Alzheimer’s Disease and Dementia

A growing challenge

About 4 million Americans—90 percent of whom are age 65 and older—have Alzheimer’s disease. The prevalence of Alzheimer’s disease doubles every five years beyond age 65. In the past 25 years scientists have made great progress in unraveling the mysteries of Alzheimer’s disease; however, much is still unknown. Unless prevention or a cure is found, the number of Americans with Alzheimer’s disease could reach 14.3 million 50 years from now.

The majority of the elderly population with Alzheimer’s disease and related dementia are in fair to poor physical health, and experience limitations in their daily activities. Caring for people with dementia is a time-consuming responsibility, and often requires caregivers to forgo other activities, such as work and time with family and friends.

Alzheimer’s disease affects patients and their caregivers

The majority of people with Alzheimer’s disease receive care at home from family and friends. Although many aspects of caregiving can be rewarding, providing care for people with Alzheimer’s disease is particularly demanding. Caregivers of people with Alzheimer’s disease and related dementia provide more hours of care and suffer more adverse consequences than caregivers of people without dementia. Compared to non-dementia caregivers, a larger proportion of dementia caregivers

- experience employment complications,
- have less time for their own leisure activities and other family members,
- and suffer from physical, mental, and emotional stress due to caregiving.

**DEMENTIA AFFECTS CAREGIVERS**

<table>
<thead>
<tr>
<th></th>
<th>DEMENTIA CAREGIVERS (%)</th>
<th>NONDEMENTIA CAREGIVERS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Took time off work</td>
<td>57</td>
<td>49</td>
</tr>
<tr>
<td>Went from full- to part-time work or took a less demanding job</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>Turned down a job promotion</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Chose early retirement</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Gave up own leisure activities</td>
<td>55</td>
<td>41</td>
</tr>
<tr>
<td>Had less time for family members</td>
<td>52</td>
<td>38</td>
</tr>
<tr>
<td>Had mental or physical problems</td>
<td>22</td>
<td>13</td>
</tr>
</tbody>
</table>

Alzheimer’s disease is highly associated with aging, but not income

Although Alzheimer’s disease is diagnosed in adults of any age, it is much more common among people age 75 and older. Some 77 percent of the elderly population with Alzheimer’s disease is age 75 and older.

Unlike many other chronic conditions, Alzheimer’s disease is not associated with income. There are only minimal differences between the elderly population with Alzheimer’s disease and the general elderly population with respect to the distribution of income. The elderly population with Alzheimer’s disease is less educated than the general elderly population, however (see Figure 1).

Most of the population with Alzheimer’s disease is female and white

Because Alzheimer’s disease is highly associated with aging, and women have a longer life expectancy than men, women account for over two-thirds of the elderly population with this disease.

Whites account for the majority of the elderly population with Alzheimer’s disease (see Figure 2). The proportion of non-whites in the elderly population with Alzheimer’s disease—15 percent—is larger than in the general elderly population—10 percent, however.

WHAT IS ALZHEIMER’S DISEASE?

Alzheimer’s disease is an irreversible, progressive brain disorder related to changes in nerve cells that result in the death of brain cells. Alzheimer’s disease occurs gradually, and is not a normal part of the aging process. It is the most common cause of dementia. Dementia is the loss of intellectual abilities, such as thinking, remembering, and reasoning, that is severe enough to interfere with daily functioning. Dementia is not a disease, but rather a group of symptoms that may accompany certain diseases or conditions. Symptoms of dementia may also include changes in personality, mood, and behavior. This Profile describes the elderly population (people age 65 and older) with Alzheimer’s disease and related dementia.
Dementia is common among nursing home residents

Slightly over half—51 percent—of elderly nursing home residents suffer from dementia. Dementia is most common among residents age 85 and older. Some 54 percent of residents age 85 and older have dementia, compared to 39 percent of residents age 65 to 74. And up to one-third of nursing home residents may have Alzheimer’s disease. Increasing awareness of Alzheimer’s disease and related dementia has contributed to the dramatic growth in the number of special care units (SCUs) in nursing homes for people with dementia.

Many people with Alzheimer’s disease are limited in their daily activities

Over three-quarters—80 percent—of people age 70 and older with Alzheimer’s disease are limited in one or more activities of daily living, or ADLs, such as walking, dressing, eating, using the toilet, bathing, and getting into and out of bed. Almost all—94 percent—people in this same population are limited in one or more instrumental activities of daily living, or IADLs, such as meal preparation, grocery shopping, making telephone calls, taking medications, and money management. Some 84 percent are limited in grocery shopping and managing their money.

Behavioral problems are common symptoms of dementia

Behavioral problems, such as agitation, psychosis, and wandering, are common symptoms of Alzheimer’s disease and related dementia. Over half of the population with dementia display agitated behaviors such as aggression and irritability, for example. And disruptive behaviors, such as physical violence and wandering, may occur in up to 70 percent of people with dementia. Behavioral problems pose a significant challenge to the caregivers of people with Alzheimer’s disease and related dementia.
Alzheimer’s disease is on the rise

As the U.S. population ages, the number of people with Alzheimer’s disease is expected to rise substantially. Researchers are looking for better methods to diagnose the disease in its early stages. Scientists and health care professionals are seeking better ways to help patients and their caregivers cope with the decline in mental and physical abilities associated with Alzheimer’s disease. Unless prevention or a cure is found, the number of Americans with Alzheimer’s disease is projected to more than triple over the next 50 years, from 4 million to 14.3 million (see Figure 4).

Alzheimer’s disease is associated with poor physical health

Some 66 percent of the elderly population with Alzheimer’s disease, compared to 27 percent of the elderly population without it, report being in fair to poor physical health (see Figure 5).

Among the elderly population with Alzheimer’s disease, over one-quarter—27 percent—report staying overnight at the hospital, and almost half—49 percent—report spending five or more days in bed in the past year.
Alzheimer’s disease often coexists with other conditions

It is not uncommon for this population to have coexisting conditions, both acute and chronic. Among Medicare beneficiaries with Alzheimer’s disease and related dementia, for example, almost one-third—32 percent—suffer from pneumonia. Common chronic conditions among this population include coronary artery disease and osteoarthritis (see Figure 6).

Alzheimer care is costly

Direct care for people with Alzheimer’s disease costs the U.S. over $50 billion a year. Alzheimer’s disease costs U.S. businesses $33 billion a year in lost productivity and absenteeism. Costs associated with Alzheimer caregivers, such as absences from work, account for the majority—$26 billion—of the total cost.8

FIGURE 7
Annual Cost of Paid Home Care per Alzheimer Patient, by Type of Care and Payer

<table>
<thead>
<tr>
<th>TYPE OF CARE</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>$1,648</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>62</td>
</tr>
<tr>
<td>Physician Visits</td>
<td>459</td>
</tr>
<tr>
<td>Medications</td>
<td>232</td>
</tr>
<tr>
<td>Medical Items</td>
<td>472</td>
</tr>
<tr>
<td>Social Services</td>
<td>9,585</td>
</tr>
<tr>
<td>Other</td>
<td>114</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>$12,572</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TYPE OF PAYER</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>1,527</td>
</tr>
<tr>
<td>Medicaid</td>
<td>47</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>250</td>
</tr>
<tr>
<td>HMO</td>
<td>83</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>7,864</td>
</tr>
<tr>
<td>Other</td>
<td>2,802</td>
</tr>
</tbody>
</table>

**SOURCE:** UCSF-UCD Alzheimer’s Disease Cost of Care Study, 1991.

Alzheimer’s disease is associated with high out-of-pocket costs

The average annual cost of paid home care per Alzheimer patient in the community is $12,572. Social services, such as adult day care, homemaker services, and home-delivered meals, account for 76 percent of this cost. Because most health insurance does not cover the cost of social services, out-of-pocket payments account for 63 percent of the cost of paid home care. Other sources, such as the Department of Veteran Affairs and state and local governments, account for the second largest payer of home care (see Figure 7).

MUCH OF ALZHEIMER HOME CARE IS UNPAID

The total annual cost of care—both paid and unpaid—for an Alzheimer patient at home is $47,083, compared to $47,591 at a nursing home. The distribution of costs for paid care and unpaid care for the two care settings is very different, however. Unpaid care, for example, accounts for 12 percent of the total cost of nursing home care, compared to 73 percent of the total cost of home care.6
Alzheimer’s disease research could cut costs

The federal government will spend approximately $466 million on Alzheimer’s disease research in 2000. Interventions that delay the onset of the disease could reduce the costs borne by society. For example, an average one-year delay in disease onset would reduce the projected number of people with Alzheimer’s disease by nearly 210,000, and annual costs by nearly $10 billion, 10 years after initiating the interventions.


ABOUT THE PROFILES

This series, Challenges for the 21st Century: Chronic and Disabling Conditions, is supported by a grant from the Robert Wood Johnson Foundation. This Profile was written by Lee Shirey with assistance from Laura Summer and Greg O’Neill. It is the 11th in the series. Previous Profiles include:

1. Chronic Conditions: A challenge for the 21st century
2. Hearing Loss: A growing problem that affects quality of life
3. Heart Disease: A disabling yet preventable condition
4. At Risk: Developing chronic conditions later in life
5. Arthritis: A leading cause of disability in the United States
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The National Academy on an Aging Society is a Washington-based nonpartisan policy institute of The Gerontological Society of America. The Academy studies the impact of demographic changes on public and private institutions and on the economic and health security of families and people of all ages.

ABOUT THE DATA

Unless otherwise noted, the data presented in this Profile are from two national surveys of the community-dwelling population in the United States. The 1994 National Health Interview Survey of Disability, Phase I (NHIS-D) was conducted by the National Center for Health Statistics (NCHS). The NHIS-D asks the entire population about Alzheimer’s disease and other senility disorders in the past 12 months. Wave 1 of the study of Assets and Health Dynamics Among the Oldest Old (AHEAD) asks respondents age 70 and older in 1993 and 1994 about Alzheimer’s disease. It is sponsored by the National Institute on Aging and conducted by the Institute for Social Research at the University of Michigan.