to live alone.⁽¹⁷³⁾ These disparities may extend to individuals with Alzheimer's disease or other dementias. In one study among older, community-dwelling African-Americans with probable Alzheimer's disease living in one region of the United States, 52 percent lived alone.⁽¹⁷⁴⁾ More studies are needed to establish the existence of racial and geographic disparities and to determine the underlying causes of such disparities.

Typical Characteristics of People with Alzheimer's Disease and Other Dementias Who Live Alone

Several studies have collected information about people who have dementia and live alone in the community and compared them with people who have dementia and live with at least one other person in the community.^(168-169, 171-172, 175-176) These studies have described common characteristics of people with dementia who live alone. On average, people with dementia who live alone in the community tend to be older, female and less cognitively impaired than people with dementia who live in the community but do not live alone. Those living alone are also more likely to live in poverty, to have had dementia for a shorter period and to have fewer impairments in performing daily activities. Note, however, that many individuals with dementia who live alone do not share these average characteristics.

Despite findings that people with dementia who live alone are less impaired, on average, than those with dementia who live with others, most people with dementia who live alone still have significant

impairments in their ability to perform tasks such as managing money, shopping, traveling in the community, housekeeping, preparing meals and taking medications correctly.⁽¹⁷⁶⁻¹⁷⁷⁾

Risks Encountered by People with Alzheimer's Disease and Other Dementias Who Live Alone

Even people with early-stage Alzheimer's disease experience memory loss that disrupts daily life, challenges in planning or solving problems, difficulty completing familiar tasks, confusion with time or place, and other disruptions in their ability to function in the home.⁽¹⁷⁸⁻¹⁷⁹⁾ As the disease progresses, an affected individual needs help with basic activities of daily living such as bathing, dressing, eating and using the bathroom. They are also likely to have complete loss of orientation in time and space, and they tend to wander or become lost.⁽¹⁷⁹⁾ They may be unable to solve problems or make good judgments, and they may experience frequent bowel and bladder incontinence.⁽¹⁸⁰⁾

Despite the declines in function associated with Alzheimer's disease, many studies have shown that most older people prefer to live in their homes as long as possible, even if they live alone.⁽¹⁸¹⁾ Improved support services, including in-home care, transportation and financial services, have helped many older community-dwelling people stay in their homes longer than would have been possible otherwise.⁽¹⁸¹⁻¹⁸²⁾ Nevertheless, in many communities support services are still inadequate for people with dementia who live alone. Cognitive impairment and dementia do not rule out living alone,⁽¹⁶²⁾ but all people with progressive dementia will be unable to safely live alone in the later stages of the disease. Furthermore, people with dementia who live alone are exposed to risks that exceed the risks encountered by people with dementia who live with others. As discussed in the remainder of this section, these risks have important implications for the affected person, caregivers, health care providers, social service providers and policymakers.

Delayed or Missed Diagnosis

As described in *2011 Alzheimer's Disease Facts and Figures*,⁽¹⁸³⁾ as many as one-half of people who satisfy the criteria for Alzheimer's and other dementias have never received a diagnosis. Delayed or missed diagnosis may be even more common among people who live alone.

In a study of people with dementia who live in the community, those living alone were less likely to recognize their own cognitive impairment and therefore less likely to recognize dangerous situations or problems performing tasks that are critical for daily living.⁽¹⁷⁶⁾ In the same study, physicians and caregivers were significantly less likely to recognize cognitive impairment in people living alone than people living with others.⁽¹⁷⁶⁾ Several previous studies found similar results.^(177, 184-185) One study, however, found that people diagnosed with dementia while living alone were at an earlier stage of disease than people diagnosed while living with others.⁽¹⁸⁶⁾

As discussed in *2011 Alzheimer's Disease Facts and Figures*, delayed or missed diagnosis of dementia can lead to unnecessary burdens on the affected person and their caregivers.⁽¹⁸³⁾ Detrimental consequences of delayed or missed diagnosis include:

- Lost opportunities to manage symptoms.
- Potential misuse of medications that may worsen cognitive function.
- Missed opportunities to manage coexisting medical conditions that may worsen cognitive function.
- Inadequate support from health care providers and unpaid caregivers who can help the affected person manage their own health care and use of prescription medication.
- Increased anxiety about the causes of symptoms.
- Lost opportunities for caregivers to obtain training, education and support services.
- Lost opportunities to obtain in-home support services.
- Increased burden on caregivers owing to lack of access to support services.

- Missed opportunities to prevent falls and injuries, including potentially fatal injuries.
- Potential financial mismanagement and susceptibility to scams and fraud.
- Delays in planning for future functional declines.
- Delays in planning for future care needs as well as legal and financial issues.
- Lost opportunities to participate in clinical trials, which often provide expert medical care at little or no cost.

Nursing Home Placement

Older people with dementia have a number of housing options, including remaining in their own homes, living with relatives or others in the community, or residing in an independent living or retirement community, an assisted living facility or a nursing home. Although the services provided by specific facilities differ across states, nursing homes provide the most comprehensive services, allow the least independence and are the most expensive. As noted in this report's Use and Costs of Care section (page 47), average annual costs for nursing homes are more than double the average annual costs of assisted living facilities.

Because of the increased cost and loss of independence associated with placement in a nursing home, strategies to prevent or delay nursing home placement are desirable. It has been estimated that delaying long-term care by one month for each person in the United States age 65 or older could save \$60 billion each year.⁽¹⁸⁷⁾

Two studies have found that people with dementia who live alone are placed into nursing homes earlier, on average, than otherwise similar people with dementia who do not live alone.^(111, 188) The reasons for earlier placement in nursing homes are not clear, but they may be related to the increased risk of malnutrition, illness and fall-related and other injuries among people with dementia who live alone compared with those who live with others.

Self-Neglect

Although many people with dementia are able to perform basic aspects of self-care, several studies have found that people with dementia who live alone are at increased risk of inadequate self-care, including malnutrition, untreated medical conditions, inadequate clothing or housing, and poor hygiene.^(171, 189-192)

Inadequate self-care has been cited as a cause of increased need for emergency medical services among people with dementia who live alone.^(190, 193)

The issue of inadequate self-care is compounded by the observation that many people who are unable to care for themselves refuse help.⁽¹⁹⁴⁾

Falls, Wandering, Emergencies and Fatal Injuries

People with Alzheimer's disease and other dementias commonly have impaired judgment, problem-solving abilities, visual perception and spatial perception, as well as disorientation. These impairments significantly increase the risk of falls.⁽¹⁹⁵⁻¹⁹⁶⁾ Falls are a major cause of serious injury and emergency department visits in the elderly.⁽¹⁹⁷⁾ Individuals who live alone are less likely to obtain timely medical assistance when needed, such as after a fall.⁽¹⁹⁸⁾

People with Alzheimer's disease and other dementias, especially those living alone, are also at increased risk of wandering away from home unattended.⁽¹⁹⁹⁾

Wandering is a significant safety risk for these individuals and frequently ends in injuries or death.⁽¹⁹⁹⁾

When someone lives alone, there is no one to promptly notice and report their absence; thus, wandering forays may be prolonged, increasing the chance that they result in injury or death.

The impairments associated with Alzheimer's disease and other dementias can be compounded when an individual lives alone. For example, an analysis of household fires found that older people who live alone are at higher risk of dying from those fires than other older people.⁽²⁰⁰⁾ In addition, older people with dementia who live alone are more likely to need emergency medical services because of self-

neglect.^(190, 193) Overall, people with dementia who live alone are at greater risk of accidental death than those living with others. This increased risk may be due to lack of recognition of harm and delays in seeking medical help.⁽¹⁹⁸⁾

Psychiatric Symptoms

In general, people with Alzheimer's disease and other dementias have high rates of psychiatric symptoms — including depression, agitation and psychosis — compared with people who have normal cognitive function.^(176, 201-206) These symptoms are associated with functional limitations⁽²⁰¹⁾ and increased risk of nursing home placement.⁽¹¹¹⁾ Among people with dementia, psychiatric symptoms have not been found to be more common among those living alone than among those living with others.^(176, 189) This issue may not have been thoroughly studied, however, because people who develop psychiatric symptoms while living in the community are often moved to residential care facilities, where they are no longer included in studies of people living in the community.

Social Isolation and Loneliness

Social isolation and loneliness are significant problems for people with dementia who live alone.⁽²⁰⁷⁾ Unfortunately, these problems have received only limited attention from research studies.

People with dementia tend to withdraw from situations that provide social support, such as working, volunteering and community activities,⁽²⁰⁷⁾ exacerbating social isolation and loneliness. But they also recognize the importance of having a strong social support network, having the reassurance of regular contact with someone who checks on them, getting assistance with daily activities and having companionship.^(175, 207) Future research that explores how to bridge the desire for social connections with the tendency to withdraw from social experiences may result in ways to decrease the isolation and loneliness experienced by many people with Alzheimer's disease and other dementias who live alone.

Caregiving for People with Dementia Who Live Alone

Among people with dementia who live alone, as many as one-third to one-half do not have an identifiable caregiver.⁽¹⁶⁸⁻¹⁷⁰⁾ Such individuals may have little or no support for conducting activities of daily living (ADLs), and they are likely to be even more isolated from formal sources of support than are those with a regular caregiver. For example, lack of a caregiver may hinder the detection and diagnosis of dementia^(175, 208-209) and place the individual at further disadvantage with regard to accessing health and social services. As a consequence, people with dementia who live alone and have no regular caregiver are more likely than those with a caregiver to require an emergency response from agencies providing medical, law enforcement or adult protective services.⁽²¹⁰⁻²¹¹⁾

In some communities, informal support networks may provide assistance to people who have dementia and live alone in their homes.^(175, 211) Such networks may involve neighbors, letter carriers, utility service personnel and other individuals who provide services to households. These individuals can be invaluable, but they rarely have the resources or commitment that dedicated caregivers provide and that are often needed by a person who has dementia and lives alone. Some municipalities have experimented with programs to train service providers how to recognize people in need of assistance and refer them to an appropriate agency, but these programs are not widespread and their effectiveness is not known.⁽¹⁷⁵⁾

Unmet Needs of People with Alzheimer's Disease and Other Dementias Who Live Alone

The preceding discussion of the risks experienced by people with Alzheimer's disease and other dementias who live alone brings to the forefront many of the unmet needs of this population. Studies specifically focusing on this issue have consistently found that

people with dementia who live alone have significantly more unmet needs than people with dementia who live with others.^(189, 212) Commonly identified unmet needs include:^(175, 189, 212)

- Having someone to take care of household chores.
- Getting help for self-care.
- Prevention of accidents and accidental self-harm.
- Need for social interaction.
- Recognition of — and help for — psychological distress and health issues, such as eyesight and hearing problems.

Health Care Utilization

Studies have examined the use of health care and social resources among people with dementia. Most have found that those living alone use health care services at lower rates but social services (such as home-delivered meals, day care and home care services) at higher rates than people with dementia who live with others.^(168, 172, 191, 213-217)

Data from the 2008 MCBS, summarized in Table 12, show that people who had a diagnosis of dementia and lived alone had similar total health care costs as people who had a diagnosis of dementia but did not live alone.⁽¹³⁸⁾ The types of health care services used by these two groups differed to some degree, as those who lived alone had higher costs for home health care and outpatient health care institutions but lower costs for inpatient hospital services, hospice care and prescription medications.

The MCBS also collected information about the number of hospital stays and use of skilled nursing facilities. For every 1,000 people who had dementia and lived alone there were 744 hospital stays and 272 stays in a skilled nursing facility. The corresponding numbers for people who had a diagnosis of dementia but lived with someone else were 705 hospital stays and 139 stays in a skilled nursing facility.⁽¹³⁸⁾

table 12:

Average Per-Person Payments for Health Care Services, Medicare Beneficiaries Age 65 and Older with a Reported Diagnosis of Dementia and Who Live in the Community, by Living Situation, 2008 Current Beneficiary Survey, 2011 Dollars

Type of Health Care Service	Average Costs Per Person		Percentage Difference (Live Alone/Live with Someone Else)
	Beneficiaries Who Live Alone	Beneficiaries Who Live with Someone Else	
Inpatient hospital	\$7,377	\$9,782	-25%
Medical care provider	7,015	6,794	+3%
Hospice	418	1,285	-67%
Other health care institutions*	3,851	1,219	+216%
Home health care	2,162	1,327	+63%
Prescription medications	3,671	4,638	-21%
Total**	25,389	25,943	-2%

*Defined by Medicare as institutional charges for hospital outpatient services. When a patient visits a hospital as an outpatient and incurs charges for medical services, payments for health care providers such as physicians are recorded as "Medical Care Provider" payments, but costs for supplies, laboratory services, other staff, equipment and facilities are recorded as "Other institutions" payments.

**Payments to services do not equal total payments exactly, due to the effect of population weighting.

Created from data from the Medicare Current Beneficiary Survey for 2008.⁽¹³⁸⁾

In-Home Support Services

In recent years, in-home support services for older adults and allied services such as transportation have become more widely available.⁽¹⁸¹⁾ However, they often do not meet the unique needs of people with dementia who live alone, which often require a trusting relationship so the affected person is willing to accept help. People with dementia also need regular contact and interaction with the same caregivers so that changes in their functional abilities can be observed and accommodated, their health care can be coordinated, and they have someone to escort them while traveling or going to the doctor. Further improvements in meeting the needs of people with dementia who live alone may improve their quality of life and reduce overall health care costs.^(187, 218)

Conclusion

At least 800,000 people in the United States who have Alzheimer's disease are living alone, and people who have other forms of dementia add substantially to that total. People with dementia who live alone are at greater risk of missed or delayed diagnosis, inadequate self-care, social isolation, falls, unattended wandering, injuries and death than people who have dementia but who live with others in the community. In addition, those who live alone are more likely to be placed into a nursing home earlier than those who live with others, increasing overall health care costs. Better ways to meet the needs of people who have dementia and who live alone may improve their quality of life and reduce overall health care costs.

End Notes

A1. Number of Americans age 65 and older with Alzheimer's disease for 2012: 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;60:1119–22. These prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP). A recent analysis of CHAP data showed that the risk of Alzheimer's did not change over 11 years, which supports the validity of a linear extrapolation based on current census data. See Hebert LE, Bienias JL, Aggarwal NT, Wilson RS, Bennett DA, Shaw RC, et al. Change in risk of Alzheimer disease over time. *Neurology* 2010;75(9):786-91.

A2. Proportion of Americans age 65 and older with Alzheimer's disease: The 13 percent is calculated by dividing the estimated number of people age 65 and older with Alzheimer's disease (5.2 million) by the U.S. population age 65 and older in 2010, the latest available data from the U.S. Census Bureau (40.3 million) = 13 percent. Thirteen percent is the same as 1 in 8.

A3. Proportion of Americans age 85 and older with Alzheimer's disease: The 45 percent is calculated by dividing the number of people age 85 and older with Alzheimer's disease (2.5 million) by the U.S. population age 85 and older in 2010, the latest available data from the U.S. Census Bureau (5.5 million) = 45 percent. Forty-five 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 (in millions) for people 65 to 74 (0.3), 75 to 84 (2.4), and 85+ (2.5) 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;60:1119-22. 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 age 71 and older in 2002. See Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(12):125-32. At a 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):74-9). Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's disease and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common (see Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer's disease and mild cognitive impairment. *Annals of Neurology* 2009;66(2):200-8), the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's disease in the United States.

A6. Number of women and men age 65 and older with Alzheimer's disease in the United States: The estimates for number of U.S. women (3.3 million) and men (1.8 million) age 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, 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;60:1119–22. For 2012, we took the proportion of U.S. women and men age 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 age 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 68 seconds number is calculated by dividing the number of seconds in a year (31,536,000) by the number of new cases in a year. 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;15:169–73. The Alzheimer's Association calculated that the incidence of new cases in 2012 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.2 (for the number of years from 2010 to 2012 divided by the number of years from 2010 to 2020), adding that result (7,400) to the Hebert et al. (2001) estimate for 2010 (454,000) = 461,400. The number of seconds in a year (31,536,000) divided by 461,400 = 68.3 seconds, rounded to 68 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (from Hebert et al., 2001) = 32.8 seconds, rounded to 33 seconds.

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;49:1498–504.

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 age 43 to 61 in November 2007, used here to estimate the number of women and men age 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.

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;60:1119-22. 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):1337-42) because they relied on more conservative methods for counting people who currently have Alzheimer's disease.^{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 age 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the Centers for Disease Control and Prevention, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2011. Available at www.census.gov/popest/data. Accessed on Jan. 5, 2012. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or other dementias, 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/CaregivingUSAIIIAgesExecSum.pdf). The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care. In response, 26 percent of caregivers said that: (1) Alzheimer's or 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. Alzheimer's Association 2010 Women and Alzheimer's Poll: This poll contacted 3,118 adults nationwide by telephone from Aug. 25 to Sept. 3, 2010. Telephone numbers were randomly chosen in separate samples of landline and cell phone exchanges across the nation, allowing listed and unlisted numbers to be contacted, and multiple attempts were made to contact each number. Within households, individuals were randomly selected. Interviews were conducted in English and Spanish. The survey "oversampled" African-Americans and Hispanics, selected from U.S. Census tracts with higher than 8 percent concentration of each group. It also included an oversample of Asian-Americans using a listed sample of Asian-American households. The combined samples include: 2,295 white, non-Hispanic; 326 African-American; 309 Hispanic; 305 Asian-American; and 135 respondents of another race. Cases were weighted to account for differential probabilities of selection and to account for overlap in the landline and cell phone sampling frames. The sample was adjusted to match U.S. Census demographic benchmarks for gender, age, education, race/ethnicity, region and telephone service. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. This national survey included 202 caregivers of people with Alzheimer's or other dementias. This was supplemented with 300 interviews from a listed sample of caregivers of people with Alzheimer's for a total of 502 caregiver interviews. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or other dementias. The weight of the caregiver sample adjusted all 502 caregiver cases to the weighted estimates for gender and race/ethnicity derived from the base survey of caregivers. Questionnaire design and interviewing were conducted by Abt SRBI of New York. Susan Pinkus of S.H. Pinkus Research and Associates coordinated the polling and helped in the analysis of the poll data.

A14. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's 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 (15,248,740) by the average hours of care per year (1,139), which equals 17,365,265,478 hours of care.

A15. 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;18:182-8). This method uses the average of the federal minimum hourly wage (\$7.25 in 2011) and the mean hourly wage of home health aides (\$16.99 in July 2011) [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 2011. Available at www.bls.gov/ces]. The average is \$12.12. We multiplied the number of hours of unpaid care by \$12.12, which equals \$210,467,017,597.

A16. Higher health care costs of Alzheimer's caregivers: This figure is based on a methodology originally developed by Brent Fulton, Ph.D., for The Shriver Report: A Woman's Nation Takes on Alzheimer's. A survey of 17,000 employees of a multinational firm based in the United States estimated that caregivers' health care costs were 8 percent higher than non-caregivers' (Albert SM, Schulz R. The MetLife Study of Working Caregivers and Employer Health Care Costs, New York, N.Y.: MetLife Mature Market Institute, 2010). To determine the dollar amount represented by that 8 percent figure nationally and in each state, the 8 percent figure and the proportion of caregivers from the 2009 Behavioral Risk Factor Surveillance System ^{A12} were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009, inflated to 2011 dollars (Centers for Medicare and Medicaid Services, Center for Strategic Planning, Health Expenditures by State of Residence 1991-2009. Available at www.cms.gov/NationalHealthExpendData/05_NationalHealthAccountsStateHealthAccountsResidence.asp#TopOfPage. Accessed on Dec. 30, 2011.). The dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state (reflecting the 8 percent higher costs for caregivers) produced the average additional health care costs for caregivers in each state. Nationally, this translated into an average of \$567. The amount of the additional cost in each state, which varied by state from a low of \$418 in Utah to a high of \$865 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state ^{A12} to arrive at that state's total additional health care costs of Alzheimer's and other dementia caregivers as a result of being a caregiver. 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."⁽¹¹⁶⁾

A17. 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 using data from the Medicare Current Beneficiary Survey (MCBS). The model was constructed based on 2004 MCBS data; those data have been replaced with the more recent 2008 MCBS data. ^{A19} Nursing facility care costs in the model are based on The Lewin Group's Long-Term Care Financing Model. More information on the model, its long-term projections and its methodology is available at www.alz.org/trajectory.

A18. All cost estimates were inflated to year 2011 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 2008 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The MCBS, a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries, is linked to Medicare Part B claims. The survey is supported by the U.S. Centers for Medicare and Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a nurse who is familiar with the survey participant and his or her medical record. Data from the MCBS analysis that are included in *2012 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

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

A20. Percentage of Americans age 65 or older who live alone: The percentage and total number of Americans age 65 or older who live alone were calculated from the cited table, which was compiled by the U.S. Census Bureau from data obtained during the March Current Population Survey for the Nation (U.S. Census Bureau. America's Families and Living Arrangements: 2011. Table A2: Family Status and Household Relationship of People 15 Years and Over, by Marital Status, Age, and Sex. Available at www.census.gov/population/www/socdemo/hh-fam/cps2011.html). The total was calculated by summing the number of householders (of both sexes and all marital statuses) who lived alone for the three age categories of 65 to 74 years, 75 to 84 years, and 85+. The percentage was calculated by dividing the total number of householders who lived alone by the total number of people in the same age ranges. Data for the graph of age- and sex-specific values were obtained from the sex-specific sections (all marital statuses) of the same Census Bureau table.

A21. MCBS estimates of the percentage and number of Americans who live alone: Participants in the MCBS and those having a diagnosis of dementia were identified, and data about health care utilization by these individuals were collected in 2008. Anyone who reported living in a facility that provides residential support for any part of the year was not considered to be living in the community. People who lived in the community for the entire year were asked how many people lived in their household, including themselves. Those living in the community and listing only one household member were identified as living alone.

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The Alzheimer's Association acknowledges the contributions of Lisa Fredman, Ph.D., Bryan D. James, Ph.D., Tricia J. Johnson, Ph.D., Ken P. Scholz, Ph.D., and Jennifer Weuve, M.P.H., Sc.D., in the preparation of *2012 Alzheimer's Disease Facts and Figures*.

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