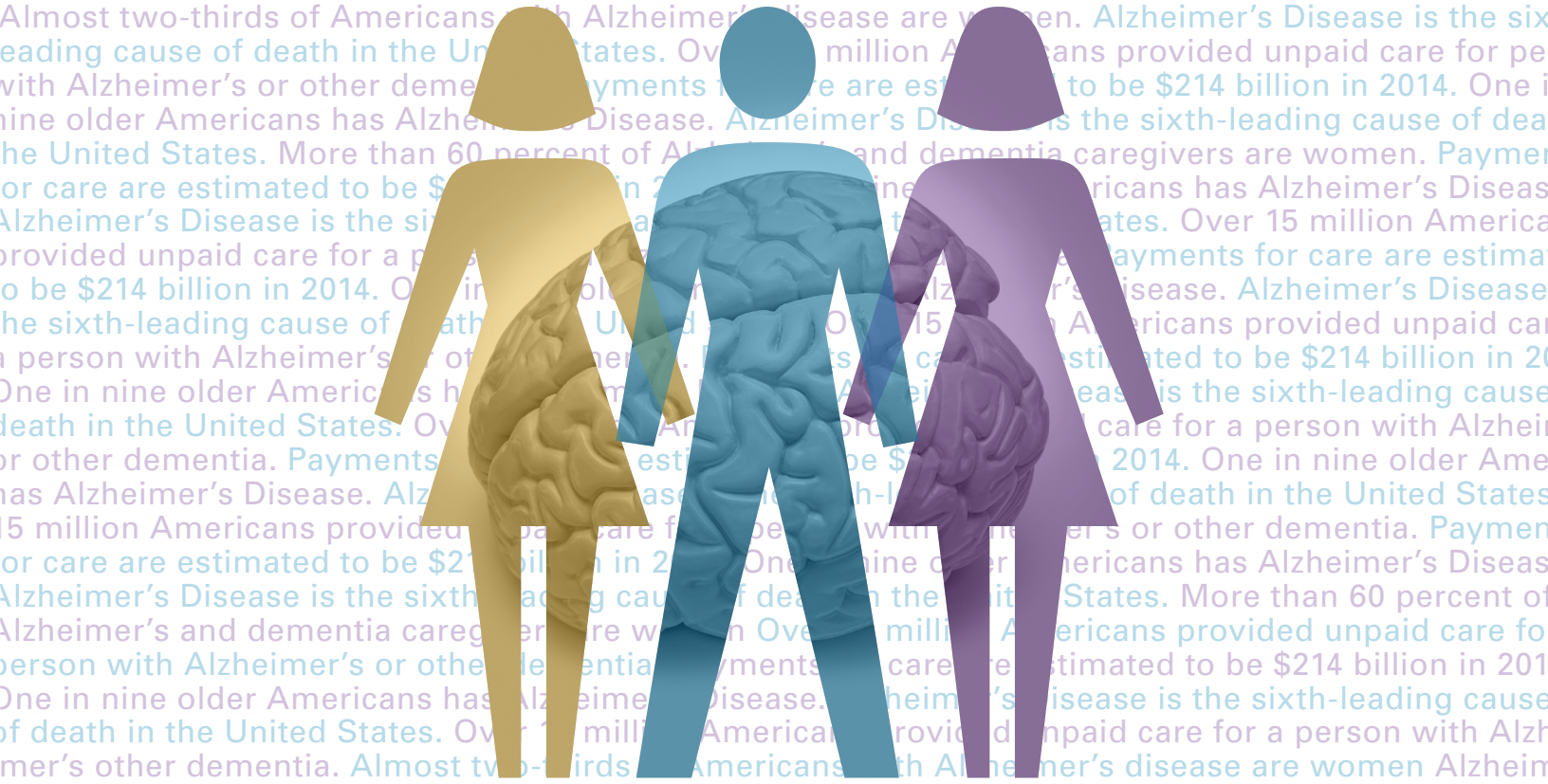
2014 Alzheimer's Disease
Facts and Figures

Includes a Special Report on
Women and Alzheimer's Disease



alzheimer's association®

THE BRAINS BEHIND SAVING YOURS.™

About this report

2014 Alzheimer's Disease Facts and Figures is a statistical resource for U.S. data related to Alzheimer's disease, the most common type of dementia, as well as other dementias. Background and context for interpretation of the data are contained in the Overview. This information includes definitions of the various types of dementia and a summary of current knowledge about Alzheimer's disease. Additional sections address prevalence, mortality and morbidity, caregiving and use and costs of care and services. The Special Report discusses women and Alzheimer's disease.

Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia,* Volume 10, Issue 2.

SPECIFIC INFORMATION IN THIS YEAR'S *ALZHEIMER'S DISEASE FACTS AND FIGURES* INCLUDES:

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

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

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

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

Contents

Overview of Alzheimer's Disease

Alzheimer's disease is the most common type of dementia.

Dementia is an overall term for diseases and conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities. Dementia is caused by damage to nerve cells in the brain, which are called neurons. As a result of the damage, neurons can no longer function normally and may die. This, in turn, can lead to changes in one's memory, behavior and ability to think clearly. In Alzheimer's disease, the damage to and death of neurons eventually impair one's ability to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease are bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal.

Dementia

Definition and Diagnosis

Physicians often define dementia based on the criteria given in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. In 2013 the American Psychiatric Association released the fifth edition of the *DSM (DSM-5)*, which incorporates dementia into the diagnostic categories of major and mild neurocognitive disorders.[1]

To meet *DSM-5* criteria for *major neurocognitive disorder*, an individual must have evidence of significant cognitive decline (for example, decline in memory, language or learning), and the cognitive decline must interfere with independence in everyday activities (for example, assistance may be needed with complex activities such as paying bills or managing medications).

To meet *DSM-5* criteria for *mild neurocognitive disorder*, an individual must have evidence of modest cognitive decline, but the decline does not interfere with everyday activities (individuals can still perform complex activities such as paying bills or managing medications, but the activities require greater effort).

For both major and mild neurocognitive disorders, *DSM-5* instructs physicians to specify whether the condition is due to Alzheimer's disease, frontotemporal lobar degeneration, Lewy body disease or a variety of other conditions.

Types of Dementia

When an individual has symptoms of dementia, a physician must conduct tests to identify the underlying brain disease or other condition that is causing symptoms. Different types of dementia are associated with distinct symptom patterns and brain abnormalities, as described in Table 1. Increasing evidence from long-term observational and autopsy studies indicates that many people with dementia, especially those in the older age groups, have brain abnormalities associated with more than one type of dementia.[2-6] This is called mixed dementia.

Some conditions result in symptoms that mimic dementia but that, unlike dementia, may be reversed with treatment. An analysis of 39 articles describing 5,620 people with dementia-like symptoms reported that 9 percent had symptoms that were mimicking dementia and potentially reversible.[7] Common causes of these symptoms are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. In contrast, Alzheimer's disease and other dementias cannot be reversed with current treatments.

table 1 | Types of Dementia and Their Typical Characteristics*

Type of Dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for an estimated 60 percent to 80 percent of cases. About half of these cases involve solely Alzheimer's pathology; many have evidence of pathologic changes related to other dementias. This is called mixed dementia (see mixed dementia in this table). Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing and walking. Revised criteria and guidelines for diagnosing Alzheimer's were proposed and published in 2011 (see pages 12-13). They recommend that Alzheimer's be considered a slowly progressive brain disease that begins well before clinical symptoms emerge. The hallmark pathologies of Alzheimer's are the progressive accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons.
Vascular dementia	Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. However, it is very common in older individuals with dementia, with about 50 percent having pathologic evidence of vascular dementia (infarcts). In most cases, the infarcts coexist with Alzheimer's pathology.[8] Impaired judgment or the ability to make decisions, plan or organize are more likely to be initial symptoms, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. Vascular dementia occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected. In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer's (and vice versa). That practice is no longer considered consistent with the pathological evidence, which shows that the brain changes of both types of dementia commonly coexist. When two or more types of dementia are present at the same time, the individual is considered to have mixed dementia (see mixed dementia in this table).
Dementia with Lewy bodies (DLB)	People with DLB have some of the symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and slowness, gait imbalance or other parkinsonian movement features. These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment. Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein that accumulate in neurons. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease (PD), in which it is accompanied by severe neuronal loss in a part of the brain called the substantia nigra. While people with DLB and PD both have Lewy bodies, the onset of the disease is marked by motor impairment in PD and cognitive impairment in DLB. The brain changes of DLB alone can cause dementia. But very commonly brains with DLB have coexisting Alzheimer's pathology. In people with both DLB and Alzheimer's pathology, symptoms of both diseases may emerge and lead to some confusion in diagnosis. Vascular dementia can also coexist and contribute to the dementia. When evidence of more than one dementia is present, the individual is said to have mixed dementia (see mixed dementia in this table).

table 1 (cont.) | Types of Dementia and Their Typical Characteristics*

Type of Dementia	Characteristics
Frontotemporal lobar degeneration (FTLD)	Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy. Typical early symptoms include marked changes in personality and behavior and difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease. Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have protein inclusions (usually tau protein or the transactive response DNA-binding protein). The brain changes of behavioral-variant FTLD may occur in those age 65 years and older, similar to Alzheimer's disease, but most people with this form of dementia develop symptoms at a younger age (at about age 60). In this younger age group, FTLD is the second most common degenerative dementia.
Mixed dementia	Characterized by the hallmark abnormalities of more than one type of dementia — most commonly Alzheimer's combined with vascular dementia, followed by Alzheimer's with DLB, and Alzheimer's with vascular dementia and DLB. Vascular dementia with DLB is much less common.[3-4] Recent studies suggest that mixed dementia is more common than previously recognized, with about half of those with dementia having mixed pathologies.[3-4]
Parkinson's disease (PD) dementia	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD. In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine. The incidence of PD is about one-tenth that of Alzheimer's. As PD progresses, it often results in dementia secondary to the accumulation of Lewy bodies in the cortex (similar to DLB) or the accumulation of beta-amyloid clumps and tau tangles (similar to Alzheimer's disease).
Creutzfeldt-Jakob disease	This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes. Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction. May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection. A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.
Normal pressure hydrocephalus	Symptoms include difficulty walking, memory loss and inability to control urination. Caused by impaired reabsorption of cerebrospinal fluid and the consequent build-up of fluid in the brain, increasing pressure in the brain. People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

* For more information on these and other types of dementia, visit www.alz.org.

Alzheimer's Disease

Alzheimer's disease was first identified more than 100 years ago, but research into its symptoms, causes, risk factors and treatment has gained momentum only in the last 30 years. Although research has revealed a great deal about Alzheimer's, much is yet to be discovered about the precise biologic changes that cause Alzheimer's, why it progresses at different rates among affected individuals, and how the disease can be prevented, slowed or stopped.

Symptoms

Alzheimer's disease affects people in different ways. The most common initial symptom is a gradually worsening ability to remember new information. This occurs because the first neurons to malfunction and die 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 Alzheimer's:

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

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

Individuals progress through Alzheimer's at different rates. As they pass through different stages of the disease, individuals' cognitive and functional abilities decline. In the final, advanced stage of the disease, people need help with basic activities of daily living, such as bathing, dressing, eating and using the bathroom; lose their ability to communicate; fail to recognize loved ones; and become bed-bound and reliant on around-the-clock care. When individuals have difficulty moving, they are more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer's-related pneumonia is often a contributing factor to the death of people with Alzheimer's disease.

Changes in the Brain That Are Associated with Alzheimer's Disease

A healthy adult brain has about 100 billion neurons, each with long, branching extensions. These extensions enable individual neurons to form connections with other neurons. At such connections, called synapses, information flows in tiny bursts of chemicals that are released by one neuron and detected by a receiving neuron. The brain contains about 100 trillion synapses. They allow signals to travel rapidly through the brain's circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills. Alzheimer's disease interferes with the proper functioning of neurons and synapses.

Among the brain changes believed to contribute to the development of Alzheimer's are the accumulation of the protein beta-amyloid *outside* neurons (called beta-amyloid plaques) and the accumulation of an abnormal form of the protein tau *inside* neurons (called tau tangles). In Alzheimer's disease, information transfer at synapses begins to fail, the number of synapses declines, and neurons eventually die. The accumulation of beta-amyloid 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 Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

The brain changes of Alzheimer's may begin 20 or more years[9-11] before symptoms appear. The time between the initial brain changes of Alzheimer's and the symptoms of advanced Alzheimer's is considered by scientists to represent the "continuum" of Alzheimer's. At the start of the continuum, the individual is able to function normally despite these brain changes. Further along the continuum, the brain can no longer compensate for the neuronal damage that has occurred, and the individual shows subtle decline in cognitive function. Later, 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. Later still, basic bodily functions such as swallowing are impaired.

Genetic Mutations That Cause Alzheimer's Disease

A small percentage of Alzheimer's cases, an estimated 1 percent or less,[12] develop as a result of mutations in any of three genes. A genetic mutation is an abnormal change in the sequence of chemical pairs that make up genes. These mutations involve the gene for the amyloid precursor protein and the genes for the presenilin 1 and presenilin 2 proteins. Inheriting any of these genetic mutations guarantees that an individual will develop Alzheimer's disease. In such individuals, disease symptoms tend to develop before age 65, sometimes as early as age 30, while the vast majority of individuals with Alzheimer's have late-onset disease, occurring at age 65 or later.

Risk Factors for Alzheimer's Disease

With the exception of the rare cases of Alzheimer's caused by known genetic mutations, experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. Following are known risk factors for Alzheimer's.

Age

The greatest risk factor for Alzheimer's disease is advanced age. Most people with Alzheimer's disease are diagnosed at age 65 or older. People younger than 65 can also develop the disease, although this is much rarer. (See the Prevalence section, pages 15-23). While age is the greatest risk factor, Alzheimer's is not a normal part of aging and advanced age alone is not sufficient to cause the disease.

Family History

Individuals who have a parent, brother or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.[13-15] Those who have more than one first-degree relative with Alzheimer's are at even higher risk.[16] 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 Alzheimer's is not entirely explained by whether the individual has inherited the apolipoprotein E-ε4 risk gene.

Apolipoprotein E (APOE)-ε4 Gene

The APOE gene provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the APOE gene — ε2, ε3 or ε4 — from each parent. The ε3 form is the most common,[17] with about 60 percent of the U.S. population inheriting ε3 from both parents.[18] The ε2 and ε4 forms are much less common. An estimated 20 to 30 percent of individuals in the United States have one or two copies of the ε4 form;[17-18] approximately 2 percent of the U.S. population has two copies of ε4.[18] The remaining 10 to 20 percent have one or two copies of ε2.

Having the ε3 form is believed to neither increase nor decrease one's risk of Alzheimer's, while having the ε2 form may decrease one's risk. The ε4 form, however, increases the risk of developing Alzheimer's disease and of developing it at a younger age. Those who inherit two ε4 genes have an even higher risk. Researchers estimate that between 40 and 65 percent of people diagnosed with Alzheimer's have one or two copies of the APOE-ε4 gene.[17,19-20]

Unlike inheriting a known genetic mutation that causes Alzheimer's, inheriting the ε4 form of the APOE gene does not guarantee that an individual will develop Alzheimer's. This is also true for several genes that appear to increase the risk of Alzheimer's, but that have a limited overall effect in the population because they are rare or only slightly increase risk.

Mild Cognitive Impairment (MCI)

MCI is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities. People with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's and other dementias than people without MCI. 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 mistakenly diagnosed. Therefore, it's important that people experiencing cognitive impairment seek help as soon as possible for diagnosis and possible treatment.

The proposed criteria and guidelines for diagnosis of Alzheimer's disease published in 2011[21-24] (pages 12-13) suggest that in some cases MCI is actually an early stage of Alzheimer's or another dementia.

Cardiovascular Disease Risk Factors

Growing evidence suggests that the health of the brain is closely linked to the overall health of the heart and blood vessels. The brain is nourished by one of the body's richest networks of blood vessels. A healthy heart helps ensure that enough blood is pumped through these blood vessels, 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 Alzheimer's and other dementias. These factors include smoking,[25-27] obesity (especially in midlife),[28-34] diabetes,[27,35-39] high cholesterol in midlife[30,40] and hypertension in midlife.[30,33,41-43]

Conversely, factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer's and other dementias. Physical activity[37,44-46] 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 Alzheimer's and dementia risk.[37]

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, Alzheimer's and other forms of dementia.

Social and Cognitive Engagement

Additional studies suggest that other modifiable risk factors, such as remaining mentally and socially active, may support brain health and possibly reduce the risk of Alzheimer's and other dementias.[47-59] Remaining socially and cognitively active may help build cognitive reserve (see Education), but the exact mechanism by which this may occur is unknown. More research is needed to better understand how social and cognitive engagement may affect biological processes to reduce risk.

Education

People with fewer years of formal education are at higher risk for Alzheimer's and other dementias than those with more years of formal education.[60-64] Some researchers believe that having more years of education builds a "cognitive reserve" that enables individuals to better compensate for changes in the brain that could result in symptoms of Alzheimer's or another dementia.[63,65-67] 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 Alzheimer's by using alternate routes of neuron-to-neuron communication to complete a cognitive task. However, 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.[68]

Traumatic Brain Injury (TBI)

Moderate and severe TBI increase the risk of developing Alzheimer's disease 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 post-traumatic amnesia that lasts more than 30 minutes. If loss of consciousness or post-traumatic amnesia lasts more than 24 hours, the injury is considered severe. Half of all moderate and severe TBIs are caused by motor vehicle accidents.[70] Moderate TBI is associated with twice the risk of developing Alzheimer's and other dementias compared with no head injuries, and severe TBI is associated with 4.5 times the risk.[71] Groups that experience repeated head injuries, such as boxers, football players and combat veterans, are at higher risk of dementia, cognitive impairment and neurodegenerative disease than individuals who experience no head injury.[72-78] Evidence suggests that even repeated mild TBI might promote neurodegenerative disease.[79-81] Some of these neurodegenerative diseases, such as chronic traumatic encephalopathy, can only be distinguished from Alzheimer's upon autopsy.

Diagnosis

A diagnosis of Alzheimer's disease is most commonly made by an individual's primary care physician. The physician obtains a medical and family history, including psychiatric history and history of cognitive and behavioral changes. 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 neurologic examinations and may request that the individual undergo magnetic resonance imaging (MRI) scans. MRI scans can help identify brain changes, such as the presence of a tumor or evidence of a stroke, that could explain the individual's symptoms

A Modern Diagnosis of Alzheimer's Disease: Proposed Criteria and Guidelines

In 2011, the National Institute on Aging (NIA) and the Alzheimer's Association proposed revised criteria and guidelines for diagnosing Alzheimer's disease.[21-24] 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.[82] In 2012, the NIA and the Alzheimer's Association also proposed new guidelines to help pathologists describe and categorize the brain changes associated with Alzheimer's disease and other dementias.[83]

It is important to note that more research is needed before the proposed diagnostic criteria and guidelines can be used in clinical settings, such as in a doctor's office.

Differences Between the Original and New Criteria

The 1984 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:

(1) They identify three stages of Alzheimer's disease, with the first occurring before symptoms such as memory loss develop. In contrast, for Alzheimer's disease to be diagnosed using the 1984 criteria, memory loss and a decline in thinking abilities must have already occurred.

(2) 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, and cholesterol level is a biomarker of heart disease risk. Levels of certain proteins in fluid (for example, levels of beta-amyloid and tau in the cerebrospinal fluid and blood) are among several factors being studied as possible biomarkers for Alzheimer's.

The Three Stages of Alzheimer's Disease Proposed by the 2011 Criteria and Guidelines

The three stages of Alzheimer's disease proposed by the 2011 criteria and guidelines are preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease, and dementia due to Alzheimer's disease. An individual who does not yet have outward symptoms of Alzheimer's but does have some of the early brain changes of Alzheimer's (as detected by brain imaging and other biomarker tests) would be said to have preclinical Alzheimer's disease. Those who have very mild symptoms but can still perform everyday tasks would be described as having MCI due to Alzheimer's. Individuals whose symptoms are more pronounced and interfere with carrying out everyday tasks would be said to have dementia due to Alzheimer's disease.

Preclinical Alzheimer's Disease — In this stage, individuals have measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, but they have not yet developed noticeable symptoms such as memory loss. This preclinical or presymptomatic stage reflects current thinking that Alzheimer's-related brain changes may begin 20 years or more before symptoms occur.[9-11] Although the 2011 criteria and guidelines identify preclinical disease as a stage of Alzheimer's, they do not establish diagnostic criteria that doctors can use now. Rather, they state that additional research is needed before this stage of Alzheimer's can be identified.

MCI Due to Alzheimer's Disease — Individuals with MCI have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday

activities. Studies indicate that as many as 10 to 20 percent of people age 65 or older have MCI.[84-86] Among people whose MCI symptoms cause them enough concern to contact their physicians for an exam, as many as 15 percent progress from MCI to dementia each year. Nearly half of all people who have visited a doctor about MCI symptoms will develop dementia in three or four years.[87]

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 percentage who will progress to Alzheimer's is slightly lower — up to 10 percent per year.[88] Further cognitive decline is more likely among individuals whose MCI involves memory problems than among those whose MCI does not involve memory problems. Over one year, most individuals with MCI who are identified through community sampling remain cognitively stable. Some, primarily those without memory problems, experience an improvement in cognition or revert to normal cognitive status.[89] 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.

After accurate and reliable biomarker tests for Alzheimer's have been identified, the 2011 criteria and guidelines recommend biomarker testing for people with MCI to learn whether they have biological changes that put them at high risk of developing Alzheimer's disease and other dementias. If testing shows that changes in the brain, cerebrospinal fluid and/or blood are similar to the changes of Alzheimer's, the proposed criteria and guidelines recommend a diagnosis of MCI due to Alzheimer's disease. However, this diagnosis cannot currently be made, as additional research is needed to validate the 2011 criteria before they can be used in clinical settings.

Dementia Due to Alzheimer's Disease —This stage, as described by the 2011 diagnostic criteria and guidelines, is characterized by quite noticeable memory, thinking and behavioral symptoms that, unlike MCI, impair a person's ability to function in daily life.

Biomarker Tests

The 2011 criteria and guidelines identify two biomarker categories: (1) biomarkers showing the level of beta-amyloid 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 Alzheimer's disease and preserve brain function (called "disease-modifying" treatments) will be most effective when administered during the preclinical and MCI stages of the disease. Biomarker tests will be essential to identify which individuals are in these early stages and should receive disease-modifying treatment. They 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 better understand which biomarker test or combination of tests is most effective in diagnosing Alzheimer's disease. The most effective test or combination of tests may differ depending on the stage of the disease and the type of dementia.[90]

Progress Toward Implementing Criteria and Validating Biomarkers

Since the revised criteria were published in 2011, dozens of scientists have published results of studies implementing the revised criteria in research settings, examining the accuracy of biomarker tests in detecting and predicting Alzheimer's, and using biomarker tests to distinguish Alzheimer's from other forms of dementia. Although additional studies are needed before the revised criteria and guidelines are ready for use in physicians' offices, preliminary evidence supporting the revised criteria and biomarker tests is growing.[91-107]

Treatment of Alzheimer's Disease

Pharmacologic Treatment

Pharmacologic treatments are treatments in which medication is administered to slow or stop an illness or treat its symptoms. None of the treatments available today for Alzheimer's disease slows or stops the malfunction and death of neurons in the brain that cause Alzheimer's symptoms and eventually make the disease fatal. However, dozens of drugs and therapies aimed at slowing or stopping neuronal malfunction and death are being studied by scientists around the world. Five drugs have been approved by the U.S. Food and Drug Administration that temporarily improve symptoms of Alzheimer's disease by increasing the amount of chemicals called neurotransmitters in the brain. The effectiveness of these drugs varies from person to person.

Despite the lack of disease-modifying therapies, studies have consistently shown that active management of Alzheimer's and other dementias can improve quality of life through all stages of the disease for individuals with dementia and their caregivers.[108-110] 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 day care programs and (5) taking part in support groups and supportive services.

Non-Pharmacologic Therapy

Non-pharmacologic therapies are those that employ approaches other than medication, such as physical therapy and reminiscence therapy (therapy in which photos and other familiar items may be used to elicit recall). As with pharmacologic therapies, non-pharmacologic therapies have not been shown to alter the course of Alzheimer's disease. Rather than altering the disease course, non-pharmacologic therapies are often used with the goal of maintaining cognitive function or helping the brain compensate for impairments. Non-pharmacologic therapies are also used with the goals of improving quality of life or reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression.

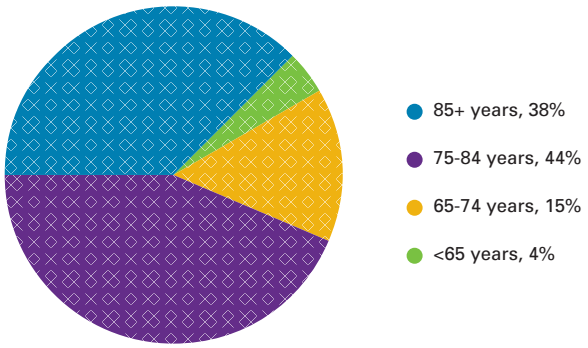
A wide range of non-pharmacologic interventions have been proposed or studied. The Cochrane Database of Systematic Reviews of published articles on non-pharmacologic therapies found that few have sufficient evidence supporting their effectiveness.[111] Of the 25 categories of non-pharmacologic therapies reviewed in the Cochrane Database, only cognitive stimulation had findings that suggested a beneficial effect. A different systematic review found that there were too few high-quality studies to show that non-pharmacologic therapy for dementia was effective. However, of the high-quality studies reviewed, cognitive training, cognitive stimulation and training in activities of daily living appeared most successful in reaching the aims of the interventions.[112] A meta-analysis, which combines results from many studies, found the most successful non-pharmacological interventions for neuropsychiatric symptoms of dementia were multicomponent, tailored to the needs of the caregiver and person with dementia, and delivered at home with periodic follow-up.[113]

Prevalence

older Americans has
Alzheimer's disease.

Millions of Americans have Alzheimer's disease and other dementias. The number of Americans with Alzheimer's disease and other dementias will grow each year as the size 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.

figure 1 | Proportion of People With Alzheimer's Disease in the United States by Age



Percentages may not total 100 because of rounding.
Created from data from Hebert et al.[114), A3]

Estimates from selected studies on the prevalence and characteristics of people with Alzheimer's and other dementias vary depending on how each study was conducted. Data from several studies are used in this section.

Prevalence of Alzheimer's Disease and Other Dementias

The prevalence of Alzheimer's disease refers to the proportion of people in a population who have Alzheimer's at a given point in time. People who have Alzheimer's at a given time are said to have prevalent disease. Prevalence and the number of prevalent cases describe the magnitude of the burden of Alzheimer's on the community and the health care system, but it does not provide an estimate of the risk of developing the disease. An estimated 5.2 million Americans of all ages have Alzheimer's disease in 2014. This includes an estimated 5 million people age 65 and older[114),A1] and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.[115)]

- One in nine people age 65 and older (11 percent) has Alzheimer's disease.[A2]
- About one-third of people age 85 and older (32 percent) have Alzheimer's disease.[114)]
- Of those with Alzheimer's disease, the vast majority (82 percent) are age 75 or older (Figure 1).[114),A3]

The estimated prevalence of Alzheimer's disease for people age 65 and older comes from a recent 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.[114)]

National estimates of the prevalence of all forms of dementia are not available from CHAP, but are available from other population-based studies, including the Aging, Demographics, and Memory Study (ADAMS), a nationally representative sample of older adults.[116-117),A4] Based on estimates from ADAMS, 13.9 percent of people age 71 and older in the United States have dementia.[116)]

Prevalence studies such as CHAP and ADAMS are designed so that all individuals with dementia are detected. But in the community, only about half of those who would meet the diagnostic criteria for Alzheimer's disease and other dementias have received a diagnosis of dementia from a physician.[118)] Because Alzheimer's disease is under-diagnosed, half of the estimated 5.2 million Americans with Alzheimer's may not know they have it.

Preclinical Alzheimer's Disease

The estimates from CHAP and ADAMS are based on commonly accepted criteria for diagnosing Alzheimer's disease that have been used since 1984. These criteria are applicable only after the onset of symptoms. But as described in the Overview, revised criteria and guidelines by the Alzheimer's Association and National Institute on Aging were published in 2011[21-24] proposing that Alzheimer's begins before the onset of symptoms. The 2011 criteria identify three stages of Alzheimer's disease: preclinical Alzheimer's, mild cognitive impairment (MCI) due to Alzheimer's and dementia due to Alzheimer's (see pages 12-13). Because more research is needed to validate the accuracy of biomarker tests in detecting preclinical Alzheimer's and MCI due to Alzheimer's, the number of people in these stages is difficult to estimate. However, if Alzheimer's disease could be detected before symptoms developed, the number of people reported to have Alzheimer's disease (both preclinical and clinical) would be much larger than what is presented in this report.

Subjective Cognitive Decline

The experience of worsening or more frequent confusion or memory loss (often referred to as subjective cognitive decline) can be one of the earliest warning signs of Alzheimer's disease. Because of this, researchers have recently begun to study subjective cognitive decline as a way to identify people who are at high risk of developing Alzheimer's disease and other dementias[119-120] as well as MCI. Subjective cognitive decline does not refer to occasionally forgetting your keys or the name of someone you recently met; it refers to more serious issues such as having trouble remembering how to do things you've always done or forgetting things that you would normally know. Not all of those who experience subjective cognitive decline go on to develop MCI or Alzheimer's disease and other dementias, but many do.[121] In 2011, 22 states added questions on self-perceived confusion and memory loss to their Behavioral Risk Factor Surveillance System (BRFSS) surveys, which are developed in coordination with the Centers for Disease Control and Prevention (CDC). Data from 21 of the states showed that 12.7 percent of Americans age 60 and older reported experiencing worsening confusion or memory loss, but 81 percent of them had not consulted a health care professional.[122] Individuals experiencing serious declines in memory and other cognitive abilities should consult a health care professional about these issues.

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

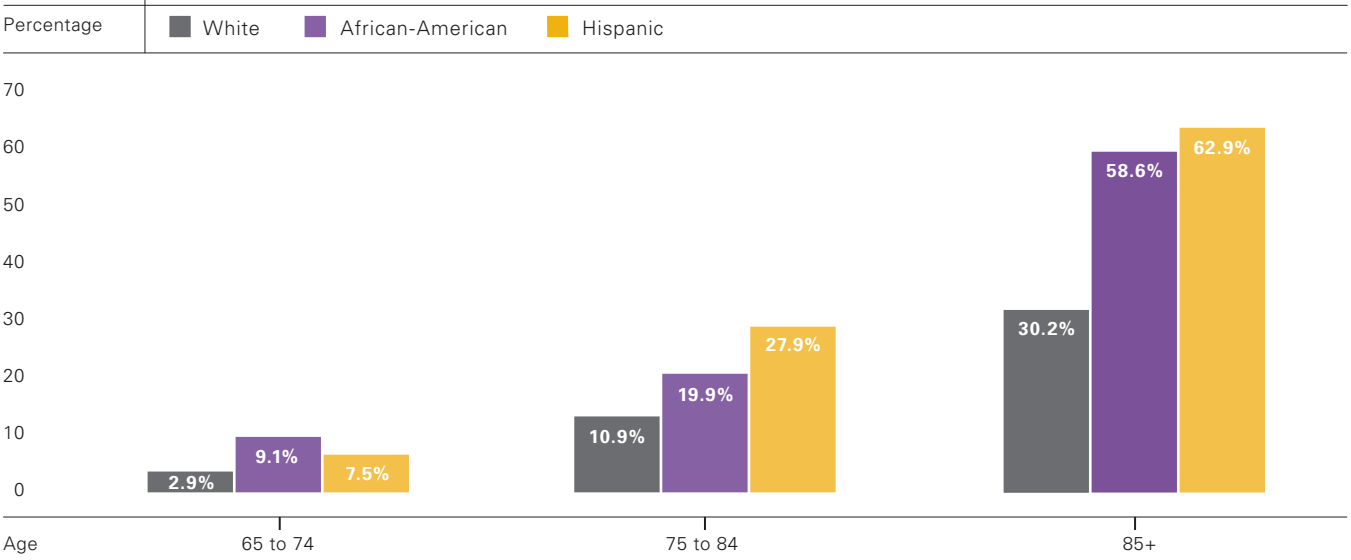
More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women.[114),A5] Of the 5 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.8 million are men.[114),A5] Based on estimates from ADAMS, among people age 71 and older, 16 percent of women have Alzheimer's disease and other dementias compared with 11 percent of men.[116,123]

The observation that more women than men have Alzheimer's disease and other dementias is primarily explained by the fact that women live longer, on average, than men, and older age is the greatest risk factor for Alzheimer's.[123-124] Many studies of the age-specific incidence (development of new cases) of Alzheimer's disease[61-62,124-128] or any dementia[60-61,125-126,129] have found no significant difference between the percentage of men and percentage of women who develop Alzheimer's or other dementias. Thus, there is no evidence that women are more likely than men to develop dementia at any given age.

Prevalence of Alzheimer's Disease and Other Dementias by Years of Education

People with fewer years of education appear to be at higher risk for Alzheimer's and other dementias than those with more years of education.[60-64] Some of the possible reasons are explained in the Risk Factors for Alzheimer's Disease section of the Overview (pages 9-11).

figure 2 | Proportion of People Age 65 and Older with Alzheimer's Disease and Other Dementias*



*The Hispanic group for this study was primarily Caribbean-American.
Created from data from Gurland et al. [133]

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

While there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older African-Americans and Hispanics are more likely than older whites to have Alzheimer's disease and other dementias.[130-131] A review of many studies by an expert panel concluded that older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites,[132] and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites.[133),A6] Figure 2 shows the estimated prevalence for each group, by age, according to one large study. (Note: the Hispanic group for this study was primarily Caribbean-American, while most Hispanics in the United States are Mexican-American. The prevalence in Caribbean-Americans may be more similar to that in African-Americans, contributing to the higher observed prevalence for Hispanics in this study than estimated by the expert panel.)

Despite some evidence of racial differences in the influence of genetic risk factors on Alzheimer's and other dementias,[134] genetic factors do not appear to account for the large prevalence differences among racial groups.[135-136] Instead, health conditions such as high blood pressure and diabetes that may increase one's risk for Alzheimer's disease or another dementia are believed to account for these differences because they are more prevalent in African-American 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.[61,116]

There is evidence that missed diagnoses are more common among older African-Americans and Hispanics than among older whites,[137-138] but it is unclear whether disparities in missed diagnoses have lessened in recent years. Recent data for Medicare beneficiaries found that Alzheimer's disease or another dementia had been diagnosed in 8.2 percent of white beneficiaries, 11.3 percent of African-American beneficiaries and

12.3 percent of Hispanic beneficiaries.[139] Although rates of diagnosis were higher among African-Americans than among whites, this difference was not as great as would be expected (twice the percentage of whites) based on the estimated differences found in prevalence studies (Figure 2), which are designed to detect all people who have dementia.

Incidence of Alzheimer's Disease

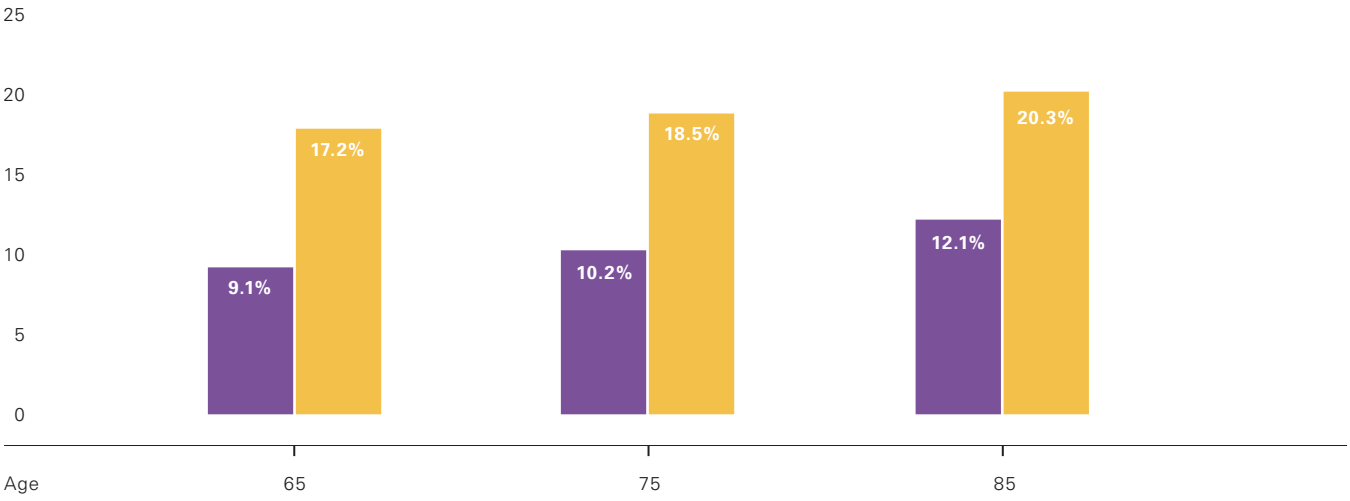
While prevalence is the number of *existing* cases of a disease in a population at a given time, incidence is the number of *new* cases of a disease that develop in a given period of time in a defined population — in this case the United States population age 65 or older. Approximately 469,000 people age 65 or older will develop Alzheimer's disease in the United States in 2014.[A7] The number of new cases of Alzheimer's increases dramatically with age: in 2014, there will be approximately 59,000 new cases among people age 65 to 74, 172,000 new cases among people age 75 to 84, and 238,000 new cases among people age 85 and older (the "oldest-old").[140],[A7] Though some studies have reported that incidence rates do not continue to rise after age 90, at least one large study indicates that previous observations of a leveling off of incidence among the oldest-old may be due to sparse data for this group.[141] Because of the increasing number of people age 65 and older in the United States, particularly the oldest-old, the annual number of new cases of Alzheimer's and other dementias is projected to double by 2050.[140]

- Every 67 seconds, someone in the United States develops Alzheimer's.[A8]
- By mid-century, someone in the United States will develop the disease every 33 seconds.[A8]

Lifetime Risk of Alzheimer's Disease

Lifetime risk is the probability that someone of a given age will develop a condition during his or her remaining lifespan. Data from the Framingham Study were used to estimate lifetime risks of Alzheimer's disease and of any dementia.[142],[A9] The study found that 65-year-old women without dementia had a 20 percent chance of developing dementia during the remainder of their lives (estimated lifetime risk), compared with a 17 percent chance for men. As shown in Figure 3, for Alzheimer's disease specifically, the estimated lifetime risk at age 65 was nearly one in six (17.2 percent) for women compared with nearly one in eleven (9.1 percent) for men.[142]

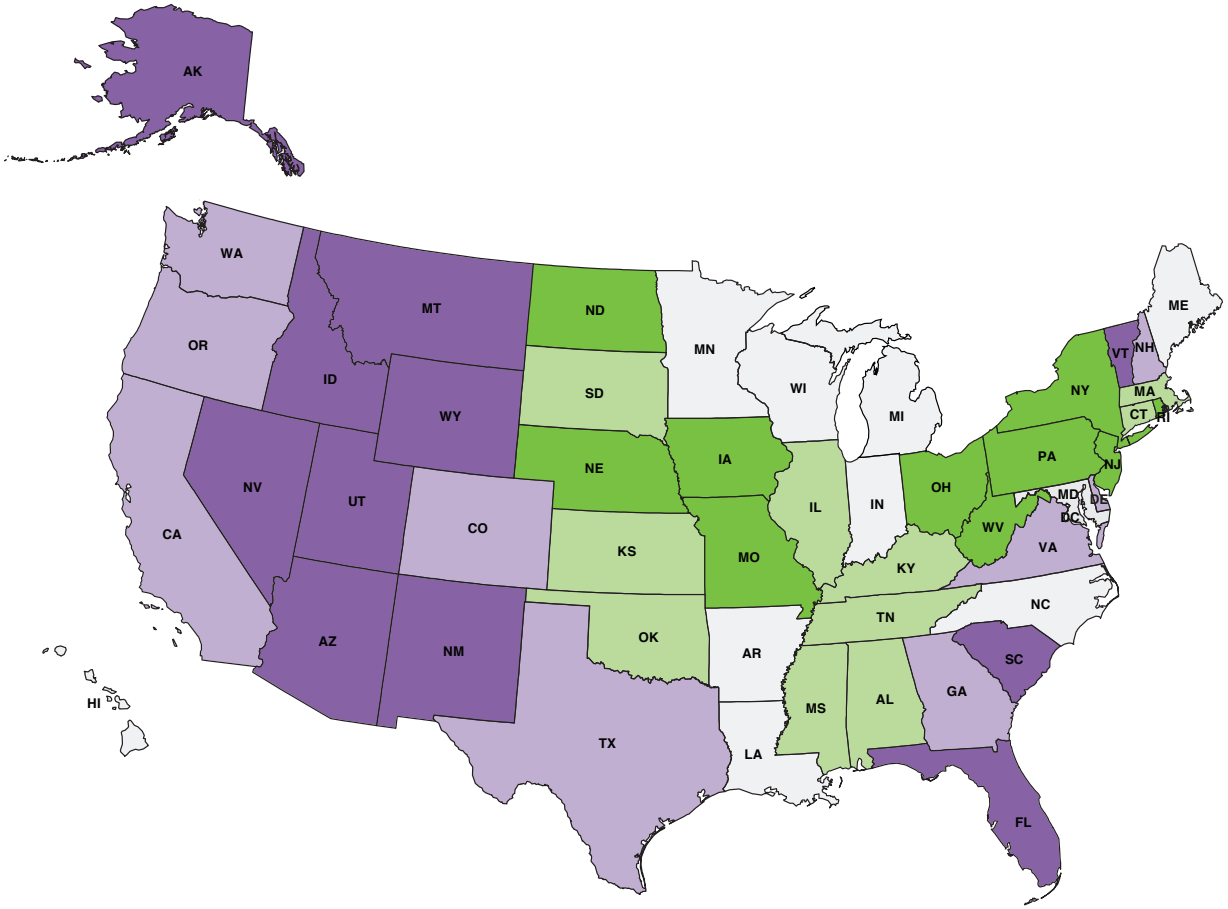
figure 3 Estimated Lifetime Risks for Alzheimer's, by Age and Sex, from the Framingham Study



Created from data from Seshadri et al. [142]

figure 4 | Projected Changes Between 2014 and 2025 in Alzheimer's Disease Prevalence by State

14.3% - 23.5% | 23.6% - 28.5% | 28.6% - 40.0% | 40.1% - 49.9% | 50.0% - 80.3%



Change from 2014 to 2025 for Washington, D.C.: -2.2%

Created from unpublished data provided to the Alzheimer's Association by Hebert et al.[A10]

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

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

Estimates of the Number of People with Alzheimer's Disease by State

Table 2 (page 22) summarizes the projected number of people age 65 and older with Alzheimer's disease (prevalent cases of Alzheimer's) by state for 2014 and the projected percentage change in the number of people with Alzheimer's between 2014 and 2025.[A10] (Note: the total number of people with Alzheimer's 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 Figure 4, between 2014 and 2025 every state and region across the country is expected to experience double-digit percentage increases in the numbers of people with Alzheimer's due to increases in the proportion of the population age 65 and older. The West and Southeast are expected to experience the largest increases in numbers of people with Alzheimer's between 2014 and 2025. The increasing number of individuals with Alzheimer's will have a marked impact on states' health care systems, as well as on families and caregivers.

Looking to the Future

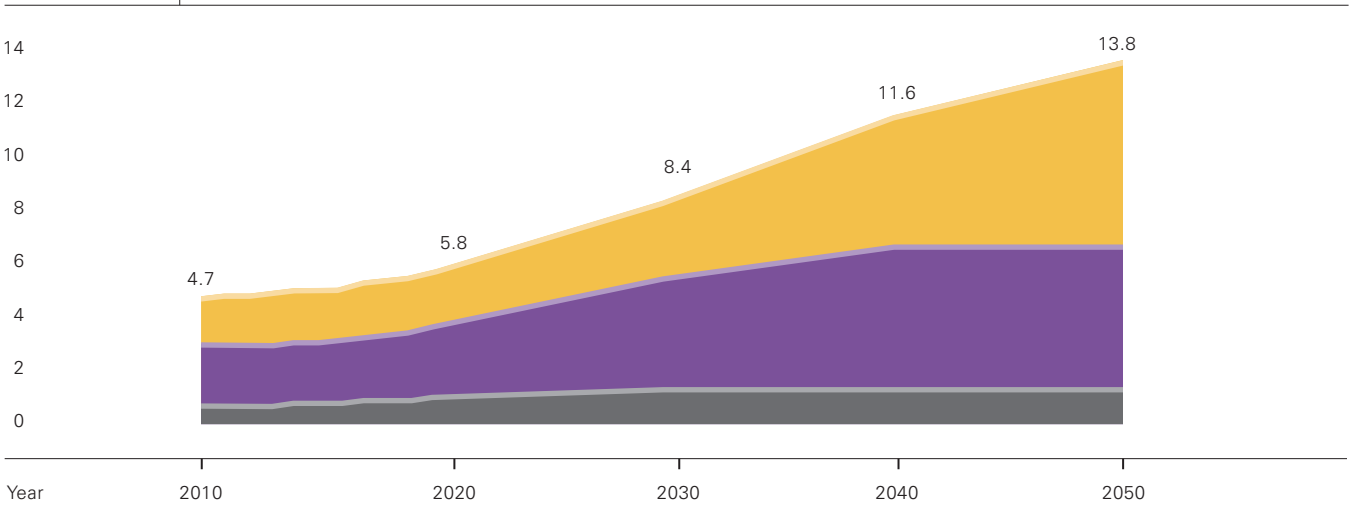
The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions.[143] Additionally, a large segment of the American population — the baby boom generation — has begun to reach the age range of elevated risk for Alzheimer's 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 grow dramatically, and the estimated 72 million older Americans will make up approximately 20 percent of the total population (up from 13 percent in 2010).[143]

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's disease, as shown in Figure 5.[114),A11]

- In 2000, there were an estimated 411,000 new cases of Alzheimer's disease. For 2010, that number was estimated to be 454,000 (a 10 percent increase); by 2030, it is projected to be 615,000 (a 50 percent increase from 2000); and by 2050, 959,000 (a 130 percent increase from 2000).[140]
- By 2025, the number of people age 65 and older with Alzheimer's disease is estimated to reach 7.1 million — a 40 percent increase from the 5 million age 65 and older currently affected.[114),A12]
- By 2050, the number of people age 65 and older with Alzheimer's disease 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.[114),A11] Previous estimates based on high range projections of population growth provided by the U.S. Census suggest that this number may be as high as 16 million.[144),A13]

figure 5

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



Created from data from Hebert et al.[114), A11]

table 2 | Projections of Total Numbers of Americans Age 65 and Older with Alzheimer's by State

State	Projected Number w/Alzheimer's (in thousands) 2014	Projected Number w/Alzheimer's (in thousands) 2025	Percentage Change 2014-2025	State	Projected Number w/Alzheimer's (in thousands) 2014	Projected Number w/Alzheimer's (in thousands) 2025	Percentage Change 2014-2025
Alabama	86.0	110.0	27.9	Montana	18.0	27.0	50.0
Alaska	6.1	11.0	80.3	Nebraska	33.0	40.0	21.2
Arizona	120.0	200.0	66.7	Nevada	37.0	64.0	73.0
Arkansas	52.0	67.0	28.8	New Hampshire	22.0	32.0	45.5
California	580.0	840.0	44.8	New Jersey	170.0	210.0	23.5
Colorado	63.0	92.0	46.0	New Mexico	34.0	53.0	55.9
Connecticut	72.0	91.0	26.4	New York	380.0	460.0	21.1
Delaware	16.0	23.0	43.8	North Carolina	150.0	210.0	40.0
District of Columbia	9.2	9.0	-2.2	North Dakota	14.0	16.0	14.3
Florida	480.0	720.0	50.0	Ohio	210.0	250.0	19.0
Georgia	130.0	190.0	46.2	Oklahoma	60.0	76.0	26.7
Hawaii	25.0	35.0	40.0	Oregon	59.0	84.0	42.4
Idaho	22.0	33.0	50.0	Pennsylvania	270.0	320.0	18.5
Illinois	210.0	260.0	23.8	Rhode Island	22.0	27.0	22.7
Indiana	100.0	130.0	30.0	South Carolina	79.0	120.0	51.9
Iowa	62.0	73.0	17.7	South Dakota	16.0	20.0	25.0
Kansas	50.0	62.0	24.0	Tennessee	110.0	140.0	27.3
Kentucky	67.0	86.0	28.4	Texas	330.0	490.0	48.5
Louisiana	81.0	110.0	35.8	Utah	28.0	42.0	50.0
Maine	25.0	35.0	40.0	Vermont	11.0	17.0	54.5
Maryland	97.0	130.0	34.0	Virginia	130.0	190.0	46.2
Massachusetts	120.0	150.0	25.0	Washington	97.0	140.0	44.3
Michigan	170.0	220.0	29.4	West Virginia	36.0	44.0	22.2
Minnesota	88.0	120.0	36.4	Wisconsin	100.0	130.0	30.0
Mississippi	51.0	65.0	27.5	Wyoming	8.5	13.0	52.9
Missouri	110.0	130.0	18.2				

Created from unpublished data provided to the Alzheimer's Association by Hebert et al.[A10]

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 percent of all people age 65 and older in the United States to 20 percent of all people age 65 and older.[143] This will result in an additional 13 million oldest-old people — individuals at the highest risk for developing Alzheimer's.[143]

- In 2014, the 85-years-and-older population includes about 2 million people with Alzheimer's disease, or 40 percent of all people with Alzheimer's age 65 and older.[114]
- When the first wave of baby boomers reaches age 85 (in 2031), it is projected that more than 3 million people age 85 and older will have Alzheimer's.[114]
- By 2050, there could be as many as 7 million people age 85 and older with Alzheimer's disease, accounting for half (51 percent) of all people 65 and older with Alzheimer's.[114]

Mortality and Morbidity

of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia.

Alzheimer's disease is officially listed as the sixth-leading cause of death in the United States.[145] It is the fifth-leading cause of death for those age 65 and older.[145] However, it may cause even more deaths than official sources recognize. In addition to being a leading cause of death, Alzheimer's is a leading cause of disability and poor health (morbidity). Before a person with Alzheimer's dies, he or she lives through years of morbidity as the disease progresses.

Deaths from Alzheimer's Disease

It is difficult to determine how many deaths are caused by Alzheimer's disease each year because of the way causes of death are recorded. According to final data from the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), 83,494 people died from Alzheimer's disease in 2010 (the most recent year for which final data are available).[145] The CDC considers a person to have died *from* Alzheimer's if the death certificate lists Alzheimer's as the underlying cause of death, defined by the World Health Organization as "the disease or injury which initiated the train of events leading directly to death."[146] However, death certificates for individuals with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death rather than Alzheimer's.[147-149] 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 Alzheimer's disease and other dementias.[150-151] The number of people with Alzheimer's disease who die while experiencing these other conditions may not be counted among the number of people who died *from* Alzheimer's disease according to the CDC definition, even though Alzheimer's disease is likely a contributing cause of death. Thus, it is likely that Alzheimer's disease 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."[152] According to data from the Chicago Health and Aging Project (CHAP), an estimated 600,000 people age 65 and older died *with* Alzheimer's in the United States in 2010, meaning they died after developing Alzheimer's disease.[153],A14 Of these, an estimated 400,000 were age 85 and older and an estimated 200,000 were age 65 to 84. Other investigators, using data from the Rush Memory and Aging Project, estimate that 500,000 deaths among people age 75 and older were attributed to Alzheimer's disease in the U.S. in 2010 (estimates for people age 65 to 74 were not available).[154] Furthermore, according to Medicare data, one-third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia.[139,155] Although some seniors who die with Alzheimer's disease die from causes that are unrelated to Alzheimer's, many of them die from Alzheimer's disease itself or from conditions in which Alzheimer's was a contributing cause, such as pneumonia. A recent study evaluating the contribution of individual common diseases to death using a nationally representative sample of older adults found that dementia was the second largest contributor to death behind heart failure.[156] Thus, for people who die with Alzheimer's, the disease is expected to be a significant direct contributor to their deaths.

Based on CHAP data, an estimated 700,000 people in the United States age 65 or older will die *with* Alzheimer's in 2014.[153], A14 The true number of deaths caused by Alzheimer's is likely to be somewhere between the official estimated numbers of those dying from Alzheimer's (as indicated by death certificates) and those dying with Alzheimer's. Regardless of the cause of death, among people age 70, 61 percent of those with Alzheimer's are expected to die before age 80 compared with 30 percent of people without Alzheimer's.[157]

Public Health Impact of Deaths from Alzheimer's Disease

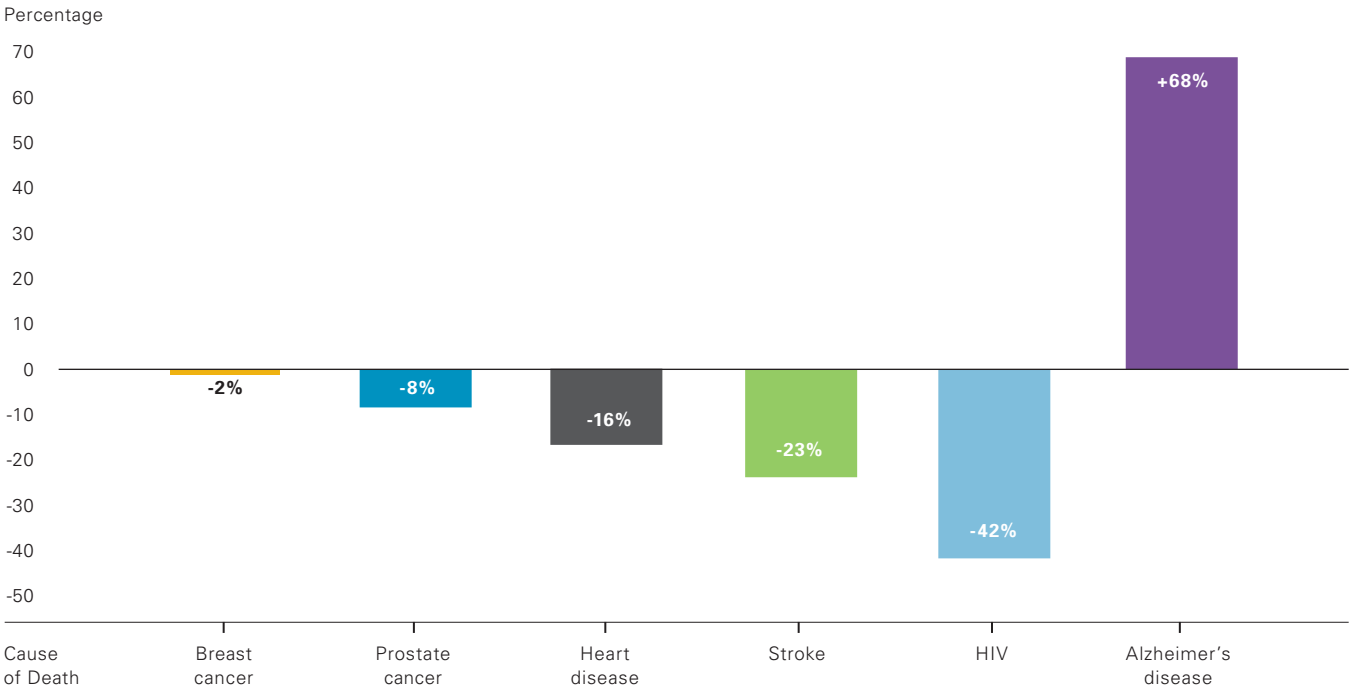
As the population of the United States ages, Alzheimer's is becoming a more common cause of death. While deaths from other major causes have decreased significantly, deaths from Alzheimer's disease have increased significantly. Between 2000 and 2010, deaths attributed to Alzheimer's disease increased 68 percent, while those attributed to the number one cause of death, heart disease, decreased 16 percent (Figure 6).[145,158] The increase in the number and proportion of death certificates listing Alzheimer's as the underlying cause of death reflects both changes in patterns of reporting deaths on death certificates over time as well as an increase in the actual number of deaths attributable to Alzheimer's.

Another way to describe the impact of Alzheimer's disease on mortality is through a statistic known as population attributable risk. It represents the proportion of deaths (in a specified amount of time) in a population that may be preventable if a disease were eliminated. The population attributable risk of Alzheimer's disease on mortality over five years in people age 65 and older is estimated to be between 5 percent and 15 percent.[159-160] This means that over the next 5 years, 5 percent to 15 percent of all deaths in older people can be attributed to Alzheimer's disease.

State-by-State Deaths from Alzheimer's Disease

Table 3 provides information on the number of deaths due to Alzheimer's by state in 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 due to Alzheimer's disease across states with varying population sizes and attributes. For the United States as a whole, in 2010, the mortality rate for Alzheimer's disease was 27 deaths per 100,000 people.[145]

figure 6 | Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2010



Created from data from the National Center for Health Statistics.[145,158]

table 3 | Number of Deaths and Annual Mortality Rate (per 100,000) Due to Alzheimer's Disease by State, 2010

State	Number of Deaths	Mortality Rate	State	Number of Deaths	Mortality Rate
Alabama	1,523	31.9	Montana	302	30.5
Alaska	85	12.0	Nebraska	565	30.9
Arizona	2,327	36.4	Nevada	296	11.0
Arkansas	955	32.8	New Hampshire	396	30.1
California	10,856	29.1	New Jersey	1,878	21.4
Colorado	1,334	26.5	New Mexico	343	16.7
Connecticut	820	22.9	New York	2,616	13.5
Delaware	215	23.9	North Carolina	2,817	29.5
District of Columbia	114	18.9	North Dakota	361	53.7
Florida	4,831	25.7	Ohio	4,109	35.6
Georgia	2,080	21.5	Oklahoma	1.015	27.1
Hawaii	189	13.9	Oregon	1,300	33.9
Idaho	410	26.2	Pennsylvania	3,591	28.3
Illinois	2,927	22.8	Rhode Island	338	32.1
Indiana	1,940	29.9	South Carolina	1,570	33.9
Iowa	1,411	46.3	South Dakota	398	48.9
Kansas	825	28.9	Tennessee	2,440	38.4
Kentucky	1,464	33.7	Texas	5,209	20.7
Louisiana	1,295	28.6	Utah	375	13.6
Maine	502	37.8	Vermont	238	38.0
Maryland	986	17.1	Virginia	1,848	23.1
Massachusetts	1,773	27.1	Washington	3,025	45.0
Michigan	2,736	27.7	West Virginia	594	32.1
Minnesota	1,451	27.4	Wisconsin	1,762	31.0
Mississippi	927	31.2	Wyoming	146	25.9
Missouri	1,986	33.2	**U.S. Total**	**83,494**	**27.0**

Created from data from the National Center for Health Statistics.[145], A15

Death Rates by Age

Although people younger than age 65 can develop and die from Alzheimer's disease, the highest risk of death from Alzheimer's is in people age 65 or older. As seen in Table 4, death rates for Alzheimer's increase dramatically with age. The increase in deaths attributed to Alzheimer's disease over time has disproportionately affected the oldest-old: Between 2000 and 2010, death rates from Alzheimer's increased 6 percent for people age 65 to 74, 32 percent for people age 75 to 84, and 48 percent for people age 85 and older.[161]

table 4 U.S. Annual Alzheimer's death rates (per 100,000) by Age

Age	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	1,002.2	987.1
Total Death Rate*	**18.1**	**20.8**	**22.6**	**23.7**	**25.8**	**25.1**

*Reflects overall death rate for ages 45 and older.

Created from data from the National Center for Health Statistics.[161]

Duration of Illness from Diagnosis to Death

Studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's.[160,162-166] This indicates the slow, insidious nature of the progression of Alzheimer's. On average, a person with Alzheimer's disease will spend more years (40 percent of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stage.[157] Much of this time will be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer's compared with only 4 percent of the general population.[157] In all, an estimated two-thirds of those dying of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions.[167]

Burden of Alzheimer's Disease

The long duration of illness before death contributes significantly to the public health impact of Alzheimer's disease because much of that time is spent in a state of disability and dependence. Scientists have developed methods to measure and compare the burden of different diseases on a population in a way that takes into account both the number of years of life lost due to that disease as well as the number of healthy years of life lost by virtue of being in a state of disability. These measures indicate that Alzheimer's is a very burdensome disease and that the burden of Alzheimer's has increased more dramatically in the United States in recent years than other diseases. The primary measure of disease burden is called disability-adjusted life-years (DALYs), which is the sum of the number of years of life lost due to premature mortality and the number of years lived with disability. Based on DALYs, between 1990 and 2010, Alzheimer's rose from the 25th most burdensome disease in the United States to the 12th; no other disease or condition increased that much.[168] Looking at years of life lost, Alzheimer's disease rose from 32nd to 9th, the largest increase for any disease. Looking at years lived with disability, Alzheimer's disease went from ranking 17th to 12th; only kidney disease equaled Alzheimer's in as high a jump in rank.

Taken together, the numbers in this section indicate that not only is Alzheimer's disease responsible for the deaths of more and more Americans, the disease is also contributing to more and more cases of poor health and disability in the United States.

Caregiving

In 2013, Americans provided

billion hours of unpaid care to people with Alzheimer's disease and other dementias.

Caregiving refers to attending to another individual's health needs. Caregiving often includes assistance with one or more activities of daily living (ADLs; such as bathing and dressing).[169-170] More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias.[A16]

Unpaid Caregivers

Unpaid caregivers are usually immediate family members, but they also may be other relatives and friends. In 2013, these individuals provided an estimated 17.7 billion hours of informal (that is, unpaid) care, a contribution to the nation valued at over $220.2 billion. This is approximately half of the net value of Wal-Mart sales in 2012 ($443.9 billion)[171] and nearly eight times the total revenue of McDonald's in 2012 ($27.6 billion).[172] According to a recent report,[173] the value of informal care was nearly equal to the direct medical and long-term care costs of dementia. Eighty-five percent of help provided to all older adults in the United States is from family members.[174]

Who Are the Caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's disease and other dementias.[175],[A17] Data from the 2009 and 2010 Behavioral Risk Factor Surveillance System (BRFSS) surveys conducted in eight states and the District of Columbia[175] found that 65 percent of caregivers of people with Alzheimer's disease and other dementias were women; 21 percent were 65 years old and older; 44 percent had some college education or had received a degree; 64 percent were currently employed, a student or a homemaker; and 71 percent were married or in a long-term relationship.[175]

The Aging, Demographics, and Memory Study (ADAMS), based on a nationally representative subsample of older adults from the Health and Retirement Survey,[176] compared two types of "primary" caregivers (individuals who indicate having the most responsibility for helping their relatives): those caring for people with dementia and those caring for people with cognitive problems who did not reach the threshold of dementia. The primary caregiver groups did not differ significantly by age (60 versus 61, respectively), gender (71 percent versus 81 percent female), race (66 percent versus 71 percent non-Hispanic white) or marital status (70 percent versus 71 percent married). Over half of primary caregivers (55 percent) of people with dementia took care of parents.[177]

Ethnic and Racial Diversity in Caregiving

Among caregivers of people with Alzheimer's disease and other dementias, the National Alliance for Caregiving (NAC) and AARP found the following:[178]

- Fifty-four percent of white caregivers assist a parent, compared with 38 percent of individuals from other racial/ethnic groups.
- On average, Hispanic and African-American caregivers spend more time caregiving (approximately 30 hours per week) than non-Hispanic white caregivers (20 hours per week) and Asian-American caregivers (16 hours per week).
- Hispanic (45 percent) and African-American (57 percent) caregivers are more likely to experience high burden from caregiving than whites (33 percent) and Asian-Americans (30 percent).

Sandwich Generation Caregivers

Traditionally, the term "sandwich generation caregiver" has referred to a middle-aged person who simultaneously cares for dependent minor children and aging parents. The phenomenon of sandwich generation caregiving has received a good deal of attention in recent years as it has been argued that demographic changes (such as parents of dependent minors being older than in the past and the aging of the U.S. population) have led to increases in the number of sandwich generation caregivers.[179,180-181] NAC/AARP found that 30 percent of Alzheimer's disease and dementia caregivers had children under 18 years old living with them.[178] Other studies have found that sandwich generation caregivers are present in 8 to 13 percent of households in the United States.[182-183] It is not clear what proportion of care recipients in these studies had Alzheimer's disease or another dementia, but in other studies about one-third of elderly care recipients have Alzheimer's disease or another dementia.[184] Various studies have concluded that sandwich generation caregivers experience unique challenges related to the demands of providing care for both aging parents and dependent children. Such challenges include limited time, energy and financial resources.[180,185-186] Some authors have therefore concluded that sandwich generation caregivers can experience anxiety and depression as well as lower quality of life due to the unique challenges these individuals experience.[186-187]

Caregiving Tasks

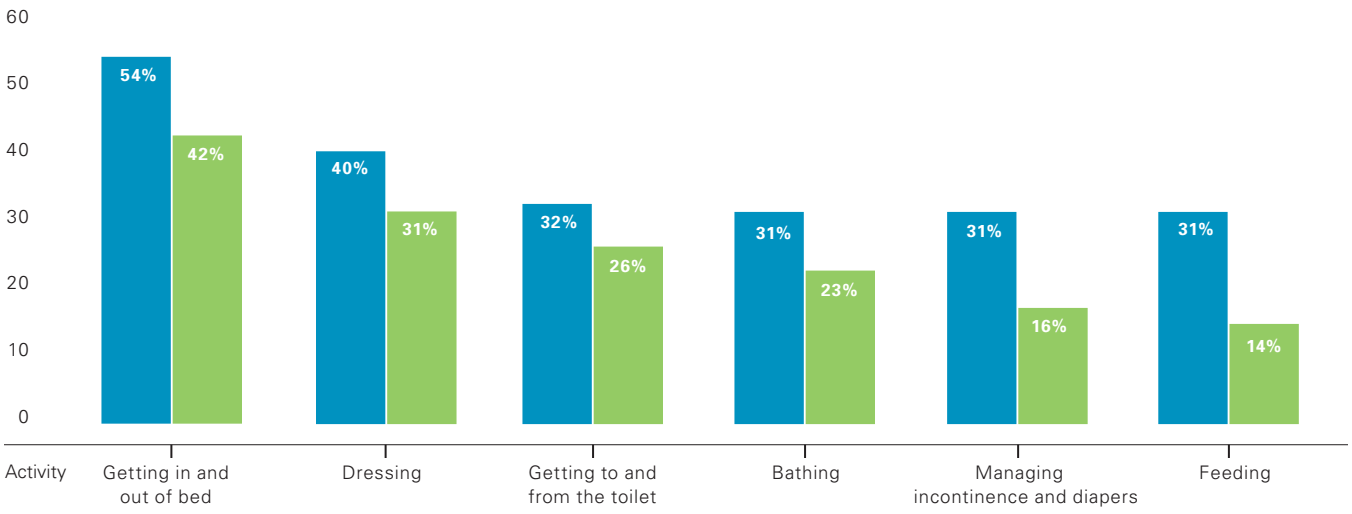
The care provided to people with Alzheimer's disease and other dementias is wide-ranging and in some instances all-encompassing. Table 5 summarizes some of the most common types of dementia care provided.

Though the care provided by family members of people with Alzheimer's disease and other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance. Family caregivers of people with dementia are more likely than caregivers of other older people to assist with any ADL (Figure 7). More than half of dementia caregivers report

table 5	Dementia Caregiving Tasks
	Help with instrumental activities of daily living (IADLs), such as household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs and answering the telephone.
	Helping the person take medications correctly, either via reminders or direct administration of medications.
	Helping the person adhere to treatment recommendations for dementia or other medical conditions.
	Assisting with personal activities of daily living (ADLs), such as bathing, dressing, grooming, feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.
	Managing behavioral symptoms of the disease such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
	Finding and using support services such as support groups and adult day service programs.
	Making arrangements for paid in-home, nursing home or assisted living care.
	Hiring and supervising others who provide care.
	Assuming additional responsibilities that are not necessarily specific tasks, such as: • Providing overall management of getting through the day. • Addressing family issues related to caring for a relative with Alzheimer's disease, including communication with other family members about care plans, decision-making and arrangements for respite for the main caregiver.

figure 7

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



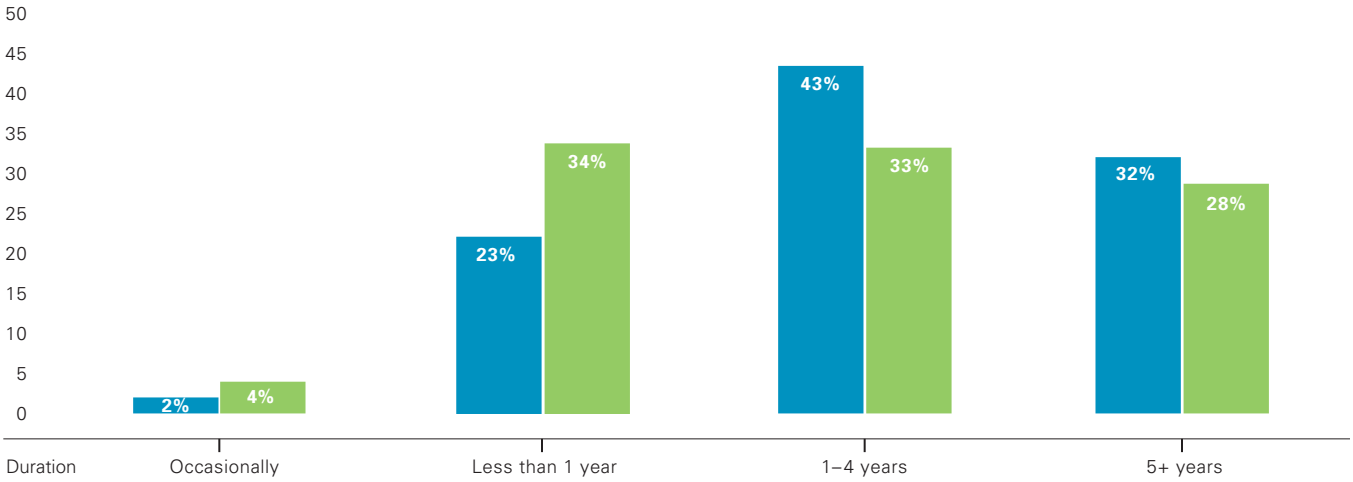
Created from data from the National Alliance for Caregiving and AARP.[178]

providing help with getting in and out of bed, and about one-third provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence and feeding. These findings are consistent with the heightened degree of dependency experienced by some people with Alzheimer's disease and other dementias. Fewer caregivers of other older people report providing help with each of these types of care.[178]

In addition to assisting with ADLs, almost two-thirds of caregivers of people with Alzheimer's and other dementias advocate for their care recipient with government agencies and service providers (64 percent), and nearly half arrange and supervise paid caregivers from community agencies (46 percent). By contrast, caregivers of other older adults are less likely to advocate for their family member (50 percent) and supervise community-based care (33 percent).[178] 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 Alzheimer's or another dementia moves to an assisted living residence or nursing home, the help provided by his or her family caregiver usually changes from the comprehensive care summarized in Table 5 to providing emotional support, interacting with facility staff, and advocating for appropriate care. However, some family caregivers continue to help with bathing, dressing and other ADLs.[188-190] Admitting a relative to a residential care setting 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.[190-191] The relationship between the caregiver and person with

figure 8 | Proportion of Alzheimer's and Dementia Caregivers versus Caregivers of Other Older People by Duration of Caregiving, United States, 2009



Created from data from the National Alliance for Caregiving and AARP.[178]

dementia may explain these discrepancies. For example, husbands, wives and daughters are significantly more likely than other family caregivers to indicate persistent burden up to 12 months following placement, while husbands are more likely than other family caregivers to indicate persistent depression up to a year following a relative's admission to a residential care facility.[191]

Duration of Caregiving

Caregivers of people with Alzheimer's and other dementias provide care for a longer time, on average, than do caregivers of older adults with other conditions. As shown in Figure 8, 43 percent of caregivers of people with Alzheimer's and other dementias provide care for 1 to 4 years compared with 33 percent of caregivers of people without dementia. Similarly, 32 percent of dementia caregivers provide care for over 5 years compared with 28 percent of caregivers of people without dementia.[178]

Hours of Unpaid Care and Economic Value of Caregiving

In 2013, the 15.5 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 17.7 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.[A18] With this care valued at $12.45 per hour,[A19] the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was $220.2 billion in 2013. Table 6 (pages 35-36) shows the total hours of unpaid care as well as the value of care provided by family and other unpaid caregivers for the United States and each state. Unpaid caregivers of people with Alzheimer's 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.

Other studies suggest that primary family caregivers (or those who indicate the most responsibility in caring for their relatives) provide particularly extensive amounts of care. For example, a 2011 report from ADAMS found that primary family caregivers of people with dementia reported spending an average of 9 hours per day providing help to their relatives.[177]

Impact of Alzheimer's Disease Caregiving

Caring for a person with Alzheimer's or another dementia poses special challenges. For example, people with Alzheimer's disease experience losses in judgment, orientation and the ability to understand and communicate effectively. Family caregivers must often help people with Alzheimer's manage these issues. The personality and behavior of a person with Alzheimer's are affected as well, and these changes are often among the most challenging for family caregivers.[192] Individuals with dementia may also require increasing levels of supervision and personal care as the disease progresses. As symptoms worsen with the progression of a relative's dementia, the care required of family members can result in increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment and depleted income and finances.[193-198],[A17] 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 due to the memory loss, functional impairment and psychiatric/behavioral disturbances that can accompany the progression of Alzheimer's.

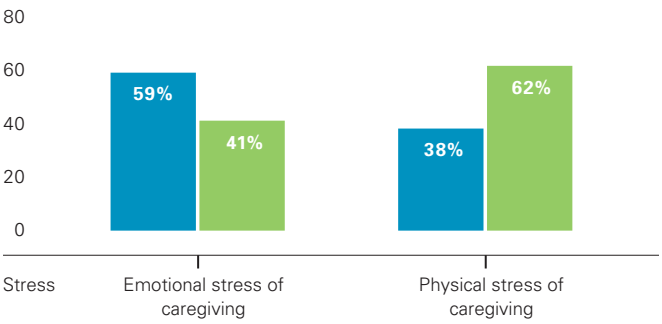
Caregiver Emotional Well-Being

Although caregivers report some positive feelings about caregiving, including family togetherness and the satisfaction of helping others,[199],[A17] they also report high levels of stress over 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 than caregivers of people without dementia (16 percent versus 31 percent, respectively).[178]
- Fifty-nine percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high (Figure 9).[A17]
- Most family caregivers report "a good amount" to "a great deal" of caregiving strain concerning financial issues (47 percent) and family relationships (52 percent).[A17]
- Earlier research in smaller samples found that over one-third (39 percent) of caregivers of people with dementia suffered from depression compared with 17 percent of non-caregivers.[200-201] A meta-analysis of research comparing caregivers affirmed this disparity in the prevalence of depression between caregivers of people with dementia and non-caregivers.[197] In the ADAMS sample, 44 percent of primary caregivers of people with dementia indicated depressive symptoms, compared with 27 percent of primary caregivers of people who had cognitive impairment but no dementia.[177] Among family members supporting an older person who has

figure 9

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



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

table 6 | Number of Alzheimer's and Dementia (AD/D) Caregivers, Hours of Unpaid Care, Economic Value of the Care and Higher Health Care Costs of Caregivers by State, 2013*

State	AD/D Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	Higher Health Care Costs of Caregivers (in millions of dollars)
Alabama	299	341	$4,240	$164
Alaska	33	37	$466	$26
Arizona	307	350	$4,358	$147
Arkansas	173	197	$2,455	$94
California	1,547	1,761	$21,927	$853
Colorado	229	261	$3,254	$121
Connecticut	176	201	$2,497	$134
Delaware	52	59	$732	$39
District of Columbia	27	31	$381	$25
Florida	1,037	1,181	$14,709	$654
Georgia	499	569	$7,080	$240
Hawaii	64	73	$910	$39
Idaho	77	88	$1,091	$38
Illinois	587	668	$8,322	$350
Indiana	330	376	$4,686	$194
Iowa	133	151	$1,884	$81
Kansas	149	170	$2,112	$89
Kentucky	267	304	$3,789	$155
Louisiana	228	260	$3,237	$137
Maine	68	77	$964	$51
Maryland	286	326	$4,056	$189
Massachusetts	325	370	$4,610	$266
Michigan	505	575	$7,163	$294
Minnesota	245	280	$3,481	$161
Mississippi	205	233	$2,900	$117
Missouri	310	354	$4,402	$190

*State totals may not add up to the U.S. total due to rounding.
Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.[A13, A16, A17, A18]

table 6 (cont.) Number of Alzheimer's and Dementia (AD/D) Caregivers, Hours of Unpaid Care, Economic Value of the Care and Higher Health Care Costs of Caregivers by State, 2013*

State	AD/D Caregivers (in thousands)	Hours of Unpaid Care (in millions)	Value of Unpaid Care (in millions of dollars)	Higher Health Care Costs of Caregivers (in millions of dollars)
Montana	48	54	$677	$28
Nebraska	80	91	$1,134	$50
Nevada	137	156	$1,938	$69
New Hampshire	65	74	$919	$45
New Jersey	443	505	$6,287	$296
New Mexico	105	120	$1,495	$62
New York	1,010	1,150	$14,316	$742
North Carolina	442	504	$6,272	$252
North Dakota	29	33	$415	$20
Ohio	591	674	$8,386	$369
Oklahoma	218	248	$3,093	$125
Oregon	173	196	$2,446	$100
Pennsylvania	669	762	$9,492	$456
Rhode Island	52	60	$744	$38
South Carolina	291	331	$4,127	$161
South Dakota	37	42	$521	$23
Tennessee	418	476	$5,922	$235
Texas	1,302	1,482	$18,457	$679
Utah	140	159	$1,980	$62
Vermont	30	34	$422	$20
Virginia	447	509	$6,342	$247
Washington	319	363	$4,518	$191
West Virginia	108	123	$1,536	$73
Wisconsin	190	217	$2,698	$122
Wyoming	28	31	$392	$17
U.S. Totals	**15,533**	**17,689**	**$220,233**	**$9,332**

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

Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.[A13, A16, A17, A18]

mild cognitive impairment (MCI), 23 percent were found to have depression,[202] a much higher percentage than found in the general population (7 percent).[203] In a small, recent study of dementia family caregiving and hospitalization,[204] clinical depression rates of 63 percent and 43 percent were found among family caregivers of people with dementia who were or were not hospitalized, respectively.

- In the 2009 NAC/AARP survey, caregivers most likely to indicate stress were women, older, residing with the care recipient, and white or Hispanic. In addition, these caregivers often believed there was no choice in taking on the role of caregiver.[178]
- 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.[178,205]
- Seventy-six percent of family caregivers of people with Alzheimer's disease and other dementias said that they somewhat agree or strongly agree that it is neither "right nor 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 admission (for example, interacting with care staff to determine an appropriate care role for the family member).[188,190,206-207],A17
- The demands of caregiving may intensify as people with dementia approach the end of life.[208] In the year before the person's death, 59 percent of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful.[209] One study of end-of-life care found that 72 percent of family caregivers said they experienced relief when the person with Alzheimer's disease or another dementia died.[209]

Caregiver Physical Health

For some caregivers, the demands of caregiving may cause declines in their own health. Forty-three percent of caregivers of people with Alzheimer's disease and other dementias reported that the physical impact of caregiving was high to very high (Figure 9).[A17] Sleep disturbances, which can occur frequently when caring for a relative with Alzheimer's disease or dementia, have also been shown to negatively influence family caregivers' health.[210]

General Health

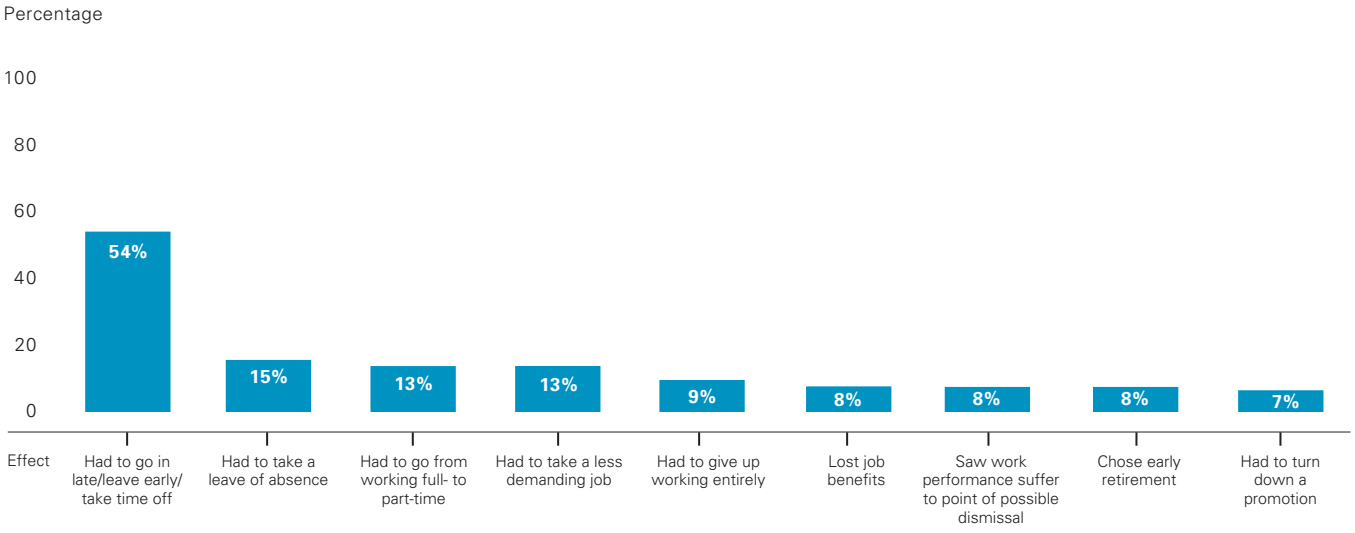
Seventy-four percent of caregivers of people with Alzheimer's disease and other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver.[A17] Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor.[195] Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse.[178,211] Data from the 2009 and 2010 BRFSS caregiver surveys found that 7 percent of dementia caregivers say the greatest difficulty of caregiving is that it creates or aggravates their own health problems compared with 2 percent of other caregivers.[175] Other studies suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.[212]

Physiological Changes

The chronic stress of caregiving is associated with physiological changes that could increase the risk of developing chronic conditions. For example, a series of recent studies found that under certain conditions some Alzheimer's caregivers were more likely to have elevated biomarkers of cardiovascular disease risk and impaired kidney function risk than those who were not caregivers.[213-218]

Caregivers of a spouse with Alzheimer's or another dementia are more likely than married non-caregivers to have physiological changes that may reflect declining physical health, including high levels of stress hormones,[219] reduced immune function,[193,220] slow wound healing,[221] and increased incidence of

figure 10 | 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.[A17]

hypertension,[222] coronary heart disease[223] 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.[224] Overall, the literature is fairly consistent in suggesting that the chronic stress of dementia care can have potentially negative influences on caregiver health.

Health Care Utilization

The physical and emotional impact of dementia caregiving is estimated to have resulted in $9.3 billion in health care costs in the United States in 2012.[A20] Table 6 (pages 35-36) shows the estimated higher health care costs for Alzheimer's and dementia caregivers in each state.

Dementia caregivers were more likely to visit the emergency department or be hospitalized in the preceding six 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.[225]

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 dementia in their medical records were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers.[226] However, other studies have found that caregivers have lower mortality rates than non-caregivers.[227-228] One study reported that higher levels of stress were associated with higher rates of mortality in both caregivers and non-caregivers.[228] 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 Alzheimer's disease or another dementia may not consistently result 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 of these factors are important to consider when understanding the health impact of caring for a person with dementia.[229]

Caregiver Employment

Among caregivers of people with Alzheimer's disease and other dementias, 75 percent reported being employed at any time since assuming care responsibilities. Eighty-one percent of Alzheimer's caregivers under the age of 65 were employed while 35 percent age 65 and over were employed.[178] Employed dementia caregivers indicate having to make major changes to their work schedules because of their caregiving responsibilities. Fifty-four percent said they had to go in late, leave early or take time off, and 15 percent had to take a leave of absence while caregiving.[A17] Other work-related changes pertaining to caregiving are summarized in Figure 10.

Caregiver Interventions That May Improve Caregiver Outcomes

Intervention strategies to support family caregivers of people with Alzheimer's disease have been developed and evaluated. The types and focus of these interventions are summarized in Table 7.[230]

In general, these interventions aim to ameliorate negative aspects of caregiving with the goal of improving the health and well-being 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, interventions that approach dementia care as an issue for the entire family, and interventions that train dementia caregivers in the management of behavioral problems.[231-234] Multidimensional interventions appear particularly effective. These approaches combine individual consultation, family sessions and support, and ongoing assistance to help caregivers manage changes that occur as dementia progresses. Examples of successful multidimensional interventions are the New York University Caregiver Intervention,[235-236] the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II protocol,[198,230,237-239] and the Savvy Caregiver program.[240-242] Other multidimensional approaches that recently have demonstrated promising results include Partners in Dementia Care, a care coordination program that enhances access to needed services and strengthens the family care support network,[243] and Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS), a program that incorporates caregiver skills training with cognitive rehabilitation for the person with dementia.[244]

Although less consistent in their demonstrated benefits, support group strategies and respite services such as adult day programs have the potential to offer encouragement or relief to enhance caregiver outcomes. The effects of pharmacologic therapies for treating symptoms of dementia (for example, acetylcholinesterase inhibitors, memantine, antipsychotics and antidepressants) also appear to modestly reduce caregiver stress.[245] Mindfulness-based stress reduction (a strategy to reduce stress through meditation techniques that create attention focused on the moment and non-judgmental awareness) has shown recent promise as an effective approach to reduce dementia caregiver distress.[246] Structured, group-based psychoeducational programs that include both family care providers and care recipients with early-stage Alzheimer's disease have helped to improve feelings of preparation and confidence among family members and emotional well-being among people with early-stage Alzheimer's disease.[247-249]

Several sources[230,234-235,250-255] recommend that clinicians identify the risk factors and outcomes

table 7 | Type and Focus of Caregiver Interventions

Type of Intervention	Description
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational	Includes a structured program that provides information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (that is, cognitive impairment, behavioral symptoms and care-related needs). Includes lectures, discussions and written materials and is led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Support groups	Less structured than psychoeducational or therapeutic interventions, support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation.
Respite	Planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite for a certain number of weekly hours.
Training of the person with dementia	Memory clinic or similar programs aimed at improving the competence of the care recipient, which may also have a positive effect on caregiver outcomes.
Psychotherapeutic approaches	Involves the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Multicomponent approaches	Intensive support strategies that combine multiple forms of interventions, such as education, support and respite into a single, long-term service (often provided for 12 months or more).

Created from data from Sörensen et al.[230] and Pinquart et al.[260]

perceived as important to each caregiver and select interventions appropriate for them.[234] More work is needed, however, to test the efficacy of intervention programs among different caregiver groups to ensure their benefits for caregivers across diverse clinical, racial, ethnic, socioeconomic and geographic contexts.[256]

Caregiver Interventions and Their Effects on People with Alzheimer's Disease

Several reviews have sought to determine whether caregiver interventions improve outcomes for people with Alzheimer's disease or other dementias. One recent review found that caregiver-focused interventions are effective in reducing behavioral or psychiatric problems in people with dementia.[113] Multidimensional interventions for dementia caregivers have also been shown to prevent or delay nursing home admission.[112,257-258] However, it is important to note that these conclusions are not uniform; a recent review that restricted its scope to high-quality evaluations (that is, randomized controlled trials) indicated a lack of consistent effects of caregiver interventions on people with Alzheimer's disease and other dementias.[259]

Paid Caregivers

Direct-Care Workers for People with Alzheimer's Disease 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 Alzheimer's disease and other dementias). In nursing homes, nursing assistants make up the majority of staff who work with cognitively impaired residents.[261-263] Most nursing assistants are women and they come from increasingly diverse ethnic, racial and international backgrounds. 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.[262,264] 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.[262] Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.[265] Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest, positive benefits.[266-267]

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 others.[265] 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.[265] 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.[268] In 2010, there were 4,278 physicians practicing geriatric medicine in the United States.[269] An estimated 36,000 geriatricians will be required to adequately meet the needs of older adults in the United States by 2030.[265] 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 percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics.[265] Similarly, although 73 percent of social workers serve clients age 55 and older and about 8 percent of social workers are employed in long-term care settings, only 4 percent have formal certification in geriatric social work.[265] While the complex care challenges of many people with dementia often require the simultaneous expertise of professionals trained in multiple care disciplines, there is a continuing need for interprofessional collaboration and education to enhance the overall care of people with dementia.[270]

Use and Costs of Health Care, Long-Term Care and Hospice

Medicare and Medicaid
are expected to pay

in 2014 for health care,
long-term care and hospice
for people with Alzheimer's
and other dementias.

The costs of health care, long-term care and hospice for individuals with Alzheimer's disease and other dementias are substantial, and Alzheimer's disease is one of the costliest chronic diseases to society.[173]

Total payments in 2014 (in 2014 dollars) for all individuals with Alzheimer's disease and other dementias are estimated at $214 billion (Figure 11). Medicare and Medicaid are expected to cover $150 billion, or 70 percent, of the total health care and long-term care payments for people with Alzheimer's disease and other dementias. Out-of-pocket spending is expected to be $36 billion, or 17 percent of total payments.[A21] Unless otherwise indicated, all costs in this section are reported in 2013 dollars.[A22]

Payments for Health Care, Long-Term Care and Hospice

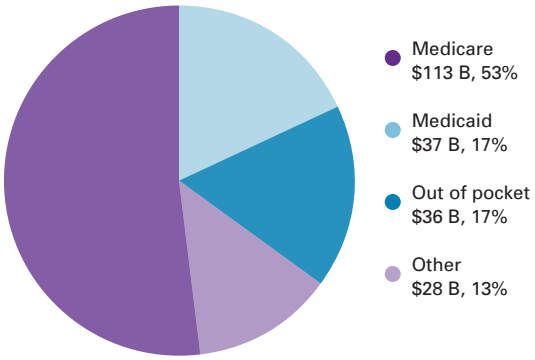
Table 8 reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries with and without Alzheimer's disease and other dementias. Total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer's and other dementias were three times as great as payments for other Medicare beneficiaries in the same age group ($46,669 per person for those with dementia compared with $14,772 per person for those without dementia).[155],[A23]

Twenty-nine percent of older individuals with Alzheimer's disease and other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia.[155] Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs for the Medicaid program. Average Medicaid payments per person for Medicare beneficiaries with Alzheimer's disease and other dementias ($10,771) were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's disease and other dementias ($561) (Table 8).[155]

Despite these and other sources of financial assistance, individuals with Alzheimer's disease 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. Medicare beneficiaries age 65 and older with Alzheimer's and other dementias paid $9,970 out of pocket on average for health care and long-term care services not covered by other sources (Table 8).[155] Average per-person out-of-pocket payments were highest ($19,196 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 Alzheimer's disease and other dementias living in the community.[155]

figure 11 — Aggregate Cost of Care by Payer for Americans Age 65 and Older with Alzheimer's Disease and Other Dementias, 2014*

Total cost: $214 Billion (B)



*Data are in 2014 dollars.

Created from data from the application of The Lewin Model[A21] to data from the Medicare Current Beneficiary Survey for 2008.[155] "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

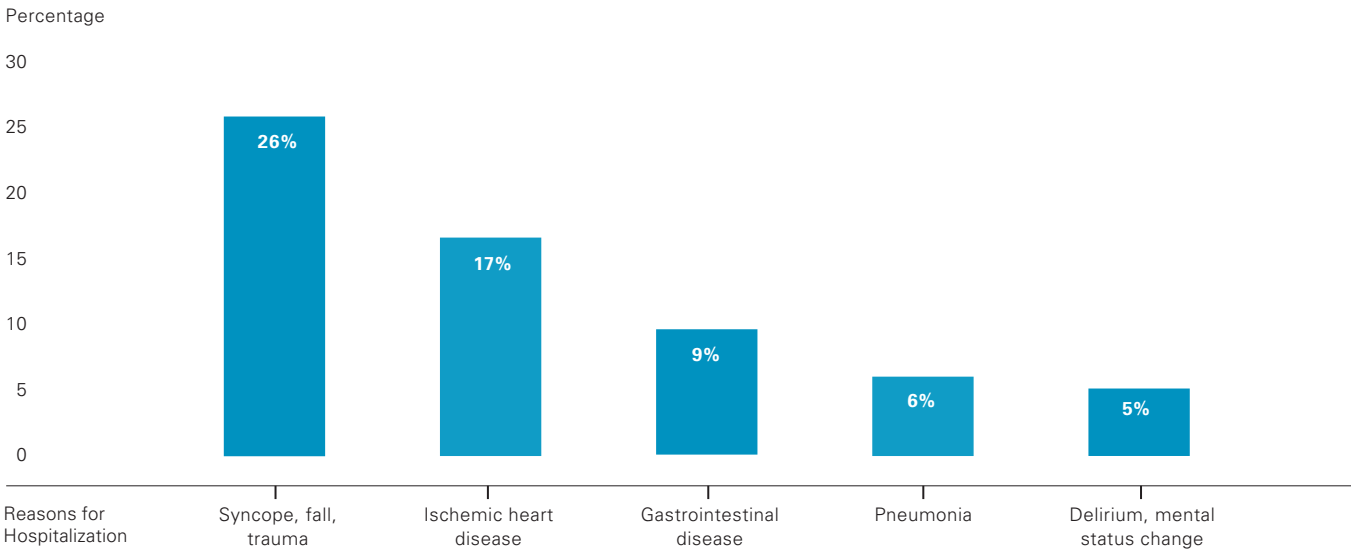
table 8 | Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's Disease and Other Dementias and by Place of Residence, in 2013 Dollars

	Beneficiaries with Alzheimer's Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer's Disease and Other Dementias
Payment Source	Overall	Community-Dwelling	Residential Facility	
Medicare	$21,095	$18,787	$24,319	$8,005
Medicaid	10,771	237	25,494	561
Uncompensated	290	417	114	328
HMO	1,058	1,642	241	1,543
Private insurance	2,407	2,645	2,074	1,619
Other payer	964	174	2,067	153
Out of pocket	9,970	3,370	19,196	2,431
Total*	**46,669**	**27,465**	**73,511**	**14,772**

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

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.[155]

figure 12 | Reasons for Hospitalization of Individuals with Alzheimer's Disease: Percentage of Hospitalized Individuals by Admitting Diagnosis*



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

Created from data from Rudolph et al.[272]

Recently, researchers evaluated the *incremental* health care and caregiving costs of dementia (that is, the costs specifically attributed to dementia for people with the same coexisting medical conditions and demographic characteristics).[173,271] One group of researchers found that the incremental health care and nursing home cost for those with dementia was $31,141.[173, A24]

Use and Costs of Health Care Services

People with Alzheimer's disease and other dementias have more than three times as many hospital stays per year as other older people.[155] 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 artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD), stroke or cancer who also have Alzheimer's and other dementias have higher use and costs of health care services than people with these medical conditions but no coexisting dementia.

Use of Health Care Services

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

- *Hospital.* There are 780 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries age 65 and older without these conditions.[155] The most common reasons for hospitalization of people with Alzheimer's disease include syncope (fainting), fall and trauma (26 percent); ischemic heart disease (17 percent); and gastrointestinal disease (9 percent) (Figure 12).[272]
- *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.[273] There are 349 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 39 stays per 1,000 beneficiaries for people without these conditions.[155]
- *Home health care.* Twenty-three percent of Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias have at least one home health visit during the year, compared with 10 percent of Medicare beneficiaries age 65 and older without Alzheimer's and other dementias.[139]

Costs of Health Care Services

With the exception of prescription medications, average per-person payments for health care services (hospital, physician and other medical provider, nursing home, skilled nursing facility, hospice and home health care) were higher for Medicare beneficiaries with Alzheimer's disease and other dementias than for other Medicare beneficiaries in the same age group (Table 9).[155] The fact that only payments for prescription drugs are lower for those with Alzheimer's and other dementias underscores the lack of effective treatments available to those with dementia.

table 9 Average Annual Per-Person Payments for Health Care Services Provided to Medicare Beneficiaries Age 65 and Older with and without Alzheimer's Disease and Other Dementias, in 2013 Dollars

Service	Beneficiaries with Alzheimer's Disease and Other Dementias	Beneficiaries without Alzheimer's Disease and Other Dementias
Inpatient hospital	$10,748	$4,321
Medical provider*	6,220	4,124
Skilled nursing facility	4,072	474
Nursing home	18,898	840
Hospice	1,880	184
Home health	1,507	486
Prescription medications**	2,799	2,853

*"Medical provider" includes physician, other medical provider and laboratory services, and medical equipment and supplies.
**Information on payments for prescription drugs is only available for people who were living in the community; that is, not in a nursing home or assisted living facility.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.[155]

Use and Costs of Health Care Services for Individuals Newly Diagnosed with Alzheimer's Disease

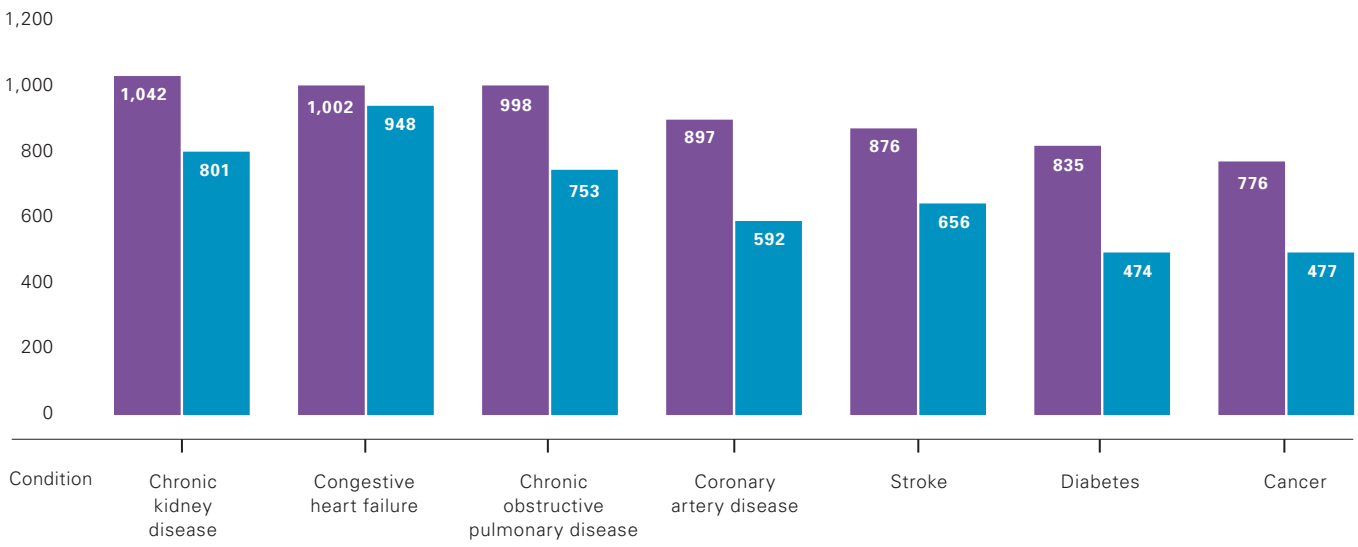
Those newly diagnosed with Alzheimer's disease have higher health care use and costs in the year prior to diagnosis and in the two subsequent years than those who do not receive this diagnosis, according to a study of Medicare Advantage enrollees (that is, Medicare beneficiaries enrolled in a private Medicare health insurance plan).[274] Enrollees with a new diagnosis of Alzheimer's disease had $2,472 more in health care costs (medical and pharmacy) in the year prior to diagnosis, $9,896 more in costs in the year following diagnosis, and $6,109 more in costs in the second year following diagnosis. While more work is needed to understand the underlying drivers of increased utilization immediately prior to and after receiving a diagnosis of Alzheimer's disease, the additional health care use may be attributed to treatments related to the cognitive impairment or coexisting medical conditions, and care related to diagnosing the disease.

table 10 **Specific Coexisting Medical Conditions Among Medicare Beneficiaries Age 65 and Older with Alzheimer's Disease and Other Dementias, 2009**

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

Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.[139]

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



Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.[139]

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

Medicare beneficiaries with Alzheimer's disease and other dementias are more likely than those without dementia to have other chronic conditions.[139] Table 10 reports the proportion of people with Alzheimer's disease and other dementias who have certain coexisting medical conditions. In 2009, 30 percent of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 29 percent also had diabetes, 22 percent also had congestive heart failure, 17 percent also had chronic kidney disease and 17 percent also had chronic obstructive pulmonary disease.[139]

People with Alzheimer's and other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Figure 13).[139] Research has

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 Alzheimer's Disease and Other Dementias, 2009, in 2013 Dollars*

Medical Condition by Alzheimer's Disease/Dementia (AD/D) Status	Average Per-Person Medicare Payment					
	Total Medicare Payments	Hospital Care	Physician Care	Skilled Nursing Facility Care	Home Health Care	Hospice Care
Coronary artery disease						
With AD/D	**27,033**	9,769	1,701	4,309	2,721	2,348
Without AD/D	**16,768**	7,020	1,301	1,160	1,171	342
Diabetes						
With AD/D	**26,381**	9,296	1,593	4,177	2,803	2,121
Without AD/D	**14,581**	5,730	1,121	1,193	1,111	240
Congestive heart failure						
With AD/D	**25,907**	11,095	1,756	4,777	2,848	2,944
Without AD/D	**29,756**	11,359	1,755	2,589	2,244	833
Chronic kidney disease						
With AD/D	**31,892**	12,246	1,884	4,807	2,659	2,560
Without AD/D	**24,538**	10,264	1,649	1,983	1,646	530
Chronic obstructive pulmonary disease						
With AD/D	**29,326**	10,914	1,793	4,709	2,821	2,651
Without AD/D	**20,072**	8,554	1,474	1,716	1,516	665
Stroke						
With AD/D	**27,517**	9,625	1,653	4,521	2,578	2,759
Without AD/D	**19,755**	7,461	1,405	2,317	1,891	652
Cancer						
With AD/D	**25,322**	8,653	1,552	3,624	2,221	2,890
Without AD/D	**16,572**	5,871	1,190	981	788	593

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

Created from unpublished data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009.[139]

demonstrated that Medicare beneficiaries with Alzheimer's disease and other dementias have more potentially avoidable hospitalizations for diabetes complications and hypertension, meaning that the hospitalizations could possibly be prevented through proactive care management in the outpatient setting.[275]

Similarly, Medicare beneficiaries who have Alzheimer's and other dementias and a serious coexisting medical condition have higher average per-person payments for most health care services than Medicare beneficiaries who have the same medical condition without dementia. Table 11 shows the average per-person Medicare payments for seven specific medical conditions among beneficiaries who have Alzheimer's disease and other dementias and beneficiaries who do not have dementia.[139] Medicare beneficiaries with dementia had higher average per-person payments in all categories except total Medicare and hospital care payments for individuals with congestive heart failure.

Use and Costs of Long-Term Care Services

An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias.[155,276] Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone.[155] People with Alzheimer's disease 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 in more than one of these settings at different times in the often long course of the disease. Given the high average costs of these services (adult day services, $72 per day;[276] assisted living, $43,756 per year;[276] and nursing home care, $83,230 to $92,977 per year),[276] 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.

Use of Long-Term Care Services by Setting

Most people with Alzheimer's disease and other dementias who live at home receive unpaid help from family members and friends, but some also receive paid home- and community-based services, such as personal care and adult day care. A study of older people who needed help to perform daily activities — such as dressing, bathing, shopping and managing money — found that those who also had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care.[277] 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.[277]

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

- *Home care.* According to state home care programs in Connecticut, Florida and Michigan, more than one-third (about 37 percent) of older people who receive primarily non-medical home care services, such as personal care and homemaker services, have cognitive impairment consistent with dementia.[278-280]
- *Adult day services.* At least half of elderly attendees at adult day centers have dementia.[281-282]
- *Assisted living.* Forty-two percent of residents in assisted living facilities (that is, housing that includes services to assist with everyday activities, such as medication management and meals) had Alzheimer's disease and other dementias in 2010.[283]
- *Nursing home care.* Of all Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias, 31 percent live in a nursing home.[155] Of all Medicare beneficiaries residing in a nursing home, 64 percent have Alzheimer's disease and other dementias.[155]
- *Alzheimer's special care units.* An Alzheimer's special care unit is a dedicated unit in a nursing home that has tailored services for individuals with Alzheimer's and other dementias. Nursing homes had a total of 75,876

table 12 | Total Nursing Home Beds and Alzheimer's Special Care Unit Beds by State, 2013

State	Total Beds	Alzheimer's Special Care Unit Beds	Alzheimer's Beds as a Percentage of Total Beds
Alabama	26,685	1,245	4.7
Alaska	778	37	4.8
Arizona	16,668	887	5.3
Arkansas	24,527	321	1.3
California	121,356	2,984	2.5
Colorado	20,462	2,078	10.2
Connecticut	27,837	1,691	6.1
Delaware	4,986	375	7.5
District of Columbia	2,766	70	2.5
Florida	83,145	3,880	4.7
Georgia	39,817	1,455	3.7
Hawaii	4,260	106	2.5
Idaho	5,842	226	3.9
Illinois	99,196	4,835	4.9
Indiana	59,480	6,166	10.4
Iowa	34,831	1,672	4.8
Kansas	25,643	422	1.6
Kentucky	26,161	541	2.1
Louisiana	35,592	1,652	4.6
Maine	7,020	640	9.1
Maryland	28,536	884	3.1
Massachusetts	48,640	3,874	8.0
Michigan	47,007	1,039	2.2
Minnesota	30,526	2,512	8.2
Mississippi	18,576	229	1.2
Missouri	55,138	4,487	8.1
Montana	6,713	542	8.1
Nebraska	15,936	1,278	8.0
Nevada	5,979	278	4.6
New Hampshire	7,513	592	7.9
New Jersey	52,281	1,008	1.9
New Mexico	6,716	510	7.6
New York	116,849	3,903	3.3
North Carolina	44,549	1,608	3.6
North Dakota	6,151	454	7.4
Ohio	91,785	3,630	4.0
Oklahoma	29,296	758	2.6
Oregon	12,267	259	2.1
Pennsylvania	88,200	6,351	7.2
Rhode Island	8,715	1,162	13.3
South Carolina	19,721	89	0.5
South Dakota	6,903	552	8.0
Tennessee	37,234	124	0.3
Texas	135,066	2,462	1.8
Utah	8,464	590	7.0
Vermont	3,199	195	6.1
Virginia	32,667	1,254	3.8
Washington	21,654	864	4.0
West Virginia	10,888	137	1.3
Wisconsin	34,960	2,663	7.6
Wyoming	2,984	305	10.2
U.S.	**1,702,165**	**75,876**	**4.4**

Created from data from the American Health Care Association.[284]

beds in Alzheimer's special care units in 2013, a decrease of 4 percent compared with the previous year.[284] These Alzheimer's special care unit beds accounted for 72 percent of all special care unit beds and 4.5 percent of all nursing home beds. Rhode Island has the largest percentage of Alzheimer's special care unit beds as a proportion of total beds (13.3 percent), while Tennessee has the smallest percentage of Alzheimer's special care unit beds (0.3 percent) (Table 12).

Recent research demonstrates that individuals with dementia often move between a nursing facility, hospital and home, rather than remaining in a nursing facility.[285] In a longitudinal study of primary care patients with dementia, researchers found that those discharged from a nursing facility were nearly equally as likely to be discharged home (39 percent) as discharged to a hospital (44 percent). Additionally, 74 percent of individuals admitted to a nursing facility came directly from a hospital. Individuals with dementia may also transition between a nursing facility and hospital or between a nursing facility, home and hospital, creating challenges for caregivers and providers to ensure that care is coordinated across settings. Other research has shown that nursing home residents frequently have burdensome transitions at the end of life, including admission to an intensive care unit in the last month of life, late enrollment in hospice and receipt of a feeding tube.[286] Care coordination for nursing home residents with advanced cognitive impairment, as measured by the number of care transitions, varies substantially across geographic regions of the United States.[287] Researchers also found that both the number of transitions between health care settings and the odds of having a feeding tube inserted at the end of life varied across the country. Furthermore, individuals with frequent transitions between health care settings were more likely to have feeding tubes at the end of life, even though feeding tube placement has little or no benefit.

Research has also demonstrated a decrease in the proportion of individuals with Alzheimer's disease who die in an acute care hospital, with end-of-life care shifting to home and nursing homes.[288] Additionally, more than twice as many individuals with the disease were receiving hospice care at the time of death in 2009 compared with 2000 (19.5 percent in 2000 versus 48.3 percent in 2009).

Demand for nursing home services and services from long-term care hospitals is increasing. Long-term care hospitals serve individuals whose acute medical conditions require long-term care. Individuals 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. Despite this increasing demand, there have been a number of restrictions on adding facilities and increasing the number of beds in existing facilities. In addition, the Medicare, Medicaid and SCHIP (State Children's Health Insurance Program) Extension Act of 2007 issued a three-year moratorium on both the designation of new long-term care hospitals and increases in Medicare-certified beds for existing long-term care hospitals.[289] This moratorium was in response to the need for Medicare to develop criteria for admitting beneficiaries to long-term care hospitals, where stays average more than 25 days.[290] The moratorium expired in late 2012.[289,291] In 2011, certificate-of-need programs were in place in 37 states to regulate the number of nursing home beds, and a number of these states had implemented a certificate-of-need moratorium to prevent growth in the number of beds and/or facilities.[292]

Costs of Long-Term Care Services

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

- *Home care.* In 2012, the average cost for a paid non-medical home health aide was $21 per hour, or $168 for an eight-hour day.[276]

- *Adult day centers*. In 2012, the average cost of adult day services was $72 per day. Ninety-five percent of adult day centers provided care for people with Alzheimer's disease and other dementias, and 2 percent of these centers charged an additional fee for these clients.[276]
- *Assisted living facilities*. In 2012, the average cost for basic services in an assisted living facility was $3,646 per month, or $43,756 per year. Seventy-two percent of assisted living facilities provided care to people with Alzheimer's disease and other dementias, and 52 percent had a specific unit for people with Alzheimer's and other dementias. In facilities that charged a different rate for individuals with dementia, the average rate was $4,937 per month, or $59,250 per year, for this care.[276]
- *Nursing homes*. In 2012, the average cost for a private room in a nursing home was $255 per day, or $92,977 per year. The average cost of a semi-private room in a nursing home was $228 per day, or $83,230 per year. Approximately 80 percent of nursing homes that provide care for people with Alzheimer's disease charge the same rate for those with Alzheimer's as they do for those without the disease. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with Alzheimer's disease was $13 higher ($268 per day, or $97,820 per year), and the average cost for a semi-private room was $8 higher ($236 per day, or $86,140 per year).[276] Fifty-five percent of nursing homes that provide care for people with Alzheimer's disease and other dementias had separate Alzheimer's special care units.[276]

Affordability of Long-Term Care Services

Few individuals with Alzheimer's disease 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 Alzheimer's and other dementias specifically, but 50 percent of Medicare beneficiaries had incomes of $22,604 or less, and 25 percent had incomes of $13,616 or less in 2010.[293-294]
- Fifty percent of Medicare beneficiaries had retirement accounts of $2,236 or less, 50 percent had financial assets of $32,319 or less, and 50 percent had total savings of $56,224 or less, equivalent to less than one year of nursing home care in 2010.[294]

Long-Term Care Insurance

In 2010, about 7.3 million people had long-term care insurance policies.[295] Private health and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2009, representing $19 billion of the $271 billion in long-term care spending.[296] 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.[297]

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 of their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only makes up the difference if the nursing home resident cannot pay the full cost of care or has a financially dependent spouse.

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

long-term care was allocated to institutional care, and the remaining 42 percent was allocated to home and community-based services.[296]

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be $37 billion in 2014 (in 2014 dollars).[A21] Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were 19 times as great as Medicaid payments for other Medicare beneficiaries. Much of the difference in payments for beneficiaries with Alzheimer's and other dementias is due to the costs associated with long-term care (nursing homes and other residential care facilities, such as assisted living facilities) and the greater percentage of people with dementia who are eligible for Medicaid. Medicaid paid an average of $25,494 per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility compared with $237 for those with the diagnosis living in the community and an average of $561 for older adults without the diagnosis living in the community and long-term care facilities (Table 8, page 44).[155]

In a study of Medicaid beneficiaries with a diagnosis of Alzheimer's disease, researchers found significant differences in the cost of care by race/ethnicity. These results demonstrated that non-Hispanic blacks had significantly higher cost of care than whites or Hispanics, primarily due to more inpatient care and greater severity of illness. These differences may be attributable to delays in accessing timely primary care, lack of care coordination and duplication of services across providers. However, more research is needed to understand the reasons for this health care disparity.[298]

Use and Costs of Hospice Care

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

In 2009, 6 percent of people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (61,146 people).[299] An additional 11 percent of those admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (119,872 people).[299] Hospice length of stay has increased over the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of Alzheimer's disease increased from 67 days in 1998 to 106 days in 2009.[299] The average length of stay for hospice beneficiaries with a primary diagnosis of non-Alzheimer's dementia increased from 57 days in 1998 to 92 days in 2009.[299] Average per-person hospice care payments for beneficiaries with Alzheimer's disease and other dementias were 10 times as great as for all other Medicare beneficiaries ($1,880 per person compared with $184 per person).[155]

Projections for the Future

Total annual payments for health care, long-term care and hospice care for people with Alzheimer's disease and other dementias are projected to increase from $214 billion in 2014 to $1.2 trillion in 2050 (in 2014 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.[A21]

Special Report:
Women and Alzheimer's Disease

Women are

times

more likely than men
to provide "on duty" care
24 hours a day in the
late stage of the disease.

In 2010, the Alzheimer's Association in partnership with Maria Shriver and *The Shriver Report*, conducted a groundbreaking poll with the goal of exploring the compelling connection between Alzheimer's disease and women. Data from that poll were published in *The Shriver Report: A Woman's Nation Takes on Alzheimer's,*[300] which also included essays and reflections that gave personal perspectives to the poll's numbers. For the first time, that report revealed not only the striking impact of the disease on individual lives, but also its especially strong effects on women — women living with the disease, as well as women who are caregivers, relatives, friends and loved ones of those directly affected.

Inspired by compelling findings published in *The Shriver Report*, the Alzheimer's Association conducted a follow-up poll in 2014[A17] to continue exploring how Alzheimer's disease affects the lives of Americans. This Special Report reveals results of this new poll with a focus on women, and it discusses recent research discoveries on Alzheimer's disease and gender.

Incidence and Prevalence

As discussed in the Prevalence section (pages 15–23), almost two-thirds of Americans with Alzheimer's disease are women. The prevailing view as to why women account for such a high percentage of existing cases is that, on average, women have longer lifespans than men, and are thereby more likely to reach an age of high risk for Alzheimer's. As noted in the Prevalence section, there is no evidence that women are more likely than men to develop dementia at any given age. Nevertheless, various explanations have been proposed to explain the differing prevalence of Alzheimer's disease between women and men.

Earlier in the report (page 19), incidence data from the Framingham Study were presented showing that, at age 65, women have a higher lifetime risk of Alzheimer's disease than men. Another type of analysis from the Framingham Study was published very recently; the goal of that analysis was to explore how the incidence of Alzheimer's disease or dementia was affected by other causes of death in people between ages 45 and 65.[301] The study confirmed that men have a higher rate of death from cardiovascular disease than women in that age range. Furthermore, because a high risk of cardiovascular disease is also associated with a high risk of Alzheimer's disease, the researchers concluded that the death of men from cardiovascular disease between ages 45 and 65 was reducing the pool of men at high risk for Alzheimer's disease at later ages. They estimated that this effect explained 20 to 50 percent of the difference in incidence of Alzheimer's disease among men and women older than 65.

Other possible explanations for the higher incidence and prevalence of Alzheimer's disease among women have been proposed,[301-302] but definitive scientific evidence is sparse. There are well-established differences in brain structure between men and women, some of which may be associated with an increased risk of cognitive decline or dementia. Furthermore, women and men exhibit different forms of behavioral changes associated with the disease,[303] possibly suggesting that the disease affects male and female brains in different ways. This concept is supported by recent evidence from imaging studies suggesting that the disease causes structural changes in the brain that differ between men and women.[304]

Women and men also have different hormonal physiology, and sex-specific hormones are known to have effects on the brain. There are also differences in the molecular characteristics of cells in women and men, including genetic differences. Several genetic variants have been shown to be associated with an increased risk of Alzheimer's disease, including the epsilon4 variant of the apolipoprotein E gene (APOE-ε4, page 9). This gene variant is the strongest genetic risk factor yet identified

for late-onset Alzheimer's disease. Increasing evidence suggests that the higher risk for Alzheimer's disease associated with APOE-ε4 is more pronounced in women than men.[305]

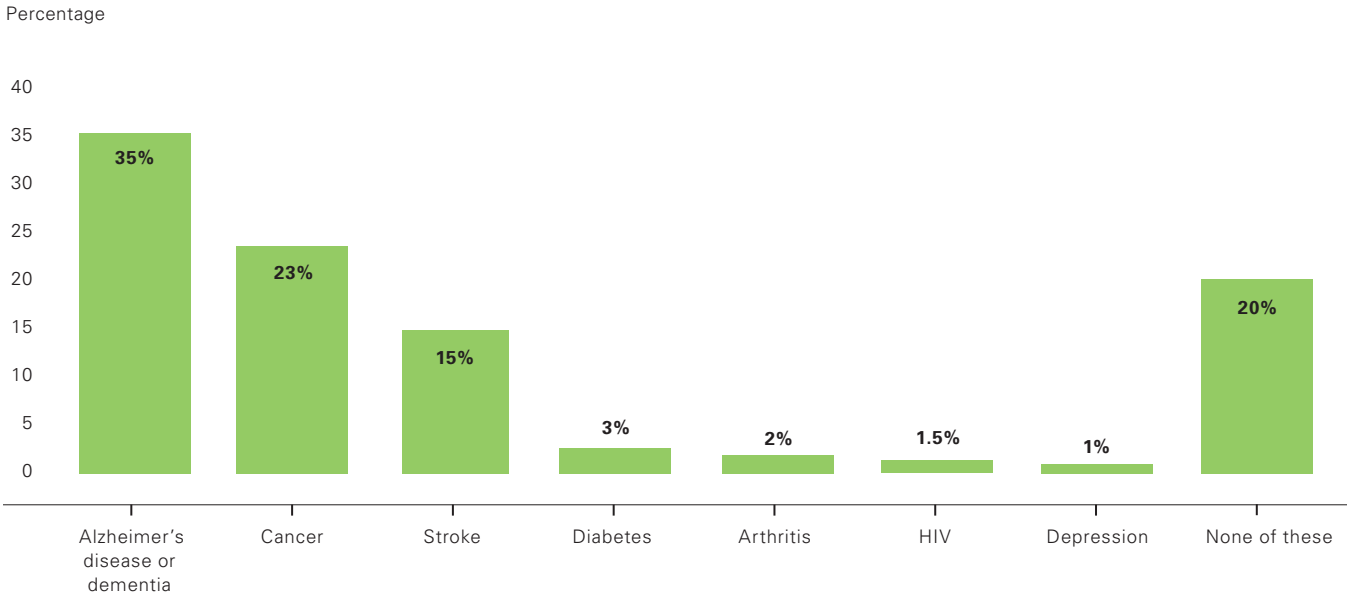
Several studies have found brain changes associated with Alzheimer's disease or MCI that differ between men and women, including a recent study using brain imaging in which specific brain regions changed at different rates in women versus men.[306] At this time, however, much more research is needed to define biological differences in the disease process between women and men.

Knowledge and Attitudes About Alzheimer's Disease and Dementia

The 2014 Alzheimer's Association Women and Alzheimer's Poll[A17] questioned 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's disease and dementia. Adults identified as informal caregivers were asked additional questions about their caregiving experiences (see the subsequent section on Caregiving).

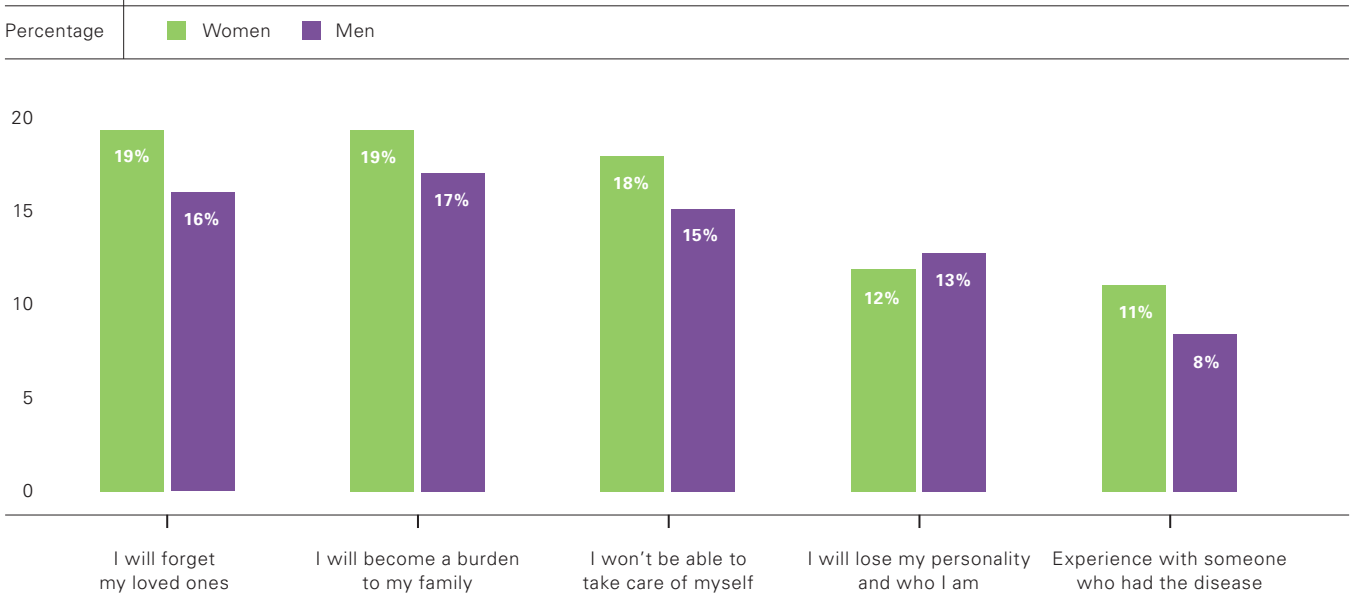
Peggye Dilworth-Anderson, Ph.D., is Professor of Health Policy and Management in the Gillings School of Global Public Health at the University of North Carolina-Chapel Hill. Her areas of expertise include family caregiving to dementia patients, minority aging and health and chronic disease management in cultural context. Dr. Dilworth-Anderson is a past board member of the Alzheimer's Association and recipient of the Alzheimer's Association Ronald and Nancy Reagan Award for her innovative research.

figure 14 | Responses of Americans Age 60 or Older When Asked Which Condition They Were Most Afraid of Getting



Created from data from the YouGov survey.[A25]

figure 15 | Why Does the Possibility of Getting Alzheimer's Disease Frighten You?



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

Fifty-six percent of all respondents reported knowing someone with Alzheimer's. Those who knew someone with the disease were also more likely to have heard or read about the disease than those who did not know someone with the disease.

As discussed in the Overview, heredity (family history) is only one of many risk factors for Alzheimer's disease (page 9), and many cases occur in people with little or no family history. However, 24 percent of poll respondents agreed with the erroneous statement that Alzheimer's must run in their family for them to be at risk. The rates of agreement were similar among women and men, but there were large differences across ethnic groups. Among people who self-identified as Latino or Asian, 33 percent and 45 percent, respectively, agreed with this statement. These findings reveal a need for additional education about risk factors for Alzheimer's disease across all sectors of the population, and an even greater need in certain ethnic groups.

Women showed higher levels of concern than men that they or someone in their immediate family would get Alzheimer's disease or dementia, with 56 percent of women and 44 percent of men saying they were "very concerned" about that possibility. When asked if the idea of getting Alzheimer's disease "frightened" them, 58 percent of women said yes, compared with 43 percent of men. These findings are consistent with a recent survey[A25] of people age 60 and older conducted by YouGov, which found that Alzheimer's disease or dementia was more feared than other chronic conditions, including cancer, heart disease and stroke (Figure 14, page 55).

The 2014 Alzheimer's Association poll also asked respondents about the aspects of Alzheimer's disease that frightened them most. The five most common answers are shown in Figure 15 (multiple responses were allowed). Overall, women and men gave similar responses to this question.

Concern or fear about the possibility of getting Alzheimer's disease may have psychological or behavioral consequences, but those consequences are not well understood, and more research into this issue has been recommended.[302] Excessive fear or concern

about developing a chronic condition can be associated with unproductive anxiety, chronic stress and ill-advised behaviors, such as seeking unnecessary testing or treatment, or attempting to ward off the disease by using unproven and potentially dangerous "remedies." On the other hand, some degree of concern may be beneficial as it may promote better education, appropriate screening and healthful behaviors such as physical activity and a healthy diet.

In the 2014 Alzheimer's Association poll, 26 percent of women had thought about what care options might be available to them if they were to get Alzheimer's or dementia. Only 19 percent of men had thought about potential care options. Caregivers of someone with Alzheimer's or dementia, and especially women caregivers, were much more likely to have thought about potential care options (women, 48 percent, and men, 25 percent).

When asked about the care options they would prefer if they were to get Alzheimer's or dementia, women and men gave similar responses. About 36 percent would prefer to be taken care of at home by a spouse or children, and nearly the same percentage (38 percent) would want to be placed in an assisted living home that specializes in Alzheimer's care. Fewer (20 percent) stated that they would want to receive care in their own home from a paid caregiver.

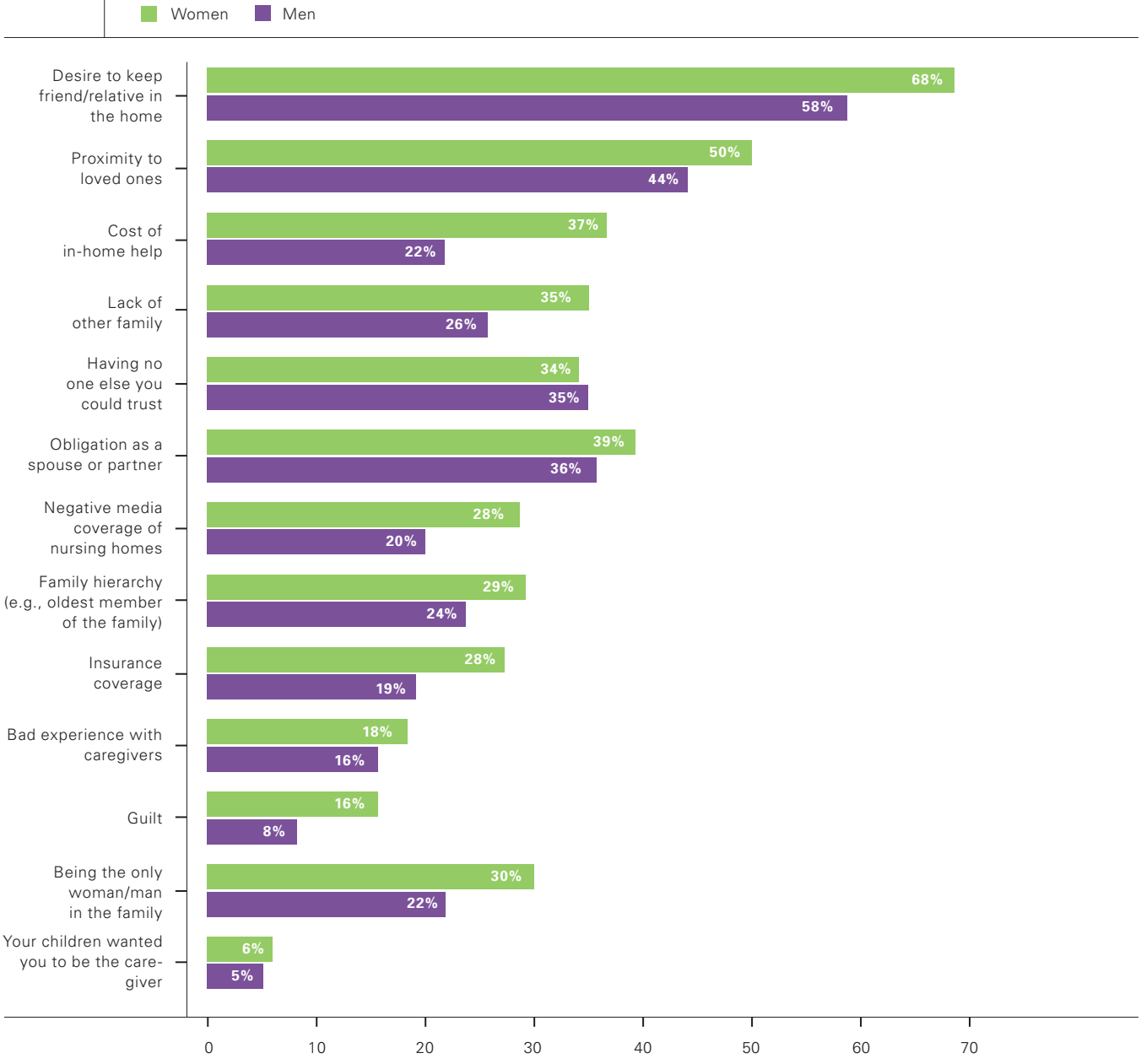
Caregiving

In the 2014 Alzheimer's Association poll, 512 people[A26] identified themselves as providing the majority of care for someone (not living in a residential care facility) with Alzheimer's disease or dementia, or equally sharing those responsibilities with another person. Of these informal caregivers, 63 percent were women, consistent with *The Shriver Report* and other studies that have found that women constitute about 60 percent to 70 percent of all informal caregivers for seniors.[177,178,184,300,307-308] Because many people do not report the care of an ailing spouse as caregiving, and because it is more common for a wife to be caring for an ailing husband than the converse, women may account for even more informal caregiving than these studies suggest.[307]

Lisa P. Gwyther, MSW, LCSW, is an associate professor in the Duke Department of Psychiatry and Behavioral Sciences and a Senior Fellow of Duke's Center for the Study of Aging and Human Development. A social worker with more than 40 years of experience in aging and Alzheimer's services, Gwyther started the Duke Center for Aging's Alzheimer's Family Support Program where she continues to serve as director. Gwyther is a past president of the Gerontological Society of America.

Many factors influence how, why and when a person becomes a caregiver for someone with Alzheimer's or dementia. In the 2014 Alzheimer's Association poll, 37 percent of caregivers agreed with the statement, "I had no choice in becoming a caregiver." A higher percentage of female caregivers agreed with that statement (39 percent) than male caregivers (33 percent), consistent with previous studies.[184,300] These findings have important implications for the caregiver's experience and the perceived burden of caregiving. For example, caregivers who believed they had no choice in accepting the caregiving role, or who felt captured by that role, perceived the emotional stress and burden of caregiving to be significantly higher than caregivers who felt they had a choice.[309-310] Research indicates that women who anticipated becoming caregivers for their aging parents were better able to adapt to their caregiving role than those who become caregivers unexpectedly.[311]

figure 16 Factors Cited by Caregivers as Having "A Lot" of Influence on Their Decision to Assume Caregiving Responsibilities



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

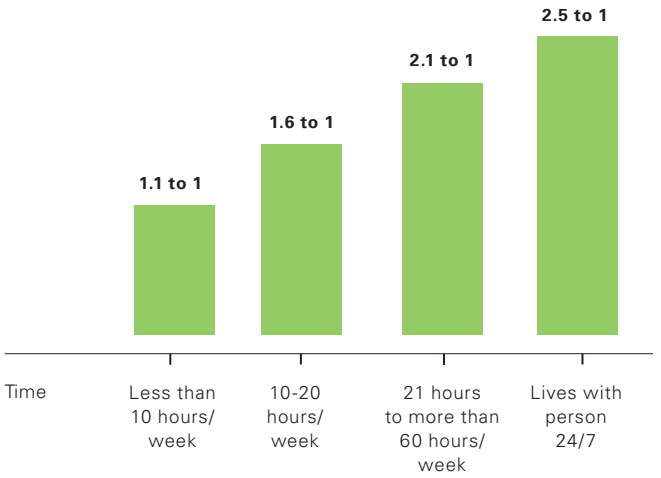
Like the 2010 poll, the 2014 Alzheimer's Association poll explored other factors that influenced why respondents became caregivers for someone with Alzheimer's disease or dementia. The results of the 2014 poll are shown in Figure 16, and are similar to the results from the 2010 poll. In both polls, the factors most frequently cited has having "a lot" of importance were the desire to keep the care recipient in their home and the proximity of the caregiver to the care recipient. Women and men shared many values regarding the factors affecting their decisions to become caregivers. The factors with the largest differences were desire to keep the care recipient in their home, cost of in-home help, insurance coverage and guilt.

In the 2014 Alzheimer's Association poll, informal caregivers were asked about the number of hours they spent each week performing caregiving duties. About half of all caregivers spent 20 hours or less each week performing those duties. However, there is a distinct group of caregivers who live with the care recipient and are "on duty" as caregivers 24 hours a day, 7 days a week. They account for about 23 percent of all caregivers. These full-time caregivers are much more likely to be women than men. Figure 17 shows ratios of female to male caregivers in different categories according to the amount of time spent in caregiving activities each week. Among caregivers reporting less than 10 hours per week of caregiving activity, the ratio of women to men was 1.1 to 1, indicating that there were 1.1 female caregivers for every male caregiver in that category. As the amount of time dedicated to caregiving activity increased, the ratio of female to male caregivers increased in a marked and step-wise manner. Among caregivers spending 21 to more than 60 hours per week, there were more than 2 women for every man. Among caregivers who live with the care recipient and are on duty 24 hours a day, there were 2.5 women for every man.

These results of the 2014 poll are similar to results of a 2008 Canadian poll, a 2009 NAC/AARP poll and the 2010 Alzheimer's Association poll.[178,300,307] Considered together, these studies support the conclusion that

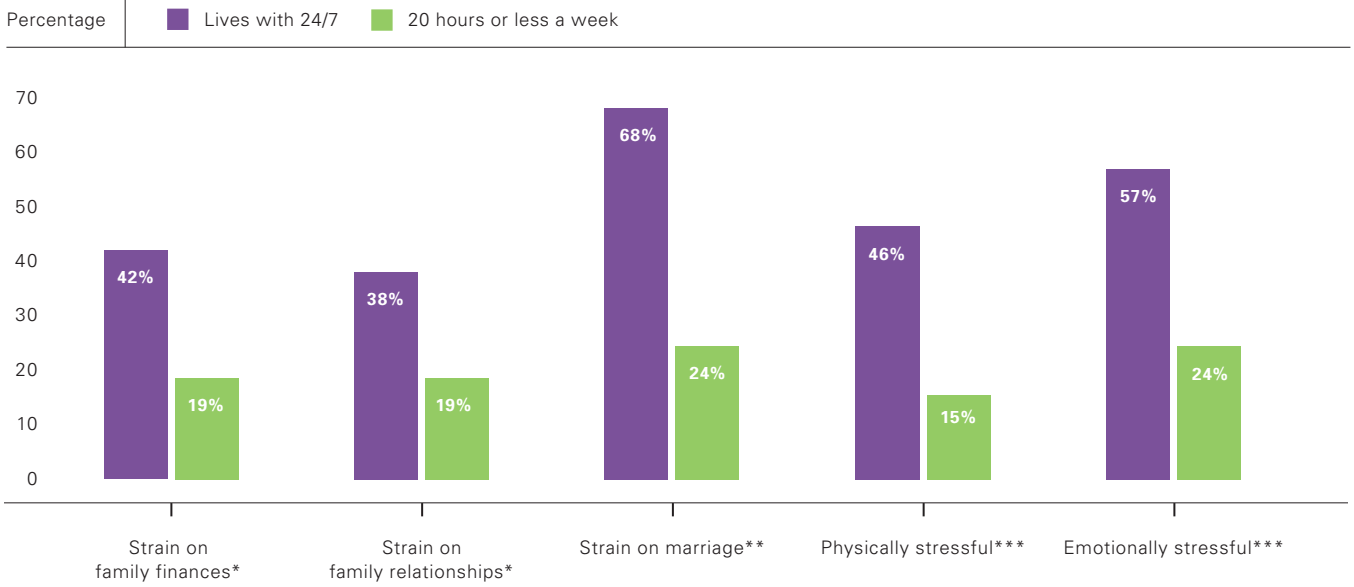
Darlene Edwards has been a caregiver to her mother, Pearl Hopkins, who is living with Alzheimer's disease, for 3 years. Edwards considers herself to be the "CEO of her mother's care," coordinating nearly constant care among family members in addition to her full-time job. Edwards has attended the Alzheimer's Association Advocacy Forum where she met with her legislators about making Alzheimer's a national priority. She and her mother also participated in a national advertising campaign to raise awareness of Alzheimer's disease.

figure 17 Ratios of the Number of Female to Male Caregivers According to the Amount of Time Spent Caregiving Each Week



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

figure 18 | Burdens of Caregiving Among Women Providing Around-the-Clock Informal Care or 20 Hours or Less of Informal Care for Someone with Alzheimer's Disease or Dementia



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

* A "great deal" or "good amount" of strain reported.
** Responded "Yes" when questioned whether caregiving was causing marital strain.
*** Responded 5 (very stressful) when asked to rate stress on a scale of 1-5.

women are substantially more likely than men to assume intensive, time-consuming caregiving roles such as those in which the care recipient lives in the caregiver's household and requires around-the-clock care.

Caregiving Burden

As discussed in the Caregiving section (pages 29–41), providing informal care for someone with Alzheimer's disease or dementia can be a heavy burden, straining finances, employment, family relationships and the caregiver's own health and well-being. Some older studies have found that those strains are even more severe when the caregiver lives with the care recipient and is on duty 24 hours a day.[312] As shown in Figure 18, the percentage of female caregivers reporting stresses and strains associated with caregiving are substantially higher among full-time caregivers than among those providing care for 20 hours per week or less.

Even though full-time caregivers carried a much heavier burden than those providing care for less than 20 hours per week, the burden carried by the latter group was still quite heavy, with the potential to cause significant disruption in life. For example, among those providing care for less than 20 hours each week, 24 percent reported that it led to marital strain or was emotionally stressful. Nearly as many reported strains on finances and family relationships.

Studies have consistently found that the burden of caregiving is felt more strongly by women than men, and the 2014 poll reaffirms those findings.

- 47 percent of women and 24 percent of men considered their caregiving role to be physically stressful (defined as 4 or 5 on a scale of 1-5, with 5 being "very stressful").

- 62 percent of women and 52 percent of men considered their caregiving role to be emotionally stressful.
- About 30 percent of caregivers reported feeling isolated in their caregiving roles, and this rate was similar among men and women. But among those who reported feeling isolated, women were much more likely than men to link isolation with feeling depressed (17 percent compared with 2 percent) .
- Women were also more likely than men to report marital strain and spending less time with their spouse as consequences of caregiving.
- Among those caregivers who were employed when they started caregiving, women were more likely than men to experience several adverse consequences related to employment. The consequences showing the greatest difference between men and women are shown in Figure 19. Nearly seven times as many women as men went from working full-time to working part-time while being a caregiver, and more than twice as many women as men reported having to give up work entirely or to have lost job benefits.

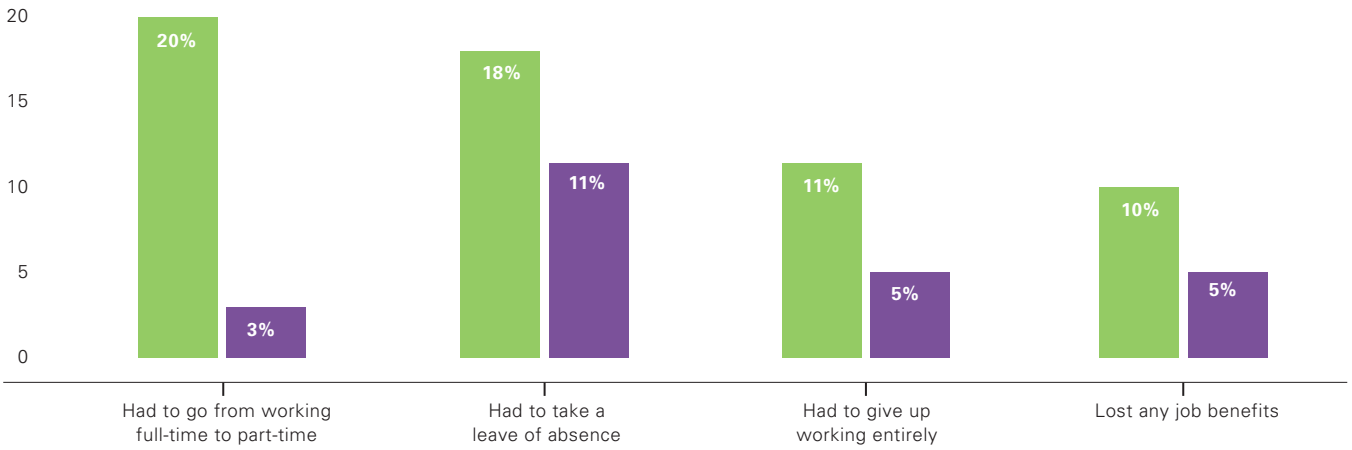
Sources of Caregiving Burden

Several explanations have been offered as to why the burden of caregiving is heavier on women than men, and it is likely that several factors contribute. One factor has already been discussed: women are more likely than men to be caring for a loved one who lives in their household and to be on duty 24 hours a day.

Another contributing factor may be differences in caregiving duties assumed by women and men. In at least two previous polls of caregivers, female caregivers were substantially more likely than male caregivers to help the care recipient with personal aspects of care, such as bathing, dressing, toileting and managing incontinence.[300,307] At least one other study reached similar conclusions.[313]

Another study of caregivers for elderly people found that women were more likely than men to perform caregiving tasks requiring a regular schedule, possibly adding to the burden of caregiving and competing with other responsibilities such as employment.[307] This aspect of caregiving may be related to responses to a question in the 2014 Alzheimer's Association poll

figure 19 | Consequences of Caregiving on Aspects of Employment Among Female and Male Caregivers



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

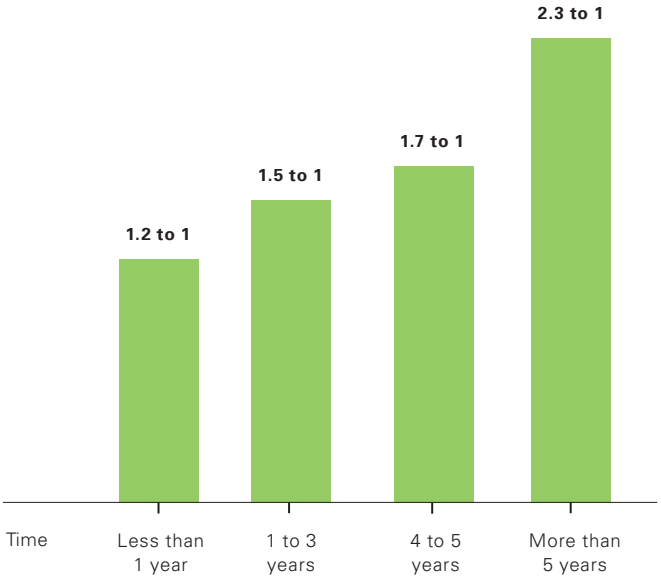
asking caregivers assisting someone outside of their household how often they visited that person. Thirty-seven percent of female caregivers answered that they visited every day, whereas only 25 percent of male caregivers visited every day.

Another factor contributing to the burden of caregiving is the availability of other caregivers and sources of support. In the 2014 Alzheimer's Association poll, slightly fewer female caregivers (56 percent) than male caregivers (60 percent) reported that another person provided caregiving help to the care recipient. Conversely, 56 percent of female caregivers and 47 percent of male caregivers reported seeking additional caregiving resources. Other studies have also found that female caregivers received less caregiving support than male caregivers.[307,314-315] Even women caring for husbands with advanced Alzheimer's disease or near the end of life received less support from family and friends than men caring for wives in similar situations.[313,316]

Another difference between female and male caregivers found in the 2014 Alzheimer's Association poll, as well as the 2009 NAC/AARP poll, was that women, on average, had been providing informal caregiving for longer than men. In the 2014 poll, 35 percent of female caregivers and 26 percent of male caregivers had been providing care for more than 5 years. Among caregivers reporting that they had been providing care for less than a year (Figure 20), the ratio of female to male caregivers was 1.2 (for every male caregiver, there were 1.2 female caregivers). As the duration of caregiving increased, the ratio of female to male caregivers also increased, to 1.5 (1 to 3 years), 1.7 (4 to 5 years) and 2.3 (more than 5 years). These results suggest that women are more likely than men to continue caregiving for prolonged durations.

Several studies have found that the burden of caregiving is dependent not only on the gender of the caregiver,[310] but also on the gender of the care recipient.[317] Furthermore, caregiver burden is substantially higher when the care recipient exhibits behavioral problems.[177,310,318] A recent study comparing the experiences of men and women caring for spouses

figure 20 | Ratio of Female to Male Caregivers According to Duration of Caregiving



Created from data from the 2014 Alzheimer's Association Women and Alzheimer's Poll.[A17]

Cynthia Guzman, a mother and grandmother, was diagnosed with Alzheimer's disease on her 63rd birthday. Prior to her diagnosis, Guzman was a nurse for 30 years, working closely with people with Alzheimer's. Today, Guzman is a National Early-Stage Advisor to the Alzheimer's Association and hopes to raise awareness of Alzheimer's and reduce the stigma attached to the disease. Guzman is also a participant in an Alzheimer's clinical trial.

with dementia confirmed earlier studies showing that men with dementia exhibited more severe behavioral problems than women with dementia.[315] As a consequence, women caring for a husband with dementia were more likely to experience a high burden due to behavioral problems than men caring for a wife. In the 2014 Alzheimer's Association poll, 16 percent of caregivers were caring for a spouse, and the situation in which a wife was caring for a husband with dementia was about twice as common as a husband caring for a wife with dementia.

Paid Personal Care and Home Health Aides

Personal care aides assist older people or others with activities of daily living, either in the care recipient's home or in a care facility. Home health aides work in the care recipient's home and may assist with health care as well as personal care such as bathing, dressing and grooming. Personal care aides and home health aides provide valuable services for people with Alzheimer's disease or dementia, allowing many to stay in their own homes. They also provide support and respite to family and friends and other informal caregivers, and they perform services that some informal caregivers are unable to perform. For many people with Alzheimer's disease or dementia, a personal care aide or home health aide is the only personal contact they experience on a daily basis.

According to the U.S. Department of Labor, women account for about 85 percent of all personal care aides and home health aides.[319] Despite the fact that these occupations are among the fastest growing occupations with the highest demand for workers in the United States, the average wage for such workers was only slightly above $10 per hour in 2012.[320-321] Average annual wages for personal care aides and home health aides were below $22,000 in 2012, only 51 percent of the national average of $42,700 for all workers. Surprisingly, even these professions exhibit a gender pay gap; in 2012, the median weekly earnings of male personal care aides were about 13 percent higher than earnings of female personal care aides.[319]

Dr. Helen Lamont has been instrumental in advancing the fight against Alzheimer's disease on the federal level. Through her role as the federal officer working with the Advisory Council on Alzheimer's Research, Care, and Services, Dr. Lamont has facilitated quarterly meetings and the development of Advisory Council recommendations. The recommendations inform the National Plan to Address Alzheimer's Disease, which Dr. Lamont coordinates for the federal government. Her work demonstrates a commitment to implementing the National Alzheimer's Project Act to its fullest extent.

Conclusions

Results of the 2014 Alzheimer's Association Women and Alzheimer's Poll provide yet more evidence that Alzheimer's disease takes a stronger toll on women than men. More women than men develop the disease, and women are more likely than men to be informal caregivers for someone with Alzheimer's disease or dementia. Results from the 2014 poll also reveal that, as caregiving responsibilities become more time-consuming and burdensome or extend for prolonged durations, women assume an even greater share of the caregiving burden. In addition, women are less likely than men to receive outside help for caregiving. The higher caregiving burden placed on women has many consequences, including higher emotional and physical stress, strained family relationships and lost employment opportunities.

End Notes

A1. Number of Americans age 65 and older with Alzheimer's disease for 2014 (prevalence of Alzheimer's in 2014): 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.[114]

A2. Proportion of Americans age 65 and older with Alzheimer's disease: The 11 percent is calculated by dividing the estimated number of people age 65 and older with Alzheimer's disease (5 million) by the U.S. population age 65 and older in 2014, as projected by the U.S. Census Bureau (44.7 million) = 11 percent. Eleven percent is the same as one in nine.

A3. Percentage of total Alzheimer's disease cases by age groups: Percentages for each age group are based on the estimated 200,000 under 65, plus the estimated numbers (in millions) for people 65 to 74 (0.8), 75 to 84 (2.3), and 85+ (2.0) based on prevalence estimates for each age group and incidence data from the Chicago Health and Aging Project (CHAP).[114]

A4. Differences between CHAP and ADAMS estimates for Alzheimer's disease prevalence: The Aging, Demographics, and Memory Study (ADAMS) estimates the prevalence of Alzheimer's disease to be lower than does the Chicago Health and Aging Project (CHAP), at 2.3 million Americans age 71 and older in 2002.[116] [Note that the CHAP estimates referred to in this end note are from an earlier study using 2000 U.S. Census data.[144]] At a 2009 conference convened by the National Institute on Aging and the Alzheimer's Association, researchers determined that this discrepancy was mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's.[117] Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's disease and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,[4] the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's disease in the United States.

A5. Number of women and men age 65 and older with Alzheimer's disease in the United States: The estimates for the number of U.S. women (3.2 million) and men (1.8 million) age 65 and older with Alzheimer's in 2013 is from unpublished data from the Chicago Health and Aging Project (CHAP). For analytic methods, see Hebert et al.[114]

A6. Prevalence of Alzheimer's disease and other dementias in older whites, African-Americans and Hispanics: The statement that African-Americans are twice as likely and Hispanics one and one-half times as likely as whites to have Alzheimer's disease and other dementias is the conclusion of an expert review of a number of multiracial and multi-ethnic data sources, as reported in detail in the Special Report of *2010 Alzheimer's Disease Facts and Figures*.

A7. Number of new cases of Alzheimer's disease this year (incidence of Alzheimer's in 2014): The CHAP study estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020. See Hebert et al.[140] The Alzheimer's Association calculated that the incidence of new cases in 2014 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.4 (for the number of years from 2010 to 2014 divided by the number of years from 2010 to 2020), adding that result (14,800) to the Hebert et al.[140] estimate for 2010 (454,000) = 468,800. Rounded to the nearest thousand, this is 469,000 new cases of Alzheimer's disease in 2014. The same technique for linear extrapolation from 2000 to 2010 projections was used to calculate the number of new cases in 2014 for ages 65-74, 75-84, and 85 and older. The increases in number of new cases of Alzheimer's disease from year to year appears to be mostly due to changes in demographics rather than changes in the underlying incidence rate for Alzheimer's disease, which in a recent analysis was shown to remain stable over a decade.[322] The age group-specific Alzheimer's disease incident rate is the number of new people with Alzheimer's per population at risk (the total number of people in the age group in question). These incidence rates are expressed as number of new cases per 1,000 people. The total number of people per age group for 2014 was obtained from population projections from the 2000 U.S. Census (see 2000 National Population Projections: Summary Tables located at http://www.census.gov/population/projections/files/natproj/summary/np-t3-d.pdf).

A8. Number of seconds for the development of a new case of Alzheimer's disease: Although Alzheimer's does not present suddenly like stroke or heart attack, the rate at which new cases occur can be computed in a similar way. The 67 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.[A7] The number of seconds in a year (31,536,000) divided by 468,800 = 67.3 seconds, rounded to 67 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 [from Hebert et al.[140]]= 32.8 seconds, rounded to 33 seconds.

A9. Criteria for identifying subjects with Alzheimer's disease and other dementias in the Framingham Study: Starting in 1975, nearly 2,800 people from the Framingham Study who were age 65 and free of dementia were followed for up to 29 years. Standard diagnostic criteria (DSM-IV criteria) were used to diagnose dementia in the Framingham Study, but, in addition, the subjects had to have at least "moderate" dementia according to the Framingham Study criteria, which is equivalent to a score of 1 or more on the Clinical Dementia Rating (CDR) Scale, and they had to have symptoms for six months or more. Standard diagnostic criteria (the NINCDS–ADRDA criteria from 1984) were used to diagnose Alzheimer's disease. The examination for dementia and Alzheimer's disease is described in detail in Seshadri et al.[123]

A10. State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on an unpublished analysis of incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality provided to the Alzheimer's Association in 2013 by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

A11. Projected number of people with Alzheimer's disease: This comes from the CHAP study.[114] Other projections are somewhat lower [see for example, Brookmeyer et al.[323]] because they relied on more conservative methods for counting people who currently have Alzheimer's disease.[A4] Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's disease over the coming decades.

A12. Projected number of people age 65 and older with Alzheimer's disease in 2025: The number 7.1 million is based on a linear extrapolation from the projections of prevalence of Alzheimer's for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP.[114]

A13. Previous high and low projections of Alzheimer's disease prevalence in 2050: High and low prevalence projections for 2050 from the U.S. Census were not available for the most recent analysis of CHAP data.[114] The previous high and low projections indicate that the projected number of Americans with Alzheimer's in 2050 age 65 and older will range from 11 to 16 million.[144]

A14. Deaths with Alzheimer's disease: The estimates for the number of Americans dying with Alzheimer's disease, 600,000 in 2010 and 700,000 in 2014, come from Weuve et al.[153] Please note that the numbers reported in *2013 Alzheimer's Disease Facts and Figures* reflected only individuals age 85 and older.

A15. Annual mortality rate due to Alzheimer's disease by state: Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the true burden of mortality for each state. States such as Florida with a larger population of older people will have a larger burden of mortality due to Alzheimer's.

A16. Number of family and other unpaid caregivers of people with Alzheimer's and other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS). In 2009, the BRFSS survey asked respondents age 18 and over whether they had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the Centers for Disease Control and Prevention, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2013. Available at www.census.gov/popest/data/datasets.html. Accessed on Jan. 6, 2014. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer's or another dementia, the Alzheimer's Association used data from the results of a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC)/AARP.[184] The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care. In response, 26 percent of caregivers said that: (1) Alzheimer's or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26 percent figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 15,553,389 Alzheimer's and dementia caregivers.

A17. The 2014 Alzheimer's Association Women and Alzheimer's Poll: This poll was conducted by telephone between January 9 and January 29, 2014. Target respondents were community-dwelling adults age 18 and older living in the United States. Telephone numbers were chosen randomly in separate samples of landline and cell-phone exchanges from across the nation. Respondents were contacted by either landline or cellular telephone. When a household was contacted by landline, one adult from the household was chosen at random to respond to survey questions. The survey was designed to contain "oversamples" of Hispanics, Asian-Americans and households known to have an adult with Alzheimer's disease. Respondents included 1,746 women and 1,356 men (total of 3,102 respondents); 2,278 respondents identified themselves as white, non-Hispanic; 469 as of Hispanic Latino or Spanish origin; 413 as black or African-American; 131 as Asian or Asian-American; and 293 as another racial or ethnic group. These cases were weighted to account for differential probabilities of selection and overlap in the landline and cell-phone sampling frames. The sample was adjusted to match census demographic benchmarks for gender, age, education, race/ethnicity, region and telephone service. The resulting interviews (including the oversamples) comprise a probability-based, nationally representative sample of U.S. adults. The margin of sampling error is plus or minus approximately 2 percentage points at the 95 percent confidence interval. For subgroups, the margin of error will be higher.

A18. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's and other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. The number of family and other unpaid caregivers (15,533,389)[A16] was multiplied by the average hours of care per year, which totals 17,689,423,440 hours of care.

A19. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Amo et al.[324] This method uses the average of the federal minimum hourly wage ($7.25 in 2013) and the mean hourly wage of home health aides ($17.65 in July 2013).[325] The average is $12.45, which was multiplied by the number of hours of unpaid care (17,689,423,440)[A18] to derive the total value of unpaid care ($220,233,321,824).

A20. Higher health care costs of Alzheimer's caregivers: This figure is based on a methodology originally developed by Brent Fulton, Ph.D., for *The Shriver Report: A Woman's Nation Takes on Alzheimer's.* A survey of 17,000 employees of a multinational firm based in the United States estimated that caregivers' health care costs were 8 percent higher than non-caregivers'.[326] To determine the dollar amount represented by that 8 percent figure nationally and in each state, the 8 percent figure and the proportion of caregivers from the 2009 Behavioral Risk Factor Surveillance System[A16] were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009, inflated to 2013 dollars.[327] The dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state (reflecting the 8 percent higher costs for caregivers) produced the average additional health care costs for caregivers in each state. Nationally, this translated into an average of $601. The amount of the additional cost in each state, which varied by state from a low of $443 in Utah to a high of $916 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state[A16] to arrive at that state's total additional health care costs of Alzheimer's and other dementia caregivers as a result of being a caregiver. The combined total for all states was $9,331,554,412. 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."[300]

A21. Lewin Model on Alzheimer's and dementia and costs: These numbers come from a model created for the Alzheimer's Association by The Lewin Group, modified to reflect the more recent estimates and projections of the prevalence of Alzheimer's disease.[114] 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.[A23] 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.

A22. All cost estimates were inflated to year 2013 dollars using the Consumer Price Index (CPI): All cost estimates were inflated using the seasonally adjusted average prices for medical care services for all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

A23. Medicare Current Beneficiary Survey Report: These data come

from an analysis of findings from the 2008 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research.[155] The MCBS, a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries, is linked to Medicare Part B claims. The survey is supported by the U.S. Centers for Medicare and Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a nurse who is familiar with the survey participant and his or her medical record. Data from the MCBS analysis that are included in *2014 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

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

Costs from the MCBS analysis are based on responses from 2008 and reported in 2013 dollars.

A24. Differences in estimated costs reported by Hurd and colleagues: Hurd et al.[173] estimated per-person costs using data from participants in ADAMS, a cohort in which all people underwent diagnostic assessments for dementia. *2014 Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS). One reason that the per-person costs estimated by Hurd et al. are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified people with less severe or undiagnosed Alzheimer's. By contrast, people with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that Hurd et al.'s estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's disease and other dementias (those costs attributed only to dementia), while the per-person costs in *Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

A25. YouGov survey: Sample targets for this August 2013 survey by YouGov were set based on demographic characteristics of adults age 60 years or older from the 2010 American Community Survey. After proximity matching, the matched set of survey respondents were then weighted to known characteristics in the United States using propensity score weighting. The final weights were then post-stratified by demographic characteristics to be representative of the general population age 60 years or older. The YouGov survey was conducted with financial support from the Alzheimer's Association; data analysis was supported by the Centers for Disease Control and Prevention.

A26. Number of respondents who identified themselves as caregivers for someone with Alzheimer's disease or dementia: The 2014 Alzheimer's Association Women and Alzheimer's Poll[A17] included 205 caregivers of people with Alzheimer's or dementia. This was supplemented with 310 interviews from a listed sample of caregivers to people with Alzheimer's. For this survey, a caregiver was defined as an adult over age 18 who, in the past 12 months, has provided unpaid care to a relative or friend age 50 or older with Alzheimer's or dementia. Furthermore, caregivers had to report that they provided the majority of care or equally shared caregiving responsibilities with another person. Unfortunately, there are no official demographic benchmarks for the Alzheimer's caregiver population. As a substitute, benchmark estimates for this population were derived from the characteristics of the caregivers reached in the landline and cell-phone samples, which are probability-based and nationally representative. The weight for the caregiver sample balances all caregiver cases to the weighted estimates for gender and race/ethnicity derived from the landline and cell-phone caregivers. This weighting adjusted for the fact that the caregivers reached through the list sample were somewhat more likely to be female and white than those reached in the probability-based component of the study.

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th edition). Arlington, Va.: American Psychiatric Publishing; 2013.
2. Viswanathan A, Rocca WA, Tzourio C. Vascular risk factors and dementia: How to move forward? Neurology 2009;72:368–74.
3. Schneider JA, Arvanitakis Z, Bang W, Bennett DA. Mixed brain pathologies account for most dementia cases in community-dwelling older persons. Neurology 2007;69:2197–204.
4. Schneider JA, Arvanitakis Z, Leurgans SE, Bennett DA. The neuropathology of probable Alzheimer disease and mild cognitive impairment. Ann Neurol 2009;66(2):200–8.
5. Jellinger KA, Attems J. Neuropathological evaluation of mixed dementia. J Neurol Sci 2007;257(1–2):80–7.
6. Jellinger KA. The enigma of mixed dementia. Alzheimers Dement 2007;3(1):40–53.
7. Clarfield AM. The decreasing prevalence of reversible dementias: An updated meta-analysis. Arch Intern Med 2003;163(18):2219–29.
8. Fernando MS, Ince PG. MRC Cognitive Function and Ageing Neuropathology Study Group: Vascular pathologies and cognition in a population-based cohort of elderly people. J Neurol Sci 2004;226(1–2):13–7.
9. Villemagne VL, Burnham S, Bourgeat P, Brown B, Ellis KA, Salvado O, et al. Amyloid deposition, neurodegeneration, and cognitive decline in sporadic Alzheimer's disease: A prospective cohort study. Lancet Neurol 2013;12(4):357–67.
10. Reiman EM, Quiroz YT, Fleisher AS, Chen K, Velez-Pardos C, Jimenez-Del-Rio M, et al. Brain imaging and fluid biomarker analysis in young adults at genetic risk for autosomal dominant Alzheimer's disease in the presenilin 1 E280A kindred: A case-control study. Lancet Neurology 2012;11(2):1048–56.
11. Jack CR, Lowe VJ, Weigand SD, Wiste HJ, Senjem ML, Knopman DS, et al. Serial PIB and MRI in normal, mild cognitive impairment and Alzheimer's disease: Implications for sequence of pathological events in Alzheimer's disease. Brain 2009;132:1355–65.
12. Bekris LM, Yu CE, Bird TD, Tsuang DW. Genetics of Alzheimer disease. J Geriatr Psychiatry Neurol 2010;23(4):213–227.
13. Green RC, Cupples LA, Go R, Benke KS, Edeki T, Griffith PA, et al. Risk of dementia among white and African American relatives of patients with Alzheimer disease. JAMA 2002;287(3):329–36.
14. Fratiglioni L, Ahlbom A, Viitanen M, Winblad B. Risk factors for late-onset Alzheimer's disease: A population-based, case-control study. Ann Neurol 1993;33(3):258–66.
15. Mayeux R, Sano M, Chen J, Tatemichi T, Stern Y. Risk of dementia in first-degree relatives of patients with Alzheimer's disease and related disorders. Arch Neurol 1991;48(3):269–73.
16. Lautenschlager NT, Cupples LA, Rao VS, Auerbach SA, Becker R, Burke J, et al. Risk of dementia among relatives of Alzheimer's disease patients in the MIRAGE Study: What is in store for the oldest old? Neurology 1996;46(3):641–50.
17. Alzheimer's Disease Education and Referral Center. Alzheimer's Disease Genetics: Fact Sheet. National Institutes of Health, Bethesda, Md.; June 2011. Publication 11-6424.
18. Raber J, Huang Y, Ashford JW. ApoE genotype accounts for the vast majority of AD risk and AD pathology. Neurobiol Aging 2004;25:641–50.
19. Saunders AM, Strittmatter WJ, Schmechel D, George-Hyslop PH, Pericak-Vance MA, Joo SH, et al. Association of apolipoprotein E allele epsilon 4 with late-onset familial and sporadic Alzheimer's disease. Neurology 1993;43:1467–72.
20. Farrer LA, Cupples LA, Haines JL, Hyman B, Kukull WA, Mayeux R, et al. Effects of age, sex, and ethnicity on the association between apolipoprotein E genotype and Alzheimer disease: A meta-analysis. JAMA 1997;278:1349–56.
21. Jack CR, Albert MS, Knopman DS, McKhann GM, Sperling RA, Carrillo MC, et al. Introduction to the recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):257–62.
22. McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):263–9.
23. Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox N, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):270–9.
24. Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, et al. Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 2011;7(3):280–92.
25. Anstey KJ, von Sanden C, Salim A, O'Kearney R. Smoking as a risk factor for dementia and cognitive decline: A meta-analysis of prospective studies. Am J Epidemiol 2007;166(4):367–78.
26. Rusanen M, Kivipelto M, Quesenberry CP, Zhou J, Whitmer RA. Heavy smoking in midlife and long-term risk of Alzheimer disease and vascular dementia. Arch Intern Med 2010;171(4):333–9.
27. Pendlebury ST, Rothwell PM. Prevalence, incidence, and factors associated with pre-stroke and post-stroke dementia: A systematic review and meta-analysis. Lancet Neurol 2009; 8(11):1006–18.
28. Whitmer RA, Gustafson DR, Barrett-Connor E, Haan MN, Gunderson EP, Yaffe K. Central obesity and increased risk of dementia more than three decades later. Neurology 2008;71:1057–64.
29. Raji CA, Ho AJ, Parikshak NN, Becker JT, Lopez OL, Kuller LH, et al. Brain structure and obesity. Hum Brain Mapp 2010;31(3):353–64.
30. Kivipelto M, Ngandu T, Fratiglioni L, Viitanen M, Kåreholt I, Winblad B, et al. Obesity and vascular risk factors at midlife and the risk of dementia and Alzheimer disease. Arch Neurol 2005;62:1556–60.
31. Xu WL, Atti AR, Gatz M, Pedersen NL, Johansson B, Fratiglioni L. Midlife overweight and obesity increase late-life dementia risk: A population-based twin study. Neurology 2011; 3;76(18):1568–74.
32. Fitzpatrick AL, Kuller LH, Lopez OL, Diehr P, O'Meara ES, Longstreth WT, et al. Midlife and late-life obesity and the risk of dementia: Cardiovascular Health Study. Arch Neurol 2009;66(3):336–42.
33. Rönnemaa E, Zethelius B, Lannfelt L, Kilander L. Vascular risk factors and dementia: 40-year follow-up of a population-based cohort. Dement Geriatr Cogn Disord 2011;31(6):460–6.
34. Luchsinger JA, Cheng D, Tang MX, Schupf N, Mayeux R. Central obesity in the elderly is related to late-onset Alzheimer disease. Alzheimer Dis Assoc Disord 2012;26(2):101–5.
35. Wu W, Brickman AM, Luchsinger J, Ferrazzano P, Pichiule P, Yoshita M, et al. The brain in the age of old: The hippocampal formation is targeted differentially by diseases of late life. Ann Neurol 2008;64:698–706.

36. Ohara T, Doi Y, Ninomiya T, Hirakawa Y, Hata J, Iwaki T, et al. Glucose tolerance status and risk of dementia in the community: The Hisayama Study. Neurol 2011;77:1126–34.
37. Reitz C, Brayne C, Mayeux R. Epidemiology of Alzheimer disease. Nat Rev Neurol 2011;7(3):137–52.
38. Ahtiluoto S, Polvikoski T, Peltonen M, Solomon A, Tuomilehto J, Winblad B, et al. Diabetes, Alzheimer disease, and vascular dementia: A population-based neuropathologic study. Neurology 2010;75(13):1195–202.
39. Cheng D, Noble J, Tang MX, Schupf N, Mayeux R, Luchsinger JA. Type 2 diabetes and late-onset Alzheimer's disease. Dement Geriatr Cogn Disord 2011;31(6):424–30.
40. Solomon A, Kivipelto M, Wolozin B, Zhou, J, Whitmer, RA. Midlife serum cholesterol and increased risk of Alzheimer's and vascular dementia three decades later. Dement and Geriatr Disord 2009;28:75–80.
41. Launer LJ, Ross GW, Petrovitch H, Masaki K, Foley D, White LR, et al. Midlife blood pressure and dementia: The Honolulu-Asia Aging Study. Neurobiol Aging 2000;21(1):49–55.
42. Ninomiya T, Ohara T, Hirakawa Y, Yoshida D, Doi Y, Hata J, et al. Midlife and late-life blood pressure and dementia in Japanese elderly: The Hisayama Study. Hypertension 2011;58(1):22–8.
43. Debette S, Seshadri S, Beiser A, Au R, Himali JJ, Palumbo C, et al. Midlife vascular risk factor exposure accelerates structural brain aging and cognitive decline. Neurology 2011(77):461–8.
44. Willis BL, Gao A, Leonard D, DeFina LF, Berry JD. Midlife fitness and the development of chronic conditions in later life. Arch Intern Med 2012;172(17):1333–40.
45. Larson EB, Wang L, Bowen JD, McCormick WC, Teri L, Crane P, et al. Exercise is associated with reduced risk for incident dementia among persons 65 years of age and older. Ann Intern Med 2006;144(2):73–81.
46. Laurin D, Verreault R, Lindsay J, MacPherson K, Rockwood K. Physical activity and risk of cognitive impairment and dementia in elderly persons. Arch Neurol 2001;58(3):498–504.
47. Wang H-X, Xu W, Pei J-J. Leisure activities, cognition and dementia. BBA - Mol Basis Dis 2012;1822(3):482–91.
48. Wang HX, Karp A, Winblad B, Fratiglioni L. Late-life engagement in social and leisure activities is associated with a decreased risk of dementia: A longitudinal study from the Kungsholmen Project. Am J Epidemiol 2002;155(12):1081–7.
49. Saczynski JS, Pfeifer LA, Masaki K, Korf ES, Laurin D, White L, et al. The effect of social engagement on incident dementia: The Honolulu-Asia Aging Study. Am J Epidemiol 2006;163(5):433–40.
50. Karp A, Paillard-Borg S, Wang HX, Silverstein M, Winblad B, Fratiglioni L. Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. Dement Geriatr Cogn Disord 2005;21(2):65–73.
51. Fabrigoule C, Letenneur L, Dartigues JF, Zarrouk M, Commenges D, Barberger-Gateau P. Social and leisure activities and risk of dementia: A prospective longitudinal study. J Am Ger Soc 1995;43(5):485–90.
52. Krueger KR, Wilson RS, Kamenetsky JM, Barnes LL, Bienias JL, Bennett DA. Social engagement and cognitive function in old age. Exp Aging Res 2009;35(1):45–60.
53. Sharp ES, Reynolds CA, Pedersen NL, Gatz M. Cognitive engagement and cognitive aging: Is openness protective? Psychol Aging 2010;25(1):60–73.
54. Fratiglioni L, Paillard-Borg S, Winblad B. An active and socially integrated lifestyle in late life might protect against dementia. Lancet Neurol 2004;3(6):343–53.
55. Wilson RS, Boyle PA, Yu L, Barnes LL, Schneider JA, Bennett DA. Life-span cognitive activity, neuropathologic burden, and cognitive aging. Neurology 2013;81(4):314–21.
56. Ball K, Berch DB, Helmers KF, Jobe JB, Leveck MD, Marsiske M, et al. Effects of cognitive training interventions with older adults: A randomized controlled trial. JAMA 2002;288(18):2271–81.
57. Hall CB, Lipton RB, Sliwinski M, Katz MJ, Derby CA, Verghese J. Cognitive activities delay onset of memory decline in persons who develop dementia. Neurology 2009;73:356–61.
58. Wilson RS, Mendes De Leon CF, Barnes LL, Schneider JA, Bienias JL, Evans DA, et al. Participation in cognitively stimulating activities and risk of incident Alzheimer disease. JAMA 2002;287(6):742–8.
59. Wilson RS, Bennett DA, Bienias JL, Aggarwal NT, Mendes De Leon CF, Morris MC, et al. Cognitive activity and incident AD in a population-based sample of older persons. Neurology 2002;59(12):1910–4.
60. Fitzpatrick AL, Kuller LH, Ives DG, Lopez OL, Jagust W, Breitner JC, et al. Incidence and prevalence of dementia in the Cardiovascular Health Study. J Am Geriatr Soc 2004;52(2): 195–204.
61. Kukull WA, Higdon R, Bowen JD, McCormick WC, Teri L, Schellenberg GD, et al. Dementia and Alzheimer disease incidence: A prospective cohort study. Arch Neurol 2002;59(11):1737–46.
62. Evans DA, Bennett DA, Wilson RS, Bienias JL, Morris MC, Scherr PA, et al. Incidence of Alzheimer disease in a biracial urban community: Relation to apolipoprotein E allele status. Arch Neurol 2003;60(2):185–9.
63. Stern Y, Gurland B, Tatemichi TK, Tang MX, Wilder D, Mayeux R. Influence of education and occupation on the incidence of Alzheimer's disease. JAMA 1994;271(13):1004–10.
64. Evans DA, Hebert LE, Beckett LA, Scherr PA, Albert MS, Chown MJ, et al. Education and other measures of socioeconomic status and risk of incident Alzheimer disease in a defined population of older persons. Arch Neurol 1997;54(11):1399–405.
65. Roe CM, Xiong C, Miller JP, Morris JC. Education and Alzheimer disease without dementia: Support for the cognitive reserve hypothesis. Neurology 2007;68(3):223–8.
66. Stern Y. Cognitive reserve in ageing and Alzheimer's disease. Lancet Neurol 2012;11(11):1006–12.
67. Stern Y. Cognitive reserve and Alzheimer disease. Alzheimer Dis Assoc Disord 2006;20(2):112–7.
68. McDowell I, Xi G, Lindsay J, Tierney M. Mapping the connections between education and dementia. J Clin Exp Neuropsychol 2007;29(2):127–41.
69. Lye TC, Shores EA. Traumatic brain injury as a risk factor for Alzheimer's disease: A review. Neuropsychol Rev 2000;10:115–29.
70. National Institutes of Health. Traumatic Brain Injury. Available at http://www.nlm.nih.gov/medlineplus/traumaticbraininjury.html, Accessed October 10, 2012.
71. Plassman BL, Havlik RJ, Steffens DC, Helms MJ, Newman TN, Drosdick D, et al. Documented head injury in early adulthood and risk of Alzheimer's disease and other dementias. Neurology 2000;55(8):1158–66.
72. Crawford FC, Vanderploeg RD, Freeman MJ, Singh S, Waisman M, Michaels L, et al. APOE genotype influences acquisition and recall following traumatic brain injury. Neurology 2002;58(7):1115–8.
73. Roberts GW, Allsop D, Bruton C. The occult aftermath of boxing. J Neurol, Neurosurg Psychiatry 1990;53(5):373–8.
74. Guskiewicz KM. Association between recurrent concussion and late-life cognitive impairment in retired professional football players. Neurosurgery 2005;57:719–26.
75. Institute for Social Research. National Football League Player Care Foundation Study of NFL retired players. Ann Arbor, Mich.: University of Michigan; 2009.

76. Groswasser Z, Reider-Groswasser II, Schwab K, Ommaya AK, Pridgen A, Brown HR, et al. Quantitative imaging in late TBI. Part II: Cognition and work after closed and penetrating head injury: A report of the Vietnam Head Injury Study. Brain Inj 2002;16(8):681–90.
77. Salazar AM, Warden DL, Schwab K, Spector J, Braverman S, Walter J, et al. Cognitive rehabilitation for traumatic brain injury: A randomized trial. Defense and Veterans Head Injury Program (DVHIP) Study Group. JAMA 2000;283(23):3075–81.
78. Lehman EJ, Hein MJ, Baron SL, Gersic CM. Neurodegenerative causes of death among retired National Football League players. Neurology 2012;79(19):1970–4.
79. Omalu BI, DeKosky ST, Minster RL, Kamboh MI, Hamilton RL, Wecht CH. Chronic traumatic encephalopathy in a National Football League player. Neurosurgery 2005;57(1):128–34.
80. McKee AC, Stern RA, Nowinski CJ, Stein TD, Alvarez VE, Daneshvar DH, et al. The spectrum of disease in chronic traumatic encephalopathy. Brain 2013;136(Pt 1):43–64.
81. Monti JM, Voss MW, Pence A, McAuley E, Kramer AF, Cohen NJ. History of mild traumatic brain injury is associated with deficits in relational memory, reduced hippocampal volume, and less neural activity later in life. Front Aging Neurosci 2013;5:41.
82. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease. Neurology 1984(34):939–44.
83. Hyman BT, Phelps, CH, Beach TG, Bigio EH, Cairns NJ, Carrillo MC, et al. National Institute on Aging–Alzheimer's Association guidelines on neuropathologic assessment of Alzheimer's disease. Alzheimers Dement 2012;8(1):1–13.
84. Lopez OL, Jagust WJ, DeKosky ST, Becker JT, Fitzpatrick A, Dulberg C, et al. Prevalence and classification of mild cognitive impairment in the Cardiovascular Health Study Cognition Study. Arch Neurol 2003;60:1385–9.
85. Roberts RO, Geda YE, Knopman DS, Cha RH, Pankratz VS, Boeve BF, et al. The Mayo Clinic Study of Aging: Design and sampling, participation, baseline measures and sample characteristics. Neuroepidemiology 2008;30:58–69.
86. Hanninen T, Hallikainen M, Tuomainen S, Vanhanen M, Soininen H. Prevalence of mild cognitive impairment: A population-based study in elderly subjects. Acta Neurol Scand 2002;106:148–54.
87. Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. Mild cognitive impairment: Clinical characterization and outcome. Arch Neurol 1999;56:303–8.
88. Manly JJ, Tang MX, Schupf N, Stern Y, Vonsattel JP, Mayeux R. Frequency and course of mild cognitive impairment in a multiethnic community. Ann Neurol 2008;63:494–506.
89. Ganguli M, Snitz BE, Saxton JA, Chang CH, Lee C, Vanderbilt J, et al. Outcomes of mild cognitive impairment by definition: A population study. Arch Neurol 2011;68(8):761–7.
90. Bloudek LM, Spackman ED, Blankenburg M, Sullivan SD. Review and meta-analysis of biomarkers and diagnostic imaging in Alzheimer's disease. J Alzheimers Dis 2011;26: 627–45.
91. Rami L, Solé-Padullés C, Fortea J, Bosch B, Lladó A, Antonell A, et al. Applying the new research diagnostic criteria: MRI findings and neuropsychological correlations of prodromal AD. Int J Geriatr Psychiatry 2012;27(2):127–34.
92. Galluzzi S, Geroldi C, Amicucci G, Bocchio-Chiavetto L, Bonetti M, Bonvicini C, et al. Supporting evidence for using biomarkers in the diagnosis of MCI due to AD. J Neurol 2013;260(2): 640–50.
93. Roe CM, Fagan AM, Grant EA, Hassenstab J, Moulder KL, Maue D, et al. Amyloid imaging and CSF biomarkers in predicting cognitive impairment up to 7.5 years later. Neurology 2013; 7:80(19):1784–91.
94. Douaud G, Menke RA, Gass A, Monsch AU, Rao A, Whitcher B, et al. Brain microstructure reveals early abnormalities more than two years prior to clinical progression from mild cognitive impairment to Alzheimer's disease. J Neurosci 2013; 30:33(5):2147–55.
95. Johnson KA, Minoshima S, Bohnen NI, Donohoe KJ, Foster NL, Herscovitch P, et al. Appropriate use criteria for amyloid PET: A report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. Alzheimer's Dement 2013;9(1): E1–E16.
96. Yang X, Tan MZ, Qiu A. CSF and brain structural imaging markers of the Alzheimer's pathological cascade. PLoS One 2012;7(12):e47406.
97. Shaffer JL, Petrella JR, Sheldon FC, Choudhury KR, Calhoun VD, Coleman RE, et al. Predicting cognitive decline in subjects at risk for Alzheimer disease by using combined cerebrospinal fluid, MR imaging and PET biomarkers. Radiology 2013;266(2):583–91.
98. Bateman RJ, Xiong C, Benzinger TL, Fagan AM, Goate A, Fox NC, et al. Clinical and biomarker changes in dominantly inherited Alzheimer's disease. N Engl J Med 2012;367(9): 795–804.
99. Bendlin BB, Carlsson CM, Johnson SC, Zetterberg H, Blennow K, Willette AA, et al. CSF T-tau/A 42 predicts white matter microstructure in healthy adults at risk for Alzheimer's disease. PLoS One 2012;7(6):e37720.
100. Honea RA, Vidoni ED, Swerdlow RH, Burns JM, Alzheimer's Disease Neuroimaging Initiative. Maternal family history is associated with Alzheimer's disease biomarkers. J Alzheimers Dis 2012;31(3):659–68.
101. Stricker NH, Dodge HH, Dowling NM, Han SD, Erosheva EA, Jagust WJ, Alzheimer's Disease Neuroimaging Initiative. CSF biomarker associations with change in hippocampal volume and precuneus thickness: Implications for the Alzheimer's pathological cascade. Brain Imaging Behav 2012;6(4):599–609.
102. Schmand B, Eikelenboom P, van Gool WA, Alzheimer's Disease Neuroimaging Initiative. Value of diagnostic tests to predict conversion to Alzheimer's disease in young and old patients with amnestic mild cognitive impairment. J Alzheimers Dis 2012;29(3):641–8.
103. Vos S, van Rossum I, Burns L, Knol D, Scheltens P, Soininen H, et al. Test sequence of CSF and MRI biomarkers for prediction of AD in subjects with MCI. Neurobiol Aging 2012;33(10):2272–81.
104. Dickerson BC, Wolk DA, Alzheimer's Disease Neuroimaging Initiative. MRI cortical thickness biomarker predicts AD-like CSF and cognitive decline in normal adults. Neurology 2012;78(2):84–90.
105. Wang L, Fagan AM, Shah AR, Beg MF, Csernansky JG, Morris JC, et al. Cerebrospinal fluid proteins predict longitudinal hippocampal degeneration in early-stage dementia of the Alzheimer type. Alzheimer Dis Assoc Disord. 2012;26(4): 314–21.
106. Furney SJ, Kronenberg D, Simmons A, Güntert A, Dobson RJ, Proitsi P, et al. Combinatorial markers of mild cognitive impairment conversion to Alzheimer's disease — cytokines and MRI measures together predict disease progression. J Alzheimers Dis 2011;26(Suppl 3):395–405.
107. Schmand B, Eikelenboom P, van Gool WA, Alzheimer's Disease Neuroimaging Initiative. Value of neuropsychological tests, neuroimaging and biomarkers for diagnosing Alzheimer's disease in younger and older age cohorts. J Am Geriatr Soc 2011;59(9):1705–10.

108. Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. The effect of a disease management intervention on quality and outcomes of dementia care: A randomized, controlled trial. Ann Intern Med 2006:145(10):713–26.
109. Voisin T, Vellas B. Diagnosis and treatment of patients with severe Alzheimer's disease. Drugs Aging 2009;26(2):135–44.
110. Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ. The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: Recommendations of an expert consensus panel. Prim Care Companion J Clin Psychiatry 2010;12(1):PCC.09cs00833.
111. Dementia and Chronic Cognitive Impairment; Rehabilitation and Care. National Institute for Health Research. Available at http://dementia.cochrane.org/our-reviews. Accessed October 21, 2013.
112. Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, del Ser T, et al. Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. Dement Geriatr Cogn Disord 2010:30:161–78.
113. Brodaty H, Arasaratnam C. Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. Am J Psychiatry 2012:169:946–53.
114. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. Neurology 2013;80(19):1778–83.
115. Alzheimer's Association. Early-Onset Dementia: A National Challenge, a Future Crisis. Washington, D.C.: Alzheimer's Association; 2006.
116. Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. Neuroepidemiology 2007;29(1–2):125–32.
117. Wilson RS, Weir DR, Leurgans SE, Evans DA, Hebert LE, Langa KM, et al. Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States. Alzheimers Dement 2011;7(1):74–9.
118. Boustani M, Peterson B, Hanson L, Harris R, Lohr KN. Screening for dementia in primary care: A summary of the evidence for the U.S. Preventive Services Task Force. Ann Intern Med 2003;138(11):927–37.
119. Reisberg B, Gauthier S. Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. Int Psychogeriatr 2008;20(1):1–16.
120. Jessen F, Wiese B, Bachmann C, et al. Prediction of dementia by subjective memory impairment: Effects of severity and temporal association with cognitive impairment. Arch Gen Psychiatry. Apr 2010;67(4):414–22.
121. Reisberg B, Shulman MB, Torossian C, Leng L, Zhu W. Outcome over seven years of healthy adults with and without subjective cognitive impairment. Alzheimers Dement 2010;6(1):11–24.
122. Centers for Disease Control and Prevention. Self-reported increased confusion or memory loss and associated functional difficulties among adults aged >/= 60 years - 21 States, 2011. MMWR Morb Mortal Wkly Rep 2013;62(18):347–50.
123. Seshadri S, Wolf PA, Beiser A, Au R, McNulty K, White R, et al. Lifetime risk of dementia and Alzheimer's disease. The impact of mortality on risk estimates in the Framingham Study. Neurology 1997;49(6):1498–504.
124. Hebert LE, Scherr PA, McCann JJ, Beckett LA, Evans DA. Is the risk of developing Alzheimer's disease greater for women than for men? Am J Epidemiol 2001;153(2):132–6.
125. Bachman DL, Wolf PA, Linn RT, Knoefel JE, Cobb JL, Belanger AJ, et al. Incidence of dementia and probable Alzheimer's disease in a general population: The Framingham Study. Neurology 1993;43(3 Pt 1):515–9.
126. Rocca WA, Cha RH, Waring SC, Kokmen E. Incidence of dementia and Alzheimer's disease: A reanalysis of data from Rochester, Minn., 1975–1984. Am J Epidemiol 1998;148(1):51–62.
127. Barnes LL, Wilson RS, Schneider JA, Bienias JL, Evans DA, Bennett DA. Gender, cognitive decline, and risk of AD in older persons. Neurology 2003;60(11):1777–81.
128. Miech RA, Breitner JC, Zandi PP, Khachaturian AS, Anthony JC, Mayer L. Incidence of AD may decline in the early 90s for men, later for women: The Cache County Study. Neurology 2002;58(2):209–18.
129. Fillenbaum GG, Heyman A, Huber MS, Woodbury MA, Leiss J, Schmader KE, et al. The prevalence and 3-year incidence of dementia in older black and white community residents. J Clin Epidemiol 1998;51(7):587–95.
130. Dilworth-Anderson P, Hendrie HC, Manly JJ, Khachaturian AS, Fazio S. Diagnosis and assessment of Alzheimer's disease in diverse populations. Alzheimers Dement 2008;4(4):305–9.
131. Manly J, Mayeux R. Ethnic differences in dementia and Alzheimer's disease. In: Anderson N, Bulatao R, Cohen B, eds. Critical perspectives on racial and ethnic differentials in health in late life. Washington, D.C.: National Academies Press; 2004: p. 95–141.
132. Potter GG, Plassman BL, Burke JR, Kabeto MU, Langa KM, Llewellyn DJ, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and whites. Alzheimers Dement 2009;5(6):445–53.
133. Gurland BJ, Wilder DE, Lantigua R, Stern Y, Chen J, Killeffer EH, et al. Rates of dementia in three ethnoracial groups. Int J Geriatr Psychiatry 1999;14(6):481–93.
134. Reitz C, Jun G, Naj A, et al. Variants in the ATP-binding cassette transporter (ABCA7), apolipoprotein E 4, and the risk of late-onset Alzheimer disease in African Americans. JAMA. 2013;309(14):1483–1492.
135. Chin AL, Negash S, Hamilton R. Diversity and disparity in dementia: The impact of ethnoracial differences in Alzheimer disease. Alzheimer Dis Assoc Disord 2011;25(3):187–95.
136. Yaffe K, Falvey C, Harris TB, Newman A, Satterfield S, Koster A, et al. Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study. BMJ 2013;347:f7051.
137. Clark PC, Kutner NG, Goldstein FC, Peterson-Hazen S, Garner V, Zhang R, et al. Impediments to timely diagnosis of Alzheimer's disease in African Americans. J Am Geriatr Soc 2005;53(11):2012–7.
138. Fitten LJ, Ortiz F, Ponton M. Frequency of Alzheimer's disease and other dementias in a community outreach sample of Hispanics. J Am Geriatr Soc 2001;49(10):1301–8.
139. Unpublished tabulations based on data from the National 20% Sample Medicare Fee-for-Service Beneficiaries for 2009. Prepared under contract by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School, November 2011.
140. Hebert LE, Beckett LA, Scherr PA, Evans DA. Annual incidence of Alzheimer disease in the United States projected to the years 2000 through 2050. Alzheimer Dis Assoc Disord 2001;15(4):169–73.
141. Corrada MM, Brookmeyer R, Paganini-Hill A, Berlau D, Kawas CH. Dementia incidence continues to increase with age in the oldest old: The 90+ Study. Ann Neurol 2010;67(1):114–21.
142. Seshadri S, Beiser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB, et al. The lifetime risk of stroke: Estimates from the Framingham Study. Stroke 2006;37(2):345–50.
143. Vincent GK, Velkof VA. The Next Four Decades: The Older Population in the United States: 2010 to 2050. Washington, D.C.: U.S. Census Bureau; 2010.

144. Hebert LS, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 census. Arch Neurol 2003;60: 1119–22.
145. Murphy SL, Xu JQ, Kochanek KD. Deaths: Final data for 2010. National Vital Statistics Reports; Vol. 61, No 4. National Center for Health Statistics, Hyattsville, Md.; 2013. Available at: http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf. Accessed Dec 12, 2013.
146. World Health Organization. International Statistical Classification of Diseases and Related Health Problems. 10th revision. 2nd edition. Geneva, Switzerland; 2004.
147. Ives DG, Samuel P, Psaty BM, Kuller LH. Agreement between nosologist and Cardiovascular Health Study review of deaths: Implications of coding differences. J Am Geriatr Soc 2009;57(1):133–9.
148. Macera CA, Sun RK, Yeager KK, Brandes DA. Sensitivity and specificity of death certificate diagnoses for dementing illnesses, 1988-1990. J Am Geriatr Soc 1992;40(5):479–81.
149. Olichney JM, Hofstetter CR, Galasko D, Thal LJ, Katzman R. Death certificate reporting of dementia and mortality in an Alzheimer's Disease Research Center cohort. J Am Geriatr Soc 1995;43(8):890–3.
150. Burns A, Jacoby R, Luthert P, Levy R. Cause of death in Alzheimer's disease. Age Ageing 1990;19(5):341–44.
151. Brunnstrom HR, Englund EM. Cause of death in patients with dementia disorders. Eur J Neurol 2009;16(4):488–92.
152. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: A community study. J Am Geriatr Soc 1999;47(7):842–9.
153. Weuve J, Hebert LE, Scherr PA, Evans DA. Deaths in the United States among persons with Alzheimer's disease (2010-2050). Alzheimer Dement. In press.
154. James BD, Leurgans S, Hebert LE, Scherr PA, Yaffe K, Bennett DA. The contribution of Alzheimer's disease to mortality in the United States. Neurology. In press.
155. Unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2008. Prepared under contract by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School; November 2011.
156. Tinetti ME, McAvay GJ, Murphy TE, Gross CP, Lin H, Allore HG. Contribution of individual diseases to death in older adults with multiple diseases. J Am Geriatr Soc 2012;60(8):1448–56.
157. Arrighi HM, Neumann PJ, Lieberburg IM, Townsend RJ. Lethality of Alzheimer disease and its impact on nursing home placement. Alzheimer Dis Assoc Disord 2010;24(1):90–5.
158. National Center for Health Statistics. Deaths: Final Data for 2000. National Vital Statistics Reports. Hyattsville, Md.: National Center for Health Statistics; 2002.
159. Aguero-Torres H, Fratiglioni L, Guo Z, Viitanen M, Winblad B. Mortality from dementia in advanced age: A 5-year follow-up study of incident dementia cases. J Clin Epidemiol 1999;52(8):737–43.
160. Ganguli M, Dodge HH, Shen C, Pandav RS, DeKosky ST. Alzheimer disease and mortality: A 15-year epidemiological study. Arch Neurol 2005;62(5):779–84.
161. Tejada-Vera B. Mortality from Alzheimer's disease in the United States: Data for 2000 and 2010. National Center for Health Statistics Data Brief, No. 116. National Center for Health Statistics, Hyattsville, Md.; 2013.
162. Waring SC, Doody RS, Pavlik VN, Massman PJ, Chan W. Survival among patients with dementia from a large multi-ethnic population. Alzheimer Dis Assoc Disord 2005;19(4): 178–83.
163. Brookmeyer R, Corrada MM, Curriero FC, Kawas C. Survival following a diagnosis of Alzheimer disease. Arch Neurol 2002;59(11):1764–7.
164. Larson EB, Shadlen MF, Wang L, McCormick WC, Bowen JD, Teri L, et al. Survival after initial diagnosis of Alzheimer disease. Ann Intern Med 2004;140(7):501–9.
165. Helzner EP, Scarmeas N, Cosentino S, Tang MX, Schupf N, Stern Y. Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. Neurology 2008;71(19):1489–95.
166. Xie J, Brayne C, Matthews FE. Survival times in people with dementia: Analysis from a population based cohort study with 14-year follow-up. BMJ 2008;336(7638):258–62.
167. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005;53(2):299–305.
168. U.S. Burden of Disease Collaborators. The state of U.S. health, 1990–2010: Burden of diseases, injuries, and risk factors. JAMA 2013;310(6):591–608.
169. Gaugler JE, Kane RL, Kane RA. Family care for older adults with disabilities: Toward more targeted and interpretable research. Int J Aging Hum Dev 2002;54(3):205–31.
170. Schulz R, Quittner AL. Caregiving through the life-span: Overview and future directions. Health Psychol 1998;17: 107–11.
171. Wal-Mart Sales Report 2012. Available at http://www.walmartstores.com/sites/annual-report/2012/WalMart_AR.pdf.
172. McDonald's Corporation Report. Available at https://www.google.com/finance?fstype=ii&q=nyse:mcd.
173. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. N Engl J Med 2013;368:1326–34.
174. Gitlin LN, Schulz R. Family caregiving of older adults. In: Prohaska RT, Anderson LA, Binstock RH, eds. Public health for an aging society. Baltimore, Md.: The Johns Hopkins University Press; 2012: p. 181–204.
175. Bouldin ED, Andresen E. Caregiving Across the United States: Caregivers of Persons with Alzheimer's Disease or Dementia in 8 States and the District of Columbia. Data from the 2009 & 2010 Behavioral Risk Factor Surveillance System. Available at http://www.alz.org/documents_custom/public-health/2009-2010-combined-caregiving.pdf.
176. Langa KM, Plassman BL, Wallace RB, Herzog AR, Heeringa SG, Ofstedal MB, et al. The Aging, Demographics, and Memory Study: Study design and methods. Neuroepidemiol 2005;25(4)181–91.
177. Fisher GG, Franks MM, Plassman BL, Brown SL, Potter GG, Llewellyn D, et al. Caring for individuals with dementia and cognitive impairment, not dementia: Findings from The Aging, Demographics, and Memory Study. J Am Ger Soc 2011;59(3):488–94.
178. National Alliance for Caregiving and AARP. Caregiving in the U.S. Unpublished data analyzed under contract for the Alzheimer's Association; 2009.
179. Brody EM. "Women in the middle" and family help to older people. Gerontologist 1981;21(5):471–80.
180. Riley LD, Bowen CP. The sandwich generation: Challenges and coping strategies of multigenerational families. The Family Journal 2005;13(1):52–8.
181. Schumacher LAP, MacNeil R, Mobily K, Teague M, Butcher H. The leisure journey for sandwich generation caregivers. Ther Recreation J 2012;46(1):42–60.
182. Spitze G, Logan J. More evidence on women (and men) in the middle. Res Aging 1990;12(2):182–98.

183. Hammer LB, Neal MB. Working sandwiched-generation caregivers: Prevalence, characteristics, and outcomes. Psychol-Manager J 2008;11(1):93–112.
184. National Alliance for Caregiving and AARP. Caregiving in the U.S., November 2009. Available at http://assets.aarp.org/rgcenter/il/caregiving_09_fr.pdf.
185. Loomis LS, Booth A. Multigenerational caregiving and well-being. J Fam Issues 1995;16(2):131–48.
186. Rubin R, White-Means S. Informal caregiving: Dilemmas of sandwiched caregivers. J Fam Econ Issues 2009;30(3):252–67.
187. Boustani M, Perkins AJ, Fox C, Unverzagt F, Austrom MG, Fultz B, et al. Who refuses the diagnostic assessment for dementia in primary care? Int J Geriatr Psych 2006;21(6):556–63.
188. Garity J. Caring for a family member with Alzheimer's disease: Coping with caregiver burden post-nursing home placement. J Gerontol Nurs 2006;32(6):39–48.
189. Port CL, Zimmerman S, Williams CS, Dobbs D, Preisser JS, Williams SW. Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. Gerontologist 2005;45(Special Issue 1):87–95.
190. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. JAMA 2004;292(8):961–7.
191. Gaugler JE, Mittelman MS, Hepburn K, Newcomer R. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. BMC Medicine 2010;8:85.
192. Ornstein K, Gaugler JE. The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. Int Psychogeriatr 2012;24(10):1536–52.
193. Kiecolt-Glaser JK, Glaser R, Gravenstein S, Malarkey WB, Sheridan J. Chronic stress alters the immune response to influenza virus vaccine in older adults. Proc Natl Acad Sci 1996;93:3043–7.
194. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. JAMA 1999;282:2215–60.
195. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. Psychol Bull 2003;129(6):946–72.
196. Liu W, Gallagher-Thompson D. Impact of dementia caregiving: Risks, strains, and growth. In: Qualls SH, Zarit SH, eds. Aging families and caregiving. Hoboken, N.J.: John Wiley & Sons, Inc.; 2009: p. 85–112.
197. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. J Gerontol B Psychol Sci Soc Sci 2003;58(2):112–28.
198. Sörensen S, Duberstein P, Gill D, Pinquart M. Dementia care: Mental health effects, intervention strategies, and clinical implications. Lancet Neurol 2006;5(11):961–73.
199. Zarit S. Positive aspects of caregiving: More than looking on the bright side. Aging Ment Health 2012;16(6):673–74.
200. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. Gerontologist 1995;35(6):771–91.
201. Baumgarten M, Battista RN, Infante-Rivard C, Hanley JA, Becker R, Gauthier S. The psychological and physical health of family members caring for an elderly person with dementia. J Clin Epidemiol 1992;45(1):61–70.
202. Seeher K, Low L-F, Reppermund S, Brodaty H. Predictors and outcomes for caregivers of people with mild cognitive impairment: A systematic literature review. Alzheimers Dement 2013;9(3):346–55.
203. Kessler RC, Chiu WT, Demler O, Merikangas KR, Walters EE. Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. Arch Gen Psychiatry 2005;62:617–27.
204. Epstein-Lubow G, Gaudiano B, Darling E, Hinckley M, Tremont G, Kohn R, et al. Differences in depression severity in family caregivers of hospitalized individuals with dementia and family caregivers of outpatients with dementia. Am J Geriatr Psychiatry 2012:20(9):815–9.
205. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. Med Care 2009;47(2):191–8.
206. Marziali E, Shulman K, Damianakis T. Persistent family concerns in long-term care settings: Meaning and management. J Am Med Dir Assoc 2006;7(3):154–62.
207. Strang VR, Koop PM, Dupuis-Blanchard S, Nordstrom M, Thompson B. Family caregivers and transition to long-term care. Clin Nurs Res 2006;15(1):27–45.
208. Peacock SC. The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review. Palliat Support Care 2013;11(2):155–68.
209. Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. N Engl J Med 2003;349(20):1936–42.
210. Peng H-L, Chang Y-P. Sleep disturbance in family caregivers of individuals with dementia: A review of the literature. Perspect Psychiatr Care 2012;49(2):135–46.
211. MetLife Mature Market Institute. The MetLife Study of Alzheimer's disease: The caregiving experience. Aug. 2006. Available at https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-alzheimers-disease-caregiving-experience-study.pdf. Accessed on December 8, 2013.
212. Fredman L, Bertrand RM, Martire LM, Hochberg M, Harris EL. Leisure-time exercise and overall physical activity in older women caregivers and non-caregivers from the Caregiver-SOF Study. Prev Med 2006;43:226–9.
213. Roepke SK, Allison M, Von Kanel R, Mausbach BT, Chattillion, EA, Harmell AL, et al. Relationship between chronic stress and carotid intima-media thickness (IMT) in elderly Alzheimer's disease caregivers. Stress 2012;15(2):121–9.
214. Gouin J, Glaser R, Malarkey WB, Beversdorf D, Kiecolt-Glaser J. Chronic stress, daily stressors, and circulating inflammatory markers. Health Psychol 2012;31(2):264–8.
215. von Kanel R, Mills PJ, Mausbach BT, Dimsdale JE, Patterson TL, Ziegler MG, et al. Effect of Alzheimer caregiving on circulating levels of C-reactive protein and other biomarkers relevant to cardiovascular disease risk: A longitudinal study. Gerontology 2012;58(4):354–65.
216. von Kanel R, Mausbach BT, Dimsdale JE, Mills PJ, Patterson TL, Ancoli-Israel S, et al. Effect of chronic dementia caregiving and major transitions in the caregiving situation on kidney function: A longitudinal study. Psychosom Med 2012;74(2);214–20.
217. Mausbach BT, Chattillion E, Roepke SK, Ziegler MG, Milic M, von Kanel R, et al. A longitudinal analysis of the relations among stress, depressive symptoms, leisure satisfaction, and endothelial function in caregivers. Health Psychol 2012;31(4):433–40.
218. Chattillion EA, Mausbach BT, Roepke SK, von Kanel R, Mills PJ, Dimsdale JE, et al. Leisure activities, caregiving demands and catecholamine levels in dementia caregivers. Psychol Health 2012;27(10):1134–49.

219. von Kanel R, Dimsdale JE, Mills PJ, Ancoli-Israel S, Patterson TL, Mausback BT, et al. Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. J Gerontol A Biol Sci Med Sci 2006;61(9):963–9.
220. Kiecolt-Glaser JK, Dura JR, Speicher CE, Trask OJ, Galser R. Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. Psychosom Med 1991;53:345–62.
221. Kiecolt-Glaser JK, Marucha PT, Mercado AM, Malarkey WB, Glaser R. Slowing of wound healing by psychological stress. Lancet 1995;346(8984):1194–6.
222. Shaw WS, Patterson TL, Ziegler MG, Dimsdale JE, Semple SJ, Grant I. Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. J Psychosom Res 1999;46(3):215–27.
223. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler I. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. Psychosom Med 2002;64:418–35.
224. Mausbach BT, Roepke SK, Ziegler MG, Milic M, Von Kanel R, Dimsdale JE, et al. Association between chronic caregiving stress and impaired endothelial function in the elderly. J Am Coll Cardiol 2010;55(23):2599–606.
225. Schubert CC, Boustani M, Callahan CM, Perkins AJ, Hui S, Hendrie HC. Acute care utilization by dementia caregivers within urban primary care practices. J Gen Intern Med 2008;23(11):1736–40.
226. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. N Engl J Med 2006;354:719–30.
227. Brown SL, Smith DM, Schulz R, Kabeto MU, Ubel PA, Poulin M, et al. Caregiving behavior is associated with decreased mortality risk. Psychol Sci 2009;20:488–94.
228. Fredman L, Cauley JA, Hochberg M, Ensrud KE, Doros G. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of Caregiver Study of Osteoporotic Fractures. J Am Ger Soc 2010;58:937–43.
229. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ. Profiles in caregiving: The unexpected career. San Diego, Calif.: Academic Press; 1995.
230. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist 2002;42(3):356–72.
231. Mittelman M. Psychosocial interventions to address the emotional needs of caregivers of individuals with Alzheimer's disease. In: Zarit SH, Talley RC, eds., Caregiving for Alzheimer's disease and related disorders. New York, N.Y.: Springer; 2013: p. 17–34.
232. Logsdon RG. Dementia: Psychosocial interventions for family caregivers. Lancet 2008;372(9634):182–3.
233. Logsdon RG, McCurry SM, Teri L. Evidence-based psychological treatments for disruptive behaviors in individuals with dementia. Psychol and Aging 2007;22(1):28–36.
234. Zarit SH. Empirically supported treatment for family caregivers. In: Qualls SH, Zarit SH, eds. Aging families and caregiving. Hoboken, N.J.: John Wiley & Sons, Inc.; 2009: p. 131–54.
235. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. Neurology 2006;67(9):1592–9.
236. Mittelman MS, Epstein C, Pierzchala A. Counseling the Alzheimer's caregiver: A resource for health care professionals. Chicago: AMA Press; 2003.
237. Gaugler JE. Dementia and families: Interventions that work; 2008. Available at http://www.mngero.org/downloads/dementiawebinar.pdf. Accessed October 22, 2008.
238. Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D. Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Investigators. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. Ann Intern Med 2006;145(10):727–38.
239. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. Res Nurs Health 2001;24:349–60.
240. Ostwald SK, Hepburn KW, Caron W, Burns T, Mantell R. Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. Gerontologist 1999;39(3):299–309.
241. Hepburn KW, Tornatore J, Center B, Ostwald SW. Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. J Am Geriatr Soc 2001;49(4):450–7.
242. Hepburn KW, Lewis M, Sherman CW, Tornatore J. The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. Gerontologist 2003;43(6):908–15.
243. Bass DM, Judge KS, Snow LA, Wilson NL, Morgan R, Looman WJ, et al. Caregiver outcomes of partners in dementia care: Effect of a care coordination program for veterans with dementia and their family members and friends. J Am Geriatr Soc 2013;61(8):1377–86.
244. Judge KS, Yarry SJ, Looman WJ, Bass DM. Improved strain and psychosocial outcomes for caregivers of individuals with dementia: Findings from Project ANSWERS. Gerontologist 2013;53(2):280–92.
245. Levy K, Lanctot KL, Farber SB, Li A, Herrmann N. Does pharmacological treatment of neuropsychiatric symptoms in Alzheimer's disease relieve caregiver burden? Drug Aging 2012;29(3):167–79.
246. Whitebird RR, Kreitzer M, Crain AL, Lewis BA, Hanson LR, Enstad CJ. Mindfulness-based stress reduction for family caregivers: A randomized controlled trial. Gerontologist 2013;53(4):676–86.
247. Zarit SH, Reamy AM. Developmentally appropriate long-term care for people with Alzheimer's disease and related disorders. In: Zarit SH, Talley RC, eds., Caregiving for Alzheimer's disease and related disorders. New York, N.Y.: Springer; 2013: p. 51–69.
248. Gaugler JE, Gallagher-Winker K, Kehrberg K, Lunde AM, Marsolek CM, Ringham K, et al. The memory club: Providing support to persons with early-stage dementia and their care partners. Am J Alzheimers Dis Other Demen 2011;26(3):218–26.
249. Logsdon RG, Pike KC, McCurry SM, Hunter P, Maher J, Snyder L, et al. Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. J Gerontol B Psychol Sci Soc Sci 2010;65(6):691–7.
250. Schulz R, Lustig A, Handler S, Martire LM. Technology-based caregiver intervention research: Current status and future directions. Gerontol Tech J 2002;2(1):15–47.
251. Elliott AF, Burgio LD, DeCoster J. Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention. J Am Ger Soc 2010;58(1):30–7.
252. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacological intervention. J Am Ger Soc 2010;58:1465–74.
253. Gitlin LN, Winter L, Dennis MP. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. JAMA 2010;304(9):983–91.

254. Lee CC, Czaja SJ, Schultz R. The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups. J Gerontol B Psychol Sci Soc Sci 2010;65(2):185–94.
255. Gaugler JE, Roth DL, Haley WE, Mittelman MS. Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University Caregiver Intervention Study. J Am Ger Soc 2008;56:421–8.
256. Llanque SM, Enriquez M. Interventions for Hispanic caregivers of patients with dementia: A review of the literature. Am J Alzheimers Dis Other Demen 2012;27(1):23–32.
257. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. J Am Geriatr Soc 2003;51(5):657–64.
258. Smits CH, de Lange J, Dröes RM, Meiland F, Vernooij-Dassen M, Pot AM. Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. Int J Geriatr Psychiatry 2007;22(12):1181–93.
259. Griffin JM, Meis L, Greer N, Jensen A, MacDonald R, Rutks I, et al. Effectiveness of family and caregiver interventions on patient outcomes among adults with cancer or memory-related disorders: A systematic review. VA ESP Project 2013. Available at http://www.hsrd.research.va.gov/publications/esp/caregiver-interventions.cfm#.Ui5DMD89X2w.
260. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: Which interventions work and how large are their effects? Int Psychogeriatr 2006;18(4):577–95.
261. Jones AL, Dwyer LL, Bercovitz AR, Strahan GW. The National Nursing Home Survey: 2004 overview. Vital Health Stat 13 2009;(167):1–155.
262. Kramer NA, Smith MC. Training nursing assistants to care for nursing home residents with dementia. In: Molinari V, editor. Professional psychology in long term care. New York, N. Y.: Hatherleigh Press; 2000: p. 227–56.
263. McCabe MP, Davison TE, George K. Effectiveness of staff training programs for behavioral problems among older people with dementia. Aging Ment Health 2007;11(5):505–19.
264. Beck C, Ortigara A, Mercer S, Shue V. Enabling and empowering certified nursing assistants for quality dementia care. Int J Geriatr Psychiatry 1999;14(3):197–211.
265. Institute of Medicine. Retooling for an aging America: Building the health care workforce. Washington, D.C.: The National Academies Press 2008. Available at http://www.nap.edu.
266. Cohen-Mansfield J. Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. Am J Geriatr Psychiatry 2001;9(4):361–81.
267. Lawrence V, Fossey J, Ballard C, Moniz-Cook E, Murray J. Improving quality of life for people with dementia in care homes: Making psychosocial interventions work. Br J Psychiatry 2012;201(5):344–51.
268. Eldercare Workforce Alliance. Geriatrics workforce shortage: A looming crisis for our families. Washington, D.C.: Eldercare Workforce Alliance; 2012.
269. Association of American Medical Colleges. 2012 Physician Specialty Data Book. Available at https://members.aamc.org/eweb/upload/2012%20Physician%20Specialty%20Data%20Book.pdf.
270. Brody AA, Galvin JE. A review of interprofessional dissemination and education interventions for recognizing and managing dementia. Gerontol Geriatr Educ 2013;34(3):225–56.
271. Yang Z, Zhang K, Lin PJ, Clevenger C, Atherly A. A longitudinal analysis of the lifetime cost of dementia. Health Serv Res 2012;47(4):1660-78.
272. Rudolph JL, Zanin NM, Jones RN, Marcantonio ER, Fong TG, Yang FM, et al. Hospitalization in community-dwelling persons with Alzheimer's disease: Frequency and causes. J Am Ger Soc 2010;58(8):1542–8.
273. Medicare. Glossary. Medicare: The Official U.S. Government Site for Medicare. Available at http://www.medicare.gov/HomeHealthCompare/Resources/Glossary.html. Accessed December 8, 2013.
274. Suehs BT, Davis CD, Alvir J, van Amerongen D, Patel NC, Joshi AV, et al. The clinical and economic burden of newly diagnosed Alzheimer's disease in a Medicare Advantage population. Am J Alzheimers Dis Other Dement 2013;28(4):384–92.
275. Lin PJ, Fillit HM, Cohen JT, Neumann PJ. Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders. Alzheimers Dement 2013;9(1):30–8.
276. Met Life Mature Market Institute. Market Survey of Long-Term Care Costs: The 2012 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs. New York, N.Y.: Metropolitan Life Insurance Company; 2012.
277. Johnson RW, Wiener JM. A profile of frail older Americans and their caregivers. Washington, D.C.: Urban Institute; February 2006.
278. Fortinsky RH, Fenster JR, Judge JO. Medicare and Medicaid home health and Medicaid waiver services for dually eligible older adults: Risk factors for use and correlates of expenditures. Gerontologist 2004;44(6):739–49.
279. Hirdes JP, Fries BE, Morris JN, et al. Home care quality indicators (HCQIs) based on the MDS-HC. Gerontologist 2004;44(5):665–79.
280. Mitchell G, Salmon JR, Polivka L, Soberon-Ferrer H. The relative benefits and cost of Medicaid home- and community-based services in Florida. Gerontologist 2006:46(4):483–94.
281. Partners in Caregiving. A National Study of Adult Day Services, 2001-2002. Winston-Salem, N.C.: Wake Forest University School of Medicine; 2002.
282. O'Keeffe J, Siebenaler K. Adult day services: A key community service for older adults. Office of the Assistant Secretary for Planning and Evaluation, Washington, D.C.: U.S. Department of Health and Human Services; July 2006.
283. Mollica R, Houser A, Ujvari K. Assisted living and residential care in the states in 2010. AARP Public Policy Institute; 2012.
284. American Health Care Association. LTC Stats: Nursing Facility Operational Characteristics Report. Table 5: Nursing Facility Beds in Dedicated Special Care Units, June 2013.
285. Callahan CM, Arling G, Tu W, Rosenman MB, Counsell SR, Stump TE, Hendrie HC. Transitions in care among older adults with and without dementia. J Am Geriatr Soc 2012;60(5):813–20.
286. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. N Engl J Med 2011;365(13):1212–21.
287. Teno JM, Mitchell SL, Skinner J, et al. Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. J Palliat Med 2009;12(4):359–62.
288. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA 2013;309(5):470–7.
289. Medicare Payment Advisory Commission (MedPAC). Report to the Congress: Medicare Payment Policy. Chapter 10: Long-Term Care Hospital Services. Washington, D.C.: MedPAC; March 15, 2012.
290. Centers for Medicare and Medicaid Services. What are long-term care hospitals? CMS Publication No. 11347; 2012.

291. Centers for Medicare and Medicaid Services. Moratorium on Classification of Long-Term Care Hospitals or Satellites/ Increase in Certified LTCH Beds. MLN Matters. Medicare Learning Network. MLN Matters Number MM6172; 2008.
292. National Conference of State Legislatures. Certificate of Need: State Health Laws and Programs. Updated March 2012. Available at http://www.ncsl.org/issues-research/health/con-certificate-of-need-state-laws.aspx#moratoria. Accessed on December 16, 2012.
293. U.S. Census Bureau. Poverty Thresholds by Size of Family and Number of Children. Available at http://www.census.gov/hhes/www/poverty/data/threshld/.
294. Kaiser Family Foundation Program on Medicare Policy. Projecting income and assets: What might the future hold for the next generation of Medicare beneficiaries? Menlo Park, Calif.: Henry J. Kaiser Family Foundation; 2011.
295. American Association for Long-Term Care Insurance. The 2011 Sourcebook for Long-Term Care Insurance Information. Westlake Village, Calif.
296. Kaiser Commission on Medicaid and the Uninsured 2012. Medicaid and Long-Term Care Services and Supports No. 2168-09. Washington, D.C.: Henry J. Kaiser Family Foundation.
297. Moody's Investors Service. Special Comment: Long-Term Care Insurance: Sector Profile. September 18, 2012.
298. Gilligan AM, Malone DC, Warholak TL, Armstrong EP. Health disparities in cost of care in patients with Alzheimer's disease: An analysis across 4 state Medicaid populations. American J Alzheimers Dis Other Dement 2013;28(1):84–92.
299. U.S. Centers for Medicare and Medicaid Services. Hospice Center. Available at http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare_Hospice_Data.html.
300. Shriver M. The Shriver Report: A Woman's Nation Takes on Alzheimer's. Chicago, Ill.: Alzheimer's Association; 2010.
301. Chene G, Beiser A, Au R, Preis SR, Wolf PA, Dufouil C, et al. Gender and incidence of dementia in the Framingham Heart Study from mid-adult life. Alzheimers Dement 2014. Epub ahead of print.
302. Carter CL, Resnick EM, Mallampalli M, Kalbarczyk A. Sex and gender differences in Alzheimer's disease: Recommendations for future research. J Womens Health 2012;21(10):1018–1023.
303. Ott BR, Tate CA, Gordon NM, Heindel WC. Gender differences in the behavioral manifestations of Alzheimer's disease. J Am Geriatr Soc 1996;44(5):583–587.
304. Radiological Society of North America. Researchers Discover Gender-based Differences in Alzheimer's Disease. Oak Brook, Ill.; 2012. Available at http://www2.rsna.org/timssnet/media/pressreleases/pr_target.cfm?id=634.
305. Ungar L, Altmann A, Greicius MD. Apolipoprotein E, gender, and Alzheimer's disease: An overlooked, but potent and promising interaction. Brain Imaging Behav 2013. Epub ahead of print.
306. Skup M, Zhu H, Wang Y, Giovanello KS, Lin JA, Shen D, et al. Sex differences in grey matter atrophy patterns among AD and aMCI patients: Results from ADNI. Neuroimage 2011;56(3):890-906.
307. Cranswick K, Dosman D. Eldercare: What we know today. Statistics Canada; 2008. Available at http://www.statcan.gc.ca/pub/11-008-x/2008002/article/10689-eng.pdf.
308. Bouldin ED, Andresen E. Caregiving Across the United States: Caregivers of Persons with Alzheimer's Disease or Dementia in Connecticut, New Hampshire, New Jersey, New York, and Tennessee. Data from the 2010 Behavioral Risk Factor Surveillance System. Seattle, Wash.; 2010.
309. National Alliance for Caregiving and AARP. Caregiving in the U.S., April 2004. Available at http://www.caregiving.org/data/04finalreport.pdf.
310. Campbell P, Wright J, Oyebode J, Job D, Crome P, Bentham P, et al. Determinants of burden in those who care for someone with dementia. Int J Geriatr Psychiatry 2008;23(10):1078–1085.
311. Pope ND, Kolomer S, Glass AP. How women in late midlife become caregivers for their aging parents. J Women Aging 2012;24(3):242–261.
312. Bedard M, Raney D, Molloy DW, Lever J, Pedlar D, Dubois S. The experience of primary and secondary caregivers caring for the same adult with Alzheimer's disease. J Ment Health Aging 2001;7(2):287.
313. Brazil K, Thabane L, Foster G, Bédard M. Gender differences among Canadian spousal caregivers at the end of life. Health Soc Care Comm 2009;17(2):159–166.
314. Bedard M, Kuzik R, Chambers L, Molloy DW, Dubois S, Lever JA. Understanding burden differences between men and women caregivers: the contribution of care-recipient problem behaviors. Int Psychogeriatr 2005;17(1):99–118.
315. Gibbons C, Creese J, Tran M, Brazil K, Chambers L, Weaver B, et al. The psychological and health consequences of caring for a spouse with dementia: A critical comparison of husbands and wives. J Women Aging 2014;26(1):3–21.
316. Feld S, Dunkle RE, Schroepfer T, Shen HW. Does gender moderate factors associated with whether spouses are the sole providers of IADL care to their partners? Res Aging 2010;32(4):499–526.
317. Nagatomo I, Akasaki Y, Uchida M, Tominaga M, Hashiguchi W, Takigawa M. Gender of demented patients and specific family relationship of caregiver to patients influence mental fatigue and burdens on relatives as caregivers. Int J Geriatr Psychiatry 1999;14(8):618–625.
318. Gaugler JE, Davey A, Pearlin LI, Zarit SH. Modeling caregiver adaptation over time: The longitudinal impact of behavior problems. Psychol Aging 2000;15(3):437–450.
319. U.S. Department of Labor. 20 Leading Occupations for Employed Women, 2012. Washington, D.C.; 2012. Available at http://www.dol.gov/wb/stats/Occupations.htm#Lofw.
320. U.S. Department of Labor, Bureau of Labor Statistics. Occupational Employment and Wages, May 2012: 31-1011 Home Health Aides. Available at http://www.bls.gov/oes/current/oes311011.htm. Accessed on Feb. 14, 2014.
321. U.S. Department of Labor, Bureau of Labor Statistics. Occupational Employment and Wages, 2012: 39-9021 Personal Care Aides. Available at http://www.bls.gov/oes/current/oes399021.htm. Accessed on Feb. 14, 2014.
322. Hebert LE, Bienias JL, Aggarwal NT, et al. Change in risk of Alzheimer disease over time. Neurology 2010;75:786–91.
323. Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. Am J Public Health 1998;88(9):1337–42.
324. Amo PS, Levine C, Memmott MM. The economic value of informal caregiving. Health Aff 1999;18:182–8.
325. U.S. Department of Labor, Bureau of Labor Statistics. Employment, Hours, and Earnings from the Current Employment Statistics Survey. Series 10-CEU 6562160008, Home Health Care Services (NAICS code 6216), Average Hourly Earnings, July 2012. Available at www.bls.gov/ces. Accessed on Dec. 7, 2012.
326. Albert SM, Schulz R. The MetLife Study of Working Caregivers and Employer Health Care Costs, New York, N.Y.: MetLife Mature Market Institute, 2010.
327. Centers for Medicare and Medicaid Services, Center for Strategic Planning, Health Expenditures by State of Residence 1991–2009. Available at www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/National-HealthExpendData/NationalHealthAccountsStateHealthAccountsResidence.html.

The Alzheimer's Association acknowledges the contributions of Joseph Gaugler, Ph.D., Bryan James, Ph.D., Tricia Johnson, Ph.D., Ken Scholz, Ph.D., and Jennifer Weuve, M.P.H., Sc.D., in the preparation of *2014 Alzheimer's Disease Facts and Figures*.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.®

Alzheimer's Association
National Office
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601-7633

Alzheimer's Association
Public Policy Office
1212 New York Ave., N.W., Suite 800
Washington, DC 20005-6105

800.272.3900
alz.org®

alzheimer's association®

THE BRAINS BEHIND SAVING YOURS.™