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Featured Articles

2008 Alzheimer's disease facts and figures

Alzheimer's Association*

Abstract Alzheimer's disease is the seventh leading cause of all deaths in the United States and the fifth leading cause of death in Americans older than the age of 65 years. More than 5 million Americans are estimated to have Alzheimer's disease. Every 71 seconds someone in America develops Alzheimer's disease; by 2050 it is expected to occur every 33 seconds. During the coming decades, baby boomers are projected to add 10 million people to these numbers. By 2050, the incidence of Alzheimer's disease is expected to approach nearly a million people per year, with a total estimated prevalence of 11 to 16 million persons. Significant cost implications related to Alzheimer's disease and other dementias include an estimated $148 billion annually in direct (Medicare/Medicaid) and indirect (eg, caregiver lost wages and out-of-pocket expenses, decreased business productivity) costs. Not included in these figures are the estimated 10 million caregivers who annually provide $89 billion in unpaid services to individuals with Alzheimer's disease. This report provides information to increase understanding of the public health impact of Alzheimer's disease, including incidence and prevalence, mortality, lifetime risks, costs, and impact on family caregivers.

Keywords: Alzheimer's disease; Incidence; Prevalence; Mortality; Lifetime risks; Caregivers; Health care costs; Direct costs; Indirect costs

1. About this report

The 2008 *Alzheimer's Disease Facts and Figures* report is a comprehensive statistical abstract of U.S. data on Alzheimer's disease, the most common type of dementia. To provide background and context for interpreting the data, the next section, Overview of Alzheimer's disease, defines dementia, summarizes current knowledge about Alzheimer's disease, and briefly explains other specific types of dementia. The following sections address prevalence, family caregiving, use and costs of care, mortality, and lifetime risk of Alzheimer's disease.

Statistical benchmarks documented in *Alzheimer's Disease Facts and Figures* include the following:

- Overall number of Americans with Alzheimer's disease nationally and for each state
- Proportion of women and men with Alzheimer's and other dementias
- Projections of the future growth of 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
- Impact on Medicare, Medicaid, U.S. businesses, and individuals and their families
- Number of deaths due to Alzheimer's disease nationally and for each state, and death rates by age, gender, and ethnicity
- Remaining lifetime risk for developing Alzheimer's disease and other dementias at age 55

The sources and methods used to derive these figures are presented in the Appendices. References for specific facts and figures are listed in the Reference section.

Many of the research studies and surveys included in the report do not differentiate between Alzheimer's disease and other dementias. As a result, the report frequently cites statistics that apply broadly to individuals with all types of

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Table 1
Common types of dementia and their typical characteristics

Type of dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for 60% to 80% of cases. Difficulty remembering names and recent events is often an early clinical symptom; later symptoms include impaired judgment, disorientation, confusion, behavior changes, and trouble 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 might not be as seriously affected.
Mixed dementia	Characterized by the presence of 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, frontotemporal dementia, and normal pressure hydrocephalus.
Dementia with Lewy bodies	Pattern of decline might be similar to Alzheimer's, including problems with memory, judgment, and behavior changes. Alertness and severity of cognitive symptoms might 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 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 urine. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

dementia. In these cases, the reference is to "Alzheimer's disease and other dementias."

2. 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, risk factors for, and treatment of Alzheimer's disease. More detailed information on these topics is available at www.alz.org.

2.1. Dementia: definition and specific types

Dementia is a clinical syndrome of loss 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 syndrome must meet the following criteria:

- It must include decline in memory and in at least one of the following cognitive abilities:
  (1) Ability to generate coherent speech and 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 microscopic 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.

Mild cognitive impairment 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 tests but not severe enough to interfere with daily life. Some people with mild cognitive impairment go on to develop dementia. For others, the symptoms of mild cognitive impairment do not progress to dementia, and some people who have mild

cognitive impairment at one point in time later revert to normal cognitive status.

2.2. 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. In a brain with advanced Alzheimer's, there is dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

Scientists do not yet fully understand the processes resulting in the catastrophic brain damage associated with Alzheimer's disease. According to a leading theory called the amyloid hypothesis, the prime suspect is a tiny protein fragment called beta-amyloid. Trouble begins when yet-to-be-identified factors trigger overproduction of beta-amyloid or reduce the brain's ability to dispose of it. The excess jams signaling at the synapses, blocking information flow and leading to a cascade of damaging events ending in cell death.

Beta-amyloid fragments gradually accumulate into the microscopic plaques considered to be one pathologic hallmark of Alzheimer's. The other hallmark is tangles, formed when a different protein called tau twists into strands inside dead and dying neurons. Other abnormalities seen in Alzheimer's brain tissue include inflammation and oxidative damage due to highly reactive oxygen-containing products of cellular metabolism.

2.3. 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 also experience confusion, disorganized thinking, impaired judgment, trouble expressing themselves, and disorientation to time, space, and location, which might lead to unsafe wandering and socially inappropriate behavior. 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. Alzheimer's disease is ultimately fatal.

Although families generally prefer to keep the person with Alzheimer's at home as long as possible, most people with the disease eventually need more assistance than families can provide, and they move into a nursing home or other residential care facility.

2.4. Risk factors for Alzheimer's disease

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

The greatest risk factor for Alzheimer's disease is advancing age. Most Americans with Alzheimer's disease are age 65 or older, although individuals younger than 65 can also develop the disease.

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

A small percentage of Alzheimer's disease, probably less than 5%, is caused by rare genetic variations found in a small number of families worldwide. 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 Alzheimer's disease that develops after age 65 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, but there is still no certainty that they will develop Alzheimer's.

2.5. Treatment and prevention of Alzheimer's disease

No treatment is available to delay or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration has so far approved five drugs that temporarily slow worsening of symptoms for about 6 to 12 months, on average, for about half of the individuals who take them. On the basis of deepening insight into the underlying biology of Alzheimer's and emerging conceptual frameworks for understanding the disease, researchers have identified several new treatment strategies that might have the potential to change its course. A number of experimental therapies based on the amyloid hypothesis and other targets have reached various stages of 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. Ac-

tive management includes appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan, and utilization of supportive services such as counseling, activity and support groups, and adult day programs.

Many scientists consider the emerging field of prevention one of the most exciting recent developments in the dementia research arena. 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, and overweight, might help avoid or delay cognitive decline. Additional evidence points to a significant role for regular physical exercise in maintaining lifelong cognitive health. More limited data suggest that a low-fat diet rich in fruits and vegetables might support brain health, as might a robust social network and a lifetime of intellectual curiosity and mental stimulation.

3. Prevalence

Millions of Americans now have Alzheimer's disease or other dementias. More women than men have Alzheimer's and other dementias, primarily because women live longer, on average, than men, and their longer life expectancy increases the time during which they could develop Alzheimer's or other dementias. The prevalence of Alzheimer's and other dementias also differs for people with fewer versus more years of education and for African Americans versus whites.

The number of Americans with Alzheimer's and other dementias is increasing every year because of the steady growth in the older population. The number will continue to increase and escalate rapidly in the coming years as the baby boom generation ages.

Figures 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, years of education, race, and cause of dementia. Data sources and methodology are described in the Appendices and References. Lifetime risk of Alzheimer's disease and other dementias is discussed in a special report beginning on page 127.

3.1. Prevalence of Alzheimer's disease and other dementias

An estimated 5.2 million Americans of all ages have Alzheimer's disease in 2008. This figure includes 5 million people age 65 and older (Appendix 1) and 200,000 individuals younger than 65 who have young-onset Alzheimer's (Appendix 2). The Alzheimer's Association estimates that there are approximately 500,000 Americans younger than age 65 who have Alzheimer's or another dementia, and about 40% of them have Alzheimer's disease.

- One in eight persons age 65 and older (13%) has Alzheimer's disease (Appendix 3).
- Every 71 seconds, someone in America develops Alzheimer's disease. By mid-century, someone will develop Alzheimer's every 33 seconds (Appendix 4).

(In late 2007, findings on the prevalence of Alzheimer's disease and other dementias from the Aging, Demographics, and Memory Study [ADAMS] were published. See Appendix 5 for further information about this study.)

3.2. Prevalence of Alzheimer's disease and dementia in women and men

Women are more likely than men to have Alzheimer's disease and dementia. Fourteen percent of all people age 71 and older have dementia [1]. As shown in Fig. 1, this includes 16% of women and 11% of men in that age group. This difference amounts to more than 1.4 million people age 71 and older in 2008 (2.4 million women compared with about 1 million men).

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 [1]. Likewise, many studies of the age-specific incidence (new cases) of dementia have found no significant difference by gender [2–6].

The same is true for Alzheimer's disease. The larger proportion of older women than men who have Alzheimer's disease is primarily explained by the fact that women live longer [1]. Again, many studies of the age-specific inci-

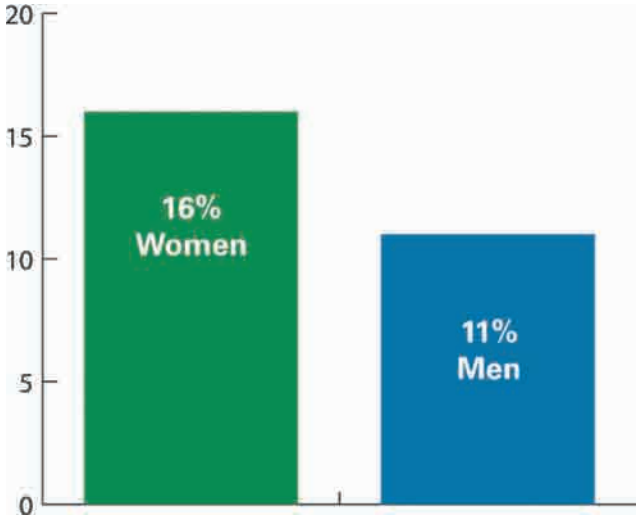

Fig. 1. Percentage of people age 71+ with dementia by gender, ADAMS, 2002. Figure created from data from Plassman, BL; Langa, KM; Fisher, GG; Heeringa, SG; Weir, DR; Ofstedal, MB; et al. "Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study." *Neuroepidemiology* 2007;29:125-32.

dence of Alzheimer's disease show no significant difference for women and men [2,5–10]. Thus, it appears that female gender is not a risk factor for Alzheimer's disease or dementia once age is taken into account. Essentially, women are more likely to have Alzheimer's disease and other dementias because they live long enough to develop these conditions.

3.3. Prevalence of Alzheimer's disease and dementia by years of education

People with fewer years of education are more likely than people with more years of education to have Alzheimer's disease and dementia. Studies of the prevalence of dementia show that having fewer years of education is associated with greater likelihood of having dementia [1,11], and incidence studies show that having fewer years of education is associated with a greater risk of developing dementia [4,5,12]. One study found, for example, that people with less than 12 years of education had a 15% greater risk of developing dementia than people with 12 to 15 years of education and a 35% greater risk of developing dementia than people with more than 15 years of education [5].

The same is true for Alzheimer's disease. Studies of the prevalence of Alzheimer's disease show that having fewer years of education is associated with higher likelihood of having Alzheimer's disease [1,11], and incidence studies show that having fewer years of education is associated with greater risk of developing Alzheimer's disease [5,8,12,13].

Some researchers believe that having more years of education might provide "cognitive reserve" that either protects a person from Alzheimer's and other dementias or at least allows the person to compensate for a longer time before the symptoms of Alzheimer's and dementia are observable [11,12,14,15]. Other researchers point out that years of education might be a surrogate marker for factors that affect access to education in childhood, such as socioeconomic status and where one lived as a child [13,16]. Having fewer years of education is generally related to additional factors, such as lower levels of occupational attainment and higher prevalence of physical health conditions in adulthood, that are also associated with the development of dementia. Studies that have considered these additional factors have shown, however, that having fewer years of education is a risk factor for Alzheimer's and other dementias, even when these factors are taken into account [12–14,17].

3.4. Prevalence of Alzheimer's disease and dementia in African Americans and whites

African Americans are more likely than whites to have Alzheimer's disease and dementia, but further analyses of this relationship indicate that it is primarily explained by factors other than race. Most analyses that have combined age, gender, years of education, African American versus white race, and other factors show that African Americans do not have a statistically significant increased risk of dementia or that their increased risk in comparison with whites is greatly reduced once these factors are taken into account [1,3–5,11,18].

The same is true for Alzheimer's disease. Most analyses that have combined age, gender, years of education, African American versus white race, and *APOE* status (see the section on risk factors for Alzheimer's disease, page 112, for a brief discussion of *APOE*) have found that the higher prevalence of Alzheimer's disease in African Americans is primarily explained by these other factors or that their increased risk is greatly reduced once these factors are taken into account [1,3–5,8,11].

Years of education seems to be a particularly important factor in explaining why African Americans are more likely than whites to have Alzheimer's disease and dementia. In fact, one study that included only African Americans found that having fewer years of education was associated with increased likelihood of having Alzheimer's and dementia [14]. Some researchers point out that quality of education and socioeconomic factors that affect access to education are probably also important factors in explaining why African Americans are more likely than whites to have Alzheimer's and dementia [5,14,18,19].

3.5. Prevalence of Alzheimer's disease by state

The number of people with Alzheimer's disease varies greatly by state. Table 2 shows the estimated number of people age 65 and older with Alzheimer's disease for each state in 2000 and 2010, as well as the percentage change expected during this decade (Appendix 6). Similar data are not available on the prevalence of dementia by state.

The most important reason for the differences among states in estimated number of people with Alzheimer's disease is differences in the number of older people. In addition, within states' older populations, the proportion of people in the age group 80 and older that has the highest prevalence of Alzheimer's disease also affects the estimated number of people with the disease.

As shown in Table 2, the estimated number of people with Alzheimer's disease in 2000 varies from 3,400 in Alaska to 440,000 in California. The percentage change from 2000 to 2010 is greater in states that start with a lower estimated number of people with Alzheimer's disease. In Alaska, for example, the projected change from 2000 to 2010 is 47%, even though the estimated number of people with Alzheimer's disease only increases from 3,400 to 5,000 people in that period. In contrast, the projected change from 2000 to 2010 in California is 9%, despite an estimated increase from 440,000 to 480,000 people with Alzheimer's disease.

State-specific factors that are likely to increase the num-

Table 2
Number and percentage change in people age 65+ with Alzheimer's disease between 2000 and 2010, by state

State	No. of people with Alzheimer's in 2000	Estimated no. of people with Alzheimer's in 2010	Percentage change from 2000 to 2010
Alabama	84,000	91,000	8
Alaska	3,400	5,000	47
Arizona	78,000	97,000	24
Arkansas	56,000	60,000	7
California	440,000	480,000	9
Colorado	49,000	72,000	47
Connecticut	68,000	70,000	3
Delaware	12,000	14,000	17
District of Columbia	10,000	9,100	–9
Florida	360,000	450,000	25
Georgia	110,000	120,000	9
Hawaii	23,000	27,000	17
Idaho	19,000	26,000	37
Illinois	210,000	210,000	0
Indiana	100,000	120,000	20
Iowa	65,000	69,000	6
Kansas	50,000	53,000	6
Kentucky	74,000	80,000	8
Louisiana	73,000	83,000	14
Maine	25,000	25,000	0
Maryland	78,000	86,000	10
Massachusetts	120,000	120,000	0
Michigan	170,000	180,000	6
Minnesota	88,000	94,000	7
Mississippi	51,000	53,000	4
Missouri	110,000	110,000	0
Montana	16,000	21,000	31
Nebraska	33,000	37,000	12
Nevada	21,000	29,000	38
New Hampshire	19,000	22,000	16
New Jersey	150,000	150,000	0
New Mexico	27,000	31,000	15
New York	330,000	320,000	–3
North Carolina	130,000	170,000	31
North Dakota	16,000	18,000	13
Ohio	200,000	230,000	15
Oklahoma	62,000	74,000	19
Oregon	57,000	76,000	33
Pennsylvania	280,000	280,000	0
Rhode Island	24,000	24,000	0
South Carolina	67,000	80,000	19
South Dakota	17,000	19,000	12
Tennessee	100,000	120,000	20
Texas	270,000	340,000	26
Utah	22,000	32,000	45
Vermont	10,000	11,000	10
Virginia	100,000	130,000	30
Washington	83,000	110,000	33
West Virginia	40,000	44,000	10
Wisconsin	100,000	110,000	10
Wyoming	7,000	10,000	43

Reprinted from online material by Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. State-specific projections through 2025 of Alzheimer disease prevalence. Neurology 2004;62:1645.

ber of people with Alzheimer's disease in the future include growth in the state's older population, especially the population age 80 and older, and reduced mortality from other causes. States that experience an increase in average years of education in the future might see a slower increase in the total number of people with Alzheimer's disease because having more years of education is associated with decreased risk of the disease.

3.6. Causes of dementia

Alzheimer's disease is the most frequent cause of dementia. As shown in Fig. 2, Alzheimer's accounts for 70% of all cases of dementia in Americans age 71 and older [1]. Vascular dementia accounts for 17% of cases of dementia, and other diseases and conditions, including Parkinson's disease, Lewy body disease, frontotemporal dementia, and normal pressure hydrocephalus, account for the remaining 13%. (These data reflect the conclusions of an expert panel of physicians and psychologists about the primary cause of dementia in each subject found to have dementia in the ADAMS [1]. Some subjects were also given secondary diagnoses in recognition of the growing awareness that dementia is often associated with more than one disease or condition. See Table 1 in the section, Overview of Alzheimer's disease, for a brief explanation of "mixed dementia," that is, dementia with symptoms and brain abnormalities associated with two or more diseases and conditions, for example, Alzheimer's disease and vascular dementia.)

The proportion of dementia caused by Alzheimer's disease increases with age. In people age 90 and older, Alzheimer's disease accounts for 80% of all dementia, compared with 47% for people age 71 to 79 [1].

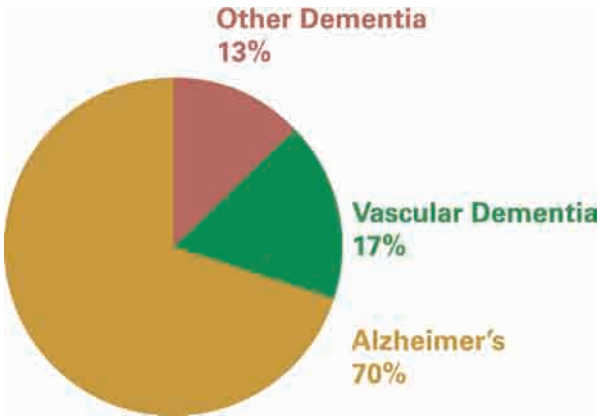

Fig. 2. Causes of dementia in people age 71+, ADAMS, 2002. Figure created from data from Plassman, BL; Langa, KM; Fisher, GG; Heeringa, SG; Weir, DR; Ofstedal, MB; et al. "Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study." *Neuroepidemiology* 2007;29:125-32.

3.7. Looking to the future

The number of Americans surviving into their 80s and 90s is expected to grow because of advances in medicine, medical technology, and social and environmental conditions. Because the incidence and prevalence of Alzheimer's disease and dementia increase with age, the number of people with these conditions will also grow rapidly.

- In 2000, there were an estimated 411,000 new cases of Alzheimer's disease. That number is expected to increase to 454,000 new cases a year by 2010, 615,000 new cases a year by 2030, and 959,000 new cases a year by 2050 [20].
- The number of people age 65 and older with Alzheimer's disease is estimated to reach 7.7 million in 2030, a greater than 50% increase from the 5 million age 65 and older who are currently affected [21].
- By 2050, the number of individuals age 65 and older with Alzheimer's could range from 11 million to 16 million unless science finds a way to prevent or effectively treat the disease. By that date, more than 60% of people with Alzheimer's disease will be age 85 or older [21].

4. Family caregiving

Almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia. These unpaid caregivers are primarily family members but also include friends and neighbors. In 2007, they provided 8.4 billion hours of unpaid care, a contribution to the nation valued at $89 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.

4.1. Number of caregivers

In 2007, 9.8 million family members, friends, and neighbors provided unpaid care for a person with Alzheimer's disease or another dementia (Appendix 7). Table 3 shows the number of family and other unpaid caregivers for the United States and each state. The number of caregivers by state ranges from about 14,000 in Alaska to 1.1 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, friend, or neighbor [22].

Many people with Alzheimer's or another dementia also have other serious medical conditions such as diabetes and congestive heart failure [23]. Their family and other unpaid caregivers often help to manage these conditions in addition to the person's Alzheimer's or other dementia. In all, 29% of all unpaid caregivers of older people in the United States are caring for a person with Alzheimer's or another dementia (Appendix 7).

Table 3
Number of Alzheimer's and dementia caregivers, hours of unpaid care, and economic value of the care by state, 2007

State	No. of Alzheimer's/ dementia caregivers	Hours of unpaid care per year	Economic value of unpaid care
United States	9,753,995	8,419,648,576	$89,079,881,929
Alabama	166,665	143,865,378	$1,522,095,700
Alaska	14,391	12,422,462	$131,429,647
Arizona	174,663	150,769,220	$1,595,138,351
Arkansas	110,789	95,633,442	$1,011,801,813
California	1,103,073	952,172,799	$10,073,988,212
Colorado	141,507	122,148,846	$1,292,334,794
Connecticut	112,782	97,353,432	$1,029,999,306
Delaware	29,245	25,244,341	$267,085,124
District of Columbia	16,653	14,374,638	$152,083,668
Florida	568,591	490,808,160	$5,192,750,333
Georgia	347,782	300,205,131	$3,176,170,284
Hawaii	30,380	26,223,828	$277,448,101
Idaho	46,222	39,898,964	$422,131,038
Illinois	347,136	299,647,682	$3,170,272,472
Indiana	209,767	181,070,551	$1,915,726,433
Iowa	95,733	82,636,586	$874,295,079
Kansas	83,841	72,371,874	$765,694,424
Kentucky	152,098	131,290,818	$1,389,056,858
Louisiana	156,569	135,150,133	$1,429,888,403
Maine	46,045	39,745,633	$420,508,797
Maryland	166,761	143,948,324	$1,522,973,268
Massachusetts	206,596	178,333,582	$1,886,769,293
Michigan	364,855	314,942,511	$3,332,091,763
Minnesota	174,700	150,800,808	$1,595,472,550
Mississippi	132,187	114,103,801	$1,207,218,215
Missouri	179,524	154,965,127	$1,639,531,039
Montana	32,975	28,464,272	$301,151,994
Nebraska	54,319	46,888,454	$496,079,839
Nevada	74,596	64,390,945	$681,256,200
New Hampshire	41,021	35,409,456	$374,632,043
New Jersey	289,983	250,313,426	$2,648,316,049
New Mexico	57,963	50,033,284	$529,352,141
New York	643,151	555,168,160	$5,873,679,133
North Carolina	311,578	268,953,971	$2,845,533,016
North Dakota	17,436	15,051,128	$159,240,931
Ohio	389,214	335,969,370	$3,554,555,932
Oklahoma	112,708	97,289,148	$1,029,319,184
Oregon	120,459	103,979,935	$1,100,107,711
Pennsylvania	430,794	371,861,053	$3,934,289,940
Rhode Island	35,397	30,554,564	$323,267,288
South Carolina	159,221	137,439,556	$1,454,110,507
South Dakota	26,940	23,254,275	$246,030,226
Tennessee	222,830	192,346,581	$2,035,026,828
Texas	746,713	644,562,329	$6,819,469,443
Utah	87,494	75,524,914	$799,053,589
Vermont	15,770	13,612,589	$144,021,192
Virginia	247,503	213,644,244	$2,260,356,101
Washington	178,787	154,328,964	$1,632,800,442
West Virginia	84,283	72,752,680	$769,732,359
Wisconsin	178,748	154,295,166	$1,632,442,856
Wyoming	15,561	13,432,044	$142,111,020

4.2. Hours of unpaid care

In 2007, the 9.8 million family and other unpaid caregivers of people with Alzheimer's and other dementias provided 8.4 billion hours of care. This number represents an average of 16.6 hours of care per caregiver per week or 863 hours of care per caregiver per year (Appendix 8). Table 3 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 31 million hours of unpaid care in 2007.

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. One study found that 23% of caregivers of people with Alzheimer's and other dementias provided more than 40 hours a week, compared with 16% of caregivers of other older people [22]. Another study found that 40% of caregivers of people with Alzheimer's and other dementias provided more than 40 hours a week of help, compared with 28% of caregivers of other older people [24].

The average number of hours of unpaid care provided for people with Alzheimer's and other dementias increases as the person's disease worsens [25]. 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 [25].

Some family and other unpaid caregivers who live with a person who has Alzheimer's or another 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 [26,27]. 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.

4.3. Economic value of caregiving

In 2007, the economic value of the care provided by family and other unpaid caregivers of people with Alzheimer's and other dementias was $89 billion. This number represents 8.4 billion hours of care valued at $10.58 per hour, which is the average of the minimum wage ($5.85 per hour) and the average wage of a home health care aide in July 2007 ($15.32 per hour) (Appendix 9). Table 3 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 31 states. Unpaid caregivers in California, Florida, New York, and Texas provided care valued at more than $4 billion.

4.4. Who are the caregivers?

Family and other unpaid caregivers of people with Alzheimer's and other dementias are more likely to be women than men. About 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives, friends, and neighbors [22,24,28]. The remaining 40% are husbands, sons, sons-in-law, grandsons, and other male relatives, friends, and neighbors.

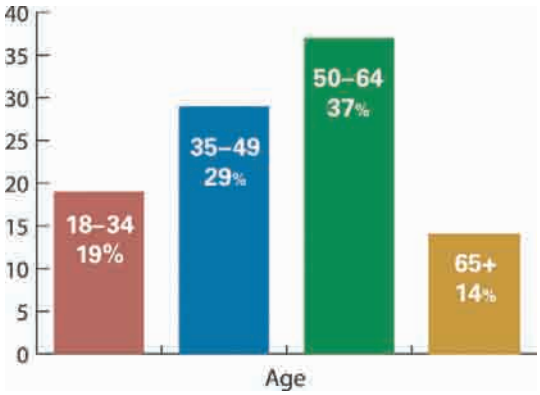

Fig. 3. Age of Alzheimer's and dementia caregivers, 2003. Figure created from data from Alzheimer's Association and National Alliance for Caregiving data. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

Caregivers range in age from very young to very old. As shown in Fig. 3, among caregivers age 18 and older, 19% were younger than 35, 29% were 35 to 49, 37% were 50 to 64, and 14% were age 65 and older [22]. Their average age was 48.

In addition, about 250,000 American children ages 8 to 18 are unpaid caregivers for a person with Alzheimer's or another dementia [29]. These children represent 18% of the 1.4 million American children ages 8 to 18 who provide unpaid help for any person. About two thirds of the 1.4 million children caregivers live in the same household as the person they are helping, usually a parent or grandparent, and more than half of children caregivers assist with bathing, dressing, feeding, and/or helping the person use the toilet [29].

4.5. Long-distance caregivers

Ten percent of the 9.8 million family and other unpaid caregivers of people with Alzheimer's and other dementias live more than 2 hours from the person for whom they provide care, and another 4% live 1 to 2 hours from the person [22]. Depending on the definition of long-distance caregiving, these numbers indicate that 980,000 to 1.4 million caregivers of people with Alzheimer's and other dementias are long-distance caregivers.

4.6. Caregiving tasks

The kinds of help provided by family and other unpaid caregivers depend on the needs of the person and change as the person's Alzheimer's or other dementia worsens. Caregiving tasks can include the following [22,24]:

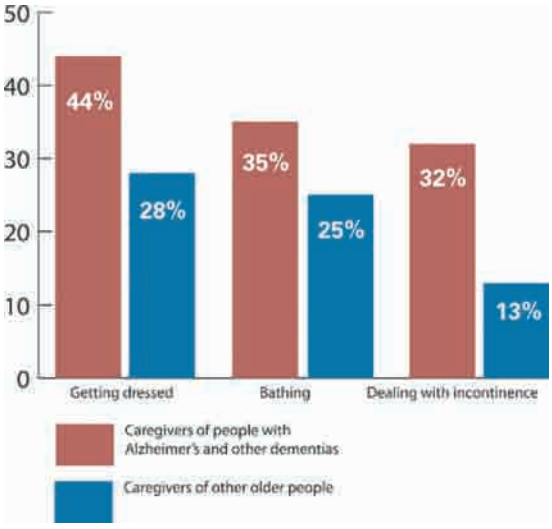

Fig. 4. Percentage of Alzheimer's and dementia caregivers compared with caregivers of other older people who provide help with specific daily tasks, 2003. Figure created from Alzheimer's Association and National Alliance for Caregiving data. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

- 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 unsafe activities, such as wandering and getting lost;
- Bathing, dressing, feeding, and helping the person use the toilet or providing incontinence care;
- Making arrangements for medical care and paid in-home, assisted living, or nursing home care; and
- Managing behavioral symptoms.

As shown in Fig. 4, 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 all kinds of personal care, for example, bathing the person (35% of Alzheimer and dementia caregivers versus 25% of other caregivers) and dealing with bladder and bowel incontinence (32% of Alzheimer's and dementia caregivers versus 13% of other caregivers) [22]. These tasks are often made more difficult by the confusion and disorientation of the person with dementia, who might be unable to cooperate and might even resist care.

When a person with Alzheimer's or another dementia moves to an assisted living residence 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 personal care needs [30,31].

4.7. Duration of caregiving

Because Alzheimer's and other dementias usually progress slowly, most caregivers spend many years in the caregiving role. At any one time, 32% of family and other unpaid caregivers of people with Alzheimer's and other dementias have been providing help for 5 years or longer, and 39% have been providing care for 1 to 4 years [22]. In contrast, 27% of caregivers of other older people have been providing help for 5 years or longer, and 32% have been providing care for 1 to 4 years. Fig. 5 shows the percentage of Alzheimer's and dementia caregivers compared with caregivers of other older people who have provided care for various lengths of time.

4.8. Impact of caregiving on the caregiver

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, ability to understand and communicate effectively, and, frequently, changes in personality and behavior. 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.

4.8.1. Impact on the caregiver's emotional well-being

Most family and other unpaid caregivers are proud of the help they provide, and some manage caregiving tasks with little difficulty [32,33]. Yet many caregivers experience high levels of stress and depression associated with caregiving.

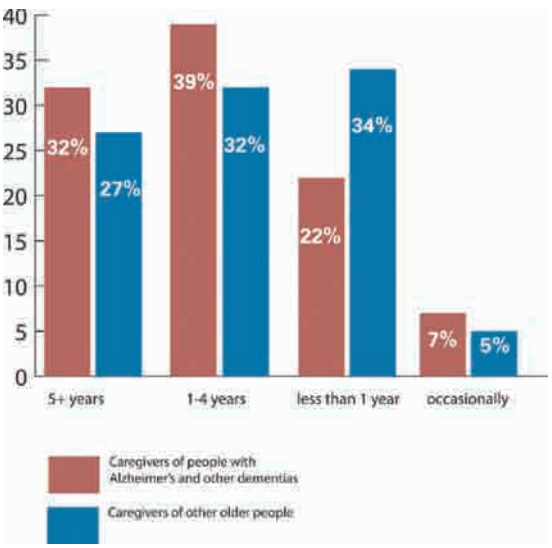

Fig. 5. Percentage of Alzheimer's and dementia caregivers compared with caregivers of other older people by duration of caregiving, 2003. Figure created from Alzheimer's Association and National Alliance for Caregiving data. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

- More than 40% 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 [22].
- About one third of family caregivers of people with Alzheimer's and other dementias have symptoms of depression [34].
- 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% felt that they were "on duty" 24 hours a day, and many felt that caregiving in this end-of-life period was extremely stressful [27]. The stress of caregiving was so great that 72% of the family caregivers said they experienced relief when the person died.
- Caregiver stress, especially stress related to the person's behavioral symptoms, is associated with nursing home placement [35,36]. One study found, however, that family caregiver stress and depression were just as high after the person was placed in a nursing home as before placement [30].

4.8.2. 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 noncaregivers to report that their health is fair or poor [37,38]. They are also more likely than unpaid caregivers of other older people to say that caregiving made their health worse [22,24].
- Family and other unpaid caregivers of people with Alzheimer's or another dementia are more likely than noncaregivers to have high levels of stress hormones [38–41], reduced immune function [38,42], slow wound healing [43], new hypertension [44], and new coronary heart disease [45].
- Family caregivers of people with Alzheimer's disease have significantly shorter telomeres, on average, than other people of the same age and gender [46]. (Telomeres are the genetic material at the end of chromosomes that promotes error-free cell division. Shortened telomeres are an indication of the body's aging processes.)
- One study of spouse caregivers of people hospitalized for various diseases and conditions found that caregivers of people hospitalized for dementia were more likely than caregivers of people hospitalized for other diseases and conditions to die in the following year [47]. (These findings were adjusted for the age of the spouse caregiver.) Among men, 9% died in the year after a wife's hospitalization for dementia, compared with 6% who died in the year after a wife's hospitalization for colon cancer and 7% who died in the year after a wife's hospitalization for stroke. Among women, 5% died in the year after a husband's hospitalization for dementia, compared with 3% who died in the year after a husband's hospitalization for colon cancer and 4% who died in the year after a husband's hospitalization for stroke.

4.8.3. 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.

- One study of family and other unpaid caregivers of people with Alzheimer's and other dementias found that 57% 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, 18% had to take a leave of absence, 13% had reduced their hours, and 8% had turned down promotions [22]. Eight percent of caregivers in the study had to quit work entirely because of caregiving.
- 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 dementias without behavioral symptoms were 31% more likely than caregivers of other older people to have reduced their hours or quit work [48]. Caregivers of people who had Alzheimer's or other dementias with behavioral symptoms were 68% more likely than caregivers of other older people to have reduced their hours or quit work.

4.8.4. Impact on the caregiver's income and financial security

Family and other unpaid caregivers who turn down promotions, reduce their work hours, and quit work 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. (See section on Use and costs of long-term care, page 122.) Some of this care is covered for some people by public programs and private insurance, but the person and family must pay out-of-pocket for much of the care.

- One study found that 49% 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 [22].
- Another study of family caregivers of people age 50 and older, including people with Alzheimer's and other dementias, found that long-distance caregivers had higher caregiving-related out-of-pocket expenditures than did other caregivers [49].

5. Use and costs of care

People with Alzheimer's disease and other dementias are high users of health care and long-term care services, and all people who have these conditions will eventually need end-of-life care unless they die suddenly of another cause. Almost all older people with Alzheimer's and other dementias have Medicare (Appendix 10), and their high use of hospital and other health care services translates into high costs for Medicare. Medicaid pays for nursing home and other long-term care services for some people with very low income and assets (Appendix 11), and high use of these services by people with Alzheimer's and other dementias translates into high costs for Medicaid. American business also incurs high indirect costs due to lost productivity, missed work, and replacement expenses for employees who are caring for a person with Alzheimer's or another dementia and have to reduce their hours, take time off, or quit work entirely because of the demands of caregiving.

The direct costs to Medicare and Medicaid for care for people with Alzheimer's and other dementias and the indirect costs to business for employees who are caregivers of persons with Alzheimer's and other dementias amount to more than $148 billion annually, including the following:

- $91 billion in Medicare costs for care of beneficiaries with Alzheimer's and other dementias in 2005; this figure is projected to increase to $160 billion by 2010 and $189 billion by 2015 [50].
- $21 billion in state and federal Medicaid costs for nursing home care for people with Alzheimer's and other dementias in 2005; this figure is projected to increase to $24 billion in 2010 and $27 billion in 2015 [50].
- $36.5 billion in indirect costs to business for employees who are caregivers of people with Alzheimer's and other dementias [51] (Appendix 12).

The $148 billion does not include the costs of care for people with Alzheimer's and other dementias that are paid by the U.S. Department of Veterans Affairs, private health care and long-term care insurance, and other public and private payers. It also does not include the high out-of-pocket expenditures for people with Alzheimer's and other dementias and their families for health care, long-term care, and end-of-life care services that are not covered by Medicare, Medicaid, and other public and private payers. All of these costs will continue to rise each year as the number of people with Alzheimer's and other dementias grows with the aging of our population.

5.1. Use and costs of health care

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 more than three times higher than other Medicare beneficiaries. Use and costs of health care services for people with Alzheimer's and other dementias are strongly related to coexisting medical conditions, that is, people with other serious medical conditions, such as diabetes and congestive heart failure, who also have Alzheimer's or other dementias have much higher use and costs of health care services than people with these other medical conditions but no Alzheimer's or dementia.

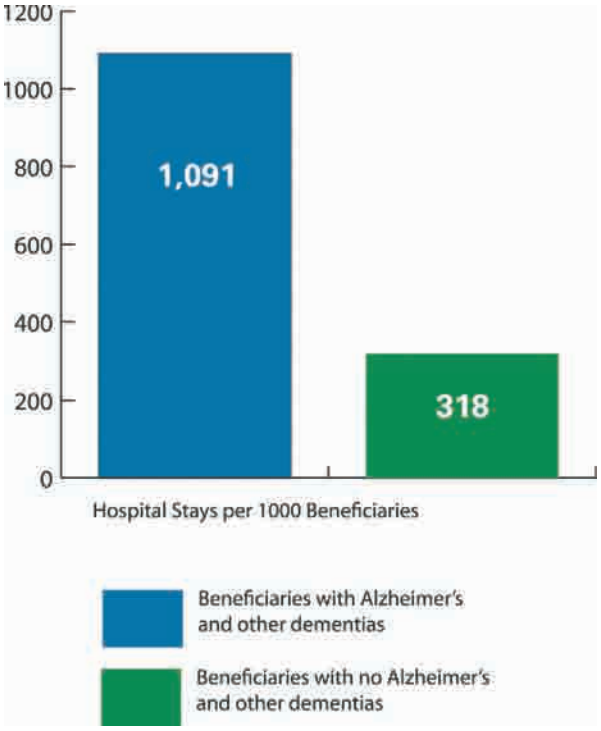

Fig. 6. Hospital stays per 1,000 Medicare beneficiaries age 65+ for beneficiaries with Alzheimer's disease and other dementias compared with other Medicare beneficiaries, 2000. Figure created from Alzheimer's Association data. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare*. (Washington, DC: Alzheimer's Association, 2003.)

5.1.1. Use of health care services by setting

Older people with Alzheimer's disease and other dementias have many more hospital stays and slightly more physician visits than other older people. As noted earlier, almost all people age 65 and older have Medicare, and the following information about hospital stays and physician visits is based primarily on data from Medicare claims.

- In 2000, Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were 3.4 times more likely than other Medicare beneficiaries in the same age group to have a hospital stay (1,091 hospital stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 318 hospital stays per 1,000 beneficiaries for other Medicare beneficiaries) [52] (Fig. 6).
- In 2000, Medicare beneficiaries age 65 and older with Alzheimer's and other dementias had an average of 1.3 times more physician visits than did other Medi-

Table 4
Percentage of Medicare beneficiaries age 65+ with Alzheimer's disease and other dementias who had specified coexisting medical conditions, 1999

Coexisting condition	Percentage with Alzheimer's or other dementias and the coexisting condition
Hypertension	60
Coronary heart disease	30
Congestive heart failure	28
Osteoarthritis	26
Diabetes	21
Peripheral vascular disease	19
Chronic obstructive pulmonary disease	17
Thyroid disease	16
Stroke, late effects	10

Reprinted from Bynum JPW, Rabins PV, Weller W, Niefeld M, Anderson GF, Wu AW. The relationship between a dementia diagnosis, chronic illness, Medicare expenditures and hospital use. J Am Geriatr Soc 2004; 52:187–94.

care beneficiaries in the same age group (14.5 physician visits per beneficiary with Alzheimer's and other dementias compared with 11.3 physician visits per beneficiary for other Medicare beneficiaries) [52].

- On average, at any one time, about 25% of older hospital patients are people with Alzheimer's and other dementias [53].

5.1.2. Impact of coexisting medical conditions

Most people with Alzheimer's and other dementias have one or more other serious medical conditions. For example, 30% of Medicare beneficiaries age 65 and older with Alzheimer's and other dementias also have coronary heart disease, and 28% have congestive heart failure [23] (Table 4).

As shown in Table 4, the percentages of Medicare beneficiaries with Alzheimer's disease and other dementias who also have various coexisting medical conditions sum to more than 100%. This means that many Medicare beneficiaries with Alzheimer's and other dementias have more than one other serious medical condition.

Alzheimer's and other dementias greatly increase the use of health care services for people with other serious medical conditions, and conversely, these other medical conditions increase the use of health care services for people with Alzheimer's and other dementias. In 2000, for example, Medicare beneficiaries with diabetes but no Alzheimer's or other dementia had 587 hospital stays per 1,000 beneficiaries compared with 1,589 hospital stays per 1,000 for beneficiaries with diabetes and Alzheimer's or another dementia [52]. Likewise, in 2000, Medicare beneficiaries with congestive heart failure but no Alzheimer's and other dementias had 1,259 hospital stays per 1,000 beneficiaries compared with 1,901 hospital stays per 1,000 for beneficiaries with congestive heart failure and Alzheimer's or another dementia [52].

People with Alzheimer's and other dementias are most often hospitalized for treatment of their coexisting medical conditions [54,55], and data from an analysis of 1999 Medicare claims suggest that some of these hospitalizations are potentially preventable [23]. A 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 avoiding the hospitalization. In 1999, Medicare beneficiaries age 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 [23].

5.1.3. Medicare coverage

Medicare costs for people with Alzheimer's and other dementias are much higher than for other older people, and these costs are strongly related to coexisting medical conditions.

- In 2000, total Medicare costs per beneficiary for Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were three times higher, on average, than for other older Medicare beneficiaries ($13,207 versus $4,454 per beneficiary). Average Medicare costs per beneficiary for hospital care for those age 65 and older with Alzheimer's and other dementias were 3.2 times higher, on average, than for other older Medicare beneficiaries ($7,074 versus $2,204) [52] (Fig. 7).
- Total Medicare costs per beneficiary for beneficiaries with diabetes and Alzheimer's or another dementia were $19,994 in 2000, compared with $8,011 for beneficiaries with diabetes but no Alzheimer's or other dementia. Likewise, total Medicare costs per beneficiary for beneficiaries with congestive heart failure and Alzheimer's or another dementia were $22,939 in 2000, compared with

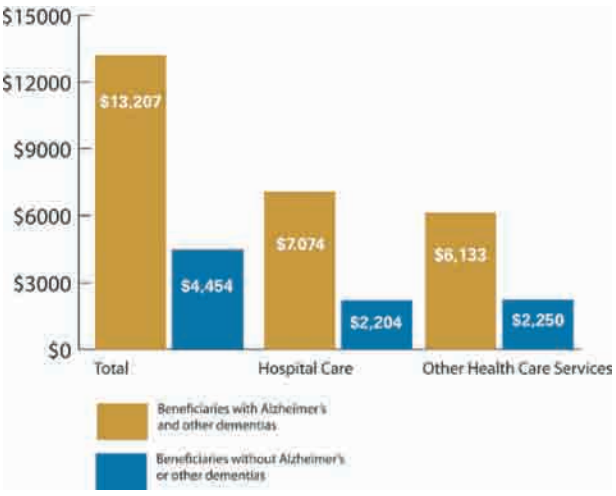

Fig. 7. Total Medicare costs per beneficiary and Medicare costs for hospital and other health care services for beneficiaries age 65+ with Alzheimer's disease and other dementias compared with other Medicare beneficiaries, 2000. Figure created from Alzheimer's Association data. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare,* 2003.

$15,441 for beneficiaries with congestive heart failure but no Alzheimer's or other dementia [52].

- Average Medicare costs per beneficiary for hospital care for beneficiaries with diabetes and Alzheimer's or another dementia were $10,943 in 2000, compared with $4,207 for beneficiaries with diabetes but no Alzheimer's or other dementia [52]. Likewise, average Medicare costs per beneficiary for hospital care for beneficiaries with congestive heart failure and Alzheimer's or another dementia were $13,178 in 2000, compared with $9,441 for beneficiaries with congestive heart failure but no Alzheimer's or other dementia [52].

5.1.4. Costs to individuals and their families

Although Medicare covers most hospital and other health care services for older people with Alzheimer's and other dementias, individuals and their families still incur high out-of-pocket expenditures for Medicare premiums, deductibles, and co-payments and other health care costs that are not covered by Medicare.

According to an AARP analysis, Medicare beneficiaries age 65 and older spent an average of $3,455 (22%) of their income on health care in 2003. About 45% of those expenditures were for Medicare Part B premiums, private Medicare plans (such as health maintenance organizations), and private supplemental insurance [56].

Out-of-pocket expenditures for health and long-term care are higher, on average, for older people with Alzheimer's and other dementias than for other older people. One analysis based on a large nationally representative sample from the Health and Retirement Study found that in 1995, average out-of-pocket expenditures for hospitalization, nursing home care stays, outpatient treatment, home care, and prescription medications were $1,350 for people with no dementia and $2,150 for people with mild or moderate dementia, an increase of $800 [57]. (These figures are in 1995 dollars, without adjustment for inflation. The figures were adjusted for many other factors including a person's other medical conditions, age, race, gender, marital status, living situation, and insurance coverage.) For people with severe dementia, average out-of-pocket expenditures were $3,010 in 1995, an increase of $1,660 from the average for people with no dementia.

The study found that the $1,660 increase in out-of-pocket expenditures for people with severe dementia was greater than the increases in expenditures for people with any of the other conditions included in the analysis [57]. The increase from the averages for those other conditions were heart disease, $670; stroke, $820; diabetes, $760; hypertension, $630; cancer, $670; lung disease, $460; psychiatric problems, $630; and arthritis, $270. The $800 increase in out-of-pocket expenditures for people with mild to moderate dementia was greater than the increase for people with any of those other conditions except stroke.

5.2. Use and costs of long-term care

Most people with dementia live at home, usually with help from family and friends. These caregivers provide more help to their loved ones than caregivers of people with physical disabilities. As the dementia progresses, caregivers provide more and more care, until they can no longer manage their caregiving responsibilities on their own. Some families hire home care workers or place their loved ones in assisted living residences or nursing homes. People with dementia make up about one quarter of those receiving home care from governmental programs and half or more of residents in assisted living or nursing homes. Paying for these services for very long is not affordable for most people with dementia and their families, with home care costing $152 for an 8-hour day and assisted living averaging $3,000 a month. Nursing home care is even more expensive. Medicaid is the only federal program that will cover the long nursing home stays that most people with dementia require, but this program requires beneficiaries to be poor to receive coverage. Private long-term care insurance is only an option for those healthy and wealthy enough to purchase policies before developing dementia.

5.2.1. Use of long-term care services by setting

Seventy percent of people with Alzheimer's and other dementias are living at home at any one time [58]. Most of these people receive unpaid help from family members and friends. Many also receive paid home and community services, especially as their Alzheimer's or other dementia worsens.

People with dementia are high users of home and community services such as personal care and adult day center services. The likelihood of needing services increases if an older person who cannot perform daily activities such as dressing, bathing, shopping, and managing money also has cognitive impairment. A 2002 study of community-living older adults who could not perform at least one daily activity found the following [59]:

- About 92% of those with cognitive impairment received assistance from family, friends, or paid workers, compared with about 56% of those who had no cognitive impairment.
- On average, those with cognitive impairment received 325 hours of help a month compared with 134 hours a month for those without cognitive impairment.
- About 29% of those with cognitive impairment used paid services, usually in combination with unpaid assistance. Only 12% of those who had no cognitive impairment used paid services.
- On average, those with cognitive impairment who used paid services used almost twice as many hours monthly as those without cognitive impairment (200 hours compared with 108 hours).

- About 27% of older community-living adults with severe disabilities (those unable to perform three or more daily activities) were also cognitively impaired.

Eventually, many people with dementia enter assisted living residences or nursing homes because their needs overwhelm their family caregivers or no caregivers are available. At any one time, about 30% of people with dementia are living in such long-term care settings [58].

Those with dementia represent about one quarter of elderly users of home care services and about half of users of adult day center services, assisted living facilities, and nursing homes. Many of these elders have never received a formal diagnosis of the disease.

- Twenty-four percent of people of all ages who received Medicare- or Medicaid-funded home health care have moderate to severe cognitive impairment [60].
- At least half of the elderly participants in adult day center services have Alzheimer's disease or another dementia [61,62].
- Estimates from various studies indicate that 45% to 67% of residents of assisted living residences have Alzheimer's disease or another dementia [63]. The most recent study (2003) of disease severity shows that about 60% of assisted living residents with dementia were in the moderate or severe stages of the disease [63].
- As shown in Table 5, in 2006, 69% of all nursing home residents had some degree of cognitive impairment, including 27% who had mild cognitive impairment and 42% who had moderate to severe cognitive impairment [64]. In June 2007, 46.4% of all nursing home residents had a diagnosis of Alzheimer's or another dementia in their nursing home record [65].
- Nursing home Alzheimer's special care units had 90,285 beds in June 2007 [66]. Although the number of these units has grown since the 1980s, they represent only 5.26% of all nursing home beds. Thus, most nursing home residents with dementia are not in special care units.

5.2.2. Costs to individuals and their families

Although Medicaid covers some long-term care costs, families coping with dementia often incur considerable costs in caring for a person with Alzheimer's disease or another dementia. Costs are high for care at home or in an adult day center, assisted living residence, or nursing home.

- The average hourly rate for home health aides in 2007 was $19 or $152 for an 8-hour day. For homemaker or companion services, costs ran $18 an hour [67].
- Adult day center services cost an average of $61 per day in 2007 [67].
- The average monthly cost for a private, one-bedroom unit in an assisted living facility was $2,969 or

Table 5
Cognitive impairment in nursing home residents by state, 2006

State	Total nursing home residents*	Percentage of residents at each level of cognitive impairment		
		None	Very mild/mild	Moderate /severe
Alabama	49,642	26	26	48
Alaska	1,309	27	28	45
Arizona	40,272	45	23	32
Arkansas	33,228	24	28	48
California	253,542	33	26	41
Colorado	37,843	27	31	42
Connecticut	62,135	36	27	37
Delaware	8,919	36	25	39
District of Columbia	5,758	41	24	35
Florida	203,196	40	23	37
Georgia	64,837	15	25	60
Hawaii	8,138	25	21	54
Idaho	12,442	31	28	41
Illinois	166,451	30	31	39
Indiana	84,861	34	25	41
Iowa	49,349	22	30	48
Kansas	35,392	21	31	48
Kentucky	49,138	30	24	46
Louisiana	42,159	23	28	49
Maine	17,961	34	24	42
Maryland	64,689	38	23	39
Massachusetts	102,235	34	24	42
Michigan	97,009	29	26	45
Minnesota	70,104	29	30	41
Mississippi	27,564	23	29	48
Missouri	76,758	29	30	41
Montana	11,671	29	28	43
Nebraska	26,540	24	30	46
Nevada	11,896	38	25	37
New Hampshire	15,139	30	25	45
New Jersey	115,252	42	25	33
New Mexico	13,183	28	29	43
New York	224,340	34	26	40
North Carolina	85,402	31	24	45
North Dakota	10,647	22	29	49
Ohio	185,224	28	27	45
Oklahoma	37,225	28	31	41
Oregon	26,731	34	28	38
Pennsylvania	177,643	31	27	42
Rhode Island	16,994	29	29	42
South Carolina	36,035	28	22	50
South Dakota	11,494	22	29	49
Tennessee	70,201	25	25	50
Texas	179,508	24	31	45
Utah	17,568	36	29	35
Vermont	6,792	26	28	46
Virginia	67,923	29	27	44
Washington	57,092	30	28	42
West Virginia	21,567	36	21	43
Wisconsin	73,194	33	27	40
Wyoming	4,937	19	30	51
U.S. total	3,169,129	31	27	42

Reprinted from U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. Nursing home data compendium 2007 edition.

* These figures include all individuals who spent any time in a nursing home in 2006.

$35,628 a year in 2007. Assisted living residences that provide specialized dementia care often charge additional monthly fees averaging $1,110 for that care [68].

- The average daily cost for a private room in a nursing home was $213 in 2007 or $77,745 a year [68].
- Medicare beneficiaries age 65 and older paid 37% of the cost of their nursing home care out of pocket in 2002 [69]. U.S. National Health Expenditure Accounts show that consumers' out-of-pocket payments funded 26% of all spending on nursing homes in 2006 [70].

5.2.3. Affordability of long-term care

Few individuals or families coping with dementia can afford to pay the cost of long-term care without eventually getting help from governmental sources, primarily Medicaid.

- Detailed income and asset data are not available for those with Alzheimer's or other dementias, but the median income for all women age 65 or older in 2005 was $12,495; for men, it was $21,784 [71]. The median income for households headed by an older person was $37,765. Even for older adults whose incomes fall comfortably above the median, the costs of home care, assisted living or nursing home care can quickly exhaust their resources.
- Sixty-five percent of elderly people living in the community and 84% of those at high risk of needing nursing home care have assets that would pay for less than a year in a nursing home [72]. Fifty-seven percent of the elderly in the community and 75% of those at high risk of needing nursing home care do not have enough assets to cover even a month in a nursing home.

5.2.4. Medicaid coverage

Medicaid covers nursing home care and various 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 as a result of their expenditures on these services. The federal government and the states share in managing and funding the program.

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.

- Twenty-nine percent of Medicare beneficiaries age 65 and older with Alzheimer's disease or other dementias were also Medicaid beneficiaries in 2000 [58]. Of that total, about half were nursing home residents, and the rest lived in the community.
- Among nursing home residents with Alzheimer's disease and other dementias, 51% relied on Medicaid to help pay for their nursing home care in 2000 [58].
- 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.
- When baby boomers begin to reach the median age for admission to a nursing home in 2025, Medicaid spending for nursing home residents with Alzheimer's disease will increase rapidly, from $21 billion in 2005 to $38 billion in 2025 [50].
- Among older people with Alzheimer's disease and other dementias who were living in the community in 2000, 18% relied on Medicaid to help pay for their care [58]. 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, or respite services, among other services.

5.2.5. 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 people who filed claims in that year [73]. Private health and long-term care insurance policies funded only about 7% of national long-term care spending in 2004 [74]. However, long-term care insurance plays a significant role in paying for the care of people with dementia who are able to afford policies before developing the disease.

A study of persons filing claims on their long-term care insurance policies for the first time during 2003, 2004, or 2005 shows that about two thirds of persons filing claims for care in assisted living (63%) and nursing homes (64%) had cognitive impairment [75]. The figure was 28% for those filing claims for paid home care.

5.3. Use and costs of hospice care

5.3.1. Use of hospice services

People who are dying from dementia generally are bedbound and cannot carry out any daily activities without help. They might stop eating and drinking and most likely cannot say that they are in pain. One study showed that hospital patients with Alzheimer's disease often had untreated or undertreated pain [76]. Palliative care is a service designed to relieve such symptoms, and the Medicare hospice benefit is one way to fund that care.

Hospices specialize in pain management, comfort care, spiritual services, and bereavement for families. Individuals can receive hospice in their homes, assisted living residences, or nursing homes. Medicare will cover hospice if a physician certifies that a beneficiary is likely to die within 6 months. In general, the Medicare hospice benefit, and hospice care in general, are underused. A 2005 study estimated that only 43% of patients eligible for hospice ever receive services [77].

Consistent with the general population, people dying

with dementia underuse hospice. A study investigated hospice referral in people age 65 and older with advanced dementia who died within 1 year of admission to either a nursing home in Michigan or the state's publicly funded home and community-based services. The results showed that only 5.7% of nursing home residents and 10.7% of home care clients dying with advanced dementia were referred to hospice [78]. However, the situation has been improving in recent years as the following data indicate.

- The number of hospice admissions for persons with dementia increased from 6.8% of all hospice admissions in 2001 to 10.0% of all hospice admissions in 2006 [79,80].
- Medicare data from CMS show that Alzheimer's disease and senile dementia are among the top 10 diagnoses for beneficiaries receiving hospice services. Alzheimer's is number 5, and senile dementia is number 8 [81].
- The number of Medicare beneficiaries receiving hospice due to Alzheimer's disease is increasing rapidly from a very small base. In 2000, 20,633 persons with the disease received hospice; this rose to 48,980 by 2005 [81].

These data indicate that more people with dementia are getting access to a service that can help them die a more comfortable death.

6. Mortality

Alzheimer's disease is among the top 10 leading causes of death for people of all ages and is number 5 for those aged 65 and older. In 2005, about 72,000 people were reported on death certificates to have died of this disease; this number is likely to be low because many studies say that death certificates substantially underreport the occurrence of deaths due to Alzheimer's. Death rates from the disease vary a great deal across the states as a result of differences in state demographics and reporting practices. Death rates from Alzheimer's disease increase with age and have been increasing over time. For example, the death rate from Alzheimer's disease for those aged 85 and older increased by 22.6% between 2000 and 2004. More than two thirds of those dying from dementia did so in nursing homes, compared with roughly 70% of cancer patients who died at home or in the hospital. Location of death varies across the states.

6.1. Deaths from Alzheimer's disease

Alzheimer's disease was listed as the underlying cause of death for 71,696 Americans in 2005. It was the seventh leading cause of death for people of all ages and the fifth leading cause of death for people aged 65 and older [82].

The total number of deaths attributed to Alzheimer's disease has increased over the last 15 years. In 1991, only 14,112 death certificates recorded Alzheimer's as the underlying cause [83]. From 2000 to 2005, deaths attributed to Alzheimer's disease increased by 44.7%, whereas the number 1 cause of death, heart disease, decreased by 8.6%. Table 6 and Fig. 8 show the number of deaths and percentage change in number of deaths from selected diseases from 2000 to 2005.

Even though deaths attributed to Alzheimer's are increasing, the number might fail to reflect the disease's full public health impact. Numerous studies have suggested that death certificates substantially underreport Alzheimer's disease as a cause of death for people living in the community. Because most individuals with Alzheimer's are age 65 and older, they also tend to have other serious coexisting medical conditions associated with aging, such as heart disease or stroke. Physicians might tend to attribute death primarily to one of these other conditions even when Alzheimer's disease is present. In the large percentage of cases where the medical record fails to reflect an Alzheimer's diagnosis, the certifying physician might not be aware that the individual had the disease.

In cases where Alzheimer's is not listed as the underlying cause of death, it might not even be listed as a contributing factor. Nevertheless, people with Alzheimer's disease in all age groups generally have decreased survival when compared with survival in the general U.S. population. One 2004 study noted that people newly diagnosed with Alzheimer's survived about half as long as those of similar age who did not have the disease [84]. In this study, average survival time was 4 to 6 years after diagnosis, but survival can be as long as 20 years from the first symptoms (although these early symptoms might be fairly subtle and not immediately recognized). Another study reported that when persons with Alzheimer's were hospitalized for pneumonia or hip fracture, more than half died within 6 months, compared with about 13% of cognitively intact patients, after receiving the same types of treatments [76].

The mechanisms by which dementia leads to death might create ambiguity about the underlying cause of death. Severe dementia frequently causes such complications as immobility, swallowing disorders, or 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 persons with Alzheimer's disease and other dementias. One researcher described the situation as a "blurred distinction between death *with* dementia and death *from* dementia" [85].

6.2. State-by-state deaths from Alzheimer's disease

The state with the highest age-adjusted death rate attributed to Alzheimer's disease in 2004 was Washington, where the rate was 36.1 per 100,000 (2,233 deaths); the lowest rate was 9.2 per 100,000 in New York or 1,989 deaths [86] (Table 7). Differences across states in death rates attributed to Alzheimer's disease can result from several factors. For

Table 6
Percentage change in leading causes of death from 2000 to 2005

Cause	2000	2005	Percentage change
Heart disease	710,760	649,399	−8.6
Breast cancer	41,200	40,870	−0.8
Prostate cancer	31,900	30,350	−4.9
Stroke	167,661	143,497	−14.4
Alzheimer's disease	49,558	71,696	+44.7

Reprinted from the Centers for Disease Control and Prevention, National Vital Statistics Reports, and Reports of the American Cancer Society. See Appendix 13.

example, death rates from Alzheimer's disease vary by ethnicity, so a state's rate is likely to reflect its population's ethnic profile. Another possible reason for the differences in these rates is variability across states in how the cause of death is reported on death certificates.

6.3. Death rates by age, gender, and ethnicity

Alzheimer's disease death rates increase rapidly with age and have increased for the oldest age groups since 2000. For example, the death rate for those aged 75 to 84 increased from 139.6 per 100,000 in 2000 to 168.7 per 100,000 in 2004 [86] (Table 8). The death rate for those aged 85 and older increased by 22.6% during the same time period to reach 818.8 per 100,000 in 2004. It is important to note that people younger than age 65 also die from Alzheimer's disease, although at a much lower rate than older age groups. Reasons for increased death rates due to Alzheimer's disease might include the fact that death rates from other diseases, such as heart disease and cancer, are declining. Thus, people who would have died of these diseases could live longer and have an increased risk of dying of Alzheimer's disease.

In 2004, age-adjusted death rates for Alzheimer's disease

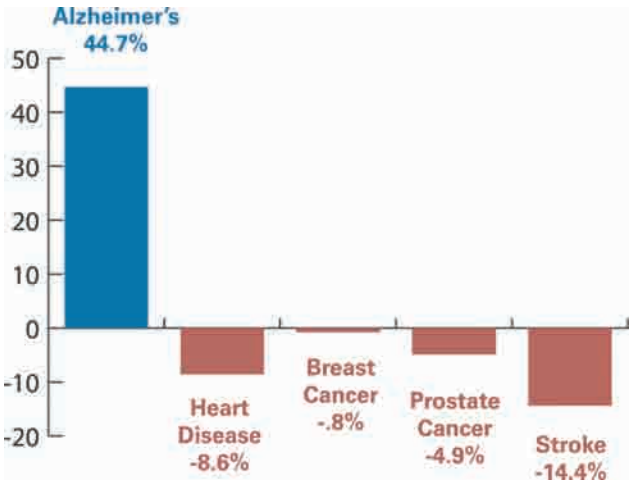

Fig. 8. Percentage Change in Leading Causes of Death From 2000 to 2005.

Table 7
Number of deaths due to Alzheimer's disease and rate per 100,000 population by state, 2004

State	Number of deaths	Age-adjusted rate per 100,000
Alabama	1,385	31.1
Alaska	48	17.6
Arizona	1,675	30.0
Arkansas	622	20.7
California	6,964	21.8
Colorado	912	25.7
Connecticut	684	14.7
Delaware	155	18.2
District of Columbia	119	20.6
Florida	4,307	17.8
Georgia	1,710	27.5
Hawaii	171	10.8
Idaho	343	25.4
Illinois	2,595	19.6
Indiana	1,552	23.8
Iowa	968	23.3
Kansas	769	23.8
Kentucky	982	25.1
Louisiana	1,267	31.5
Maine	512	32.4
Maryland	905	17.3
Massachusetts	1,673	20.8
Michigan	2,232	20.7
Minnesota	1,231	21.7
Mississippi	630	23.9
Missouri	1,381	21.8
Montana	228	21.1
Nebraska	459	21.7
Nevada	292	17.2
New Hampshire	331	24.8
New Jersey	1,711	17.0
New Mexico	328	18.8
New York	1,989	9.2
North Carolina	2,188	27.8
North Dakota	313	33.5
Ohio	2,927	22.4
Oklahoma	867	24.4
Oregon	1,262	30.6
Pennsylvania	3,277	18.6
Rhode Island	283	18.7
South Carolina	1,245	32.0
South Dakota	243	23.5
Tennessee	1,615	29.3
Texas	4,336	26.4
Utah	376	22.9
Vermont	173	24.9
Virginia	1,480	22.4
Washington	2,233	36.1
West Virginia	493	22.8
Wisconsin	1,419	21.6
Wyoming	105	22.1
UNITED STATES	65,965	21.8

Reprinted from U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports. Deaths: final data for 2004. vol 55, no. 19, August 21, 2007.

varied by ethnicity, with white women having the highest rates at 24.7 per 100,000 persons [86] (Table 9.). Black women were next, with a death rate of 19.9 per 100,000.

Table 8
Death rates by age for Alzheimer's disease, 2000 and 2004

Age (y)	2000	2004
45 to 54	0.2	0.2
55 to 64	2.0	1.9
65 to 74	18.7	19.7
75 to 84	139.6	168.7
85+	667.7	818.8

Reprinted from U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports. Deaths: final data for 2004. vol. 55, no. 19, August 21, 2007.

Hispanic persons had the lowest death rates, with male Hispanics' rate being the lowest of all groups at 10.8 per 100,000.

6.4. Location of death

A study of national death certificates for 2001 found that 66.9% of people aged 65 and older who died from dementia did so in nursing homes [87] (Table 10). Only 15.6% of this group died in the hospital and only 12.7% at home. In contrast, 37.8% of cancer patients died at home and 35.4% in the hospital. About half of people who died from other diseases did so in the hospital. These percentages vary a great deal across regions of the country. For example, the percentage of dementia deaths in hospitals ranged from 5.0% in Rhode Island to 37% in the District of Columbia. Those with dementia died more frequently in the hospital in the Southeastern states.

7. Special report: Lifetime risk

One in six women and one in 10 men who live to be at least age 55 will develop Alzheimer's disease in their remaining lifetime. Higher proportions, one in five women and one in seven men who reach age 55, will develop any dementia, including Alzheimer's disease. The risk of developing Alzheimer's disease and dementia is higher for women than men because women live longer, on average, than men. As deaths from other causes decrease in the future, the average life span for the U.S. population will increase, thus increasing the lifetime risk of Alzheimer's and other dementias. Even without that increase, however, about 10 million of the 78 million baby boomers who are alive today can expect to develop Alzheimer's disease. About 14 million baby boomers who are alive today can expect to develop any dementia, including Alzheimer's disease. The personal and societal implications of these numbers are daunting.

Table 9
Death rates by ethnicity and gender for Alzheimer's disease, 2004

	Male	Female
All races	17.7	23.8
Black	15.2	19.9
Hispanic	10.8	14.1
White	18.3	24.7

Reprinted from U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports. Deaths: final data for 2004. vol 55, no. 19, August 21, 2007.

Table 10
Location of death for people age 65+, 2001

Location of death	Dementia	Cancer	All other conditions
Hospital	15.6%	35.4%	52.2%
Nursing home	66.9	20.6	28.0
Home	12.7	37.8	17.0
Other	4.7	6.2	2.8

Reprinted from Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005;53:299–305.

7.1. Lifetime risk of developing Alzheimer's disease and dementia

The lifetime risk of a disease or condition is the likelihood that a person will develop the disease or condition at any time in his or her life. Currently, there is no information to calculate risk from birth for Alzheimer's disease or dementia. The figures presented here pertain to the risk of developing Alzheimer's disease or dementia for Americans who live to be at least age 55 (Appendix 14).

As shown in Fig. 9, remaining lifetime risk of Alzheimer's disease for women at age 55 is 17%. Thus, one in six American women who live to be at least age 55 can expect to develop Alzheimer's disease in their remaining lifetime. Remaining lifetime risk of Alzheimer's disease for men is 9% or almost one in 10 men who live to be at least age 55.

Figure 10 shows remaining lifetime risk of any dementia, including Alzheimer's disease, for women and men. Remaining lifetime risk of dementia for women who live to be at least age 55 is 21%. Thus, more than one in five American women who live to be at least age 55 can expect to develop dementia in their remaining lifetime. Remaining lifetime risk of dementia for men is 14% or one in seven men who live to be at least age 55.

Remaining lifetime risk at age 55 is higher for women than for men because women live longer, on average. Their longer life expectancy increases the time during which they could develop Alzheimer's disease or other dementia.

These figures for remaining lifetime risk are conservative because the study on which they are based, the Framingham Heart Study, used a relatively high threshold for including an individual as a person with dementia. The study required that the individual must have dementia specified as at least moderate, according to the study criteria, and that the individual's dementia symptoms must have been present for at least 6 months (Appendix 15). Thus, individuals who had very early or mild dementia and individuals with moderate dementia of less than 6 months' duration were not counted

as having dementia. If these individuals had been counted as having dementia, the figures for remaining lifetime risk shown in Fig. 9 would be higher.

7.2. Impact of future reductions in deaths from other causes

As discussed in the Mortality section, the number of deaths due to heart disease, cancer, and stroke, the three leading causes of death, is decreasing. As a result, unless there are new treatments to prevent Alzheimer's and other dementias, the remaining lifetime risk of Alzheimer's and dementia will increase substantially in the future because the decreasing number of deaths from heart disease, cancer, and stroke means that more people live long enough to develop Alzheimer's and other dementias.

7.3. Implications for baby boomers

The baby boomers are people living in the United States now who were born from 1946 through 1964. In 2008, the oldest baby boomers, people born in 1946, will be 62. The youngest baby boomers, people who were born in 1964, will be 44.

The remaining lifetime risks of Alzheimer's disease and dementia shown in Figs. 9 and 10 apply to baby boomers who are already age 55 or older. The remaining lifetime risks of Alzheimer's and other dementias also apply to baby boomers who are younger than 55, assuming that they live to be at least 55.

The baby boomer group now includes about 78 million Americans, of whom 27 million are ages 55 to 62 and 51 million ages 44 to 54. Applying the proportions in Figs. 9 and 10, the Alzheimer's Association estimates that 10 million of these baby boomers can expect to develop Alzheimer's disease in their remaining lifetime (Appendix 16). Similarly, about 14 million baby boomers can expect to develop dementia, including Alzheimer's disease.

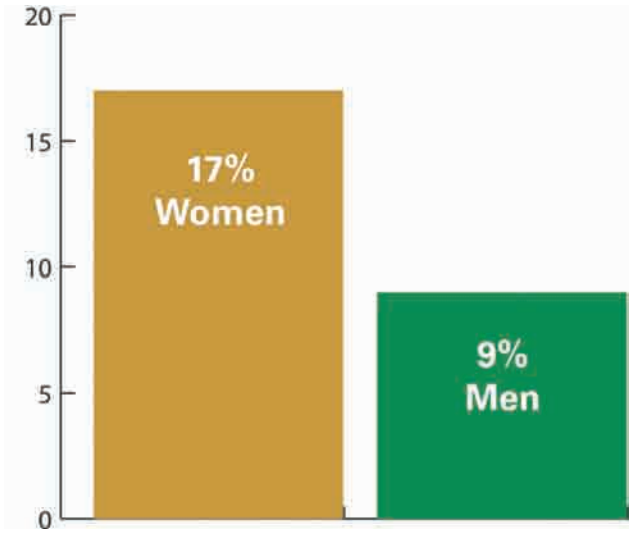

Fig. 9. Percentage of women and men who will develop Alzheimer's disease in their remaining lifetime if they live to be at least age 55, Framingham Heart Study. Figure created from data from Beiser, A; Seshadri, S; Au, R; and Wolf PA. Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, Unpublished Data from the Framingham Heart Study, 2008.

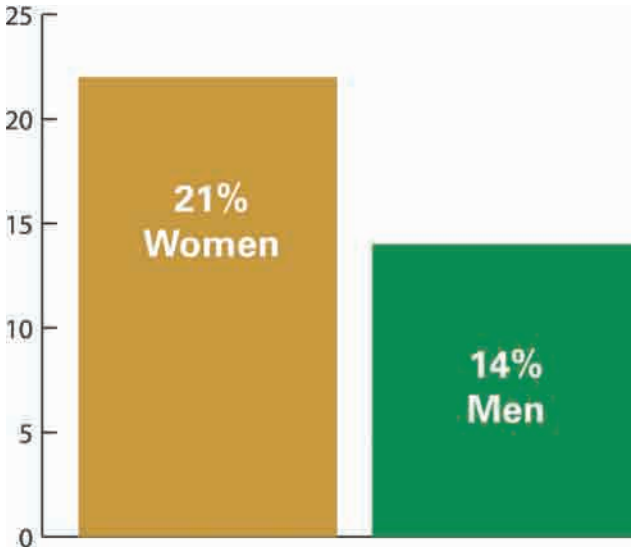

Fig. 10. Percentage of women and men who will develop dementia in their remaining lifetime if they live to be at least age 55, Framingham Heart Study. Figure created from data from Beiser, A; Seshadri, S; Au, R; and Wolf PA. Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, Unpublished Data from the Framingham Heart Study, 2008.

As noted earlier, these figures are conservative because of the relatively high threshold for including an individual as a person with dementia in the Framingham Heart Study, which is the source of the lifetime risk estimates (Appendix 16). True lifetime risk for baby boomers will probably be greater for this reason. True lifetime risk for baby boomers will also be greater because deaths from heart disease, cancer, and stroke will probably continue to drop, increasing the life span during which the boomers could develop Alzheimer's or other dementias.

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Appendix 1. Number of Americans age 65 and over with Alzheimer's disease

Denis Evans, MD, and colleagues computed the 5 million number in early 2007, at the request of the Alzheimer's Association. The number is based on linear extrapolation from their previously published prevalence estimates for

2000 (4.5 million) and 2010 (5.1 million) [21]. These prevalence numbers are based on incidence data from the Chicago Health and Aging Project (CHAP).

Appendix 2. Number of Americans younger than age 65 with Alzheimer's disease

The 200,000 number is based on data from a 2006 Alzheimer's Association report (Alzheimer's Association. Early onset dementia: a national challenge, a future crisis. Washington, DC: Alzheimer's Association; available at http://www.alz.org, search "early onset report"). The report shows that about 500,000 Americans age 55 to 64 have Alzheimer's disease or other dementias. The Alzheimer's Association estimates that about 40% of these people have Alzheimer's disease, or about 200,000 people. The 200,000 number does not include Americans younger than 65 with other dementias.

Appendix 3. Proportion of Americans with Alzheimer's disease

The 13% number is calculated by dividing the number of people age 65 and older with Alzheimer's disease (5 million) by the U.S. population age 65 and older in November 2007, the latest available data from the U.S. Census Bureau (38 million) = 13%. Thirteen percent is the same as 1 in 8.

Appendix 4. Number of seconds for development of a new case of Alzheimer's disease

The 71 seconds number is calculated by dividing the number of seconds in a year (31,536,000) by the number of new cases in a year. Hebert et al [20] estimated that there would be 411,000 new cases in 2000 and 454,000 new cases in 2010. The Alzheimer's Association calculated that the incidence of new cases in 2008 would be 445,000 by multiplying the 10-year change from 411,000 to 454,000 (43,000) by 0.8 (for the number of years from 2000 to 2008 divided by the number of years from 2000 to 2010), adding that result (34,400) to the estimate by Hebert et al for 2000 (411,000) = 445,400. 31,536,000 divided by 445,400 = 70.8 seconds, rounded to 71 seconds. Using the same method of calculation for 2050, 31,536,000 divided by 959,000 (Hebert et al [20]) = 32.8 seconds, rounded to 33 seconds.

Appendix 5. The Aging, Demographics, and Memory Study (ADAMS)

ADAMS provides estimates of the number of Americans age 71 and older who had Alzheimer's disease and other dementias in 2002 [1]. Updated to 2008, ADAMS data indicate that there are now about 3.7 million Americans age 71 and older who have dementia, including about 2.6 million people in that age group who have Alzheimer's disease. These figures do not include Americans younger than 71 who have Alzheimer's and other dementias, an estimated 1 million people in 2008. Analysis of the reasons for the difference in prevalence estimates from the Chicago Health and Aging Project (CHAP) study (Hebert et al [21]) and the ADAMS study is ongoing. Conclusions from this analysis, which are not available at the time this Alzheimer's Association report is being published, will help to clarify the difference in estimates from the two studies. Forthcoming data from ADAMS about subjects who had cognitive impairment but did not meet the study criteria for dementia will probably also help clarify the difference in estimates from the studies.

Appendix 6. 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 (Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. State-specific projections through 2025 of Alzheimer disease prevalence. Neurology 2004;62:1645). The numbers in Table 2 are found in online material related to this article at www.neurology.org.

Appendix 7. 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 older 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 by state, we applied the proportion of caregivers for each state from the 2000 BRFSS (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 in each state from the U.S. Census Bureau report for July 2007. 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 national telephone survey conducted in 2003 for the National Alliance for Caregiving (NAC) and AARP (National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda, MD: National Alliance for Caregiving and AARP, February 2004). This survey asked respondents age 18 and older 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, 23% of caregivers 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. The 23% figure pertains to caregivers of people 18 and older, but almost all people with Alzheimer's and other dementias are at least 50 years old, and we needed a percentage figure to use with the BRFSS state numbers for caregivers of people 60 and older. To estimate that percentage, we divided the proportion of caregivers of people with Alzheimer's and other dementias from the NAC/AARP survey (23%) by the proportion of caregivers of people 50 and older with any health problem from the NAC/AARP survey (79%) and estimated that 29% of caregivers 18 and older are taking care of a person 50 or older with Alzheimer's or another dementia. We applied the 29% figure to the BRFSS state numbers for caregivers of people 60 and older in each state. State numbers for Alzheimer's/dementia caregivers added up to 9,753,995, rounded to 9.8 million.

Appendix 8. Number of hours of unpaid care

To calculate this number, the Alzheimer's Association used data from a follow-up analysis based on the 2003 NAC/AARP survey (Alzheimer's Association and National Alliance for Caregiving. Families care: Alzheimer's caregiving in the United States, 2004; available at www.alz.org). This analysis showed that 23% of caregivers of people with Alzheimer's and other dementias provided 40 or more hours of care a week, 8% provided an average of 30 hours per week, 21% provided an average of 15 hours a week, 47% provided an average of 4 hours a week, and 1% did not report their hours of care. Based on these proportions, the average hours of care provided per week is 16.6, or 863 hours per year. We multiplied the average hours of care per year by the number of family and other unpaid caregivers.

Appendix 9. Value of unpaid caregiving

To calculate this number, the Alzheimer's Association used the method of Arno et al (Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. Health Affairs 1999;18:182–8). This method uses the average of the minimum wage ($5.85 in July 2007) and the mean wage of home health aides ($15.32 in July 2007) (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 2007; accessed at http://data.bls.gov/cgi_bin/?srgate, Nov 29, 2007.) We calculated the value of unpaid caregiving for people with Alzheimer's and other dementias; we multiplied the total number of hours of unpaid care by $10.58.

Appendix 10. Medicare

Medicare is a medical insurance program available to all Americans age 65 and older and to a limited number of younger individuals who meet the requirements for Social Security Disability Insurance (SSDI). In 2000, 98% of people 65 and older (34,261,000 people) had Medicare (U.S. Department of Health and Human Services, Health care financing review: Medicare and Medicaid statistical supplement, 2003, Table 5, Feb. 2005). The comparable proportions for more recent years are 2003 (97%) and 2004 (98%). Medicare covers physician services, hospital care, home health care, and prescription drugs. Medicare does not cover long-term care in a nursing home. It will cover short stays in skilled nursing facilities when the need for admission immediately follows hospitalization for an acute illness such as a heart attack or broken hip. Medicare beneficiaries pay premiums, but the premiums do not cover the full cost of services to beneficiaries, and the program is also tax-supported.

Appendix 11. 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.

Appendix 12. Cost to businesses of Alzheimer's disease

This number comes from an analysis by Koppel [51]. The total cost to businesses from this analysis includes an additional $24.6 billion for the costs to businesses of health care and long-term care services for people with Alzheimer's and other dementias. The $24.6 billion consists primarily of government taxes that are used for publicly funded services. That amount is not included here because, to a great extent, it overlaps with the $91 billion for Medicare and $21 billion for Medicaid.

Appendix 13. Numbers of deaths due to heart disease, stroke, and Alzheimer's disease

The numbers of deaths due to heart disease, stroke, and Alzheimer's disease in 2000 come from U.S Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports, Deaths: final data for 2000, vol 50, no. 15, Sept. 16, 2002. The numbers of deaths due to heart disease, stroke, and Alzheimer's disease for 2005 come from U.S. Centers for Disease Con-

trol and Prevention, National Center for Health Statistics, National Vital Statistics Reports, Deaths: preliminary data for 2005, 2006. The numbers of deaths due to breast cancer and prostate cancer for 2000 come from American Cancer Society, Cancer facts and figures 2000. The numbers of deaths due to breast cancer and prostate cancer for 2005 come from American Cancer Society, Cancer facts and figures 2005.

Appendix 14. Lifetime risk

The numbers used in this report for remaining lifetime risk of Alzheimer's disease and dementia at age 55 come from the Framingham Heart Study. Numbers for remaining lifetime risk of Alzheimer's disease and dementia at age 65 have been published previously (Seshadri S, Wolf PA, Beiser A, Au R, McNulty K, White R, et al. Lifetime risk of dementia and Alzheimer's disease: the impact of mortality on risk estimates in the Framingham Study. Neurology 1997;49:1498–504 and Seshadri S, Beiser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB, et al. The lifetime risk of stroke: estimates from the Framingham Study. Stroke 2006; 37:345–50). The numbers for remaining lifetime risk at age 55 were provided to the Alzheimer's Association in January 2008 by Alexa Beiser, PhD, Sudha Seshadri, MD, Rhoda Au, PhD, and Philip A. Wolf, MD, from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, who authored the previous articles. The Framingham Heart Study began in 1948. In 1975, study participants who were dementia-free were identified. Almost 2,800 of these study participants who reached age 65 without developing dementia were followed for up to 29 years, until December 2003, to estimate remaining lifetime risk of Alzheimer's disease and dementia. Over the 29-year follow-up period, 14% (400 subjects, 270 women) developed dementia, and 73% of these (292 subjects, 211 women) developed Alzheimer's disease. Deaths from all causes were incorporated in the analyses, which reflect the study experience to December 2003 for participants in the dementia lifetime risk component of the Framingham Heart Study. An analysis of the conceptual definition and value of using measures of lifetime risk for Alzheimer's disease and dementia was published in 2007 (Seshadri S, Wolf PA. Lifetime risk of stroke and dementia: current concepts, and estimates from the Framingham Study. Lancet Neurology 2007;6:1106–14).

Appendix 15. Criteria for identifying subjects with Alzheimer's disease and dementia 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 6 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;49:1498–504.

Appendix 16. Number of baby boomers who will develop Alzheimer's disease and dementia

The numbers for remaining lifetime risk of Alzheimer's disease and dementia for baby boomers were developed by the Alzheimer's Association by applying the data provided to the Alzheimer's Association on remaining lifetime risk by Alexa Beiser, PhD, Sudha Seshadri, MD, Rhoda Au, PhD, and Philip A. Wolf, MD, from the Departments of Neurology and Biostatistics, Boston University Schools of Medicine and Public Health, to U.S. Census data for the number of women and men age 43 to 61 in Nov. 2007, the latest available data, used here to estimate the number of women and men who will be age 44 to 62 in 2008.