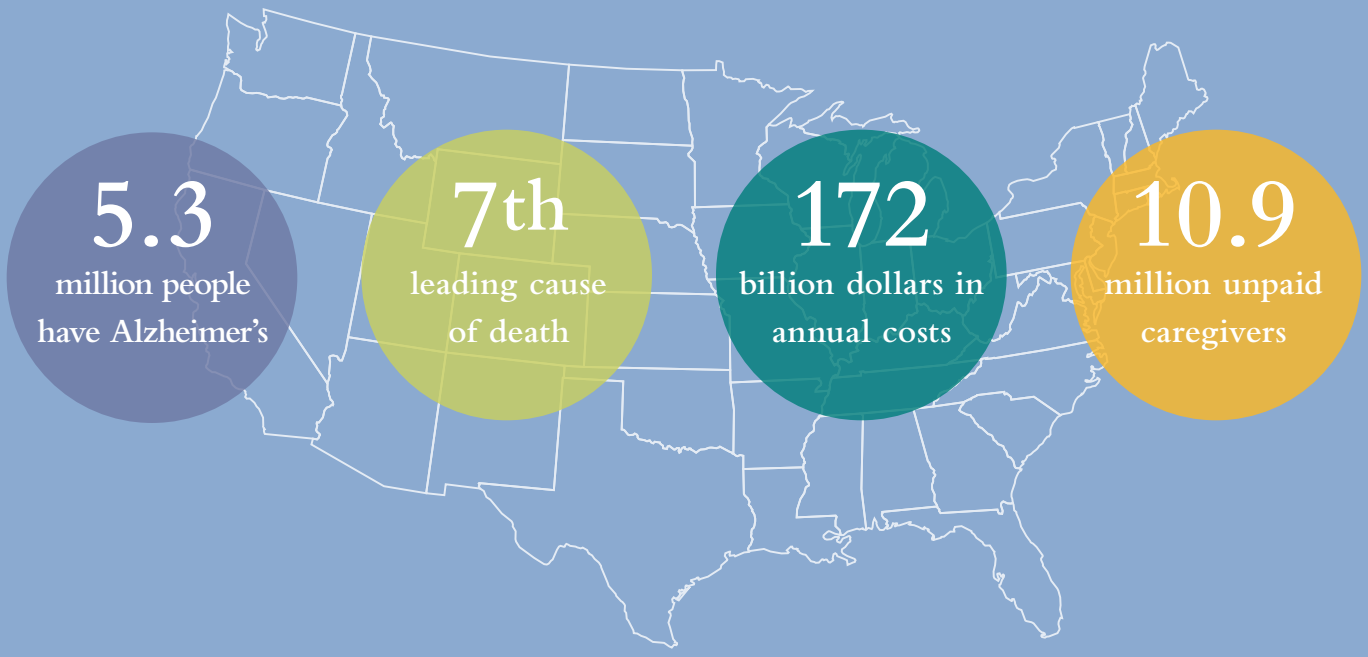
Section 1

2010 Alzheimer's Disease Facts and Figures

Includes a Special Report on Race, Ethnicity and Alzheimer's Disease



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About This Report

2010 Alzheimer's Disease Facts and Figures provides a statistical resource for United States data related to Alzheimer's disease, the most common type of dementia, as well as other dementias. Background and context for interpretation of the data are contained in the Overview. This includes definitions of the types of dementia and a summary of current knowledge about Alzheimer's disease. Additional sections address prevalence, mortality, caregiving and use and costs of care and services. The Special Report for 2010 focuses on race, ethnicity and Alzheimer's disease.

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

- Overall number of Americans with Alzheimer's disease nationally and for each state
- Proportion of women and men with Alzheimer's and other dementias
- Estimates of lifetime risk for developing Alzheimer's disease
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state and the impact of caregiving on caregivers
- Use and costs of health care, long-term care and hospice care for people with Alzheimer's disease and other dementias
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age
- Current knowledge of the prevalence of Alzheimer's and other dementias in diverse populations

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

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

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

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1 Overview of Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia. This section provides information about the definition of dementia, the characteristics of specific types of dementia and the symptoms of, risk factors for and treatment of Alzheimer's disease. More detailed information on these topics is available at www.alz.org.

Dementia: Definition and Specific Types

Dementia is characterized by the loss of or decline in memory and other cognitive abilities. It is caused by various diseases and conditions that result in damaged brain cells. To be classified as dementia, the following criteria must be met:

- It must include decline in memory and in at least one of the following cognitive abilities:

  1) Ability to generate coherent speech or understand spoken or written language;

  2) Ability to recognize or identify objects, assuming intact sensory function;

  3) Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and

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

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

Different types of dementia have been associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Increasing evidence from long-term epidemiological observation and autopsy studies suggests that many people have brain abnormalities associated with more than one type of dementia. The symptoms of different types of dementia also overlap and can be further complicated by coexisting medical conditions. Table 1 provides information about the most common types of dementia.

Table 1: Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for an estimated 60–80 percent of cases. Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking. Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).
Vascular dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	Considered the second most common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia — most commonly vascular dementia, but also other types, such as dementia with Lewy bodies. Recent studies suggest that mixed dementia is more common than previously thought.

Table 1 (Continued): Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Dementia with Lewy bodies	Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment as well as behavior changes. Alertness and severity of cognitive symptoms may fluctuate daily. Visual hallucinations, muscle rigidity and tremors are common. Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.
Parkinson's disease	Many people who have Parkinson's disease (a disorder that usually involves movement problems) also develop dementia in the later stages of the disease. The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language. No distinguishing microscopic abnormality is linked to all cases. Pick's disease, characterized by Pick's bodies, is one type of frontotemporal dementia.
Creutzfeldt-Jakob disease	Rapidly fatal disorder that impairs memory and coordination and causes behavior changes. Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease. Caused by the misfolding of prion protein throughout the brain.
Normal pressure hydrocephalus	Caused by the buildup of fluid in the brain. Symptoms include difficulty walking, memory loss and inability to control urination. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

More About Alzheimer's Disease

In Alzheimer's disease, as in other types of dementia, increasing numbers of nerve cells deteriorate and die. A healthy adult brain has 100 billion nerve cells, or neurons, with long branching extensions connected at 100 trillion points. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and taken up by the receiving cell. Different strengths and patterns of signals move constantly through the brain's circuits, creating the cellular basis of memories, thoughts and skills.

In Alzheimer's disease, information transfer at the synapses begins to fail, the number of synapses declines and eventually cells die. Brains with advanced Alzheimer's show dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

Symptoms of Alzheimer's Disease

Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty in remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals experience other difficulties. The following are warning signs of Alzheimer's:

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

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

In advanced Alzheimer's, people need help with bathing, dressing, using the bathroom, eating and other daily activities. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound and reliant on 24/7 care. The inability to move around in late-stage Alzheimer's disease can make a person more vulnerable to infections, including pneumonia (infection of the lungs). Alzheimer's disease is ultimately fatal, and Alzheimer-related pneumonia is often the cause.

Although families generally prefer to keep the person with Alzheimer's at home as long as possible, most people with the disease eventually move into a nursing home or another residence where professional care is available.

Risk Factors for Alzheimer's Disease

Although the cause or causes of Alzheimer's disease are not yet known, most experts agree that Alzheimer's, like other common chronic conditions, probably develops as a result of multiple factors rather than a single cause.

The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most Americans with Alzheimer's disease are aged 65 or older, although individuals younger than age 65 can also develop the disease.

When Alzheimer's or another dementia is recognized in a person under age 65, these conditions are referred to as "younger-onset" or "early-onset" Alzheimer's or "younger-onset" or "early-onset" dementia.

A small percentage of Alzheimer's disease cases, probably less than 1 percent, are caused by rare genetic variations found in a small number of families worldwide. These variations involve chromosome 21 on the gene for the amyloid precursor protein,

chromosome 14 on the gene for the presenilin 1 protein and chromosome 1 on the gene for presenilin 2. In these inherited forms of Alzheimer's, the disease tends to develop before age 65, sometimes in individuals as young as 30.

A genetic factor in late-onset Alzheimer's disease (Alzheimer's disease developing at age 65 or older) is apolipoprotein E-e4 (ApoE-e4). ApoE-e4 is one of three common forms of the ApoE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the ApoE gene from each of his or her parents. Those who inherit one ApoE-e4 gene have increased risk of developing Alzheimer's disease. Those who inherit two ApoE-e4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's.

A significant portion of people with mild cognitive impairment (MCI), but not all, will later develop Alzheimer's. MCI is a condition in which a person has problems with memory, language or another essential cognitive function that are severe enough to be noticeable to others and show up on cognitive tests, but not severe enough to interfere with daily life. Studies indicate that as many as 10–20 percent of people aged 65 and older have MCI. People whose MCI symptoms cause them enough concern to visit a physician appear to have a higher risk of developing dementia. It's estimated that as many as 15 percent of these individuals progress from MCI to dementia each year. From this estimate, nearly half of all people who have visited a physician about MCI symptoms will develop dementia in three or four years. It is unclear which mechanisms put those with MCI at greater risk for developing Alzheimer's or other dementia. MCI may in some cases represent a transitional state between normal aging and the earliest symptoms of Alzheimer's.

Treatment and Prevention of Alzheimer's Disease

No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration has approved five drugs that temporarily slow worsening of symptoms for about six to 12 months, on average, for about half of the individuals who take them. Researchers have identified treatment strategies that may have the potential to change its course. Approximately 90 experimental therapies aimed at slowing or stopping the progression of Alzheimer's are in clinical testing in human volunteers.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for diagnosed individuals and their caregivers. Active management includes appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan, coordination of care among physicians and others involved in maximizing quality of life for people with Alzheimer's or other dementia and use of such supportive services as counseling, activity and support groups and adult day center programs.

A growing body of evidence suggests that the health of the brain — one of the body's most highly vascular organs — is closely linked to the overall health of the heart and blood vessels. Some data indicate that management of cardiovascular risk factors, such as high cholesterol, Type 2 diabetes, high blood pressure, smoking, obesity and physical inactivity may help avoid or delay cognitive decline.[1-9] Many of these risk factors are modifiable — that is, they can be changed to decrease the likelihood of developing both cardiovascular disease and the cognitive decline associated with Alzheimer's and other forms of dementia. More limited data suggest that a low-fat diet rich in fruits and vegetables may support brain health, as may a robust social network and a lifetime of intellectual curiosity and mental stimulation.

2 Prevalence

Millions of Americans now have Alzheimer's disease or another dementia. More women than men have dementia, primarily because women live longer, on average, than men. This longer life expectancy increases the time during which women could develop Alzheimer's or other dementia.

Estimates from different studies on the prevalence and characteristics of people with Alzheimer's and other dementias vary depending on how each study was conducted. Data from several studies are used in this section to describe the prevalence of these conditions and the proportion of people with the conditions by gender and years of education. Data sources and study methods are described, and more detailed information is contained in the End Notes section in the Appendices.

Prevalence of Alzheimer's Disease and Other Dementias

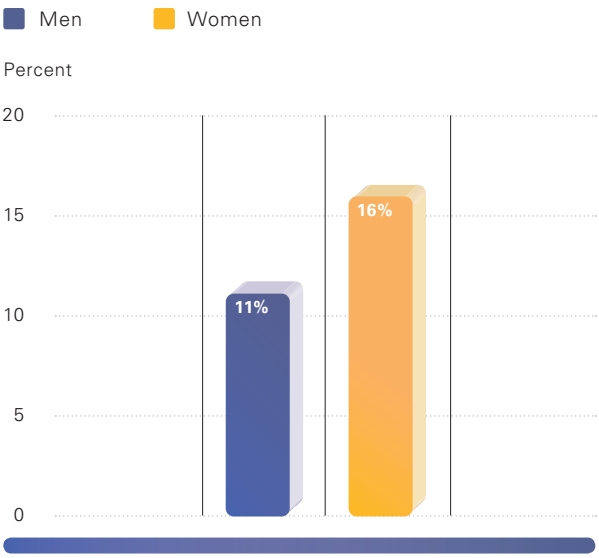
An estimated 5.3 million Americans of all ages have Alzheimer's disease. This figure includes 5.1 million people aged 65 and older[10] and 200,000 individuals under age 65 who have younger-onset Alzheimer's.[11] The Alzheimer's Association estimates that there are 500,000 Americans younger than 65 with Alzheimer's and other dementias. Of these, approximately 40 percent are estimated to have Alzheimer's.

- One in eight people aged 65 and older (13 percent) have Alzheimer's disease.[A1]
- Every 70 seconds, someone in America develops Alzheimer's. By mid-century, someone will develop the disease every 33 seconds.[A2]

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

Women are more likely than men to have Alzheimer's disease and other dementias. Based on estimates from the Aging, Demographics, and Memory Study (ADAMS), 14 percent of all people aged 71 and older have dementia.[12] As shown in Figure 1, women aged 71 and older had higher rates than men: 16 percent for women and 11 percent for men.

Figure 1: Estimated Percentage of Americans Aged 71+ with Dementia by Gender, ADAMS, 2002



Created from data from Plassman et al. [12]

Further analysis of these data shows that the larger proportion of older women than men who have dementia is primarily explained by the fact that women live longer on average than men.[12] Likewise, many studies of the age-specific incidence (new cases) of dementia have found no significant difference by gender.[13-17]

A similar explanation is believed to be true for Alzheimer's disease. The larger proportion of older women than men who have Alzheimer's disease is believed to be explained by the fact that women live longer.[12] Again, many studies of the age-specific incidence of Alzheimer's disease show no significant difference for women and men.[13, 16-21] Thus, it appears that gender is not a risk factor for Alzheimer's disease and other dementias once age is taken into account.

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

People with fewer years of education appear to be at higher risk for Alzheimer's and other dementias than those with more years of education. Prevalence and incidence studies show that having fewer years of education is associated with a greater likelihood of having dementia[12, 22] and a greater risk of developing dementia.[15-16, 19, 23-24]

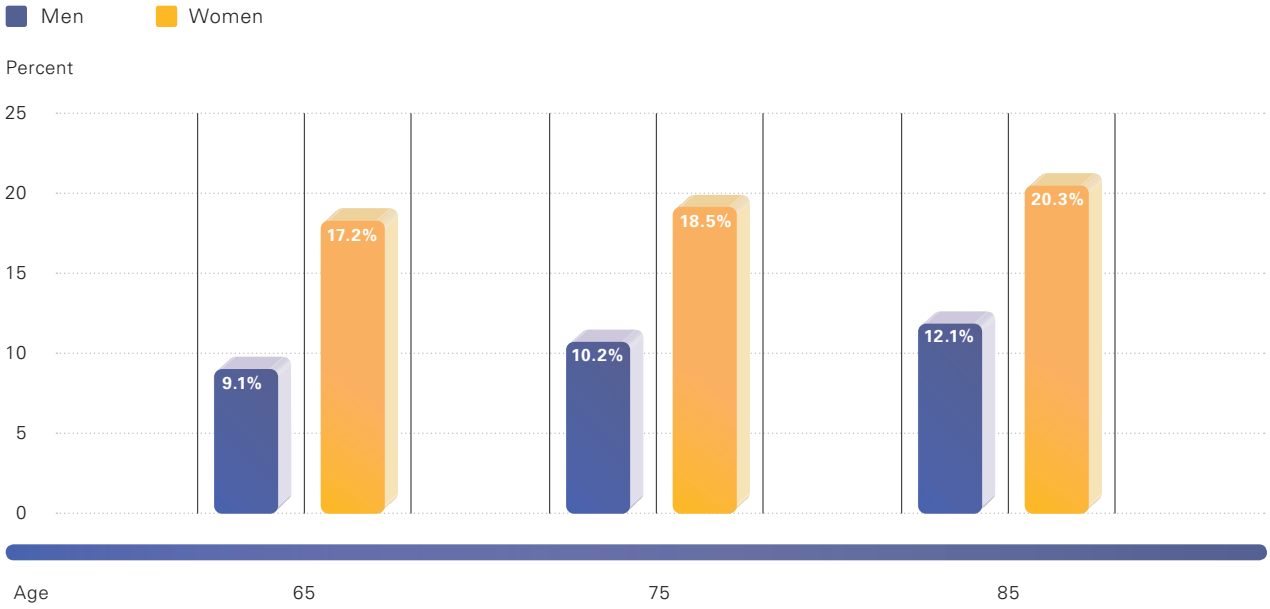
Some researchers believe that having more years of education (compared with those with fewer years) provides a "cognitive reserve" that enables individuals to compensate for symptoms of Alzheimer's or another dementia. However, others believe that these differences in education attainment and dementia risk reflect such factors as increased risks for disease in general and less access to medical care in lower socio-economic groups.

Racial and ethnic differences in rates of Alzheimer's disease and other dementias have also been reported and are discussed in the Special Report at the end of this document.

Lifetime Risk Estimates for Alzheimer's Disease

The original Framingham Study population was used to estimate short-term (10-year), intermediate (20- and 30-year) and lifetime risks for Alzheimer's disease, as well as overall risk for any dementia.[25, A3] In 1975, a cohort (group) of nearly 2,800 people who were 65 years of age and free of dementia provided the basis for an incidence study of dementia, as well as Alzheimer's disease. This cohort was followed for up to 29 years. Key findings included significantly higher lifetime risk for both dementia and Alzheimer's in women compared with men. More than 20 percent of women reaching age 65 ultimately developed dementia (estimated lifetime risk), compared with

Figure 2: Framingham Estimated Lifetime Risks for Alzheimer's by Age and Sex



Created from data from Seshadri et al.[25]

approximately 17 percent of men. For Alzheimer's, the estimated lifetime risk was nearly one in five for women compared with one in 10 for men.[25] Unpublished data from the Framingham Study indicated that at age 55, the estimated lifetime risk for Alzheimer's was 17 percent in women (approximately one in six women), compared with 9 percent in men (nearly one in 10 men). The unpublished data indicate that the lifetime risk for any dementia in women who reached age 55 was 21 percent, and for men 14 percent.[A4]

Increases in short- and intermediate-term risks for Alzheimer's were seen not only at age 65, but also were markedly increased at ages 75 and 85 for both women and men. However, compared with women, the risks were not as high in men. Figure 2 presents lifetime risks for men and women for Alzheimer's. Again, these differences in lifetime risks for women compared with men are largely due to the longer life expectancy for women.

The definition of Alzheimer's disease and other dementias used in the Framingham Study required documentation of moderate to severe disease as well as symptoms lasting a minimum of six months. When one considers the numbers of people with mild to moderate levels of dementia, as well as those with dementia of less than six months' duration, the current and future numbers of people at risk for Alzheimer's disease and other dementias far exceed those stated in the Framingham Study. The number of Americans with Alzheimer's and other dementias is increasing every year because of the steady growth in the older population. This number will continue to increase and escalate rapidly in the coming years as the baby boom generation ages. By 2030, the segment of the U.S. population aged 65 years and older is expected to double. At that time, the estimated 71 million older Americans will make up approximately 20 percent of the total population.[26]

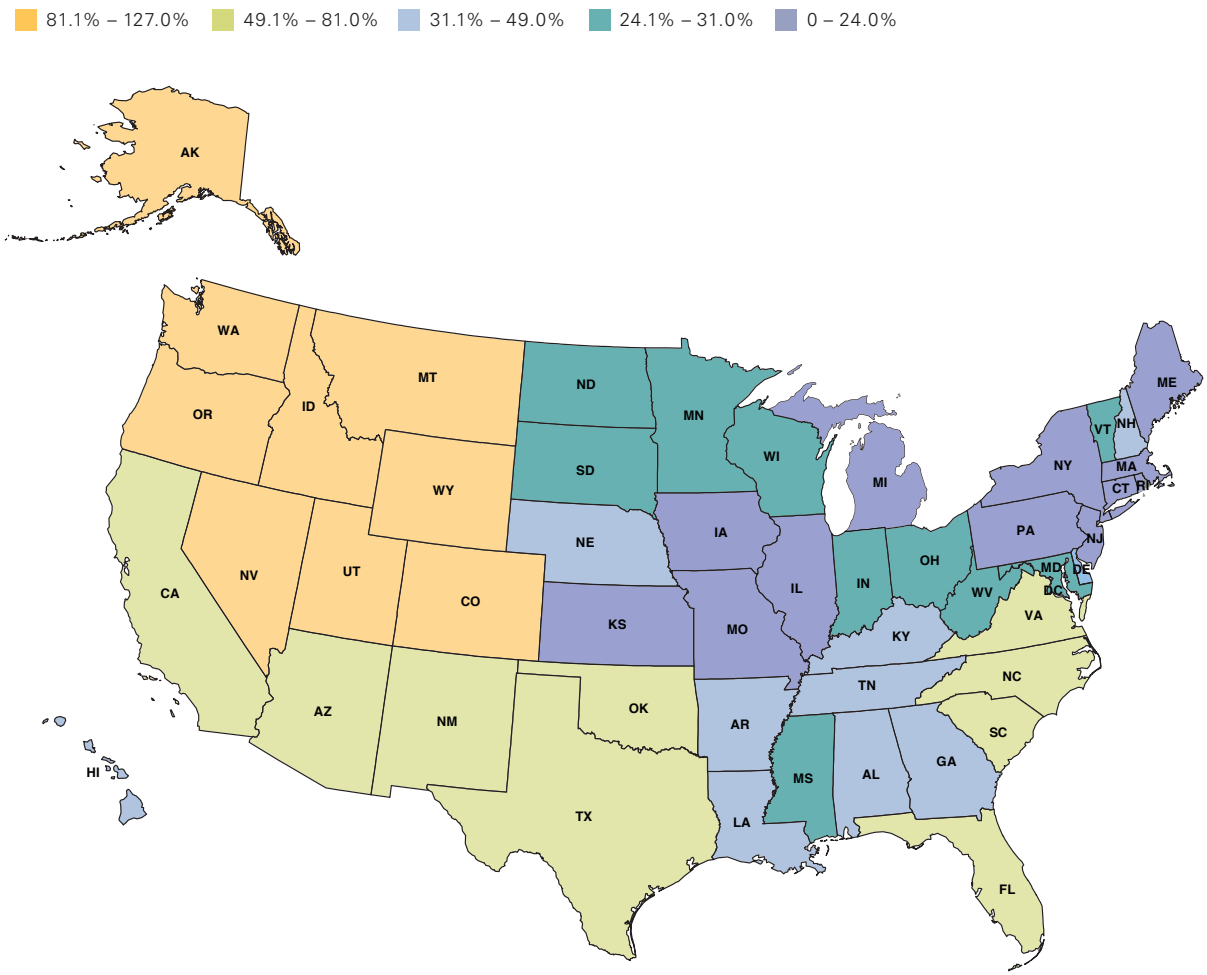
Longer life expectancies and aging baby boomers will also increase the numbers and percentages of Americans who will be among the oldest-old (85 years and older). Between 2010 and 2050, the oldest old are expected to increase from 29.5 percent of all older people in the United States to 35.5 percent. Although this projected change may appear to be modest, it means an increase of 17 million oldest-old people — individuals who will be at high risk for developing Alzheimer's.[27]

Estimates for the Numbers of People with Alzheimer's Disease by State

Table 2 (pages 15-16) summarizes the projected total number of people aged 65 and older with Alzheimer's disease by state for the years 2000, 2010 and 2025. The percentage changes in Alzheimer's between 2000 and 2010, and between 2000 and 2025 are also shown. Comparable projections for dementia are not available.

Not only is there substantial variability by state in the projected numbers of people with Alzheimer's, but this variability is also reflected among different regions of the country. The bulk of the difference is clearly due to where the 65-and-older population resides within the United States. However, between 2000 and 2025, it also is clear that some states and regions across the country are expected to experience double-digit percentage increases in the overall numbers of people with Alzheimer's. Compared with the numbers of people with Alzheimer's estimated for 2000, the South, Midwest and West are expected to experience increases that will result in 30- to 50-percent (and greater) increases over the 25-year period. Some states in the West (Alaska, Colorado, Idaho, Nevada, Utah and Wyoming) are projected to experience a doubling (or more) of their populations aged 65 and older with Alzheimer's.

Figure 3: Projected Changes Between 2000 and 2025 in Alzheimer Prevalence by State



Created from data from Hebert et al.[28, A5]

The increased numbers of people with Alzheimer's will have a marked impact on states' healthcare systems, not to mention families and caregivers. Although the projected increases in the Northeast are not nearly as marked as those in other regions of the United States, it should be noted that this section of the country currently has a large proportion of people aged 65 and older with Alzheimer's.

Figure 3 summarizes how the prevalence of Alzheimer's in Americans aged 65 and older is expected to change by state between 2000 and 2025. Of particular note are the states anticipated to experience growth exceeding 80 percent.

Causes of Dementia

Although Alzheimer's disease is the most common form of dementia, data are emerging to suggest that the attribution of dementia to specific types may not be as clear cut as previously believed.[29] A study by Schneider and colleagues reports that most older community-dwelling people (mean age at death, approximately 88 years) have changes in the brain suggestive of disease. People with dementia often have evidence of multiple types of brain disease.[30]

Of the first 141 autopsies in this study, 80 examined brain tissue samples from people with intermediate or high likelihood of having Alzheimer's based on clinical evaluation, which included medical history, neuropsychological tests and physical examination with an emphasis on neurologic function. Less than half of the 80 autopsies showed evidence of Alzheimer's alone. Nearly a third showed evidence of Alzheimer's and infarcts; 15 percent showed evidence of Alzheimer's and Parkinson's disease/Lewy body disease; 5 percent showed evidence of all three diseases; and 2.5 percent showed evidence of Alzheimer's and a brain disease other than infarcts or Parkinson's disease/Lewy body disease. Although 50 percent of participants with little or no likelihood of having Alzheimer's disease based on clinical evaluation also had no evidence of dementia on autopsy, approximately one-third showed signs of brain infarcts. Thus, there is reason to believe that the causes of dementia may be much more complicated than originally believed.

Looking to the Future

The number of Americans surviving into their 80s and 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions. Since the incidence and prevalence of Alzheimer's disease and other dementias increase with age, the number of people with these conditions will also grow rapidly.

- In 2000, there were an estimated 411,000 new (incident) cases of Alzheimer's disease. For 2010, that number is projected to be 454,000 new cases; by 2030, 615,000; and by 2050, 959,000.[31]
- This year, more than an estimated 5.5 million Americans are 85 years and older; by 2050, that number will nearly quadruple to 19 million.
- While the number of Americans aged 100 years and older is estimated at 80,000 in 2010, by 2050 there will be more than a half million Americans aged 100 years and older.
- The 85-years-and-older population currently includes about 2.4 million people with Alzheimer's disease, or 47 percent of the Alzheimer population aged 65 and over. When the first wave of baby boomers reaches age 85 years (2031), an estimated 3.5 million people aged 85 and older will have Alzheimer's.[10]
- The number of people aged 65 and older with Alzheimer's disease is estimated to reach 7.7 million in 2030 — more than a 50 percent increase from the 5.1 million aged 65 and older currently affected.[10]
- By 2050, the number of individuals aged 65 and older with Alzheimer's is projected to number between 11 million and 16 million — unless medical breakthroughs identify ways to prevent or more effectively treat the disease. Barring such developments, by 2050 more than 60 percent of people with Alzheimer's disease will be aged 85 or older.[10]

Table 2: Projections by State for Total Numbers of Americans Aged 65 and Older with Alzheimer's

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

Table 2 (Continued): Projections by State for Total Numbers of Americans Aged 65 and Older with Alzheimer's

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

Created from data from Hebert et al.[28], A5

3 Mortality

Alzheimer's disease was the seventh-leading cause of death across all ages in the United States in 2006. It was the fifth-leading cause of death for those aged 65 and older.[32]

In final data for 2006,[33] Alzheimer's was reported as the underlying cause of death for 72,432 people. Of note are the nearly identical numbers of deaths for those attributed to diabetes (the sixth-leading cause of death) and Alzheimer's disease. In fact, only 17 deaths separated the sixth and seventh rankings.

The underreporting of Alzheimer's disease as an underlying cause of death has been well documented, and it occurs in both local communities and in nursing homes.[34-37] Death rates from the disease can vary a great deal across states and result from differences in state demographics and reporting practices. Death rates among people with Alzheimer's disease dramatically increase with age. From one community-based, 15-year prospective study, the mortality rate for people aged 75–84 with Alzheimer's was nearly 2.5 times greater than for those aged 55–74 with the disease. At age 85 and older, the rate was nearly twice that of those with Alzheimer's aged 75–84.[38] Two-thirds of those dying of dementia did so in nursing homes, compared with 20 percent of cancer patients and 28 percent of people dying from all other conditions.

Deaths from Alzheimer's Disease

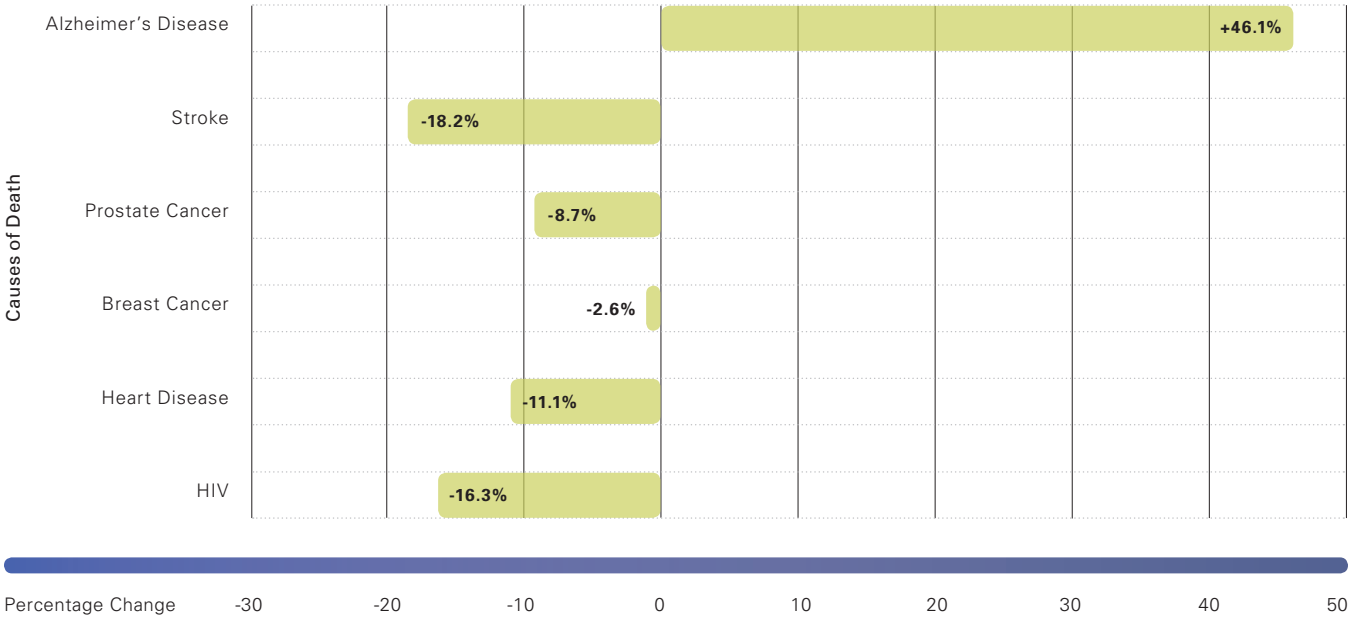
While other major causes of death continue to experience significant declines, those from Alzheimer's disease have continued to rise. In 1991, only 14,112 death certificates recorded Alzheimer's disease as the underlying cause.[39] Comparing changes in selected causes of death between final data for 2000 and final data for 2006 (Figure 4), deaths attributed to Alzheimer's disease increased 46.1 percent, while those attributed to the number one cause of death, heart disease, decreased 11.1 percent. Patterns of reporting deaths on death certificates change substantially over time, however, for Alzheimer's and for other causes of death. Alzheimer's is a major cause of death and is clearly becoming a more common cause as the populations of the United States and other countries age. The increase in the number and proportion of death certificates listing Alzheimer's may strongly reflect both changes in patterns of reporting deaths on death certificates as well as an increase in the actual number of deaths attributable to Alzheimer's.

People with a diagnosis of Alzheimer's disease have an increased risk of death. One study found that people aged 60 and older with diagnosed Alzheimer's disease survived an average of four to six years after the diagnosis.[40] How dementia leads to death may create ambiguity about the underlying cause of death. Severe dementia frequently causes such complications as immobility, swallowing disorders and malnutrition. These complications can significantly increase the risk of developing pneumonia, which has been found in several studies to be the most commonly identified cause of death among elderly people with Alzheimer's disease and other dementias. One researcher described the situation as a "blurred distinction between death *with* dementia and death *from* dementia."[38]

State-by-State Deaths from Alzheimer's Disease

Table 3 (page 20) provides information on the number of deaths due to Alzheimer's by state and overall in the United States. The information was obtained from death certificates and reflects the underlying cause of death: "the disease or injury which initiated the train of events leading directly to death."[33] The table also provides age-adjusted rates by state. Age adjustment should not be viewed as providing a measurement of actual risk, but should be viewed as providing an indication of relative risk between the states. Thus in terms of relative comparisons, the highest age-adjusted rates for deaths due to Alzheimer's occurred in southern states (Alabama, Louisiana, South Carolina and Tennessee), with the exceptions of Arizona, North Dakota and Washington. The age-adjusted rate for Florida would suggest, on the surface, that the risk of mortality from Alzheimer's is more modest in that state compared with others. Florida is home to a large number of people aged 65 years and older, and this is the age group at highest risk for Alzheimer's and Alzheimer-related death. However, it may be that the large number of active, healthy retirees aged 65 and older in that state help moderate Florida's overall age-adjusted Alzheimer risk.

Figure 4: Percentage Changes in Selected Causes of Death Between 2000[a] and 2006[b]



a National Center for Health Statistics. *Deaths: Final Data for 2000.*[41]
b Heron et al.[33]

Table 3: Number of Deaths Due to Alzheimer's and Age-Adjusted Rates* (per 100,000), by State, 2006

State	Number of Deaths	Age-Adjusted Rate per 100,000	State	Number of Deaths	Age-Adjusted Rate per 100,000
Alabama	1,497	30.3	Montana	226	19.6
Alaska	73	24.7	Nebraska	500	22.6
Arizona	2,066	31.4	Nevada	281	14.7
Arkansas	783	23.9	New Hampshire	372	26.5
California	8,146	24.1	New Jersey	1,649	16.5
Colorado	1,058	27.7	New Mexico	348	17.7
Connecticut	728	16.2	New York	2,021	9.1
Delaware	189	20.4	North Carolina	2,265	26.4
District of Columbia	117	18.3	North Dakota	318	33.6
Florida	4,689	17.0	Ohio	3,565	27.0
Georgia	1,820	25.7	Oklahoma	928	23.5
Hawaii	201	12.2	Oregon	1,231	29.0
Idaho	400	28.1	Pennsylvania	3,311	18.9
Illinois	2,794	20.6	Rhode Island	297	20.3
Indiana	1,696	25.2	South Carolina	1,364	31.5
Iowa	1,121	26.3	South Dakota	329	29.8
Kansas	830	24.3	Tennessee	2,115	34.6
Kentucky	1,153	26.7	Texas	4,887	25.9
Louisiana	1,282	30.5	Utah	390	21.4
Maine	477	29.0	Vermont	186	26.2
Maryland	915	17.1	Virginia	1,574	22.3
Massachusetts	1,560	19.4	Washington	2,470	38.3
Michigan	2,331	21.7	West Virginia	496	21.8
Minnesota	1,299	22.2	Wisconsin	1,596	24.2
Mississippi	744	25.0	Wyoming	112	21.8
Missouri	1,632	24.1	**U.S. Total**	**72,432**	**22.6**

*Age-adjusted to year 2000 standard population.
Created from data from Heron et al.[33]

Death Rates by Age

Although Alzheimer's disease and death from Alzheimer's can occur in people under age 65, the highest risk is in the elder years. As seen in Table 4, death rates for Alzheimer's increase dramatically between the elderly age groups of 65–74, 75–84 and 85 and older. To put such age-related differences into perspective, for U.S. deaths in 2006, the differences in total mortality rates from all causes of death for those aged 65–74 and those aged 75–84 was 2.5-fold, and between the 75–84 age group and the 85 and older age group, 2.6-fold. For diseases of the heart, the differences were 2.8-fold and 3.2-fold, respectively. For all cancers, the differences were 1.7-fold and 1.3-fold respectively. The corresponding differences for Alzheimer's were 8.7-fold and 4.8-fold. This large increase in death rates due to Alzheimer's among America's oldest age groups underscores the impact of having neither a cure for Alzheimer's nor highly effective treatments.[33]

Table 4: U.S. Alzheimer Death Rates (per 100,000) by Age, 2000, 2004 and 2006

Age	2000	2004	2006
45–54	0.2	0.2	0.2
55–64	2.0	1.9	2.1
65–74	18.7	19.7	20.2
75–84	139.6	168.7	175.6
85+	667.7	818.8	848.3

Created from data from Heron et al.[33]

4 Caregiving

In 2011, the first baby boomers will reach their 65th birthdays. By 2029, all baby boomers will be at least 65 years old. This group, totaling an estimated 70 million people aged 65 and older, will have a significant impact on the U.S. healthcare system.

Paid Caregiving

Older Americans represent approximately 12 percent of the population. However, they comprise 26 percent of physician office visits, approximately a third of all hospital stays, a third of all prescriptions, nearly 40 percent of all emergency medical responses and 90 percent of nursing home residents, according to the National Academy of Sciences.[42] Alzheimer's disease will clearly require a significant portion of future healthcare workforce.

In its executive summary, the National Academy of Sciences states that an estimated 3.5 million additional formally trained healthcare providers will be needed by 2030 — more than a one-third increase in the current ratio of providers to the total population — just to maintain current levels of staffing. The executive summary also documents that the vast majority of healthcare workers who provide the bulk of services to the elderly do not have training in geriatrics. Currently, less than 1 percent of physician assistants specialize in geriatrics. A similar percentage of pharmacists and registered nurses are certified in geriatrics. It's estimated that only about 4 percent of social workers — 33 percent of what's needed — specialize in geriatrics.

As of 2007, the number of physicians certified in geriatric medicine totaled 7,128; those certified in geriatric psychiatry equaled 1,596.[42] By 2030, the need for geriatricians is estimated to number approximately 36,000.[42] Some have estimated that the increase from current levels will amount to less than 10 percent, while others believe there will be a net loss of physicians for geriatric patients.[42]

Thus, significant formal healthcare staffing needs are anticipated to be unmet or underserved as America approaches unparalleled demands for these services in its elderly population groups. It should be noted that the National Academy of Sciences report only provides a snapshot of the health worker needs and the shortages thereof impacting people with Alzheimer's and other dementias and their families. Increased staffing to meet the needs of the dementia population must include not only increased numbers of staff, but also specific dementia-care training of physicians, nurses, social workers and other healthcare providers working in these settings.

Family Caregiving

Almost 11 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia.[A6] These unpaid caregivers are primarily family members but also include friends. In 2009, they provided 12.5 billion hours of unpaid care, a contribution to the nation valued at almost $144 billion.

Caring for a person with Alzheimer's or another dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving also has a negative impact on the health, employment, income and financial security of many caregivers.

Number of Caregivers

In 2009, an estimated 10.9 million family members and friends provided unpaid care for a person with Alzheimer's disease or another dementia.[A6] Table 5 (pages 31-32) shows the number of family and other unpaid caregivers in the United States and each state. The number of caregivers by state ranges from about 16,000 in Alaska to 1.2 million in California.

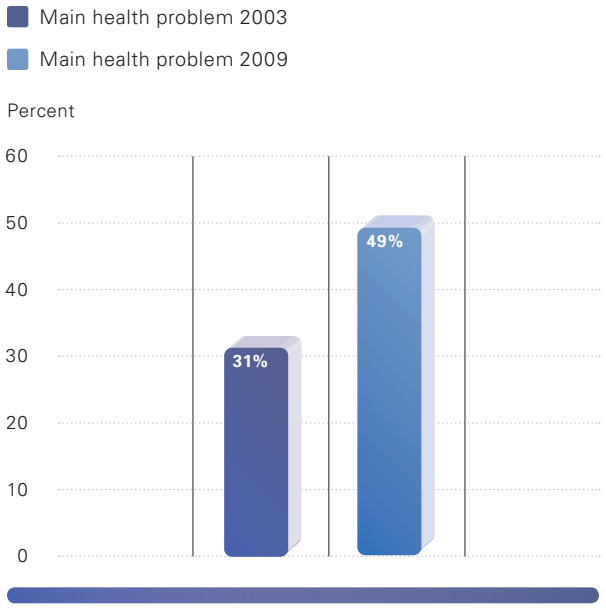
Some people with Alzheimer's and other dementias have more than one unpaid caregiver, for example, people who live with their primary caregiver and receive help from another relative or friend.[43]

Caregivers' Perception of the Person's Main Health Problem

Many people with Alzheimer's or another dementia also have other serious medical conditions, such as heart disease, diabetes and cancer (Table 8, page 37). Their family and other unpaid caregivers often help to manage these medical conditions in addition to the Alzheimer's or other dementia.

In 2009, almost one-half (49 percent) of unpaid caregivers of people with Alzheimer's and other dementias said the person's Alzheimer's or other dementia was his or her main health problem.[43] This proportion has increased significantly since 2003, when only 31 percent of caregivers of people with Alzheimer's and other dementias said that the person's Alzheimer's or other dementia was his or her main health problem (Figure 5).[43-44] The reasons for this increase are not known but could include growing awareness of Alzheimer's and dementia as well as greater willingness of caregivers to name Alzheimer's or dementia as the main health problem of the person for whom they provide care.

Figure 5: Proportion of Persons with Alzheimer's Disease or Other Dementia Whose Caregivers Say Alzheimer's Disease or Other Dementia is the Person's Main Health Problem, United States, 2003 and 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, Nov. 11, 2009.[43]

Four states — Florida, Minnesota, North Carolina and Washington — have conducted surveys that ask caregivers of all types whether the person for whom they provide care has Alzheimer's or another dementia and whether Alzheimer's or another dementia is that person's main health problem. The survey results show that only 14 percent of Florida caregivers of people with Alzheimer's and other dementias say that Alzheimer's or dementia is the person's main health problem,[45] compared with 21 percent of Minnesota caregivers,[46] 29 percent of North Carolina caregivers[47] and 36 percent of Washington State caregivers.[48] These percentages could reflect true differences in the main health problem of people with Alzheimer's and other dementias in these states, differences by state in the willingness of caregivers to name Alzheimer's or dementia as the person's main health problem, or other factors. Comparable data are not available for other states.

Hours of Unpaid Care

In 2009, the 10.9 million family and other unpaid caregivers of people with Alzheimer's and other dementias provided an estimated 12.5 billion hours of 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.[A7] Table 5 (pages 31-32) shows the total hours of unpaid care provided for the United States and each state. Even in a small state such as Rhode Island, caregivers of people with Alzheimer's and other dementias provided 44.6 million hours of unpaid care in 2009.

Caregivers of people with Alzheimer's and other dementias provide more hours of help, on average, than caregivers of other older people. The number of hours varies in findings from different studies. The 2009 National Alliance for Caregiving (NAC)/AARP survey on caregiving in the United States found that 15 percent of caregivers of people with Alzheimer's and other dementias provided more than 40 hours of care a week, compared with 10 percent of caregivers of other older people.[43] Another study found that 40 percent of caregivers who were caring for people

with Alzheimer's and other dementias provided more than 40 hours a week of help, compared with 28 percent of those who were caring for other older people.[49]

The average number of hours of unpaid care provided for people with Alzheimer's and other dementias increases as the person's disease worsens.[50] The number of hours of unpaid care is also greater, on average, for people with coexisting medical conditions in addition to Alzheimer's or another dementia.[50]

Some family and other unpaid caregivers who live with a person who has Alzheimer's or other dementia provide supervision and help 24 hours a day, 7 days a week, getting up with the person at night and assisting with all daily activities.[43, 51-52] Such around-the-clock care is needed when the person cannot be left alone because of risk of wandering, getting lost and other unsafe activities.

Economic Value of Caregiving

In 2009, the estimated economic value of the care provided by family and other unpaid caregivers of people with Alzheimer's and other dementias was $144 billion. This number represents 12.5 billion hours of care valued at $11.50 per hour.[A8] Table 5 shows the value of the 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 36 states. Unpaid caregivers in each of nine states — California, Florida, Georgia, Illinois, Michigan, New York, Ohio, Pennsylvania and Texas — provided care valued at more than $5 billion.

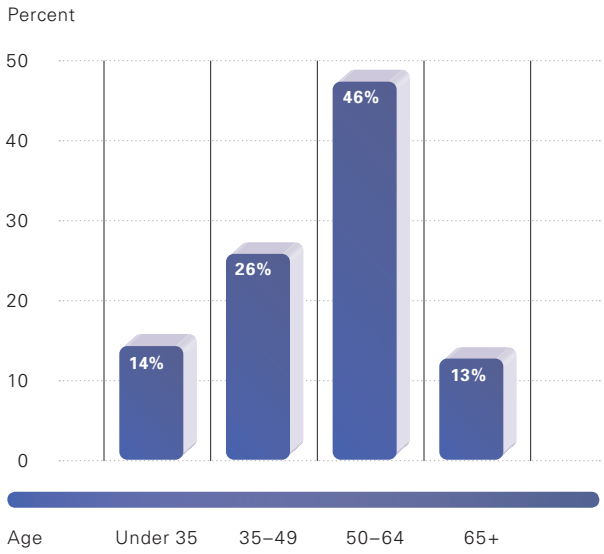
Who are the Caregivers?

About 60 percent of family and other unpaid caregivers of people with Alzheimer's disease and other dementias are women.[43, 49] The 2009 NAC/AARP survey on caregiving in the United States found that 94 percent of caregivers of people with Alzheimer's and other dementias were taking care of a relative, including a parent or parent-in-law (62 percent), a grandparent (17 percent), a spouse (6 percent) or another relative (9 percent). The remaining 6 percent of caregivers were taking care of a friend.[43]

The 2009 NAC/AARP survey also found that 21 percent of caregivers of people with Alzheimer's and other dementias lived in the same household as the person for whom they were providing care.[43] This proportion varies in different studies, however, depending on how caregivers were recruited for the study. Another study found that two-thirds of caregivers of people with Alzheimer's and other dementias lived in the same household as the person for whom they were providing care.[49]

Caregivers range in age from very young to very old. The 2009 NAC/AARP survey found that 14 percent of caregivers of people with Alzheimer's and other dementias were under age 35; 26 percent were aged 35–49; 46 percent were aged 50–64; and 13 percent were aged 65 and over (Figure 6).[43] Their average age was 51.

Figure 6: Ages of Alzheimer's and Other Dementia Caregivers, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, Nov. 11, 2009.[43]

In addition, a 2003 survey found that about 250,000 American children aged 8–18 were unpaid caregivers for a person with Alzheimer's or another dementia.[53] These children represent 18 percent of the 1.4 million American children aged 8–18 who provided unpaid help for any person.

"Sandwich Generation" Caregivers

Some caregivers of people with Alzheimer's and other dementias also have children living at home. The 2009 NAC/AARP survey on caregiving in the United States found that 30 percent of family and other unpaid caregivers of people with Alzheimer's and other dementias had children or grandchildren under age 18 living at home.[43] Another study found that 17 percent of caregivers of people with Alzheimer's and other dementias had children living at home.[49]

State surveys of family caregivers show variable estimates for individuals with children living at home. Surveys conducted in Florida and Minnesota in 2008 found that about one-third of caregivers of people with Alzheimer's or other dementia had children under age 18 living at home.[45-46] A 2007 survey conducted in Washington State found that 27 percent of caregivers of people with Alzheimer's and other dementias had children under age 18 living at home, including 12 percent with one child and 15 percent with two or more children.[48]

Long-Distance Caregivers

Nine percent of the 10.9 million family and other unpaid caregivers of people with Alzheimer's and other dementias live more than two hours from the person for whom they provide care, and another 6 percent live one to two hours away.[43] Depending on the definition of "long-distance caregiving," these numbers indicate that 981,000 to 1.6 million caregivers of people with Alzheimer's and other dementias are "long-distance caregivers."

Caregiving Tasks

The kinds of help provided by family and other unpaid caregivers depend on the needs of the person with Alzheimer's or other dementia and change as the disease worsens. Caregiving tasks can include:[43, 49]

- Shopping for groceries, preparing meals and providing transportation;
- Helping the person take medications correctly and follow treatment recommendations for his or her dementia and other medical conditions;
- Managing finances and legal affairs;
- Supervising the person to avoid such unsafe activities as wandering and getting lost;
- Bathing, dressing, feeding and helping the person use the toilet or managing incontinence;
- Making arrangements for medical care and paid in-home, assisted living or nursing home care; and
- Managing behavioral symptoms.

Family and other unpaid caregivers of people with Alzheimer's and other dementias are more likely than caregivers of other older people to assist with activities of daily living (ADLs). Findings from the 2009 NAC/AARP survey on caregiving in the United States show that 38 percent of caregivers of people with Alzheimer's and other dementias were assisting with three or more ADLs, compared with 27 percent of caregivers of other older people.[43] As shown in Figure 7, 31 percent of Alzheimer and dementia caregivers manage incontinence and diapers compared with 16 percent of other caregivers. Likewise, 31 percent of Alzheimer and dementia caregivers handle feeding compared with 14 percent of other caregivers.[43]

In addition to activities of daily living, caregivers of people with Alzheimer's and other dementias are more likely than caregivers of other older people to arrange and supervise services from an agency (46 percent

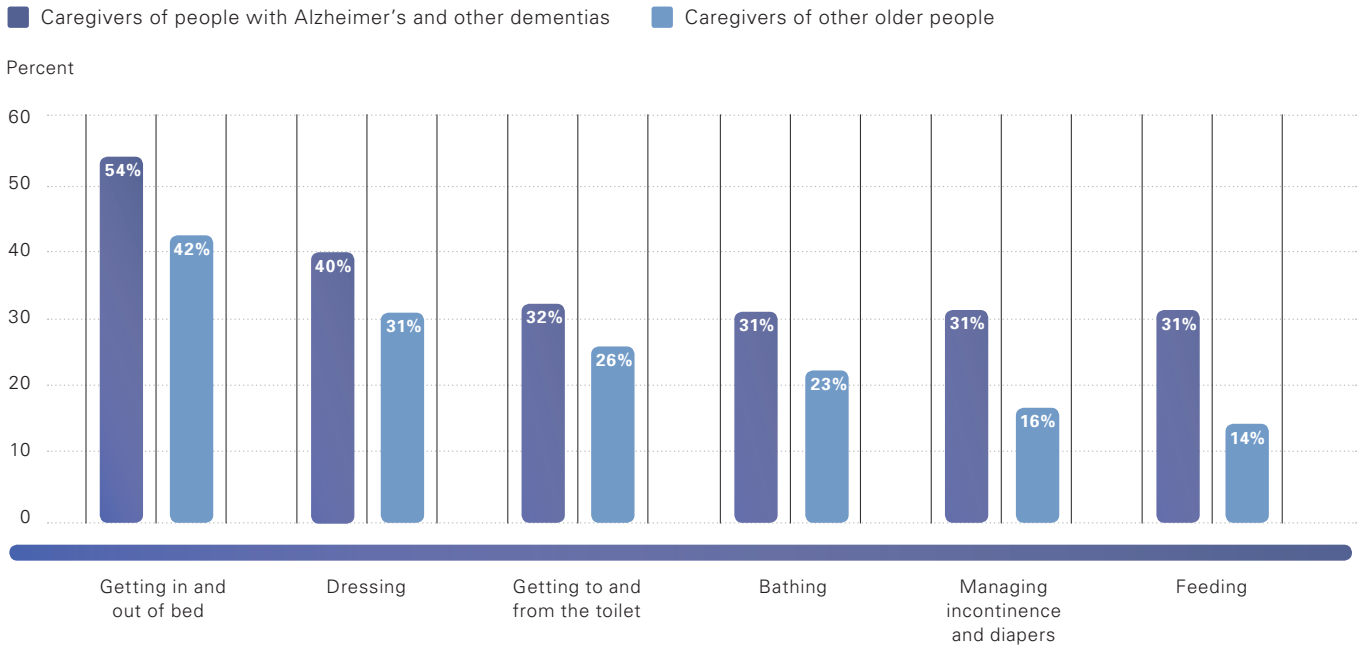
versus 33 percent, respectively).[43] Caregivers of people with Alzheimer's and other dementias are also more likely to advocate for the person with government agencies and service providers (64 percent of caregivers of people with Alzheimer's and other dementias versus 50 percent of caregivers of other older people.)

When a person with Alzheimer's or another dementia moves to an assisted living facility or nursing home, the kinds of help provided by his or her family and other unpaid caregivers usually change, but many caregivers continue to assist with financial and legal affairs and arrangements for medical care and to provide emotional support. Some also continue to help with bathing, dressing and other activities of daily living.[54-56]

Duration of Caregiving

Because Alzheimer's and other dementias usually progress slowly, most caregivers spend many years in the caregiving role. At any point in time, 32 percent of family and other unpaid caregivers of people with Alzheimer's and other dementias have been providing help for five years or longer, including 12 percent who have been providing care for 10 years or longer. An additional 43 percent have been providing care for one to four years, and 23 percent have provided care for less than a year.[43] Caregivers of other older people are less likely to have provided care for 1–4 years (33 percent) and five or more years (28 percent), and more likely to have provided care for less than one year (34 percent) (Figure 8, page 28).

Figure 7: Proportion of Caregivers of People with Alzheimer's or Other Dementia vs. Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, Nov. 11, 2009.[43]

Impact of Caregiving

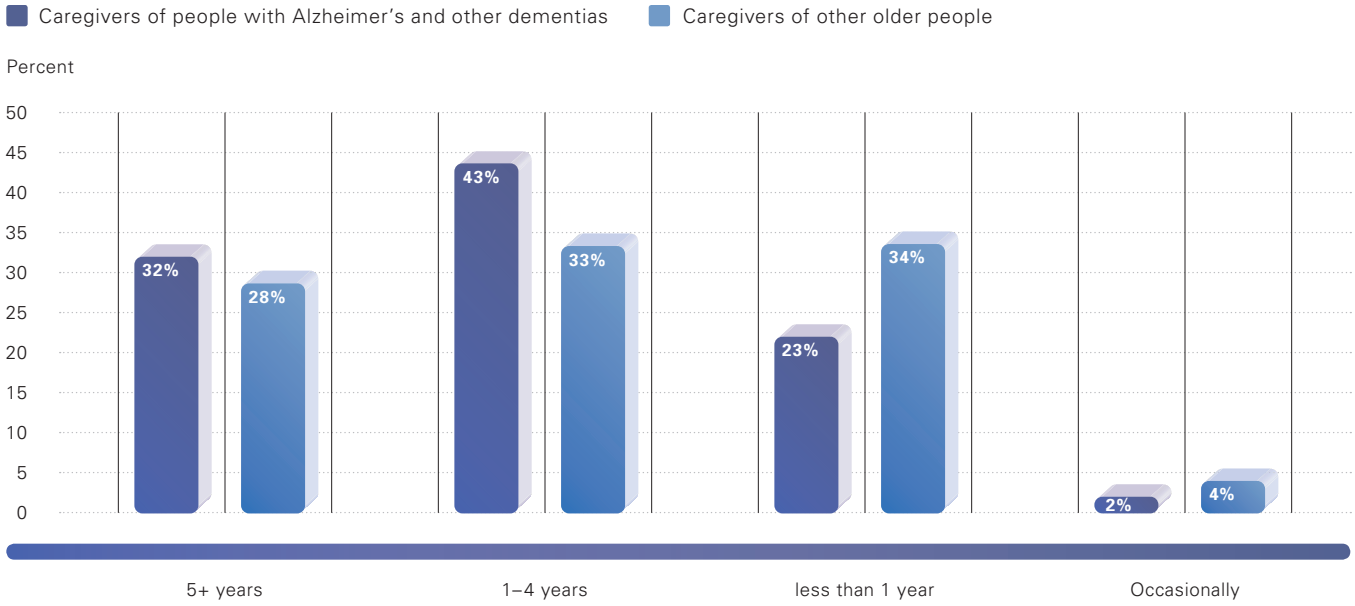
Caring for a person with Alzheimer's or another dementia poses special challenges. Although memory loss is the best-known symptom, these diseases also cause loss of judgment, orientation, and the ability to understand and communicate effectively. Personality and behavior are affected as well. Individuals require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security.

Impact on the Caregiver's Emotional Well-Being

Most family and other unpaid caregivers are proud of the help they provide, and most have positive feelings about caregiving.[57-58] Yet many caregivers also experience high levels of stress and depression associated with caregiving.

- More than 40 percent of family and other unpaid caregivers of people with Alzheimer's and other dementias rate the emotional stress of caregiving as high or very high, compared with 28 percent of caregivers of other older people (Figure 9).[43]
- About one-third of family caregivers of people with Alzheimer's and other dementias have symptoms of depression.[59-60]
- One study of family care provided for people with dementia in the year before the person's death found that half the caregivers spent at least 46 hours a week assisting the person; 59 percent felt that they were "on duty" 24 hours a day; and many felt that caregiving in this end-of-life period was extremely stressful. The stress of caregiving was so great that 72 percent of the family caregivers said they experienced relief when the person died.[52]

Figure 8: Proportion of Alzheimer and Dementia Caregivers vs. Caregivers of Other Older People by Duration of Caregiving, United States, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, Nov. 11, 2009.[43]

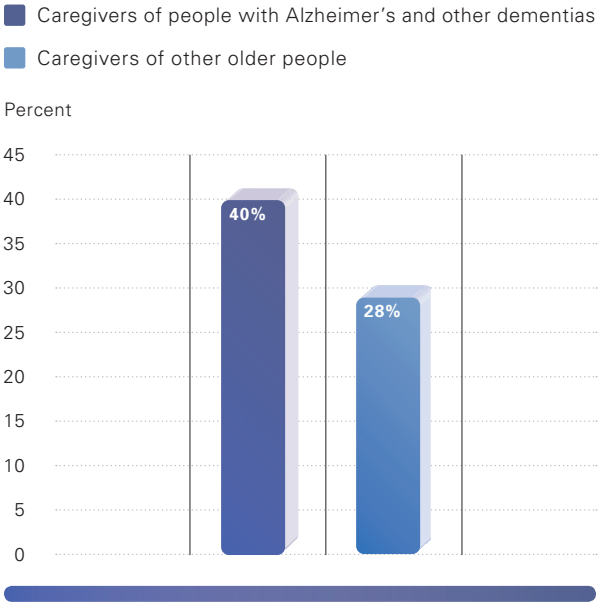
- Caregiver stress, especially stress related to the person's behavioral symptoms, is associated with nursing home placement.[61-62] Still, many family caregivers continue to experience high stress even when the person is living in a nursing home.[54, 56, 63]

Impact on the Caregiver's Health

Many caregivers of people with Alzheimer's and other dementias experience negative health outcomes associated with caregiving.

- Family and other unpaid caregivers of people with Alzheimer's and other dementias are more likely than non-caregivers to report that their health is fair or poor.[64-65] They are also more likely than unpaid caregivers of other older people to say that caregiving made their health worse.[43, 49]

Figure 9: Proportion of Alzheimer and Dementia Caregivers vs. Caregivers of Other Older People Who Report High or Very High Emotional Stress Due to Caregiving, United States, 2009



Created from data from the 2009 National Alliance for Caregiving/AARP survey on caregiving in the United States, prepared under contract for the Alzheimer's Association by Matthew Greenwald and Associates, November 11, 2009.[43]

- Family and other unpaid caregivers of people with Alzheimer's or another dementia are more likely than non-caregivers to have high levels of stress hormones,[66-68] reduced immune function,[66, 69] slow wound healing,[70] new hypertension[71] and new coronary heart disease.[72]
- One study of spouse caregivers of people with Alzheimer's or another dementia found that 24 percent of the caregivers had an emergency department visit or hospitalization in the previous six months; caregivers who were more depressed and those who were taking care of individuals who needed greater help with daily activities and had more behavioral symptoms were more likely to have an emergency department visit or hospitalization.[73]
- One study of spouse caregivers of people who were hospitalized for various diseases found that caregivers of people who were hospitalized for dementia were more likely than caregivers of people who were hospitalized for other diseases to die in the following year.[74] (These findings were adjusted for the age of the spouse caregiver.) Among male caregivers, 9 percent died in the year after their wife's hospitalization for dementia, compared with 6 percent who died in the year after the wife's hospitalization for colon cancer and 7 percent who died in the year after the wife's hospitalization for stroke. Among female caregivers, 5 percent died in the year after their husband's hospitalization for dementia, compared with 3 percent who died in the year after the husband's hospitalization for colon cancer and 4 percent who died in the year after the husband's hospitalization for stroke.[74]

Impact on the Caregiver's Employment

Many caregivers of people with Alzheimer's and other dementias have to quit work, reduce their work hours or take time off because of caregiving responsibilities.

- The 2009 NAC/AARP survey on caregiving in the United States found that 60 percent of family caregivers of people with Alzheimer's and other dementias were employed full time or part time. Of those who were employed, two-thirds said they had to go in late, leave early or take time off because of caregiving; 14 percent had to take a leave of absence; 10 percent had to reduce their hours or take a less demanding job and 10 percent had to quit work entirely or take early retirement due to caregiving.[43]
- Another study of family and other unpaid caregivers of more than 2,000 older people found that caregivers of people who had Alzheimer's or other dementia without behavioral symptoms were 31 percent more likely than caregivers of other older people to have reduced their hours or quit work.[75] Caregivers of people who had Alzheimer's or other dementia with behavioral symptoms were 68 percent more likely than caregivers of other older people to have reduced their hours or quit work.[75]
- The recent economic downturn and upheavals in the financial and mortgage markets have increased employment-related difficulties for family caregivers, including caregivers of people with Alzheimer's and other dementias. In response to a survey conducted for Evercare and the NAC in February and March 2009, one-half of family caregivers said they had become more cautious about taking time off from work; one-third said they had to work more hours or get a second job; 43 percent said their work hours or pay had been cut and 15 percent said they had lost their job.[76]

Impact on the Caregiver's Income and Financial Security

Family and other unpaid caregivers who turn down promotions, reduce their work hours or quit work also lose job-related income and benefits, including employer contributions to their own retirement savings. In addition, people with Alzheimer's and other dementias use substantial amounts of paid care. Some of this care is covered for some people by public programs and private insurance, but the family often has to pay out-of-pocket for much of the care.

- One study found that 49 percent of family and other unpaid caregivers of people with Alzheimer's and other dementias (not including spouse caregivers) had caregiving-related out-of-pocket expenditures that averaged $219 a month.[44]
- Another study of family caregivers of people age 50 and over, including people with Alzheimer's and other dementias, found that long-distance caregivers had higher caregiving-related out-of-pocket expenditures than other caregivers.[77]
- The 2009 Evercare/NAC survey found that the economic downturn has increased financial difficulties for family caregivers. In response to the survey, 24 percent of the family caregivers said they have had to cut back on care-related spending because of changes in their own financial situation. Another 13 percent said they have had to increase their care-related spending because of changes in the financial situation of the person for whom they provide care, and many of these caregivers said that, as a result, they have had difficulty paying for their own basic necessities (65 percent) and saving for their own retirement (63 percent).[76]

Table 5: Number of Alzheimer and Dementia Caregivers, Hours of Unpaid Care and Economic Value of the Care by State, 2009*

State	Number of Alzheimer/ Dementia Caregivers	Hours of Unpaid Care per Year	Value of Unpaid Care
Alabama	187,870	213,946,599	$2,460,385,885
Alaska	16,313	18,577,116	$213,636,835
Arizona	200,776	228,643,676	$2,629,402,278
Arkansas	124,841	142,168,622	$1,634,939,155
California	1,233,164	1,404,327,156	$16,149,762,293
Colorado	161,600	184,029,717	$2,116,341,750
Connecticut	125,758	143,213,278	$1,646,952,695
Delaware	33,201	37,809,522	$434,809,501
District of Columbia	18,803	21,413,136	$246,251,059
Florida	639,445	728,200,485	$8,374,305,572
Georgia	396,469	451,499,270	$5,192,241,609
Hawaii	33,762	38,447,996	$442,151,956
Idaho	52,635	59,941,041	$689,321,970
Illinois	386,207	439,812,201	$5,057,840,312
Indiana	235,114	267,747,257	$3,079,093,454
Iowa	106,474	121,252,735	$1,394,406,454
Kansas	94,022	107,071,851	$1,231,326,281
Kentucky	171,061	194,804,396	$2,240,250,556
Louisiana	181,101	206,237,562	$2,371,731,962
Maine	51,267	58,383,133	$671,406,028
Maryland	187,814	213,882,421	$2,459,647,842
Massachusetts	234,497	267,045,164	$3,071,019,381
Michigan	402,327	458,170,316	$5,268,958,629
Minnesota	196,105	223,324,620	$2,568,233,134
Mississippi	148,180	168,747,146	$1,940,592,184

Table 5 (Continued): Number of Alzheimer and Dementia Caregivers, Hours of Unpaid Care and Economic Value of the Care by State, 2009*

State	Number of Alzheimer/ Dementia Caregivers	Hours of Unpaid Care per 100,000	Value of Unpaid Care
Missouri	202,662	230,791,080	$2,654,097,424
Montana	37,214	42,379,684	$487,366,362
Nebraska	60,685	69,108,542	$794,748,232
Nevada	84,761	96,525,424	$1,110,042,377
New Hampshire	46,059	52,452,237	$603,200,730
New Jersey	321,903	366,582,650	$4,215,700,478
New Mexico	65,255	74,312,763	$854,596,776
New York	720,796	820,842,714	$9,439,691,215
North Carolina	356,851	406,381,406	$4,673,386,174
North Dakota	19,471	22,173,851	$254,999,287
Ohio	435,059	495,444,985	$5,697,617,333
Oklahoma	126,673	144,255,073	$1,658,933,342
Oregon	136,067	154,953,263	$1,781,962,527
Pennsylvania	484,404	551,639,745	$6,343,857,071
Rhode Island	39,138	44,569,838	$512,553,133
South Carolina	182,657	208,009,979	$2,392,114,762
South Dakota	30,393	34,611,825	$398,035,992
Tennessee	252,062	287,047,687	$3,301,048,405
Texas	852,820	971,191,823	$11,168,705,965
Utah	101,151	115,191,322	$1,324,700,201
Vermont	17,600	20,042,455	$230,488,238
Virginia	280,043	318,912,890	$3,667,498,236
Washington	203,784	232,069,356	$2,668,797,592
West Virginia	93,568	106,554,842	$1,225,380,682
Wisconsin	200,196	227,982,824	$2,621,802,480
Wyoming	17,809	20,280,871	$233,230,016
U.S. Totals	**10,987,887**	**12,513,005,548**	**$143,899,563,806**

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

Created from data from the 2000 BRFSS, U.S. Census Bureau, National Alliance for Caregiving, AARP and U.S. Department of Labor.[A6, A7, A8]

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

People with Alzheimer's disease and other dementias are high users of health care, long-term care and hospice.

Total payments for these types of care from all sources, including Medicare and Medicaid, are three times higher for older people with Alzheimer's and other dementias than for other older people. As the number of people with these conditions grows in the future, payments for their care will increase dramatically.

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

In 2004, total per person payments from all sources for health care, long-term care and hospice were three times higher for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias than for other Medicare beneficiaries in the same age group.[78], [A9]

Most older people with Alzheimer's disease and other dementias have Medicare,[A10] and their high use of hospital and other healthcare services translates into high costs for Medicare. In 2004, Medicare payments per person for beneficiaries aged 65 and older with Alzheimer's and other dementias were almost three times higher than average Medicare payments for other Medicare beneficiaries in the same age group ($15,145 compared with $5,272 per person; Table 6).[78]

Medicaid pays for nursing home and other long-term care services for some people with very low income and low assets,[A11] and the high use of these services by people with Alzheimer's and other dementias translates into high costs for Medicaid. In 2004, Medicaid payments per person for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were more than nine times higher than Medicaid payments for other Medicare beneficiaries in the same age group ($6,605 compared with $718 per person; Table 6).[78]

Based on the average per person payments from all sources for health care and long-term care services for people aged 65 and older with Alzheimer's disease and other dementias in 2004, as shown in Table 6, total payments for 2010 are expected to be $172 billion, including $123 billion for Medicare and Medicaid.[A12]

Table 6: Average per Person Payments for Healthcare and Long-Term Care Services, Medicare Beneficiaries Aged 65 and Older, with and without Alzheimer's Disease or Other Dementia, 2004 Medicare Current Beneficiary Survey

	Beneficiaries with Alzheimer's or Other Dementia	Beneficiaries with No Alzheimer's or Other Dementia
Total Payments*	$33,007	$10,603
Payments from Specified Sources		
Medicare	15,145	5,272
Medicaid	6,605	718
Private insurance	1,847	1,466
Other payers	519	211
HMO	410	704
Out-of-pocket	2,464	1,916
Uncompensated	261	201

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

Created from data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey,* 2009.[78]

Costs to U.S. Businesses of Care for People with Alzheimer's and Other Dementias

American businesses incur high costs due to lost productivity, missed work and replacement expenses for employees who are caring for a person with Alzheimer's or other dementia and have to reduce their hours, take time off or completely quit working because of the demands of caregiving. One study estimated that in 2002, the cost to U.S. businesses for employees who are caregivers of people with Alzheimer's and other dementias was $36.5 billion.[79] This study also estimated that in 2002, U.S. businesses paid an additional $24.6 billion for health care, long-term care and hospice for people with Alzheimer's and other dementias. These payments included direct payments by businesses for care of their own retirees as well as government taxes that are used for Medicare, Medicaid and other publicly funded programs that pay for health care, long-term care and hospice.

Use and Costs of Healthcare Services

People with Alzheimer's disease and other dementias have more than three times as many hospital stays as other older people. Their total Medicare costs and Medicare costs for hospital care are almost three times higher than for other Medicare beneficiaries. Moreover, use of healthcare services for people with other serious medical conditions is strongly affected by the presence or absence of coexisting Alzheimer's or other dementia. In particular, people with coronary heart disease, diabetes, congestive heart failure and cancer who also have Alzheimer's or other dementia have higher use and costs of healthcare services than people with these medical conditions but no Alzheimer's or dementia.

Use of Healthcare Services by Setting

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

- *Hospital*. In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were 3.1 times more likely than other Medicare beneficiaries in the same age group to have a hospital stay (828 hospital stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 266 hospital stays per 1,000 beneficiaries for other Medicare beneficiaries).[78] At any point in time, about one-quarter of all hospital patients aged 65 and older are people with Alzheimer's and other dementias.[80]
- *Skilled nursing facility*. In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were eight times more likely than other Medicare beneficiaries in the same age group to have a Medicare-covered stay in a skilled nursing facility (319 stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 39 stays per 1,000 beneficiaries for other beneficiaries).[78]
- *Home health care*. In 2004, one-quarter of Medicare beneficiaries aged 65 and older who received Medicare-covered home health care services were people with Alzheimer's and other dementias,[81] about twice as many as one would expect given the proportion of Medicare beneficiaries with Alzheimer's and other dementias among all Medicare beneficiaries.

Costs of Healthcare Services by Setting

In 2004, average per person payments from all sources for healthcare services, including hospital, physician and other medical provider, skilled nursing facility, home health care and prescription medications, were higher for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias than for other Medicare beneficiaries in the same age group (Table 7).

As shown in Figure 10, average per person payments from all sources for hospital care for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias were 2.8 times higher than for other Medicare beneficiaries in the same age group ($7,663 per person compared with $2,748 per person for beneficiaries with no Alzheimer's or other dementia).[78]

Some of the use and costs of hospital care for people with Alzheimer's disease and other dementias are potentially preventable. A *potentially preventable hospitalization* is defined as a hospitalization for a condition that can be prevented altogether or whose course can be mitigated with optimum outpatient management, thus preventing the hospitalization.[82] In 1999, Medicare beneficiaries aged 65 and older with Alzheimer's disease and other dementias were 2.4 times more likely than other Medicare beneficiaries in that age group to have a potentially preventable hospitalization.[82]

One study of a large, nationally representative sample of people aged 70 and older found that those with cognitive impairment who said (or their proxy respondent said) that a doctor had told them they had Alzheimer's disease or other dementia had significantly more physician contacts (including both in-person and telephone contacts) and significantly fewer hospital days than a comparison group of people with cognitive impairment who said (or their proxy respondent said) that a doctor had not told them they had Alzheimer's disease or other dementia.[83] This finding suggests that recognition of Alzheimer's or other dementia by the doctor, the person with the condition and/or the family may increase optimum outpatient management and reduce hospital days.

Table 7: Average per Person Payments for Healthcare Services, Medicare Beneficiaries Aged 65 and Older with or without Alzheimer's Disease and Other Dementias, 2004 Medicare Current Beneficiary Survey

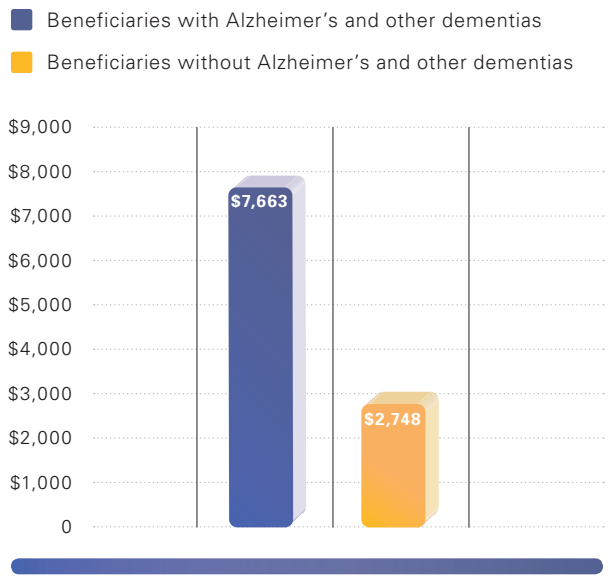
Healthcare Service	Average per Person Payment for Those with No Alzheimer's or Other Dementia	Average per Person Payment for Those with Alzheimer's or Other Dementia
Hospital	$2,748	$7,663
Medical provider*	3,097	4,355
Skilled nursing facility	333	3,030
Home health care	282	1,256
Prescription medications**	1,728	2,509

*"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 data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey,* 2009.[78]

Figure 10: Average per Person Payments for Hospital Care for Medicare Beneficiaries Aged 65 and Older Who Have Alzheimer's Disease and Other Dementias Compared with Other Medicare Beneficiaries, 2004 Medicare Current Beneficiary Survey



Created from data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey,* 2009.[78]

Table 8: Percentages of Medicare Beneficiaries Aged 65 and Older with Alzheimer's Disease and Other Dementias by Specified Coexisting Medical Conditions, 2004 Medicare Current Beneficiary Survey

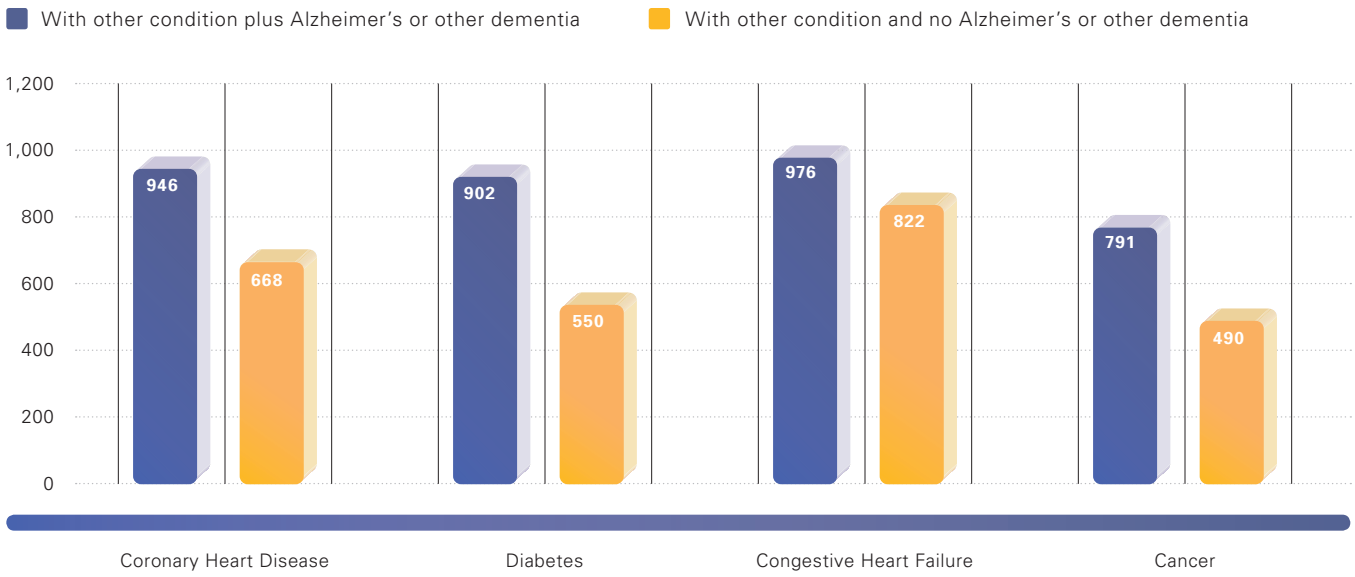
Coexisting Condition	Percentage with Alzheimer's or Other Dementia and the Coexisting Condition
Hypertension	60%
Coronary heart disease	26%
Stroke—late effects	25%
Diabetes	23%
Osteoporosis	18%
Congestive heart failure	16%
Chronic obstructive pulmonary disease	15%
Cancer	13%
Parkinson's disease	8%

Created from data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey,* 2009.[78]

Impact of Coexisting Medical Conditions on Use and Costs of Healthcare Services

Most people with Alzheimer's and other dementias have one or more other serious medical conditions. For example, in 2004, 26 percent of Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias also had coronary heart disease; 23 percent also had diabetes; 16 percent also had congestive heart failure and 13 percent also had cancer (Table 8).[78]

Figure 11: Hospital Stays per 1,000 Medicare Beneficiaries Aged 65 and Older with Selected Medical Conditions by Presence or Absence of Alzheimer's Disease and Other Dementias, 2004



Created from data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries,* 2009.[84]

People with serious medical conditions and Alzheimer's or other dementia are more likely to be hospitalized than people with the same serious medical conditions but no Alzheimer's or other dementia (Figure 11). They also have longer hospital stays.

Average per person payments for many healthcare services are also higher for people who have other serious medical conditions and Alzheimer's or other dementia than for people who have the other serious medical conditions but no Alzheimer's or other dementia. Table 9 shows the total average per person Medicare payments and average per person Medicare payments for selected Medicare services for beneficiaries with other serious medical conditions who either do or do not have Alzheimer's or other dementia.[84] With one exception, Medicare beneficiaries with a serious medical condition and Alzheimer's or other dementia had higher average per person payments than Medicare beneficiaries with the same medical condition but no Alzheimer's or other dementia. The one exception is average per person payment for physician visits for people with congestive heart failure, where the average per person payment is $29 lower for Medicare beneficiaries with congestive heart failure and Alzheimer's or other dementia than for Medicare beneficiaries with congestive heart failure and no Alzheimer's or other dementia ($1,470 per person compared with $1,499 per person).[84]

Table 9: Average per Person Payments by Type of Service and Medical Condition, Medicare Beneficiaries with or without Alzheimer's Disease and Other Dementias, 2006 Medicare Claims*

Selected Medical Condition by Alzheimer's Disease/ Dementia (AD/D) Status	Average per Person Medicare Payment				
	Total Payment	Payment for Hospital Care	Payment for Physician Care	Payment for Skilled Nursing Facility Care	Payment for Home Health Care
Coronary Heart Disease					
With AD/D	$20,780	$7,453	$1,494	$3,072	$1,497
Without AD/D	14,640	5,809	1,292	963	743
Diabetes					
With AD/D	20,655	7,197	1,412	3,071	1,651
Without AD/D	12,979	4,799	1,129	923	757
Congestive Heart Failure					
With AD/D	21,315	7,642	1,470	3,203	1,504
Without AD/D	17,739	7,172	1,499	1,424	1,026
Cancer					
With AD/D	18,775	6,198	1,328	2,488	1,283
Without AD/D	13,600	4,308	1,095	704	499

*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 data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries,* 2009.[84], A13

Use and Costs of Long-Term Care Services

Most people with Alzheimer's disease and other dementias live at home, usually with help from family and friends. As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers. Many people with Alzheimer's and other dementias also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times in the often long course of their illness. Given the high average cost of these services (e.g., adult day center services, $67 a day, assisted living, $37,572 a year, and nursing home care, $72,270–$79,935 a year), most people with Alzheimer's and other dementias and their families cannot afford them for long. Medicaid is the only federal program that will cover the long nursing home stays that most people with dementia require in the late stages of their illness, but Medicaid requires beneficiaries to be poor to receive coverage. Private long-term care insurance is only an option for those who have the foresight and are healthy and wealthy enough to purchase policies before developing dementia.

Use of Long-Term Care Services by Setting

At any one time, about 70 percent of people with Alzheimer's and other dementias are living at home.[85] Most of these people receive unpaid help from family members and friends, but some also receive paid home and community-based services, such as personal care and adult day center care. A study of

older people who needed help to perform daily activities, such as dressing, bathing, shopping and managing money, found that those who also had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care.[86] 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.[86]

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

- *Home care*. More than one-third (about 37 percent) of older people who received primarily non-medical home care services, such as personal care and homemaker services, through state home care programs in Connecticut, Florida and Michigan had cognitive impairment consistent with dementia.[87-89]
- *Adult day center services*. At least half of elderly adult day center participants have Alzheimer's disease or other dementia.[90-91]
- *Assisted living care*. Estimates from various studies indicate that 45–67 percent of residents of assisted living facilities have Alzheimer's disease or other dementia.[78, 92]
- *Nursing home care*. In 2008, 68 percent of all nursing home residents had some degree of cognitive impairment, including 27 percent who had mild cognitive impairment and 41 percent who had moderate to severe cognitive impairment (Table 10).[93] In June 2009, 47 percent of all nursing home residents had a diagnosis of Alzheimer's or other dementia in their nursing home record.[94]
- *Alzheimer's special care unit*. Nursing homes had a total of 84,221 beds in Alzheimer's special care units in June 2009,[95] accounting for 5 percent of all nursing home beds at that time. The number of nursing home beds in Alzheimer's special care units increased in the 1980s but has decreased since 2004, when there were 93,763 beds in such units.[96] Since almost half of nursing home residents have Alzheimer's or other dementia, and only 5 percent of nursing home beds are in Alzheimer's special care units, it is clear that the great majority of nursing home residents with Alzheimer's and other dementias are not in Alzheimer's special care units.

Costs of Long-Term Care Services by Setting

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

- *Home care*. In 2009, the average hourly rate for non-medical home care, including personal care and homemaker services, was $19 or $152 for an eight-hour day.[97]
- *Adult day center services*. In 2009, the average cost of adult day services was $67 a day.[97] Ninety-five percent of adult day centers provided care for people with Alzheimer's and other dementias, and 2 percent of these centers charged an additional fee for these clients.

Table 10: Cognitive Impairment in Nursing Home Residents by State, 2008

State	Total Nursing Home Residents*	Percentage of Residents at Each Level of Cognitive Impairment**		
		None	Very Mild/ Mild	Moderate/ Severe
Alabama	51,482	28	27	45
Alaska	1,291	31	28	41
Arizona	41,443	46	25	29
Arkansas	34,114	24	29	47
California	258,863	35	26	39
Colorado	40,195	31	30	39
Connecticut	63,283	38	26	36
Delaware	9,716	35	27	38
District of Columbia	5,176	37	23	40
Florida	208,486	40	23	37
Georgia	66,743	16	23	61
Hawaii	8,631	27	23	51
Idaho	12,296	31	28	41
Illinois	170,454	29	32	39
Indiana	85,600	36	27	37
Iowa	49,620	22	30	47
Kansas	36,106	23	31	46
Kentucky	51,147	31	24	45
Louisiana	43,506	24	27	49
Maine	18,434	35	25	40
Maryland	65,573	40	23	37
Massachusetts	103,502	35	24	42
Michigan	102,649	32	26	42
Minnesota	71,003	30	30	40
Mississippi	28,567	23	28	49
Missouri	79,422	30	31	39
Montana	11,283	25	30	45
Nebraska	27,381	27	30	43
Nevada	13,072	41	26	33
New Hampshire	15,867	33	24	43
New Jersey	119,505	42	24	34
New Mexico	13,116	30	28	43

Table 10 (Continued): Cognitive Impairment in Nursing Home Residents by State, 2008

State	Total Nursing Home Residents*	Percentage of Residents at Each Level of Cognitive Impairment**		
		None	Very Mild/ Mild	Moderate/ Severe
New York	229,599	35	26	40
North Carolina	89,223	34	24	42
North Dakota	10,594	21	31	48
Ohio	191,179	30	27	43
Oklahoma	37,668	30	30	40
Oregon	27,336	35	29	36
Pennsylvania	185,933	32	27	41
Rhode Island	17,242	32	28	40
South Carolina	38,530	29	23	49
South Dakota	11,372	20	30	49
Tennessee	70,494	25	27	48
Texas	189,553	24	32	45
Utah	17,743	38	28	34
Vermont	6,912	29	25	46
Virginia	72,214	33	26	41
Washington	56,775	32	29	39
West Virginia	22,104	36	22	42
Wisconsin	74,358	35	28	38
Wyoming	4,828	20	29	52
U.S. Total	**3,261,183**	**32**	**27**	**41**

*These figures include all individuals who spent any time in a nursing home in 2008.
**Percentages for each state may not sum to 100 percent because of rounding.

Created from data from U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. *Nursing Home Data Compendium,* 2009 Edition.[93]

- *Assisted living facility*. In 2009, the average cost for basic services in an assisted living facility was $3,131 a month, or $37,572 a year.[97] Fifty-nine percent of assisted living facilities provided specialized Alzheimer's and dementia care and charged an average of $4,435 a month, or $53,220 a year, for this care.
- *Nursing home*. In 2009, the average cost for a private room in a nursing home was $219 a day, or $79,935 a year. The average cost of a semi-private room in a nursing home was $198 a day, or $72,270 a year.[97] Twenty-nine percent of nursing homes had separate Alzheimer's special care units. The average cost for a private room in an Alzheimer's special care unit was $233 a day, or $85,045 a year, and the average cost for a semi-private room was $208 a day, or $75,920 a year.[97]

Affordability of Long-Term Care Services

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

- Income and asset data are not available for people with Alzheimer's or other dementia, but the median income for people aged 65 and older was $18,208 in 2008.[98] The median income for households headed by an older person was $31,157.[98] Even for older people whose incomes fall comfortably above the median, the costs of home care, adult day center services, assisted living care or nursing home care can quickly exceed their income.
- In 2005, 65 percent of older people living in the community, and 84 percent of those at high risk of needing nursing home care, had assets that would pay for less than a year in a nursing home.[99] Fifty-seven percent of older people in the community and 75 percent of those at high risk of needing nursing home care did not have enough assets to cover even a month in a nursing home.[99]

Long-Term Care Insurance

In 2002, about 6 million people had long-term care insurance policies, which paid out $1.4 billion for services for those who filed claims in that year.[100] Private health and long-term care insurance policies funded only about 9 percent of total long-term care spending in 2006.[101] However, long-term care insurance plays a significant role in paying for the care of people with dementia who purchase policies before developing the disease.

A study of people filing claims on their long-term care insurance policies for the first time during 2003, 2004 and 2005 shows that about two-thirds of those filing claims for care in assisted living (63 percent) and nursing homes (64 percent) had cognitive impairment.[102] The figure was 28 percent for those filing claims for paid home care.

Medicaid Costs

Medicaid covers nursing home care and other long-term care services in the community for individuals who meet program requirements for level of care, income and assets. To receive coverage, beneficiaries must have low incomes or be poor due to their expenditures on these services. The federal government and the states share in managing and funding the program, and states differ greatly in the services covered by their Medicaid programs.

Medicaid plays a critical role for people with dementia who can no longer afford to pay for their long-term care expenses on their own.

- In 2004, 28 percent of Medicare beneficiaries aged 65 and older with Alzheimer's disease or other dementia were also Medicaid beneficiaries.[78]
- About half of all Medicaid beneficiaries with Alzheimer's or other dementia are nursing home residents, and the rest live in the community.[85]
- Among nursing home residents with Alzheimer's and other dementias, 51 percent relied on Medicaid to help pay for their nursing home care in 2000.[85]

- Most nursing home residents who qualify for Medicaid must spend all their Social Security checks 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 resident cannot pay the full cost of care or has a financially dependent spouse.
- Among older people with Alzheimer's disease and other dementias who were living in the community in 2000, 18 percent relied on Medicaid to help pay for their care.[85] Depending on which home and community-based services are covered by Medicaid in their state, these people could receive personal care, which provides assistance with daily activities like bathing and dressing; homemaker services; adult day care; respite care or other services.
- In 2004, total per person Medicaid payments for Medicaid beneficiaries aged 65 and older with Alzheimer's and other dementias were 3.8 times higher than Medicaid payments for other Medicaid beneficiaries in the same age group ($23,631 per Medicaid beneficiary with Alzheimer's or other dementia compared with $6,236 per Medicaid beneficiary with no Alzheimer's or other dementia).[78]

Much of the difference in Medicaid payments for beneficiaries with Alzheimer's and other dementias compared with other Medicaid beneficiaries is due to Medicaid payments for beneficiaries with Alzheimer's and other dementias who live in nursing homes and other residential care facilities, such as assisted living facilities. Including the large Medicaid payments for Medicaid beneficiaries with Alzheimer's and other dementias in nursing homes and other residential care facilities, total Medicaid payments for beneficiaries aged 65 and older with Alzheimer's and other dementias were almost as high in 2004 as total Medicaid payments for all other Medicaid beneficiaries in that age group combined ($19 billion compared with $22.6 billion);[78] this was true even though Medicaid beneficiaries aged 65 and older with Alzheimer's and other dementias accounted for only 18 percent of all Medicaid beneficiaries aged 65 and older in that year.

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

Although Medicare, Medicaid and other sources such as the Veterans Health Administration and private insurance pay for most hospital and other healthcare services and some long-term care services for older people with Alzheimer's and other dementias, individuals and their families still incur high out-of-pocket costs. These costs are for Medicare and other health insurance premiums, deductibles and co-payments and healthcare and long-term care services that are not covered by Medicare, Medicaid or other sources.

In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's disease and other dementias had average per person out-of-pocket costs totaling $2,464 for healthcare and long-term care services that were not covered by other sources (Table 6).[78] Average per person out-of-pocket costs were highest for people with Alzheimer's and other dementias who were living in nursing homes and assisted living facilities ($16,689 per person). Out-of-pocket costs for people aged 65 and older with Alzheimer's and other dementias who were living in the community were 1.2 times higher than the average for all other Medicare beneficiaries in that age group ($2,298 per person for people with Alzheimer's and other dementias compared with $1,916 per person for all Medicare beneficiaries).[78]

Before the implementation of the Medicare Part D Prescription Drug Benefit in 2006, out-of pocket expenses were increasing annually for Medicare beneficiaries.[103] In 2003, out-of-pocket costs for prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries aged 65 and older.[104] Other important components of out-of-pocket costs were premiums for Medicare and private insurance (45 percent) and payments for hospital, physician and other healthcare services that were not covered by other sources (31 percent). The Medicare Part D Prescription Drug Benefit has helped to reduce out-of-pocket costs for prescription drugs for many Medicare beneficiaries,

including beneficiaries with Alzheimer's and other dementias.[105] Clearly, however, the biggest component of out-of-pocket costs for people with Alzheimer's and other dementias is nursing home and other residential care, and out-of-pocket costs for these services are likely to continue to grow over time.

Use and Costs of Hospice Care

Hospices provide medical care, pain management and emotional and spiritual support for people who are dying, including people with Alzheimer's disease and other dementias. Hospices also provide emotional and spiritual support and bereavement services for families of people who are dying. The main purpose of hospice care is to allow individuals to die with dignity and without pain and other distressing symptoms that often accompany terminal illness. Individuals can receive hospice 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.

Use of Hospice Services

In 2008, 6 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of Alzheimer's disease or other dementia (60,488 people).[106] An additional 11 percent of all people admitted to hospices in the United States had a primary hospice diagnosis of non-Alzheimer's dementia (113,204 people).

The number of people with Alzheimer's and other dementias who receive hospice care has increased in the past decade. In 1998, only 3 percent of all people who received hospice care had a primary hospice diagnosis of Alzheimer's disease (12,839 people).[106] An additional 4 percent were people with a primary hospice diagnosis of non-Alzheimer's dementia (15,148 people).

Hospice length of stay has also 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 105 days in 2008.[106] The average length of stay for hospice beneficiaries with a primary diagnosis of non-Alzheimer's dementia increased from 57 days in 1998 to 89 days in 2008. Over the same period, average length of stay also increased for hospice beneficiaries with other primary hospice diagnoses, including congestive heart failure (52 days in 1998 to 75 days in 2008) and stroke (36 days in 1998 to 53 days in 2008).

Costs of Hospice Services

In 2004, total payments from all sources for hospice care for Medicare beneficiaries aged 65 and older with Alzheimer's and other dementias totaled $2.8 billion.[78] Average per person payments for hospice care for beneficiaries aged 65 and older with Alzheimer's or other dementia were eight times higher than for other Medicare beneficiaries in the same age group ($976 per person compared with $120 per person).[78]

6 Special Report: Race, Ethnicity and Alzheimer's Disease

Older African-Americans and Hispanics are considerably more likely than older whites to have Alzheimer's disease and other dementias.[107-108]

Findings from different studies vary, but the available research indicates that in the United States, older African-Americans are probably about two times more likely than older whites to have Alzheimer's and other dementias. Older Hispanics are probably at least one and one-half times more likely than older whites to have these conditions.

When differences between racial and ethnic groups are found, it is sometimes assumed that the differences must be due to genetic factors, but no known genetic factors can account for the differences in the prevalence of Alzheimer's disease and other dementias among older whites, African-Americans and Hispanics. On the other hand, conditions such as high blood pressure and diabetes, both of which are known risk factors for Alzheimer's disease and dementia, are more common in older African-Americans and Hispanics than in older whites and probably account for some of the differences in prevalence of Alzheimer's and other dementias among these groups. Likewise, lower levels of education and other socioeconomic characteristics that are associated with increased risk for Alzheimer's disease and other dementias are more common in older African-Americans and Hispanics than in older whites and probably also account for some of the differences in prevalence among the groups.

This Special Report provides information about the prevalence of Alzheimer's disease and other dementias by race and ethnicity and the factors that are associated with and probably account for some of the differences in prevalence among whites, African-Americans and Hispanics. The report also provides information about the extent to which Alzheimer's and other dementias are diagnosed in different racial and ethnic groups, the proportion of older Medicare beneficiaries with Alzheimer's and other dementias by race and ethnicity and differences in the use and costs of medical services for older white, African-American, Hispanic and other Medicare beneficiaries with these conditions.

To develop this report, the Alzheimer's Association convened an Expert Panel[A14] and reviewed findings from published studies. The Association also contracted for information from the 2006 Health and Retirement Study (HRS) survey, a large-scale survey of a nationally representative sample of older Americans, and obtained new Medicare data on the proportion of older Medicare beneficiaries with Alzheimer's and other dementias by race and ethnicity and the use and costs of medical services in different racial and ethnic groups.

Ideally, information about the prevalence of Alzheimer's disease and other dementias in different racial and ethnic groups would be based on studies that conducted a standardized diagnostic evaluation to identify people with these conditions and included a nationally representative sample large enough to allow for valid estimates of prevalence by race and ethnicity. The only such study completed to date is the Aging, Demographics, and Memory Study (ADAMS), which provides information about the prevalence of Alzheimer's and other dementias in whites and African-Americans aged 71 and older.[12, 109] Findings from ADAMS show that African-Americans aged 71 and older are almost two times more likely than whites in the same age group to have Alzheimer's or other dementia (21.3 percent of African-Americans compared with 11.2 percent of whites).[109]

To estimate the prevalence of Alzheimer's and other dementias in white and African-American people under age 71 and Hispanics of any age, this report uses findings from other studies that conducted a standardized diagnostic evaluation to identify people with Alzheimer's and other dementias and included a sample representative of the population of a given geographic area. The report uses findings from the HRS, which pertain to cognitive impairment rather than Alzheimer's or dementia specifically, to provide a broad national context and foundation for thinking about the prevalence of cognitive impairment, Alzheimer's and

Alzheimer's Association Positions on

Diversity and Inclusiveness

Diversity Definition

The Alzheimer's Association recognizes a broad concept of diversity, which includes considerations of, but is not limited to, race; ethnicity; gender; age; socioeconomic status; sexual orientation; regional, place or national origin; religion; language and disability.

Inclusiveness Definition

The Alzheimer's Association is inclusive of its diverse constituents and ensures that their interests and needs are welcomed and fully considered in our multiple communications platforms, mission activities and business practices.

Diversity and Inclusiveness Statement

At the Alzheimer's Association, diversity is imperative and integral to our mission. It is vital to what we do and is a promise we make to those we serve. Our team of dedicated professionals understands that valuing diversity and inclusiveness is critical to the success of our mission.

We seek to be inclusive of the millions of people currently affected by Alzheimer's disease, their caregivers and the communities in which they live. As the American population ages and becomes increasingly diverse, the Alzheimer's Association will expand its mission activities to remain inclusive and meet the demand for culturally and linguistically sensitive information and increased awareness of people living with the disease.

We at the Alzheimer's Association will continue to cultivate relationships within diverse communities by sharing our time, talent and resources and by exchanging ideas. Our diversity and inclusiveness charter will help us to fulfill our vision of a world without Alzheimer's disease.

Special Report on Race, Ethnicity and Alzheimer's Disease

The following Special Report on Race, Ethnicity and Alzheimer's Disease addresses one important aspect of diversity and inclusion. The Alzheimer's Association understands that many diversity and inclusiveness issues can have significant impact on diagnosis, treatment and individuals' and families' experiences with Alzheimer's disease, as well as on our understanding of key research questions. The Alzheimer's Association is committed to increasing awareness, knowledge and understanding of these factors and will continue to address them in service delivery, research and publications.

other dementias in the United States and about the health and socioeconomic factors that probably account for some of the differences in prevalence among racial and ethnic groups.

From 2010 to 2050, as the total number of Americans aged 65 and older increases from 40 million to 89 million, the proportion of older Americans in different racial and ethnic groups is expected to change markedly. In 2010, whites constitute about 80 percent of the U.S. population aged 65 and older.[110] African-Americans constitute about 9 percent, and Hispanics constitute about 7 percent. Other racial and ethnic groups, including Asian-Americans, American Indians and Alaskan Natives, and Native Hawaiians and Pacific Islanders, constitute the remaining 4 percent. In 2050, it is expected that whites will constitute a smaller proportion of the older population (59 percent). African-Americans will constitute a larger proportion (12 percent), Hispanics will constitute a much larger proportion (20 percent), and other racial and groups will constitute the remaining 9 percent. Improved understanding about the prevalence of Alzheimer's disease and other dementias in different racial and ethnic groups and the factors that are associated with and probably account for some of the differences in prevalence among these groups is essential for addressing the needs of people with these conditions and their families now and in the future.

Understanding the Concepts of Race and Ethnicity

Race and ethnicity are complex concepts that have different meanings to different people. In the U.S. Census, most national surveys and all the studies cited in this report, race and ethnicity are self-reported—that is, individuals identify their own race and ethnicity, often from a list of categories.

Most of the information in this Special Report pertains to two very broad racial groups (whites and African-Americans) and one ethnic group—Hispanics. Clearly, each of these groups includes many subgroups defined by country or place of origin, heritage and other factors. For example, the broad group referred to as Hispanics includes Americans of Caribbean, Mexican and Central and South American origin. Available information about the prevalence of Alzheimer's disease and other dementias in Caribbean- and Mexican-Americans is presented in the report.

Within each of the three broad groups there are tremendous differences in the culture, language, religion and life experiences of individuals. These differences are also evident within subgroups, no matter how narrowly defined. Thus, the findings presented in this report, although useful for thinking about race, ethnicity, Alzheimer's and other dementias, cannot be assumed to apply to any particular individual or even any particular racial or ethnic subgroup unless the findings come from a study that focused specifically on that subgroup.

Prevalence of Cognitive Impairment in Older Whites, African-Americans and Hispanics

Findings from the 2006 HRS survey provide information about the prevalence of cognitive impairment in the three broad racial and ethnic groups that are the main focus of this Special Report—whites, African-Americans and Hispanics. As described earlier, the HRS survey is a large-scale survey of a nationally representative sample of older Americans. The survey is conducted by telephone or face-to-face.[A15] For survey participants who are able to respond to the interview, the survey includes a 27-item test of cognitive abilities, including memory and speed of mental processing, and asks the participant to rate his or her own memory. For survey participants who are not able to respond to the interview, a proxy respondent (usually a family member) responds for them. Proxy respondents are asked to rate the survey participant's memory and his or her ability to perform

daily activities. The survey interviewer is also asked to make a judgment about the survey participant's cognitive ability. For this report, information from these different sources was combined to identify the cognitive status of survey participants.[A15]

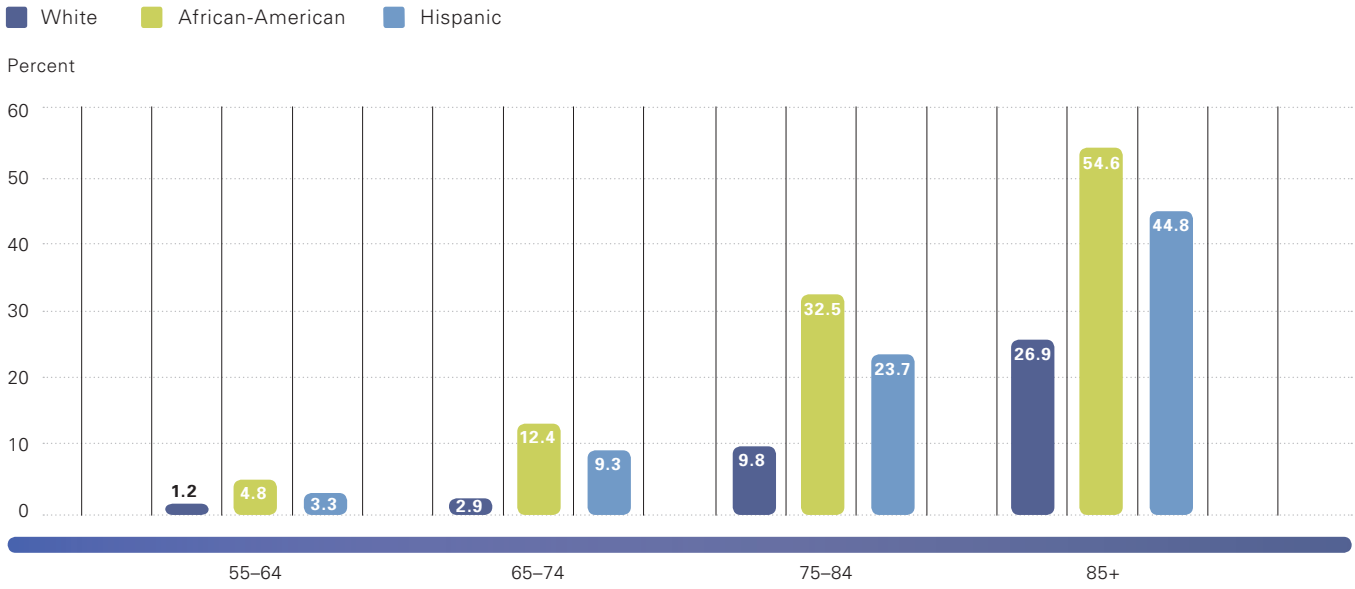
The 2006 HRS survey included more than 16,000 participants aged 55 and older, representing 68 million Americans in that age group.[111] The survey participants identified themselves or their proxy respondent identified them as white, African-American, Hispanic or another racial or ethnic group. Although Hispanics can be any race, the HRS participants who identified themselves or were identified by their proxy respondent as "Hispanic" are categorized as being in that group regardless of their race. Thus, for this report, "whites" include only non-Hispanic whites, and "African-Americans" include only non-Hispanic African-Americans.

Findings from the HRS show that in 2006, the prevalence of cognitive impairment was 10.5 percent for Americans aged 65 and older, including 8.8 percent for whites, 23.9 percent for African-Americans and 17.5 percent for Hispanics.[111] Figure 12 shows the proportion of whites, African-Americans and Hispanics with cognitive impairment for four age groups: 55–64, 65–74, 75–84 and 85 and older.

The most striking observation from Figure 12 is the relationship between age and the prevalence of cognitive impairment. Across all three racial and ethnic groups and for each group, the prevalence of cognitive impairment is higher in older versus younger age groups.

As shown in Figure 12, African-Americans are, on average, two to three times more likely than whites to have cognitive impairment, and these differences are greater in the younger than the older age groups. Among people aged 55–64, for example, African-Americans are four times more likely than whites to have cognitive impairment, but among people aged 85

Figure 12: Proportion of Americans Aged 55 and Older with Cognitive Impairment, by Race/Ethnicity, Health and Retirement Study, 2006, N=16,273



Created from data from the Health and Retirement Study, 2006.[111], [A15]

and older, African-Americans are only about two times more likely than whites to have cognitive impairment.

The HRS findings show that Hispanics are, on average, two times more likely than whites to have cognitive impairment, and these differences are greater in the younger than in the older age groups. Among people aged 55–64, for example, Hispanics are almost three times more likely than whites to have cognitive impairment, but among people aged 85 and older, Hispanics are only 1.6 times more likely than whites to have cognitive impairment. In each age group, Hispanics are less likely than African-Americans to have cognitive impairment.

Although the HRS findings shown in Figure 12 provide information about the national prevalence of cognitive impairment in the three broad racial and ethnic groups, it is not clear how closely these findings on cognitive impairment would match findings on the national prevalence of Alzheimer's disease and dementia by race and ethnicity. With the exception of the findings from ADAMS discussed below, such findings do not exist.

Two difficulties limit interpretation of the HRS findings. The first is that a one-time measurement of cognitive function cannot represent the decline in cognition that is required for a diagnosis of Alzheimer's disease and other dementias. The second is that individuals in various racial and ethnic groups tend to differ in ways that can affect their performance on cognitive tests. For the 58 percent of HRS survey participants with cognitive impairment who responded to the interview for themselves, information about their cognitive status is based on the results of the 27-item standardized cognitive test that is part of the survey. Many researchers and clinicians question whether such tests result in valid findings about cognitive status, especially for people with low education and other sociodemographic characteristics that could affect their performance on the test. Extensive research has been conducted on this issue over the past 20 years.[108, 112-117] Some researchers and clinicians who generally accept the results of a brief mental status test as an indicator of cognitive status for research purposes still have concerns about the extent to which the results can be used to identify people with Alzheimer's disease and other dementias.

Concerns about these two difficulties in interpreting the HRS findings are legitimate. Studies that have been conducted to test the extent to which the cognitive test used in the HRS is a valid indicator of cognitive status and the extent to which the results of this test can be used to identify people with Alzheimer's and other dementias are discussed in the Appendices.[A15]

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

Findings from ADAMS indicate that African-Americans aged 71 and older were almost two times more likely than whites in the same age group to have Alzheimer's disease or other dementias (21.3 percent of African-Americans compared with 11.2 percent of whites).[109] Participants in ADAMS were drawn from the HRS and, with weighting, constitute a nationally representative sample of Americans in that age group.[12] Each ADAMS participant received a comprehensive, standardized evaluation for Alzheimer's disease and other dementias and a diagnosis by a committee of expert dementia clinicians.[12] The ADAMS sample included Hispanics, but the number was too small to provide valid estimates of the prevalence of Alzheimer's or other dementia for that group.

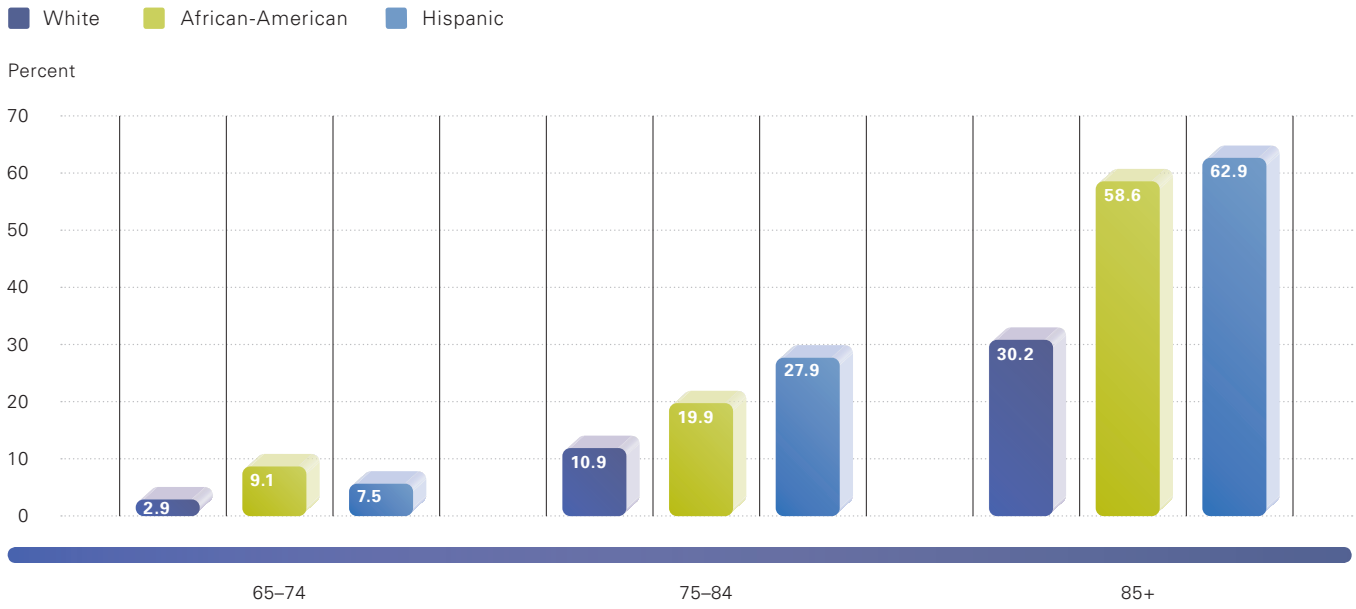
The Expert Panel convened by the Alzheimer's Association to provide guidance for this Special Report identified other studies that: 1) provide information about the prevalence of Alzheimer's disease and other dementias in age-specific subgroups of older people, 2) used a population-based sample of people from one or more racial or ethnic groups in the United States and 3) conducted a standardized evaluation to identify

people with Alzheimer's and other dementias. Only one study, the Washington Heights-Inwood Columbia Aging Project (WHICAP), met all the Expert Panel's criteria and reported information about the prevalence of Alzheimer's and other dementias for whites, African- Americans and Hispanics.[22] Several other studies met the Expert Panel's criteria and reported information about prevalence for one or two racial or ethnic groups.

Findings from WHICAP show that the prevalence of Alzheimer's disease and other dementias was 7.8 percent in whites aged 65 and older, 18.8 percent in African-Americans aged 65 and older and 20.8 percent in Hispanics aged 65 and older.[22] Across the three groups and for each group, the prevalence of Alzheimer's and other dementias in WHICAP was higher in older versus younger age groups (Figure 13). In the age groups 75–84 and 85 and older, African-Americans were about two times more likely than whites to have Alzheimer's and other dementias, whereas in the age group 65–74, African-Americans were about three times more likely than whites to have Alzheimer's and other dementias. In the age groups 65–74 and 75–84, Hispanics were two and a half times more likely than whites to have Alzheimer's and other dementias. The difference was somewhat smaller in the age group 85 and older, where Hispanics were about two times more likely than whites to have these conditions.

The overall prevalence figures for whites and African-Americans aged 65 and older from WHICAP (7.8 percent and 18.8 percent, respectively) are somewhat lower than the figures for whites and African-Americans aged 71 and older from ADAMS (11.2 percent and 21.3 percent, respectively). This difference is understandable, since the inclusion of younger people (those aged 65 to 70) in the WHICAP sample would be expected to result in lower

Figure 13: Proportion of People Aged 65 and Older with Alzheimer's Disease and Other Dementias, by Race/Ethnicity, Washington Heights-Inwood Columbia Aging Project, 2006, N=2,162



Created from data from Gurland et al.[22]

prevalence of Alzheimer's and other dementias. Nevertheless, the findings from both studies show that African-Americans are about two times more likely than whites to have these conditions.

Findings from other studies that met the Expert Panel's criteria and provide information about the prevalence of Alzheimer's and other dementias in specific racial and ethnic groups are as follows:

- A study of a population-based sample of whites and African-Americans in four states, Maryland, North Carolina, Pennsylvania and California, found that 8.9 percent of whites under age 70 had Alzheimer's disease and other dementias, increasing to 46.9 percent of those aged 85 and older.[15] Prevalence in African-Americans was about 1.6 times higher for all age groups in the study sample.[118]
- A study of a population-based sample of African-Americans in Indianapolis, Indiana, found that 2.6 percent of those aged 65–74 had Alzheimer's disease or other dementias, increasing to 32.4 percent of those aged 85 and older.[119]
- A study of a population-based sample of Mexican-Americans in Sacramento, California, found that 1.2 percent of those aged 65–74 had Alzheimer's disease or other dementias, increasing to 26.1 percent of those aged 85 and older.[120]

All the studies described above vary in many ways, including sample composition, participation rates and the precise methods used to identify people with Alzheimer's and other dementias. This variation may account for some of the differences in their findings about the prevalence of Alzheimer's and other dementias.

One important aspect of sample composition is whether a study includes nursing home residents. The prevalence of Alzheimer's and other dementias is high in nursing homes (see Use and Costs of Care section), and inclusion or exclusion of nursing home residents is likely to have a strong effect on study findings. The study of African-Americans in Indianapolis included nursing home residents and reported findings about the prevalence of Alzheimer's and other dementias for sample members who were living in the community and nursing homes separately as well as for the sample as a whole. While the difference in prevalence of Alzheimer's and other dementias for African-Americans aged 65–74 who were living in the community versus in a nursing home is small (1.8 percent versus 2.6 percent), the difference in prevalence for those aged 85 and older is large: 17 percent for African-Americans who were living in the community compared with 76.3 percent for those who were living in nursing homes.[119]

Findings from the two studies described above that include Hispanics show large differences in the prevalence of Alzheimer's and other dementias, especially in the age group 85 and older. The WHICAP findings show that 62.9 percent of the Hispanics aged 85 and older, described as mostly Caribbean-Americans, had Alzheimer's and other dementias compared with only 26.1 percent of the Mexican-Americans in the Sacramento study.[22, 120] It is unclear whether these differences reflect true differences in prevalence among subgroups of Hispanics, differences in the way the two studies were conducted or both.

One additional group for which there is information about the prevalence of Alzheimer's and other dementias is Japanese-Americans. One study of Japanese-Americans in Seattle found that about 1 percent of those aged 65–74 had Alzheimer's disease and other dementias, increasing to 30 percent of those aged 85–89, 50 percent of those aged 90–94 and 74 percent of those aged 95 and older.[121] Another study of Japanese-American men in Honolulu found that 3 percent of those aged 71–74 had Alzheimer's disease or dementia, increasing to 46.2 percent of those aged 85 and older.[122]

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

Findings from the studies discussed in this section provide a range of figures for the prevalence of Alzheimer's disease and other dementias in different racial and ethnic groups. For the purposes of this Special Report, the most useful findings come from ADAMS, because it had a nationally representative sample, and WHICAP, because it is the only study that has reported prevalence information for three major racial and ethnic groups in the United States. Based on these findings, the Alzheimer's Association estimates that older African-Americans are about two times more likely than older whites to have Alzheimer's disease and other dementias.

ADAMS findings are not available for Hispanics, and as discussed earlier, findings from WHICAP based on a sample of mostly Caribbean-Hispanics show a much higher prevalence of Alzheimer's and other dementias than findings from the Sacramento study based on a sample of Mexican-Americans. The findings from the Sacramento study are important because Mexican-Americans are the largest group of Hispanics in the United States. The HRS findings on the prevalence of cognitive impairment do not differentiate subgroups of Hispanics. But they show that among people aged 65 and older, Hispanics were two times more likely than whites to have cognitive impairment (8.8 percent and 17.5 percent, respectively), with the difference decreasing with older age. Hispanics aged 65–74 were 3.2 times more likely than whites to have cognitive impairment, while those aged 75–84 were 2.4 times more likely, and those aged 85 and older were only 1.6 times more likely than whites to have cognitive impairment.[111] Given these findings, the Alzheimer's Association believes it is reasonable at this time to estimate that older Hispanics are at least one and a half times more likely than older whites to have Alzheimer's and other dementias.

The HRS findings on cognitive impairment in people aged 55–64 show large differences among whites, African-Americans and Hispanics. Among people aged 55–64, African-Americans were four times more likely than whites to have cognitive impairment. Hispanics in this age group were almost three times more likely than whites to have cognitive impairment. No information is available about the prevalence of Alzheimer's disease and other dementias in people under age 65 from studies that have used a population-based sample. One study of whites and Hispanics with Alzheimer's or other dementia who were evaluated at five specialized medical centers across the country found that the average age of symptom onset was 6.8 years earlier for Hispanics than for whites.[123] More research is clearly needed to address questions about the prevalence of Alzheimer's and other dementias in white, African-American and Hispanic people under age 65, as well as questions about prevalence in subgroups of the Hispanic population and many other racial and ethnic groups in the United States for which no prevalence information is currently available.

Relationship of Genetic Factors and Prevalence of Alzheimer's Disease and Dementia in Different Racial and Ethnic Groups

As discussed in the Overview, a small percentage of Alzheimer's disease cases are caused by rare genetic mutations that are found in a few families worldwide. Individuals who inherit these mutations often experience the onset of Alzheimer symptoms before age 65, some as early as age 30. Given the relatively small number of people worldwide who are known to have inherited these genetic mutations, it is unlikely that the mutations are responsible for the greater prevalence of Alzheimer's and other dementias in African-Americans and Hispanics.

A genetic factor that is associated with late-onset Alzheimer's disease is apolipoprotein E (ApoE). People

inherit one form of the ApoE gene from each parent. Those who inherit the e4 form of the ApoE gene from one parent have an increased risk of developing Alzheimer's disease. Those who inherit the e4 form of the gene from both parents have an even higher risk.

The relationship between ApoE-e4 and Alzheimer's disease has been studied in white, African-American, Hispanic and other populations in the United States and around the world. A widely cited meta-analysis that combined findings from 5,930 people with Alzheimer's disease and 8,607 without the disease showed that whites who inherited the e4 form of the ApoE gene from one parent had a 3.2 times greater risk of developing Alzheimer's disease than whites who did not inherit this form of the gene from one parent.[124] Hispanics who inherited the e4 form of the ApoE gene from one parent had a 2.2 times greater risk of developing Alzheimer's disease than Hispanics who did not inherit this form of the gene from one parent. The risk of Alzheimer's disease was 14.9 times higher for whites who inherited the e4 form of the ApoE gene from both parents and 5.7 times higher for African-Americans who inherited the e4 form of the gene from both parents. On the other hand, African-Americans who inherited the e4 form of the ApoE gene from one parent and Hispanics who inherited the e4 form of the gene from both parents did not have an increased risk for developing Alzheimer's disease.[124] Thus, the relationship between inheritance of the e4 form of the ApoE gene and the development of Alzheimer's disease in African-American and Hispanic populations is ambiguous.

Research on genetic factors in Alzheimer's and other dementias is important because it increases our understanding of the causes of these conditions. As such research continues to evolve, additional genetic factors in Alzheimer's and other dementias will undoubtedly be discovered. At this time, however, the relatively small number of people worldwide who have the known genetic mutations that cause Alzheimer's disease, the ambiguity of findings about the impact of inheriting the e4 form of the ApoE gene on African-Americans and Hispanics, and the implication from the meta-analysis findings that inheritance of the e4 form may have less impact on African-Americans and Hispanics than on whites all suggest that these genetic factors probably do not account for the greater prevalence of Alzheimer's and other dementias in African-Americans and Hispanics.

Relationship of Certain Diseases and Prevalence of Alzheimer's Disease and Dementia in Different Racial and Ethnic Groups

High blood pressure, heart disease, diabetes and stroke are known risk factors for Alzheimer's disease and other dementias.[114, 125-134] Some people have more than one of the four diseases, and they are at even greater risk of developing Alzheimer's and other dementias.[135]

Findings from the HRS show that these four diseases are more common in people with cognitive impairment than in people with normal cognition, regardless of race or ethnicity (Table 11, page 56). For example, high blood pressure was more common in people aged 55 and older with cognitive impairment than in those with normal cognition in each of the three broad racial and ethnic groups.[111] Among whites, 61 percent of those with cognitive impairment had high blood pressure, compared with 52 percent of those with normal cognition. Likewise, among African-Americans, 80 percent of those with cognitive impairment had high blood pressure, compared with 69 percent of those with normal cognition. For Hispanics, 68 percent of those with cognitive impairment had high blood pressure, compared with 52 percent of those with normal cognition.[111]

The same relationship between cognitive status and the presence or absence of a particular disease is true for heart disease, diabetes and stroke in all three racial and ethnic groups (Table 11, page 56).

Table 11: Percentage of Americans Aged 55 and Older with Selected Diseases by Race/Ethnicity and Cognitive Status, Health and Retirement Study, 2006

Race/Ethnicity and Cognitive Status	Disease				
	High Blood Pressure N=9,744	Heart Disease N=4,468	Diabetes N=3,463	Stroke N=1,361	Cancer N=2,519
White					
All	54	26	17	7	16
With normal cognition	52	13	16	5	15
With cognitive impairment	61	41	20	27	14
African-American					
All	72	24	31	11	11
With normal cognition	69	19	30	8	10
With cognitive impairment	80	36	33	25	13
Hispanic					
All	55	17	29	6	9
With normal cognition	52	15	26	4	7
With cognitive impairment	68	24	39	17	14

Created from data from the Health and Retirement Study, 2006.[111]

The consistent relationship of cognitive impairment and the presence of high blood pressure, heart disease, diabetes and stroke, all of which are known risk factors for Alzheimer's disease and other dementias, does not hold true for other diseases. One example is cancer. As shown in Table 11, cancer was not uniformly more common in people with cognitive impairment than in those with normal cognition across the three racial and ethnic groups.[111]

In addition to the consistent relationship of cognitive impairment and high blood pressure, heart disease, diabetes and stroke, the HRS findings in Table 11 show that high blood pressure was more common in African-Americans overall than in whites and Hispanics (72 percent, 54 percent and 55 percent, respectively).[111] Diabetes was more common in African-Americans and Hispanics overall than in whites (31 percent, 29 percent and 17 percent, respectively).[111] In contrast, in the HRS findings, heart disease was more common in whites overall than in African-Americans and Hispanics (26 percent, 24 percent and 17 percent, respectively). It is possible that some of these findings are due to differences across racial and ethnic groups in access to health care and, more specifically, diagnostic evaluation. In the HRS, the presence of diseases is based on self-report or the report of a proxy respondent, so it is also possible that some of the findings are due to differences across racial and ethnic groups in awareness of or willingness to report certain diseases. As shown in Table 11, cancer was more common in whites overall than in African-Americans and Hispanics (16 percent, 11 percent and 9 percent, respectively), even though other sources show that many cancers are more

common in African-Americans than in whites.[136] Despite these caveats, however, it is clear that high blood pressure is more common in African-Americans overall and diabetes is more common in both African-Americans and Hispanics compared with whites, and it is likely that the greater prevalence of these conditions in African-Americans and Hispanics than in whites accounts for at least some of the differences among these groups in prevalence of Alzheimer's and other dementias.

High blood pressure and diabetes are treatable conditions, and many researchers and clinicians have proposed that treatment of these diseases, especially if it were begun in people who have the conditions in midlife, could reduce the prevalence of Alzheimer's and other dementias.[29, 127, 129-130, 134, 137] Since these diseases are more common in African-Americans and Hispanics, effective treatment of these potentially modifiable conditions could be especially beneficial for African-Americans and Hispanics.

Relationship of Socioeconomic Characteristics and Prevalence of Alzheimer's Disease and Other Dementias in Different Racial and Ethnic Groups

Having a low level of education, having low income and having lived in a rural area as a child are socioeconomic characteristics that have been found to be associated with greater risk of developing Alzheimer's disease and other dementias.[16, 23-24, 111-112, 114, 121, 138] Individuals with more than one of these characteristics possess an even greater risk of developing these conditions.[139]

Some studies indicate that it is not only low level of education but also poorer quality of education that is associated with greater risk of developing Alzheimer's and other dementias. For African-Americans at least, having lived in a rural area as a child may be a proxy for having received a poorer quality of education. One study of African-Americans aged 65 and older found that both low educational level and having lived in a rural area until age 60 were independently associated with greater risk of developing Alzheimer's and other dementias.[138] Another study conducted in the same sample of older African-Americans found that the risk of developing Alzheimer's and other dementias was six times greater for those who had a low educational level and had lived in a rural area as a child than for those who had a low educational level but had lived in an urban area as a child.[139] A third study found that older people who said their school performance was below average were 4.5 times more likely than older people who said their school performance was average or above average to have Alzheimer's disease or other dementias, even after adjustment for years of education.[140]

Findings from the HRS show that having a low level of education, having low income and having lived in a rural area as a child, all of which are associated with greater risk of developing Alzheimer's and other dementias, are more common in people with cognitive impairment than in people with normal cognition, regardless of race or ethnicity (Table 12, page 58). Among whites with cognitive impairment, 47 percent had less than 12 years of education, compared with only 11 percent of those with normal cognition.[111] Likewise, among African-Americans, 76 percent of those with cognitive impairment had less than 12 years of education, compared with only 21 percent of those with normal cognition, and for Hispanics, 89 percent of those with cognitive impairment had less than 12 years of education, compared with only 49 percent of those with normal cognition.[111]

The same relationship between cognitive status and the presence or absence of a socioeconomic characteristic that has been shown to be associated with Alzheimer's and other dementias is also true for having income below $18,000 a year and having lived in a rural area before age 16 (Table 12).[111]

Table 12: Percentage of Americans Aged 55 and Older with Selected Socioeconomic Characteristics by Race/Ethnicity and Cognitive Status, Health and Retirement Study, 2006

Race/Ethnicity and Cognitive Status	Socioeconomic Characteristics			
	Level of Education Below 12 Years N=4,181	Income Below $18,000 a Year N=4,118	Lived in a Rural Area before Age 16 N=7,045	Was Born in the United States N=14,805
White				
All	16	18	45	96
With normal cognition	11	14	43	96
With cognitive impairment	47	48	50	93
African-American				
All	37	43	50	95
With normal cognition	21	29	44	95
With cognitive impairment	76	74	68	97
Hispanic				
All	60	48	43	55
With normal cognition	49	38	40	56
With cognitive impairment	89	76	57	56

Created from data from the Health and Retirement Study, 2006.[111]

The consistent relationship of cognitive impairment and having a low level of education, having low income and having lived in a rural area as a child, all of which have been found to be associated with greater risk for developing Alzheimer's and other dementias, does not hold true for other socioeconomic characteristics. One example is the characteristic of having been born in the United States. This characteristic was not uniformly more common in people with cognitive impairment than in those with normal cognition across the three racial and ethnic groups (Table 12).[111]

In addition to the consistent relationship across racial and ethnic groups between cognitive impairment and the three socioeconomic characteristics that have been found to be associated with greater risk for developing Alzheimer's disease and other dementias, the HRS findings in Table 12 show that two of these three characteristics were more common in African-Americans and Hispanics than in whites.[111]

The exception is having lived in a rural area as a child. It is possible that the greater prevalence of the other two characteristics in African-Americans and Hispanics than in whites accounts for at least some of the differences among these groups in prevalence of Alzheimer's and other dementias.

Diagnosis of Alzheimer's Disease and Other Dementias in Different Racial and Ethnic Groups

Several studies conducted in clinical settings indicate that African-Americans and Hispanics with Alzheimer's disease or other dementias are less likely than whites to have been diagnosed with the condition.[141-142] Although focus groups and individual research interviews indicate that African-American family members recognize the value of having a diagnosis, long delays often occur between family members' first recognition of symptoms of Alzheimer's

and other dementias and the scheduling of a medical evaluation.[107, 141, 143-144] The same is true for people in other racial and ethnic minority groups.[107, 142, 145]

Findings from the 2006 HRS survey provide some support for the conclusion that African-Americans and Hispanics with Alzheimer's disease and other dementias are less likely than whites with these conditions to have been diagnosed. The findings show that African-Americans and Hispanics with cognitive impairment are less likely than whites with cognitive impairment to report (or their proxy respondents are less likely to report) that a physician has said the person has "a memory-related disease."[111] The HRS findings show that 46 percent of whites aged 55 and older with cognitive impairment (or their proxy respondents) reported that a physician has said the person had a "memory-related disease," compared with 33 percent of African-Americans with cognitive impairment and 34 percent of Hispanics with cognitive impairment.[111] These findings may be due to a greater willingness among whites with cognitive impairment or their proxy respondents to report a diagnosis, but they probably also reflect a greater likelihood that whites with cognitive impairment have been diagnosed.

New Medicare data, which are based on diagnostic codes used on Medicare claims, show that in 2006, 9.9 percent of Medicare beneficiaries aged 65 and older had a claims-based diagnosis of Alzheimer's disease or other dementia.[146], [A16] The proportions varied, however, for white, African-American, Hispanic and other Medicare beneficiaries. Among white Medicare beneficiaries, 9.6 percent had a claims-based diagnosis of Alzheimer's or other dementia, compared with 12.7 percent of African-American Medicare beneficiaries and 14 percent of Hispanic Medicare beneficiaries.[146]

Although these new Medicare data show that African-American and Hispanic Medicare beneficiaries were somewhat more likely than white beneficiaries to have a claim-based diagnosis of Alzheimer's and other dementias, the differences are not as great as one would expect based on the prevalence figures presented in this Special Report. In particular, the report estimates that older African-Americans are two times more likely than older whites to have Alzheimer's and other dementias, whereas the new Medicare data show that African-American beneficiaries were only 32 percent more likely than white Medicare beneficiaries to have a claims-based diagnosis of Alzheimer's or other dementia (12.7 percent versus 9.6 percent, respectively).[146] Likewise, this report estimates that older Hispanics are at least one and a half times more likely than older whites to have Alzheimer's and other dementias, whereas the new Medicare data show that Hispanic beneficiaries were only 46 percent more likely than white Medicare beneficiaries to have a claims-based diagnosis of Alzheimer's or other dementia (14 percent versus 9.6 percent, respectively).[146] Thus, even though the new Medicare data show that older African-Americans and Hispanics are somewhat more likely than older whites to have a claims-based diagnosis of Alzheimer's and other dementias, they probably still reflect substantial underdiagnosis of these conditions in older African-Americans and Hispanics.

Medicare data for 2006 are also available for two other racial and ethnic groups, Asian-Americans and North American Natives. Among Asian-American Medicare beneficiaries aged 65 and older, 8.1 percent had a claims-based diagnosis of Alzheimer's disease or other dementia in 2006.[146] Among North American Native Medicare beneficiaries, 9 percent had a claims-based diagnosis of Alzheimer's or other dementia in 2006.[146]

Many reasons have been proposed for the different proportions of people with Alzheimer's and other dementias in different racial and ethnic groups who have a diagnosis. These reasons include the cost of the evaluation, lack of insurance coverage for the evaluation, general distrust of doctors and medical clinics, fear that the person will lose insurance coverage or his or her driver's license and perceptions that Alzheimer's and other dementias are a normal consequence of aging.[107, 141-142, 144-145] One study found that older people with Alzheimer's and other dementias who lived alone were less likely to have a diagnosis than other older people with these conditions who lived with a caregiver.[147]

Table 13: Use of and Medicare Payments for Healthcare Services for Medicare Beneficiaries Aged 65 and Older with a Dementia Diagnosis, by Race/Ethnicity, 2006

Medicare Services and Payments	Medicare Beneficiaries Aged 65 and Older with Alzheimer's Disease or Other Dementias			
	All	White Beneficiaries	African-American Beneficiaries	Hispanic Beneficiaries
Total average Medicare payment per beneficiary	$15,333	$14,498	$21,044	$19,933
Average Medicare payment for hospital care per beneficiary	$4,964	$4,563	$7,687	$6,632
Average hospital discharges per 1,000 beneficiaries	660	632	887	731
Average number of hospital days per beneficiary	4.2	3.9	6.4	5.2
Average Medicare payment for physician visits per beneficiary	$1,018	$956	$1,390	$1,411
Average number of physician visits per beneficiary	12.7	12.1	16.4	17.1
Average Medicare payment for home health care per beneficiary	$1,118	$1,025	$1,591	$2,453
Percentage of beneficiaries with at least one home health claim	18.8%	18.2%	22.1%	25.9%
Average Medicare payment for hospice per beneficiary	$1,732	$1,789	$1,514	$1,225
Percentage of beneficiaries with at least one hospice claim	13.7%	14.2%	11.3%	8.8%

Created from data from Alzheimer's Association, *Characteristics, Costs and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 2: National 20% Sample Medicare Fee-for-Service Beneficiaries,* 2009.[84]

Use and Costs of Medical Services for Different Racial and Ethnic Groups

Use and costs of Medicare-funded medical services are substantially higher for African-American and Hispanic Medicare beneficiaries aged 65 and older with a claims-based diagnosis of Alzheimer's disease or other dementias than for white Medicare beneficiaries with a claims-based diagnosis of these conditions.[84] As shown in Table 13, total per beneficiary Medicare payments for African-Americans with a claims-based diagnosis of Alzheimer's disease or other dementias were 45 percent higher than for whites with such a diagnosis ($21,044 compared with $14,498).[84] Likewise, total per beneficiary Medicare payments for Hispanics with a claims-based diagnosis of Alzheimer's or other dementias were 37 percent higher than total per beneficiary payments for whites with the such a diagnosis ($19,933 compared with $14,498).[84] Table 13 also shows that the use and costs of Medicare-funded hospital, physician and home health services are substantially higher for African-American and Hispanic beneficiaries than for white beneficiaries.

The reasons for these discrepancies are unknown, but given the lower proportion of African-Americans and Hispanics with Alzheimer's and other dementias who have been diagnosed, it is possible that the African-American and Hispanic Medicare beneficiaries who have a claims-based diagnosis of Alzheimer's or other dementias in these Medicare data are, on average, in a more advanced stage of Alzheimer's or other dementia than the white beneficiaries with such a diagnosis, and therefore are more cognitively and physically impaired. As a result, it is logical that they would be more likely than the white beneficiaries to require hospital, physician and other Medicare-covered medical services.

One exception to the higher use and costs of Medicare-funded services by African-American and Hispanic beneficiaries than white beneficiaries is hospice care. As shown in Table 13, white Medicare beneficiaries are more likely to use hospice care than African-American and Hispanic beneficiaries, and the average Medicare payment for hospice per beneficiary is higher for white beneficiaries than for African-American and Hispanic beneficiaries.[84] Another exception is use of Alzheimer medications. At least two studies have found that white people with Alzheimer's disease are more likely to use Alzheimer's medications than African-American and Hispanic people with these conditions.[148-149]

End Notes

A1. Proportion of Americans with Alzheimer's disease: The 13 percent is calculated by dividing the number of people aged 65 and older with Alzheimer's disease (5.1 million) by the U.S. population aged 65 and older in 2008, the latest available data from the U.S. Census Bureau (38 million) = 13 percent. Thirteen percent is the same as 1 in 8.

A2. Number of seconds for development of a new case of Alzheimer's disease: The 70 seconds number is calculated by dividing the number of seconds in a year (31,536,000) by the number of new cases estimated for 2010 (454,000), which equals a new case every 69.5 seconds, rounded to 70 seconds. See Hebert, LE; Beckett, LA; Scherr, PA; Evans, DA. "Annual incidence of Alzheimer's disease in the United States projected to the years 2000 through 2050." *Alzheimer's Disease and Associated Disorders* 2001;15:169–173. Using the same source and method of calculation for 2050—31,536,000 seconds divided by an estimated 959,000 new cases—results in 32.8 seconds, rounded to 33 seconds.

A3. Criteria for identifying subjects with Alzheimer's disease and other dementias in the Framingham Study: Standard diagnostic criteria (DSM IV criteria) were used to diagnose dementia in the Framingham Study, but, in addition, the subjects had to have at least "moderate" dementia according to the Framingham criteria, which is equivalent to a score of 1 or more on the Clinical Dementia Rating Scale (CDR), and they had to have symptoms for six months or more. Standard diagnostic criteria (the NINCDS-ADRDA criteria) were used to diagnose Alzheimer's disease. The examination for dementia and Alzheimer's disease is described in detail in Seshadri, S; Wolf, PA; Beiser, A; Au, R; McNulty, K; White, R; et al. "Lifetime risk of dementia and Alzheimer's disease: The impact of mortality on risk estimates in the Framingham Study." *Neurology* 1997;49:1498–1504.

A4. Number of baby boomers who will develop Alzheimer's disease and other dementias: The numbers for remaining lifetime risk of Alzheimer's disease and other dementias for baby boomers were developed by the Alzheimer's Association by applying the data provided to the Association on remaining lifetime risk by Alexa Beiser, Ph.D.; Sudha Seshadri, M.D.; Rhoda Au, Ph.D.; and Philip A. Wolf, M.D., from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health to U.S. Census data for the number of women and men aged 43 to 61 in November 2007, used here to estimate the number of women and men aged 44–62 in 2008.

A5. State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific gender, years of education, race and mortality. See Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans DA. "State-specific projections through 2025 of Alzheimer's disease prevalence." *Neurology* 2004; 62:1645. The numbers in Table 2 are found in online material related to this article at www.neurology.org.

A6. 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 2000, 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 age 60 or older who had a 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 2000 BRFSS (as reported in McKune, SL; Andresen, EM; Zhang, J; Neugaard, B. *Caregiving: A National Profile and Assessment of Caregiver Services and Needs.* University of Florida and Rosalynn Carter Institute, 2006) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2009 accessed at http://www.census.gov/popest/states/asrh/files/SCPRC-EST2009-18+POP-RES.csv on Jan. 12, 2010. To calculate the proportion of family and other unpaid caregivers that provides care for a person with Alzheimer's or another dementia, we used data from a follow-up analysis of results from a national telephone survey conducted in 2009 for the National Alliance for Caregiving (NAC) and AARP (data provided under contract with Matthew Greenwald and Associates, Nov. 11, 2009). 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, 32% of caregivers of people age 60 or older said that: 1) Alzheimer's or dementia was the main problem of the person for whom they provided care, or 2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. We applied the 32% figure to the total number of caregivers of people age 60 and older nationally and in each state.

A7. Number of hours of unpaid care: To calculate this number, the Alzheimer's Association used data from a follow-up analysis of results from the 2009 NAC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov. 11, 2009). These data show that caregivers of people with Alzheimer's and other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. We multiplied the number of family and other unpaid caregivers (10,987,887) by the average hours of care per year (1,139), which equals 12,513,005,548 hours of care.

A8. Value of unpaid caregiving: To calculate this number, the Alzheimer's Association used the method of Arno et al. (see Arno, PS; Levine, C; and Memmott, MM. "The economic value of informal caregiving." *Health Affairs* 1999;18:182-188). This method uses the average of the minimum hourly wage ($6.55 for July 1, 2009) and the mean hourly wage of home health aides ($16.44 in July 2009) (see, U.S. Department of Labor, Bureau of Labor Statistics. "Employment, Hours, and Earnings from Current Employment Statistics Survey," Series 10-CEU 6562160008, Home Health Care Services [NAICS code 6216], Average Hourly Earnings, July 2009, accessed at http://data.bls.gov/ces on Dec. 4, 2009). The average is $11.50. We multiplied the number of hours of unpaid care by $11.50, which equals $143,899,563,806.

A9. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2004 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Julie Bynum, MD, MPH, Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research. The MCBS is a continuous survey of a nationally representative sample of about 16,000 Medicare beneficiaries which 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 *2010 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries aged 65 and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of Alzheimer's disease or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's disease or other dementia in 2004. The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician or other healthcare 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 290.11.

A10. Medicare: Medicare is a medical insurance program available to all Americans aged 65 and older and to a limited number of younger individuals who meet the requirements for Social Security Disability Insurance (SSDI). In 2007, 95 percent of people aged 65 and older had Medicare (U.S. Department of Health and Human Services, *Health Care Financing Review: Medicare and Medicaid Statistical Supplement, Brief Summaries of Medicare and Medicaid,* November 1, 2008). Original, fee-for-service Medicare covers hospital care; physician services; home health care; laboratory and imaging tests; physical, occupational, and speech therapy; hospice and other medical services. Medicare beneficiaries can choose to enroll in a Medicare health maintenance organization (HMO) as an alternative to the original, fee-for-service Medicare. Medicare does not cover long-term care in a nursing home, but it does cover short stays in "skilled nursing facilities" when the stay follows within 30 days of a hospitalization of three days or more for an acute illness such as a heart attack or broken hip. Medicare beneficiaries pay premiums for coverage and generally pay deductibles and co-payments for particular services. Medicare premiums, deductibles and co-payments do not cover the full cost of services to beneficiaries. The program is tax-supported.

A11. Medicaid: Medicaid is a publicly funded health services program for low-income Americans. It is jointly funded by the federal government and the states according to a complex formula. In addition to basic health services, Medicaid covers nursing home care and various home- and community-based long-term care services for individuals who meet program requirements for level of care, income and assets. States have considerable flexibility about which services are covered in their Medicaid programs, and covered services vary greatly in different states.

A12. Lewin Model on Alzheimer's and Dementia Prevalence and Costs: These numbers come from an analysis conducted for the Alzheimer's Association by The Lewin Group. The analysis estimated total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias for 2010 based on findings from the previous analysis of data from the 2004 Medicare Current Beneficiary Survey (MCBS).[(78) A9]

A13. National 20% Sample Medicare Fee-for-Service Beneficiaries Report: These data come from an analysis of Medicare claims data for 2005-2006. The analysis was conducted by Julie Bynum, MD, MPH, Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy. The data come from Medpar files (hospital and skilled nursing facility services), outpatient files (outpatient hospital services), carrier files (physician and supplier services), hospice files (hospice services), DME (durable medical equipment) files, and home health files (home health services). Data from the analysis that are included in *2010 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries aged 65 and older. For this analysis, people with dementia are defined as those who have at least one claim with a diagnostic code for Alzheimer's disease or other dementia in Medpar, Medicare Part B, hospice or home health files in 2005. 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 290.11. People with other chronic conditions are defined as those who had at least one Medicare Part A claim or two Part B claims occurring at least seven days apart with a diagnostic code for the condition. Medicare beneficiaries with Alzheimer's disease, other dementias and other chronic conditions were identified in 2005 Medicare claims, and outcomes (use and costs of services) were taken from 2006 Medicare claims. This prospective method decreases the influence of people with a new diagnosis, which is usually associated with higher use and costs of services compared with ongoing management of the condition.

A14. The Expert Panel convened by the Alzheimer's Association to provide guidance for the development of the Special Report: Panel members are Helena Chui, M.D., Mary N. Haan, M.P.H., Dr.P.H., Eric B. Larson, M.D., M.P.H., and Jennifer J. Manly, Ph.D. Additional assistance to the panel and the Alzheimer's Association was provided by Nicole Schupf, Ph.D, Dr.P.H., and Ling Zheng, M.B.B.S., Ph.D. These individuals provided information about and analysis of research conducted in the United States on the incidence and prevalence of Alzheimer's disease and other dementias in various racial and ethnic groups. Only some of the information and analysis they provided is included in the Special Report. While these individuals provided valuable information and guidance to the Alzheimer's Association in the development of the report, the Alzheimer's Association is solely responsible for the content of the report.

A15. The Health and Retirement Study (HRS) survey: The HRS survey is a large scale, longitudinal survey of a nationally representative sample of people age 50 and older in the United States, including people living in the community, nursing homes, and other institutions. The survey is conducted by the University of Michigan's Institute for Social Research and Survey Research Center, under a contract with the National Institute on Aging. Details of HRS design and methods are available at the study's website, http://hrsonline.isr.umich.edu. The HRS data used in this Special Report were provided under contract with the Alzheimer's Association by Kenneth M. Langa, M.D., Ph.D., Mohammed U. Kabeto, M.S., and David Weir, Ph.D. These data were valuable to the Alzheimer's Association in the development of the report, but the Alzheimer's Association is solely responsible for the content of the report.

Survey Sample: The HRS data used in this Special Report come from the 2006 survey and pertain to people age 55 and older. The Alzheimer's Association contracted for data on four groups: whites, African-Americans, Hispanics, and "other." Data on the "other" group are not included in the report because of the relatively small number of survey participants with cognitive impairment in that group. The sample included 12,357 whites, 2,253 African-Americans, and 1,397 Hispanics. With weighting, these survey participants represent about 56.2 million whites; 6.1 million African-Americans; and 4.4 million Hispanics.

Self- and Proxy Respondents: The HRS conducts telephone and face-to-face interviews with survey participants who are able to respond to the interview. If the designated survey participant is not able to respond to the interview, the interview is conducted with a proxy respondent, who is usually a family member. In 2006, 96 percent of the 4,925 survey participants aged 55-64 were able to participate in the interview, and 4 percent had a proxy respondent; 92 percent of the 11,348 survey participants age 65 and older were able to participate in the interview, and 8 percent had a proxy respondent.

Measures of Cognitive Status: For self-respondents, the HRS interview includes a modified version of the Telephone Interview for Cognitive Status (TICS). (See Brandt, J; Spencer, M; and Folstein, M. "The Telephone Interview for Cognitive Status." *Neuropsychiatry, Neuropsychology, and Behavioral Neurology* 1988;1(2):111-117.) The version of the TICS that is used for self-respondents under age 65 is shorter than the version used for self-respondents aged 65 and older. To obtain comparable information on cognitive status for the two age groups for this report, scores based on items in the shorter version of the TICS were used for all self-respondents. The shorter version includes: 1) an immediate and delayed 10-word free recall test to measure memory; 2) a serial seven subtraction test to measure working memory; and 3) a counting backward test to measure speed of mental processing. Respondent scores were calculated on a 27-point scale, and cut-scores to identify respondents with cognitive impairment were based on findings from the Aging, Demographics, and Memory Study.[12]

For survey participants with proxy respondents, the HRS interview included a question about the survey participant's memory and a question about the survey participant's ability to perform five instrumental activities of daily living (IADLs). In addition, for these survey participants, the interviewer is asked whether he or she thinks the survey participant has cognitive impairment. For this report, responses to these three proxy and interviewer questions were combined to determine cognitive status for survey participants with proxy respondents.

Validity of the Modified TICS: Many studies have been conducted to test the extent to which various versions of the TICS provide valid results about cognitive status and dementia. Results from the original TICS were shown to be highly sensitive and specific for cognitive impairment in a clinic sample of people with Alzheimer's disease. (See Brandt, J; Spencer, M; and Folstein, M. "The Telephone Interview for Cognitive Status." *Neuropsychiatry, Neuropsychology, and Behavioral Neurology* 1988;1(2):111-117.) Other studies have shown that the TICS has high sensitivity and specificity for cognitive impairment and dementia in community samples of older people. (See de Jager, CA; Budge, MM; and Clarke, R. "Utility of the TICS-M for the assessment of cognitive function in older adults." *International Journal of Geriatric Psychiatry* 2003;18(4):318-324. Plassman, B; Newman, TT; Welsh, KA; Helms, M; Breitner, J. "Properties of the telephone interview for cognitive status." *Neuropsychiatry, Neuropsychology, and Behavioral Neurology* 1994;7:235-241. Welsh, KA; Breitner, JCS; and Magruder-Habib, KM. "Detection of dementia in the elderly using telephone screening of cognitive status." *Neuropsychiatry, Neuropsychology, and Behavioral Neurology* 1993;6(2):103-110.) One study that compared a modified version of the TICS and a gold standard, in-person evaluation found that the results of the TICS had specificity of 1.0 for dementia, thus all individuals identified as having dementia by the TICS were also identified as having dementia by the gold standard evaluation; it had a specificity of 0.83, missing one person with dementia who had a high educational level and high IQ (premorbid verbal IQ of 120). (See Crooks, VC; Clark, L; Petitti, DB; Chui, H; and Chiu, V. "Validation of multi-stage telephone-based identification of cognitive impairment and dementia." *BMC Neurology* 2005;5(8):1-8.)

A16. Claims-based diagnoses of Alzheimer's Disease and Other Dementias: Data from the Medicare Chronic Condition Warehouse (CCW): The CCW, created and maintained by the U.S. Centers for Medicare and Medicaid Services (CMS), provides data on the proportion of Medicare beneficiaries who have a Medicare claim for hospital, skilled nursing facility (SNF), home health agency, or outpatient or professional Part B services that includes an ICD-9 diagnostic code for Alzheimer's disease or other dementias. For this report, Medicare beneficiaries aged 65 and older who were alive in 2006 and had at least one such Medicare claim in 2004, 2005, or 2006 were considered to have a claims-based diagnosis of Alzheimer's disease or other dementia. Data on the prevalence of Alzheimer's disease and other dementias in various racial and ethnic groups in 2006, using claims-based diagnoses, were provided to the Alzheimer's Association by Frank Porell, Ph.D., University of Massachusetts Boston.

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The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.

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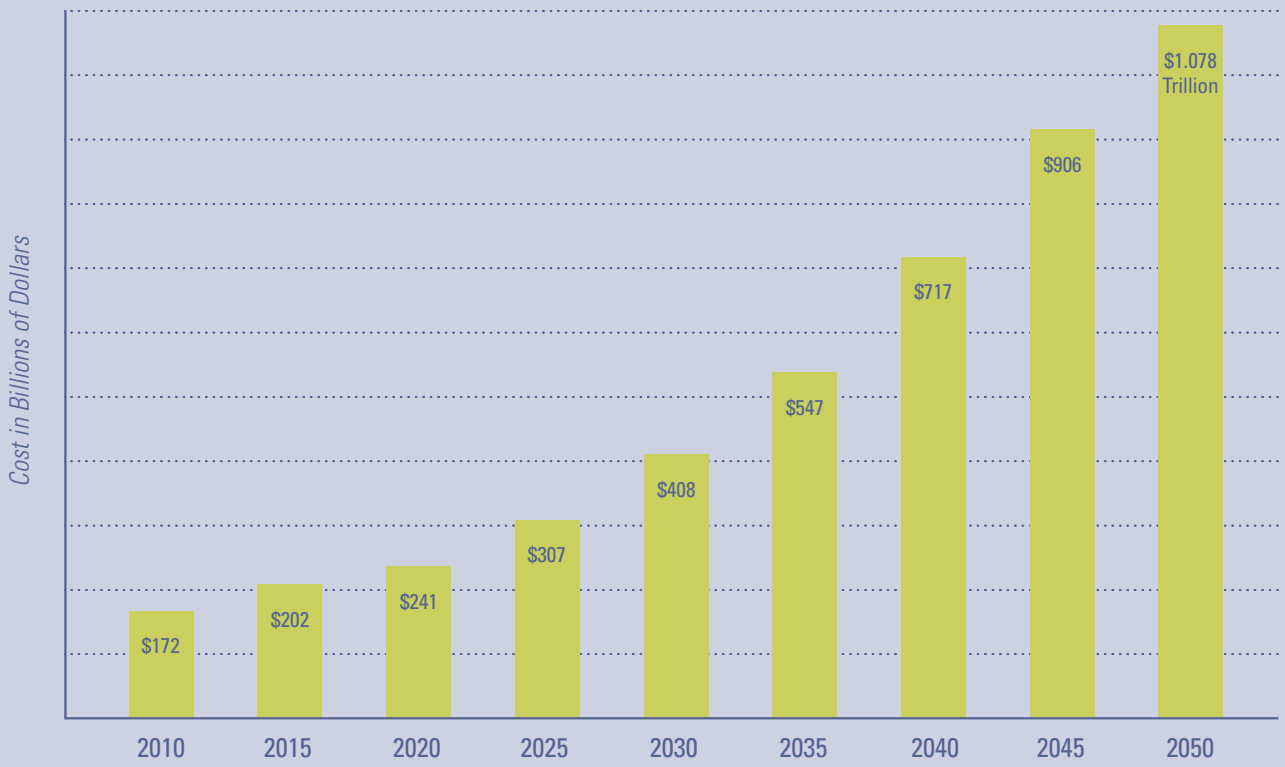
Changing the Trajectory of Alzheimer's Disease: A National Imperative



Costs for Care of People with Alzheimer's Diesase

alzheimer's association®

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About the Cover

During the 40-year period from 2010 to 2050, the total costs of care for Americans age 65 and older with Alzheimer's disease will increase five-fold, from $172 billion to $1.08 trillion per year. These dollar amounts represent the direct costs of care to all payers, including Medicare, Medicaid, out-of-pocket costs to people with the conditions and their families, and costs to other payers (such as private insurance, HMOs and other managed care organizations, and uncompensated care).

All the cost information in the cover chart and throughout the report is in constant, 2010 dollars. Cost figures in the cover chart and throughout the report do not include the costs of care for Americans under age 65 with Alzheimer's because the data is unavailable. The figures also do not include the value of unpaid care provided by families and others, estimated to be $144 billion in 2009.

Introduction

Alzheimer's disease is a devastating condition that results in the loss of memory and other cognitive abilities, and in the ability to care for oneself independently. In 2010, more than 5 million Americans age 65 and older are living with Alzheimer's, and that number will increase rapidly as the baby boomers age.[1]

Millions of family members and friends are also affected by Alzheimer's. These individuals bear the emotional impact of watching someone they care about succumb to and eventually die with the condition. In addition, many face the difficulty of providing increasing amounts of physical, financial and additional assistance for the person. In 2009, an estimated 11 million Americans provided 12.5 billion hours of unpaid care for people with Alzheimer's and other dementias.

People with Alzheimer's disease are also high users of medical, nursing home and other residential care, in addition to in-home and community-based services. Their high use of these services results in high costs to Medicare, Medicaid and other payers, and high out-of-pocket costs for people with the condition and their families.

Currently, there are no known treatments to prevent, cure or even delay the onset or slow the progression of Alzheimer's disease and other dementias. The five medications that are approved for Alzheimer's disease by the U.S. Food and Drug Administration (FDA) temporarily reduce symptoms for some, but they cannot change the underlying course of the disease. Clearly, the ultimate goal is to have treatments that completely prevent or cure Alzheimer's disease and other dementias – eventually resulting in a world without these conditions. Yet, as this report illustrates, even modest and, perhaps, more readily available treatments could prove to be tremendously valuable.

The report presents information about the current trajectory and impact of Alzheimer's disease based on data from a model developed for the Alzheimer's Association by the Lewin Group.[2] Using this model, the report then describes two alternate trajectories in which hypothetical scientific advances result in treatments that can change the course of Alzheimer's disease, either by delaying onset or slowing progression. For these current and alternate trajectories, the report provides estimates of the number of Americans age 65 and older who will have Alzheimer's from 2010 to 2050, the number that will be in the mild, moderate or severe stage of the disease at any point in time, and the costs of their care to all payers.

[1] In addition to people age 65 and older with Alzheimer's and other dementias, the Alzheimer's Association estimates that there are now about half a million Americans under age 65 with these conditions, including about 200,000 people with Alzheimer's disease. This report does not provide information about these individuals because the data needed to develop that information are not available.

[2] See the appendices found at www.alz.org/trajectory for a description of the model and the research findings used to develop it.

The Current Trajectory

Number of Americans with Alzheimer's Disease

The number of Americans age 65 and older who have or will have Alzheimer's disease is projected to increase from 5.1 million in 2010 to 13.5 million in 2050 (see Fig. 1).[3]

In 2010, an estimated 13 percent of Americans age 65 and older will have Alzheimer's disease. By 2050, an estimated 16 percent of Americans age 65 and older will have the condition.

Figure 1:
Number of Americans Age 65 and Older with Alzheimer's Disease, 2010–2050

[3] These numbers include only Americans age 65 and older because the data needed to project the number of people under age 65 with Alzheimer's disease and other dementias is not available.

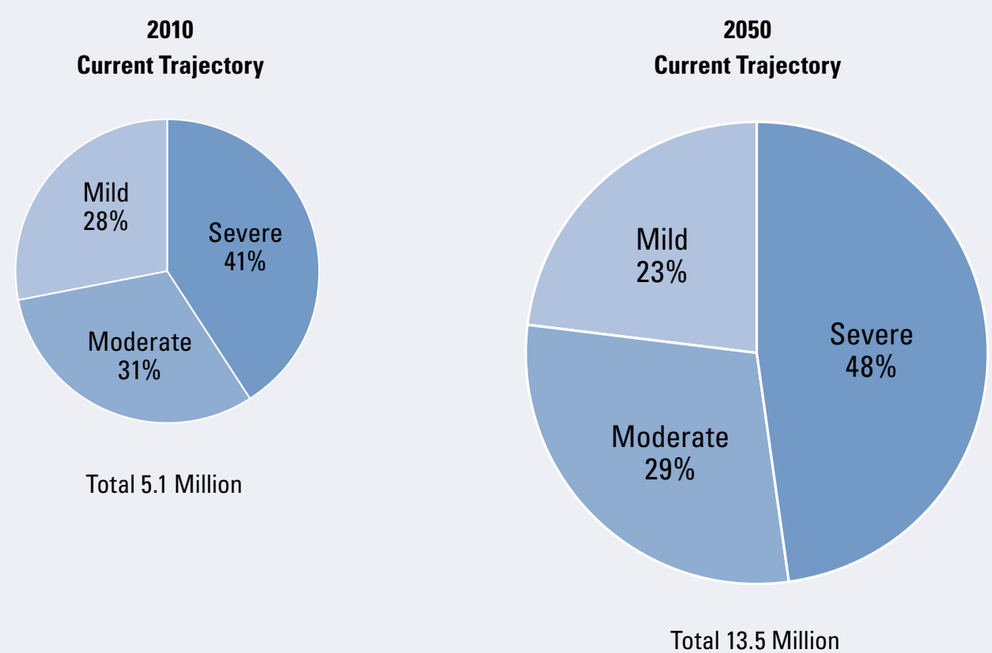
Stage of Disease

At any point in time, some people with Alzheimer's disease are in the mild stage of the condition, some are in the moderate stage, and some are in the severe stage.

As shown in Figure 2, the proportion of people age 65 and older with Alzheimer's in the mild stage will decrease from 28 percent in 2010 to 23 percent in 2050. Likewise, the proportion of people with the condition in the moderate stage will decrease from 31 percent in 2010 to 29 percent in 2050.

In contrast, the proportion in the severe stage will increase from 41 percent in 2010 to 48 percent in 2050. The pie chart for 2050 increases in size to represent the growth of the number of people with Alzheimer's from 5.1 million in 2010 to 13.5 million in 2050. In 2050, 6.5 million people, almost half (48 percent) of the projected 13.5 million Americans with Alzheimer's in that year, will be in the severe stage. In contrast, 3.1 million will be in the mild stage and 3.9 million will be in the moderate stage.

Figure 2:
Proportion of Americans Age 65 and Older with Alzheimer's Disease by Stage of Disease, 2010–2050



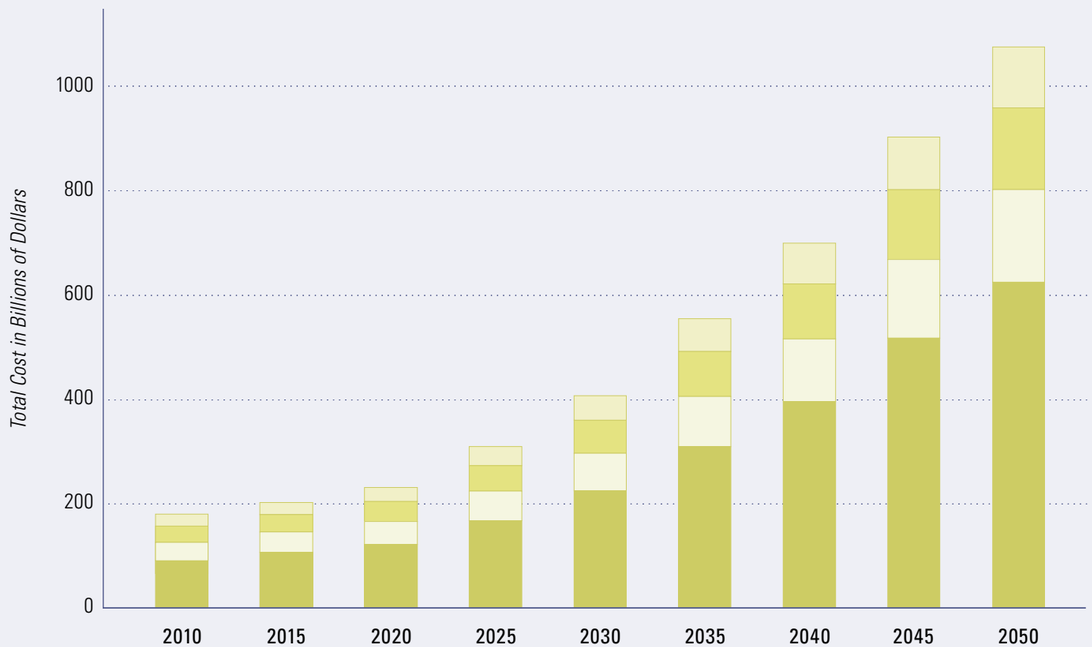
Costs of Care[4]

The figure on the front cover of this report shows that total annual costs to all payers for the care of people with Alzheimer's disease will increase from $172 billion in 2010 to $1.08 trillion in 2050. Figure 3 shows the amounts paid by specific payers, including Medicare, Medicaid, out-of-pocket costs paid by people with the conditions and their families, and costs to other payers (such as private insurance, HMOs and other managed care organizations, and uncompensated care).

As shown in Figure 3, Medicare costs for the care of people with Alzheimer's will increase more than 600 percent, from $88 billion in 2010 to $627 billion in 2050. Medicaid costs will increase 400 percent, from $34 billion in 2010 to $178 billion in 2050. Out-of-pocket costs to people with Alzheimer's and their families will increase more than 400 percent, from $30 billion in 2010 to $157 billion in 2050. Costs to other payers will also increase more than 400 percent from $22 billion in 2010 to $117 billion in 2050.

Cumulative costs to all payers for the care of people with Alzheimer's in the 40-year period from 2010 to 2050 will amount to $20.4 trillion. Cumulative Medicare costs for the care of people with the condition will amount to $11.4 trillion, and cumulative Medicaid costs for their care will amount to $3.6 trillion over the same period.

Figure 3:
Costs of Care for Americans Age 65 and Older with Alzheimer's Disease and Other Dementias, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Other Payers	$22	$23	$28	$36	$47	$62	$80	$101	$117
Out-of-pocket	$30	$33	$40	$48	$63	$85	$108	$134	$157
Medicaid	$34	$39	$46	$56	$72	$95	$123	$151	$178
Medicare	$88	$107	$128	$166	$225	$306	$406	$519	$627

[4] All cost figures are reported in constant, 2010 dollars and do not include inflation. Costs of care include the costs of medical care, nursing home and other residential care, paid in-home and community-based services, and medications.

Changing the Trajectory

There are currently no known treatments to prevent, cure or delay the progression of Alzheimer's disease. Although the ultimate goal is to have treatments that completely prevent or cure Alzheimer's, more modest and, perhaps, more readily available treatments could also prove very beneficial.

The following sections describe the impact of two hypothetical treatment breakthroughs: one that would delay onset and one that would slow progression. Delaying onset would mean that people would have more disease-free years before developing Alzheimer's. Slowing progression would mean that those who developed the conditions would spend more years in the mild and moderate stages before progressing to the severe stage.

Impact of a Hypothetical Treatment Breakthrough that Delayed Onset

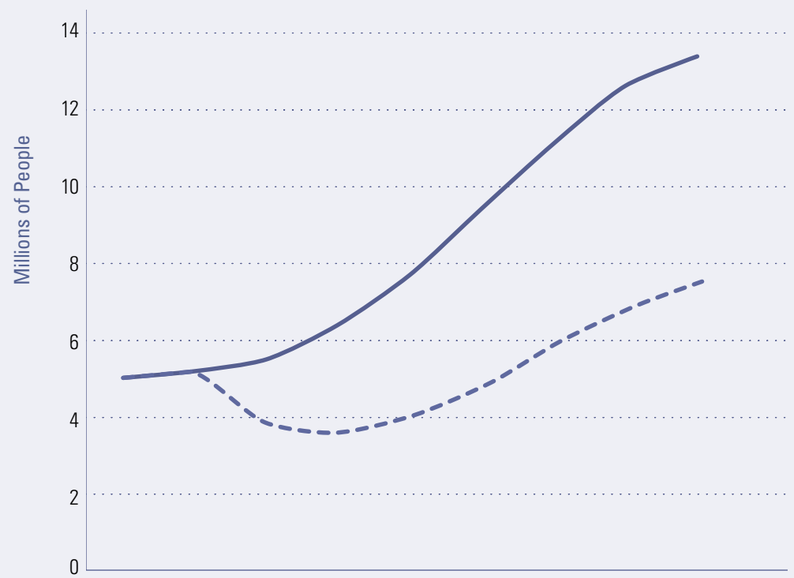
A treatment breakthrough that delayed the onset of Alzheimer's disease would result in an immediate and long-lasting reduction in the number of Americans with the condition and the cost of their care. The hypothetical treatment might be a vaccine that would be given once in a person's life, a medication or cocktail of medications that would be taken one or more times a day starting at different times in a person's life, or a change in diet, exercise or other lifestyle behaviors. The treatment described in the following text and figures would delay the age of onset of Alzheimer's by five years. It is assumed that this treatment would become available in 2015 and begin to show its effects in that year.

Number of Americans with Alzheimer's Disease[5]

A treatment breakthrough that delayed the age of onset of Alzheimer's disease by five years and began to show its effects in 2015 would decrease the total number of Americans age 65 and older with Alzheimer's disease from 5.6 million to 4 million by 2020 (see Fig. 4). As a result, 1.6 million Americans who would be expected to have the condition in 2020 would be free of the condition. In addition, five years later, in 2025, 2.7 million Americans – 42 percent of the 6.5 million people who would be expected to have Alzheimer's in that year – would be disease-free. The biggest effect would be in 2050 when 5.8 million people – 43 percent of the 13.5 million Americans who would be expected to have Alzheimer's without the breakthrough – would not have the condition.

A treatment breakthrough that delayed the age of onset of Alzheimer's disease by five years would reduce the proportion of Americans age 65 and older who have the condition from 10 percent to 7 percent in 2020, and from 16 percent to 9 percent in 2050.

Figure 4:
Americans Age 65 and Older with Alzheimer's Disease, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Current Trajectory	5.1	5.3	5.6	6.5	7.8	9.5	11.2	12.7	13.5
Delayed Onset	5.1	5.3	4.0	3.8	4.2	5.1	6.1	7.1	7.7
Decrease		0.0	1.6	2.7	3.6	4.4	5.1	5.6	5.8

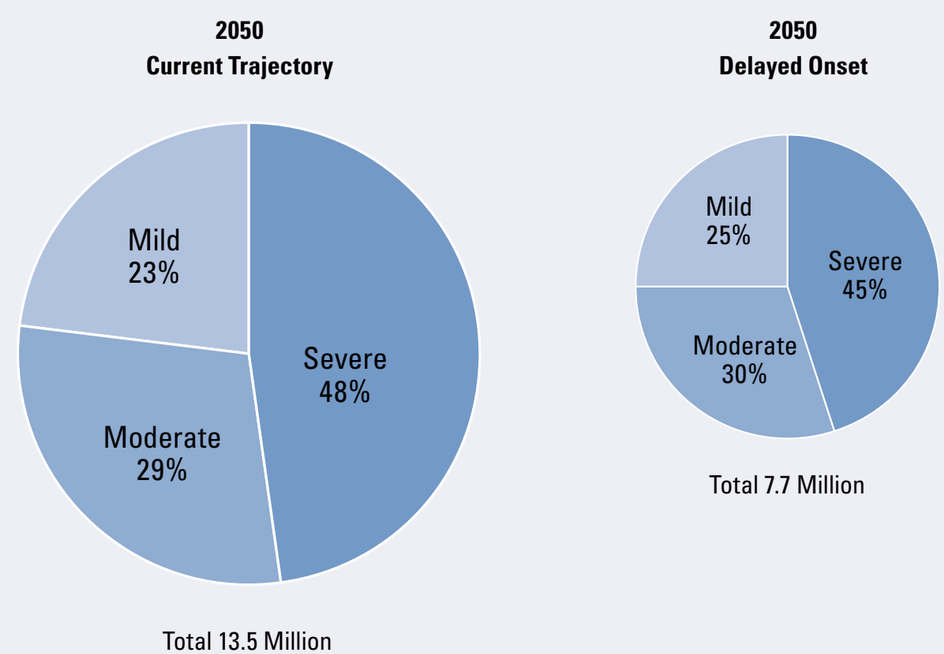
[5] The numbers below include only Americans age 65 and older because the data that would be needed to project the number of people under age 65 with Alzheimer's disease in future years is not available.

Stage of Disease

Although a treatment breakthrough delaying the onset of Alzheimer's disease by five years would reduce the *number* of Americans with the condition, for a time it would increase the *proportion* of those with the condition who were in the severe stage. In 2020, more than half (53 percent) of those with Alzheimer's would be in the severe stage, compared with 42 percent who would be expected to be in the severe stage without the treatment breakthrough. This would occur because no new people would develop the condition starting in 2015, thus greatly reducing the number of individuals in the mild stage, while the new treatment would have no effect on those who already had the condition. As shown in Figure 5, in 2050, 45 percent of Americans age 65 and older with Alzheimer's would be in the severe stage, compared with 48 percent who would be expected to be in the severe stage without the treatment breakthrough.

At no time would this hypothetical treatment increase the number of people in the severe stage. For instance, even though (as shown in Figure 5) the *proportion* of people age 65 and older with Alzheimer's who are in the severe stage would be almost the same in 2050 with or without the treatment breakthrough (45 percent versus 48 percent), the *number* of people in the severe stage would be much smaller (3.5 million with the treatment breakthrough versus 6.5 million without it). This is because the treatment breakthrough would decrease the total number of people with Alzheimer's.

Figure 5:
Impact of a 5-Year Delay in Onset by Stage of Disease, Americans Age 65 and Older with Alzheimer's Disease, 2050

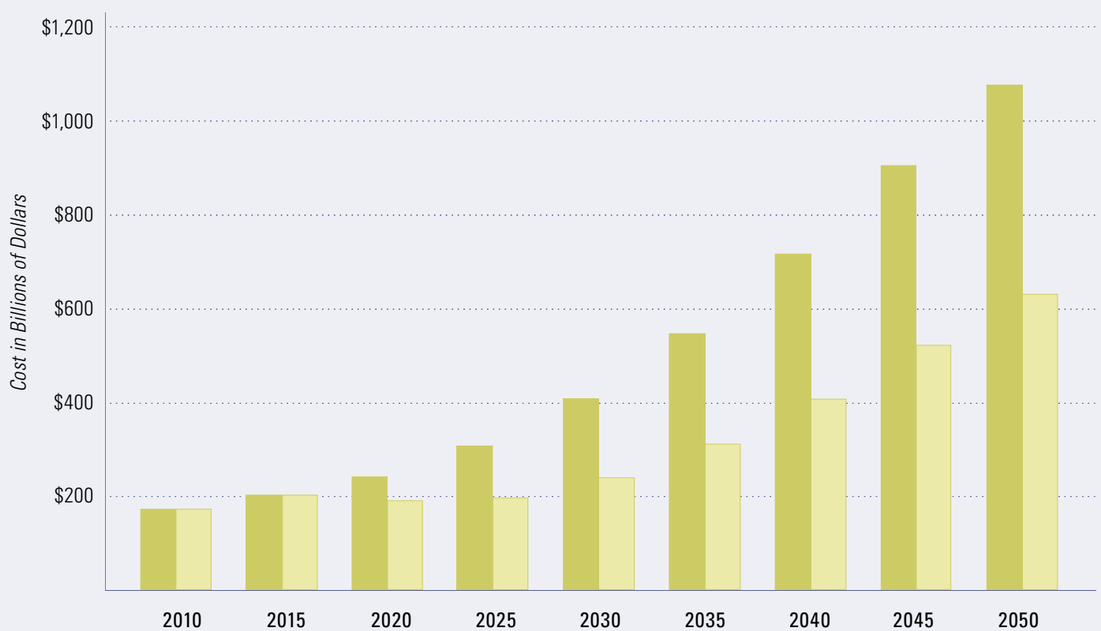


Costs of Care[6]

A treatment breakthrough that delayed the age of onset of Alzheimer's by five years would reduce total costs immediately. By 2020, five years after the introduction of the treatment in 2015, total costs to all payers for the care of people with the condition would be $50 billion less than would be expected without the breakthrough (see Fig. 6). By 2050, the reduction in total costs to all payers would be $447 billion; decreasing from an expected $1.078 trillion to $631 billion with the breakthrough.

Reductions in Medicare costs would account for almost half of the decrease in costs to all payers from a treatment breakthrough delaying the average age of onset of Alzheimer's by five years. In 2020, Medicare costs for the care of people with the condition would be reduced by $33 billion, from $128 billion to $95 billion. The cost reduction for Medicare in 2050 would be $283 billion, from $627 billion to $344 billion (see Fig. 7).

Figure 6:
Impact of a 5-Year Delay in Onset on Costs, Americans Age 65 and Older with Alzheimer's Disease, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Current Trajectory	$172	$202	$240	$307	$408	$547	$717	$906	$1,078
Delayed Onset	$172	$202	$190	$196	$239	$311	$407	$522	$631
Reduced Cost	$0	$0	$50	$111	$170	$236	$310	$384	$447

[6] All cost figures are reported in constant, 2010 dollars and do not include inflation. Costs of care include the same categories of costs for medical care, nursing home and other residential care, paid in-home and community-based services, and medications that were included in the current trajectory costs.

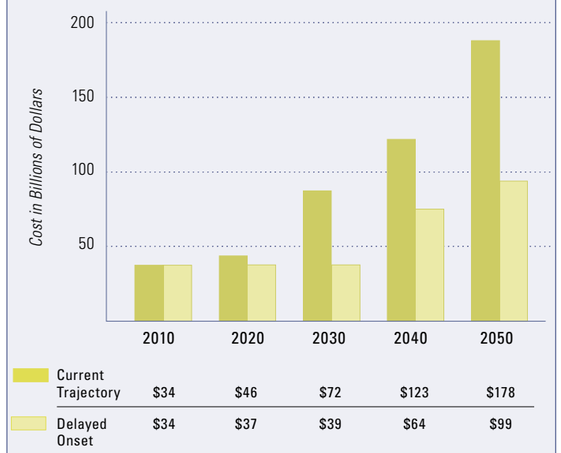
In 2020, Medicaid costs for the care of people with Alzheimer's would be reduced from the expected $46 billion to $37 billion for a savings of $9 billion. In 2050, Medicaid costs would be reduced from $178 billion to $99 billion for a savings of $79 billion (see Fig. 8).

Out-of-pocket costs to people with Alzheimer's and their families would be reduced from $40 billion to $30 billion in 2020 for a savings of $10 billion. In 2050, out of pocket costs would be reduced from $157 billion to $87 billion for a savings of $70 billion (see Fig. 9).

Costs to other payers would also be reduced, from $28 billion to $21 billion in 2020, and from $117 billion to $64 billion in 2050.

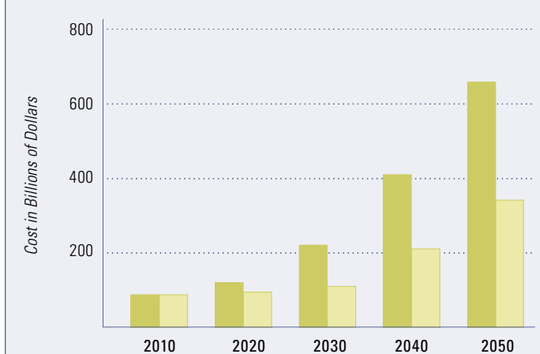
The costs in this section do not include the costs of the hypothetical treatment to delay onset. This is because the possible treatments range so widely in cost, from a relatively low cost treatment, such as a change in diet or exercise, to a relatively high cost treatment, such as a medication or a cocktail of medications that would be taken several times a day. Treatment costs would also be affected by additional factors, such as length of treatment, number of individuals requiring treatment and any related government policy changes.

Figure 8:
Medicaid Costs, 5-Year Delayed Onset



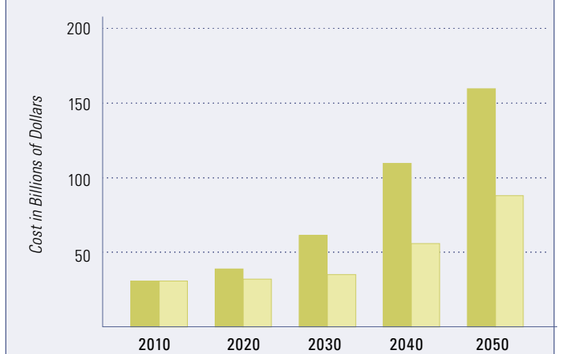
	2010	2020	2030	2040	2050
Current Trajectory	$34	$46	$72	$123	$178
Delayed Onset	$34	$37	$39	$64	$99

Figure 7:
Medicare Costs, 5-Year Delayed Onset



	2010	2020	2030	2040	2050
Current Trajectory	$88	$128	$225	$406	$627
Delayed Onset	$88	$95	$118	$212	$344

Figure 9:
Out-of-Pocket Costs, 5-Year Delayed Onset



	2010	2020	2030	2040	2050
Current Trajectory	$30	$40	$63	$108	$157
Delayed Onset	$30	$30	$34	$58	$87

Impact of a Hypothetical Treatment Breakthrough That Slowed Progression

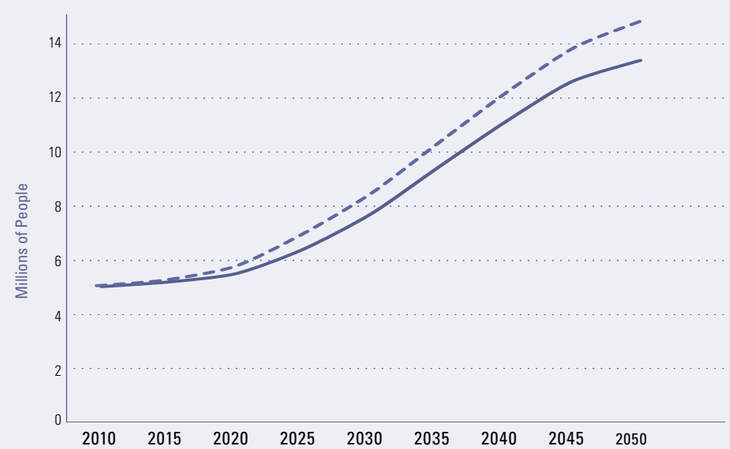
A treatment breakthrough that slowed the progression of Alzheimer's disease would result in more people with the condition in 2050 than would be expected without such a breakthrough because more people would be living longer with the disease. A larger segment would be in the mild stage and the costs of their care would be substantially reduced for all payers. The hypothetical treatment might be a medication or cocktail of medications that would be taken one or more times a day or a change in diet, exercise or other lifestyle behaviors. With the hypothetical treatment breakthrough described in this section, people would still develop Alzheimer's, but on average they would remain in the mild stage five times longer than they do now. Once they transitioned to the moderate stage, they would remain in that stage about five times longer than they do now. In the following text and graphs, it is assumed that the hypothetical treatment would become available in 2015 and begin to show its effects gradually starting in that year.

Number of Americans with Alzheimer's Disease [7]

A treatment breakthrough to slow the progression of Alzheimer's disease, as described above, would begin to show its effects in 2015, increasing the number of Americans age 65 and older with Alzheimer's from 5.6 million to 5.8 million in 2020. As shown in Figure 10, 15 million Americans age 65 and older would have Alzheimer's in 2050, as compared with 13.5 million who would be expected to have the condition without the treatment breakthrough.

This hypothetical treatment breakthrough would increase the proportion of Americans age 65 and older who have the condition from 10 percent to 11 percent in 2020, and from 16 percent to 18 percent in 2050.

Figure 10:
Impact of Slowed Progression on Alzheimer's Disease Growth, Americans Age 65 and Older with Alzheimer's, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Current Trajectory	5.1	5.3	5.6	6.5	7.8	9.5	11.2	12.7	13.5
Slowed Progression	5.1	5.3	5.8	7.0	8.5	10.4	12.3	14.0	15.0

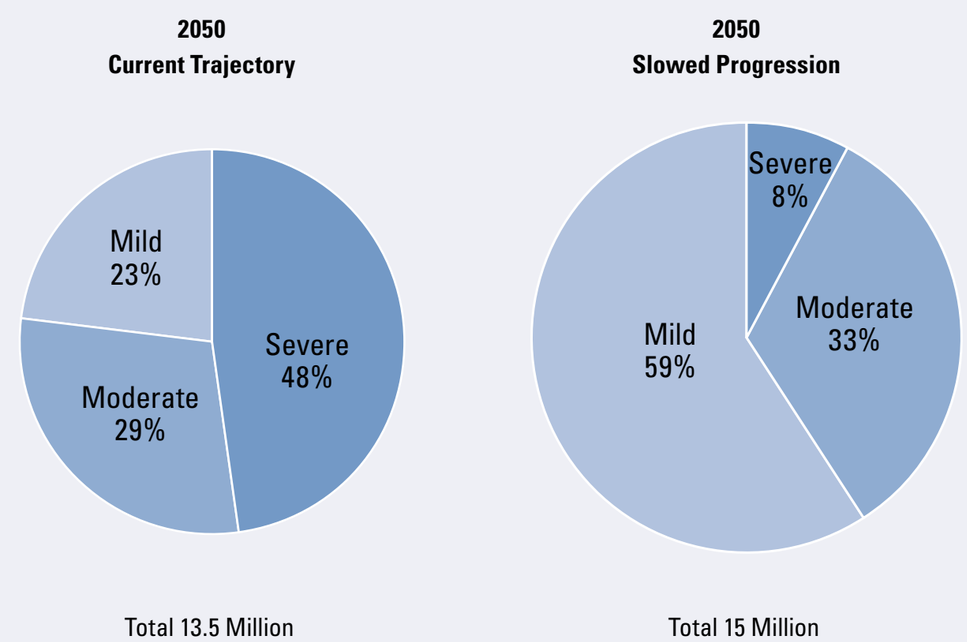
[7] The numbers below include only Americans age 65 and older because the data needed to project the number of people under age 65 with Alzheimer's disease in future years is not available.

Stage of Disease

Although a treatment breakthrough that slowed the progression of Alzheimer's disease would increase the total number of Americans age 65 and older with the condition, it would also greatly decrease the number and proportion of those with the condition who were in the severe stage. In 2020, the number of people with the condition who were in the severe stage would drop from 2.4 million to 1.1 million and the proportion would drop from 42 percent to 18 percent. Figure 11 shows the results for 2050, when only 8 percent of people with Alzheimer's disease would be in the severe stage, compared with the 48 percent that would have been in the severe stage without the treatment breakthrough. The number in the severe stage in 2050 would drop from an expected 6.5 million to 1.2 million.

Conversely, in 2020, the number of Americans age 65 and older with Alzheimer's who were in the mild stage would increase from 1.6 million to 3.3 million and the proportion of those in the mild stage would double from 28 percent to 56 percent. In 2050, 59 percent of people with Alzheimer's would be in the mild stage, compared with the 23 percent that would have been in the mild stage without the treatment breakthrough (see Fig. 11). In 2050, the number in the mild stage would increase from the expected 3.1 million to 8.9 million.

Figure 11:
Impact of Slowed Progression by Stage of Disease, Americans Age 65 and Older with Alzheimer's Disease, 2050

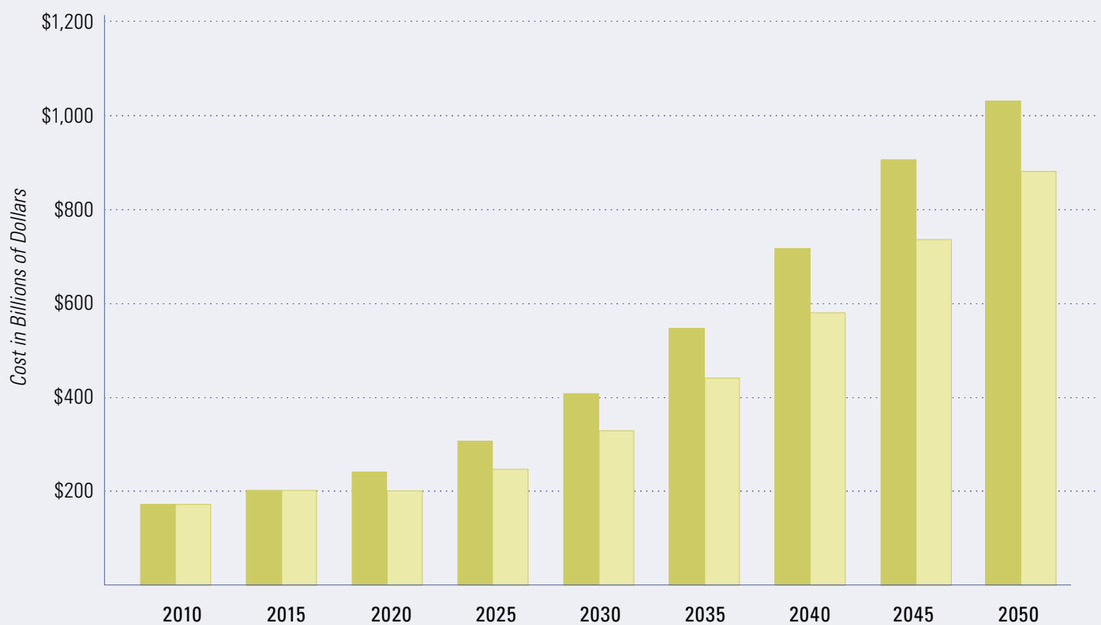


Costs of Care[8]

A treatment breakthrough that slowed the progression of Alzheimer's would reduce the costs to all payers of care for people with the condition from $241 billion to $201 billion in 2020 for a savings of $40 billion (see Fig. 12). By 2050, the reduction in total costs to all payers would be $197 billion ($881 billion versus the expected $1.078 trillion without the breakthrough).

In 2020, Medicare costs for the care of people with Alzheimer's disease would be reduced from the expected $128 billion to $108 billion for a savings of $20 billion. In 2050, Medicare costs would be reduced from the expected $627 billion to $509 billion for a savings of $118 billion (see Fig. 13).

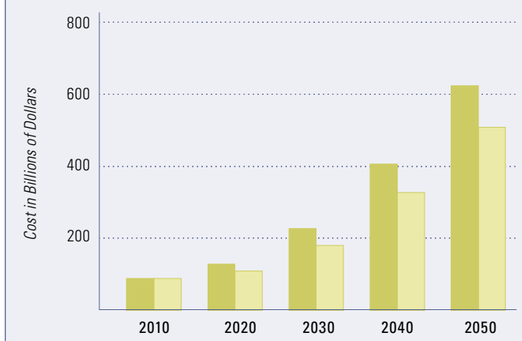
Figure 12:
Impact of a Slowed Progression on Costs, Americans Age 65 and Older with Alzheimer's Disease, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Current Trajectory	$172	$202	$241	$307	$408	$547	$717	$906	$1,078
Delayed Onset	$172	$202	$201	$247	$329	$441	$580	$736	$881
Reduced Cost	$0	$0	$40	$61	$79	$105	$136	$170	$197

[8] All cost figures are reported in constant, 2010 dollars and do not include inflation. Costs of care include the costs of medical care, nursing home and other residential care, and paid in-home and community-based services.

Figure 13:
Medicare Costs, Slowed Progression



	2010	2020	2030	2040	2050
Current Trajectory	$88	$128	$225	$406	$627
Slowed Progression	$88	$108	$181	$328	$509
Cost Savings	$0	$20	$44	$78	$118

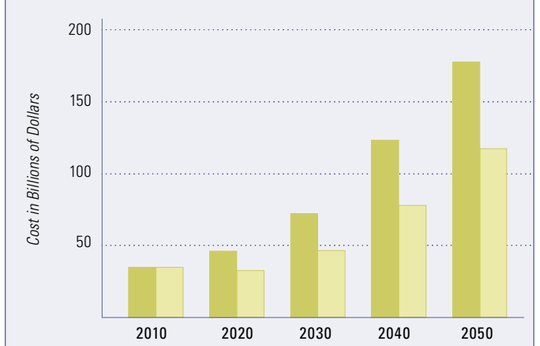
In 2020, Medicaid costs for the care of people with the condition would be reduced from the expected $46 billion to $32 billion for a savings of $14 billion. In 2050, Medicaid costs would be reduced from the expected $178 billion to $116 billion for a savings of $62 billion (see Fig. 14).

Out-of-pocket costs to people with Alzheimer's and their families would be reduced from the expected $40 billion to $32 billion in 2020 for a savings of $8 billion. In 2050, out-of-pocket costs would be reduced from the expected $157 billion to $132 billion for a savings of $25 billion (see Fig. 15).

Costs to other payers would not change in 2020 or 2025, but would begin to increase from $1 billion in 2030 to $6 billion in 2050.

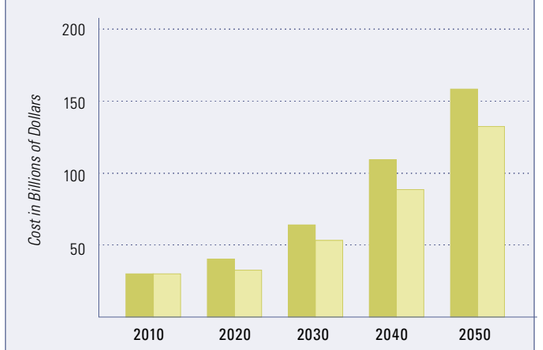
The costs in this section do not include the costs of the hypothetical treatment to delay onset. This is because possible treatments range so widely in cost, from a relatively low cost treatment, such as a change in diet or exercise, to a relatively high cost treatment, such as a medication or a cocktail of medications that would be taken several times a day. It is also unclear how many people would need the treatment and for how long.

Figure 14:
Medicaid Costs, Slowed Progression



	2010	2020	2030	2040	2050
Current Trajectory	$34	$46	$72	$123	$178
Slowed Progression	$34	$32	$46	$77	$116
Cost Savings	$0	$14	$26	$46	$62

Figure 15:
Out-of-Pocket Costs, Slowed Progression

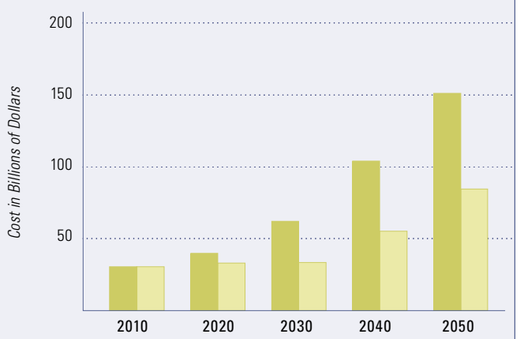


	2010	2020	2030	2040	2050
Current Trajectory	$30	$40	$63	$108	$157
Slowed Progression	$30	$32	$53	$89	$132
Cost Savings	$0	$8	$10	$18	$25

A Closer Look: Medicaid Costs for Nursing Home Care[9]

About half of all nursing home residents in the United States are people with Alzheimer's disease, and about half of nursing home residents with Alzheimer's rely on Medicaid to help pay for their nursing home care. As a result, Medicaid costs for nursing home care for people with the condition are substantial. In 2010 Medicaid costs for nursing home care for people with Alzheimer's will be $30 billion. Without a treatment breakthrough, these costs will increase to $150 billion in 2050 (see Fig. 16).

Figure 16:
Medicaid Nursing Home Costs, Delayed Onset



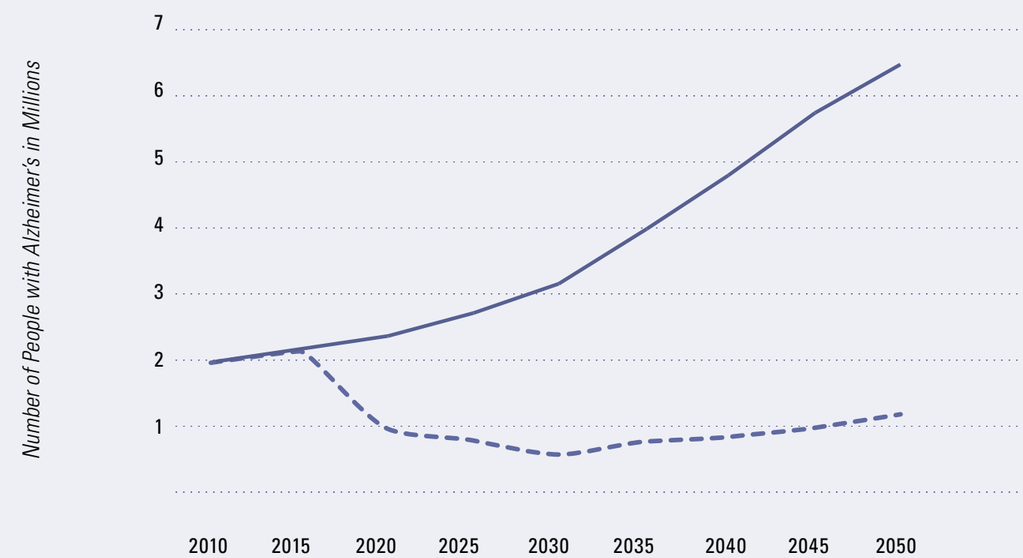
	2010	2020	2030	2040	2050
Current Trajectory	$30	$40	$62	$104	$150
Delayed Onset	$30	$32	$33	$55	$84
Cost Savings	$0	$8	$29	$49	$66

The federal government and state governments share Medicaid costs, including Medicaid costs for nursing home care. The federal share of Medicaid costs for nursing home care for people with Alzheimer's will be $17 billion in 2010 and $85 billion in 2050. The state share of Medicaid costs for nursing home care for people with the condition will be $14 billion 2010 and $67 billion in 2050.

People with Alzheimer's disease are most likely to use nursing home care when they are in the severe stage of their condition. This is not always true since some people with Alzheimer's who are in the mild or moderate stage need nursing home care because they have other serious medical conditions. Nevertheless, nursing home residents with Alzheimer's are most likely to be in the severe stage, and it is reasonable to expect that a reduction in the total number of people with the condition who are in the severe stage would result in costs savings for Medicaid.

[9] These Medicaid costs are included in the total costs and Medicaid costs cited previously in this report. They are pulled out and discussed separately in this section because of the importance of Medicaid costs for nursing home care, particularly for state governments.

Figure 17:
Impact of Slowed Progression on Severe Stage, Americans Age 65 and Older with Alzheimer's, 2010–2050



	2010	2015	2020	2025	2030	2035	2040	2045	2050
Current Trajectory	2.0	2.2	2.4	2.7	3.2	4.0	4.9	5.8	6.5
Delayed Progression	2.0	2.2	1.1	0.7	0.6	0.7	0.8	1.0	1.2
Decrease	0.0	0.0	1.3	2.0	2.6	3.3	4.1	4.8	5.3

Figure 17 shows the reduction in the total number of people with Alzheimer's who would be in the severe stage from 2015 to 2050, assuming a treatment breakthrough that slows the progression of the condition. With a treatment breakthrough, the number of people with Alzheimer's would be reduced from 2.4 million to 1.1 million in 2020 and from 6.5 million to 1.2 million in 2050.[10] A treatment breakthrough that delayed the onset of Alzheimer's who were in the severe stage from 2.4 million to 1.1 million in 2020 and from 6.5 million to 1.2 million in 2050.[11] Thus, both hypothetical treatment breakthroughs described in this report would reduce the total number of people with Alzheimer's who are in the severe stage and would be expected to result in cost savings for Medicaid.

[10] The impact of this reduction in 2050 was illustrated earlier in terms of the percentage of all people with the condition who would be in the severe stage (See Fig. 11).

[11] The impact of this reduction in 2050 was illustrated earlier in terms of the percentage of all people with the condition who would be in the severe stage (See Fig. 5).

Figures 16 and 18 confirm this expectation based on the Lewin Group model. As shown in Figure 16, a treatment breakthrough that delayed the onset of Alzheimer's disease by five years would reduce Medicaid costs for nursing home care of people with the condition by 20 percent in 2020, from the expected $40 billion to $32 billion, resulting in $8 billion in savings for Medicaid. In 2050, Medicaid costs for nursing home care of people with Alzheimer's would decrease by 44 percent, from the expected $150 billion to $84 billion, resulting in $66 billion in savings for Medicaid. The federal share of these costs would be 18 percent lower than expected in 2020 ($18 billion versus $22 billion) and 44 percent lower than expected in 2050 ($47 billion versus $84 billion). State Medicaid costs would be 22 percent lower than expected in 2020 ($14 billion versus $18 billion) and 44 percent lower than expected in 2050 ($37 billion versus $66 billion).

Figure 18 shows that a treatment breakthrough that slowed progression of Alzheimer's disease would also result in savings for Medicaid. Such a treatment breakthrough would reduce Medicaid costs for nursing home care of people with the condition by 35 percent in 2020, from the expected $40 billion to $26 billion, resulting in $14 billion in savings for Medicaid. In 2050, Medicaid costs for nursing home care of people with Alzheimer's would be reduced by 43 percent, from the expected $150 billion to $86 billion, resulting in $64 billion in savings for Medicaid. The federal share of these costs would be 32 percent lower than expected in 2020 ($15 billion versus $22 billion), and 43 percent lower than expected in 2050 ($48 billion versus $84 billion). The state share of Medicaid costs for nursing home care of people with Alzheimer's would be 39 percent lower than expected in 2020 ($11 billion versus $18 billion) and 42 percent lower than expected in 2050 ($38 billion versus $66 billion).

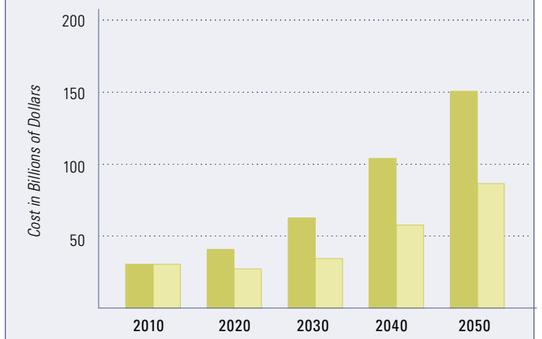
Although this section has focused on Medicaid costs for nursing home care of people with Alzheimer's disease, it should be noted that a treatment breakthrough that delayed the onset or slowed the progression of the condition would also reduce nursing home costs for other payers, including Medicare, individuals with the condition and their families, and other payers.

- Medicare costs: A treatment breakthrough that delayed the onset of Alzheimer's by five years would reduce Medicare costs for nursing home care of people with Alzheimer's in 2050 from the expected $53 billion to $29 billion, resulting in $24 billion in Medicare savings in that year; likewise, a treatment breakthrough that slowed progression would reduce Medicare costs for nursing home care of people with the condition in 2050 from the expected $53 billion to $30 billion, resulting in $23 billion in Medicare savings.

- Out-of-pocket costs: A treatment breakthrough that delayed the onset of Alzheimer's by five years would reduce out-of-pocket costs paid for nursing home care by people with the condition and their families in 2050 from the expected $76 billion to $42 billion, resulting in $34 billion in savings in that year; a treatment breakthrough that slowed progression would reduce out-of-pocket costs for nursing home care for people with the condition in 2050 by the same amount, from the expected $76 billion to $42 billion, resulting in $34 billion in savings in out-of-pocket costs for people with the condition and their families.

- Costs to other payers: A treatment breakthrough that delayed the onset of Alzheimer's by five years would reduce the costs to other payers for nursing home care of people with Alzheimer's in 2050 from the expected $9 billion to $5 billion, resulting in $4 billion in savings for other payers in that year; a treatment breakthrough that slowed progression would reduce costs to other payers for nursing home care of people with the condition in 2050 by the same amount, from the expected $9 billion to $5 billion, resulting in $4 billion in savings for other payers.

Figure 18:
Medicaid Nursing Home Costs, Slowed Progression



	2010	2020	2030	2040	2050
Current Trajectory	$30	$40	$62	$104	$150
Slowed Progression	$30	$26	$34	$57	$86
Cost Savings	$0	$14	$28	$47	$64

Conclusion

This report describes the current trajectory of Alzheimer's disease and its projected impact, and contrasts this baseline with the impact of the condition under two hypothetical treatment scenarios.

Both of the hypothetical treatments described in this report would result in substantial positive outcomes for people with Alzheimer's, and for the nation as a whole, even if the outcomes are well short of a cure.

In fact, these scenarios are similar in assumptions and results as to what has already been achieved in other diseases and conditions, including heart disease, stroke, some cancers and HIV/AIDS, where there has been a substantial and sustained societal commitment to overcome these diseases. A similar commitment to overcome Alzheimer's could reduce the devastating impact of the condition and significantly decrease the expected costs of caring for those with them.

Appendices

The appendices include a detailed description of the model developed for the Alzheimer's Association by the Lewin Group and detailed tables showing baseline data and changes that would result from the two hypothetical treatment breakthroughs.

These appendices, along with a copy of this report, can be found on the Association's Web site at: www.alz.org/trajectory.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.

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