

Alzheimer's Association Report

2012 Alzheimer's disease facts and figures

Alzheimer's Association*

Abstract

This report provides information to increase understanding of the public health impact of Alzheimer's disease (AD). Topics addressed include incidence, prevalence, mortality rates, health expenditures and costs of care, and effect on caregivers and society. The report also explores issues that arise when people with AD and other dementias live alone. The characteristics, risks, and unmet needs of this population are described.

An estimated 5.4 million Americans have AD, including approximately 200,000 age <65 years who comprise the younger-onset AD population. Over the coming decades, the aging of the baby boom generation is projected to result in an additional 10 million people with AD. Today, someone in America develops AD every 68 seconds. By 2050, there is expected to be one new case of AD every 33 seconds, or nearly a million new cases per year, and AD prevalence is projected to be 11 million to 16 million. Dramatic increases in the number of "oldest-old" (those age ≥ 85 years) across all racial and ethnic groups are expected to contribute to the increased prevalence of AD.

AD is the sixth leading cause of death in the United States and the fifth leading cause of death in Americans age ≥ 65 years. Although the proportions of deaths due to other major causes of death have decreased in the last several years, the proportion due to AD has risen significantly. Between 2000 and 2008, the proportion of deaths due to heart disease, stroke, and prostate cancer decreased by 13%, 20%, and 8%, respectively, whereas the proportion due to AD increased by 66%.

In 2011, more than 15 million family members and other unpaid caregivers provided an estimated 17.4 billion hours of care to people with AD and other dementias, a contribution valued at more than \$210 billion. Medicare payments for services to beneficiaries age ≥ 65 years with AD and other dementias are three times as great as payments for beneficiaries without these conditions, and Medicaid payments are 19 times as great. In 2012, payments for health care, long-term care, and hospice services for people age ≥ 65 years with AD and other dementias are expected to be \$200 billion (not including the contributions of unpaid caregivers).

An estimated 800,000 people with AD (one in seven) live alone, and up to half of them do not have an identifiable caregiver. People with dementia who live alone are exposed to risks that exceed the risks encountered by people with dementia who live with others, including inadequate self-care, malnutrition, untreated medical conditions, falls, wandering from home unattended, and accidental deaths.

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Keywords:

Alzheimer's disease Dementia; Diagnostic criteria; Prevalence; Incidence; Mortality; Caregivers; Family caregiver; Spouse caregiver; Health care costs; Health care expenditures; Long-term care costs; Hospice care costs; Medicare spending; Medicaid spending; Live alone; Living arrangements; Unmet needs

1. About this report

2012 Alzheimer's Disease Facts and Figures provides a statistical resource for U.S. data related to Alzheimer's dis-

ease (AD), 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 AD. Additional sections address prevalence, mortality, caregiving, and use and costs of care and services. The Special Report focuses on the challenges of people with AD and other dementias who live alone.

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

- Overall number of Americans with AD nationally and for each state.
- Proportion of women and men with AD and other dementias.
- Estimates of lifetime risk for developing AD.
- 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 AD and other dementias.
- Number of deaths due to AD 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 AD is provided; in other cases, the reference may be a more general one of “AD and other dementias.”

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

2. Overview of AD

AD 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 AD, these brain changes eventually impair an individual's ability to carry out such basic bodily functions as walking and swallowing. AD is ultimately fatal.

2.1. Dementia: Definition and specific types

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed [1]. To meet *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed, 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.

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].

2.2. Alzheimer's disease

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

2.2.1. Symptoms of AD

AD 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 AD:

- 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 AD, visit www.alz.org/10signs.

Table 1
Common types of dementia and their typical characteristics

Type of dementia	Characteristics
AD	<p>Most common type of dementia, accounts for an estimated 60%–80% 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 AD were proposed and published in 2011. They recommend that AD be considered a disease with three stages, beginning well before the development of symptoms.</p> <p>Hallmark abnormalities are deposits of the protein fragment β-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 poststroke dementia, vascular dementia is less common as a sole cause of dementia than is AD. 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 AD.</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 for vascular dementia was used to exclude a diagnosis of AD (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>
DLB	<p>People with DLB have some of the symptoms common in AD, but are more likely than people with AD 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 α-synuclein. When they develop in a part of the brain called the cortex, dementia can result. α-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 AD 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>
Mixed dementia	<p>Characterized by the hallmark abnormalities of AD and another type of dementia—most commonly, vascular dementia, but also other types, such as DLB.</p> <p>Recent studies suggest that mixed dementia is more common than previously thought.</p>
Parkinson's disease	<p>As Parkinson's disease progresses, it often results in a severe dementia similar to DLB or AD.</p> <p>Problems with movement are a common symptom early in the disease.</p> <p>α-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 AD.</p>
FTLD	<p>Includes dementias such as bvFTD, 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 bvFTD may be present at the same time as the brain changes of AD, but people with bvFTD generally develop symptoms at a younger age (at about age 60 years) and survive for fewer years than those with AD.</p>
Creutzfeldt–Jakob disease	<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>
Normal pressure hydrocephalus	<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>

Abbreviations: AD, Alzheimer's disease; DLB, dementia with Lewy bodies; FTLD, frontotemporal lobar degeneration; bvFTLD, behavioral variant frontotemporal lobar degeneration.

Individuals progress from mild AD to moderate and severe disease at different rates. As the disease progresses, the individual's cognitive and functional abilities decline. In advanced AD, people need help with basic activities of daily living (ADLs), such as bathing, dressing, eating, and using the bathroom. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones, and become bedbound and reliant on around-the-clock

care. When an individual has difficulty moving because of AD, he or she is more vulnerable to infections, including pneumonia (infection of the lungs). AD is ultimately fatal, and AD-related pneumonia is often a contributing factor.

2.2.2. Diagnosis of AD

A diagnosis of AD 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 scans to identify brain changes, such as the presence of a tumor or evidence of a stroke, that could cause cognitive decline.

2.2.3. A modern diagnosis of AD: 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 AD [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 AD 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 past 3 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.

2.2.3.1. 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 AD, 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 AD 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 (e.g., levels of β -amyloid and tau in the cerebrospinal fluid and blood) are among several factors being studied as possible biomarkers for AD.

2.2.3.2. The three stages of AD proposed by the new criteria and guidelines for the diagnosis of AD

The three stages of AD identified in the new criteria and guidelines are preclinical AD, mild cognitive impairment

(MCI) due to AD, and dementia due to AD. These stages are different from the stages now used to describe AD. Currently, the stages of AD are often described as mild/early stage, moderate/mid stage, or severe/late stage. The new criteria propose that AD begins before the mild/early stage and that new technologies have the potential to identify AD-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 AD or MCI due to AD. The third stage of the new criteria, dementia due to AD, encompasses all stages of AD as described today, from mild/early stage to severe/late stage.

2.2.3.2.1. Preclinical AD

In this stage, individuals have measurable changes in the brain, cerebrospinal fluid, and/or blood (biomarkers) that indicate the earliest signs of disease, but they have not yet developed symptoms such as memory loss. This preclinical or presymptomatic stage reflects current thinking that AD 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 AD, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional biomarker research is needed before this stage of AD can be diagnosed.

2.2.3.2.2. MCI due to AD

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% of people aged ≥ 65 years have MCI [11–13]. It is estimated that as many as 15% of people whose MCI symptoms cause them enough concern to contact their doctor's office for an examination 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 3 or 4 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% 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 1 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 AD or other dementias. If it can be shown that changes in the brain, cerebrospinal fluid, and/or blood are caused by physiological processes associated with AD, the new criteria and guidelines recommend a diagnosis of MCI due to AD. Before doctors can make such a diagnosis, however, researchers must prove that the biomarker tests accurately indicate risk.

2.2.3.2.3. *Dementia due to AD*

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 AD-related processes.

2.2.3.3. *Biomarker tests*

The new criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of β -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 AD 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.

2.2.4. *Causes of AD*

The cause or causes of AD are not yet known. However, most experts agree that AD, 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 period between the initial brain changes of AD and the symptoms of advanced AD is considered by scientists to represent the “continuum” of AD. 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 are 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 AD would diagnose the individual as having AD. The new criteria and guidelines propose that the entire continuum, not just the symptomatic points on the continuum, represents AD. 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 AD are the accumulation of the protein β -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 AD, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of β -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 AD show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

One known cause of AD is genetic mutation. A small percentage of AD cases, probably <1%, 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 AD. In such individuals, the disease tends to develop before age 65 years, sometimes in individuals as young as 30 years.

2.2.5. *Risk factors for AD*

The greatest risk factor for AD is advancing age, but AD is not a normal part of aging. Most people with AD are diagnosed at age ≥ 65 years. These individuals are said to have late-onset AD. However, people aged <65 years can also develop the disease. When AD develops in a person aged <65 years, it is referred to as “younger-onset” (or “early-onset”) AD.

Advancing age is not the only risk factor for AD. The following sections describe other risk factors.

2.2.5.1. *Family history*

Individuals who have a parent, brother, or sister with AD are more likely to develop the disease than those who do not have a first-degree relative with AD [17–19]. Those who have more than one first-degree relative with AD 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.

2.2.5.2. *Apolipoprotein E $\epsilon 4$*

Individuals with the $\epsilon 4$ form of the gene apolipoprotein E (APOE $\epsilon 4$) are at increased risk of developing AD. APOE $\epsilon 4$

is one of three common forms ($\epsilon 2$, $\epsilon 3$, and $\epsilon 4$) 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* $\epsilon 4$ gene have increased risk of developing AD and of developing it at an earlier age than those who inherit the $\epsilon 2$ or $\epsilon 3$ forms of the *APOE* gene. Those who inherit two *APOE* $\epsilon 4$ genes have an even higher risk. Unlike inheriting a known genetic mutation for AD, inheriting one or two copies of this form of the *APOE* gene does not guarantee that an individual will develop AD.

2.2.5.3. Mild cognitive impairment

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 AD 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 is 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 AD, published in 2011 [7–10], suggest that in some cases, MCI is actually an early stage of AD or another dementia.

2.2.5.4. 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 AD 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 AD and other forms of dementia.

2.2.5.5. 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 AD risk.

2.2.5.6. Head injury and traumatic brain injury

Head injury, head trauma, and traumatic brain injury are associated with an increased risk of AD and other dementias. Moderate head injuries are associated with twice the risk of developing AD 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 posttraumatic amnesia lasting >30 minutes; if either of these lasts >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 AD) at autopsy [36–41]. Some studies suggest that *APOE* $\epsilon 4$ carriers who experience moderate or severe head injury are at higher risk of developing AD than *APOE* $\epsilon 4$ 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 AD.

2.2.6. Treatment of AD

No treatment is available to slow or stop AD. 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 AD 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.

3. Prevalence

Millions of Americans have AD and other dementias. One in eight older Americans has AD.

The number of Americans with AD and other dementias will grow each year as the proportion of the U.S. population

aged >65 years continues to increase. The number will escalate rapidly in coming years as the baby boomer generation ages.

Estimates from selected studies on the prevalence and characteristics of people with AD 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 sex, race, and ethnicity, and years of education. Data sources and study methods are described in the [Appendices](#).

3.1. Prevalence of AD and other dementias

An estimated 5.4 million Americans of all ages will have AD in 2012. This figure includes 5.2 million people aged ≥65 years [47],^{A1} and 200,000 individuals aged <65 years who have younger-onset AD [48].

- One in eight people aged ≥65 years (13%) has AD.^{A2}
- Nearly half of people aged ≥85 years (45%) have AD.^{A3}
- Of those with AD, an estimated 4% are aged <65 years, 6% are 65 to 74 years, 44% are 75 to 84 years, and 46% are ≥85 [47].^{A4}

The estimated numbers for people aged >65 years come from the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people. In 2009, the 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 AD. 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% of people aged ≥71 years 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 AD 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. It is unclear exactly how these new criteria, if adopted, could change the estimated prevalence of AD. However, if AD can be detected earlier—in the preclinical stage, as defined by the new criteria—the number of people reported to have AD 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 AD or other dementias have been diagnosed [51]. Because AD is underdiagnosed, more than half of the 5.4 million Americans with AD may not know they have it.

3.1.1. Prevalence of AD and other dementias in women and men

More women than men have AD and other dementias. Almost two-thirds of Americans with AD are women.^{A6} Of the 5.2 million people aged >65 years with AD in the United States, 3.4 million are women and 1.8 million are men.^{A6} Based on estimates from ADAMS, 16% of women aged ≥71 years have AD or other dementias compared with 11% of men [49,52].

The larger proportion of older women who have AD 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 AD [53–59] or any dementia [54–56,60,61] have found no significant difference by sex. Thus, women *are not* more likely than men to develop dementia at any given age.

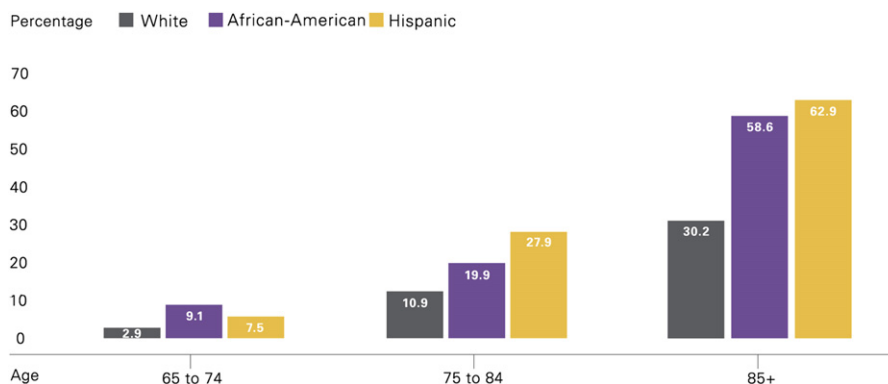


Fig. 1. Proportion of people aged ≥65 years with Alzheimer's disease (AD) and other dementias by race/ethnicity from the Washington Heights-Inwood Columbia Aging Project, 2006. Created from data from Gurland et al. *Int J Geriatr Psychiatry* 1999;14:481–93 [62].

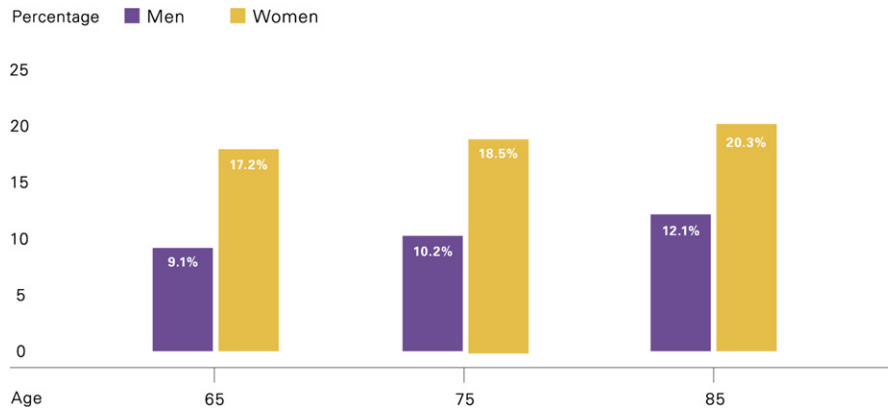


Fig. 2. Framingham estimated lifetime risks for AD by age and sex. Created from data from Seshadri et al. Stroke 2006;37:345–50 [78].

3.1.2. Prevalence of AD and other dementias by years of education

People with fewer years of education appear to be at higher risk for AD 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 AD 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].

3.1.3. Prevalence of AD and other dementias in older whites, African Americans, and Hispanics

Although most people in the United States living with AD and other dementias are non-Hispanic whites, older African Americans and Hispanics are proportionately more likely than older whites to have AD and other dementias [68,69]. Data indicate that in the United States, older African Americans are probably about twice as likely to have AD and other dementias as older whites [70], and Hispanics are approximately 1.5 times as likely to have AD 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 AD and other dementias, genetic factors do not appear to account for these large prevalence differences across racial groups [71]. Instead, health conditions that increase one’s risk for AD and other dementias, such as high blood pressure and diabetes, 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 AD and other dementias had been diagnosed in 9.6% of white beneficiaries, 12.7% of African American beneficiaries, and 14% 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.

3.2. Incidence and lifetime risk of AD

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 period. The estimated annual incidence (rate of developing disease in a 1-year period) of AD appears to increase dramatically with age, from approximately 53 new cases per 1000 people aged 65 to 74 years, to 170 new cases per 1000 people aged 75 to 84 years, to 231 new cases per 1000 people aged >85 years (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 aged >65 years in the United States, the annual incidence of AD and other dementias is projected to double by 2050 [76].

Table 2
Projections by state for total numbers of Americans aged ≥ 65 years with AD

State	Projected total numbers (in 1000s) with AD			Percentage change in AD (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
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
U.S. total*	4500	5100	6700	13	49

NOTE. Created from data from Hebert et al. *Neurology* 2004;62:1645 [79].^{A10}

*Differences between totals and summing of state numbers are due to rounding.

- Every 68 seconds, someone in America develops AD.^{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 life span. Data from the original Framingham Study population were used to estimate lifetime risks of AD and of any dementia [78].^{A8} Starting in 1975, nearly 2800 people from the Framingham Study who were aged 65 years and free of dementia were followed for up to 29 years. The study found that 65-year-old women without dementia had a 20% chance of developing dementia during the remainder of their lives (estimated lifetime risk), compared with a 17% chance for men. For AD, the estimated lifetime risk was nearly 1 in 5 (17.2%) for women compared with nearly 1 in 10 (9.1%) for men [78].^{A9} Figure 2 presents lifetime risks of AD 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 AD and other dementias used in the Framingham Study required documentation of moderate-to-severe disease as well as symptoms lasting a minimum of 6 months. Using a definition that also includes milder disease and disease of <6 months' duration, lifetime risks of AD and other dementias would be much higher than those estimated by this study.

3.3. Estimates of the number of people with AD by state

Table 2 summarizes the projected total number of people aged 65 years and older with AD by state for years 2000, 2010, and 2025.^{A10} The percentage changes in the number of people with AD between 2000 and 2010 and between 2000 and 2025 are also shown. Note that the total number of people with AD 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 Fig. 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 AD due to increases in the proportion of the population aged >65 years. The South and West are expected to experience 50% and greater increases in numbers of people with AD 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 AD. 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 AD relative to other regions because this region already has a high proportion of people aged >65 years. The increasing number of people with AD will have a marked impact on states' health care systems, not to mention families and caregivers.

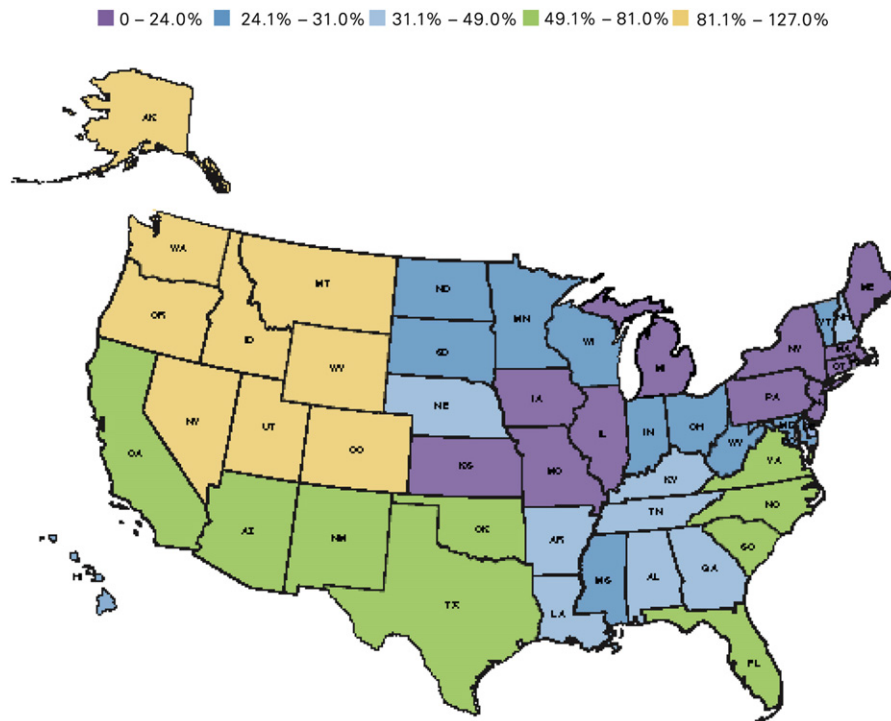


Fig. 3. Projected changes between 2000 and 2025 in AD prevalence by state. Created from data from Hebert et al. *Neurology* 2004;62:1645 [79].^{A10}

3.4. Looking to the future

The number of Americans surviving into their 80s and 90s and beyond is expected to grow dramatically owing 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 boomer generation—is reaching the age of greater risk for AD and other dementias. In fact, the first baby boomers reached age 65 years in 2011. By 2030, the segment of the U.S. population aged ≥ 65 years is expected to double, and the estimated 71 million older Americans will make up approximately 20% of the total population [81].

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of AD, as shown in Fig. 4.^{A11}

- In 2000, there were an estimated 411,000 new cases of AD. For 2010, that number was estimated to be 454,000 (a 10% increase); by 2030, it is projected to be 615,000 (a 50% increase from 2000); and by 2050, it is expected to be 959,000 (a 130% increase from 2000) [76].
- By 2025, the number of people aged ≥ 65 years with AD is estimated to reach 6.7 million, a 30% increase from the 5.2 million aged ≥ 65 years currently affected [47].

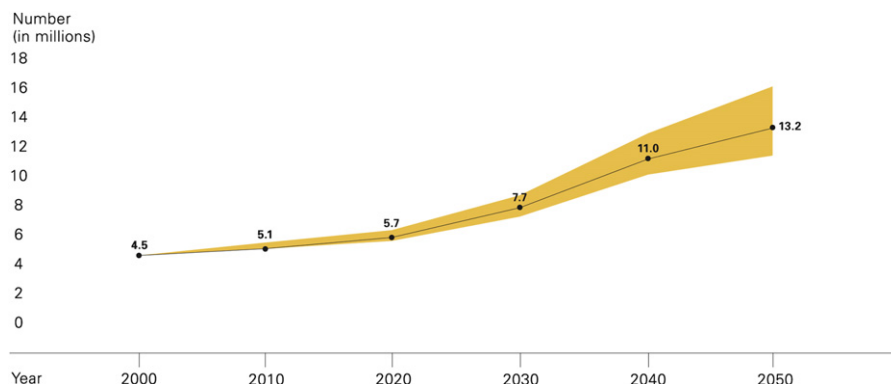


Fig. 4. Projected numbers of people aged ≥ 65 years in the U.S. population with AD using the U.S. Census Bureau estimates of population growth. Numbers indicate middle estimates per decade. Shaded area indicates high and low estimates per decade. Created from data from Hebert et al. *Arch Neurol* 2003;60:1119–22 [47].^{A11}

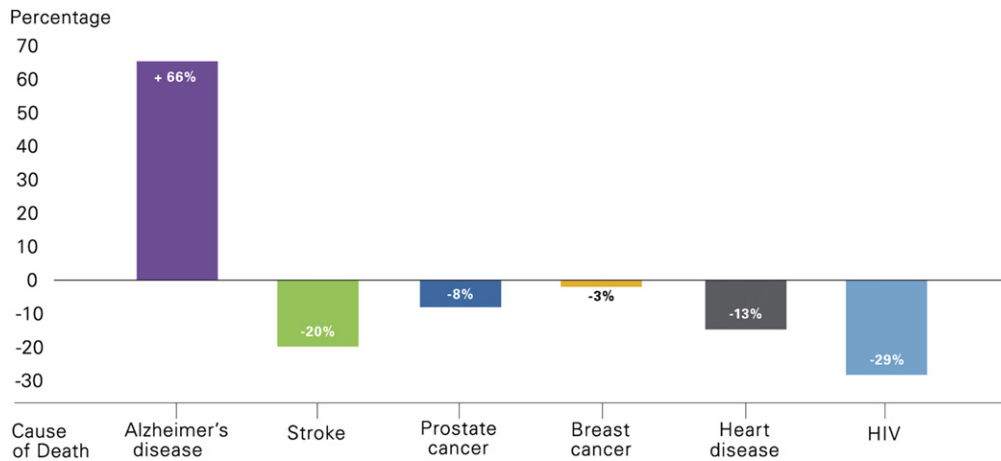


Fig. 5. Percentage changes in selected causes of death (all ages) between 2000 and 2008. Created from data from the National Center for Health Statistics. Deaths: final data for 2000. National Vital Statistics Report. National Center for Health Statistics; 2002 [87] and Miniño et al. Deaths: final data for 2008. National Vital Statistics Reports. National Center for Health Statistics; 2011 [82].

- By 2050, the number of people aged ≥ 65 years with AD may triple, from 5.2 million to a projected 11 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% of all older people in the United States to one in every four older Americans (24%) [80]. This will result in an additional 15 million oldest-old people, individuals at high risk for developing AD [80].

- By 2050, the number of Americans aged ≥ 85 years will nearly quadruple to 21 million [80].
- In 2012, the population aged ≥ 85 years will include approximately 2.5 million people with AD, or 48% of the AD population aged ≥ 65 years [47].
- When the first wave of baby boomers reaches age 85 years (in 2031), an estimated 3.5 million people aged ≥ 85 years will have AD [47].

4. Mortality

AD is the sixth leading cause of death in the United States [82]. It is the fifth leading cause of death for those aged ≥ 65 years [82].

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

4.1. Deaths from AD

AD is becoming a more common cause of death as the populations of the United States and other countries age. Al-

though deaths from other major causes continue to experience significant declines, those from AD have continued to rise. Between 2000 and 2008, deaths attributed to AD increased 66%, whereas those attributed to heart disease—the number one cause of death—decreased 13% (Fig. 5) [82,87]. The increase in the number and proportion of death certificates listing AD 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 AD.

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 AD 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% of people with AD at age 70 years are expected to die before age 80 years compared with 30% of people at age 70 years without AD [91].

Another way to describe the impact of AD 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 AD on mortality over 5 years in people aged ≥ 65 years is estimated to be between 5% and 15% [92,93]. This means that 5% to 15% of all deaths in older people can be attributed to AD.

4.2. State-by-state deaths from AD

Table 3 provides information on the number of deaths due to AD by state in 2008. The information was obtained from death certificates and reflects the condition identified by the

Table 3

Number of deaths and annual mortality rate (per 100,000) due to AD, by state, 2008

State	Number of deaths	Rate
Alabama	1518	32.6
Alaska	80	11.7
Arizona	2099	32.3
Arkansas	893	31.3
California	10,098	27.5
Colorado	1353	27.4
Connecticut	839	24.0
Delaware	204	23.4
District of Columbia	132	22.3
Florida	4743	25.9
Georgia	1929	19.9
Hawaii	218	16.9
Idaho	393	25.8
Illinois	3192	24.7
Indiana	1971	30.9
Iowa	1332	44.4
Kansas	961	34.3
Kentucky	1370	32.1
Louisiana	1361	30.9
Maine	450	34.2
Maryland	1016	18.0
Massachusetts	1832	28.2
Michigan	2739	27.4
Minnesota	1344	25.7
Mississippi	916	31.2
Missouri	2010	34.0
Montana	294	30.4
Nebraska	610	34.2
Nevada	279	10.7
New Hampshire	393	29.9
New Jersey	1857	21.4
New Mexico	366	18.4
New York	2303	11.8
North Carolina	2624	28.5
North Dakota	312	48.6
Ohio	4285	37.3
Oklahoma	1061	29.1
Oregon	1302	34.4
Pennsylvania	3863	31.0
Rhode Island	359	34.2
South Carolina	1492	33.3
South Dakota	402	50.0
Tennessee	2423	39.0
Texas	5280	21.7
Utah	409	14.9
Vermont	218	35.1
Virginia	1763	22.7
Washington	3105	47.4
West Virginia	662	36.5
Wisconsin	1655	29.4
Wyoming	125	23.5
U.S. total	82,435	27.1

NOTE. Created from data from Miniño et al. Deaths: final data for 2008. National Vital Statistics Reports. National Center for Health Statistics; 2011 [82].

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

Table 4

U.S. AD 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

NOTE. Created from data from Miniño et al. Deaths: final data for 2008. National Vital Statistics Reports. National Center for Health Statistics; 2011 [82].

*Reflects average death rate for ages ≥ 45 years.

compare the risk of death due to AD across states with varying population sizes. For the United States as a whole, in 2008, the mortality rate for AD was 27.1 deaths per 100,000 people.

4.3. Death rates by age

Although people aged < 65 years can develop and die from AD, the highest risk of death from AD is among people aged ≥ 65 years. As seen in Table 4, death rates for AD 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 aged 75 to 84 years and 6.5 times as high for those aged ≥ 85 years compared with people aged 65 to 74 years. 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, AD death rates were 9.0 times as high for people aged 75 to 84 years and 42.3 times as high for people aged ≥ 85 years compared with people aged 65 to 74 years [82]. This large age-related increase in death rates due to AD underscores the lack of a cure or effective treatments for the disease.

4.4. Duration of illness from diagnosis to death

Studies indicate that people aged ≥ 65 years survive an average of 4 to 8 years after a diagnosis of AD; yet, some live as long as 20 years with AD [93–97]. This indicates the slow, insidious nature of the progression of AD. On average, a person with AD will spend more years (40% of the total number of years with AD) 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 years is expected for 75% of people with AD compared with only 4% of the general population [91]. In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20% of cancer patients and 28% of people dying from all other conditions [98]. Thus, in addition to AD being the sixth leading cause of death, the long duration of illness may be an equally telling statistic of the public health impact of AD.

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 support, psychotherapy, and technological approaches. These interventions are led by skilled professionals.

NOTE. Created from data from Sørensen et al. *Gerontologist* 2002;42(3):356–72 [100].

5. Caregiving

5.1. Unpaid caregivers

More than 15 million Americans provide unpaid care for a person with AD 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 more than \$210 billion.

Eighty percent of care provided at home is delivered by family caregivers; fewer than 10% of older adults receive all of their care from paid workers [99]. Caring for a person with AD 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).

5.1.1. Who are the caregivers?

Information on caregivers of people with AD 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 [101]. 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 AD or other dementias and other caregivers [102]. More than 6800 caregivers in these states were surveyed. Compared with caregivers of individuals with other conditions, AD and dementia caregivers were more likely to be older (52 years vs 46 years), female (70.3% vs 59.2%), married (72.8% vs 63.1%), and white (81.0% vs 68.6%).

Surveys conducted for the Alzheimer's Association^{A13} and the National Alliance on Caregiving (NAC) and AARP [103] found no difference in mean age, sex, or marital status between caregivers of people with AD and other dementias and caregivers of people without AD and other dementias. This may reflect variations in the surveys' sampling approach (e.g., age and race differences between caregivers and noncaregivers 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 AD and other dementias. Most (56%) were aged ≥ 55 years (Fig. 6) and had less than a college degree (67%).^{A13} They tended to be the primary breadwinners of their household (55%), and nearly half were employed full or part time (44%).^{A13} Half of these caregivers lived in the same household as the person for whom they provided care. Thirty percent had children <18 years old living with them; such

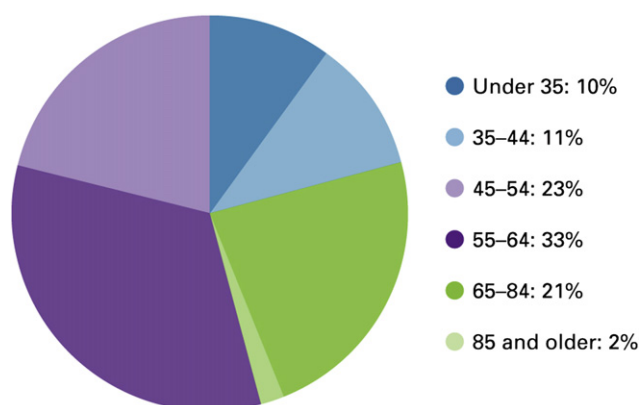


Fig. 6. Ages of AD and other dementia caregivers, 2010. Created from data from the Alzheimer's Association.^{A13}

caregivers are sometimes called the “sandwich generation” because they simultaneously provide care for two generations [103]. Almost half of caregivers take care of parents [103].^{A13} Between 6% [103] and 17%^{A13} take care of a spouse.

Nine percent of unpaid caregivers of people with AD and other dementias live >2 hours from the person for whom they provide care, and another 6% live 1 to 2 hours away [103]. Depending on the definition of “long-distance caregiving,” these numbers indicate that 1.4 to 2.3 million caregivers of people with AD and other dementias are long-distance caregivers.

5.1.2. Care provided by ethnic communities

Information about the ethnic distribution of caregivers of people with AD and other dementias varies by survey. The proportion of caregivers who are non-Hispanic whites ranged from 70%^{A13} to 81% [102,103]. Non-Hispanic African Americans comprised between 8% [103] and 15%^{A13} of caregivers. Hispanics made up from 1% [102] to 12% of caregivers,^{A13} and Asian Americans and other ethnic groups made up 1% to 2% of caregivers in several surveys^{A13} [103].

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 AD or other dementias, specifically, notable differences from the NAC/AARP survey included the following [103]:

- Non-Hispanic whites were more likely than caregivers of other racial/ethnic groups to care for a parent (54% vs 38%).
- Non-Hispanic white and Asian American caregivers were more likely to care for a married person (30% and 48%, respectively) compared with non-Hispanic African American caregivers (11%).
- Hispanic and non-Hispanic African American caregivers spent more time caregiving (approximately 30 h/wk) than non-Hispanic white caregivers (19.8 h/wk) and Asian American caregivers (15.8 h/wk).
- Hispanic and non-Hispanic African American caregivers were more likely to experience high burden from caregiving (45% and 57%, respectively), whereas only one-third of non-Hispanic whites and Asian Americans reported high burden.

5.1.3. Caregiving tasks

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

- Instrumental ADLs:
 - Shopping for groceries, preparing meals, and providing transportation.
 - Helping the person take medications correctly and follow treatment recommendations for dementia and other medical conditions.
 - Managing finances and legal affairs.
- Personal ADLs:
 - Bathing, dressing, grooming, feeding, and helping the person use the toilet or manage incontinence.
- Managing safety issues and behavioral symptoms of the disease:
 - Assisting with mobility needs and transferring from bed to chair.
 - Supervising the person to avoid unsafe activities such as wandering and getting lost.
- Finding and using supportive services:
 - Making arrangements for medical care and paid in-home, assisted living, or nursing home care.
- Hiring and supervising others who provide care.
- Performing household chores.
- 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 AD, including communication with other family members about care plans, decision making, and arrangements for respite for the main caregiver.

Family and other unpaid caregivers of people with AD and other dementias are more likely than caregivers of other older people to assist with any given ADL. More than half of the caregivers of people with AD and other dementias report providing help with getting in and out of bed. Approximately one-third also provide help with getting to and from the toilet, bathing, managing incontinence, and feeding (Fig. 7). Fewer caregivers of other older people report providing help with each of these types of care [103].

In addition to assisting with ADLs, almost two-thirds of caregivers of people with AD and other dementias advocate for their care recipient with government agencies and service providers (64%), and nearly half arrange and supervise paid caregivers from outside community agencies (46%). By contrast, caregivers of other older adults are less likely to advocate for their family member (50%) and supervise community-based care (33%) [103].

When a person with AD 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 [105–107].

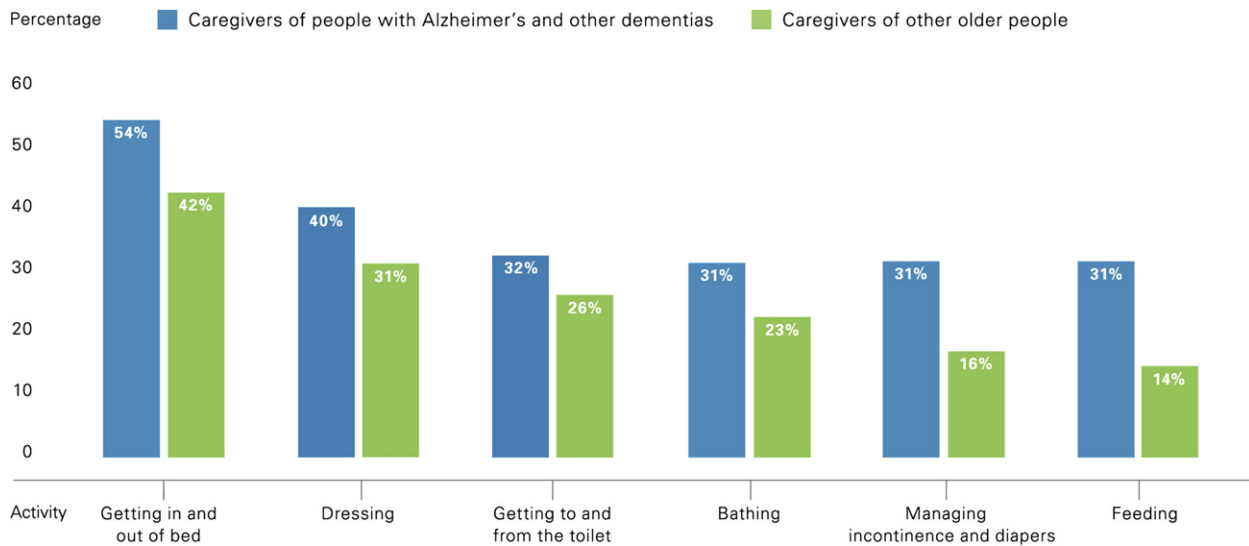


Fig. 7. Proportion of caregivers of people with AD and other dementias versus caregivers of other older people who provide help with specific activities of daily living, United States, 2009. Created from data from the National Alliance for Caregiving and AARP [103].

5.1.4. Duration of caregiving

Caregivers of people with AD 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 AD, 23% had been caregivers for <1 year, 43% for 1 to 4 years, and 32% for ≥5 years. In contrast, more of their non-AD caregiver counterparts had been caregiving for <1 year (34%), and fewer of them had been caregiving for 1 to 4 years (33%) or longer (28%) (Fig. 8) [103].

5.1.5. Hours of unpaid care and economic value of caregiving

In 2011, the 15.2 million family and other unpaid caregivers of people with AD 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 1139 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 AD and other dementias was \$210.5 billion in 2011. Table 6 shows the total hours of unpaid care as well as the value of the care provided by family and other unpaid caregivers for the United States and each state.

Unpaid caregivers of people with AD 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.

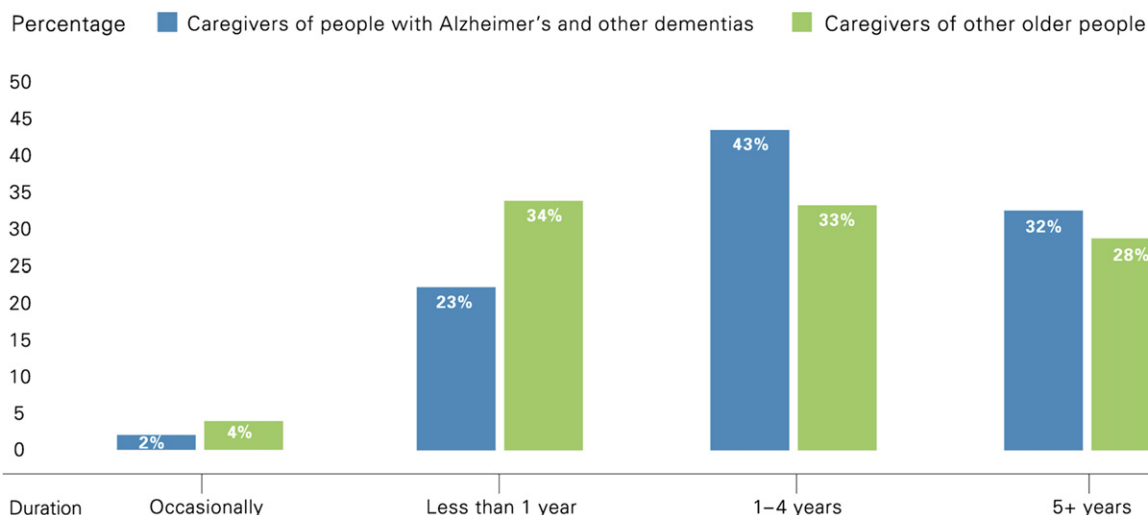


Fig. 8. Proportion of AD and dementia caregivers versus caregivers of other older people by duration of caregiving, United States, 2009. Created from data from the National Alliance for Caregiving and AARP [103].

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	AD/D caregivers	Hours of unpaid care	Value of unpaid care	Higher caregiver health care costs
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
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. total	15,248,740	17,365,265,478	\$210,467,017,597	\$8,652,903,101

NOTE. Differences between U.S. totals and summing 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–A16}

Abbreviation: AD/D, Alzheimer's disease and other dementias.

The average hours per week of unpaid care provided for people with AD and other dementias is greater if the caregiver lives with the care recipient, if the care recipient has coexisting medical conditions, and as the recipient's disease progresses [103,108–110].

5.1.6. Impact of caregiving

Caring for a person with AD 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

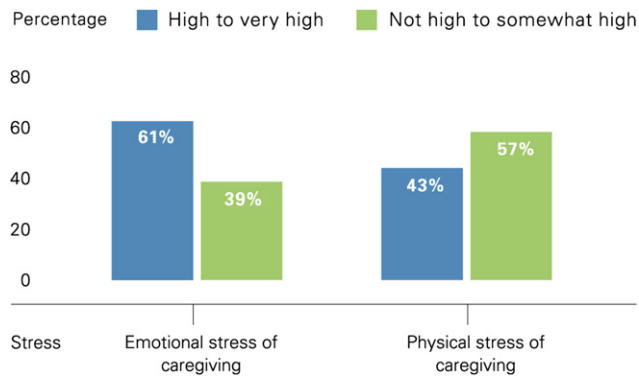


Fig. 9. Proportion of AD and dementia caregivers who report high or very high emotional and physical stress due to caregiving. Created from data from the Alzheimer's Association.^{A13}

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 [111].

5.1.6.1. 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:

- Sixty-one percent of family caregivers of people with AD and other dementias rated the emotional stress of caregiving as high or very high (Fig. 9).^{A13} In addition, approximately 33% of family caregivers of people with AD and other dementias reported symptoms of depression [112,113]. Family caregivers of people with AD and other dementias reported “a good amount” to “a great deal” of caregiving strain concerning financial issues (56%) and family relationships (53%).^{A13}
- The BRFSS caregiver survey administered in three states and the District of Columbia found that 36.5% of AD and dementia caregivers rated stress as the greatest difficulty they faced, compared with 23.6% of non-AD and dementia caregivers [102].
- The NAC/AARP survey found that 40% of caregivers reported high emotional stress. This survey found that caregivers who reported high emotional stress tended to be women, the primary caregiver, those living with the care recipient, and those who believed that they had no choice in taking on the role of caregiver [103].
- Caregivers who reported being stressed because of the impaired person's behavioral symptoms were more likely to place their care recipient in a nursing home

[112,113]. However, even after caregivers placed their family member in a nursing home, many still reported high levels of emotional and physical stress [103,105,107]. Seventy-seven percent of family caregivers of people with AD 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% of caregivers believed they were “on duty” 24 hours a day, and many believed that caregiving during this time was extremely stressful. A total of 72% of family caregivers said they experienced relief when the person died [110,114,115].

5.1.6.2. 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 [116]. Forty-three percent of caregivers of people with AD or other dementias reported that the physical stress of caregiving was high to very high (Fig. 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 shows the estimated higher health care costs for AD and dementia caregivers in each state.

5.1.6.2.1. General health and risk for chronic disease

Caregivers of people with AD and other dementias said they were “somewhat” to “very concerned” about maintaining their own health since becoming a caregiver (75%).^{A13} Dementia caregivers were more likely than noncaregivers to report that their health was fair or poor, and they were more likely than caregivers of other older people to say that caregiving made their health worse [103,104,116]. Data from the BRFSS caregiver survey found that AD and dementia caregivers were more than twice as likely as non-AD caregivers to say the *greatest* difficulty of caregiving is that it creates or exacerbates their own health problems [102].

Caregivers of people with AD and other dementias may also have difficulty maintaining healthy behaviors, as only 3% reported using exercise as a way of getting relief from their caregiving responsibilities [117]. However, other studies suggest that caregiving tasks keep older caregivers more physically active than noncaregivers [118].

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 [119].

5.1.6.2.2. Physiological changes

Caregivers of a spouse with AD or other dementias were also more likely than married noncaregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones [120], reduced immune function [121,122], slow wound healing [123], and increased incidence of hypertension [124], coronary heart disease [125], and impaired endothelial function, all of which may be associated with increased risk of cardiovascular disease [126].

5.1.6.2.3. 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 6 months if they were depressed or were taking care of individuals who needed more help with ADLs and had more behavioral symptoms [127].

5.1.6.2.4. 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 of a spouse who was hospitalized but did not have dementia, even after accounting for the age of the caregiver [128]. 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 noncaregivers [129,130].

One study found that higher stress levels were associated with higher rates of mortality in both caregivers and noncaregivers [130]. 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 addi-

tional research to better understand the subtleties of the connection between caregiving and mortality.

5.1.6.3. Caregiver employment

Although 44% of caregivers reported being employed full or part time, many caregivers of people with AD and other dementias reported making major changes to their work schedules because of their caregiving responsibilities: 65% said they had to go in late, leave early, or take time off, and 20% had to take a leave of absence. Other work-related changes pertaining to caregiving are summarized in Fig. 10.^{A13}

5.1.6.4. Interventions that may improve caregiver outcomes

A variety of interventions have been tested with family caregivers of people with AD and other dementias. The types and focus of these interventions are summarized in Table 5 [100]. 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 [100,131–135]; and delaying time to nursing home placement for the individual with AD or dementia, which could reduce overall health care costs [136,137].

5.2. Paid caregivers

Paid caregivers of people with AD 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

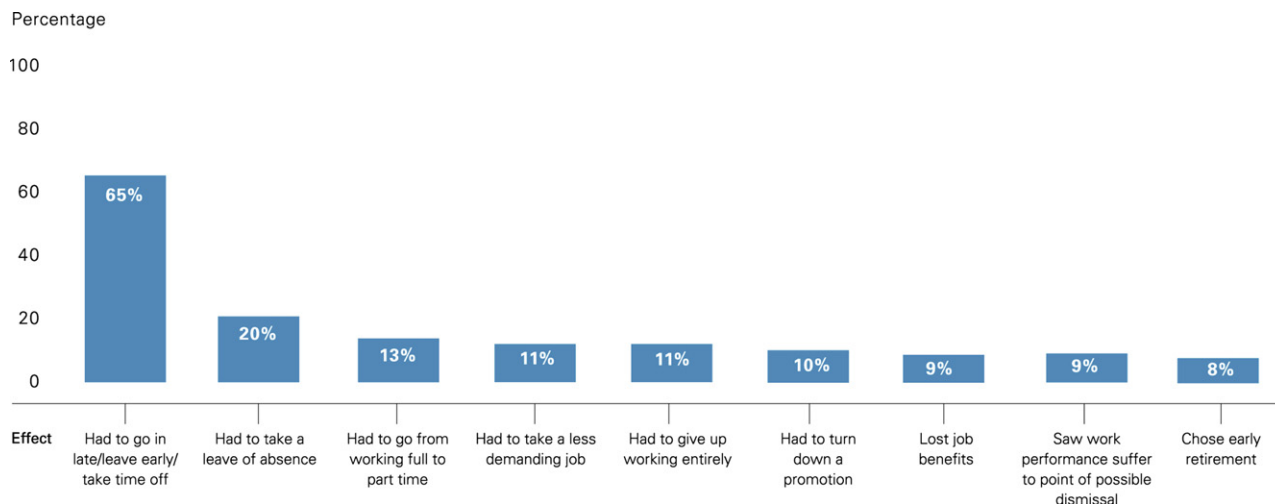


Fig. 10. Effect of caregiving on work: caregiver work-related changes. Created from data from the Alzheimer's Association.^{A13}

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 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 7128; those certified in geriatric psychiatry equaled 1596. By 2030, an estimated 36,000 geriatricians will be needed. Some have estimated that the increase from current levels will amount to <10%, whereas others believe there will be a net loss of physicians for geriatric patients [99].

Other professions also have low numbers of geriatric specialists: 4% of social workers and <1% of registered nurses, physician assistants, and pharmacists identify themselves as specializing in geriatrics [99].

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

As the number of people with AD and other dementias grows, aggregate payments for their care will increase dra-

matically. For people with these conditions, aggregate payments for health care, long-term care, and hospice 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% of the costs of care. All costs that follow are reported in 2011 dollars,^{A18} unless otherwise indicated.

6.1. 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 AD and other dementias. In 2008, total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with AD and other dementias were 3 times as great as payments for other Medicare beneficiaries in the same age group (\$43,847 per person for those with AD and other dementias compared with \$13,879 per person for those without AD and other dementias) [138].^{A19}

Twenty-nine percent of older individuals with AD and other dementias who have Medicare also have Medicaid coverage, compared with 11% 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 AD and other dementias translates into high costs for the Medicaid program. In 2008, average Medicaid payments per person for Medicare beneficiaries aged ≥65 years with AD and other dementias were 19 times as great as average Medicaid payments for Medicare beneficiaries without AD and other dementias (\$10,120 per person for individuals with AD and other dementias compared with \$527

Table 7

Average annual per-person payments for health care and long-term care services, Medicare beneficiaries aged ≥65 years, with and without AD/D and by place of residence, 2008 Medicare Current Beneficiary Survey, 2011 dollars

Payment source	Beneficiaries with AD/D by place of residence			Beneficiaries without AD/D
	Overall	Community dwelling	Residential facility	
Medicare	\$19,820	\$17,651	\$22,849	\$7521
Medicaid	10,120	222	23,953	527
Uncompensated	273	392	107	308
HMO	994	1543	227	1450
Private insurance	2262	2485	1948	1521
Other payer	906	164	1942	143
Out-of-pocket	9368	3167	18,035	2284
Total*	\$43,847	\$25,804	\$69,066	\$13,879

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [138].

*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with AD/D include payments for community-dwelling and facility-dwelling beneficiaries.

Total cost: \$200 Billion (B)

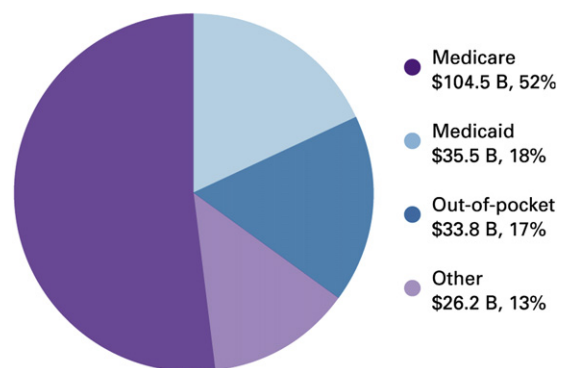


Fig. 11. Aggregate costs of care by payer for Americans aged ≥65 years with AD and other dementias, 2012. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations, and uncompensated care. Data are in 2012 dollars. Created from data from the application of the Lewin Model^{A17} to data from the Medicare Current Beneficiary Survey for 2008. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [138].

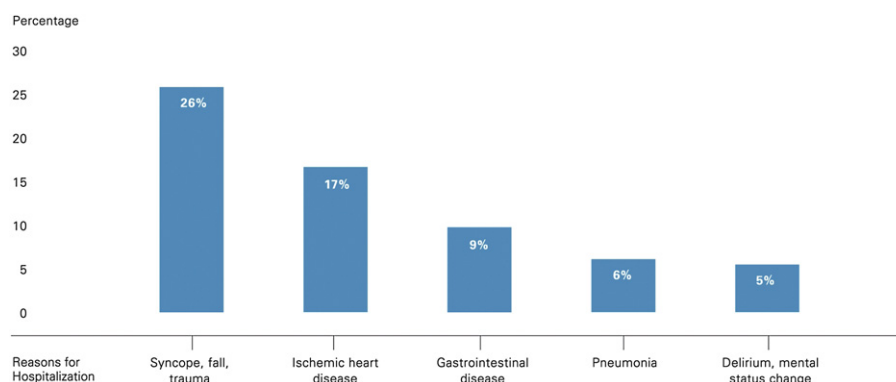


Fig. 12. Reasons for hospitalization of people with AD: percentage of hospitalized people by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible AD were used to calculate percentages. The remaining 37% of hospitalizations were due to other reasons. Created from data from Rudolph et al. *J Am Geriatr Soc* 2010;58:1542–8 [139].

for individuals without AD and other dementias; Table 7) [138].

Total payments for 2012 are estimated at \$200 billion, including \$140 billion for Medicare and Medicaid combined in 2012 dollars (Fig. 11). These figures are derived from a model developed by The Lewin Group using data from the Medicare Current Beneficiary Survey (MCBS) and The Lewin Group's long-term care financing model.^{A17}

6.2. Use and costs of health care services

People with AD and other dementias have >3 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 AD and other dementias. In particular, people with coronary heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke, or cancer who *also* have AD and other dementias have higher use and costs of health care services than do people with

these medical conditions but no coexisting AD and other dementias.

6.2.1. Use of health care services

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

6.2.1.1. Hospital

In 2008, there were 780 hospital stays per 1000 Medicare beneficiaries aged ≥65 years with AD and other dementias compared with 234 hospital stays per 1000 Medicare beneficiaries without these conditions [138]. The most common reasons for hospitalization of people with AD include syncope, fall, and trauma (26%); ischemic heart disease (17%); and gastrointestinal disease (9%) (Fig. 12) [139].

6.2.1.2. Skilled nursing facility

In 2008, there were 349 skilled nursing facility stays per 1000 beneficiaries with AD and other dementias compared with 39 stays per 1000 beneficiaries for people without these conditions [138].

6.2.1.3. Home health care

In 2008, 23% of Medicare beneficiaries aged ≥65 years with AD and other dementias had at least one home health

Table 8

Average annual per-person payments, from all sources, for health care services provided to Medicare beneficiaries aged ≥65 years with and without AD/D, 2008 Medicare Current Beneficiary Survey, 2011 dollars

Health care service	Beneficiaries with AD/D	Beneficiaries without AD/D
Inpatient hospital	\$9732	\$3912
Medical provider*	5967	3956
Skilled nursing facility	3812	444
Nursing home	17,693	786
Hospice	1749	171
Home health care	1402	452
Prescribed medications†	2681	2732

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [138].

*“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.

Table 9

Specific coexisting medical conditions among Medicare beneficiaries aged ≥65 years with AD/D, 2009

Coexisting condition	Percentage of people with AD/D 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%

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [140].

visit during the year, compared with 10% of Medicare beneficiaries without AD and other dementias [140].

6.2.2. 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 AD and other dementias than for other Medicare beneficiaries in the same age-group (Table 8) [138].

6.2.3. Impact of coexisting medical conditions on use and costs of health care services

Medicare beneficiaries with AD and other dementias are more likely than those without dementia to have other chronic conditions [140]. Table 9 reports the proportion of people with AD and other dementias who have certain coexisting medical conditions. In 2009, 30% of Medicare beneficiaries aged ≥ 65 years with AD and other dementias also had coronary heart disease, 29% also had diabetes, 22% also had congestive heart failure, 17% also had chronic kidney disease, and 17% also had chronic obstructive pulmonary disease [140].

People with serious coexisting medical conditions and AD and other dementias are more likely to be hospitalized than people with the same coexisting medical conditions but without AD and other dementias (Fig. 13) [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 AD and other dementias than for people who have the same medical conditions but no AD 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 AD and other dementias [140]. Medicare beneficiaries with a serious medical condition and AD 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.

6.3. Use and costs of long-term care services

An estimated 60% to 70% of older adults with AD and other dementias live in the community compared with 98% of older adults without AD and other dementias [138,141]. Of those with AD and other dementias who live in the community, 75% live with someone and the remaining 25% live alone [138]. As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers [78]. Many people with AD 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.

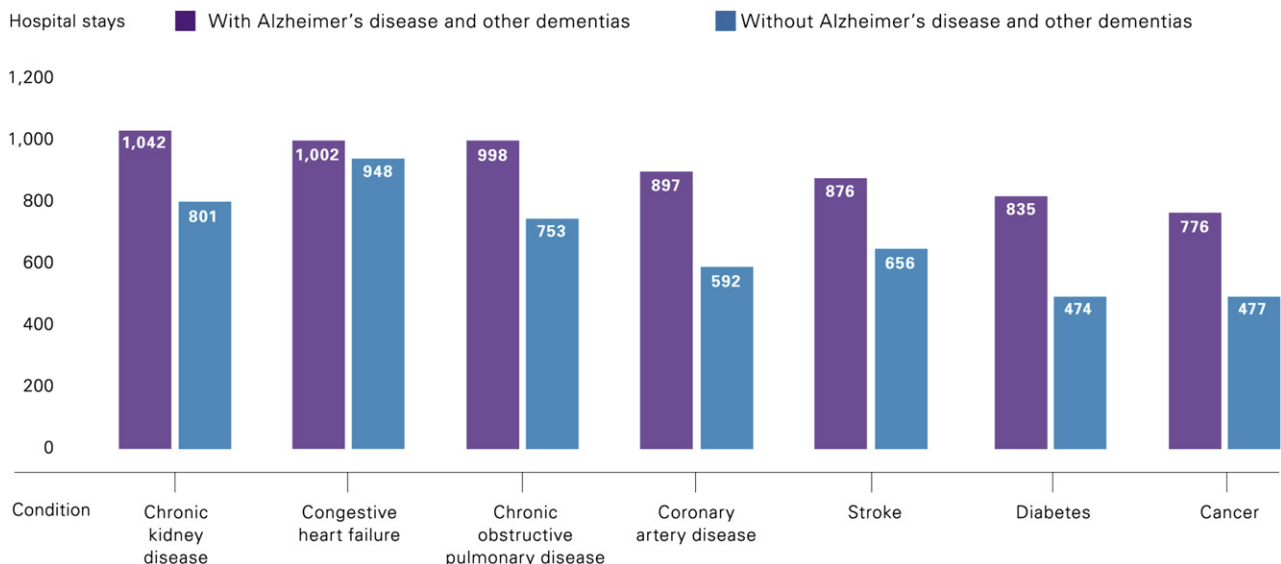


Fig. 13. Hospital stays per 1000 beneficiaries aged ≥ 65 years with specified coexisting medical conditions, with and without AD and other dementias, 2009. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [140].

Table 10

Average annual per-person payments by type of service and coexisting medical condition for Medicare beneficiaries aged ≥ 65 years, with and without AD/D, 2009, in 2011 dollars*

Medical condition by AD/D status	Total Medicare payments	Hospital care	Physician care	Skilled nursing facility care	Home health care	Hospice care
Coronary heart disease						
With AD/D	\$25,389	9138	1632	4034	2531	2184
Without AD/D	15,748	6566	1248	1229	1090	318
Diabetes						
With AD/D	24,776	8696	1528	3911	2608	1973
Without AD/D	13,695	5359	1075	1117	1033	223
Congestive heart failure						
With AD/D	24,331	10,378	1685	4472	2650	2739
Without AD/D	27,946	10,626	1683	2423	2088	775
Chronic kidney disease						
With AD/D	29,952	11,455	1807	4500	2474	2382
Without AD/D	23,045	9601	1582	1856	1532	493
Chronic obstructive pulmonary disease						
With AD/D	27,543	10,209	1720	4409	2625	2466
Without AD/D	18,851	8001	1413	1607	1410	619
Stroke						
With AD/D	25,843	9003	1585	4232	2398	2567
Without AD/D	18,554	6979	1348	2170	1760	607
Cancer						
With AD/D	23,782	8095	1489	3392	2066	2689
Without AD/D	15,564	5492	1142	918	733	551

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [140].

*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.

6.3.1. Use of long-term care services by setting

Most people with AD 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 AD 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.

6.3.1.1. Home care

According to state home care programs in Connecticut, Florida, and Michigan, more than one-third (approximately 37%) 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].

6.3.1.2. Adult day center services

At least half of elderly attendees at adult day centers have dementia [146,147].

6.3.1.3. Nursing home care

Sixty-four percent of Medicare beneficiaries aged ≥ 65 years living in a nursing home have AD and other dementias [138]. In 2009, 68% of all nursing home residents had some degree of cognitive impairment, including 27% who had very mild to mild cognitive impairment and 41% who had moderate to severe cognitive impairment (Table 11) [148]. In June 2011, 47% of all nursing home residents had a diagnosis of dementia in their nursing home record [149].

6.3.1.4. AD special care units

Nursing homes had 80,866 beds in AD special care units in June 2011 [150]. These AD special care unit beds accounted for 72% of all special care unit beds and 5% of all nursing home beds at that time. The number of nursing home beds in AD special care units increased in the 1980s but has decreased since 2004, when there were 93,763 beds in such units [151].

6.3.2. 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 AD special care units in nursing homes, which only applies to the people with AD and other dementias who are in these units.

6.3.2.1. 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].

Table 11
Cognitive impairment in nursing home residents, by state, 2009*

States	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	1328	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	9842	35	28	37
District of Columbia	5448	36	26	38
Florida	212,553	41	23	36
Georgia	68,186	16	23	61
Hawaii	8574	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
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	7106	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	4792	19	28	54
U.S. total	3,279,669	32	27	41

NOTE. Created from data from the U.S. Department of Health and Human Services. Nursing Home Data Compendium, 2010 [148].

*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.

6.3.2.2. 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 AD and other dementias, and 2% of these centers charged an additional fee for these clients.

6.3.2.3. Assisted living

In 2011, the average cost for basic services in an assisted living facility was \$3477 per month, or \$41,724 per year [141]. Seventy-two percent of assisted living facilities provided care to people with AD and other dementias, and 52% had a specific unit for people with AD and other dementias. In facilities that charged a different rate for individuals with AD and other dementias, the average rate was \$4619 per month, or \$55,428 per year, for this care.

6.3.2.4. 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 semiprivate 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 AD charged the same rate. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with AD was \$12 higher (\$251 per day, or \$91,615 per year), and the average cost for a semiprivate room was \$8 higher (\$222 per day, or \$81,030 per year) [141]. Thirty-six percent of nursing homes had separate AD special care units [141].

6.3.3. Affordability of long-term care services

Few individuals with AD 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 AD and other dementias specifically, but 50% of Medicare beneficiaries had incomes of \$21,774 or less and 25% 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 \$2095 or less, 50% had financial assets of \$30,287 or less, and 50% had total savings of \$52,793 or less, equivalent to <1 year of nursing home care [152].

6.3.4. Long-term care insurance

In 2010, approximately 7.3 million people had long-term care insurance policies [154]. Private health and long-term care insurance policies funded only about 9% 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].

6.3.5. 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% of Medicaid spending on long-term care was allocated to institutional care, and the remaining 42% was allocated to home- and community-based services [155].

Total Medicaid spending for people with AD and other dementias is projected to be \$35.5 billion in 2012.^{A17} Approximately half of all Medicaid beneficiaries with AD and other dementias are nursing home residents, and the rest live in the community [156]. Among nursing home residents with AD and other dementias, 51% rely on Medicaid to help pay for their nursing home care [156].

In 2008, total per-person Medicaid payments for Medicare beneficiaries aged ≥ 65 years with AD and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with AD 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 AD and other dementias living in a long-term care facility compared with \$222 for those with the same diagnosis but living in the community and \$527 for those without the diagnosis (Table 7) [138].

6.4. Out-of-pocket costs for health care and long-term care services

Despite other sources of financial assistance, individuals with AD 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 aged ≥ 65 years with AD and other dementias paid \$9368 out of pocket, on average, for health care and long-term care services that were not covered by additional sources (Table 7) [138]. Average per-person out-of-pocket payments were highest for individuals living in nursing homes and assisted living facilities and were almost 6 times as great as the average per-person pay-

ments for individuals with AD and other dementias living in the community (\$3167 per person) [138]. In 2012, total out-of-pocket spending for individuals with AD and other dementias is estimated at \$33.8 billion (Fig. 11).^{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 approximately one-quarter of total out-of-pocket costs for all Medicare beneficiaries aged ≥ 65 years [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 AD 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–\$133.40) [159]. As noted earlier, however, the most expensive component of out-of-pocket costs for people with AD and other dementias is nursing home and other residential care. Out-of-pocket costs for these services are likely to continue increasing.

6.5. 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 AD 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% of all people admitted to hospices in the United States had a primary hospice diagnosis of AD (61,146 individuals) [160]. An additional 11% of all people admitted to hospices in the United States had a primary hospice diagnosis of non-AD dementia (119,872 individuals) [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 AD 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-AD dementia increased from 57 days in 1998 to 92 days in 2009 [160]. Average per-person hospice care payments across all beneficiaries with AD and other dementias were 10 times as great as average per-person payments for all other Medicare beneficiaries (\$1749 per person compared with \$171 per person) [138].

6.6. Projections for the future

Total payments for health care, long-term care, and hospice for people with AD 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 sixfold increase in government spending under Medicare and Medicaid and a fivefold increase in out-of-pocket spending.^{A17}

7. Special report: People with AD and other dementias who 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, "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, "No one shall be arbitrarily deprived of his property" [161]. As people grow older, reaching age 65 years 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 [112,162]. This special report attempts to raise awareness of the issues that arise when individuals with AD and other dementias live alone, and to stimulate discussion of better ways to meet the unique needs of these individuals.

7.1. How many people in the United States with AD and other dementias live alone?

7.1.1. Older Americans living alone

According to 2011 data from the U.S. Census Bureau [163], approximately 29% of Americans aged ≥ 65 years—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 (Fig. 14). Among American women at least 85 years old, more than 56% live alone.

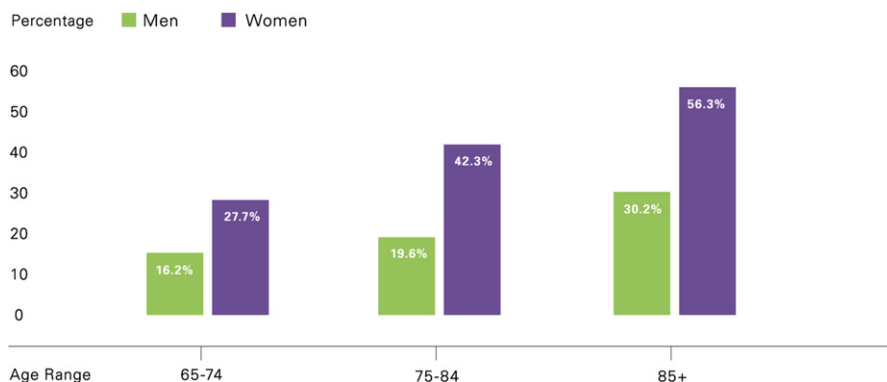


Fig. 14. Percentage of men and women aged ≥ 65 years in the United States who live alone. Created from data from the U.S. Census Bureau, America's families and living arrangements: 2011. Table A2: family status and household relationship of people 15 years and over, by marital status, age, and sex [163].

7.1.2. Living alone with dementia

The percentage of Americans with AD 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, people who live in assisted living facilities, nursing homes, or similar facilities that provide residential support have not been included.

7.1.2.1. Medicare Current Beneficiary Survey

The MCBS is an ongoing survey of approximately 13,000 Medicare beneficiaries chosen to represent 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 AD or other dementias in the MCBS, 42% lived in a nursing home or other facility that provided residential support (e.g., assisted living facility), 44% lived in the community with another person, and the remaining 15% lived alone in the community. Among those who lived in the community, 25%, or one 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 AD. Assuming that the living situations of people who have AD 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% of 5.4 million) people in the United States have AD and live alone in the community.

7.1.2.2. Aging, Demographics, and Memory Study

Another frequently cited resource for statistical information about people who have AD and other dementias is the ADAMS. The ADAMS data cited here included 1770 people chosen to represent the characteristics of Americans aged ≥ 71 years 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% lived alone (T. Okura, personal correspondence, September 4,

2011) [165]. 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.

7.1.2.3. Other studies

In a study of 1000 people who provide unpaid care for someone with AD or other dementias who lived in the community, 21% indicated that the care recipient lived alone [166]. 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 [167–169].

Another survey asked a nationally representative sample of caregivers about the living situation of their care recipient. Of the 423 care recipients >60 years who had AD and who lived in the community, 106 (25%) lived alone [103]. As with the preceding study, this percentage may be an underestimate.

Several smaller studies during the past 2 decades have found that 20% to 35% of people with dementia who lived in the community (not in a nursing home or assisted living facility) lived alone [167,168,170–172].

7.1.2.4. Summary

The available sources of information consistently indicate that at least 15% of Americans (or one of seven) who have AD 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 AD 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.

7.2. Racial and geographic disparities

Studies of the demographic characteristics of people with AD who live alone are sparse, but there is some evidence of substantial ethnic, geographic, and cultural differences [169]. Among all Americans aged ≥65 years living in the community, non-Hispanic white women and African American women are more likely than women of other races to live alone [172]. Also, African American men >65 years are more likely than Asian or non-Hispanic white men in the same age range to live alone [172]. These disparities may extend to individuals with AD or other dementias. In one study among older, community-dwelling African Americans with probable AD living in one region of the United States, 52% lived alone [173]. More studies are needed to establish the existence of racial and geographic disparities and to determine the underlying causes of such disparities.

7.3. Typical characteristics of people with AD 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 [167,168,170,171,174,175]. 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 [175,176].

7.4. Risks encountered by people with AD and other dementias who live alone

Even people with early-stage AD 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 [177,178]. As the disease progresses, an affected individual needs help with basic ADLs 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 [178]. They may be unable to solve problems or make good judgments, and they may experience frequent bowel and bladder incontinence [179].

Despite the declines in function associated with AD, many studies have shown that most older people prefer to live in their homes as long as possible, even if they live alone [180]. 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 [180,181]. 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.

7.4.1. Delayed or missed diagnosis

As described in 2011 *Alzheimer's Disease Facts and Figures* [182], as many as one-half of people who satisfy the

criteria for AD 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 [175]. In the same study, physicians and caregivers were significantly less likely to recognize cognitive impairment in people living alone than in people living with others [175]. Several previous studies found similar results [176,183,184]. 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 [185].

As discussed in *2011 Alzheimer's Disease Facts and Figures*, delayed or missed diagnosis of dementia can lead to unnecessary burdens on the affected persons and their caregivers [182]. Detrimental consequences of delayed or missed diagnosis include the following:

- 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 persons 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.

7.4.2. 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, 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 1 month for each person in the United States aged ≥ 65 years could save \$60 billion each year [186].

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 [112,187]. 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.

7.4.3. 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 [170,188–191]. Inadequate self-care has been cited as a cause of increased need for emergency medical services among people with dementia who live alone [189,192]. The issue of inadequate self-care is compounded by the observation that many people who are unable to care for themselves refuse help [193].

7.4.4. Falls, wandering, emergencies, and fatal injuries

People with AD 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 [194,195]. Falls are a major cause of serious injury and emergency department visits in the elderly population [196]. Individuals who live alone are less likely to obtain timely medical assistance when needed, such as after a fall [197].

People with AD and other dementias, especially those living alone, are also at increased risk of wandering away from home unattended [198]. Wandering is a significant safety risk for these individuals and frequently ends in injuries or death [198]. When someone lives alone, there is no one to promptly notice and report his or her absence; thus, wandering forays may be prolonged, increasing the chance that they result in injury or death.

The impairments associated with AD 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 [199]. In addition, older people with dementia who live alone are more likely to need emergency medical services because of self-neglect [189,192].

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 [197].

7.4.5. Psychiatric symptoms

In general, people with AD and other dementias have high rates of psychiatric symptoms—including depression, agitation, and psychosis—compared with people who have normal cognitive function [175,200–205]. These symptoms are associated with functional limitations [200] and increased risk of nursing home placement [112]. Among people with dementia, psychiatric symptoms have not been found to be more common among those living alone than among those living with others [175,188]. 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.

7.4.6. Social isolation and loneliness

Social isolation and loneliness are significant problems for people with dementia who live alone [206]. 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 [206], exacerbating social isolation and loneliness. However, 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 [174,206]. 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 AD and other dementias who live alone.

7.5. 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 [167–169]. Such individuals may have little or no support for conducting 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 [174,207,208] 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 [209,210].

In some communities, informal support networks may provide assistance to people who have dementia and live

alone in their homes [174,210]. 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 [174].

7.6. Unmet needs of people with AD and other dementias who live alone

The preceding discussion of the risks experienced by people with AD 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 [188,211]. Commonly identified unmet needs include the following [174,188,211]:

- 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.

7.6.1. 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 [167,171,190,212–216].

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 who 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 1000 people who had dementia and lived alone, there were 744 hospital stays and 272 stays in a skilled nursing

Table 12

Average per-person payments for health care services, Medicare beneficiaries aged ≥ 65 years with a reported diagnosis of dementia and who live in the community, by living situation, 2008 Medicare 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	\$7377	\$9782	–25%
Medical care provider	7015	6794	+3%
Hospice	418	1285	–67%
Other health care institutions*	3851	1219	+216%
Home health care	2162	1327	+63%
Prescription medications	3671	4638	–21%
Total [†]	25,389	25,943	–2%

NOTE. Created from data from the Medicare Current Beneficiary Survey for 2008. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; 2011 [138].

*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.

facility. The corresponding numbers for people who had a diagnosis of dementia but who lived with someone else were 705 hospital stays and 139 stays in a skilled nursing facility [138].

7.6.2. 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 [180]. However, they often do not meet the unique needs of people with dementia who live alone, which often include the requirement for a trusting relationship so that 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 [186,217].

8. Conclusion

At least 800,000 people in the United States who have AD 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.

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Appendices: End notes

^{A1}*Number of Americans aged ≥ 65 years with Alzheimer's disease (AD) 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. *Arch Neurol* 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 AD 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;75:786–91.

^{A2}*Proportion of Americans aged ≥ 65 years with AD:* The 13% is calculated by dividing the estimated number of people aged ≥ 65 years with AD (5.2 million) by the U.S. population aged ≥ 65 in 2010, the latest available data from the U.S. Census Bureau (40.3 million) = 13%. Thirteen percent is the same as one in eight.

^{A3}*Proportion of Americans aged ≥ 85 years with AD:* The 45% is calculated by dividing the number of people aged ≥ 85 years with AD (2.5 million) by the U.S. population aged ≥ 85 years in 2010, the latest available data from the U.S. Census Bureau (5.5 million) = 45%. Forty-five percent is nearly half.

^{A4}*Percentage of total AD cases by age-groups:* Percentages for each age-group are based on the estimated 200,000 for people aged < 65 years, plus the estimated numbers (in millions) for people aged 65 to 74 (0.3), 75 to 84 (2.4), and 85+ (2.5) years 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. *Arch Neurol* 2003;60:1119–22. These prevalence numbers are based on incidence data from the CHAP.

^{A5}*Differences between CHAP and ADAMS estimates for AD prevalence:* The Aging, Demographics, and Memory Study (ADAMS) estimates the prevalence of AD to be lower than does the CHAP, at 2.3 million Americans aged ≥ 71 years 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;29:125–32. 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 AD, even if they exhibited clinical symptoms of AD (see Wilson RS, Weir DR, Leurgans SE, Evans DA, Hebert LE, Langa KM, et al. Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States. *Alzheimers Dement* 2011;7:74–9). Because the more stringent threshold for dementia in ADAMS may miss people with mild AD and because clinical-pathologic studies have shown that mixed dementia due to both AD and vascular pathology in the brain is very common (see Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer's disease and mild cognitive impairment. *Ann Neurol* 2009;66:200–8), the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of AD in the United States.

^{A6}*Number of women and men aged ≥ 65 years with AD in the United States:* The estimates for number of U.S. women (3.3 million) and men (1.8 million) aged ≥ 65 years with AD in 2010 were provided to the Alzheimer's Association by Denis Evans, MD, 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. *Arch Neurol* 2003;60:1119–22. For 2012, we took the proportion of U.S. women and men aged ≥ 65 years with AD in 2010 (65% and 35%, respectively) and applied these proportions to the new estimate for total number of Americans aged ≥ 65 years with AD (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 AD:* Although AD 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 Dis Assoc Disord* 2001;15:169–73. The Alzheimer's Association calculated that the incidence of new cases in 2012 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.2 (for the number of years from 2010 to 2012 divided by the number of years from 2010 to 2020), adding that result (7400) 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 AD and other dementias in the Framingham Study:* Standard diagnostic criteria (*Diagnostic and Statistical Manual of Mental Disorders*, 4th ed, 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 one or more on the Clinical Dementia Rating scale, and they had to have symptoms for 6 months or more. Standard diagnostic criteria (the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association criteria) were used to diagnose AD. The examination for dementia and AD 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 AD and other dementias:* The numbers for remaining lifetime risk of AD 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, PhD, Sudha Seshadri, MD, Rhoda Au, PhD, and Philip A. Wolf, MD, from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, to U.S. Census data for the number of women and men aged 43 to 61 years in November 2007, used here to estimate the number of women and men aged 44 to 62 years in 2008.

^{A10}*State-by-state prevalence of AD:* These state-by-state prevalence numbers are based on incidence data from the CHAP, projected to each state's population, with adjustments for state-specific sex, 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 AD 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. *Arch Neurol* 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. *Am J Public Health* 1998;88:1337–42) because they relied on more conservative methods for counting people who currently have AD.^{A5} Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with AD over the coming decades.

^{A12}*Number of family and other unpaid caregivers of people with AD and other dementias:* To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS). In 2009, the BRFSS survey asked respondents aged ≥ 18 years 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 aged ≥ 18 years nationally and in each state from the U.S. Census Bureau report for July 2011 (Available at: www.census.gov/popest/data/. Accessed January 5, 2012). To calculate the proportion of family and other unpaid caregivers who provide care for a person with AD 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/CaregivingUSAllAgesExecSum.pdf). The NAC/AARP survey asked respondents aged ≥ 18 years whether they were providing unpaid care for a relative or friend aged 18 years 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% of caregivers said that: (1) AD or dementia was the main problem of the person for whom they provided care, or (2) the person had AD or other mental confusion in addition to his or her main problem. We applied the 26% 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 3118 adults nationwide by telephone from August 25 to September 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% concentration of each group. It also included an oversample of Asian Americans using a listed sample of Asian American households. The combined samples include 2295 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 sex, 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 AD or other dementias. This was supplemented with 300 interviews from a listed sample of caregivers of people with AD for a total of 502 caregiver interviews. A caregiver was defined as an adult aged >18

years who, in the past 12 months, provided unpaid care to a relative or friend aged ≥ 50 years with AD or other dementias. The weight of the caregiver sample adjusted all 502 caregiver cases to the weighted estimates for sex 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 SH 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; November 11, 2009). These data show that caregivers of people with AD and other dementias provided an average of 21.9 hours a week of care, or 1139 hours per year. We multiplied the number of family and other unpaid caregivers (15,248,740) by the average hours of care per year (1139), 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 Aff* 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 AD caregivers:* This figure is based on a methodology originally developed by Brent Fulton, PhD, 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% higher than that of noncaregivers (Albert SM, Schulz R. The MetLife study of working caregivers and employer health care costs. New York, NY: MetLife Mature Market Institute; 2010). To determine the dollar amount represented by that 8% figure nationally and in each state, the 8% figure and the proportion of caregivers from the 2009 BRFSS^{A12} were used to weight each state's caregiver and noncaregiver 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 December 30, 2011). The dollar amount difference between the weighted per-capita personal health care spending of caregivers and noncaregivers in each state (reflecting

the 8% 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 AD and dementia caregivers in that state^{A12} to arrive at that state's total additional health care costs of AD 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 AD is more stressful than caregiving for most people who don't have the disease" [117].

^{A17}*Lewin model on AD 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/trajactory.

^{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}*MCBS report:* These data come from an analysis of findings from the 2008 MCBS. The analysis was conducted for the Alzheimer's Association by Julie Bynum, MD, MPH, 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. 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 aged ≥ 65 years.

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 AD or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for AD 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 AD 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 aged ≥ 65 years who live alone:* The percentage and total number of Americans aged ≥ 65 years 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+ years. 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.