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**Alzheimer's
&
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Alzheimer's Association Report

2013 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), including incidence and prevalence, mortality rates, health expenditures and costs of care, and effect on caregivers and society in general. It also explores the roles and unique challenges of long-distance caregivers, as well as interventions that target those challenges. An estimated 5.2 million Americans have AD. Approximately 200,000 people younger than 65 years with AD comprise the younger onset AD population; 5 million comprise the older onset AD population. Throughout the coming decades, the baby boom generation is projected to add about 10 million to the total number of people in the United States with AD. Today, someone in America develops AD every 68 seconds. By 2050, one new case of AD is expected to develop every 33 seconds, or nearly a million new cases per year, and the total estimated prevalence is expected to be 13.8 million. AD is the sixth leading cause of death in the United States and the fifth leading cause of death in Americans age 65 years or older. Between 2000 and 2010, the proportion of deaths resulting from heart disease, stroke, and prostate cancer decreased 16%, 23%, and 8%, respectively, whereas the proportion resulting from AD increased 68%. The number of deaths from AD as determined by official death certificates (83,494 in 2010) likely underrepresents the number of AD-related deaths in the United States. A projected 450,000 older Americans with AD will die in 2013, and a large proportion will die as a result of complications of AD. In 2012, more than 15 million family members and other unpaid caregivers provided an estimated 17.5 billion hours of care to people with AD and other dementias, a contribution valued at more than \$216 billion. Medicare payments for services to beneficiaries age 65 years and older 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. Total payments in 2013 for health care, long-term care, and hospice services for people age 65 years and older with dementia are expected to be \$203 billion (not including the contributions of unpaid caregivers). An estimated 2.3 million caregivers of people with AD and other dementias live at least 1 hour away from the care recipient. These "long-distance caregivers" face unique challenges, including difficulty in assessing the care recipient's true health condition and needs, high rates of family disagreement regarding caregiving decisions, and high out-of-pocket expenses for costs related to caregiving. Out-of-pocket costs for long-distance caregivers are almost twice as high as for local caregivers.

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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; Medicare spending; Medicaid spending; Long-distance caregiver; Activities of daily living; Instrumental activities of daily living

1. About this report

2013 Alzheimer's Disease Facts and Figures is a statistical resource for US data related to Alzheimer's disease (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 various 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. This special report focuses on long-distance caregivers of people with AD and other dementias.

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

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- Proposed new criteria and guidelines for diagnosing AD from the National Institute on Aging (NIA) and the Alzheimer's Association
- 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
- Number of deaths resulting from AD nationally and for each state, and death rates by age
- Use and costs of health care, long-term care, and hospice care for people with AD and other dementias
- Number of long-distance caregivers and the special challenges they face

This report 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.”

2. Overview of AD

AD is the most common type of dementia. *Dementia* is an umbrella term that describes a variety of diseases and conditions that develop when nerve cells in the brain (called neurons) die or no longer function normally. The death or malfunction of 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, Fourth Edition (DSM-IV)* [1]. To meet *DSM-IV* criteria for dementia, the following are required:

- Symptoms must include decline in memory *and* in at least one of the following cognitive abilities:
 1. Ability to speak coherently or understand spoken or written language
 2. Ability to recognize or identify objects, assuming intact sensory function
 3. Ability to perform 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.

In May 2013, the American Psychiatric Association is expected to release *DSM-5*. This new version of *DSM* is ex-

pected to incorporate dementia into the diagnostic category of major neurocognitive disorder.

To establish a diagnosis of dementia using *DSM-IV*, a physician must determine the cause of the individual's symptoms. Some conditions have symptoms that mimic dementia but that, unlike dementia, may be reversed with treatment. An analysis of 39 articles describing 5620 people with dementia-like symptoms reported that 9% had potentially reversible dementia [2]. Common causes of potentially reversible dementia are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. In contrast, AD and other dementias are caused by damage to neurons that cannot be reversed with current treatments.

When an individual has 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 have brain abnormalities associated with more than one type of dementia [3–7]. This is called mixed dementia and is most often found in individuals of advanced age.

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 during the past 30 years. Although research has revealed a great deal about AD, the precise changes in the brain that trigger the development of AD, and the order in which they occur, 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. The most common symptom pattern begins with a gradually worsening ability to remember new information. This symptom occurs because the first neurons to die and malfunction are usually neurons in brain regions involved in forming new memories. As neurons in other parts of the brain malfunction and die, individuals experience other difficulties. The following are common symptoms 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

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% to 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 that begins well before the development of symptoms.</p> <p>Hallmark brain abnormalities are deposits of the protein fragment amyloid beta (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 AD.</p> <p>Impaired judgment or ability to make plans is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of AD.</p> <p>Vascular dementia occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location of the brain injury determines how the individual's thinking and physical functioning are affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of AD (and vice versa). That practice is no longer considered consistent with pathological 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 alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with PD, 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>
FTLD	<p>Includes dementias such as behavioral-variant FTLN, primary progressive aphasia, Pick's disease, and progressive supranuclear palsy.</p> <p>Typical symptoms include changes in personality and behavior, and difficulty with language.</p> <p>Nerve cells in the front and side regions of the brain are especially affected. No distinguishing microscopic abnormality is linked to all cases.</p> <p>The brain changes of behavioral-variant FTLN may be present at the same time as the brain changes of AD, but people with behavioral-variant FTLN generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with AD.</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>
PD	<p>As PD 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>Alpha-synuclein aggregates are likely to begin in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine.</p> <p>The incidence of PD is about one-tenth that of 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; FTLN, Frontotemporal lobar degeneration; PD, Parkinson's disease.

- Withdrawal from work or social activities
- Changes in mood and personality

For more information about symptoms of AD, visit www.alz.org/10signs.

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 bed-bound and reliant on around-the-clock care. When an individual has difficulty moving because of AD, they are more vulnerable to infections, including pneumonia (infection of the lungs). AD-related pneumonia is often a contributing factor to the death of people with AD.

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. The physician also asks a family member or other person close to the individual to provide input. In addition, the physician conducts cognitive tests and physical and neurological examinations, and may request that the individual undergo magnetic resonance imaging. Magnetic resonance images can help identify brain changes, such as the presence of a tumor or evidence of a stroke, that could explain the individual's symptoms.

2.2.3. A modern diagnosis of AD: Proposed new criteria and guidelines

In 2011, the NIA and the Alzheimer's Association proposed new criteria and guidelines for diagnosing AD [8–11]. These criteria and guidelines updated diagnostic criteria and guidelines published in 1984 by the Alzheimer's Association and the National Institute of Neurological Disorders and Stroke. In 2012, the NIA and the Alzheimer's Association also proposed new guidelines to help pathologists describe and categorize the brain changes associated with AD and other dementias [12].

It is important to note that these are proposed criteria and guidelines. More research is needed, especially research about biomarkers, before the 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 diagnostic criteria and guidelines were based chiefly on a doctor's clinical judgment about the cause of an individual's symptoms, taking into account reports from the individual, family members, and friends; results of cognitive tests; and general neurological assessment. The new criteria and guidelines incorporate two notable changes. First, they identify three stages of AD, with the first occurring before symptoms such as memory loss develop. In contrast, for AD to be diagnosed using the 1984 criteria, memory loss and a decline in thinking abilities severe enough to affect daily life must have already occurred. Second, they incorporate biomarker tests. A biomarker is a biological factor that can be measured to indicate the presence or absence of disease, or the risk of developing a disease. For example, blood glucose level is a biomarker of diabetes; cholesterol level is a biomarker of heart disease

risk. Levels of certain proteins in fluid (e.g., levels of amyloid beta [A β] and tau in the cerebrospinal fluid [CSF] and blood) are among several factors being studied as possible biomarkers for Alzheimer's.

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

The three stages of AD proposed by 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. The 2011 criteria proposed that AD begins before the development of symptoms, and that new technologies have the potential to identify brain changes that precede the development of symptoms. Using the new criteria, an individual with these early brain changes would be said to have preclinical AD or MCI due to AD, and those with symptoms would be said to have dementia due to AD. Dementia due to AD would encompass all stages of AD commonly described today, from mild to moderate to severe.

2.2.3.2.1. Preclinical AD

In the preclinical AD stage, individuals have measurable changes in the brain, CSF, 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-related brain changes may begin 20 years or more 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 research on biomarker tests 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 age 65 or older have MCI [13–15]. As many as 15% of people whose MCI symptoms cause them enough concern to contact their doctor's office for an exam go on to develop dementia each year. Nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in 3 or 4 years [16].

When MCI is identified through community sampling, in which individuals in a community who meet certain criteria are assessed regardless of whether they have memory or cognitive complaints, the estimated rate of progression to AD is slightly less—up to 10% per year [17]. Further cognitive decline is more likely among individuals whose MCI involves memory problems than among 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 [18]. 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.

When accurate biomarker tests for AD have been identified, the new criteria and guidelines recommend biomarker testing for people with MCI to discover whether they have brain changes that put them at high risk of developing AD and other dementias. If it can be shown that changes in the brain, CSF, and/or blood are caused by physiological processes associated with AD, the new criteria and guidelines recommend a diagnosis of MCI due to AD.

2.2.3.2.3. *Dementia due to AD*

Dementia due to AD 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 brain changes.

2.2.3.3. *Biomarker tests*

The new criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of A β accumulation in the brain and (2) biomarkers showing that neurons in the brain are injured or actually degenerating.

Many researchers believe that future treatments to slow or stop the progression of AD and to preserve brain function (called disease-modifying treatments) will be most effective when administered during the preclinical and MCI stages of the disease. Biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment. These tests also will be critical for monitoring the effects of treatment. At this time, however, more research is needed to validate the accuracy of biomarkers and to understand more completely which biomarker test or combination of tests is most effective in diagnosing AD. The most effective test or combination of tests may differ, depending on the stage of the disease and the type of dementia [19].

2.2.4. *Changes in the brain that are associated with AD*

Many experts believe that AD, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. In AD, these multiple factors are a variety of brain changes that may begin 20 years or more before symptoms appear. Increasingly, the time 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 neuronal damage that has occurred, 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, the damage to and death of neurons is so significant that the

individual shows obvious cognitive decline, including symptoms such as memory loss or confusion as to time or place. At this point, physicians following the 1984 criteria and guidelines for AD would diagnose the individual as having AD. The 2011 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 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.

These and other questions reflect the complexity of the brain. 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 such connections, called synapses, information flows in tiny chemical pulses released by one neuron and detected by the receiving neuron. The brain contains about 100 trillion synapses that allow signals to travel rapidly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements, and skills. AD interferes with the proper functioning of neurons and synapses.

Among the brain changes believed to contribute to the development of AD are the accumulation of the protein A β outside neurons in the brain (called A β plaques) and the accumulation of an abnormal form of the protein tau inside neurons (called tau tangles). In AD, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of A β is believed to interfere with the neuron-to-neuron communication at synapses and to contribute to cell death. Tau tangles block the transport of nutrients and other essential molecules in the neuron and are also believed to contribute to cell death. The brains of people with advanced AD show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

2.2.5. *Genetic mutations that cause AD*

The only known cause of AD is genetic mutation—an abnormal change in the sequence of chemical pairs inside genes. A small percentage of AD cases, probably fewer than 1%, are 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, disease symptoms tend to develop before age 65, sometimes as early as age 30. People with these genetic mutations are said to have dominantly inherited AD.

The development and progression of AD in these individuals is of great interest to researchers because the changes occurring in the brain of these individuals also occur in individuals with the more common late-onset AD (in which symptoms develop at age 65 or older). Future treatments that are effective in people with dominantly inherited AD may provide clues to effective treatments for people with late-onset disease.

The Dominantly Inherited Alzheimer Network is a worldwide network of research centers investigating disease progression in people with a gene for dominantly inherited AD who have not yet developed symptoms. Dominantly Inherited Alzheimer Network researchers have found a pattern of brain changes in these individuals. The pattern begins with decreased levels of A β in the CSF (the fluid surrounding the brain and spinal cord), followed by increased levels of the protein tau in CSF and increased levels of A β in the brain. As the disease progresses, the brain's ability to use glucose, its main fuel source, decreases. This decreased glucose metabolism is followed by impairment of a type of memory called episodic memory, and then a worsening of cognitive skills, called global cognitive impairment [20]. Whether this pattern of changes will also hold true for individuals at high risk for late-onset AD or younger onset AD (in which symptoms develop before age 65) that is not dominantly inherited requires further study.

2.2.6. Risk factors for AD

Many factors contribute to one's likelihood of developing AD. The greatest risk factor for AD is advancing age, but AD is not a typical part of aging. Most people with AD are diagnosed at age 65 or older. However, people younger than 65 can also develop the disease, although this is much more rare. Advancing age is not the only risk factor for AD. The following sections describe other risk factors.

2.2.6.1. 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 [21–23]. Those who have more than one first-degree relative with AD are at even higher risk of developing the disease [24]. When diseases run in families, heredity (genetics), shared environmental and lifestyle factors, or both, may play a role. The increased risk associated with having a family history of AD is not entirely explained by whether the individual has inherited the *apolipoprotein E (APOE) ϵ 4* risk gene.

2.2.6.2. *APOE ϵ 4* gene

The *APOE* gene provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the *APOE* gene— ϵ 2, ϵ 3 or ϵ 4—from each parent. The ϵ 3 form is the most common [25], with about 60% of the U.S. population inheriting ϵ 3 from both parents [26]. The ϵ 2 and ϵ 4 forms are much less common. An estimated 20% to 30% of individuals in the United States have one or two copies of the ϵ 4 form [25,26]; approximately 2% of the U.S. population has two copies of ϵ 4 [26]. The remaining 10% to 20% have one or two copies of ϵ 2.

Having the ϵ 3 form is believed neither to increase nor decrease one's risk of AD, whereas having the ϵ 2 form may decrease one's risk. The ϵ 4 form, however, increases the risk of developing AD and of developing it at a younger age. Those who inherit two ϵ 4 genes have an even higher risk. Researchers estimate that between 40% and 65% of

people diagnosed with AD have one or two copies of the *APOE ϵ 4* gene [25,27,28].

Inheriting the *APOE ϵ 4* gene does not guarantee that an individual will develop AD. This is also true for several genes that appear to increase risk of AD but have a limited overall effect in the population because they are rare or increase risk only slightly. Many factors other than genetics are believed to contribute to the development of AD.

2.2.6.3. 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. However, MCI does not always lead to dementia. For some individuals, MCI reverts to normal cognition on its own or remains stable. In other cases, such as when a medication causes cognitive impairment, MCI is diagnosed mistakenly. Therefore, it's important that people experiencing cognitive impairment seek help as soon as possible for diagnosis and possible treatment.

The 2011 proposed criteria and guidelines for diagnosis of AD [8–11] suggest that, in some cases, MCI is actually an early stage of AD or another dementia.

2.2.6.4. Cardiovascular disease risk factors

Increasing evidence suggests that the health of the brain is linked closely 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.

Many factors that increase the risk of cardiovascular disease are also associated with a higher risk of developing AD and other dementias. These factors include smoking [29–31], obesity (especially in midlife) [32–37], diabetes mellitus [31,38–41], high cholesterol in midlife [34,42], and hypertension in midlife [34,37,43–45]. A pattern that has emerged from these findings, taken together, is that dementia risk may increase with the presence of the metabolic syndrome, a collection of conditions occurring together—specifically, three or more of the following: hypertension, high blood glucose, central obesity (obesity in which excess weight is carried predominantly at the waist), and abnormal blood cholesterol levels [40].

Conversely, factors that protect the heart may protect the brain and reduce the risk of developing AD and other dementias. Physical activity [40,46–48] appears to be one of these factors. In addition, emerging evidence suggests that consuming a diet that benefits the heart, such as one that is low in saturated fats and rich in vegetables and vegetable-based oils, may be associated with reduced AD and dementia risk [40].

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.

2.2.6.5. Education

People with fewer years of education are at higher risk for AD and other dementias than those with more years of formal education [49–53]. Some researchers believe that having more years of education builds a “cognitive reserve” that enables individuals to compensate more fully for changes in the brain that could result in symptoms of AD or another dementia [52,54–56]. According to the cognitive reserve hypothesis, having more years of education increases the connections between neurons in the brain and enables the brain to compensate for the early brain changes of AD by using alternate routes of neuron-to-neuron communication to complete a cognitive task. In addition, some scientists 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 [57].

2.2.6.6. Social and cognitive engagement

Additional studies suggest that other modifiable factors, such as remaining mentally [58–60] and socially active, may support brain health and possibly reduce the risk of AD and other dementias [61–68]. Remaining socially and cognitively active may help build cognitive reserve, but the exact mechanism by which this may occur is unknown. Compared with cardiovascular disease risk factors, there are fewer studies of the association between social and cognitive engagement and the likelihood of developing AD and other dementias. More research is needed to understand more completely how social and cognitive engagement may affect biological processes to reduce risk.

2.2.6.7. Traumatic brain injury (TBI)

Moderate and severe TBI increase the risk of developing AD and other dementias [69]. TBI is the disruption of normal brain function caused by a blow or jolt to the head or penetration of the skull by a foreign object. Not all blows or jolts to the head disrupt brain function. Moderate TBI is defined as a head injury resulting in loss of consciousness or posttraumatic amnesia that lasts more than 30 minutes. If loss of consciousness or posttraumatic amnesia lasts more than 24 hours, the injury is considered severe. Half of all moderate or severe TBIs are caused by motor vehicle accidents [70]. Moderate TBI is associated with twice the risk of developing AD and other dementias compared with no head injury, and severe TBI is associated with 4.5 times the risk of developing AD [71]. These increased risks have not been studied for individuals experiencing occasional mild head injury or any number of common minor mishaps

such as bumping one's head against a shelf or an open cabinet door.

Groups that experience repeated head injuries, such as boxers, football players [72], and combat veterans, are at higher risk of dementia, cognitive impairment, and neurodegenerative disease than individuals who experience no head injury [73–78]. Emerging evidence suggests that even repeated mild TBI might promote neurodegenerative disease [78]. Some of these neurodegenerative diseases, such as chronic traumatic encephalopathy, can only be distinguished from AD at autopsy.

2.2.7. Treatment of AD

2.2.7.1. Pharmacological treatment

Pharmacological treatments are treatments in which medication is administered to stop an illness or treat its symptoms. None of the treatments available today for AD slows or stops the death and malfunction of neurons in the brain that cause AD symptoms and make the disease fatal. However, dozens of drugs and therapies aimed at slowing or stopping brain cell death and malfunction are being studied worldwide. Five drugs have been approved by the U.S. Food and Drug Administration that improve symptoms of AD temporarily by increasing the amount of chemicals called neurotransmitters in the brain. The effectiveness of these drugs varies across the population.

Despite the lack of disease-modifying therapies, studies have shown consistently that active medical management of AD and other dementias can improve quality of life through all stages of the disease for individuals with dementia and their caregivers [79–81]. 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/or adult daycare programs; and (5) taking part in support groups and supportive services.

2.2.7.2. Nonpharmacological therapy

Nonpharmacological therapies are those that use approaches other than medication, such as cognitive training and behavioral interventions. As with pharmacological therapies, no nonpharmacological therapies have been shown to alter the course of AD, although some are used with the goal of maintaining cognitive function or helping the brain compensate for impairments. Other nonpharmacological therapies are intended to improve quality of life or reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation, and aggression. A wide range of nonpharmacological interventions have been proposed or studied, although few have sufficient evidence supporting their effectiveness. There is some evidence that specific nonpharmacological therapies may improve or stabilize cognitive function, performance of daily activities, behavior, mood, and quality of life [82].

3. Prevalence

Millions of Americans have AD and other dementias. The number of Americans with AD and other dementias will grow each year as the number and proportion of the U.S. population age 65 and older continue to increase. The number will escalate rapidly in coming years as the baby boom generation ages.

Estimates from selected studies on the prevalence and characteristics of people with AD and other dementias vary depending on how each study was conducted. Data from several studies are used in this section. Most estimates are from a new study using the same methods as the study that provided estimates in previous years' *Facts and Figures* reports, but with updated data [83].^{A1} Although some of the estimates are slightly different than estimates in previous *Facts and Figures* reports, researchers consider them to be statistically indistinguishable from previous estimates when accounting for margins of error.

3.1. Prevalence of AD and other dementias

An estimated 5.2 million Americans of all ages have AD in 2013. This includes an estimated 5.0 million people age 65 and older [83].^{A1} and approximately 200,000 individuals younger than age 65 who have younger onset AD [84].

- One in nine people age 65 and older (11%) has AD.^{A2}
- About one-third of people age 85 and older (32%) have AD [83].
- Of those with AD, an estimated 4% are younger than age 65, 13% are 65 to 74 years old, 44% are 75 to 84 years old, and 38% are 85 years or older [83].^{A3}

The estimated prevalence for people age 65 and older comes from a new study using the latest data from the 2010 U.S. Census and the Chicago Health and Aging Project (CHAP), a population-based study of chronic health diseases of older people. Although this estimate is slightly lower than the estimate presented in previous *Facts and Figures* reports, it does not represent a real change in prevalence. According to the lead author of both the original and the new studies on the prevalence of Alzheimer's, "Statistically, [the estimates] are comparable, and, more importantly, both old and new estimates continue to show that the burden [AD] places on the population, short of any effective preventive interventions, is going to continue to increase substantially" [83].

In addition to estimates from CHAP, the national prevalence of AD and all forms of dementia has been estimated from other population-based studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults [85,86].^{A4} National estimates of the prevalence of all forms of dementia are not available from CHAP; however, based on estimates from ADAMS, 13.9% of people age 71 and older in the United States have dementia [85].

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 and other dementias have received a diagnosis of dementia from a physician [87]. Because AD is underdiagnosed, half of the estimated 5.2 million Americans with AD may not know they have it.

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 work group was convened by the Alzheimer's Association and the NIA to recommend updated diagnostic criteria and guidelines, as described in the Overview. These proposed new criteria and guidelines were published in 2011 [8–11]. If AD can be detected earlier, in the stages of preclinical AD and/or MCI due to AD, as defined by the 2011 criteria, the number of people reported to have AD would be much larger than what is presented in this report.

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 [83].^{A5} Of the 5 million people age 65 years and older with AD in the United States, 3.2 million are women and 1.8 million are men.^{A5} Based on estimates from ADAMS, 16% of women age 71 years and older have AD and other dementias compared with 11% of men [85,88].

The larger proportion of older women who have AD and other dementias is explained primarily by the fact that women live longer, on average, than men [88,89]. Many studies of the age-specific incidence (development of new cases) of AD [50,51,89–93] or any dementia [49,50,90,91,94] have found no significant difference by sex. Thus, women are not more likely than men to develop dementia at any given age.

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 [49–53]. Some of the possible reasons are explained in the Risk Factors for AD section of the Overview.

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

Although most people in the United States living with AD and other dementias are non-Hispanic whites, older blacks and Hispanics are proportionately more likely than older whites to have AD and other dementias [95,96]. Data indicate that, in the United States, older blacks are probably about twice as likely to have AD and other dementias as older whites [97], and Hispanics are about 1.5 times as likely to have AD and other dementias as older whites [98]. Fig. 1 shows the estimated prevalence for each group, by age.

Despite some evidence of racial differences in the influence of genetic risk factors on AD and other dementias, genetic factors do not appear to account for these large prevalence differences across racial groups [99]. Instead, health conditions such as high blood pressure and diabetes mellitus, which may increase one's risk for AD and other dementias, are believed to account for these differences because they are more prevalent in black and Hispanic people. 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 [50,85].

There is evidence that missed diagnoses are more common among older blacks and Hispanics than among older whites [100,101]. A recent study of Medicare beneficiaries found that AD and other dementias had been diagnosed in 8.2% of white beneficiaries, 11.3% of black beneficiaries, and 12.3% of Hispanic beneficiaries [102]. Although rates of diagnosis were higher among blacks than among whites, this 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.

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 that develop in a given time period. The estimated annual incidence (rate of developing disease in 1 year) of AD appears to increase dramatically with age, from approximately 53 new cases/1000 people age 65 to 74 years, to 170 new cases/1000 people age 75 to 84 years, to 231 new cases/1000 people age 85 years and older (the "oldest-old") [103]. Some studies have found that incidence rates decrease after age 90, but these findings are controversial. One 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 a result of sparse data for this group [104]. Because of the increasing number of people

age 65 and older in the United States, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050 [103]:

- Every 68 seconds, someone in the United States develops AD.^{A6}
- By midcentury, someone in the United States will develop the disease every 33 seconds.^{A6}

Lifetime risk is the probability that someone of a given age will develop a condition during their remaining life span. Data from the Framingham Study were used to estimate lifetime risks of AD and of any dementia [105].^{A7} 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. As shown in Fig. 2, for AD specifically, the estimated lifetime risk at age 65 was nearly one in five (17.2%) for women compared with one in 11 (9.1%) for men [105].^{A8} As noted previously, these differences in lifetime risks between women and men are largely a result of 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 less than a 6-month 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 age 65 and older with AD, by state, for 2000, 2010, and 2025.^{A9} 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 estimates and projections for other types of dementia are not available.

As shown in Fig. 3 [106], between 2000 and 2025, some states and regions across the country are expected to

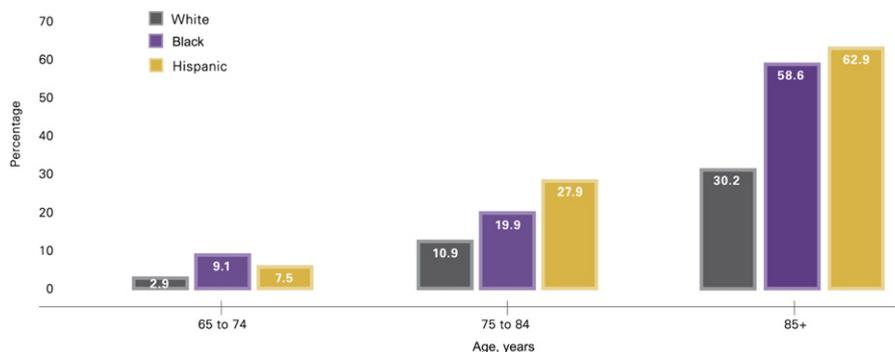


Fig. 1. Proportion of people age 65 years and older with Alzheimer's disease and other dementias. Created from data from Gurland and colleagues [98].

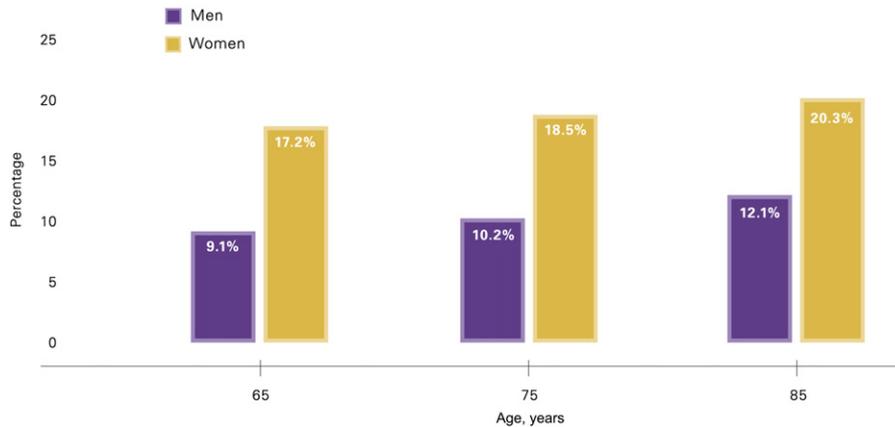


Fig. 2. Estimated lifetime risks for Alzheimer's disease, by age and sex, from the Framingham Study. Created from data from Seshadri and colleagues [105].

experience double-digit percentage increases in the numbers of people with AD as a result of increases in the proportion of the population age 65 years and older. 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 age 65 and older. The increasing number of individuals with AD will have a marked impact on states' health care systems, as well as on families and caregivers.

3.4. Looking to the future

The number of Americans surviving into their 80s, 90s, and beyond is expected to grow dramatically as a result of advances in medicine and medical technology, as well as social and environmental conditions [107]. In addition, a large segment of the American population—the baby boom generation—has begun to reach the age range of elevated risk for AD and other dementias, with the first baby boomers having reached age 65 in 2011. By 2030, the segment of the U.S. population age 65 and older is expected to increase dramatically, and the estimated 72 million older Americans will make up approximately 20% of the total population (up from 13% in 2010) [107].

As the number of older Americans increases rapidly, so, too, will the numbers of new and existing cases of AD, as shown in Fig. 4 [83].^{A10}

- 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 projected to be 959,000 (a 130% increase from 2000) [103].

- By 2025, the number of people age 65 and older with AD is estimated to reach 7.1 million—a 40% increase from the 5 million age 65 and older currently affected [83].^{A11}
- By 2050, the number of people age 65 and older with AD may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow, or stop the disease [83].^{A10} Previous estimates suggest that this number may be as high as 16 million [108].^{A12}

Longer life expectancies and aging baby boomers will also increase the number and percentage of Americans who will be among the oldest-old. Between 2010 and 2050, the oldest-old are expected to increase from 14% of all people age 65 and older in the United States to 20% of all people age 65 and older [107], which will result in an additional 13 million oldest-old—individuals at the highest risk for developing AD [107].

- By 2050, the number of Americans age 85 years and older will nearly quadruple to 21 million [107].
- In 2013, the 85-years-and-older population includes about 2 million people with AD, or 40% of all people with AD age 65 and older [83].
- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older are likely to have AD [83].

4. Mortality

AD is officially listed as the sixth leading cause of death in the United States [109]. It is the fifth leading cause of death for those age 65 and older [109]. However, it may cause even more deaths than official sources recognize.

Table 2
Projections of total numbers of Americans age 65 years and older with AD, by state

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

Abbreviation: AD, Alzheimer's disease.

NOTE. Created from data from Hebert and colleagues [106].^{A9}

4.1. Deaths from AD

It is difficult to determine how many deaths are caused by AD each year because of the way causes of death are

recorded. According to final data from the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), 83,494 people died from AD in 2010 (the most recent year for which final data are available) [109]. The CDC considers a person to have died from AD if the death certificate lists AD 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” [110]. However, death certificates for individuals with AD often list acute conditions such as pneumonia as the primary cause of death rather than AD [111–113]. Severe dementia frequently causes complications such as immobility, swallowing disorders, and malnutrition that can significantly increase the risk of other serious conditions that can cause death. One such condition is pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with AD and other dementias [114,115]. The number of people with AD and other dementias who die while experiencing these conditions may not be counted among the number of people who died from AD according to the CDC definition, even though AD is likely a contributing cause of death. Thus, it is likely that AD is a contributing cause of death for more Americans than is indicated by CDC data.

The situation has been described as a “blurred distinction between death with dementia and death from dementia” [116]. According to CHAP data, an estimated 400,000 people died with AD in 2010, meaning they died after developing AD.^{A13} Furthermore, according to Medicare data, one-third of all seniors who die in a given year have been previously diagnosed with AD or another dementia [102,117]. Although some seniors who die with AD die from causes unrelated to AD, many of them die from AD itself or from conditions in which AD was a contributing cause, such as pneumonia. A recent study evaluated the contribution of individual common diseases to death using a national representative sample of older adults and it found that dementia was the second largest contributor to death, following heart failure [118]. Thus, for people who die with AD and other dementias, dementia is expected to be a significant direct contributor to their deaths.

In 2013, an estimated 450,000 people in the United States will die with AD.^{A13} The true number of deaths caused by AD is likely to be somewhere between the official estimated numbers of those dying from AD (as indicated by death certificates) and those dying with AD (that is, dying after developing AD). Regardless of the cause of death, among people age 70 years, 61% of those with AD are expected to die before age 80 compared with 30% of people without AD [119].

4.2. Public health impact of deaths from AD

As the population of the United States ages, AD is becoming a more common cause of death. Although deaths

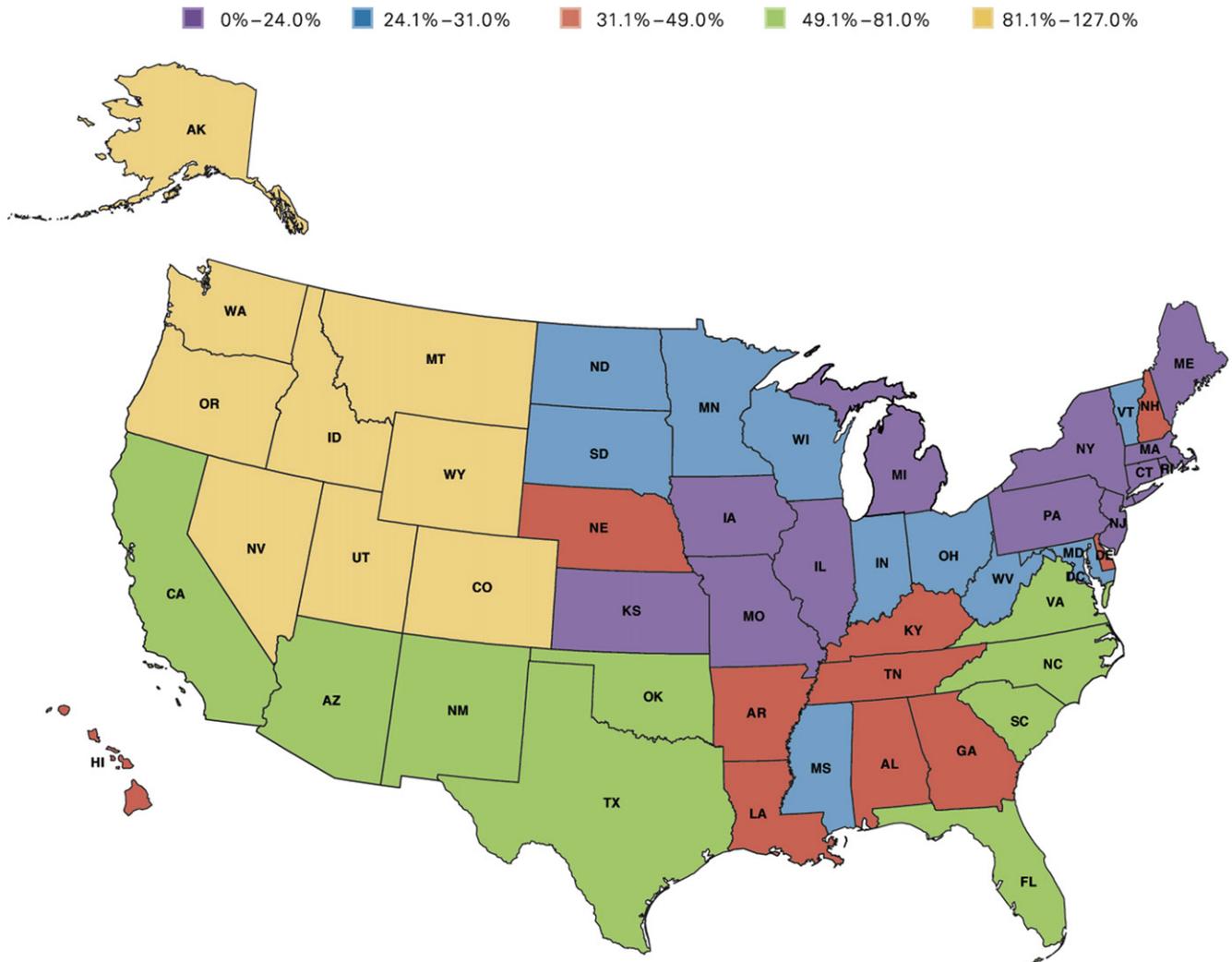


Fig. 3. Projected changes between 2000 and 2025 in Alzheimer's disease prevalence by state. Created from data from Hebert and colleagues [106].^{A9}

from other major causes have decreased significantly, deaths from AD have increased significantly. Between 2000 and 2010, deaths attributed to AD increased 68% whereas those attributed to the number one cause of death, heart disease, decreased 16% (Fig. 5) [109,120]. The increase in the number and proportion of death certificates listing AD as the underlying cause of death reflects both changes in patterns of reporting deaths on death certificates over time as well as an increase in the actual number of deaths attributable to AD.

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 age 65 and older is estimated to be between 5% and 15% [121,122], which means that during the next 5 years, 5% to 15% of all deaths in older people can be attributed to AD.

4.3. State-by-state deaths from AD

Table 3 provides information on the number of deaths resulting from AD by state in 2010, the most recent year for which state-by-state data are available. This information was obtained from death certificates and reflects the condition identified by the physician as the underlying cause of death. The table also provides annual mortality rates by state to compare the risk of death resulting from AD across states with varying population sizes. For the United States as a whole, in 2010, the mortality rate for AD was 27 deaths per 100,000 people [109].

4.4. Death rates by age

Although people younger than 65 can develop and die from AD, the highest risk of death from AD is in people age 65 or older. As seen in Table 4, death rates for AD increase dramatically with age. Compared with the rate of death from any cause among people age 65 to 74, death rates were 2.6 times as high for those age 75 to 84 and 7.4 times as high for those age 85 and older. For diseases of the heart,

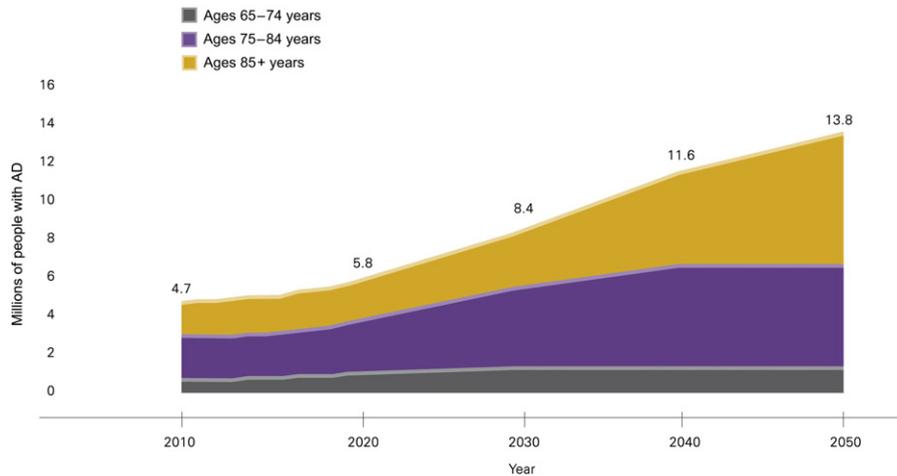


Fig. 4. Projected number of people aged 65 years and older (total and by age group) in the U.S. population with Alzheimer's disease, 2010 to 2050. Created from data from Hebert and colleagues [83].^{A10}

mortality rates were 2.9 times and 10.5 times as high, respectively. For all cancers, mortality rates were 1.8 times as high and 2.6 times as high, respectively. In contrast, AD death rates were 9.3 times as high for people age 75 to 84 and 49.9 times as high for people 85 and older compared with the AD death rate among people age 65 to 74 [109]. The high death rate at older ages for AD underscores the lack of a cure or effective treatments for the disease.

4.5. Duration of illness from diagnosis to death

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of AD, yet some live as long as 20 years with AD [122–127]. This observation 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 [119]. Much of this time will be spent in a nursing home; nursing home admission by age 80 is expected for 75% of people

with AD compared with only 4% of the general population [119]. 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 [128]. Thus, the long duration of illness before death contributes significantly to the public health impact of AD.

5. Caregiving

Caregiving refers to attending to another individual's health needs and often includes assistance with one or more ADLs, such as bathing and dressing [129,130]. More than 15 million Americans provide unpaid care for people with AD and other dementias.^{A14}

5.1. Unpaid caregivers

Unpaid caregivers are primarily immediate family members, but they also may be other relatives and friends. In 2012, these people provided an estimated 17.5 billion hours

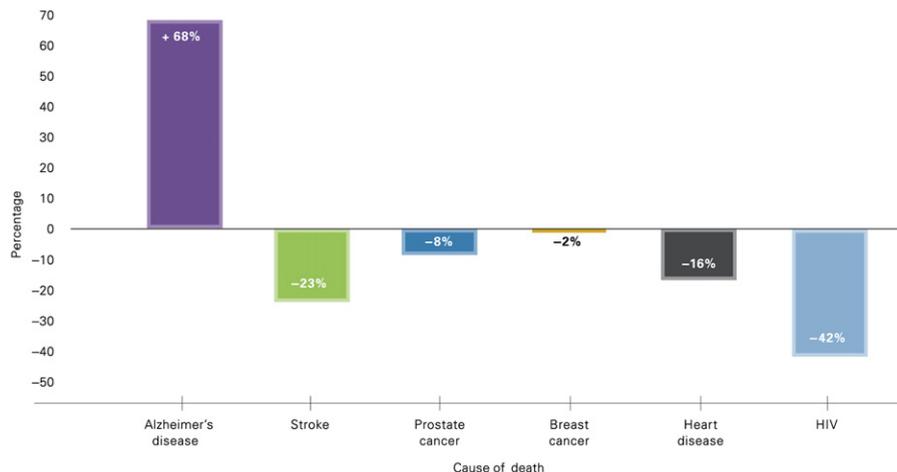


Fig. 5. Percentage changes in selected causes of death (all ages) between 2000 and 2010. HIV, human immunodeficiency virus. Created from data from the National Center for Health Statistics [109,120].

Table 3
Number of deaths and annual mortality rate (per 100,000) as a result of Alzheimer's disease, by state, 2010

State	No. of deaths	Rate	State	No. of deaths	Rate
Alabama	1523	31.9	Montana	302	30.5
Alaska	85	12.0	Nebraska	565	30.9
Arizona	2327	36.4	Nevada	296	11.0
Arkansas	955	32.8	New Hampshire	396	30.1
California	10,856	29.1	New Jersey	1878	21.4
Colorado	1334	26.5	New Mexico	343	16.7
Connecticut	820	22.9	New York	2616	13.5
Delaware	215	23.9	North Carolina	2817	29.5
District of Columbia	114	18.9	North Dakota	361	53.7
Florida	4831	25.7	Ohio	4109	35.6
Georgia	2080	21.5	Oklahoma	1015	27.1
Hawaii	189	13.9	Oregon	1300	33.9
Idaho	410	26.2	Pennsylvania	3591	28.3
Illinois	2927	22.8	Rhode Island	338	32.1
Indiana	1940	29.9	South Carolina	1570	33.9
Iowa	1411	46.3	South Dakota	398	48.9
Kansas	825	28.9	Tennessee	2440	38.4
Kentucky	1464	33.7	Texas	5209	20.7
Louisiana	1295	28.6	Utah	375	13.6
Maine	502	37.8	Vermont	238	38.0
Maryland	986	17.1	Virginia	1848	23.1
Massachusetts	1773	27.1	Washington	3025	45.0
Michigan	2736	27.7	West Virginia	594	32.1
Minnesota	1451	27.4	Wisconsin	1762	31.0
Mississippi	927	31.2	Wyoming	146	25.9
Missouri	1986	33.2	U.S. total	83,494	27.0

NOTE. Created from data from the National Center for Health Statistics [109].

of unpaid care, a contribution to the nation valued at more than \$216 billion, which is approximately half of the net value of Walmart sales in 2011 (\$419 billion) [131] and more than eight times the total sales of McDonald's in 2011 (\$27 billion) [132]. Eighty percent of care provided in the community is provided by unpaid caregivers (most often family members), whereas fewer than 10% of older adults receive all their care from paid caregivers [133].

5.1.1. Who are the caregivers?

Several sources have examined the demographic background of family caregivers of people with AD and other dementias [134].^{A15} Data from the 2010 Behavioral Risk Factor Surveillance System (BRFSS) survey conducted in Connecticut, New Hampshire, New Jersey, New York, and Tennessee [134] found that 62% of caregivers of people with AD and other dementias were women; 23% were 65 years of age and older; 50% had some college education or beyond; 59% were currently employed, a student, or a homemaker; and 70% were married or in a long-term relationship [134].

ADAMS, based on a nationally representative subsample of older adults from the Health and Retirement Survey [135], compared two types of caregivers: those caring for people with dementia and those caring for people with cognitive prob-

Table 4
U.S. Alzheimer's disease death rates (per 100,000) by age

Age, years	2000	2002	2004	2006	2008	2010
45–54	0.2	0.1	0.2	0.2	0.2	0.3
55–64	2.0	1.9	1.8	2.1	2.2	2.1
65–74	18.7	19.6	19.5	19.9	21.1	19.8
75–84	139.6	157.7	168.5	175.0	192.5	184.5
85+	667.7	790.9	875.3	923.4	1002.2	987.1
Rate*	18.1	20.8	22.6	23.7	25.8	25.1

NOTE. Created from data from National Center for Health Statistics [109].

*Reflects average death rate for ages 45 and older.

lems that did not reach the threshold of dementia. The caregiver groups did not differ significantly by age (60 years vs 61 years, respectively), sex (71% vs 81% female), race (66% vs 71% non-Hispanic white) or marital status (70% vs 71% married). Almost half of caregivers took care of parents [136].

The National Alliance for Caregiving (NAC)/AARP found that 30% of caregivers had children younger than 18 years old living with them; such caregivers are sometimes called sandwich caregivers because they provide care concomitantly for two generations [137].

5.1.2. Ethnic and racial diversity in caregiving

Among caregivers of people with AD and other dementias, the NAC/AARP found the following [137]:

- A greater proportion of white caregivers assist a parent than caregivers of individuals from other racial/ethnic groups (54% vs 38%).
- On average, Hispanic and black caregivers spend more time caregiving (approximately 30 hours/week) than non-Hispanic white caregivers (20 hours/week) and Asian caregivers (16 hours/week).
- Hispanic (45%) and black (57%) caregivers are more likely to experience high burden from caregiving than whites and Asians (about one-third and one-third, respectively).

As noted in the Prevalence section of this report, the racial/ethnic distribution of people with AD will change dramatically by 2050. Given the greater likelihood of acquiring AD among blacks and Hispanics, coupled with the increasing number of black and Hispanic older adults by 2050, it can be assumed that family caregivers will be more ethnically and racially diverse during the next 35 years.

5.1.3. Caregiving tasks

The care provided to people with AD and other dementias is wide ranging and, in some instances, all encompassing. The types of dementia care provided are shown in Table 5 [138].

Although the care provided by family members of people with AD and other dementias is somewhat similar to the help provided by caregivers of people with other diseases, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely

Table 5
Dementia caregiving tasks

Helping with instrumental ADLs, such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs and answering the telephone
Helping the person with AD or other dementias take medications correctly, either via reminders or direct administration of medications
Helping the person with AD or other dementias adhere to treatment recommendations for dementia or other medical conditions
Assisting with personal ADLs, such as bathing, dressing, grooming, and feeding, and helping the person with AD or other dementias walk, transfer from bed to chair, use the toilet, and manage incontinence
Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity, and nighttime disturbances [138]
Finding and using support services such as support groups and adult day service programs
Making arrangements for paid in-home, nursing home, or assisted living care
Hiring and supervising others who provide care
Assuming additional responsibilities that are not necessarily specific tasks, such as
<ul style="list-style-type: none"> • Providing overall management of getting through a day • Addressing family issues related to caring for a relative with AD, including communicating with other family members about care plans, decision making, and arrangements for respite for the main caregiver

Abbreviations: AD, Alzheimer's disease; ADL, activity of daily living.

than caregivers of other older people to assist with any ADLs (Fig. 6). More than half of dementia caregivers report providing help with getting in and out of bed, and about one-third of family caregivers provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence, and feeding (Fig. 6). These findings suggest the heightened degree of dependency experienced by some people with AD and other dementias. Fewer caregivers of other older people report providing help with each of these types of care [137].

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 community agencies (46%). In contrast, caregivers of other older adults are less likely to advocate for their family member (50%) and supervise community-based care (33%) [137]. Caring for a person with dementia also means managing symptoms that family caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems.

When a person with AD or other dementia moves to an assisted living residence or nursing home, the help provided by his or her family caregiver usually changes from hands-on, ADL-types of care to visiting, providing emotional support to the relative in residential care, interacting with facility staff, and advocating for appropriate care for the family member in residential care. However, some family caregivers continue to help with bathing, dressing, and other ADLs [139–141]. Admitting a relative to a residential care setting (such as a nursing home) has mixed effects on the emotional and psychological well-being of family caregivers. Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility, but other studies have found that distress declines significantly after admission [141,142]. The relationship between the caregiver and person with dementia may explain these discrepancies. For example, husbands, wives, and daughters were significantly more likely to indicate persistent burden up to 12 months after placement than other family caregivers, whereas husbands were more likely than other family caregivers to indicate persistent depression up to a year after a relative's admission to a residential care facility [142].

5.1.4. Duration of caregiving

Caregivers of people with AD and other dementias provide care for a longer time, on average, than do caregivers of older adults with other conditions. As shown in Fig. 7, 43% of caregivers of people with AD and other dementias provide care for 1 to 4 years compared with 33% of caregivers of people

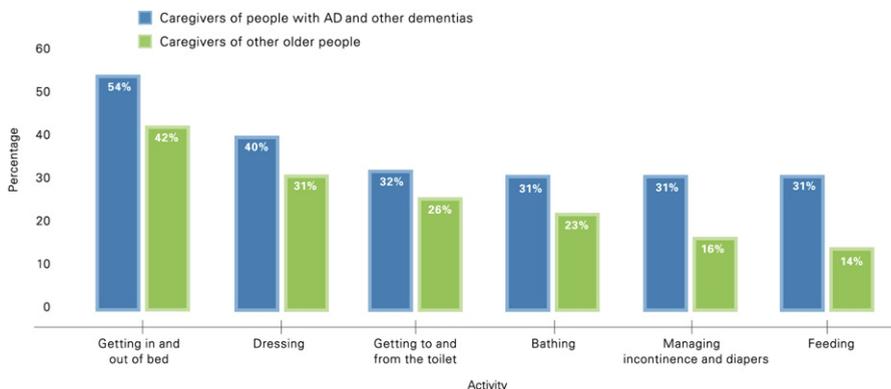


Fig. 6. Proportion of caregivers of people with Alzheimer's disease (AD) and other dementias vs caregivers of other older people who provide help with specific activities of daily living in the United States for the year 2009. Created from data from the National Alliance for Caregiving and the AARP [137].

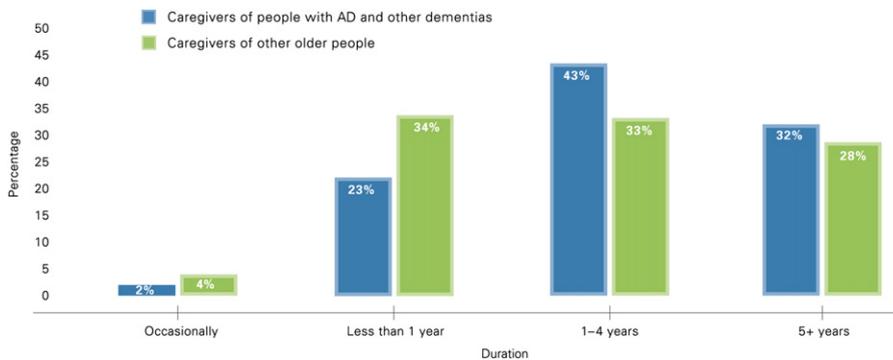


Fig. 7. Proportion of Alzheimer's disease (AD) and dementia caregivers vs caregivers of other older people by duration of caregiving in the United States for the year 2009. Created from data from the National Alliance for Caregiving and the AARP [137].

without dementia. Similarly, 32% of dementia caregivers provide care for more than 5 years compared with 28% of caregivers of people without dementia [137].

5.1.5. Hours of unpaid care and economic value of caregiving

In 2012, the 15.4 million family members and other unpaid caregivers of people with AD and other dementias provided an estimated 17.5 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.^{A16} With this care valued at \$12.33/hour,^{A17} the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was \$216.4 billion in 2012. Table 6 shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with AD and other dementias provide 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 \$14 billion.

Some studies suggest that family caregivers provide even more intensive daily support to people who reach a clinical threshold of dementia. For example, a recent report from ADAMS found that family caregivers of people who were categorized as having dementia spent an average of 9 hours/day providing help to their relatives [136].

5.1.6. Impact of AD caregiving

Caring for a person with AD and other dementias poses special challenges. For example, people with AD experience losses in judgment, orientation, and the ability to understand and communicate effectively. Family caregivers must often help people with AD manage these issues. The personality and behavior of a person with AD are affected as well, and these changes are often among the most challenging for family caregivers [138]. Individuals with dementia may also require increasing levels of supervision and personal care as the disease progresses. As these symptoms worsen with the progression of a relative's dementia,

the care required of family members can result in family caregivers' experiencing increased emotional stress, depression, impaired immune system response, health impairments, lost wages resulting from disruptions in employment, and depleted income and finances [143–148].^{A15} The intimacy and history of experiences and memories that are often part of the relationship between a caregiver and care recipient may also be threatened from the memory loss, functional impairment, and psychiatric/behavioral disturbances that can accompany the progression of AD.

5.1.6.1. Caregiver emotional well-being

Although caregivers report some positive feelings about caregiving, including family togetherness and the satisfaction of helping others,^{A15} they also report high levels of stress during the course of providing care:

- Based on a level of care index that combined the number of hours of care and the number of ADL tasks performed by the caregiver, fewer dementia caregivers in the 2009 NAC/AARP survey were classified in the lowest level of burden compared with caregivers of people without dementia (17% vs 31%, respectively) [137].
- 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. 8).^{A15}
- Most family caregivers report “a good amount” to “a great deal” of caregiving strain concerning financial issues (56%) and family relationships (53%).^{A15}
- Earlier research in smaller samples found that more than one-third (39%) of caregivers of people with dementia suffered from depression compared with 17% of noncaregivers [149,150]. A meta-analysis of research comparing caregivers affirmed this gulf in the prevalence of depression between caregivers of people with dementia and noncaregivers [147]. In the ADAMS sample, 44% of caregivers of people with dementia indicated depressive symptoms, compared with 27% of caregivers of people who had cognitive impairment but no dementia [136].

Table 6
Number of AD/D caregivers, hours of unpaid care, economic value of the care, and higher health care costs of caregivers, by state, 2012

State	AD/D caregivers (in thousands)	Hours of unpaid care per year (in millions)	Value of unpaid care (in millions of dollars)	Higher health care costs of caregivers (in millions of dollars)
Alabama	297	338	\$4171	\$161
Alaska	33	37	\$459	\$26
Arizona	303	345	\$4250	\$143
Arkansas	172	196	\$2419	\$92
California	1528	1740	\$21,450	\$830
Colorado	231	264	\$3250	\$121
Connecticut	175	200	\$2461	\$132
Delaware	51	58	\$715	\$37
District of Columbia	26	30	\$368	\$24
Florida	1015	1156	\$14,258	\$630
Georgia	495	563	\$6944	\$235
Hawaii	64	73	\$895	\$38
Idaho	76	87	\$1067	\$37
Illinois	584	665	\$8202	\$343
Indiana	328	373	\$4604	\$190
Iowa	135	154	\$1897	\$81
Kansas	149	170	\$2099	\$88
Kentucky	266	303	\$3731	\$152
Louisiana	226	258	\$3180	\$134
Maine	68	77	\$951	\$50
Maryland	282	321	\$3962	\$184
Massachusetts	325	370	\$4557	\$262
Michigan	507	577	\$7118	\$291
Minnesota	243	277	\$3415	\$157
Mississippi	203	231	\$2854	\$115
Missouri	309	351	\$4333	\$187
Montana	47	54	\$663	\$27
Nebraska	80	92	\$1128	\$49
Nevada	135	153	\$1889	\$67
New Hampshire	64	73	\$905	\$44
New Jersey	439	500	\$6166	\$289
New Mexico	105	120	\$1480	\$61
New York	1003	1142	\$14,082	\$726
North Carolina	437	497	\$6132	\$245
North Dakota	28	32	\$400	\$19
Ohio	589	671	\$8267	\$361
Oklahoma	214	244	\$3004	\$121
Oregon	167	191	\$2352	\$96
Pennsylvania	667	760	\$9369	\$447
Rhode Island	53	60	\$746	\$38
South Carolina	287	327	\$4031	\$157
South Dakota	36	41	\$510	\$22
Tennessee	414	472	\$5815	\$229
Texas	1294	1474	\$18,174	\$665
Utah	137	156	\$1918	\$60
Vermont	30	34	\$416	\$20
Virginia	443	504	\$6216	\$241
Washington	323	368	\$4538	\$190
West Virginia	108	123	\$1520	\$72
Wisconsin	189	215	\$2656	\$120
Wyoming	27	31	\$385	\$17
U.S. total	15,410	17,548	\$216,373	\$9121

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

NOTE. Differences between U.S. totals and summing the state numbers are the result of rounding. Created from data from the 2009 Behavioral Risk Factor Surveillance System (BRFSS) survey, the U.S. Census Bureau, the Centers for Medicare and Medicaid Services, the National Alliance for Caregiving, the AARP, and the U.S. Department of Labor.^{A14,A16,A17,A18}

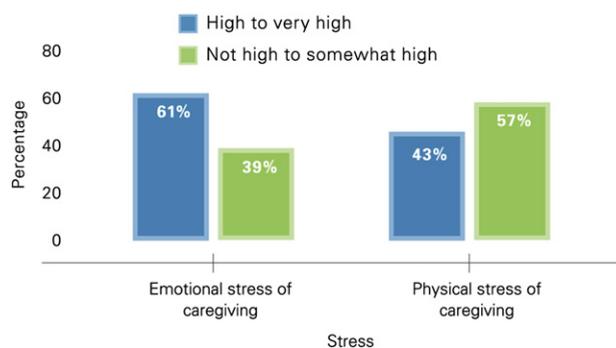


Fig. 8. Proportion of Alzheimer's disease and dementia caregivers who report high or very high emotional and physical stress resulting from caregiving. Created from data from the Alzheimer's Association.^{A15}

- In the 2009 NAC/AARP survey, caregivers most likely to indicate stress were women, older, residing with the care recipient, white or Hispanic, and believed there was no choice in taking on the role of caregiver [137].
- When caregivers report being stressed because of the impaired person's behavioral symptoms, it increases the chance that they will place the care recipient in a nursing home [134,137,151].
- 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. Yet, many such caregivers experience feelings of guilt, emotional upheaval, and difficulties in adapting to the admission transition (e.g., interacting with care staff to determine an appropriate care role for the family member) [139,141,152,153].^{A15}
- Demands of caregiving may intensify as people with dementia near the end of life. In the year before the person's death, 59% of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful. One study of end-of-life care found that 72% of family caregivers said they experienced relief when the person with AD or other dementia died [141,154,155].

5.1.6.2. Caregiver physical health

For some caregivers, the demands of caregiving may cause declines in their own health. Specifically, family caregivers of people with dementia may experience greater risk of chronic disease, physiological impairments, increased health care use, and mortality than those who are not caregivers [145]. Forty-three percent of caregivers of people with AD and other dementias reported that the physical impact of caregiving was high to very high (Fig. 8).^{A15}

5.1.6.2.1. General health

Seventy-five percent of caregivers of people with AD and other dementias reported that they were "somewhat

concerned” to “very concerned” about maintaining their own health since becoming a caregiver.^{A15} Dementia caregivers were more likely than noncaregivers to report that their health was fair or poor [145]. Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse [137,156]. Data from the 2010 BRFSS caregiver survey found that 7% of dementia caregivers say the greatest difficulty of caregiving is that it creates or aggravates their own health problems, compared with 2% of other caregivers [134]. Other studies suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than noncaregivers [157].

5.1.6.2.2. Physiological changes

The chronic stress of caregiving is associated with physiological changes that indicate risk of developing chronic conditions. For example, a series of recent studies found that, under certain conditions, some AD caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers [158–163]. Overall, the literature remains fairly consistent in suggesting that the chronic stress of dementia care can have potentially negative influences on caregiver health.

Caregivers of a spouse with AD or other dementias are more likely than married noncaregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones [164], reduced immune function [143,165], slow wound healing [166], increased incidence of hypertension [167], coronary heart disease [168], and impaired endothelial function (the endothelium is the inner lining of the blood vessels). Some of these changes may be associated with an increased risk of cardiovascular disease [169].

5.1.6.2.3. Health care use

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$9.1 billion in health care costs in the United States in 2012.^{A18} Table 6 shows the estimated higher health care costs for AD and dementia caregivers in each state.

Dementia caregivers were more likely to visit the emergency department or be hospitalized during the preceding 6 months if the care recipient was depressed, had low functional status, or had behavioral disturbances than if the care recipient did not exhibit these symptoms [170].

5.1.6.2.4. Mortality

The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings on this issue. In one study, caregivers of spouses who were hospitalized and had medical records of dementia were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers [171]. However, other studies have found that caregivers have lower mortality rates than noncaregivers [172,173]. One study reported that higher levels of stress were associated with higher rates of mortality in both caregivers and noncaregivers [173]. These findings suggest that it is high stress, not caregiving per se, that increases the risk of mortality. Such results emphasize that dementia caregiving is a complex undertaking; simply providing care to someone with AD or other dementia may not result consistently in stress or negative health problems for caregivers. Instead, the stress of dementia caregiving is influenced by a number of other factors, such as dementia severity, how challenging the caregivers perceive certain aspects of care to be, available social support, and caregiver personality. All these factors are important to consider when understanding the health impact of caring for a person with dementia [174].

5.1.6.3. Caregiver employment

Among caregivers of people with AD and other dementias, about 60% reported being employed full- or part-time [137]. Employed dementia caregivers indicate having to make major changes to their work schedules because of their caregiving responsibilities. Sixty-five percent 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. 9.^{A15}

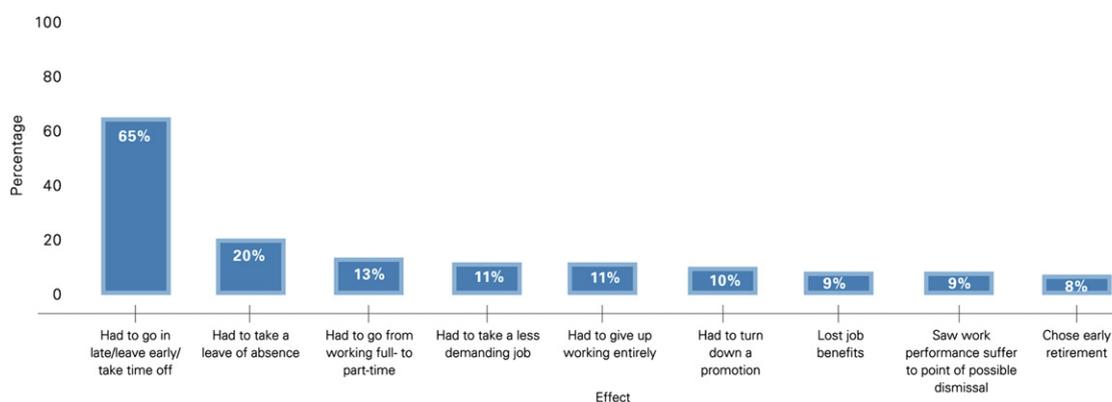


Fig. 9. Effect of caregiving on work: work-related changes among caregivers of people with Alzheimer's disease and other dementias. Created from data from the Alzheimer's Association.^{A15}

5.1.7. Interventions that may improve caregiver outcomes

Intervention strategies to support family caregivers of people with AD have been developed and evaluated. The types and focus of these interventions are summarized in Table 7 [175].

In general, these interventions aim to lessen negative aspects of caregiving with the goal of improving health outcomes of dementia caregivers. Methods used to accomplish this objective include enhancing caregiver strategies to manage dementia-related symptoms, bolstering resources through enhanced social support, and providing relief/respite from daily care demands. Desired outcomes of these interventions include decreased caregiver stress and depression, and delayed nursing home admission of the person with dementia.

Characteristics of effective caregiver interventions include programs that are administered over long periods of time, interventions that approach dementia care as an issue for the entire family, and interventions that train dementia caregivers in the management of behavioral problems [176–178]. Multidimensional interventions appear particularly effective. These approaches combine individual consultation, family sessions and support, and ongoing assistance to help dementia caregivers manage changes that occur as the disease progresses. Two

examples of successful multidimensional interventions are the New York University Caregiver Intervention [179,180] and the Resources for Enhancing Alzheimer's Caregiver Health (or REACH) II programs [148,175,181–183].

Although less consistent in their demonstrated benefits, support group strategies and respite services such as adult day programs may offer encouragement or relief to enhance caregiver outcomes. The effects of pharmacological therapies for treating symptoms of dementia (e.g., acetylcholinesterase inhibitors, memantine, antipsychotics, and antidepressants) also appear to reduce caregiver stress modestly [184].

Several sources [175,178,179,185–190] recommend that caregiver services identify “the risk factors and outcomes unique to each caregiver” [178] when selecting caregiver interventions. More work is needed, however, in testing the efficacy of these support programs among different caregiver groups to ensure their benefits for caregivers across diverse clinical, racial, ethnic, socioeconomic, and geographic contexts [191].

5.2. Paid caregivers

5.2.1. Direct-care workers for people with AD and other dementias

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 (including those with AD and other dementias). In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents [192,193]. Most nursing assistants are women, an increasing number of whom are diverse in terms of ethnic or racial background. Nursing assistants help with bathing, dressing, housekeeping, food preparation, and other activities.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care [192,194]. One review found that direct-care workers received, on average, 75 hours of training that included little focus on issues specific or pertinent to dementia care [192]. Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges [133]. An additional challenge is that, although direct-care workers are often at the forefront of dementia care delivery in nursing homes, these staff members are unlikely to receive adequate dementia training because of insufficient administrative support. Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest, positive benefits [195].

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

Professionals who may receive special training in caring for older adults include physicians, physician assistants, nurses, social workers, pharmacists, case workers, and

Table 7
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 respond effectively 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 led by professionals or peers.
Psychotherapy	Involves a relationship between the caregiver and a trained therapy professional. Therapists may teach such skills as self-monitoring, and challenging negative thoughts and assumptions; and help develop problem-solving abilities with a focus on time management, overload, management of emotions, and reengagement in pleasant activities and positive experiences.
Multicomponent	Includes various combinations of interventions, such as psychoeducational, supportive, psychotherapeutic, and technological approaches. These interventions are led by skilled professionals.

NOTE. Created from data from Sørensen and colleagues [175].

others [133]. It is projected that the United States will need an additional 3.5 million health care professionals by 2030 just to maintain the current ratio of health care professionals to the older population [133]. The need for health care professionals trained in geriatrics is escalating, but few providers choose this career path. It is estimated that the United States has approximately half the number of certified geriatricians that it currently needs [196]. In 2010, there were 4278 physicians practicing geriatric medicine in the United States. An estimated 36,000 geriatricians will be needed to meet adequately the needs of older adults in the United States by 2030 [133]. Other health-related professions also have low numbers of geriatric specialists relative to the population's needs. According to the Institute of Medicine, less than 1% of registered nurses, physician assistants, and pharmacists identify themselves as specializing in geriatrics [133]. Similarly, although 73% of social workers have clients age 55 and older, and between 7.6% and 9.4% of social workers are employed in long-term care settings, only 4% have formal certification in geriatric social work [133].

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

As the number of people with AD and other dementias grows, spending for their care will increase dramatically. For people with these conditions, aggregate payments for health care, long-term care, and hospice are projected to increase from \$203 billion in 2013 to \$1.2 trillion in 2050 (in 2013 dollars).^{A19} Medicare and Medicaid cover about 70% of the costs of care. All costs that follow are reported in 2012 dollars,^{A20} unless otherwise indicated.

6.1. Total payments for health care, long-term care, and hospice

Table 8 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 three times as great as payments for other Medicare beneficiaries in the same age group (\$45,657/person for those with dementia compared with \$14,452/person for those without dementia) [117].^{A21}

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 [117]. Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs for the Medicaid program. In 2008, average Medicaid payments per person for Medicare beneficiaries age 65 and older with AD and other dementias were 19 times as great as

Table 8

Average annual per-person payments for health care and long-term care services, Medicare beneficiaries age 65 and older, with and without AD and other dementias, and by place of residence, in 2012 dollars

Payment source	Beneficiaries with AD and other dementias by place of residence, 2012 dollars			Beneficiaries without AD and other dementias
	Overall	Community-dwelling	Residential facility	
Medicare	\$20,638	\$18,380	\$23,792	\$7832
Medicaid	10,538	232	24,942	549
Uncompensated	284	408	112	320
HMO	1036	1607	236	1510
Private insurance	2355	2588	2029	1584
Other payer	943	171	2029	149
Out of pocket	9754	3297	18,780	2378
Total*	45,657	26,869	71,917	14,452

Abbreviations: AD, Alzheimer's disease; HMO, health maintenance organization.

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [117].

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

average Medicaid payments for Medicare beneficiaries without AD and other dementias (\$10,538/person for individuals with dementia compared with \$549/person for individuals without dementia; Table 8) [117].

Total payments for 2013 are estimated at \$203 billion, including \$142 billion for Medicare and Medicaid combined in 2013 dollars (Fig. 10). These figures are derived from a model developed by The Lewin Group using data from the Medicare Current Beneficiary Survey and The Lewin Group's Long-Term Care Financing Model.^{A19}

Total cost: \$203 Billion (B)

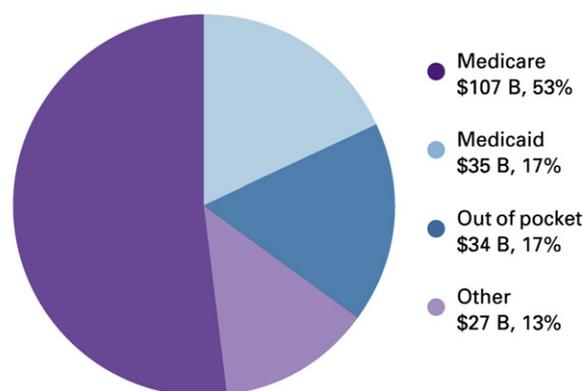


Fig. 10. Estimated aggregate costs of care by payer for Americans age 65 years and older with Alzheimer's disease and other dementias for 2013. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations, and uncompensated care. Data are in 2013 dollars. Created from data from the application of the Lewin Model^{A19} to data from the Medicare Current Beneficiary Survey for 2008 [117].

6.2. Use and costs of health care services

People with AD and other dementias have more than three times as many hospital stays per year as other older people [117]. Moreover, the use of health care services for people with other serious medical conditions is strongly affected by the presence or absence of dementia. In particular, people with coronary heart disease, diabetes mellitus, 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 people with these medical conditions but no coexisting dementia.

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:

- **Hospital:** In 2008, there were 780 hospital stays per 1000 Medicare beneficiaries age 65 and older with AD and other dementias compared with 234 hospital stays per 1000 Medicare beneficiaries age 65 and older without these conditions [117]. 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. 11) [197].
- **Skilled nursing facility:** Skilled nursing facilities provide direct medical care that is performed or supervised by registered nurses, such as giving intravenous fluids, changing dressings, and administering tube feedings [198]. 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 [117].
- **Home health care:** In 2008, 23% of Medicare beneficiaries age 65 and older with AD and other dementias had at least one home health visit during the year, com-

pared with 10% of Medicare beneficiaries age 65 and older without AD and other dementias [102].

6.2.2. Costs of health care services

With the exception of prescription medications, average per-person payments for all other health care services (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 9) [117]. The fact that only payments for prescription drugs are less for those with AD and other dementias underscores the lack of effective treatments available to those with dementia.

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 [102]. Table 10 reports the proportion of people with AD and other dementias who have certain coexisting medical conditions. In 2009, 30% of Medicare beneficiaries age 65 and older with dementia also had coronary heart disease; 29%, diabetes; 22%, congestive heart failure; 17%, chronic kidney disease; and 17%, chronic obstructive pulmonary disease [102]. People with AD and other dementias, in addition to other serious coexisting medical conditions, are more likely to be hospitalized than people with the same coexisting medical conditions but without dementia (Fig. 12) [102].

Similarly, Medicare beneficiaries who have AD and other dementias in addition to another serious coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries who have the same medical conditions without dementia. Table 11 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

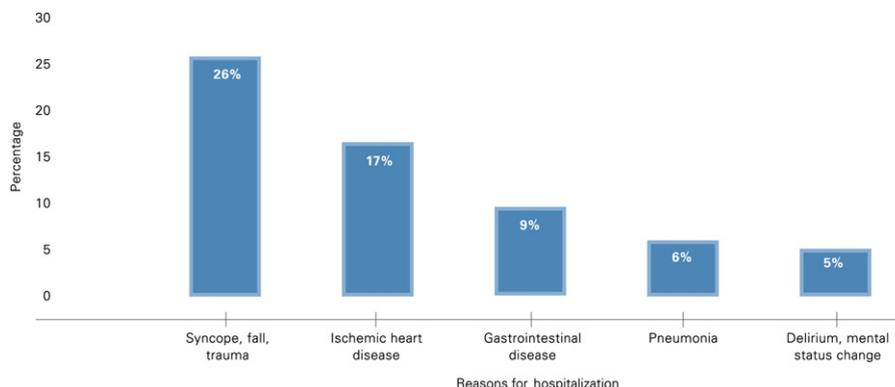


Fig. 11. Reasons for hospitalization of people with Alzheimer's disease (AD): percentage of hospitalized people by admitting diagnosis. All hospitalizations for individuals with a clinical diagnosis of probable or possible AD were used to calculate percentages. The remaining 37% of hospitalizations were from other reasons. Created from data from Rudolph and colleagues [197].

Table 9
Average annual per-person payments for health care services provided to Medicare beneficiaries age 65 and older with and without AD and other dementias

Health care services	Beneficiaries with AD and other dementias	Beneficiaries without AD and other dementias
Inpatient hospital	\$10,293	\$4138
Medical provider*	6095	4041
Skilled nursing facility	3955	460
Nursing home	18,353	816
Hospice	1821	178
Home health	1460	471
Prescribed medications†	2787	2840

Abbreviation: AD, Alzheimer's disease.

NOTE. Created from unpublished data from the Medicare Current Beneficiary Survey for 2008 [117] in 2012 dollars.

*Includes physicians, 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.

who either do or do not have AD and other dementias [102]. Medicare beneficiaries with a serious medical condition and dementia 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 beneficiaries with 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 [117,199]. Of those with dementia who live in the community, 75% live with someone and the remaining 25% live alone [117]. People with AD and other dementias generally receive more care from family members and other unpaid caregivers as their disease progresses. Many people with dementia also receive paid services at home; in adult day centers, assisted living facilities, or nursing homes; or

Table 10
Specific coexisting medical conditions among Medicare beneficiaries age 65 and older with AD and other dementias, 2009

Coexisting condition	Percentage of people with AD and other dementias who also had a coexisting medical condition
Coronary heart disease	30%
Diabetes mellitus	29%
Congestive heart failure	22%
Chronic kidney disease	17%
Chronic obstructive pulmonary disease	17%
Stroke	14%
Cancer	9%

Abbreviation: AD, Alzheimer's disease.

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [102].

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 (adult day services, \$70 per day [199]; assisted living, \$42,600 per year [199]; and nursing home care, \$81,030 to \$90,520/year [199]), individuals often deplete their income and 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 illnesses.

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 daycare. 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 [200]. 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 [200].

People with AD and other dementias make up a large proportion of all elderly people who receive nonmedical home care, adult day services, assisted living and residential care, nursing home care, and AD special care units:

- *Home care:* According to state home care programs in Connecticut, Florida, and Michigan, more than one-third (about 37%) of older people who receive primarily nonmedical home care services, such as personal care and homemaker services, have cognitive impairment consistent with dementia [201–203].
- *Adult day services:* At least half of elderly attendees at adult day centers have dementia [204,205].
- *Assisted living and residential care:* Forty-two percent of residents in assisted living and residential care facilities had AD and other dementias in 2010 [206].
- *Nursing home care:* Of all nursing home residents, 68% have some degree of cognitive impairment; 27% have very mild to mild cognitive impairment and 41% have moderate to severe cognitive impairment (Table 12) [207]. Of all Medicare beneficiaries age 65 and older living in a nursing home, 64% have AD and other dementias [117].
- *AD special care units:* An AD special care unit is a separate unit in a nursing home that has special services for individuals with AD and other dementias. Nursing homes had a total of 79,937 beds in AD special care units in June 2012 [208]. 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 during the 1980s but has decreased since 2004, when there were 93,763 beds in such units [209].

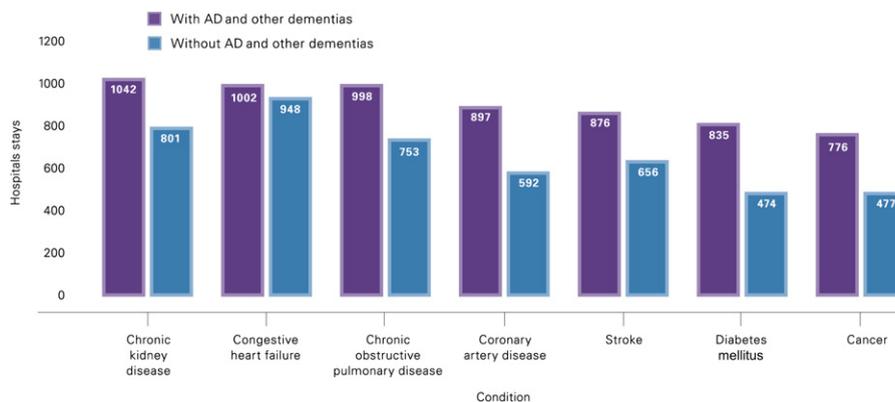


Fig. 12. Hospital stays per 1000 beneficiaries aged 65 years and older with specified coexisting medical conditions, with and without Alzheimer's disease (AD) and other dementias, in 2009. Created from unpublished tabulations based on data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [102].

Despite the increasing demand for nursing home and long-term acute hospital care services, there have been a number of restrictions on adding new facilities and increasing the number of beds in existing facilities. In addition, the Medicare, Medicaid, and State Children's Health Insurance Program Extension Act of 2007 issued a 3-year moratorium on the designation of new long-term care hospitals and increases in Medicare-certified beds for existing long-term care hospitals [210]. Long-term care hospitals are acute

care hospitals that serve patients who have long-term acute medical care needs, with average lengths of hospital stay of more than 25 days [211]. Patients are often transferred from the intensive care units of acute care hospitals to long-term care hospitals for medical care related to rehabilitation services, respiratory therapy, and pain management. This moratorium was issued in response to the need for Medicare to develop criteria for patients admitted to long-term care hospitals with Medicare coverage as a result of

Table 11

Average annual per-person payments by type of service and coexisting medical condition for Medicare beneficiaries age 65 and older, with and without AD and other dementias for 2009, in 2012 dollars*

Medical condition by AD/D status	Average per-person Medicare payments					
	Total Medicare payments	Hospital care	Physician care	Skilled nursing facility care	Home health care	Hospice care
Coronary heart disease						
With AD/D	27,286	10,312	1718	4344	2721	2347
Without AD/D	16,924	7410	1314	1324	1171	342
Diabetes mellitus						
With AD/D	26,627	9813	1608	4211	2802	2121
Without AD/D	14,718	6048	1132	1203	1110	240
Congestive heart failure						
With AD/D	26,149	11,712	1773	4816	2848	2943
Without AD/D	30,034	11,991	1772	2610	2244	833
Chronic kidney disease						
With AD/D	32,190	12,927	1902	4845	2658	2560
Without AD/D	24,767	10,834	1665	1999	1646	530
Chronic obstructive pulmonary disease						
With AD/D	29,660	11,521	1811	4748	2821	2650
Without AD/D	20,260	9029	1488	1730	1516	665
Stroke						
With AD/D	27,774	10,160	1669	4557	2578	2758
Without AD/D	19,940	7875	1419	2336	1891	652
Cancer						
With AD/D	25,559	9135	1567	3653	2221	2890
Without AD/D	16,727	6198	1202	989	788	592

Abbreviation: AD/D, Alzheimer's disease/dementia.

NOTE. Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009 [102].

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

Table 12
Cognitive impairment in nursing home residents, by state, for 2009

State	Total nursing home residents*	Percentage of residents at each stage of cognitive impairment [†]		
		None	Very mild/mild	Moderate/severe
Alabama	52,312	29	27	44
Alaska	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 [207].

*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.

continued growth in the number of long-term care facilities and beds. The moratorium expired on December 28, 2012 [210,212]. In 2011, certificate-of-need programs were in place to regulate nursing home beds in 37 states, and a number of these states had implemented a certificate-of-need moratorium on the number of beds and/or facilities [213].

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.

- *Home care:* In 2011, the average cost for a paid non-medical home health aide was \$21/hour, or \$168 for an 8-hour day [199].
- *Adult day centers:* In 2011, the average cost of adult day services was \$70/day. 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 [199].
- *Assisted living:* In 2011, the average cost for basic services in an assisted living facility was \$3550/month, or \$42,600/year. 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 dementia, the average rate was \$4807/month, or \$57,684/year, for this care [199].
- *Nursing homes:* In 2011, the average cost for a private room in a nursing home was \$248/day, or \$90,520/year. The average cost of a semiprivate room in a nursing home was \$222/day, or \$81,030/year. Approximately 80% of nursing homes that provide care for people with AD charge the same rate, regardless of whether the individual has AD. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with AD was \$13 higher (\$261/day, or \$95,265/year) and the average cost for a semiprivate room was \$8 higher (\$230/day, or \$83,950/year) [199]. Fifty-five percent of nursing homes that provide care for people with AD other dementias had separate AD special care units [199].

6.3.3. Affordability of long-term care services

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

- Income and asset data are not available for people with AD and other dementias specifically, but 50% of Medicare beneficiaries had incomes of \$22,276 or less, and

25% had incomes of \$13,418 or less in 2010 (in 2012 dollars). Two hundred percent of the U.S. Census Bureau's poverty threshold was \$21,576 for one person age 65 and older, and \$27,192 for a family of two, with the head of household age 65 and older [214,215].

- Fifty percent of Medicare beneficiaries had retirement accounts of \$2203 or less, 50% had financial assets of \$31,849 or less, and 50% had total savings of \$55,516 or less, equivalent to less than 1 year of nursing home care in 2010 (in 2012 dollars) [214].

6.3.4. Long-term care insurance

In 2010, about 7.3 million people had long-term care insurance policies [216]. Private health and long-term care insurance policies funded only about 7% of total long-term care spending in 2009, representing \$18.4 billion of the \$263 billion (in 2012 dollars) in long-term care spending [217]. The private long-term care insurance market has decreased substantially since 2010, however, with five major insurance carriers either exiting the market or substantially increasing premiums, making policies unaffordable for many individuals [218].

6.3.5. Medicaid costs

Medicaid covers nursing home care and long-term care services in the community for individuals who meet program requirements for level of care, income, and assets. To receive coverage, beneficiaries must have low incomes. Most nursing home residents who qualify for Medicaid must spend all 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.

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 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 [217].

Total Medicaid spending for people with AD and other dementias is projected to be \$35 billion in 2013.^{A19} About half of all Medicaid beneficiaries with AD and other dementias are nursing home residents, and the rest live in the community [219]. Among nursing home residents with AD and other dementias, 51% rely on Medicaid to help pay for their nursing home care [219].

In 2008, total per-person Medicaid payments for Medicare beneficiaries age 65 and older 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 a result of the costs associated with long-term care (nurs-

ing homes and other residential care facilities, such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid. Medicaid paid \$24,942/person for Medicare beneficiaries with AD and other dementias living in a long-term care facility compared with \$232 for those with the diagnosis living in the community, and \$549 for those without the diagnosis (Table 8) [117].

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 still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums and for deductibles, copayments, and services not covered by Medicare, Medicaid, or additional sources of support.

In 2008, Medicare beneficiaries age 65 and older with AD and other dementias paid \$9754 out of pocket, on average, for health care and long-term care services not covered by other sources (Table 8) [117]. Average per-person out-of-pocket payments were highest (\$3297 per person) for individuals living in nursing homes and assisted living facilities, and were almost six times as great as the average per-person payments for individuals with AD and other dementias living in the community [117]. In 2013, out-of-pocket spending for individuals with AD and other dementias is expected to total an estimated \$34 billion (Fig. 10).^{A19}

Before implementation of the Medicare Part D Prescription Drug Benefit in 2006, out-of-pocket expenses were increasing annually for Medicare beneficiaries [220]. In 2003, out-of-pocket costs for prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries age 65 and older [221]. 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 [222]. Sixty percent of all Medicare beneficiaries were enrolled in a Medicare Part D plan in 2011, and the average monthly premium for Medicare Part D was \$39 (range, \$15–\$132) [222]. 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.

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, 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 people) [223]. An additional 11% of all people admitted to hospices in the United States had a primary hospice diagnosis of non-AD dementia (119,872 people) [223]. Hospice length of stay has increased during 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 [223]. 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 [223]. 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 (\$1821/person compared with \$178/person) [117].

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 \$203 billion in 2013 to \$1.2 trillion in 2050 (in 2013 dollars). This dramatic rise includes a six-fold increase in government spending under Medicare and Medicaid and a five-fold increase in out-of-pocket spending.^{A19}

7. Special report: Long-distance caregivers

This special report describes the experiences and needs of a specific type of caregiver: long-distance caregivers—those who care for a loved one who lives far away. It describes the characteristics of long-distance caregivers, their needs, the barriers they encounter, how the caregiving situation affects them, and efforts that have been made to alleviate the caregiving burden they experience. These issues have received little attention but are the source of increasing concern.

Much of what is known about long-distance caregivers comes from studies in which the care recipient was an older person who needed assistance to perform daily activities because of cognitive or physical impairments. Most studies were not exclusive to caregivers for someone with dementia. Nevertheless, in key studies, about 30% of caregivers reported that the care recipient had AD or a related condition [224]. Therefore, it is reasonable to expect that the results of those key studies apply to caregivers for people with dementia. In some cases, findings specific to caregivers of people with AD and other dementias are available, and the findings have been included in this special report.

7.1. Definition and prevalence

Studies of long-distance caregivers have differed with respect to how they define long distance, but a common definition is one in which the caregiver lives at least 1 or 2 hours away from the care recipient. A 2009 report from the NAC/AARP [224] compiled information from 1480 caregivers of adults age 18 or older who needed assistance with self-care in the United States. In that report, 9% of caregivers lived 2 or more hours away from the care recipient and 4% lived 1 to 2 hours away. The remainder lived less than 1 hour away.

A subanalysis of the NAC/AARP study was performed in which caregivers were included only if they provided care for someone 50 years or older who had AD or a related condition. Travel times between those 404 caregivers and their care recipients are shown in Fig. 13. Nine percent of caregivers lived 2 hours or more away from the care recipient, and 6% lived 1 to 2 hours away [137].

On the basis of these findings and the estimate that more than 15.4 million people in the United States are caregivers for someone who has AD or other dementia, we estimate that about 2.3 million of those caregivers live at least 1 hour away from the care recipient. As discussed next, the types and amount of care these individuals provide vary greatly.

7.2. Factors influencing geographic separation

As noted in Section 5, most caregivers for people with dementia are relatives of the care recipient. In the subanalysis of the 2009 NAC/AARP survey, 79% of caregivers for people with dementia were caring for their parent, parent-in-law, grandparent, or grandparent-in-law [137].

Because so many caregivers are a descendant (or descendant-in-law) of the care recipient, it is worthwhile exploring the factors that influence geographic separation between the places of residence of children and their parents. Several studies have done so [225–227].

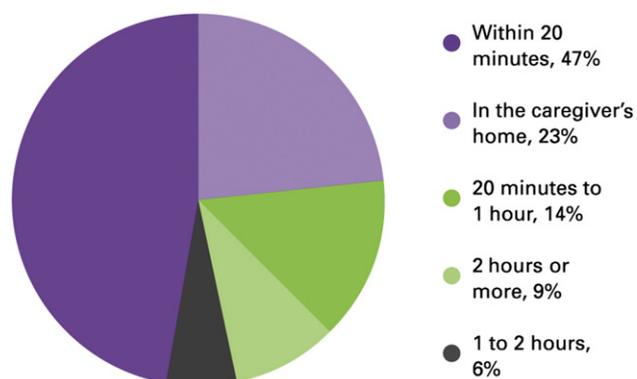


Fig. 13. Travel times between caregivers and care recipients for caregivers of people who have Alzheimer's disease or a related condition. Created from data from the National Alliance for Caregiving and the AARP [137].

The two strongest factors affecting geographic separation are as follows [225–227]:

- *Education levels of parents and children:* When parents or their adult children have many years of formal education, they tend to live farther apart than those who have fewer years of formal education.
- *Number of children:* Parents who have many adult children are more likely to have one child who lives nearby than parents who have fewer children.

Other factors affecting geographic separation of parents and children include the following [225–227]:

- *Age:* Young adult children tend to live closer to their parents than middle-age children. Parents older than 80 years tend to live closer to their children than parents younger than 80.
- *Income:* Children with higher incomes tend to live farther from their parents than children with lower incomes.
- *Children's family size:* Children with large families of their own tend to live farther from their parents than children who have small families.
- *Geography:* Parents who live in rural areas tend to live farther from their children than parents who live in urban areas. Children or parents who live in the western United States tend to live farther from each other than those who live in the eastern part of the country.
- *Geographic mobility:* Parents or children who have an extensive history of geographic mobility tend to live farther from each other than those who have less history of geographic mobility.

The gender of adult children does not strongly influence geographic separation from their parents, even though daughters are more likely to be caregivers than sons.

The cited studies were not restricted to children who were caregivers. However, in at least one study the health and disability levels of parents did not strongly influence geographic separation between them and their adult children [226]. Therefore, it is reasonable to expect that these same factors influence geographic separation when adult children are caregivers for their parents. Indeed, small studies specific to caregivers have found that long-distance caregivers, on average, are more educated, more affluent, and more likely to be married than local caregivers [137,228–231].

7.3. Roles

Caregivers for people with dementia perform a variety of caregiving tasks, and each caregiving situation is unique. In some studies, unpaid caregivers are categorized into two groups: primary caregivers and secondary caregivers. In most of the studies cited here, secondary caregivers are those who identified themselves as such—that is, they recognized that another person was the primary caregiver.

Primary caregivers of people who have dementia are more likely than secondary caregivers to help with essential activities such as dressing, personal hygiene, feeding, movement, and toileting (ADLs). Primary caregivers may also help with tasks that are less essential for basic functioning but that help the care recipient live independently; such tasks include doing housework, managing medications, shopping, managing money, and providing transportation (instrumental activities of daily living [IADLs]). Secondary caregivers are more likely to help with IADLs than ADLs.

In a nationwide survey conducted in 2004 by the MetLife Mature Market Institute, 23% of long-distance caregivers reported that they were the primary or only caregiver for their care recipient [228]. In the NAC/AARP surveys, the percentage of long-distance caregivers who identified themselves as the primary caregiver has varied from 11% (2004) to 35% (2009) [137,230]. Another study of caregivers for people with dementia in the Los Angeles area found that 19% of long-distance caregivers considered themselves the primary caregiver, whereas 65% of local caregivers did so [232]. From these studies, we estimate that, among long-distance caregivers for people with dementia, about one in five is a primary caregiver.

Despite the fact that most long-distance caregivers consider themselves secondary caregivers, the MetLife study [233] found that:

- 72% of long-distance caregivers helped the care recipient perform IADLs
- Long-distance caregivers spent an average of 3.4 hours/week arranging services for the care recipient and another 4 hours/week checking on the care recipient or monitoring care
- Almost 40% of long-distance caregivers reported that they helped the care recipient perform ADLs
- On average, long-distance caregivers spent about 22 hours/month helping with IADLs and about 12 hours/month helping with ADLs

7.4. Unique challenges

Long-distance caregivers who are the primary caregiver have the same needs as local primary caregivers, but long-distance caregivers have the added burden of having to travel more than an hour to perform most of their caregiving tasks [232]. Predictably, long-distance caregivers are more likely than local caregivers to report distance as a barrier to performing their caregiving tasks [231,233].

7.4.1. Coordinating care

Long-distance caregivers, especially those who are secondary caregivers, frequently assume the role of coordinators of care, working to assist the primary caregiver by finding, coordinating, and monitoring the recipient's formal care and social services [232,234]. Long-distance caregivers who are primary caregivers may have to take on multiple roles, providing direct care by helping with ADLs and IADLs as well as coordinating formal health care and social

services. While performing these tasks, long-distance caregivers often report difficulties in finding services available in the care recipient's community and in monitoring service providers [231]. These tasks can be especially difficult when the care recipient lives in a rural area.

7.4.2. *Assessing the care recipient's condition and needs*

Long-distance caregivers also reported greater difficulty than local caregivers in obtaining information about the care recipient [231,232]. Specifically, many long-distance caregivers report that care recipients either downplay or exaggerate their condition and needs. As a consequence, long-distance caregivers may be less able to gauge the care recipient's needs [235]. Similarly, long-distance caregivers have difficulty obtaining accurate information about the recipient's condition from local caregivers or neighbors.

7.4.3. *Communicating with health care providers*

Long-distance caregivers may not be available to accompany the care recipient to health care visits, especially when those visits are unexpected. Furthermore, long-distance caregivers often find it more difficult than local caregivers to communicate with health care providers, who may assume that the long-distance caregiver is not an important contact or is less involved in caregiving. These barriers make it difficult for long-distance caregivers to acquire accurate information about the care recipient's health status, in turn making it difficult for these caregivers to assist in making health care decisions [232,234].

7.4.4. *Family strain and disagreements with siblings*

Although many of the effects of caregiving are common to long-distance caregivers and local caregivers, long-distance caregivers report higher rates of family disagreement [232]. Sources of these problems can vary, but often include disagreements with siblings about caregiving decisions, and resentment from local caregivers that the long-distance caregivers are not more helpful [231,232,236].

7.4.5. *Psychological distress*

In some studies, long-distance caregivers reported higher rates of psychological distress than local caregivers, even though local caregivers were more likely to feel overwhelmed by their caregiving responsibilities [232]. Psychological distress among long-distance caregivers may arise from difficulties in ascertaining the care recipient's condition and needs, and the fact that long-distance caregivers are frequently asked to help during acute crises [235]. Some long-distance caregivers may also experience feelings of regret or remorse resulting from self-assessments that distance has restricted their caregiving capacity [237].

7.4.6. *Employment*

About 60% of caregivers for people with dementia are employed either part-time or full-time [137], and long-distance caregivers have similar rates of employment

[228,237]. Many caregivers miss work and use vacation or sick days for caregiving. Long-distance caregivers experience even greater disruptions in their employment because of the time required to travel to where the care recipient lives [228,232,233].

7.4.7. *Financial burden*

Given that local caregivers are much more likely to be primary caregivers than long-distance caregivers [137], it is not surprising that local caregivers provide significantly more hours of care on average than long-distance caregivers [232]. Thus, the uncompensated economic value of care provided by local caregivers is likely greatly to exceed that of long-distance caregivers. Nevertheless, long-distance caregivers have significantly higher annual out-of-pocket expenses for care-related costs than local caregivers [228,238]. In one nationwide survey published in 2007, long-distance caregivers had annual out-of-pocket expenses of \$9654 compared with \$5055 for local caregivers (in 2012 dollars) [238].^{A20} These expenses included the costs of travel as well as telephone bills, payment for hired help, and other expenses associated with long-distance caregiving [238].

7.5. *Interventions*

7.5.1. *Support for long-distance caregivers*

With the growth of the Web, an increasing number of online and computer-aided programs have been developed to provide assistance to long-distance caregivers. Whether a program is implemented online, via telephone, or in person, it should reflect the range of support and information needed by long-distance caregivers, such as

- Access to a professional family consultant who can act as a liaison between care recipients and long-distance care providers, and who can help alleviate family disagreements
- Access to print or Web-based elder care resource guides for the area in which the care recipient lives
- Access to information about elder care attorneys and financial planners in the area in which the care recipient lives
- For both long-distance and other caregivers, assistance in developing a comprehensive safety plan for the care recipient that can be accessed and implemented by both local and long-distance caregivers
- Help with caring for an individual who lives alone

7.5.2. *Technology*

Several caregiving advocacy organizations have issued calls to use technology to assist long-distance caregivers. The National Research Council of the U.S. National Academies convened the Workshop on Technology for Adaptive Aging in 2003 and outlined research priorities for the development of technological devices to assist older adults,

including those with cognitive or physical impairments [239].

The Workshop report identified core technologies in various stages of development and how they could help aging people remain independent, as well as help their caregivers monitor the care recipient, and provide care and assistance when needed. Such technologies include wireless broadband networks to connect care recipients and caregivers, biosensors and diagnostic tools, activity sensors, information processing systems to detect changes in health status based on sensor input, displays and actuators to assist in using appliances and home controls, artificial intelligence devices and systems that act as personal assistants and coaches, adaptive interfaces that allow impaired people to perform household tasks, and other devices and tools. Technological innovations may offer the potential to increase the connectedness of caregivers and care recipients and may alleviate some of the burden of caregiving, including the burden of long-distance caregiving [233,240–243]. Additional research is needed on the use of technologies to assist long-distance caregivers.

7.6. Trends

As described in Section 3, the number and percentage of Americans who have AD and other dementias are expected to increase dramatically in coming decades. Commensurate with this increase in prevalence are expected increases in the number and percentage of Americans who are caregivers for older people who have dementia or other disabilities [133].

Some have predicted that increases in geographic mobility in the United States will lead to even greater increases in the percentage of caregivers who live far away from their care recipient [231]. However, there is not widespread agreement that geographic mobility has been increasing. An extensive analysis of long-term trends in geographic mobility in the United States concluded that geographic mobility rates actually declined between the 1950s and early 2000s among all age groups [244].

Studies attempting to determine the percentage of caregivers who are long-distance caregivers have not shown a consistent increase. Two studies showed modest increases during the 1980s and 1990s [245,246], but another study found a modest decrease in recent years (2004–2009) [224]. However, even if the percentage of long-distance caregivers is not increasing, their absolute number is likely to increase along with the number of all caregivers required to care for increasing numbers of older people who have disabilities, including AD and other dementias.

7.7. Conclusions

About 2.3 million people in the United States are caregivers for a person with AD or other dementia who lives at least 1 hour away. Although most of those long-distance caregivers are secondary caregivers, about one in five is a pri-

mary caregiver, about seven in 10 help the care recipient with IADLs, and about four in 10 help with ADLs. Although long-distance caregivers may spend less time helping the care recipient than local caregivers, long-distance caregivers have greater out-of-pocket expenses on average, experience greater challenges assessing the care recipient's condition and needs, report more difficulty communicating with health care providers, and often experience higher levels of psychological distress and family discord arising from their caregiving roles. Thus, support programs tailored to the needs of long-distance caregivers are needed to address the particular challenges they encounter.

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Appendices: End Notes

^{A1}Number of Americans age 65 and older with AD for 2013: The number 5 million is from published prevalence estimates based on incidence data from the Chicago Health and Aging Project (CHAP) and population estimates from the 2010 U.S. Census [83]. The estimates of Alzheimer's prevalence in the United States reported in previous *Facts and Figures* reports come from an older analysis using the same methods but older data from CHAP and data from the 2000 U.S. Census [108].

^{A2}Proportion of Americans age 65 and older with AD: The 11% is calculated by dividing the estimated number of people age 65 and older with AD (5 million) by the U.S. population age 65 and older in 2013, as projected by the U.S. Census Bureau (44.2 million), which equals 11%. Eleven percent is the same as one in nine.

^{A3}*Percentage of total AD cases by age groups:* Percentages for each age group are based on the estimated 200,000 younger than 65 years, plus the estimated numbers (in millions) for people age 65 to 74 years (0.7), 75 to 84 years (2.3), and 85+ years (2.0) based on prevalence estimates for each age group and incidence data from the Chicago Health and Aging Project [83]. Percentages do not total 100 due to rounding.

^{A4}*Differences between CHAP and ADAMS estimates for AD prevalence:* The Aging, Demographics, and Memory Study (ADAMS) estimates the prevalence of AD to be less than does the Chicago Health and Aging Project (CHAP), at 2.3 million Americans age 71 years and older in 2002 [85]. Note that the CHAP estimates referred to in this end note are from an earlier study using 2000 U.S. Census data [108]. At a 2009 conference convened by the National Institute on Aging and the Alzheimer's Association, researchers determined that this discrepancy was mainly a result of 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 Alzheimer's [86]. Because the more stringent threshold for dementia in ADAMS may miss people with mild AD and because clinical–pathological studies have shown that mixed dementia resulting from both AD and vascular pathology in the brain is very common [5], the Alzheimer's Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of AD in the United States.

^{A5}*Number of women and men age 65 and older with AD in the United States:* The estimates for the number of U.S. women (3.2 million) and men (1.8 million) age 65 years and older with AD in 2013 is from unpublished data from the Chicago Health and Aging Project. For a description of the analytical methods, see [83].

^{A6}*Number of seconds for the 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. One study estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020 [103]. The Alzheimer's Association calculated that the incidence of new cases in 2012 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.2 (for the number of years from 2010 to 2012 divided by the number of years from 2010 to 2020), adding that result (7,400) to the estimate by Hebert and colleagues [103] 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 [103] = 32.8 seconds, rounded to 33 seconds.

^{A7}*Criteria for identifying subjects with AD and other dementias in the Framingham Study:* Starting in 1975, nearly

2800 people from the Framingham Study who were age 65 years and free of dementia were monitored for as long as 29 years. Standard diagnostic criteria (*Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, criteria) were used to diagnose dementia in the Framingham Study; but, in addition, the subjects had to have at least “moderate” dementia according to the Framingham Study criteria, which is equivalent to a score of 1 point 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 Communicable Disease and Stroke–Alzheimer's Disease and Related Disorders Association criteria from 1984) were used to diagnose AD. The examination for dementia and AD is described in detail elsewhere [88].

^{A8}*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 Dr. Alexa Beiser, Dr. Sudha Seshadri, Dr. Rhoda Au, and Dr. Philip A. Wolf from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, to U.S. Census data.

^{A9}*State-by-state prevalence of AD:* These state-by-state prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific gender, years of education, race and mortality [106]. The numbers in Table 2 are found in online material related to this article, available at <http://www.neurology.org/content/62/9/1645.extract>. These numbers do not add up exactly to the reported estimate of the total number of Americans with AD disease^{A1} because they come from slightly different data sources; the state-by-state data uses 2000 U.S. Census data.

^{A10}*The projected number of people with AD comes from the Chicago Health and Aging Project:* See [83]. Other projections are somewhat lower [247] because they relied on more conservative methods for counting people who currently have AD.^{A4} Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with AD during the coming decades.

^{A11}*Projected number of people age 65 and older with AD in 2025:* The number 7.1 million is based on a linear extrapolation from the projections of prevalence of AD for the years 2020 (5.8 million) and 2030 (8.4 million) from the Chicago Health and Aging Project [83].

^{A12}*Previous high and low projections of AD prevalence in 2050:* The latest projections provided by the U.S. Census do not include high and low series based on different predictions about future changes to the population. Therefore, a high and low range for the projection to the year 2050 was not available for the most recent analysis of Chicago Health and Aging Project data [83]. The previous high and

low projections indicate that the projected number of Americans with AD in 2050 age 65 years and older will range from 11 million to 16 million [108].

^{A13}*Deaths with AD:* The estimates for the number of Americans dying with AD—400,000 in 2010 and 450,000 in 2013—were provided to the Alzheimer's Association by Liesi Hebert as unpublished results from her study [83].

^{A14}*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 age 18 years and older 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 members and other unpaid caregivers nationally and by state, we applied the proportion of national caregivers and for each state from the 2009 BRFSS (as provided by the Centers for Disease Control and Prevention, Healthy Aging Program, unpubl. data) to the national number of people age 18 years and older and in each state from the U.S. Census Bureau report for July 2012. [accessed 2013 Jan 7]. Available at: www.census.gov/popest/data/datasets.html. To calculate the proportion of family and other unpaid caregivers who provide care for a person with AD or other dementias, the Alzheimer's Association used data from the results of a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC)/American Association of Retired Persons (AARP) [224]. The NAC/AARP survey asked respondents age 18 years and older whether they were providing unpaid care for a relative or friend age 18 years or older or had provided such care during the past 12 months. Respondents who answered yes 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 other 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. The 26% figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 15,409,609 AD and other dementias caregivers.

^{A15}*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 chosen randomly 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 selected randomly. Interviews were conducted in English and Spanish. The survey "oversampled" blacks and Hispanics, selected from U.S. Census tracts with more than 8% concentration of each group. It also included an oversample of Asians using a listed sample of Asian households. The combined samples include 2295 white, non-Hispanic; 326 black; 309 His-

panic; 305 Asian; and 135 other race respondents. Cases were weighted to account for differential probabilities of selection and to account for overlap in the landline and cell phone sampling frames. The sample was adjusted to match U.S. Census demographic benchmarks for gender, age, education, race/ethnicity, region, and telephone service. The resulting interviews comprise a probability-based, national representative sample of U.S. adults. This national survey included 202 caregivers of people with AD and other dementias and 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 age 18 years or older who, during the past 12 months, provided unpaid care to a relative or friend age 50 years or older with AD or other dementias. The weight of the caregiver sample adjusted all 502 caregiver cases to the weighted estimates for gender and race/ethnicity derived from the base survey of caregivers. Questionnaire design and interviewing were conducted by Abt SRBI of New York. Susan Pinkus of S.H. Pinkus Research and Associates coordinated the polling and helped in the analysis of the poll data.

^{A16}*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 National Alliance for Caregiving (NAC)/American Association of Retired Persons (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/week of care, or 1139 hours/year. The number of family and other unpaid caregivers (15,409,609)^{A14} was multiplied by the average hours of care per year, which totals 17,548,462,657 hours of care.

^{A17}*Value of unpaid caregiving:* To calculate this number, the Alzheimer's Association used the method of Amo and colleagues [248]. This method uses the average of the federal minimum hourly wage (\$7.25 in 2012) and the mean hourly wage of home health aides (\$17.40 in July 2012) [249]. The average is \$12.33, which was multiplied by the number of hours of unpaid care (17,548,462,657)^{A16} to derive the total value of unpaid care (\$216,372,544,560).

^{A18}*Higher health care costs of AD caregivers:* This figure is based on a methodology originally developed by Dr. Brent Fulton for *The Shriver Report: A Woman's Nation Takes on Alzheimer's* [250]. 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 noncaregivers' [251]. 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 Behavioral Risk Factor Surveillance System^{A14} were used to weight each state's caregiver and noncaregiver per capita personal health care spending in 2009, inflated to 2012 dollars [252]. 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 to an average of \$592. The amount of the additional cost in each state, which varied by state from a low of \$436 in Utah to a high of \$902 in the District of Columbia, was multiplied by the total number of unpaid AD and dementia caregivers in that state^{A14} to arrive at that state's total additional health care costs of AD and other dementia caregivers as a result of being a caregiver. The combined total for all states was \$9,121,120,080. Fulton concluded that this is "likely to be a conservative estimate because caregiving for people with Alzheimer's is more stressful than caregiving for most people who don't have the disease" [250].

^{A19}*Lewin Model on AD and dementia and costs:* These numbers come from a model created for the Alzheimer's Association by The Lewin Group, modified to reflect the more recent estimates and projections of the prevalence of AD [83]. 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.^{A21} Nursing facility care costs in the model are based on The Lewin Group's Long-Term Care Financing Model. More information on the model, its long-term projections, and its methodology is available at www.alz.org/trajectory.

^{A20}*All cost estimates were inflated to year 2012 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, and the nursing home and adult day services item within the CPI was used to inflate nursing home payments).

^{A21}*Medicare Current Beneficiary Survey Report:* These data come from an analysis of findings from the 2008 Medicare Current Beneficiary Survey (MCBS). The analy-

sis was conducted for the Alzheimer's Association by Dr. Julie Bynum, Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The MCBS, a continuous survey of a national 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 *2013 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 years and older. For this MCBS analysis, people with dementia are defined as follows:

- Community-dwelling survey participants who answered yes to the MCBS question: Has a doctor ever told you that you had AD 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)