

# 2015 Alzheimer's Disease Facts and Figures

Includes a Special Report on Disclosing a Diagnosis of Alzheimer's Disease



ALZHEIMER'S DISEASE IS THE SIXTH-LEADING CAUSE OF DEATH IN THE UNITED STATES. MORE THAN 15 MILLION AMERICANS PROVIDE UNPAID CARE FOR INDIVIDUALS WITH ALZHEIMER'S OR ANOTHER DEMENTIA. PAYMENTS FOR HEALTH CARE ARE ESTIMATED TO BE \$226 BILLION IN 2015. FEWER THAN 50 PERCENT OF PEOPLE WITH ALZHEIMER'S DISEASE REPORT BEING TOLD OF THEIR DIAGNOSIS.

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## About this report

*2015 Alzheimer's Disease Facts and Figures* is a statistical resource for U.S. data related to Alzheimer's disease, the most common cause of dementia, as well as other dementias. Background and context for interpretation of the data are contained in the Overview. This information includes descriptions of the various causes 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 health care. The Special Report addresses issues surrounding the disclosure of an Alzheimer's diagnosis to individuals with the disease.

**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.
- Challenges surrounding the disclosure of an Alzheimer's disease diagnosis to individuals with the disease.

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

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

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# Overview of Alzheimer's Disease

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

Alzheimer's disease is a degenerative brain disease and the most common cause of dementia.<sup>1-2</sup> Dementia is also caused by other diseases and conditions. It is characterized by a decline in memory, language, problem-solving and other cognitive skills that affects a person's ability to perform everyday activities. This decline occurs because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged and no longer function normally. In Alzheimer's disease, neuronal damage eventually affects parts of the brain that enable a person 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

Physicians often refer to the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* to guide them in determining if an individual has dementia and, if so, the condition causing dementia. The latest edition of the manual, *DSM-5*, classifies dementia as a neurocognitive disorder.<sup>3</sup> Dementia may be either a major or a mild neurocognitive disorder. To meet *DSM-5* criteria for a major neurocognitive disorder, an individual must have evidence of significant cognitive decline, and the 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 a 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 mental effort).

When an individual has these or other symptoms of dementia, a physician must conduct tests to identify the cause. Different causes of dementia are associated with distinct symptom patterns and brain abnormalities, as described in Table 1 (see pages 6-7). 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 cause of dementia.<sup>4-8</sup> This is called mixed dementia.

In some cases, individuals do not have dementia, but instead have a condition whose symptoms mimic those of dementia. Common causes of dementia-like symptoms are depression, delirium, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol. Unlike dementia, these conditions often may be reversed with treatment. One meta-analysis, a method of analysis in which results of multiple studies are examined, reported that 9 percent of people with dementia-like symptoms did not in fact have dementia, but had other conditions that were potentially reversible.<sup>9</sup>

TABLE 1

## Causes and Characteristics of Dementia\*

Cause	Characteristics
Alzheimer's disease	<p>Most common cause 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).</p> <p>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.</p> <p>Revised criteria and guidelines for diagnosing Alzheimer's were proposed and published in 2011 (see pages 13-14). They recommend that Alzheimer's be considered a slowly progressive brain disease that begins well before clinical symptoms emerge.</p> <p>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.</p>
Vascular dementia	<p>Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than 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 (see mixed dementia in this table).<sup>10</sup></p> <p>Impaired judgment or impaired ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.</p> <p>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.</p> <p>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 pathologic evidence, which shows that the brain changes of Alzheimer's and vascular dementia commonly coexist. When evidence of two or more causes of dementia are present at the same time, the individual is considered to have mixed dementia (see mixed dementia in this table).</p>
Dementia with Lewy bodies (DLB)	<p>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.</p> <p>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.</p> <p>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).</p>

TABLE 1 (cont.)

## Causes and Characteristics of Dementia\*

Cause	Characteristics
<b>Frontotemporal lobar degeneration (FTLD)</b>	<p>Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.</p> <p>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.</p> <p>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).</p> <p>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.</p>
<b>Mixed dementia</b>	<p>Characterized by the hallmark abnormalities of more than one cause 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.<sup>5,6</sup></p> <p>Recent studies suggest that mixed dementia is more common than previously recognized, with about half of those with dementia having pathologic evidence of more than one cause of dementia.<sup>5,6</sup></p>
<b>Parkinson's disease (PD) dementia</b>	<p>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.</p> <p>The incidence of PD is about one-tenth that of Alzheimer's.</p> <p>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).</p>
<b>Creutzfeldt-Jakob disease</b>	<p>This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes.</p> <p>Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction.</p> <p>May be hereditary (caused by a gene that runs in one's family), sporadic (unknown cause) or caused by a known prion infection.</p> <p>A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p>
<b>Normal pressure hydrocephalus</b>	<p>Symptoms include difficulty walking, memory loss and inability to control urination.</p> <p>Accounts for less than 5 percent of dementia cases.<sup>11</sup></p> <p>Caused by impaired reabsorption of cerebrospinal fluid and the consequent build-up of fluid in the brain, increasing pressure in the brain.</p> <p>People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk.</p> <p>Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</p>

\* For more information on these and other causes of dementia, visit [alz.org/dementia](http://alz.org/dementia).

## ALZHEIMER'S DISEASE

Alzheimer's disease was first identified more than 100 years ago, but 70 years passed before it was recognized as the most common cause of dementia and a "major killer."<sup>12</sup> 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 more quickly in some than in others, and how the disease can be prevented, slowed or stopped.

Researchers believe that early detection will be key to preventing, slowing and stopping Alzheimer's disease. The last 10 years have seen a tremendous growth in research on early detection. This research spurred the 2011 publication of proposed new diagnostic criteria and guidelines for Alzheimer's disease (see pages 13-14).<sup>13-16</sup> Under the proposed criteria, the disease begins before symptoms such as memory loss appear, while earlier criteria require memory loss and a decline in thinking abilities for an Alzheimer's diagnosis to be made. Because scientific evaluation of the proposed criteria is ongoing, "Alzheimer's disease" in this report refers to the disease as defined by the earlier criteria.<sup>17</sup>

### Symptoms

Alzheimer's disease symptoms vary among individuals. The most common initial symptom is a gradually worsening ability to remember new information. This memory decline 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 the symptoms of Alzheimer's, visit [alz.org](http://alz.org).

The pace at which symptoms advance from mild to moderate to severe varies from person to person. As the disease progresses, cognitive and functional abilities decline. 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 neuronal circuits, creating the cellular basis of memories, thoughts, sensations, emotions, movements and skills.

The accumulation of the protein beta-amyloid (called beta-amyloid plaques) *outside* neurons and the accumulation of an abnormal form of the protein tau (called tau tangles) *inside* neurons are two of several brain changes believed to contribute to the development of Alzheimer's. 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 inside neurons 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 associated with Alzheimer's may begin 20 or more years<sup>18-20</sup> 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, individuals are 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 individuals show subtle decline in cognitive function. Later, neuronal damage is so significant that individuals show 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)<sup>21</sup> develop as a result of mutations to any of three specific 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 (APP) and the genes for the presenilin 1 and presenilin 2 proteins. Those inheriting a mutation to the APP or presenilin 1 genes are guaranteed to develop Alzheimer's. Those inheriting a mutation in the presenilin 2 gene have a 95 percent chance of developing the disease.<sup>22</sup> Individuals with mutations in any of these three genes tend to develop Alzheimer's symptoms 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 genetic mutations, experts believe that Alzheimer's, like other common chronic diseases, develops as a result of multiple factors rather than a single cause. This section describes known risk factors for Alzheimer's. Other factors that may affect risk are being studied.

#### Age

The greatest risk factor for Alzheimer's disease is 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 more rare (see the Prevalence section). While age is the greatest risk factor, Alzheimer's is not a normal part of aging and age alone is not sufficient to cause the disease.

#### *Apolipoprotein E (APOE)-e4 Gene*

The APOE gene provides the blueprint for a protein that transports cholesterol in the bloodstream. Everyone inherits one form of the APOE gene — e2, e3 or e4 — from each parent:

- The e3 form is the most common,<sup>23</sup> with about 60 percent of the U.S. population inheriting e3 from both parents.<sup>24</sup>
- The e4 form is carried by an estimated 20 to 30 percent of individuals; approximately 2 percent of the U.S. population has two copies of e4.<sup>23-24</sup>
- The e2 form is carried by an estimated 10 to 20 percent of the population.<sup>23-24</sup>

Having the e4 form increases one's risk compared with having the e3 form, while having the e2 form may decrease one's risk compared with the e3 form. Those who inherit one copy of the e4 form have a three-fold higher risk of developing Alzheimer's than those without the e4 form, while those who inherit two copies of the e4 form have an 8- to 12-fold higher risk.<sup>25-26</sup> In addition, those with the e4 form are more likely to develop Alzheimer's at a younger age than those with the e2 or e3 forms of the APOE gene.<sup>27</sup> Researchers estimate that between 40 and 65 percent of people diagnosed with Alzheimer's have one or two copies of the APOE-e4 gene.<sup>23,28-29</sup>

Unlike inheriting a genetic mutation that causes Alzheimer's, inheriting the e4 form of the APOE gene does not guarantee that an individual will develop Alzheimer's. This is also true for more than 20 recently identified genes that appear to affect the risk of Alzheimer's. These recently identified genes are believed to have a limited overall effect in the population because they are rare or only slightly increase risk.<sup>30</sup>

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

A family history of Alzheimer's is not necessary for an individual to develop the disease. However, 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.<sup>25,31</sup> Those who have more than one first-degree relative with Alzheimer's are at even higher risk.<sup>32</sup> 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 APOE-e4 risk gene.

#### ***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 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. Revised criteria and guidelines for diagnosis of Alzheimer's disease published in 2011<sup>13-16</sup> (see pages 13-14) suggest that in some cases MCI is actually an early stage of Alzheimer's or another dementia. However, MCI does not always lead to dementia. In some individuals, MCI reverts to normal cognition 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.

#### ***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 dementia. These factors include smoking,<sup>33-35</sup> obesity in midlife<sup>36-38</sup> and diabetes.<sup>35,39-42</sup> Some evidence suggests that impaired glucose processing (a precursor to diabetes) may also result in an increased risk for dementia.<sup>36,43-44</sup> Growing evidence also implicates midlife hypertension<sup>36,45-47</sup> and midlife high cholesterol<sup>48-49</sup> as risk factors.

Conversely, factors that protect the heart may also protect the brain and reduce the risk of developing Alzheimer's and other dementias. Physical activity<sup>42,50-51</sup> 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 fruits, may be associated with reduced Alzheimer's and dementia risk.<sup>42,52-54</sup>

Unlike genetic risk factors, many 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.

Researchers have begun to study combinations of health factors and lifestyle behaviors to learn whether they are better than individual factors and behaviors at identifying increased risk.<sup>55</sup>

### ***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.<sup>56-60</sup> 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.<sup>59,61-62</sup> 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.

Some scientists believe other factors may contribute to or explain the increased risk of dementia among those with lower educational attainment. These factors include being more likely to have occupations that are less mentally stimulating.<sup>63</sup> In addition, lower educational attainment may reflect lower socioeconomic status,<sup>63</sup> which may increase one's likelihood of poor nutrition and decrease one's ability to afford health care or obtain suggested treatments.

### ***Social and Cognitive Engagement***

Additional studies suggest that remaining socially and mentally active throughout life may support brain health and possibly reduce the risk of Alzheimer's and other dementias.<sup>64-76</sup> Remaining socially and mentally active may help build cognitive reserve, 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.

### ***Traumatic Brain Injury (TBI)***

Moderate and severe TBIs increase the risk of developing Alzheimer's disease and other dementias.<sup>77</sup> 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.<sup>78</sup> 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.<sup>79</sup>

Individuals who have experienced 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 have not experienced head injury.<sup>80-86</sup> Evidence suggests that even repeated mild TBI might promote neurodegenerative disease.<sup>87-89</sup> 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. No single, simple test exists to diagnose Alzheimer's disease. A variety of approaches and tools are available to help make a diagnosis. They include the following:

- Obtaining a medical and family history from the individual, including psychiatric history and history of cognitive and behavioral changes.
- Asking a family member or other person close to the individual to provide input about changes in thinking skills or behavior.
- Seeking input from a specialist, such as a neurologist.
- Conducting cognitive tests and physical and neurologic examinations.
- Having the individual undergo a magnetic resonance imaging (MRI) scan, which can help identify brain changes, such as a tumor, that could explain the individual's symptoms.

Before making a diagnosis of Alzheimer's, physicians may refer to medical resources such as the *DSM-5* and published diagnostic criteria that delve even further into the disease.

## Treatment of Alzheimer's Disease

### *Pharmacologic Treatment*

Pharmacologic treatments employ medication to slow or stop an illness or treat its symptoms. Six drugs have been approved by the U.S. Food and Drug Administration (FDA) 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. However, none of the treatments available today for Alzheimer's disease slows or stops the damage to neurons that causes Alzheimer's symptoms and eventually makes the disease fatal.

In December 2014, the FDA approved the sixth drug, which combines two existing FDA-approved Alzheimer's drugs and is for moderate to severe disease. Prior to that, the last approval of an Alzheimer's drug was in 2003. In the decade of 2002–2012, 244 drugs for Alzheimer's were tested in clinical trials registered with ClinicalTrials.gov, a National Institutes of Health registry of publicly and privately funded clinical studies.<sup>90</sup> The drug approved in 2003 was the only drug of the 244 tested to complete the clinical trials process and receive approval. Many factors contribute to the difficulty of developing effective treatments for Alzheimer's. These factors include the high cost of drug development, the relatively long time needed to observe disease progression in Alzheimer's, and the structure of the brain, which is protected by the blood-brain barrier, through which few drugs can cross.

### *Non-Pharmacologic Therapy*

Non-pharmacologic therapies are those that employ approaches other than medication, such as music therapy and reminiscence therapy (therapy in which photos and other familiar items may be used to elicit recall). As with current pharmacologic therapies, non-pharmacologic therapies have not been shown to alter the course of Alzheimer's disease.

Non-pharmacologic therapies are often used with the goal of maintaining or improving cognitive function, the ability to perform activities of daily living, or overall quality of life. They also may be used with the goal of reducing behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression.

Systematic reviews of published research on non-pharmacologic therapies have found that some, such as exercise and cognitive activity (for example, gardening, word games, listening to music and cooking) show promise.<sup>91</sup> However, few non-pharmacologic therapies have been tested in randomized controlled studies, which provide the strongest evidence of whether a therapy is effective. In randomized controlled studies, participants are randomly assigned to receive a therapy or not receive a therapy, and results from the two groups are compared. Additional research on non-pharmacologic therapies is needed to better evaluate their effectiveness.

## Living with Alzheimer's Disease

Despite the lack of disease-modifying therapies for Alzheimer's, 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.<sup>92-94</sup> 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.

To learn more about each of these ways of helping to manage Alzheimer's, as well as practical information for living with the disease and being a caregiver for an individual with Alzheimer's, visit alz.org.

# 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.<sup>13-16</sup> These criteria and guidelines updated diagnostic criteria and guidelines published in 1984 by the National Institute of Neurological Disorders and Stroke and the Alzheimer's Association.<sup>17</sup> 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 on autopsy.<sup>95</sup>

**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 Proposed 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 the presence of particular groups of proteins in blood) are among several factors being studied as possible biomarkers for Alzheimer's. Finding a simple and inexpensive test, such as a blood test, would be ideal for patients, physicians and scientists. Research is underway to develop such a test, but no test to date has shown the accuracy and reliability needed to diagnose 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.<sup>18-20</sup> 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

## A Modern Diagnosis of Alzheimer's Disease: Proposed Criteria and Guidelines (continued)

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.<sup>96-98</sup> 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 3 or 4 years.<sup>99</sup>

When individuals in a community are assessed, regardless of whether they have memory or cognitive complaints, the estimated percentage who will progress from MCI to Alzheimer's is slightly lower — up to 10 percent per year.<sup>100</sup> Further cognitive decline is more likely among individuals whose MCI involves memory problems than among those whose MCI does not involve memory problems. Over a 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.<sup>101</sup> It is unclear why some people with MCI develop dementia and others do not.

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 or another dementia. 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 cause of dementia.<sup>102</sup>

### 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.<sup>103-119</sup>

## Prevalence



1 in 9

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.**

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. This section reports on the number and proportion of people with Alzheimer's disease to describe the magnitude of the burden of Alzheimer's on the community and the health care system. Incidence, the number of new cases per year, is also provided as an estimate of the risk of developing Alzheimer's disease and other dementias for different age groups. Estimates from selected studies on the number and proportion 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.

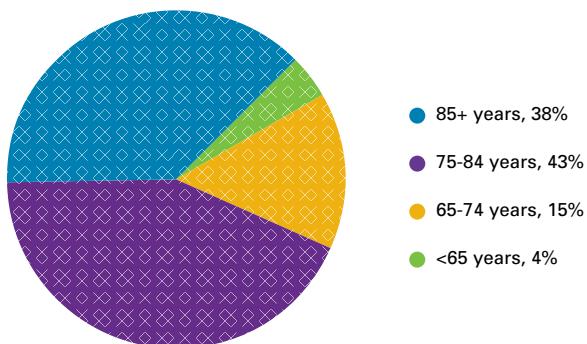
#### **PREVALENCE OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS IN THE UNITED STATES**

An estimated 5.3 million Americans of all ages have Alzheimer's disease in 2015. This number includes an estimated 5.1 million people age 65 and older<sup>120, A1</sup> and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.<sup>121</sup>

- One in nine people age 65 and older (11 percent) has Alzheimer's disease.<sup>A2</sup>
- About one-third of people age 85 and older (32 percent) have Alzheimer's disease.<sup>120</sup>
- Eighty-one percent of people who have Alzheimer's disease are age 75 or older (Figure 1).<sup>120, A3</sup>

**FIGURE 1**

#### **Ages of People with Alzheimer's Disease in the United States, 2015**



Created from data from Hebert et al.<sup>120, A3</sup>

The estimated number of individuals age 65 and older with Alzheimer's disease 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.<sup>120</sup>

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.<sup>122-123, A4</sup> Based on estimates from ADAMS, 14 percent of people age 71 and older in the United States have dementia.<sup>122</sup>

Prevalence studies such as CHAP and ADAMS are designed so that everyone in the study is tested for dementia. But in the community, only about half of those who would meet the diagnostic criteria for Alzheimer's disease and other dementias are diagnosed with dementia by a physician.<sup>124-125</sup> Because Alzheimer's disease is underdiagnosed, half of the estimated 5.3 million Americans with Alzheimer's may not have been told by a physician that they have it.

### **Preclinical Alzheimer's Disease**

The estimates of the number and proportion of people who have Alzheimer's 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 (see pages 13-14), revised criteria and guidelines by National Institute on Aging and the Alzheimer's Association published in 2011<sup>13-16</sup> propose that Alzheimer's begins before the onset of symptoms, which aligns with what most researchers now believe. 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. Because more research is needed to validate tests for 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 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) is one of the earliest warning signs of Alzheimer's disease and may be a way to identify people who are at high risk of developing Alzheimer's and other dementias as well as MCI.<sup>126-127</sup> Subjective cognitive decline does not refer to someone occasionally forgetting their keys or the name of someone they recently met; it refers to more serious issues such as having trouble remembering how to do things they have always done or forgetting things that they 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.<sup>128</sup> Data from the 2012 Behavioral Risk Factor Surveillance System (BRFSS) survey, which included questions on self-perceived confusion and memory loss for 21 states, showed that

13 percent of Americans age 45 and older reported experiencing worsening confusion or memory loss, but 77 percent had not consulted a health care professional about it.<sup>129</sup> Individuals concerned about declines in memory and other cognitive abilities should consult a health care professional.

### **Differences Between Women and Men in the Prevalence of Alzheimer's Disease and Other Dementias**

More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women.<sup>120, A5</sup> Of the 5.1 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.9 million are men.<sup>120, A5</sup> 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.<sup>122,130</sup>

There are a number of potential reasons why more women than men have Alzheimer's disease and other dementias. The prevailing view has been that this discrepancy is due to the fact that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's.<sup>130-131</sup> Many studies of incidence (which indicates risk of developing disease) of Alzheimer's<sup>57-58,131-135</sup> or any dementia<sup>56-57,132-133,136</sup> have found no significant difference between men and women in the proportion who develop Alzheimer's or other dementias at any given age. However, limited new research suggests that risk could be higher for women, potentially due to biological or genetic variations or even different life experiences (for example, type and amount of education, or occupational choices).<sup>137</sup> Data from the Framingham Study suggests that because men have a higher rate of death from cardiovascular disease than women in middle age, men who survive beyond age 65 may have a healthier cardiovascular risk profile and thus a lower risk for dementia than women of the same age, though more research is needed to support this finding.<sup>138</sup> Another large study showed that the APOE-e4 genotype, the best known genetic risk factor

for Alzheimer's disease, may have a stronger association with Alzheimer's disease in women than men.<sup>139-140</sup> It is unknown why this may be the case, but some evidence suggests an interaction between the APOE-e4 genotype and the sex hormone estrogen.<sup>141-142</sup> Finally, because low education is a risk factor for dementia,<sup>50-60</sup> it is possible that lower educational attainment in women than in men born in the first half of the 20th century could account for a higher risk of Alzheimer's and other dementias in women; however, this possibility has not been thoroughly investigated scientifically.

#### Racial and Ethnic Differences in the Prevalence of Alzheimer's Disease and Other Dementias

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than people of 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.<sup>143-144</sup> 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,<sup>145-146</sup> and Hispanics are about one and one-half times as likely to have Alzheimer's and other dementias as older whites.<sup>146-147, A6</sup>

Variations in health, lifestyle and socioeconomic risk factors across racial groups likely account for most of the differences in risk of Alzheimer's disease and other dementias by race. Despite some evidence that the influence of genetic risk factors on Alzheimer's and other dementias may differ by race,<sup>148</sup> genetic factors do not appear to account for the large prevalence differences among racial groups.<sup>149-150</sup> Instead, health conditions such as cardiovascular disease and diabetes, which increase risk for Alzheimer's disease and other dementias, are believed to account for these differences as 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 rigorous analyses that account for these factors.<sup>57,122</sup>

There is evidence that missed diagnoses of Alzheimer's disease and other dementias are more common among older African-Americans and Hispanics than among older whites,<sup>151-152</sup> but it is unclear whether disparities in missed diagnoses have lessened in recent years. Based on data for Medicare beneficiaries age 65 and older, Alzheimer's disease or another dementia had been diagnosed in 8 percent of white older adults, 11 percent of African-Americans and 12 percent of Hispanics.<sup>153</sup> Although rates of diagnosis were higher among African-Americans than among whites, according to prevalence studies that detect all people who have dementia irrespective of their use of the health care system, the rates should be twice as high (approximately 16 percent instead of 11 percent).

#### ESTIMATES OF THE NUMBER OF PEOPLE WITH ALZHEIMER'S DISEASE BY STATE

Table 2 lists the estimated number of people age 65 and older with Alzheimer's disease by state for 2015, the projected number for 2025, and the projected percentage change in the number of people with Alzheimer's between 2015 and 2025.<sup>154, A7</sup> Comparable estimates and projections for other causes of dementia are not available.

As shown in Figure 2, between 2015 and 2025 every state and region across the country is expected to experience an increase of at least 14 percent in the number of people with Alzheimer's due to increases in 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 2015 and 2025. These increases will have a marked impact on states' health care systems, as well as on families and caregivers.

#### 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 U.S. population age 65 or older. Incidence provides a measure of *risk* for developing a disease.

TABLE 2

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

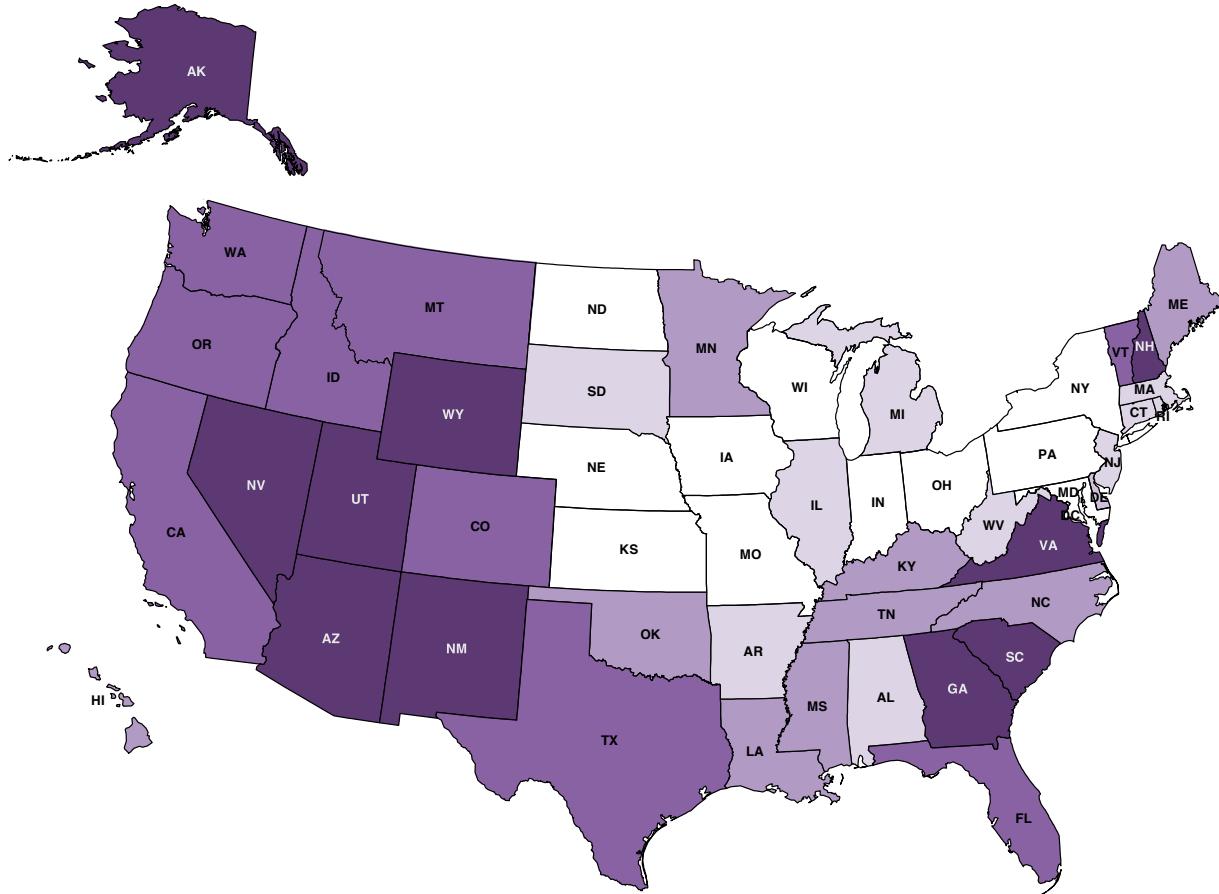
State	Projected Number w/ Alzheimer's (in thousands)		Percentage Change 2015-2025	State	Projected Number w/ Alzheimer's (in thousands)		Percentage Change 2015-2025
	2015	2025			2015	2025	
Alabama	87	110	26.4	Montana	19	27	42.1
Alaska	6.4	11	71.9	Nebraska	33	40	21.2
Arizona	120	200	66.7	Nevada	39	64	64.1
Arkansas	53	67	26.4	New Hampshire	22	32	45.5
California	590	840	42.4	New Jersey	170	210	23.5
Colorado	65	92	41.5	New Mexico	36	53	47.2
Connecticut	73	91	24.7	New York	380	460	21.1
Delaware	17	23	35.3	North Carolina	160	210	31.3
District of Columbia	9.1	9.0	-1.1	North Dakota	14	16	14.3
Florida	500	720	44.0	Ohio	210	250	19.0
Georgia	130	190	46.2	Oklahoma	60	76	26.7
Hawaii	26	35	34.6	Oregon	60	84	40.0
Idaho	23	33	43.5	Pennsylvania	270	320	18.5
Illinois	210	260	23.8	Rhode Island	22	27	22.7
Indiana	110	130	18.2	South Carolina	81	120	48.1
Iowa	63	73	15.9	South Dakota	16	20	25.0
Kansas	51	62	21.6	Tennessee	110	140	27.3
Kentucky	68	86	26.5	Texas	340	490	44.1
Louisiana	82	110	34.1	Utah	29	42	44.8
Maine	26	35	34.6	Vermont	12	17	41.7
Maryland	99	130	31.3	Virginia	130	190	46.2
Massachusetts	120	150	25.0	Washington	100	140	40.0
Michigan	180	220	22.2	West Virginia	36	44	22.2
Minnesota	89	120	34.8	Wisconsin	110	130	18.2
Mississippi	51	65	27.5	Wyoming	8.8	13.0	47.7
Missouri	110	130	18.2				

Created from data provided to the Alzheimer's Association by Weuve et al.<sup>154, A7</sup>

**FIGURE 2**

**Projected Increases Between 2015 and 2025 in Alzheimer's Disease Prevalence by State**

□ 14.3% - 21.6%    □ 21.7% - 26.4%    □ 26.5% - 34.8%    □ 34.9% - 44.1%    □ 44.2% - 71.9%



Change from 2015 to 2025 for Washington, D.C.: -1.1%

Created from data provided to the Alzheimer's Association by Weuve et al.<sup>154, A7</sup>

Approximately 473,000 people age 65 or older will develop Alzheimer's disease in the United States in 2015.<sup>A8</sup> The number of new cases of Alzheimer's increases dramatically with age: in 2015, there will be approximately 61,000 new cases among people age 65 to 74, 172,000 new cases among people age 75 to 84, and 240,000 new cases among people age 85 and older (the "oldest-old").<sup>155, A8</sup> This translates to approximately two new cases per 1,000 people age 65 to 74, 13 new cases per 1,000 people age 75 to 84, and 39 new cases

per 1,000 people age 85 and older.<sup>A8</sup> 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.<sup>155</sup>

- Every 67 seconds, someone in the United States develops Alzheimer's.<sup>A9</sup>
- By mid-century, someone in the United States will develop the disease every 33 seconds.<sup>A9</sup>

## 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 by age and sex.<sup>156, A10</sup> As shown in Figure 3, the study found that the estimated lifetime risk for Alzheimer's specifically at age 65 was one in six (17 percent) for women and one in 11 (9 percent) for men.<sup>156</sup>

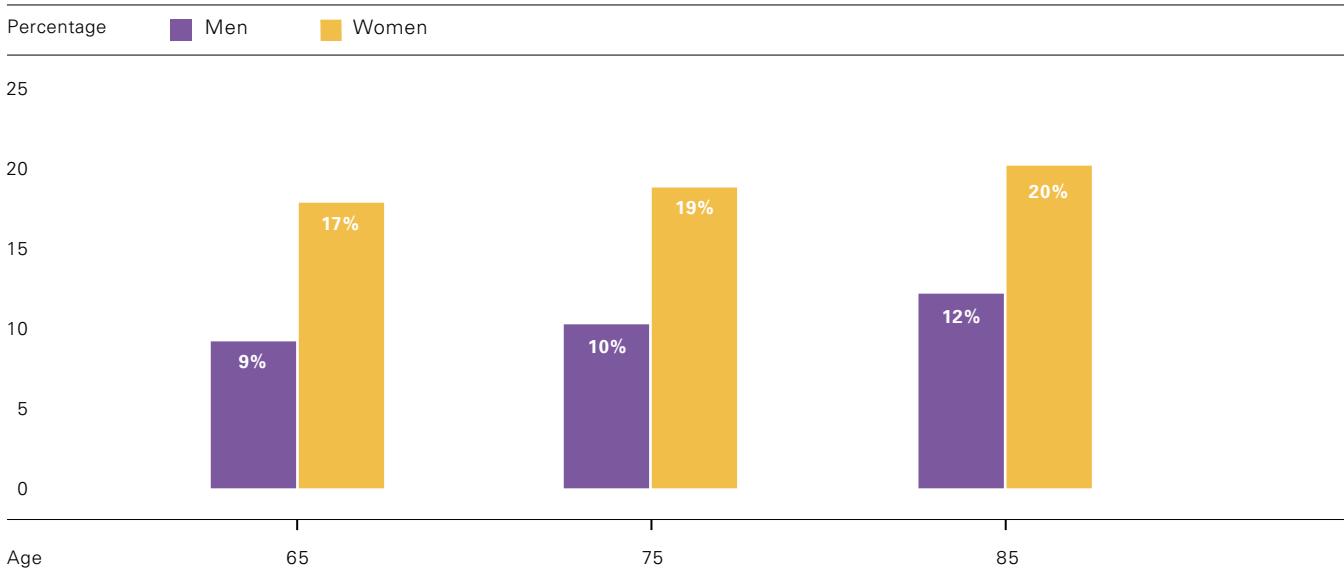
## TRENDS IN THE PREVALENCE AND INCIDENCE OF ALZHEIMER'S DISEASE

A growing number of studies indicate that the age-specific risk of Alzheimer's and other dementias in the United States and other higher-income Western countries may have declined in the past 25 years,<sup>157-164</sup>

though results are mixed.<sup>165</sup> These declines have largely been attributed to increasing levels of education and improved control of cardiovascular risk factors.<sup>159,166</sup> Such findings are promising and suggest that identifying and reducing risk factors for Alzheimer's and other dementias may be effective. Although these findings indicate that a person's risk of dementia at any given age may be decreasing slightly, it should be noted that the total number of Americans with Alzheimer's and other dementias is expected to continue to increase dramatically because of the population's shift to older ages (see Looking to the Future). Thus, while these findings are promising, they are outweighed by the aging of the population, and the social and economic burden of Alzheimer's and other dementias will continue to grow.

FIGURE 3

### Estimated Lifetime Risk for Alzheimer's, by Age and Sex, from the Framingham Study



Created from data from Seshadri et al.<sup>156</sup>

## LOOKING TO THE FUTURE

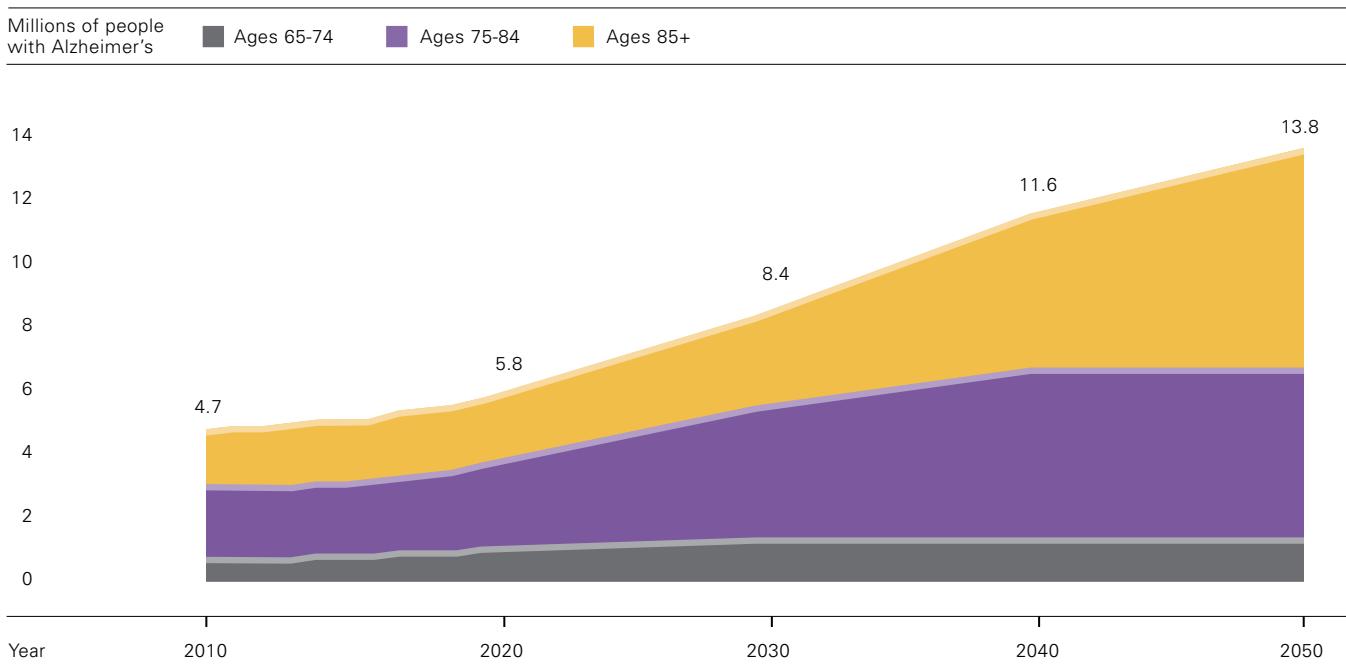
The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions.<sup>167</sup> Additionally, a large segment of the American population — the baby boom generation — has begun to reach age 65 and older, when the risk for Alzheimer's and other dementias is elevated. By 2030, the segment of the U.S. population age 65 and older will increase substantially, and the projected 72 million older Americans will make up approximately 20 percent of the total population (up from 13 percent in 2010).<sup>167</sup>

As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer's disease, as shown in Figure 4.<sup>120, A11</sup>

- In 2010, there were an estimated 454,000 new cases of Alzheimer's disease. By 2030, that number is projected to be 615,000 (a 35 percent increase), and by 2050, 959,000 (a 110 percent increase from 2010).<sup>155</sup>
- 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 5.1 million age 65 and older affected in 2015.<sup>120, A12</sup>
- By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5.1 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent or cure the disease.<sup>120, A11</sup> 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.<sup>168, A13</sup>

FIGURE 4

### 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.<sup>120, A11</sup>

## GROWTH OF THE OLDEST-OLD POPULATION

Longer life expectancies and aging baby boomers will also increase the number and percentage of Americans who will be among the oldest-old, individuals age 85 and older. 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.<sup>167</sup> This will result in an additional 13 million oldest-old people — individuals at the highest risk for developing Alzheimer's.<sup>167</sup>

- In 2015, about 2 million people who have Alzheimer's disease are age 85 or older, accounting for 38 percent of all people with Alzheimer's.<sup>120</sup>
- 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.<sup>120</sup>
- By 2050, as many as 7 million people age 85 and older may have Alzheimer's disease, accounting for half (51 percent) of all people 65 and older with Alzheimer's.<sup>120</sup>

## Mortality and Morbidity

A close-up photograph of an elderly woman with white hair, resting her chin on her hand and looking thoughtfully to the side. The background is blurred, showing other people in what appears to be a medical or institutional setting.

**1  
in  
3**

seniors who die in a given year  
has 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.<sup>169</sup> It is the fifth-leading cause of death for those age 65 and older.<sup>169</sup> However, it may cause even more deaths than official sources recognize. Alzheimer's is also 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 data from the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC), 84,767 people died *from* Alzheimer's disease in 2013.<sup>169</sup> 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."<sup>170</sup> 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.<sup>171-173</sup> 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 is the most commonly identified cause of death among elderly people with Alzheimer's disease and other dementias.<sup>174-175</sup> 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. A recent study using data from the Rush Memory and Aging Project and the Religious Orders Study supports this concept; researchers estimated that 500,000 deaths among people age 75 and older could be attributed to Alzheimer's disease in the United States in 2010 (estimates for people age 65 to 74 were not available), meaning that those deaths would not be expected to occur in that year if those individuals did not have Alzheimer's.<sup>176</sup>

The situation has been described as a "blurred distinction between death *with* dementia and death *from* dementia."<sup>177</sup> 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.<sup>178</sup> Of these, an estimated 400,000 were age 85 and older, and an estimated 200,000 were age 65 to 84. 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.<sup>153,179</sup> 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.<sup>180</sup> Thus, for people who die with Alzheimer's, the disease is expected to be a significant direct contributor to their deaths.

In 2015, an estimated 700,000 people in the United States age 65 and older will die *with* Alzheimer's based on CHAP data.<sup>178</sup> 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.<sup>181</sup>

## PUBLIC HEALTH IMPACT OF DEATHS FROM ALZHEIMER'S DISEASE

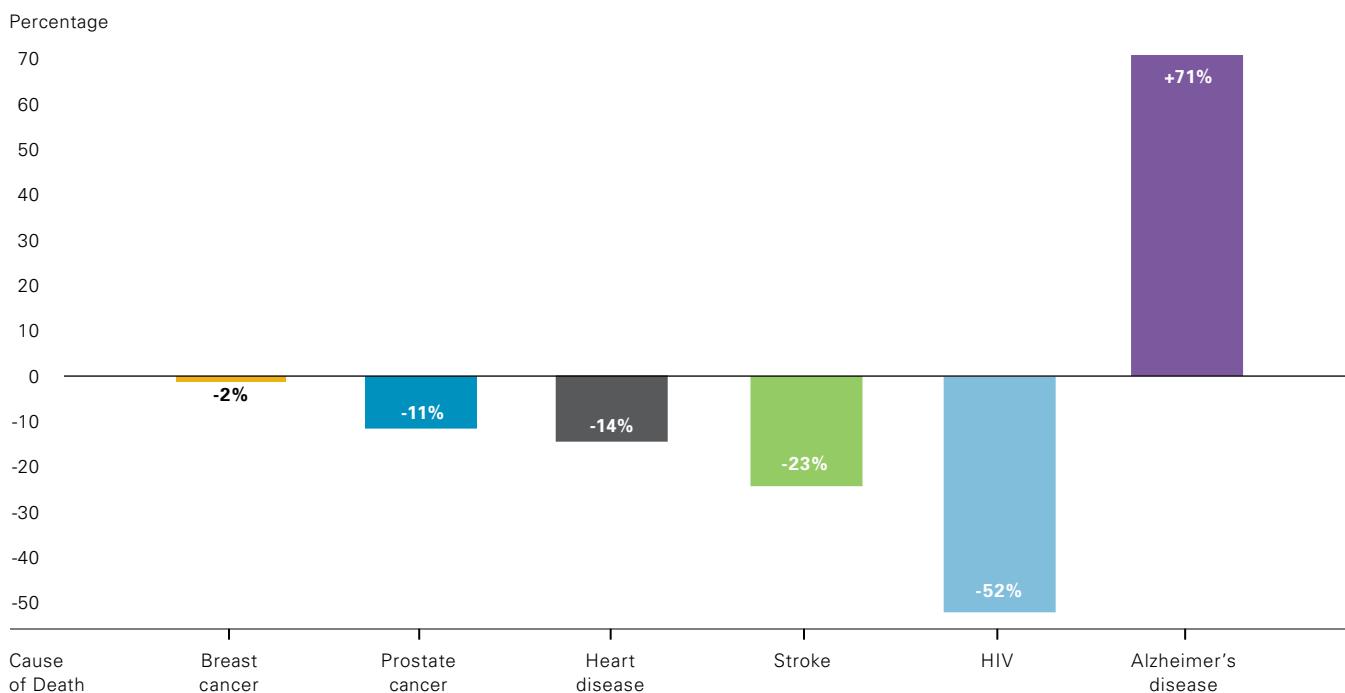
As the population of the United States ages, Alzheimer's is becoming a more common cause of death. Although deaths from other major causes have decreased significantly, official records indicate that deaths from Alzheimer's disease have increased significantly. Between 2000 and 2013, deaths attributed to Alzheimer's disease increased 71 percent, while those attributed to the number one cause of death (heart disease) decreased 14 percent (Figure 5).<sup>169</sup> 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.

## STATE-BY-STATE DEATHS FROM ALZHEIMER'S DISEASE

Table 3 provides information on the number of deaths due to Alzheimer's by state in 2013, 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 2013, the mortality rate for Alzheimer's disease was 27 deaths per 100,000 people.<sup>169</sup>

FIGURE 5

### Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2013



Created from data from the National Center for Health Statistics.<sup>169</sup>

TABLE 3

## Number of Deaths and Annual Mortality Rate (per 100,000) Due to Alzheimer's Disease by State, 2013

State	Number of Deaths	Mortality Rate	State	Number of Deaths	Mortality Rate
Alabama	1,398	28.9	Montana	267	26.3
Alaska	72	9.8	Nebraska	557	29.8
Arizona	2,383	36.0	Nevada	448	16.1
Arkansas	918	31.0	New Hampshire	351	26.5
California	11,891	31.0	New Jersey	1,812	20.4
Colorado	1,316	25.0	New Mexico	339	16.3
Connecticut	824	22.9	New York	2,556	13.0
Delaware	192	20.7	North Carolina	2,872	29.2
District of Columbia	130	20.1	North Dakota	363	50.2
Florida	5,093	26.0	Ohio	3,798	32.8
Georgia	2,048	20.5	Oklahoma	1,145	29.7
Hawaii	260	18.5	Oregon	1,312	33.4
Idaho	347	21.5	Pennsylvania	3,271	25.6
Illinois	2,919	22.7	Rhode Island	346	32.9
Indiana	2,104	32.0	South Carolina	1,623	34.0
Iowa	1,252	40.5	South Dakota	418	49.5
Kansas	742	25.6	Tennessee	2,536	39.0
Kentucky	1,462	33.3	Texas	5,293	20.0
Louisiana	1,505	32.5	Utah	412	14.2
Maine	401	30.2	Vermont	269	42.9
Maryland	919	15.5	Virginia	1,642	19.9
Massachusetts	1,699	25.4	Washington	3,277	47.0
Michigan	3,220	32.5	West Virginia	590	31.8
Minnesota	1,427	26.3	Wisconsin	1,671	29.1
Mississippi	925	30.9	Wyoming	126	21.6
Missouri	2,026	33.5	<b>U.S. Total</b>	<b>84,767</b>	<b>26.8</b>

Created from data from the National Center for Health Statistics.<sup>169, A14</sup>

TABLE 4

## U.S. Annual Alzheimer's Death Rate (per 100,000) by Age

Age	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
45-54	0.2	0.2	0.1	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.3	0.2	0.2	0.2
55-64	2.0	2.1	1.9	2.0	1.8	2.1	2.1	2.2	2.2	2.0	2.1	2.2	2.2	2.2
65-74	18.7	18.6	19.6	20.7	19.5	20.2	19.9	20.2	21.1	19.4	19.8	19.2	17.9	18.1
75-84	139.6	147.2	157.7	164.1	168.5	177.0	175.0	175.8	192.5	179.1	184.5	183.9	175.4	171.6
85+	667.7	725.4	790.9	846.8	875.3	935.5	923.4	928.7	1,002.2	945.3	987.1	967.1	936.1	929.5

Created from data from the National Center for Health Statistics.<sup>169</sup>

## ALZHEIMER'S DISEASE DEATH RATES

As shown in Figure 6, the rate of deaths attributed to Alzheimer's has risen substantially since 2000.<sup>169</sup> Table 4 shows that the rate of death from Alzheimer's increases dramatically with age, especially after age 65.<sup>169</sup> The increase in the Alzheimer's death rate over time has disproportionately affected the oldest-old.<sup>182</sup> Between 2000 and 2013, the death rate from Alzheimer's did not increase for people age 65 to 74, but increased 23 percent for people age 75 to 84, and 39 percent for people age 85 and older.

## DURATION OF ILLNESS FROM DIAGNOSIS TO DEATH

Studies indicate that people age 65 and older survive an average of 4 to 8 years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's.<sup>183-188</sup> This reflects the slow, insidious 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.<sup>181</sup> Much of this time will be spent in a nursing home. Exemplifying this, nursing home admission by

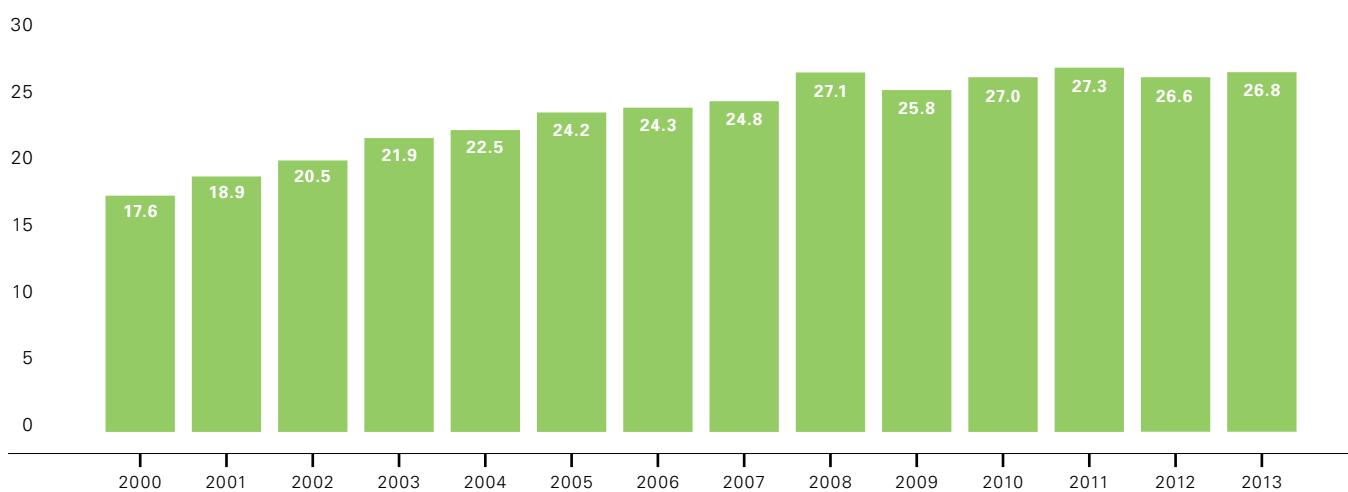
age 80 is expected for 75 percent of people with Alzheimer's compared with only 4 percent of the general population.<sup>181</sup> In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions.<sup>189</sup>

## 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 than other diseases in recent years. The primary measure of disease burden is called disability-adjusted life-years (DALYs), which is the sum of the number of

**FIGURE 6**

**U.S. Annual Alzheimer's Death Rate (per 100,000) by Year**



Created from data from the National Center for Health Statistics.<sup>169</sup>

years of life lost due to premature mortality and the number of years lived with disability. Using this measure, Alzheimer's rose from the 25th most burdensome disease in the United States in 1990 to the 12th in 2010.

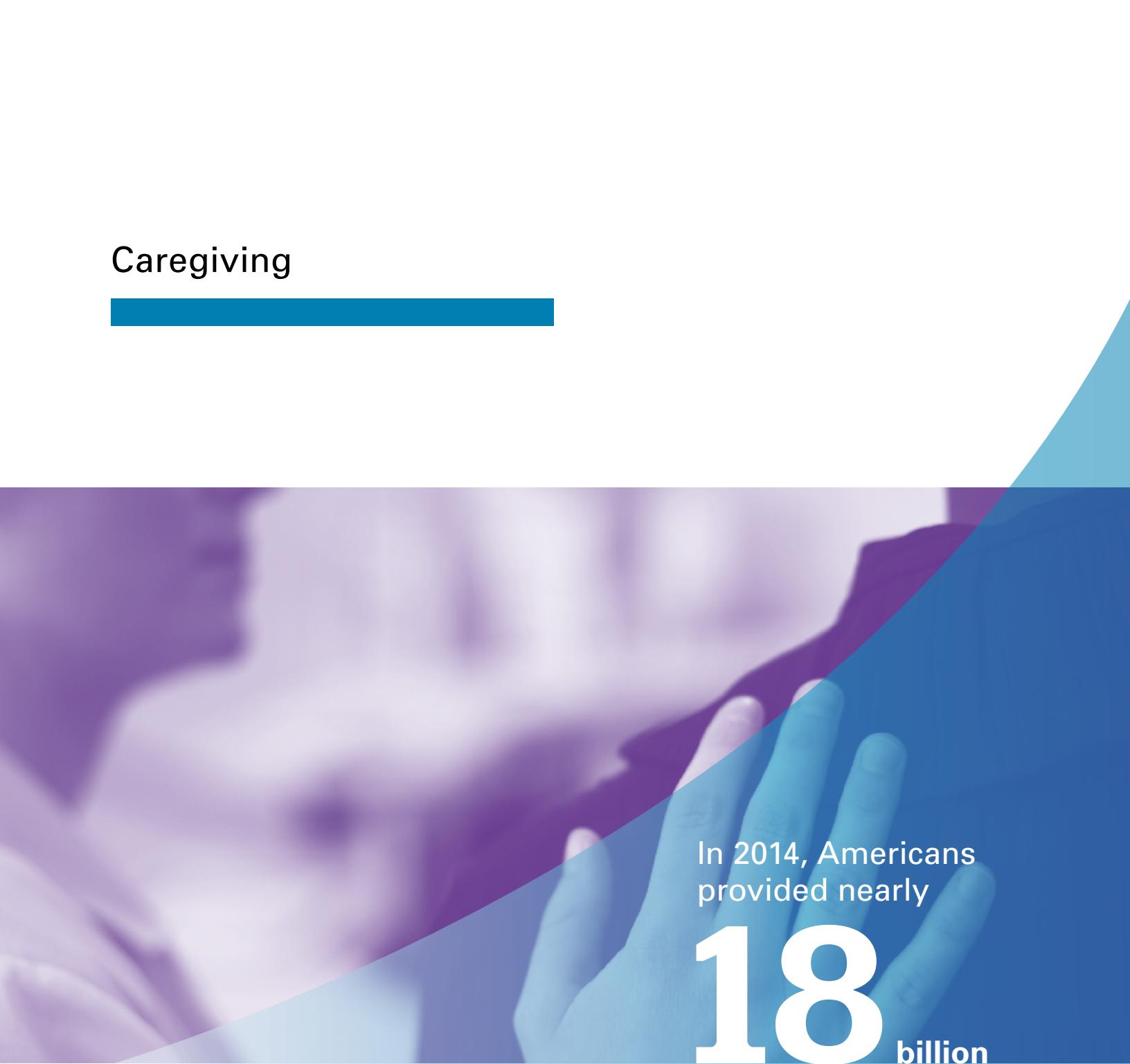
No other disease or condition increased as much.<sup>190</sup>

In terms of years of life lost, Alzheimer's disease rose from 32nd to 9th, the largest increase for any disease.

In terms of 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 2014, Americans provided nearly

**18**  
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.<sup>191-192</sup> More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias.<sup>A15</sup>**

### UNPAID CAREGIVERS

Eighty-five percent of unpaid help provided to older adults in the United States is from family members.<sup>193</sup> Friends may provide unpaid caregiving as well. In 2014, caregivers of people with Alzheimer's and other dementias provided an estimated 17.9 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at \$217.7 billion. This is approximately 46 percent of the net value of Walmart sales in 2013 (\$473.1 billion)<sup>194</sup> and nearly eight times the total revenue of McDonald's in 2013 (\$28.1 billion).<sup>195</sup> According to a recent report,<sup>196</sup> the value of informal care (not including caregivers' out-of-pocket costs) was nearly equal to the costs of direct medical and long-term care of dementia.

The three primary reasons caregivers decide to provide care and assistance to a person with Alzheimer's disease are (1) the desire to keep a family member/friend at home (65 percent), (2) proximity to the person with dementia (48 percent) and (3) the caregiver's perceived obligation as a spouse or partner (38 percent).<sup>A16</sup>

### Who Are the Caregivers?

Several sources have examined the demographic background of family caregivers of people with Alzheimer's disease and other dementias in the

United States.<sup>197-200, A16</sup> Approximately two-thirds of caregivers are women<sup>197-198, A16</sup> and 34 percent are age 65 or older.<sup>A16</sup> Over two-thirds of caregivers are married, living with a partner or in a long-term relationship.<sup>198, A16</sup> More than two-thirds of caregivers are non-Hispanic white,<sup>198, A16</sup> while 10 percent are African-American, 8 percent are Hispanic, and 5 percent are Asian.<sup>A16</sup> Over 40 percent of dementia caregivers have a college degree or greater education.<sup>198, A16</sup> Forty-one percent of caregivers have a household income of \$50,000 or less.<sup>A16</sup> Over half of primary caregivers of people with dementia (individuals who indicate having the most responsibility for helping their relatives; 55 percent) take care of parents.<sup>200</sup> Most caregivers either live with the care recipient (27 percent) or live within 20 minutes of the care recipient (46 percent).<sup>A16</sup> It is estimated that 250,000 children and young adults between ages 8 and 18 provide help to someone with Alzheimer's disease or another dementia.<sup>201</sup>

### Ethnic and Racial Diversity in Caregiving

Among caregivers of people with Alzheimer's and other dementias, the National Alliance for Caregiving (NAC) and AARP found the following in 2009:<sup>202</sup>

- Fifty-four percent of non-Hispanic 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 non-Hispanic white caregivers (33 percent) and Asian-American caregivers (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 along with the aging of the U.S. population) have led to increases in the number of sandwich generation caregivers.<sup>203-205</sup> National surveys have found that 23 percent of Alzheimer’s disease and dementia caregivers lived with children under the age of 18.<sup>A16</sup> Other studies have found that sandwich generation caregivers are present in 8 to 13 percent of households in the United States.<sup>206-207</sup> It is not clear what proportion of care recipients in these studies had Alzheimer’s disease or another dementia, but in other studies of sandwich generation caregivers about one-third of elderly care recipients have Alzheimer’s disease or another

dementia.<sup>197</sup> Sandwich generation caregivers indicate lower quality of life and diminished health behaviors (for example, less likely to choose foods based on health values; less likely to use seat belts; less likely to exercise) compared with non-sandwich generation caregivers or non-caregivers.<sup>208-209</sup>

### 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

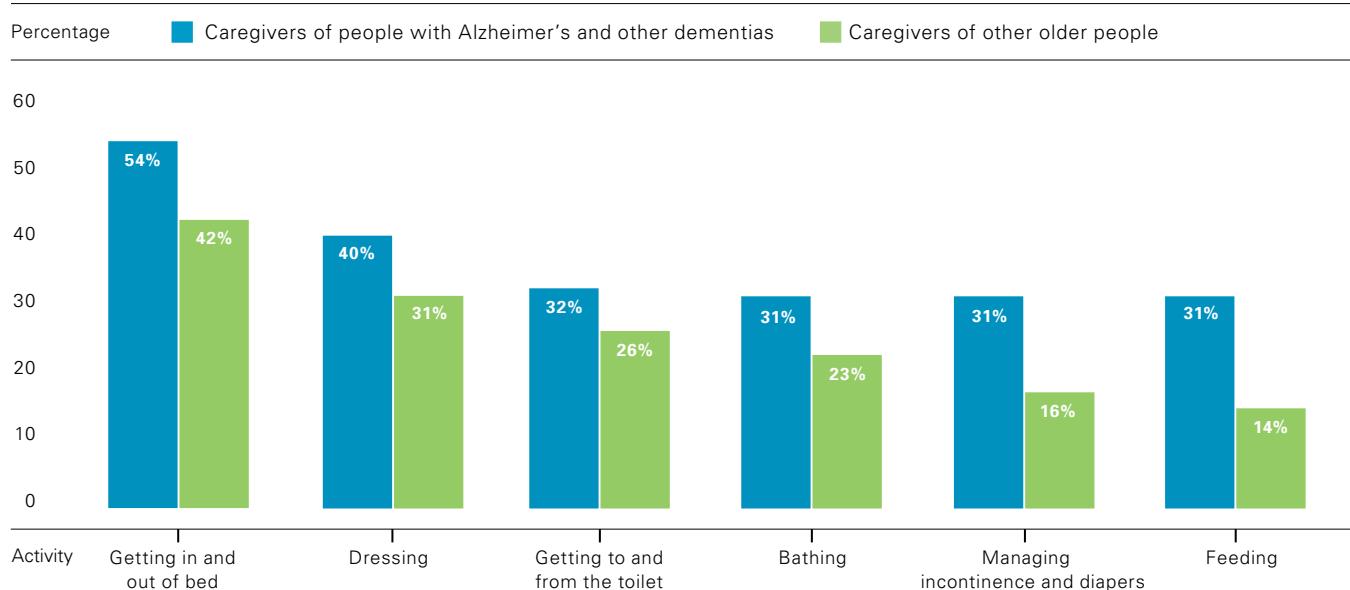
TABLE 5

#### 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: <ul style="list-style-type: none"><li>• Providing overall management of getting through the day.</li><li>• 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.</li></ul>

**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**



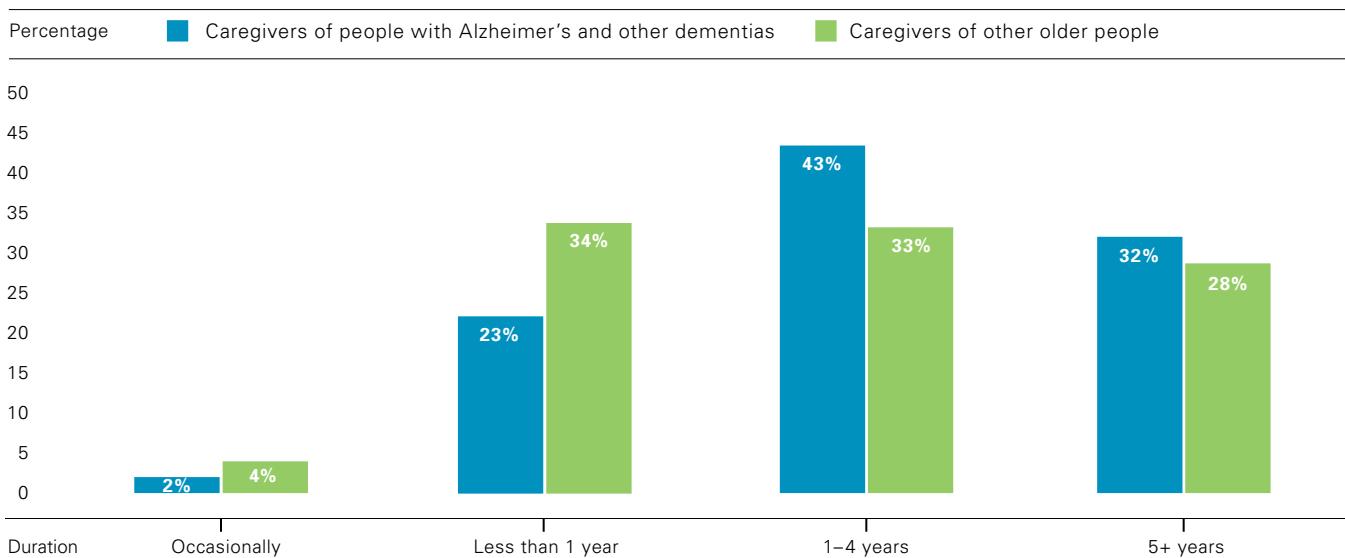
Created from data from the National Alliance for Caregiving and AARP.<sup>202</sup>

providing help with getting in and out of bed, and about one-third provide help with getting to and from the toilet, bathing, managing incontinence and feeding. These findings are consistent with the heightened degree of dependency experienced by many people with Alzheimer's disease and other dementias. Fewer caregivers of other older people report providing help with each of these types of care.<sup>202</sup> Data from the 2011 National Survey of Caregiving (NSOC) indicated that caregivers of people with dementia<sup>210</sup> are more likely than caregivers of people without dementia to provide help with self-care and mobility (85 percent versus 71 percent) and health or medical care (63 percent versus 52 percent).<sup>197,211</sup> Individuals with dementia are also more likely than those without dementia to rely on multiple unpaid caregivers; 39 percent of people with dementia rely on three or more caregivers, whereas 30 percent of people without dementia rely on three or more unpaid individuals.<sup>197</sup>

In addition to assisting with ADLs, almost two-thirds of caregivers of people with Alzheimer's and other dementias advocate for their care recipient with government agencies and service providers (64 percent), and nearly half arrange and supervise paid caregivers from 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).<sup>202</sup> Caregivers of people with dementia are more likely to coordinate health care for the care recipient compared with caregivers of people without dementia (86 percent versus 72 percent).<sup>197</sup> 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. Family caregivers often lack the information or resources necessary to manage the increasing complexity of medication regimens for people with dementia.<sup>212</sup>

**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.<sup>202</sup>

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 (see page 32) 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.<sup>213-215</sup> Admitting a relative to a residential care facility 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.<sup>215-217</sup> The relationship between the caregiver and person with 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.<sup>216</sup>

#### Duration of Caregiving

Eighty-six percent of dementia caregivers have provided care and assistance for at least the past year, according to the 2014 Alzheimer's Association Women and Alzheimer's Poll.<sup>A16</sup> Caregivers of people with Alzheimer's and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions. As shown in Figure 8, 43 percent of caregivers of people with Alzheimer's and other dementias provided 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 5 years or more compared with 28 percent of caregivers of people without dementia.<sup>202</sup>

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

In 2014, the 15.7 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 17.9 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.<sup>A17</sup> With this care valued at \$12.17 per hour,<sup>A18</sup> the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was \$217.7 billion in 2014. Table 6 (see pages 36-37) 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 provided care valued at more than \$1 billion in each of 39 states. Unpaid caregivers in each of the four most populous states — California, Florida, New York and Texas — provided care valued at more than \$14 billion. Additional research is needed to estimate the future value of family care for people with Alzheimer's disease as the U.S. population continues to age.

Caregivers of people with dementia report providing 27 hours' more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.<sup>A19</sup> Other studies suggest that primary family caregivers provide particularly extensive amounts of care to people who have dementia. For example, a 2011 report found that primary family caregivers of people with dementia reported spending an average of 9 hours per day providing help to their relatives.<sup>A20</sup> In addition, many caregivers of people with Alzheimer's disease or another dementia provide help alone. Forty-one percent of dementia caregivers in the 2014 Alzheimer's Association poll reported that no one else provided unpaid assistance.<sup>A16</sup>

### **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.<sup>A18</sup> Individuals with Alzheimer's 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 and depression; new or exacerbated health problems; and depleted income and finances due in part to disruptions in employment.<sup>A19-A24, A16</sup> 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 disease.

### ***Caregiver Emotional Well-Being***

Although caregivers report some positive feelings about caregiving such as family togetherness and the satisfaction of helping others,<sup>A25, A16</sup> they also report high levels of stress when 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).<sup>A20</sup>
- Approximately 18 percent of caregivers of people with dementia, in contrast to only 6 percent of caregivers of people without dementia, indicate substantial negative aspects of caregiving.<sup>A17</sup>
- Compared with caregivers of people without dementia, twice as many caregivers of people with dementia indicate substantial financial, emotional and physical difficulties.<sup>A17</sup>
- 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, see page 38).<sup>A16</sup>

TABLE 6

**Number of Alzheimer's and Dementia (AD/D) Caregivers, Hours of Unpaid Care, Economic Value of Unpaid Care and Higher Health Care Costs of Caregivers by State, 2014\***

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) <sup>†</sup>
Alabama	301	342	\$4,166	\$171
Alaska	33	38	\$458	\$27
Arizona	314	357	\$4,345	\$155
Arkansas	174	198	\$2,410	\$97
California	1,573	1,791	\$21,795	\$895
Colorado	234	266	\$3,243	\$128
Connecticut	177	201	\$2,450	\$139
Delaware	52	60	\$725	\$40
District of Columbia	27	31	\$378	\$26
Florida	1,058	1,205	\$14,669	\$688
Georgia	506	576	\$7,015	\$251
Hawaii	65	74	\$901	\$41
Idaho	78	89	\$1,084	\$40
Illinois	589	671	\$8,163	\$362
Indiana	332	379	\$4,608	\$201
Iowa	134	152	\$1,853	\$84
Kansas	150	171	\$2,075	\$92
Kentucky	269	306	\$3,725	\$161
Louisiana	230	262	\$3,186	\$142
Maine	68	78	\$946	\$53
Maryland	289	329	\$4,001	\$197
Massachusetts	329	374	\$4,554	\$277
Michigan	508	578	\$7,035	\$305
Minnesota	248	282	\$3,430	\$167
Mississippi	205	234	\$2,846	\$122
Missouri	312	355	\$4,326	\$198

TABLE 6 (cont.)

**Number of Alzheimer's and Dementia (AD/D) Caregivers, Hours of Unpaid Care, Economic Value of Unpaid Care and Higher Health Care Costs of Caregivers by State, 2014\***

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) <sup>†</sup>
Montana	48	55	\$668	\$29
Nebraska	81	92	\$1,117	\$52
Nevada	140	159	\$1,937	\$73
New Hampshire	65	74	\$905	\$47
New Jersey	447	509	\$6,189	\$308
New Mexico	106	121	\$1,467	\$64
New York	1,017	1,158	\$14,091	\$771
North Carolina	448	510	\$6,208	\$263
North Dakota	30	34	\$414	\$21
Ohio	594	676	\$8,229	\$382
Oklahoma	220	250	\$3,046	\$130
Oregon	175	199	\$2,422	\$105
Pennsylvania	671	765	\$9,304	\$472
Rhode Island	53	60	\$731	\$40
South Carolina	295	336	\$4,092	\$169
South Dakota	37	42	\$514	\$24
Tennessee	422	480	\$5,847	\$245
Texas	1,331	1,516	\$18,446	\$716
Utah	142	162	\$1,969	\$65
Vermont	30	34	\$413	\$21
Virginia	452	514	\$6,259	\$258
Washington	324	369	\$4,485	\$200
West Virginia	108	123	\$1,499	\$75
Wisconsin	191	218	\$2,650	\$127
Wyoming	28	32	\$384	\$18
<b>U.S. Totals</b>	<b>15,706</b>	<b>17,886</b>	<b>\$217,670</b>	<b>\$9,733</b>

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

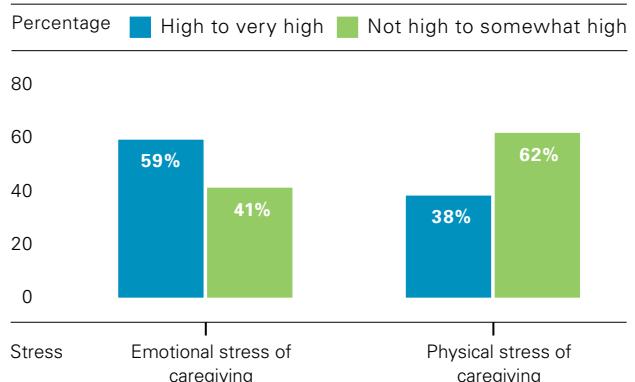
Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor.<sup>A13, A15, A16, A17</sup>

<sup>†</sup>Higher health care costs are the dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state.<sup>A19</sup>

- Many family caregivers report “a good amount” to “a great deal” of caregiving strain concerning financial issues (47 percent).<sup>A16</sup>
- Approximately 40 percent of family caregivers of people with dementia suffer from depression, compared with 5 to 17 percent of non-caregivers of similar ages.<sup>223, 226-229</sup> Rates of depression increase with the severity of cognitive impairment of the person with dementia.<sup>230-231</sup>
- In the 2009 NAC/AARP survey, caregivers most likely to indicate stress were women, older, residing with the care recipient, and white or Hispanic.<sup>202</sup>
- According to the 2014 Alzheimer’s Association poll, respondents often believed they had no choice in taking on the role of caregiver.<sup>A16</sup>
- The 2014 Alzheimer’s Association poll found that women with children under age 18 felt that caregiving for someone with Alzheimer’s disease was more challenging than caring for children (53 percent).<sup>A16</sup>
- 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.<sup>202,232</sup>
- Seventy-three percent of family caregivers of people with Alzheimer’s disease and other dementias 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 the admission transition (for example, interacting with care staff to determine an appropriate care role for the family member).<sup>213,215,233-234, A16</sup>
- The demands of caregiving may intensify as people with dementia approach the end of life.<sup>235</sup> 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.<sup>236</sup> One study of end-of-life care found that 72 percent of family caregivers experienced relief when the person with Alzheimer’s disease or another dementia died.<sup>236</sup>

**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.<sup>A16</sup>

#### Caregiver Physical Health

For some caregivers, the demands of caregiving may cause declines in their own health. Evidence suggests that the stress of dementia care provision increases caregivers’ susceptibility to disease and health complications.<sup>237</sup> As shown in Figure 9, 38 percent of Alzheimer’s and dementia caregivers indicate that the physical impact of caregiving was high to very high.<sup>A16</sup> Sleep disturbances, which can occur frequently when caring for a relative with Alzheimer’s disease or another dementia, have also been shown to negatively influence family caregivers’ health.<sup>238-239</sup>

#### 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.<sup>A16</sup> Dementia caregivers were more likely than non-caregivers to report that their health was fair or poor.<sup>221</sup> Dementia caregivers were also more likely than caregivers of other older people to say that caregiving made their health worse.<sup>202,240</sup> The 2009 and 2010 Behavioral Risk Factor Surveillance System (BRFSS) 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.<sup>198</sup> According to 1998–2010 bi-annual data from the Health and Retirement Survey, dementia caregivers were much more likely (41 percent increased odds) to become more frail from the period prior to the death of a spouse receiving care to the spouse's death.<sup>241</sup> Other studies suggest that caregiving tasks have the positive effect of keeping older caregivers more physically active than non-caregivers.<sup>242</sup>

#### 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 circumstances 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.<sup>243-248</sup>

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,<sup>249</sup> reduced immune function,<sup>219,250</sup> slow wound healing,<sup>251</sup> and increased incidence of hypertension,<sup>252</sup> coronary heart disease<sup>253</sup> 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.<sup>254</sup> 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

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$9.7 billion in health care costs in the United States in 2014.<sup>A19</sup> Table 6 (see pages 36-37) shows the estimated higher health care costs for Alzheimer's and dementia caregivers in each state. In separate studies, hospitalization and emergency department visits were more likely for dementia caregivers who helped care recipients who

were depressed, had low functional status or had behavioral disturbances.<sup>255</sup>

#### Mortality

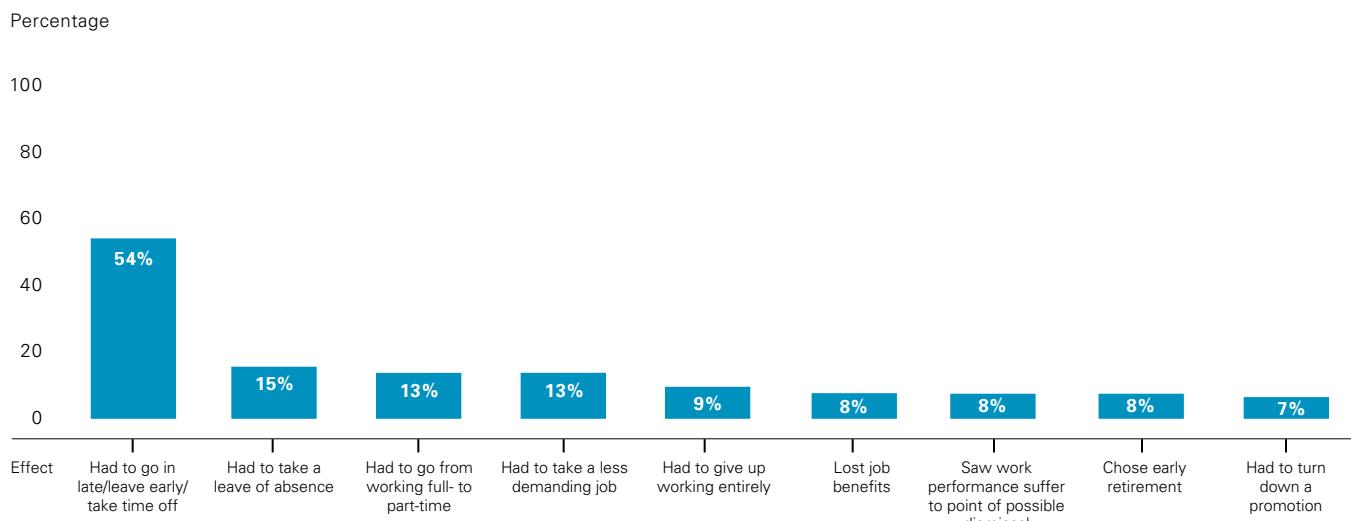
The health of a person with dementia may also affect the caregiver's risk of dying, although studies have reported mixed findings on this issue. In one study, caregivers of spouses who were hospitalized and had dementia in their medical records were more likely to die in the following year than caregivers whose spouses were hospitalized but did not have dementia, even after accounting for the age of caregivers.<sup>256</sup> However, other studies have found that caregivers in general have lower mortality rates than non-caregivers.<sup>257-258</sup> One study reported that higher levels of stress were associated with higher rates of mortality in both caregivers in general and non-caregivers.<sup>258</sup> 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 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.<sup>259</sup>

#### 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 age 65 had been or were employed, while 35 percent age 65 and older had been or were employed.<sup>202</sup> Seventeen percent of dementia caregivers had to give up their jobs before or after assuming caregiving responsibilities. Among those who were employed at any time since they became caregivers, 9 percent ultimately quit their jobs to continue providing care. Fifty-four percent had to go in late or leave early,

**FIGURE 10**

### Work-Related Changes Among Caregivers of People with Alzheimer's Disease and Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the Alzheimer's Association.<sup>A16</sup>

and 15 percent had to take a leave of absence. Other work-related challenges for dementia caregivers who had been employed at any time since beginning caregiving are summarized in Figure 10.<sup>A16</sup>

#### Interventions Designed to Assist Caregivers

Strategies to support family caregivers of people with Alzheimer's disease have been developed and evaluated. The types and focus of these strategies (often called "interventions") are summarized in Table 7.<sup>260-261</sup>

In general, interventions aim to improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Some also aim to delay nursing home admission of the person with dementia. Specific approaches used in various interventions include helping caregivers manage dementia-related symptoms, improving social support for caregivers, and providing caregivers with respite from caregiving duties.

Three characteristics distinguish interventions that have

been found to be particularly effective: they (1) assist caregivers over long periods; (2) approach dementia care as an issue for the entire family; and (3) train dementia caregivers in the management of behavioral problems.<sup>262-265</sup> Multicomponent approaches that combine individual and family counseling, education and other support over time appear especially beneficial in helping caregivers manage changes that occur as the care recipient's dementia progresses.<sup>266-267</sup> Examples of successful multicomponent interventions are the New York University Caregiver Intervention,<sup>268-270</sup> the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II protocol,<sup>271</sup> the Savvy Caregiver program,<sup>272-274</sup> the Reducing Disability in Alzheimer's Disease intervention<sup>275</sup> and the Skills2Care Program.<sup>276</sup> Other multicomponent approaches that have recently shown promise include: (1) Partners in Dementia Care, a care coordination program that improves access to needed services and strengthens the family support network<sup>277</sup> and (2) Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS),<sup>278</sup>

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	Provides 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	Includes 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	Involve 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	Are characterized by 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 Sørensen et al. and Pinquart et al.<sup>260-261</sup>

a program that combines training for the caregiver and person with dementia to help manage symptoms such as memory loss. Other current, promising intervention strategies include care coordination and approaches in which people with early-stage Alzheimer's disease and their family caregivers are educated together.<sup>279-290</sup>

Interventions for dementia caregivers that have demonstrated efficacy in randomized controlled evaluations have been gradually implemented in the community.<sup>291-298</sup> These implementation efforts are generally successful at improving how caregiver services are delivered, reaching a larger number of families and helping caregivers cope with their responsibilities. Because caregivers and the settings in which they provide care are diverse, more studies are needed to define which interventions are most effective for specific situations.<sup>299</sup> Improved tools to "personalize" services for caregivers to maximize their benefits is an emerging area of research.<sup>265,300</sup> More studies are also needed to explore the effectiveness of interventions in different racial, ethnic, socioeconomic and geographic settings.<sup>301-305</sup>

Growing evidence supports the effectiveness of respite services for caregivers.<sup>306</sup> Recent studies of adult day service programs suggest that use of these services can improve dementia caregivers' emotional well-being and can have beneficial effects on biological indicators of stress and health for caregivers.<sup>307-308</sup> Although less consistent in their demonstrated benefits, in-person and online support groups (such as alzconnected.org) have the potential to offer encouragement and enhance caregiver outcomes.

### Caregiver Interventions and Their Effects on Care Recipients

Several reviews have sought to determine whether caregiver interventions improve outcomes for care recipients who have Alzheimer's disease or other dementias. One recent review found that caregiver-focused interventions are effective at reducing behavioral or psychiatric problems in care recipients who have dementia.<sup>309</sup> Multicomponent interventions for dementia caregivers have also been shown to prevent or delay nursing home admission of the care recipient.<sup>310-312</sup> However, these conclusions are not uniform; a recent review that restricted its scope to randomized controlled evaluations found that caregiver interventions had no consistent effects on outcomes of care recipients who had Alzheimer's disease or other dementias.<sup>313</sup>

### 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, provide most of the long-term care services and supports 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.<sup>314-316</sup> Nursing assistants help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women, and they come from increasingly diverse ethnic, racial and international backgrounds.

Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care.<sup>315,317</sup> One review found that direct-care workers received, on average, 75 hours of training and that this training included little focus on issues specific or pertinent to dementia care.<sup>315</sup> Turnover rates are high among direct-care workers, and recruitment and retention are persistent challenges.<sup>318</sup> Reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have modest, positive benefits.<sup>317</sup>

### **Shortage of Geriatric Health Care Professionals in the United States**

Professionals who may receive special training in caring for older adults include physicians, nurse practitioners, registered nurses, social workers, pharmacists, physician assistants, case workers and others.<sup>318</sup> 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.<sup>318</sup> 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.<sup>319</sup> In 2010, there were 4,278 physicians practicing geriatric medicine in the United States.<sup>320</sup> An estimated 36,000 geriatricians will be required to adequately meet the needs of older adults in the United States by 2030.<sup>318</sup> 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.<sup>318</sup> Similarly, although 73 percent of social workers serve clients age 55 and older and about 8 percent are employed in long-term care settings, only 4 percent have formal certification in geriatric social work.<sup>318</sup>

Although 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.<sup>321-323</sup> Ongoing efforts have attempted to integrate innovative care management practices alongside traditional primary care for people with dementia. Dementia care management often involves a skilled professional who serves as the care "manager" of the person with dementia. The care manager collaborates with primary care physicians or nurse practitioners to develop personalized care plans. These plans can provide support to family caregivers, help

people with dementia manage care transitions (for example, a change in care provider or site of care), and ensure the person with dementia's access to appropriate community-based services. Several evaluations have suggested that such approaches have considerable potential for improving outcomes for people with dementia and their family caregivers.<sup>324-328</sup> Current research is attempting to determine the feasibility of these models beyond the specialty settings in which they currently operate.<sup>329</sup>

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



Total payments for health care, long-term care and hospice are estimated to be

**\$226** billion

in 2015 for people with Alzheimer's disease 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.<sup>196</sup>**

Total payments in 2015 (in 2015 dollars) for all individuals with Alzheimer's disease and other dementias are estimated at \$226 billion (Figure 11). Medicare and Medicaid are expected to cover \$153 billion, or 68 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 \$44 billion, or 19 percent of total payments.<sup>A20</sup>

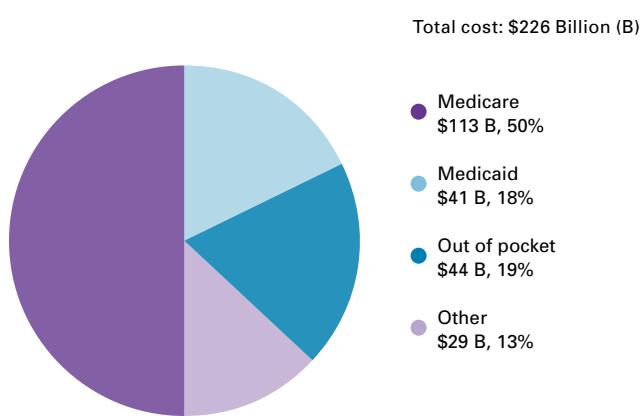
**TOTAL COST OF HEALTH CARE, LONG-TERM CARE AND HOSPICE**

Table 8 (see page 46) reports the average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's disease and other dementias. Unless otherwise indicated, all costs in this section are reported in 2014 dollars.<sup>A21</sup> Total per-person health care and long-term care payments in 2014 from all sources 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 (\$47,752 per person for those with dementia compared with \$15,115 per person for those without dementia).<sup>179, A22</sup>

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.<sup>179</sup> 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

**FIGURE 11**

**Aggregate Cost of Care by Payment Source for Americans Age 65 and Older with Alzheimer's Disease and Other Dementias, 2015\***



\*Data are in 2015 dollars.

Created from The Lewin Model.<sup>A20</sup> "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care. Totals for payment sources may not add to total cost due to rounding.

disease and other dementias (\$11,021) were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's disease and other dementias (\$574) (Table 8).<sup>179</sup>

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 \$10,202 out of pocket, on average, for health care and long-term care services not covered by other sources (Table 8).<sup>179</sup> Average per-person out-of-pocket payments were highest (\$19,642 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.<sup>179</sup>

**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 2014 Dollars**

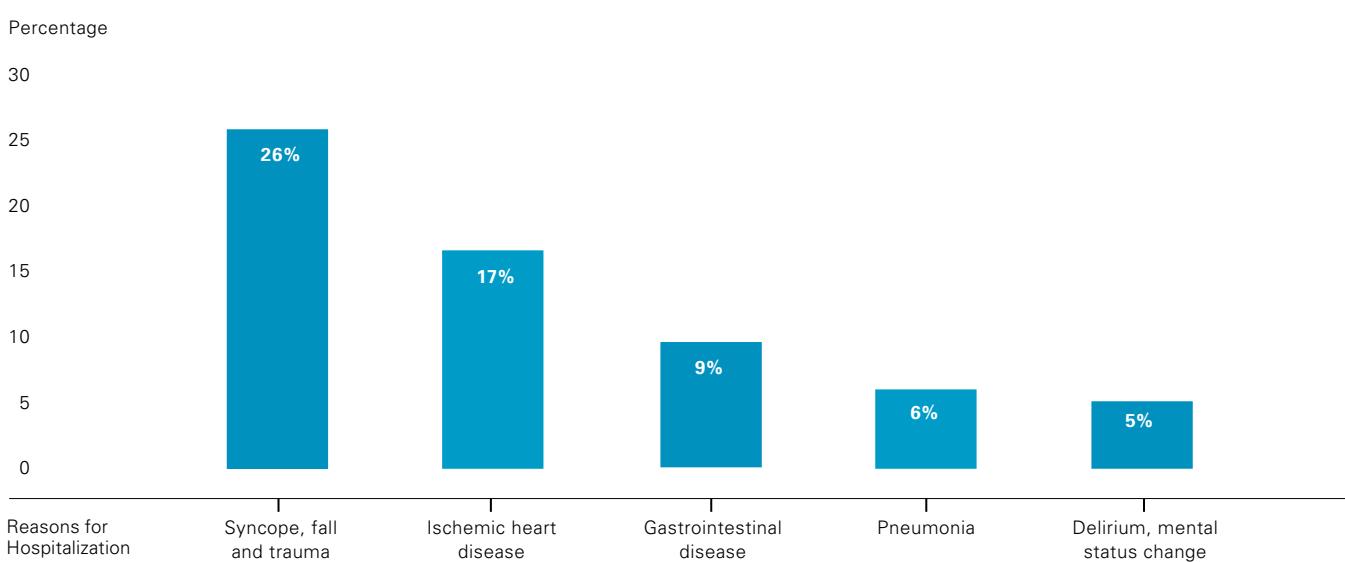
Payment Source	Beneficiaries with Alzheimer's Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer's Disease and Other Dementias
	Overall	Community-Dwelling	Residential Facility	
Medicare	\$21,585	\$19,223	\$24,884	\$8,191
Medicaid	11,021	242	26,086	574
Uncompensated	297	427	117	335
HMO	1,083	1,681	247	1,579
Private insurance	2,463	2,707	2,122	1,657
Other payer	986	178	2,115	156
Out of pocket	10,202	3,449	19,642	2,487
<b>Total*</b>	<b>\$47,752</b>	<b>28,102</b>	<b>75,217</b>	<b>15,115</b>

\*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.<sup>179</sup>

**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.<sup>331</sup>

Recently, researchers evaluated the additional or “incremental” health care and caregiving costs of dementia (that is, the costs specifically attributed to dementia when comparing people with and without dementia who have the same coexisting medical conditions and demographic characteristics).<sup>196,330</sup> One group of researchers found that the incremental health care and nursing home costs for those with dementia was \$28,501 per year in 2010 dollars (\$31,864 in 2014 dollars).<sup>196, A21, A23</sup>

## 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.<sup>179</sup> 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.<sup>179</sup> The most common reasons for hospitalization of people with Alzheimer’s disease are syncope (fainting), fall and trauma (26 percent); ischemic heart disease (17 percent); and gastrointestinal disease (9 percent) (Figure 12).<sup>331</sup>
- *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.<sup>332</sup> 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.<sup>179</sup>

- *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 care visit during the year, compared with 10 percent of Medicare beneficiaries age 65 and older without Alzheimer’s and other dementias.<sup>153</sup>

Differences in health care use between individuals with and without dementia are most prominent for those residing in the community. Based on data from the Health and Retirement Study, community-residing individuals with dementia were more likely to have a potentially preventable hospitalization, an emergency department visit that was potentially avoidable, and an emergency department visit that resulted in a hospitalization.<sup>333</sup> For individuals residing in a nursing home, there were no differences in the likelihood of being hospitalized or having an emergency department visit.

Preventable hospitalizations are one common measure of health care quality. Preventable hospitalizations are hospitalizations for conditions that could have been avoided with better access to or quality of preventive and primary care. Based on data from the 2006 to 2008 Health and Retirement Study and Medicare, preventable hospitalizations represented 25 percent of the total hospitalizations for individuals with Alzheimer’s disease and other dementias.<sup>334</sup> The proportion was substantially higher, however, for African-Americans, Hispanics and individuals with low incomes. Hispanic older adults had the highest proportion of preventable hospitalizations (34 percent). Healthy People 2020, the U.S. Department of Health and Human Services’ initiative to achieve 10-year goals for health promotion and disease prevention, has set a target to reduce preventable hospitalizations for people with Alzheimer’s disease and other dementias by 10 percent by 2020.<sup>334</sup>

### 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).<sup>179</sup> The fact that only payments for prescription drugs were lower for those with Alzheimer's and other dementias underscores the lack of effective treatments available to those with dementia.

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

Individuals newly diagnosed with Alzheimer's disease have higher health care use and costs in the year prior to diagnosis and in the 2 subsequent years after diagnosis 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).<sup>335</sup> Enrollees with a new diagnosis of Alzheimer's disease had \$2,529 more in health care costs (medical and pharmacy) in the year prior to diagnosis, \$10,126 more in costs in the year following diagnosis, and \$6,251 more in costs in the second year following diagnosis. In another study of pre-diagnosis health care costs, Medicaid enrollees with Alzheimer's disease had \$6,204 more in health care costs, with \$3,713 due to additional outpatient medical care and \$1,612 in additional home care and adult day care services.<sup>336</sup>

While more work is needed to understand the underlying causes of increased use of health care services immediately prior to and after receiving a diagnosis of Alzheimer's disease, it may be attributed to care for disability and injuries, such as falls, that might result from the early stage of the disease;<sup>337</sup> treatments related to cognitive impairment or coexisting medical conditions; and costs of diagnostic procedures.

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 2014 Dollars

Service	Beneficiaries with Alzheimer's Disease and Other Dementias	Beneficiaries without Alzheimer's Disease and Other Dementias
Inpatient hospital	\$11,370	\$4,571
Medical provider*	6,306	4,181
Skilled nursing facility	4,189	487
Nursing home	19,442	864
Hospice	1,925	188
Home health	1,543	498
Prescription medications**	2,889	2,945

\* "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.<sup>179</sup>

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.<sup>153</sup>

### Impact of Alzheimer's Disease and Other Dementias on Use and Costs of Health Care in People with Coexisting Medical Conditions

Medicare beneficiaries with Alzheimer's disease and other dementias are more likely than those without dementia to have other chronic conditions.<sup>153</sup> 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 COPD.<sup>153</sup>

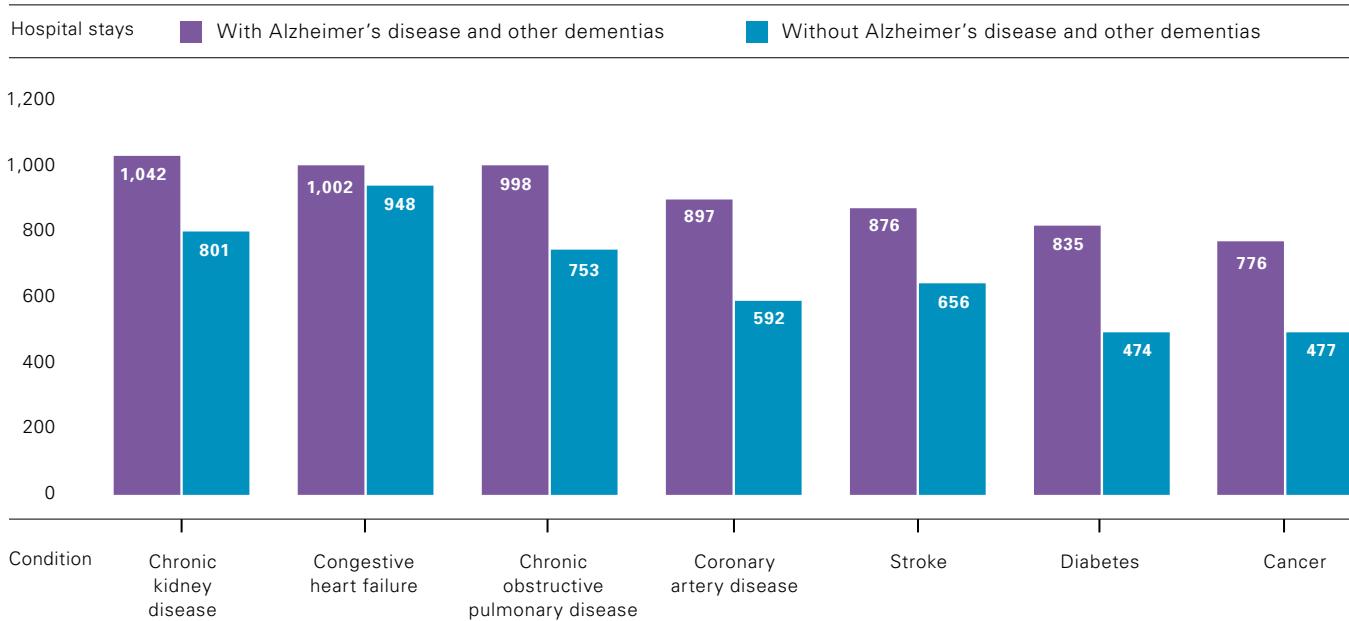
People with Alzheimer's or other dementias and a serious coexisting medical condition (for example, congestive heart failure) are more likely to be hospitalized than people with the same coexisting medical condition but without dementia (Figure 13).<sup>153</sup> Research has demonstrated that Medicare 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.<sup>338</sup>

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 (see page 50) 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.<sup>153</sup> 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.

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.<sup>153</sup>

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 2014 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
<b>Coronary artery disease</b>						
With AD/D	27,661	10,225	1,725	4,433	2,785	2,403
Without AD/D	17,157	7,347	1,319	1,351	1,199	350
<b>Diabetes</b>						
With AD/D	26,994	9,730	1,615	4,297	2,869	2,171
Without AD/D	14,920	5,997	1,136	1,228	1,137	246
<b>Congestive heart failure</b>						
With AD/D	26,509	11,613	1,780	4,915	2,916	3,014
Without AD/D	30,447	11,890	1,779	2,663	2,297	852
<b>Chronic kidney disease</b>						
With AD/D	32,633	12,817	1,910	4,945	2,722	2,621
Without AD/D	25,108	10,743	1,672	2,040	1,685	543
<b>Chronic obstructive pulmonary disease</b>						
With AD/D	30,007	10,914	1,818	4,845	2,888	2,714
Without AD/D	20,539	8,953	1,494	1,766	1,552	681
<b>Stroke</b>						
With AD/D	28,156	10,074	1,675	4,651	2,639	2,824
Without AD/D	20,214	7,809	1,425	2,384	1,936	668
<b>Cancer</b>						
With AD/D	25,910	9,057	1,573	3,728	2,274	2,959
Without AD/D	16,957	6,145	1,207	1,009	807	607

\*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.<sup>153</sup>

## USE AND COSTS OF LONG-TERM CARE SERVICES

An estimated 58 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.<sup>179</sup> Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone.<sup>179</sup> 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 (assisted living, \$42,000 per year,<sup>339, A24</sup> and nursing home care, \$77,380 to \$87,600 per year),<sup>339, A24</sup> 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.<sup>340</sup> In addition, those who had cognitive impairment and received paid services used almost twice as many hours of care monthly as those who did not have cognitive impairment.<sup>340</sup>

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.<sup>341-343</sup>
- *Adult day services.* Thirty-two percent of individuals using adult day services have Alzheimer's disease or other dementias,<sup>344</sup> and 73 percent of adult day services programs offer specific programs for individuals with Alzheimer's disease and other dementias.<sup>345</sup>
- *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.<sup>346</sup> Forty percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's disease and other dementias.<sup>347</sup> Small residential care facilities (4 to 25 beds) have a larger proportion of residents with Alzheimer's and other dementias than larger facilities (49 percent versus 41 percent in facilities with 26 to 50 beds and 38 percent in facilities with more than 50 beds).<sup>347</sup> Sixty-eight percent of residential care facilities offer programs for residents with Alzheimer's disease and other dementias, and 68 percent use a standardized tool to screen residents for cognitive impairment before or at admission.<sup>348</sup>
- *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.<sup>179</sup> Of all Medicare beneficiaries residing in a nursing home, 64 percent have Alzheimer's disease and other dementias.<sup>179</sup>

TABLE 12

## Total Nursing Home Beds and Alzheimer's Special Care Unit Beds by State, 2014

State	Total Beds	Alzheimer's Special Care Unit Beds	Alzheimer's Beds as a Percentage of Total Beds	State	Total Beds	Alzheimer's Special Care Unit Beds	Alzheimer's Beds as a Percentage of Total Beds
Alabama	26,338	1,357	5.2	Montana	6,708	534	8.0
Alaska	693	37	5.3	Nebraska	15,943	959	6.0
Arizona	16,586	936	5.6	Nevada	6,016	270	4.5
Arkansas	24,673	375	1.5	New Hampshire	7,491	710	9.5
California	120,968	2,556	2.1	New Jersey	52,310	1,213	2.3
Colorado	20,401	1,967	9.6	New Mexico	6,814	529	7.8
Connecticut	27,673	1,775	6.4	New York	117,140	3,791	3.2
Delaware	4,876	408	8.4	North Carolina	44,849	1,557	3.5
District of Columbia	2,766	22	0.8	North Dakota	6,153	449	7.3
Florida	83,513	3,922	4.7	Ohio	90,689	3,751	4.1
Georgia	39,888	1,362	3.4	Oklahoma	28,832	499	1.7
Hawaii	4,213	106	2.5	Oregon	12,263	274	2.2
Idaho	5,951	182	3.1	Pennsylvania	88,261	6,332	7.2
Illinois	99,389	4,952	5.0	Rhode Island	8,717	1,202	13.8
Indiana	60,107	5,992	10.0	South Carolina	19,631	64	0.3
Iowa	34,213	1,617	4.7	South Dakota	6,963	532	7.6
Kansas	25,751	159	0.6	Tennessee	37,442	102	0.3
Kentucky	26,779	741	2.8	Texas	135,744	2,583	1.9
Louisiana	35,533	1,403	3.9	Utah	8,577	408	4.8
Maine	6,981	349	5.0	Vermont	3,174	249	7.8
Maryland	28,073	850	3.0	Virginia	32,453	1,206	3.7
Massachusetts	48,376	3,946	8.2	Washington	21,337	871	4.1
Michigan	46,594	789	1.7	West Virginia	10,888	235	2.2
Minnesota	30,362	2,379	7.8	Wisconsin	34,060	2,574	7.6
Mississippi	18,344	200	1.1	Wyoming	2,984	312	10.5
Missouri	55,294	4,154	7.5	U.S.	1,699,774	73,742	4.4

Created from data from the American Health Care Association.<sup>349</sup>

- *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 73,742 beds in Alzheimer's special care units in 2014, a decrease of 3 percent from the previous year.<sup>349-350</sup> These Alzheimer's special care unit beds accounted for 71 percent of all special care unit beds and 4.4 percent of all nursing home beds. Rhode Island had the largest percentage of Alzheimer's special care unit beds as a proportion of total beds (13.8 percent), while Tennessee had the smallest percentage of Alzheimer's special care unit beds (0.3 percent) (Table 12).<sup>349</sup>

Recent research demonstrates that individuals with dementia often move between a nursing facility, hospital and home, rather than remaining in a nursing facility.<sup>351</sup> 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). 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.<sup>352</sup> The number of care transitions for nursing home residents with advanced cognitive impairment varies substantially across geographic regions of the United States.<sup>353</sup> 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. These differences across geographic regions were not explained by severity of illness, restrictions on the use of artificial hydration and nutrition, ethnicity or gender,

and may reflect differences in the quality of care, although more research is needed. Additionally, researchers found that feeding tube use was highest for people with dementia whose care was managed by a subspecialist physician or both a subspecialist and a general practitioner. Feeding tube use was lower among people with dementia whose care was managed by a general practitioner.<sup>354</sup>

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.<sup>355</sup> Additionally, more than twice as many individuals with the disease were receiving hospice care at the time of death in 2009 than in 2000 (48 percent in 2009 versus 20 percent in 2000).

Demands for nursing home services and services from long-term care hospitals are 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 3-year moratorium on both the designation of new long-term care hospitals and increases in Medicare-certified beds for existing long-term care hospitals.<sup>356</sup> 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.<sup>357</sup> The moratorium expired in late 2012.<sup>356,358</sup> In 2011, certificate-of-need programs (i.e., programs that require approval before building new facilities and/or expanding beds or other services) 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.<sup>359</sup>

### **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.

- **Home care.** The median cost for a paid non-medical home health aide is \$20 per hour, or \$160 for an eight-hour day.<sup>339, A24</sup>
- **Adult day centers.** The median cost of adult day services is \$65 per day.<sup>339, A24</sup> 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 in 2012.<sup>360</sup>
- **Assisted living facilities.** The median cost for basic services in an assisted living facility is \$3,500 per month, or \$42,000 per year.<sup>339, A24</sup>
- **Nursing homes.** The average cost for a private room in a nursing home is \$240 per day, or \$87,600 per year. The average cost of a semi-private room in a nursing home is \$212 per day, or \$77,380 per year.<sup>339, A24</sup>

### **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 \$23,983 or less, and 25 percent had incomes of \$14,634 or less in 2013 (in 2014 dollars).<sup>361</sup>
- Fifty percent of Medicare beneficiaries had total savings of \$62,396 or less, 25 percent had savings of \$11,483 or less, and 8 percent had no savings or were in debt in 2013 (in 2014 dollars). Median savings were substantially lower for African-American and Hispanic Medicare beneficiaries than white Medicare beneficiaries.<sup>361</sup>

### **Long-Term Care Insurance**

Enrollment in private long-term care insurance is more common for older adults with higher-than-average incomes. While only 3 percent of adults age 55 and older had long-term care insurance in 2008, 19 percent with incomes greater than \$100,000 had long-term care insurance.<sup>362</sup> The average annual long-term care insurance premium was \$2,320 in 2010.<sup>362</sup> Private health<sup>363</sup> and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2011, representing \$25 billion of the \$363 billion in long-term care spending.<sup>364</sup> The private long-term care insurance market has consolidated since 2010. Five major insurance carriers either exited the market or substantially increased premiums since then, making policies unaffordable for many individuals.<sup>365</sup>

### **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 2011, 55 percent of Medicaid spending on long-term care was allocated to institutional care, and the remaining 45 percent was allocated to home and community-based services.<sup>364</sup>

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be \$41 billion in 2015 (in 2015 dollars).<sup>A20</sup> 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 \$26,086 per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility compared with \$242 for those with the diagnosis living in the community and an average of \$574 for older adults without the diagnosis living in the community and long-term care facilities (Table 8, see page 46).<sup>179</sup>

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.<sup>366</sup> These results demonstrated that African-Americans 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 later-stage diagnosis, which may lead to higher levels of disability while receiving care; 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.

### Programs to Reduce Avoidable Health Care and Nursing Home Use

Recent research has demonstrated that two different types of programs have potential for reducing avoidable health care and nursing home use, with one type of program focusing on the caregiver and the other type of program focusing on the care delivery team.

Studies of the effectiveness of caregiver support programs suggest that these programs have promise for reducing unnecessary emergency department visits and hospitalizations and reducing transitions to residential care for individuals with Alzheimer's disease and other dementias. For example, in an evaluation of the Dementia Care Services Program in North Dakota, researchers found that hospitalizations, ambulance use, emergency department visits and 911 calls decreased significantly after caregivers began working with the program, which offered them care consultations, resources and referrals.<sup>367</sup> In another study, researchers estimated the effects of applying the New York University Caregiver Intervention on health care costs and utilization in the state of Minnesota over 15 years. They determined that this intervention, which includes individual and family caregiver counseling sessions, an ongoing weekly caregiver support group and telephone counseling, would increase the number of individuals with dementia able to continue residing in the community by 5 percent. They also predicted that nearly 20 percent fewer individuals with dementia would die in residential care,<sup>368</sup> and that the delayed and reduced number of transitions to residential care would lower health care costs in Minnesota by \$996 million over the 15-year period. More research is needed to determine the extent to which these results apply to the broader population of individuals with Alzheimer's disease and other dementias and their caregivers.

Additionally, collaborative care models — models that include not only geriatricians, but also social workers, nurses and medical assistants — improve care coordination, thereby reducing health care costs associated with hospitalizations, emergency department visits and other outpatient visits.<sup>369</sup> An interprofessional memory care clinic was shown to reduce per-person health care costs by \$3,474 over a year for individuals with memory problems, compared with others whose care was overseen by a primary care provider only.<sup>369</sup> More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of \$618.<sup>369</sup>

#### USE AND COSTS OF HOSPICE CARE

Hospice care provides medical care, pain management and emotional and spiritual support for people who are dying, including people with Alzheimer's disease and other dementias. Hospice care also provides emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice 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.

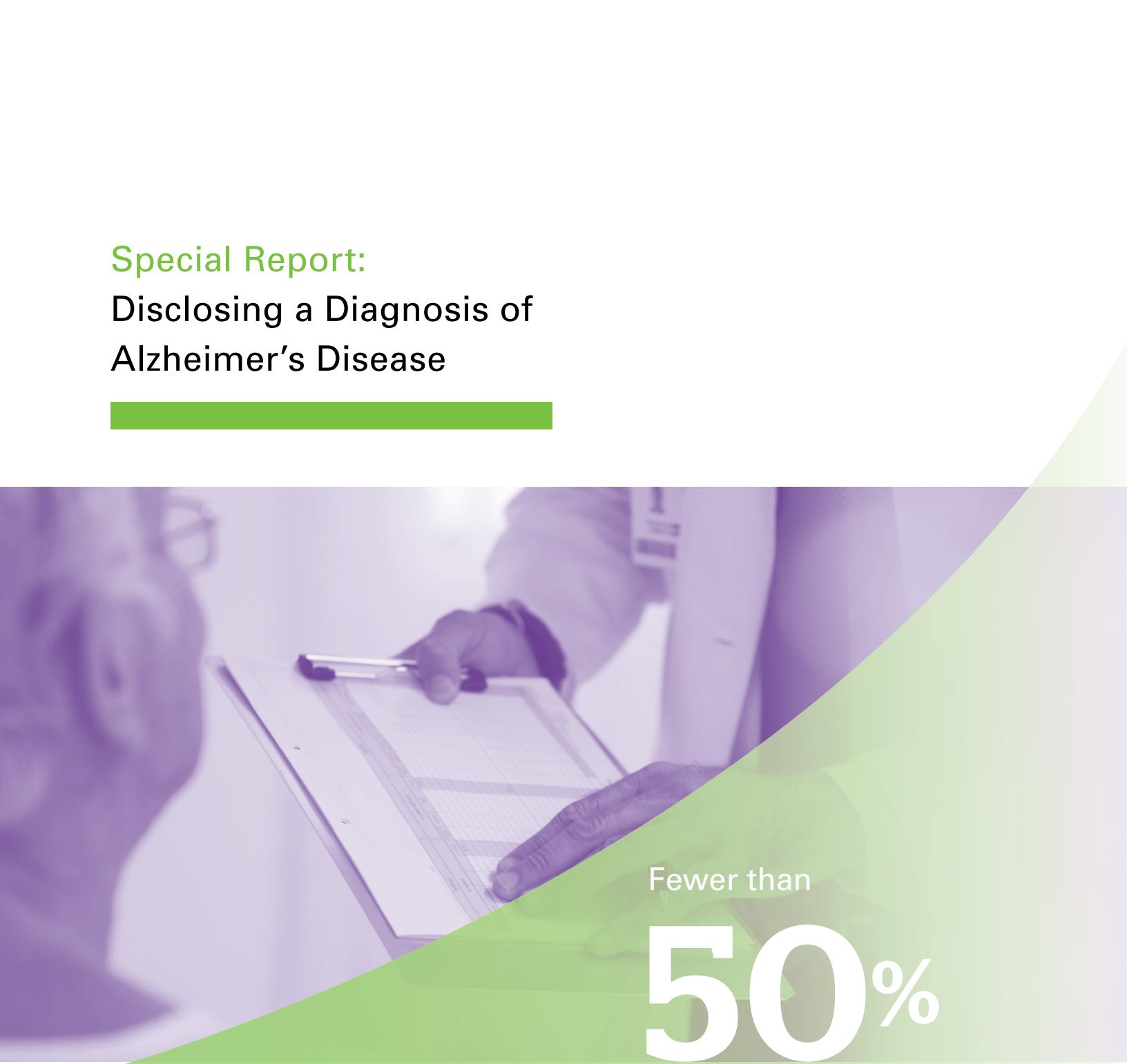
In 2009, 6 percent of people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease (61,146 people).<sup>370</sup> An additional 11 percent of those admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (119,872 people).<sup>370</sup> 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.<sup>370</sup> 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.<sup>370</sup> 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 (\$1,925 per person compared with \$188 per person).<sup>179</sup>

#### 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 \$226 billion in 2015 to more than \$1 trillion in 2050 (in 2015 dollars). This dramatic rise includes a five-fold increase in government spending under Medicare and Medicaid and a nearly five-fold increase in out-of-pocket spending.<sup>A20</sup>

## Special Report: Disclosing a Diagnosis of Alzheimer's Disease



Fewer than

**50%**

of people with  
Alzheimer's disease  
reported being told  
of their diagnosis.

## Should health care providers always tell their patients about a diagnosis? When, if ever, is it acceptable to keep the diagnosis from the patient, or to soften its impact by using less-than-clear explanations?

A limited number of studies have explored whether people who had been diagnosed with Alzheimer's disease or another dementia could recall being told their diagnosis.<sup>371-374</sup> The studies often found that fewer than 50 percent of patients recalled being told their diagnosis. The factors affecting whether individuals are told their diagnosis are numerous and complex. Understanding and addressing these factors may improve the care that patients receive, their ability to cope with the diagnosis, and their relationships with family members and caregivers.

### HISTORICAL CONTEXT

In the 1950s and early 1960s, the issue of whether to tell cancer patients about their diagnosis was much discussed. In one study published in 1961, a group of 291 physicians who treated cancer patients were asked about their usual policies regarding disclosure of a cancer diagnosis to the patient.<sup>375</sup> Almost 9 in 10 (88 percent) responded that it was their usual policy to *not* tell patients that they had been diagnosed with cancer. Reasons for not telling were varied but generally focused on the desire to protect the patient from harm and preserve hope. Many physicians thought that disclosing the diagnosis could cause the patient unnecessary anxiety or depression or lead to thoughts of suicide. However, there was very little evidence that such concerns were justified.

Physicians also had the common perception that cancer treatments available in 1961 were ineffective, so there was no benefit to revealing the diagnosis.<sup>375</sup> The survey even revealed that many physicians at the time opposed research into how patients react to such disclosures. Fortunately, much research was done and

principles of disclosure have now been elaborated and taught. Furthermore, the benefits of disclosure to patients have been recognized, and today nearly all health care providers have the usual policy of disclosing a cancer diagnosis to patients and accurately explaining prospects for the future.<sup>376</sup>

The principles guiding disclosure of a cancer diagnosis apply equally to other diagnoses. But there is evidence that these principles are not always applied in practice, especially when the diagnosis involves conditions affecting the brain. As this report will show, it is still common for patients and their caregivers to not be made aware of a diagnosis of Alzheimer's disease or dementia, or to be left with insufficient understanding of the true nature of the diagnosis.

### The Dilemma's Ancient Roots

The ancient Greeks and Romans wrestled with the same dilemma. In one mythological tradition, Prometheus — the giver of fire — claims to have brought happiness to humankind by taking away foreknowledge of life's duration.<sup>377</sup> Others disputed his claims of benevolence, asserting that unforeseen ills strike a heavier blow than expected ones.<sup>378</sup>

### A CONSENSUS FOR DISCLOSURE

Health care providers routinely encounter the situation of having to deliver a frightening or upsetting diagnosis to patients and perhaps to relatives, friends and loved ones. Like the practice of medicine itself, the ethical principles guiding health care providers during such encounters have evolved during the last half century, and today there is general agreement that patients have the right to know and understand their diagnosis.

Several professional organizations working in the realm of brain health have issued statements regarding the disclosure of a diagnosis of Alzheimer's disease or another dementia. These include the Alzheimer's Association,<sup>379</sup> Alzheimer Europe,<sup>380</sup> the American<sup>381</sup> and Canadian Medical Associations,<sup>382</sup> the American Psychiatric Association,<sup>383</sup> the European Federation of Neuroscience Societies<sup>384</sup> and other organizations.<sup>385-386</sup> Guidelines uniformly advocate revealing the diagnosis to the person who has been diagnosed and doing so in clear language. Guidance from the Alzheimer's Association, for example, advocates talking to the affected person directly and delivering the news in "plain but sensitive language."<sup>379</sup> However, almost all such guidelines recognize that there may be situations in which communicating the diagnosis to the patient is not possible or practicable. Furthermore, some individuals may prefer to not be told, and that preference must be taken into account. However, a person with Alzheimer's or another dementia — especially in the later stages of disease — should have an informed and cognitively intact caregiver to ensure their safety and appropriate care.

The widespread agreement among professionals that people with Alzheimer's disease or another dementia should be told of their diagnosis is founded upon general principles of medical ethics, as well as research into the benefits and potential harms of such disclosure. Two ethical principles that have perhaps the strongest bearing on this issue are respect for patient autonomy and truth-telling.

#### Respect for Patient Autonomy

People have the right to make decisions about their medical care, including mental health care.<sup>387</sup> One aspect of this principle is that patients have the right to decide whether they want to be told their diagnosis. But there are caveats. First, decisions should be made from an informed perspective.<sup>388</sup> Patients should understand the potential benefits and drawbacks of each decision, including the decision of whether to be

told their diagnosis. For example, not receiving the diagnosis may deprive patients of the opportunity to seek other medical opinions, plan for the future, and be involved in decisions that could impact their health care both now and in the future. Second, a person who does not have the mental capacity to understand their condition or treatment choices cannot give informed consent to treatment. In such cases, decisions are usually made by a person representing the patient's best interests. Unfortunately, accurately assessing a patient's ability to understand the diagnosis and treatment options can be challenging for the health care provider.<sup>388</sup> In Alzheimer's, those abilities may remain consistent for an extended period or change from day to day, or even hour to hour.<sup>389-390</sup> Furthermore, when decision-making responsibilities are given to a caregiver, the wishes of the caregiver may not match those of the person diagnosed. Several studies have shown, for example, that caregivers do not want care recipients to be told about a diagnosis of Alzheimer's disease or another dementia, even though the caregivers would want to be told if they were the ones being diagnosed.<sup>391-392</sup>

#### Truth-Telling

It was common in the past to withhold from patients the truth about the nature or severity of their illness. One reason that has frequently been given for withholding the truth is fear of causing distress or of taking away hope.<sup>392</sup> Research conducted in recent decades has dispelled many of these concerns, showing that most people are able to cope with knowing about their condition and that there are many benefits to patients being fully informed. It is now widely recognized that truth-telling in medical diagnosis should be the standard approach, and that more harm than good often comes from not telling patients the truth.<sup>387</sup> Withholding the truth can lead to loss of trust and cooperation among patients, family members and health care providers, and it can actually worsen the distress associated with the diagnosis.<sup>386,393-395</sup>

## ARE PEOPLE BEING TOLD THEY HAVE ALZHEIMER'S BY HEALTH CARE PROVIDERS?

Several studies have found that a large majority of physicians and other health care providers recognize the benefits of disclosing the diagnosis of Alzheimer's disease or another dementia.<sup>396</sup> Despite these findings and the existence of guidelines strongly advocating disclosure of the diagnosis, health care providers vary widely in their practices regarding disclosure.<sup>392,396-399</sup> In fact, one of the goals of the federal government's Healthy People 2020 program is to increase awareness of the diagnosis of Alzheimer's disease and other dementias among those who have been diagnosed or their caregivers.<sup>374</sup>

To explore recent disclosure practices, the Alzheimer's Association commissioned an analysis of Medicare records and responses to the Medicare Current Beneficiary Survey (MCBS), a continuous survey of a nationally representative sample of Medicare beneficiaries living in the community or in long-term care facilities. About 16,000 Medicare beneficiaries complete the survey in any given year, and an individual respondent typically participates in the survey for several consecutive years. The Centers for Medicare and Medicaid Services maintain a database of medical claims submitted by health care providers for care provided to all Medicare beneficiaries.

In the current analysis, de-identified claims records were analyzed for all people who participated in the MCBS during 2008, 2009 and 2010. These records were used to identify individuals with at least one claim related to selected medical conditions, including Alzheimer's disease, other forms of dementia, breast cancer, prostate cancer, lung cancer, colorectal cancer,<sup>A25</sup> stroke, cardiovascular disease other than stroke, Parkinson's disease, diabetes, arthritis, high blood pressure and high cholesterol. (Claims were used to indicate that the person's health care provider had given care because of an indicated medical condition.) Responses on the MCBS were then analyzed to determine whether the respondent indicated that they had been told by their doctor that they had the

indicated conditions. For example, a Medicare beneficiary with a claim that indicated a diagnosis of Alzheimer's disease would be asked, "Has a doctor ever told you that you have Alzheimer's disease?" When the beneficiary was unavailable or unable to answer the question, a similar question was posed to a proxy respondent (often a family member or caregiver). Similarly, respondents with a claim related to breast cancer had that claim linked to their MCBS response as to whether a doctor had ever told them they had cancer.

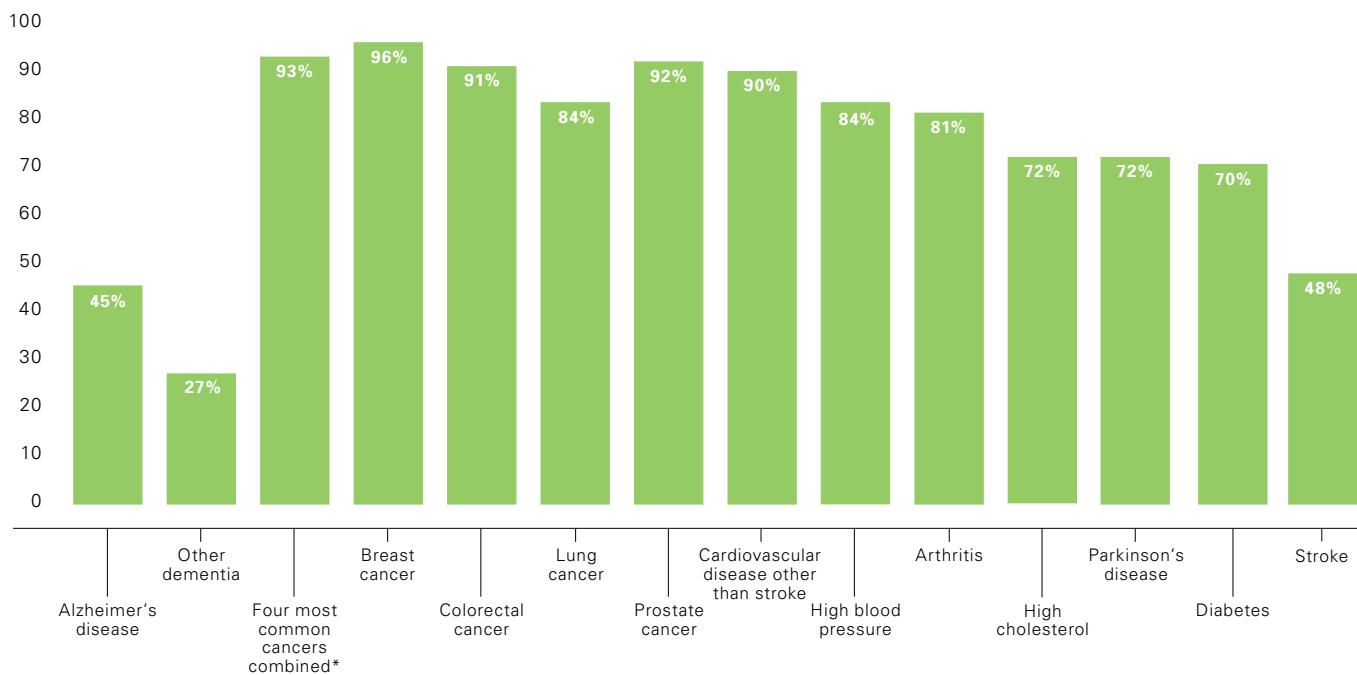
From these data, a disclosure rate was calculated to determine the percentage of respondents with a specified medical condition claim who indicated that their doctor had told them they had that medical condition.<sup>A26</sup>

Disclosure rates for several common medical diagnoses are shown in Figure 14.<sup>A27</sup> The disclosure rate for Alzheimer's disease was 45 percent. The disclosure rate was even lower (27 percent) among those diagnosed with other conditions that cause dementia. In contrast, disclosure rates were substantially higher for all other conditions studied except stroke. For example, among respondents with a Medicare claim for one of the four most common cancers (cancer of the breast, colon or rectum, lung and prostate), 93 percent reported being told of their diagnosis. With the exception of stroke (48 percent), disclosure rates were significantly lower for people with a diagnosis of Alzheimer's disease or another dementia than for those with other diagnoses.<sup>A28</sup>

These data suggest that people with Alzheimer's disease or another dementia are much less likely to be told about the diagnosis by their doctors or health care providers than people with other common medical conditions. This finding is consistent with several older studies in which generally fewer than 50 percent of patients with Alzheimer's disease or dementia reported being told their diagnosis.<sup>371-373,400</sup> The results are also comparable with those of a more recent analysis by the U.S. Centers for Disease Control and Prevention, which found that among people with Alzheimer's disease or another dementia, they or their caregivers reported

**FIGURE 14**

**Disclosure Rates Among MCBS Respondents for the Indicated Medical Conditions**



\*Breast, colorectal, lung and prostate cancer

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008, 2009 and 2010 and Medicare claims data.<sup>A27</sup> Values shown are weighted to adjust the demographics of the responding sample population to match the demographics of the U.S. population.

being aware of the diagnosis in only 35 percent of cases.<sup>374</sup>

Previous studies have also explored the attitudes and practices of health care providers regarding the disclosure of a diagnosis of Alzheimer's disease or dementia. Practices varied widely, with 38 percent to 96 percent of health care providers reporting that they usually disclose the diagnosis to the person with Alzheimer's or dementia.<sup>396</sup>

Many studies reported that health care providers were more likely to disclose the diagnosis to caregivers than to affected persons, with 64 percent to 100 percent of health care providers reporting they disclose the diagnosis to caregivers.<sup>396,400</sup> The current analysis also explored this possibility. Figure 15 (see page 62) shows the responses according to whether the respondent was the Medicare beneficiary or a proxy respondent. Notably, when people with Alzheimer's disease or

another dementia were asked if a doctor had told them they had the disease, only about one in three (33 percent) and one in five (18 percent), respectively, responded "Yes." However, when the respondent was a proxy, they were more likely to report having been told that the beneficiary had been diagnosed with Alzheimer's disease or another dementia (53 percent and 50 percent, respectively). The reason for this difference between beneficiary and proxy respondents is unclear; however, even in the best case scenario, the disclosure rate is barely more than half of cases. Other diagnoses involving brain conditions, such as stroke and Parkinson's disease, also showed differences between beneficiaries and proxy respondents, although the differences were not as prominent as for Alzheimer's and other dementias. One complicating factor in these results is that people with severe Alzheimer's or another dementia are more likely to have proxy respondents

than people in earlier stages. Thus, the greater disclosure rates reported by proxy respondents compared to beneficiary respondents could be due to the presence of more severe disease in people who required proxy respondents.

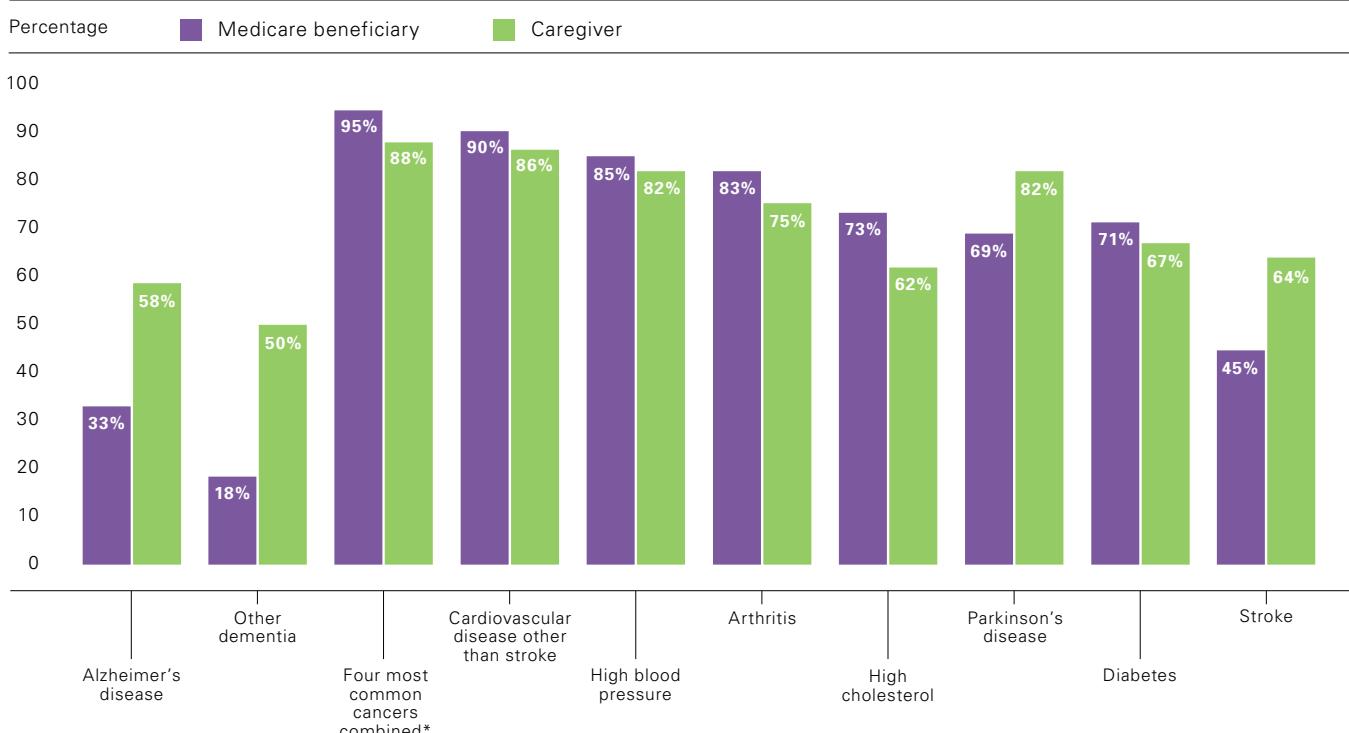
In the current analysis commissioned by the Alzheimer's Association, several factors were explored to determine if they influenced whether respondents reported that a doctor had told beneficiaries about their diagnosis of Alzheimer's disease or another dementia. Factors included the beneficiary's age, sex, race or ethnicity, income level, education level, geographic region, and the patient's degree of impairment as assessed by the number of activities of daily living (ADLs) and instrumental activities of daily living (IADLs)

for which the person needed assistance. Disclosure rates consistently and significantly varied according to only two of these factors — the number of ADLs and IADLs for which the person needed assistance (Figures 16 and 17).<sup>A29</sup>

Activities of daily living are those self-care activities that are fundamental to day-to-day life, including walking, getting into and out of bed, bathing, dressing, toileting and eating. Instrumental ADLs are less fundamental to daily living, but still promote the ability to lead an independent lifestyle. These include such activities as housework, shopping, managing one's own prescribed medications, using the phone or other forms of communication, and traveling within the community by means such as driving or using public transit.

**FIGURE 15**

### Disclosure Rates According to Whether the Respondent was a Beneficiary or a Caregiver

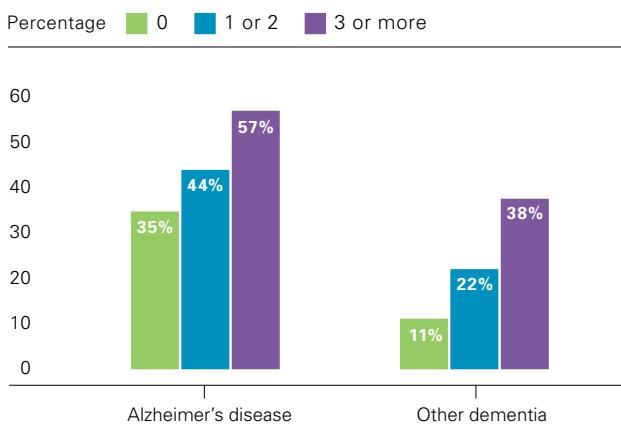


\*Breast, colorectal, lung and prostate cancer

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008, 2009 and 2010 and Medicare claims data.<sup>A27</sup>

**FIGURE 16**

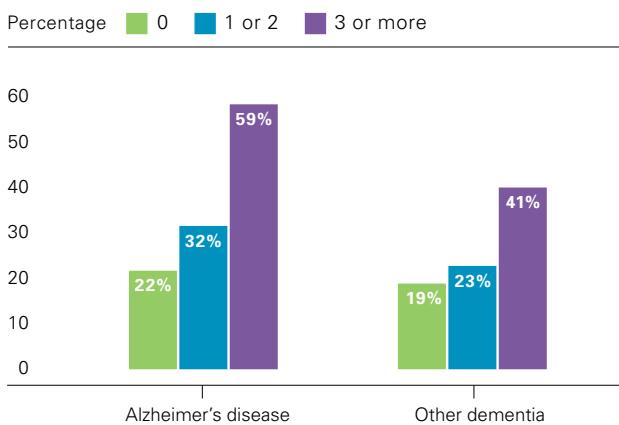
### Disclosure Rates According to the Beneficiary's Degree of Disability as Determined by the Number of ADLs for Which Assistance Was Needed



Created from unpublished data from the Medicare Current Beneficiary Survey for 2008, 2009 and 2010 and Medicare claims data.<sup>A27</sup>

**FIGURE 17**

### Disclosure Rates According to the Beneficiary's Degree of Disability as Determined by the Number of IADLs for Which Assistance Was Needed



Created from unpublished data from the Medicare Current Beneficiary Survey for 2008, 2009 and 2010 and Medicare claims data.<sup>A27</sup>

As shown in Figures 16 and 17 for ADLs and IADLs, respectively, when the beneficiary had more severe disability, they or their proxy were more likely to report being told of the diagnosis of Alzheimer's disease or dementia than when the beneficiary had less severe disability. These findings may indicate that health care providers are more likely to disclose the diagnosis when disability is more severe. It also may be a consequence of the fact that patients with more severe disability have had the disease longer and, therefore, have had more opportunities for the diagnosis to be disclosed to them. Previous studies have had conflicting results regarding whether patients with mild disease are more or less likely to be told their diagnosis than patients with more severe disease.<sup>401-403</sup> In some situations, health care providers may choose not to directly disclose the diagnosis to people with severe disease because such patients are not likely to understand or

remember.<sup>392</sup> In other situations, there is sometimes greater reluctance to reveal the diagnosis to someone who has mild disease because of fear about how they may react.<sup>400</sup>

#### Some Caveats

One problem common to many studies of people with Alzheimer's disease and other causes of dementia is that the diseases themselves may affect the ability of the affected people to remember being told their diagnosis. The current analysis argues against this explanation because disclosure rates were higher among beneficiaries with more severe disability (as measured by the number of ADLs and IADLs for which they needed assistance) than beneficiaries with less severe disability. In addition, even the proxy respondent numbers are very low — only about 50 percent — so it is unlikely that inability to recall disclosure is a significant factor.

However, studies have found that a large percentage of people with dementia and even some caregivers were unable to accurately recall the diagnosis soon after being told.<sup>371,373</sup> This underscores the need for continued efforts by health care providers to ensure that the diagnosis is disclosed fully and carefully. Another problem is that some patients and even some caregivers may deny the diagnosis or use denial as a way to cope with the diagnosis.<sup>404</sup> Using only the data shown here, it is not possible to determine how many people may have reported not being told of their diagnosis because of denial or failure to accurately remember being told.

#### REASONS CITED FOR NOT DISCLOSING A DIAGNOSIS

MCBS data do not contain information about why people are not told of their diagnosis, but numerous studies have explored this issue from the perspectives of health care providers, caregivers and people with Alzheimer's or another dementia.<sup>376,397-398</sup>

**Diagnostic Uncertainty.** Health care providers frequently cite the complexity and uncertainty of the diagnosis as one barrier to disclosure.<sup>125,376,405</sup> A further complication is that diagnostic uncertainty may prompt referral to a specialist, which itself may reveal the suspicion of Alzheimer's or dementia. Ongoing efforts are focused on developing educational programs for health care providers to improve their diagnostic skills related to dementia.<sup>406</sup>

**Time Constraints and Lack of Support.** Disclosing a diagnosis of Alzheimer's or another dementia to a patient usually requires discussion of treatment options and support services, as well as education about the disease and what to expect. In many health care settings, providers have insufficient time to dedicate to such activities.<sup>405</sup> Physicians and other health care providers have also noted that there are insufficient resources and services, including insufficient geriatric specialists and interdisciplinary teams, to provide patients and caregivers with the support needed at the time of diagnosis and afterward.<sup>407</sup>

**Communication Difficulties.** Many providers find that disclosure of the diagnosis is one of the most challenging aspects of the diagnostic process,<sup>398,405</sup> and there have been calls for educational programs to improve the communication skills of providers to address this barrier.<sup>407-408</sup> Providers may also be concerned about whether disclosure of the diagnosis will be understood and accepted by patients or caregivers.<sup>371,373,392</sup>

*"Deliver the news in plain but sensitive language. This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel."*

— Alzheimer's Association Early-Stage Advisor

**Fear of Causing Emotional Distress.** This is one of the reasons most commonly cited by family members and health care providers for not disclosing the diagnosis or for disguising its true nature.<sup>392</sup> However, studies that have explored this issue have found that few patients become depressed or have other long-term emotional problems because of the diagnosis.<sup>403,409-411</sup> One study concluded that "physicians can provide a suspected dementia diagnosis without fear of prompting a catastrophic emotional reaction in most individuals with early-stage dementia."<sup>412</sup> Although there has been fear of suicide, the evidence indicates that it is very uncommon.<sup>413</sup> Certainly, many patients experience initial shock, fear, distress, anger or other emotions, but true clinical depression is uncommon.<sup>395,411-412</sup> In one study, only 6 percent of people diagnosed with Alzheimer's disease or another dementia had clinical depression after 1 year, and those requiring treatment for depression were likely to have had a history of depression.<sup>395</sup>

**Patient or Caregiver Wishes.** Studies have shown that most patients want to be told if they have been diagnosed with Alzheimer’s or another dementia, but some patients prefer not to be told. Although most caregivers support disclosure of the diagnosis to the patient,<sup>392,398</sup> sometimes family members and caregivers request that the patient not be told.<sup>391-392</sup> These requests usually stem from concern that the affected person will have a distressing emotional response to the disclosure. Such requests can create a dilemma for providers, who must choose between respecting the patient’s autonomy or the wishes of caregivers and family members. Recent guidance generally advocates for holding the patient’s wishes as the highest priority.<sup>414</sup>

**Lack of Disease-Modifying Treatment.** In one study, 25 percent of health care providers indicated that the lack of treatments to modify the course of disease was a factor in choosing not to disclose a diagnosis to patients.<sup>392</sup> However, informed patients and caregivers have better access to support services, are more able to participate in decision-making, and are better able to adapt to the diagnosis.

**Stigma.** The stigma experienced by some people diagnosed with Alzheimer’s disease or another dementia is very real and can have detrimental consequences.<sup>415</sup> The stigma can vary widely between cultures. In one study conducted in Italy, some caregivers expressed the opinion that it was disrespectful for a health care provider to tell an older person that they had dementia.<sup>396</sup> In other cultural settings, patients expressed the sense that their friends afforded them less esteem after the diagnosis than before.<sup>415</sup> Patients may even attach a stigma to their own diagnosis, viewing a diagnosis of Alzheimer’s or another dementia differently than they would other “physical” conditions, even though the symptoms of Alzheimer’s and other dementias are manifestations of physical changes in the brain. As a consequence, it is common for patients to disguise their symptoms from

family members and health care providers and to avoid discussing memory problems.<sup>415</sup> Similarly, health care providers may avoid the issue to spare the patient from a potentially stigmatizing diagnosis.<sup>415</sup>

### BENEFITS OF DISCLOSING A DIAGNOSIS

Several studies have found benefits to promptly and clearly explaining a diagnosis of dementia to the affected person and that person’s caregiver(s).<sup>376,397-398,409</sup>

**Better Diagnosis.** When a patient understands their diagnosis, they have the opportunity to seek other medical opinions or the advice of specialists. The decision to withhold the diagnosis rests on the assumption that the diagnosis is correct. However, several reversible conditions can mimic dementia, including depression, thyroid dysfunction, vitamin deficiency and sleep disruption.<sup>416</sup> Concern about having to tell a patient that they have Alzheimer’s disease or another dementia has been cited as one barrier to early diagnosis.<sup>407</sup> However, early diagnosis is associated with numerous benefits regardless of whether a treatment is available.<sup>416</sup>

**Better Decision-Making.** When a patient is fully aware of their diagnosis in the early stages of the disease, the patient is likely to be competent to understand options and provide informed consent for current and future treatment options, including participation in research studies. In this way, the affected person can ensure that their desires and preferences are known, which may help them get better medical care and may contribute to advancing research toward better treatments.<sup>401,409</sup> Furthermore, when people are actively involved in decision-making about their care, they are more likely to follow a treatment plan and take steps to maintain their health.

**Better Medical Care.** Studies have shown that when patients understand their diagnosis and are active participants in the decision-making process, the quality of care they receive is better than the care received by uninformed patients.<sup>417-419</sup>

**Respect for the Patient's Wishes.** Although studies of the opinions and attitudes of patients with memory complaints are limited, the evidence indicates that most patients with mild dementia want to be told their diagnosis.<sup>395,398,420</sup>

**"People can overprotect you, which robs you of your independence much quicker."**

— Person with dementia<sup>421</sup>

**"It's unfortunate I waited a year to get a diagnosis because that meant an additional year of worry, concern and hiding my issues from family and friends. I was exhausting myself needlessly when getting a diagnosis actually simplified and improved my life greatly."**

— Lou B., an individual living with Alzheimer's disease

**Planning for the Future.** Prompt disclosure of the diagnosis allows patients and caregivers to get legal and financial affairs in order with the full and informed consent of the affected person.

**Understanding Changes.** People affected by memory loss and their caregivers are often aware that something is not right. Knowing the diagnosis can help them understand the symptoms they have felt or observed. Among caregivers, knowledge of the diagnosis and disease characteristics can help them better appreciate their loved one's remaining capacities.<sup>403</sup>

**Coping.** Although the initial disclosure can be shocking, distressing or embarrassing, being aware of the diagnosis gives patients and their caregivers the opportunity to express their fears and grief and to adopt positive strategies for coping with the diagnosis.<sup>403,409</sup> Health care professionals are frequently concerned that patients and their caregivers will lose hope or become depressed when they learn of the diagnosis, but several studies have found these concerns to be unwarranted or overemphasized.<sup>396</sup> Some patients and caregivers express relief when they finally know the diagnosis; it removes uncertainty and gives them the opportunity to develop a plan of action.<sup>412</sup> Some caregivers have expressed that knowing the diagnosis allows them to blame the disease for changes in their loved one's behavior, rather than blaming the person.

Knowing the diagnosis can also help caregivers prepare for and adapt to their role,<sup>403</sup> which can reduce the perceived burden of caregiving.<sup>422</sup>

**Access to Services.** Knowing the diagnosis allows patients and caregivers to obtain information about support services and make plans to use such services. Accessing support services can help patients and caregivers cope with the diagnosis and behavior changes that may accompany it.<sup>403,420</sup>

**Safety.** Awareness of the diagnosis allows caregivers to take steps to ensure the affected person's environment is safe and may help caregivers take precautionary steps to determine when certain activities (such as driving) may need to be curtailed.

**Social Support.** Knowing the diagnosis helps affected people focus on spending quality time with loved ones, garnering social support, appreciating what life has to offer and possibly traveling or fulfilling long-held wishes.

## THE PROCESS OF DISCLOSURE

The analysis described in this report gives only a snapshot of whether patients or caregivers report being told by a doctor that they or a care recipient have Alzheimer's disease or another dementia. Just as important is how the diagnosis is disclosed and who should be involved. Although autonomy of the individual is important, those involved in the diagnostic process

are encouraged to include family and other current or future caregivers during the disclosure process.<sup>414</sup>

Specific guidelines for an optimal diagnostic disclosure process are hindered by the lack of systematic studies and inconsistency of desired approaches of patients and caregivers. Some caregivers want to be told directly and others would like a gentler explanation.<sup>423</sup> However, the disclosure process should be ongoing to ensure understanding of the diagnosis and any needed changes in the follow-up plans for the patient and family.<sup>414,424</sup> It has been shown that a contributor to the caregivers' dissatisfaction with the disclosure process is lack of follow-up appointments and limited information about community services.<sup>423</sup>

To best provide diagnostic disclosure and appropriate connection to resources and services, providers need to consider the ability of the patient and caregiver to understand and cope with the diagnosis, the social and cultural context in which the patient lives,<sup>425</sup> and whether the patient has a strong support network.<sup>424</sup>

Providers sometimes tell patients about the diagnosis without using the words "Alzheimer's" or "dementia," perhaps in an attempt to soften the emotional impact of the diagnosis.<sup>376,398,409</sup> But such lack of clarity can lead to confusion for both patients and family members<sup>405</sup> and may endanger trust between patients and the medical team.<sup>409</sup>

**"Tell the truth. Even if you don't have all the answers, be honest about what you do know and why you believe it to be so."**

— Alzheimer's Association Early-Stage Advisor

Using a standard approach for disclosing a diagnosis is not likely to be satisfactory because the same approach can be perceived by different patients and caregivers as either too blunt or too indirect.<sup>396,398,426</sup> Such difficulties have led to calls for the disclosure process to be managed in ways that are sensitive to each patient's and family's individual circumstances, using patient-centered

approaches.<sup>396,414,424,426</sup> These approaches represent a distinct skill set, and providers have recognized the need for training programs to help them improve their skills in this setting.<sup>407-408</sup> Efforts to improve how health care providers diagnose and manage Alzheimer's disease and dementia include educational components designed to improve the disclosure process.<sup>406,414,420</sup>

**"Recognize that I am an individual and the way I experience this disease is unique."**

— Alzheimer's Association Early-Stage Advisor

## CONCLUSION

Despite widespread recognition of the benefits of clear and accurate disclosure, the practices of health care providers vary widely. In several studies, including the current analysis of Medicare records, fewer than half of patients with a diagnosis of Alzheimer's or another dementia reported being told the diagnosis by their health care provider. Although caregivers were more likely to report disclosure, more than 45 percent did not report disclosure. Because of the complexity of the diagnostic and disclosure processes, varying preferences of patients and caregivers, and different support networks and coping mechanisms among patients, it is recognized that the disclosure process should be managed in a way that respects each patient's situation and that of their families and caregivers. Furthermore, health care providers have recognized the need for stronger support systems for themselves and for patients newly diagnosed with Alzheimer's disease or another dementia. Improvements in such systems have the potential to improve the care of individual patients and reduce the burden of disease on both caregivers and health care providers.

## End Notes

A1. Number of Americans age 65 and older with Alzheimer's disease for 2015 (prevalence of Alzheimer's in 2015): The number 5.1 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.<sup>120</sup>

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 (5.1 million) by the U.S. population age 65 and older in 2015, as projected by the U.S. Census Bureau (47.7 million) = 11 percent. Eleven percent is the same as one in nine. (see 2012 National Population Projections: Summary Tables located at <http://www.census.gov/population/projections/data/national/2012/summarytables.html>)

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).<sup>120</sup>

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.<sup>122</sup> [Note that the CHAP estimates referred to in this end note are from an earlier study using 2000 U.S. Census data.<sup>160</sup>] 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.<sup>123</sup> 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,<sup>6</sup> 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 (1.9 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.<sup>120</sup>

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 the Alzheimer's Association's *2010 Alzheimer's Disease Facts and Figures*.

A7. State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on an 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.<sup>154</sup> Specific prevalence numbers projected for each year from 2015 to 2025 derived from this analysis were provided to the Alzheimer's Association by a team led by Liesl Hebert, Sc.D., Rush University Institute on Healthy Aging.

A8. Number of new cases of Alzheimer's disease this year (incidence of Alzheimer's in 2015): The East Boston Established Populations for Epidemiologic Study of the Elderly (EPESE) estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020. See Hebert et al.<sup>155</sup> The Alzheimer's Association calculated that the incidence of new cases in 2015 would be 461,400 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.5 (for the number of years from 2010 to 2015 divided by the number of years from 2010 to 2020), adding that result (18,500) to the Hebert et al. estimate for 2010 (454,000) = 472,500.<sup>155</sup> Rounded to the nearest thousand, this is 473,000 new cases of Alzheimer's disease in 2015. The same technique for linear interpolation from 2000 to 2010 projections was used to calculate the number of new cases in 2015 for ages 65–74, 75–84, and 85 and older. 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. Hebert et al. used the 2015 projected population generated from the 2000 U.S. Census to estimate age-specific rates, and these calculations depended on a particular 5-year age structure of the older adult population (e.g., percentage age 65–69, 70–74, etc.). To maintain compatibility with these calculations, we used the total number of people per age group (e.g., 65–74, 75–84, 85+) for 2015 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>).

A9. 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.<sup>156</sup> The number of seconds in a year (31,536,000) divided by 472,500 = 66.7 seconds, rounded to 67 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 [from Hebert et al.<sup>155</sup>] = 32.8 seconds, rounded to 33 seconds.

A10. 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.<sup>130</sup> The definition of Alzheimer's disease and other dementias used in the Framingham Study was thus very strict; using a definition that 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.

A11. Projected number of people with Alzheimer's disease: This comes from the CHAP study.<sup>120</sup> Other projections are somewhat lower [see, for example, Brookmeyer et al.<sup>427</sup>] because they relied on more conservative methods for counting people who currently have Alzheimer's disease.<sup>158</sup> 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.<sup>120</sup>

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.<sup>120</sup> 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.<sup>168</sup>

A14. [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 larger populations of older people will have a larger burden of mortality due to Alzheimer's.

A15. [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 2014. Available at: [www.census.gov/popest/data/datasets.html](http://www.census.gov/popest/data/datasets.html). Accessed on Jan. 3, 2015. 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.<sup>428</sup> 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 15,705,824 Alzheimer's and dementia caregivers.

A16. [The 2014 Alzheimer's Association Women and Alzheimer's Poll](#) questioned a nationally-representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's disease and dementia from January 9, 2014 to January 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's disease or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics, selected from U.S. Census tracts with higher than an 8 percent concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the

increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

A17. [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 (15,705,824)<sup>115</sup> was multiplied by the average hours of care per year, which totals 17,886 billion hours of care.

A18. [Value of unpaid caregiving](#): To calculate this number, the Alzheimer's Association used the method of Amo et al.<sup>429</sup> This method uses the average of the federal minimum hourly wage (\$7.25 in 2014) and the mean hourly wage of home health aides (\$17.09 in July 2014).<sup>430</sup> The average is \$12.17, which was multiplied by the number of hours of unpaid care (17,886 billion) to derive the total value of unpaid care (\$217.67 billion).

A19. [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'.<sup>431</sup> 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<sup>115</sup> were used to weight each state's caregiver and non-caregiver per capita personal health care spending in 2009,<sup>432</sup> inflated to 2014 dollars. 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 \$639. The amount of the additional cost in each state, which varied by state from a low of \$471 in Utah to a high of \$974 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer's and dementia caregivers in that state<sup>115</sup> 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 \$9,733 billion. Fulton concluded that this is "likely to be a conservative estimate because caregiving for people with Alzheimer's is more stressful than caregiving for most people who don't have the disease."<sup>433</sup>

A20. [Lewin Model on Alzheimer's and dementia costs](#): These numbers come from a model created for the Alzheimer's Association by The Lewin Group and updated in January 2015. The model estimates total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias based on cost data from the 2008 Medicare Current Beneficiary Survey. A comprehensive report on the model, *Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars*, was published by the Alzheimer's Association in February 2015. The report and additional information on the model, its long-term projections and its methodology are available at [alz.org/trajectory](http://alz.org/trajectory).

**A21. All cost estimates were inflated to year 2014 dollars using the Consumer Price Index (CPI):** All cost estimates were inflated using the seasonally adjusted average prices for medical care services from 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.

**A22. 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.<sup>179</sup> 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 *2015 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 2014 dollars.

**A23. Differences in estimated costs reported by Hurd and colleagues:** Hurd et al.<sup>196</sup> estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2015 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 individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals 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 *2015 Alzheimer's Disease 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).

**A24. The source for long-term care costs differs from the source used in prior years of this report:** Some long-term care cost figures for 2015 are lower than the figures reported in the *2014 Alzheimer's Disease Facts and Figures*. There are several possible explanations for these differences, including differences in the methodologies used, differences in the long-term care organizations included in each survey, or changes in the underlying cost structures.

**A25. Individuals with Medicare claims for more than one cancer type** were excluded from the analysis because the calculation algorithm did not support this situation.

**A26. Method of calculating the disclosure rate:** The number of respondents with a Medicare claim related to a specified medical condition and who responded "Yes" to the question of whether a doctor had that condition divided by the number of respondents with a Medicare claim related to that medical condition.

**A27. Disclosure rates are based on calculations incorporating data** from the 2008, 2009 and 2010 Medicare Current Beneficiary Surveys and Medicare claims data. Calculations and related analyses were performed under contract by Avalere Health, LLC.

**A28. Ninety-five percent confidence intervals for disclosure rates** did not overlap with the 95% confidence intervals for Alzheimer's disease or other dementias.

**A29. Comparisons were considered statistically significant** if the 95% confidence intervals did not overlap.

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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.

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