Alzheimer's Disease Facts and Figures 2008:

A Report from the Alzheimer's Association

Part 4

Alzheimer's Disease Facts and Figures 2008 is a comprehensive statistical abstract of US data on Alzheimer's disease (AD), the most common type of dementia. In the fourth of a series on AD, *Assisted Living Consult* reprints a portion of the Alzheimer's Association report. This section discusses use and costs of care. The first article in the series was on page 24 of the March/April issue of ALC; the second article on page 32 of the May/June issue; and the third on page 36 of the July/August issue (www.assistedlivingconsult.com/issues/04-04/alc78-Alzheimers-721.pdf). The November/December issue of *ALC* will contain the final article in the series.

People with AD and other dementias are high users of healthcare and long-term care (LTC) 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 AD and other dementias have Medicare, and their high use of hospital and other healthcare services translates into high costs for Medicare. Medicaid pays for nursing home and other LTC services for some people with very low income and assets, and high use of these services by people with AD 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 AD 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 AD and other dementias and the indirect costs to business for employees who are caregivers of persons with AD and other dementias amount to more than $148 billion annually, including:

- $91 billion in Medicare costs for care of beneficiaries with AD and other dementias in 2005; this figure is projected to increase to $160 billion by 2010 and $189 billion by 2015.[1]
- $21 billion in state and federal Medicaid costs for nursing home care for people with AD and other dementias in 2005; this figure is projected to increase to $24 billion in 2010 and $27 billion in 2015.[1]
- $36.5 billion in indirect costs to business for employees who are caregivers of people with AD and other dementias.[2]

The $148 billion does not include the costs of care for people with AD and other dementias that are paid by the US Department of Veterans Affairs, private healthcare and LTC insurance, and other public and private payers. It also does not include the high out-of-pocket expenditures for people with AD and other dementias and their families for healthcare, LTC, 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 AD and other dementias grows with the aging of our population.

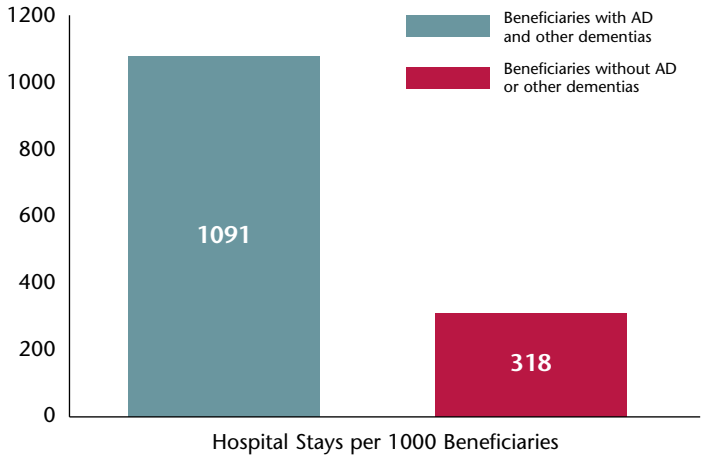
Use and Costs of Health Care

People with AD and other dementias have more than 3 times as many hospital stays as other older people. Their total Medicare costs and Medicare costs for hospital care are more than 3 times higher than those of other Medicare beneficiaries. Use and costs of healthcare services for people with AD 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 (CHF), who also have AD or other dementias have much higher use and costs of healthcare services than people with these other medical conditions but no AD or dementia.

Use of Healthcare Services by Setting

Older people with AD and other dementias have many more hospital stays and slightly more physician

Figure 1.
Hospital Stays per 1000 Medicare Beneficiaries Aged 65+ for Beneficiaries With AD and Other Dementias Compared With Stays of Other Medicare Beneficiaries, 2000



Source: Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare.* Washington, DC: Alzheimer's Association; 2003.

visits than other older people. As noted earlier, almost all people aged 65 and over have Medicare, and the following information about hospital stays and physician visits is based primarily on data from Medicare claims.

- In 2000, Medicare beneficiaries aged 65 and over with AD and other dementias were 3.4 times more likely than other Medicare beneficiaries in the same age group to have a hospital stay (1091 hospital stays per 1000 beneficiaries with AD and other dementias compared with 318 hospital stays per 1000 beneficiaries for other Medicare beneficiaries; Figure 1).[3]
- In 2000, Medicare beneficiaries aged 65 and over with AD and other dementias had an average of 1.3 times more physician visits than did other Medicare beneficiaries in the same age group (14.5 physician visits per beneficiary with AD and other dementias compared with 11.3 physician visits per beneficiary for other Medicare beneficiaries).[3]
- On average, at any one time, about 25% of older hospital patients are people with AD and other dementias.[4]

Impact of Coexisting Medical Conditions

Most people with AD and other dementias have 1 or more other serious medical conditions. For example, 30% of Medicare beneficiaries aged 65 and over with AD and other dementias also have coronary heart disease, and 28% have CHF (Table 1).[5]

As shown in Table 1, the percentages of Medicare beneficiaries with AD and other dementias who also have various coexisting medical conditions adds up to more than 100%. This means that many Medicare beneficiaries with AD and other dementias have more than 1 other serious medical condition. Alzheimer's disease and other dementias greatly increase the use of healthcare services for people with other serious medical conditions, and conversely, these other medical conditions increase the use of healthcare services for people with AD and other dementias. In 2000, for example, Medicare beneficiaries with diabetes but no AD or other dementia had 587 hospital stays per 1000 beneficiaries compared with 1589 hospital stays per 1000 for

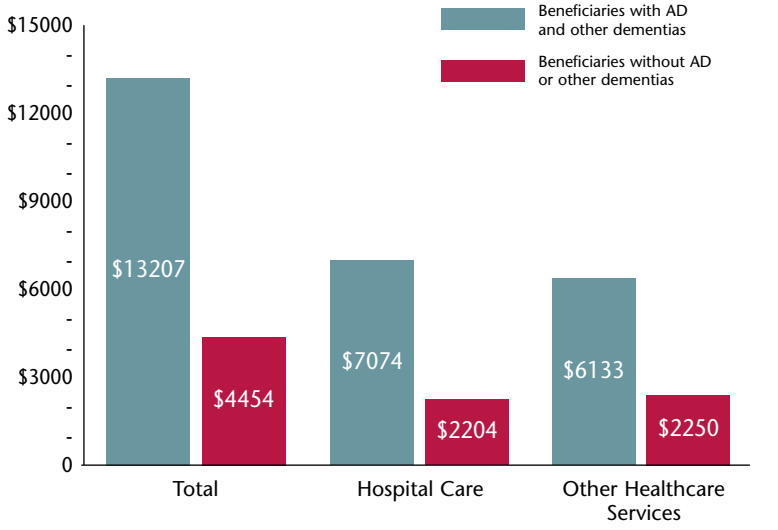
Table 1.
Percentage of Medicare Beneficiaries Aged 65+ With AD and Other Dementias Who Had Specified Coexisting Medical Conditions, 1999[5]

Coexisting Condition	Percentage (%) With AD 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

beneficiaries with diabetes and AD or another dementia.[3] Likewise, in 2000, Medicare beneficiaries with CHF but no AD and other dementias had 1259 hospital stays per 1000 beneficiaries compared with 1901 hospital stays per 1000 for beneficiaries with CHF and AD or another dementia.[3]

People with AD and other dementias are most often hospitalized for treatment of their coexisting medical conditions,[6,7] and data from an analysis of 1999 Medicare claims suggest that some of these hospitalizations are potentially preventable.[5] 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 aged 65 and over with AD and other dementias were 2.4 times more likely than other Medicare beneficiaries in that age group to have a potentially preventable hospitalization.[5]

Figure 2.
Total Medicare Costs per Beneficiary and Medicare Costs for Hospital and Other Healthcare Services for Beneficiaries Aged 65+ With AD and Other Dementias Compared With Costs of Other Medicare Beneficiaries, 2000



Source: Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare.* Washington, DC: Alzheimer's Association; 2003.

Medicare Coverage

Medicare costs for people with AD 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 aged 65 and over with AD and other dementias were 3 times higher, on average, than for other older Medicare beneficiaries ($13,207 versus $4454 per beneficiary). Average Medicare costs per beneficiary for hospital care for those aged 65 and over with AD and other dementias were 3.2 times higher, on average, than for other older Medicare beneficiaries ($7074 versus $2204; Figure 2).[3]
- Total Medicare costs per beneficiary for beneficiaries with diabetes and AD or another dementia were $19,994 in 2000, compared with $8011 for beneficiaries with diabetes but no AD or other dementia. Likewise, total Medicare costs per beneficiary for beneficiaries with CHF and AD or another dementia were $22,939 in 2000, compared with $15,441 for beneficiaries with CHF but no AD or other dementia.[3]
- Average Medicare costs per beneficiary for hospital care for beneficiaries with diabetes and AD or another dementia were $10,943 in 2000, compared with $4207 for beneficiaries with diabetes but no AD or other dementia.[3] Likewise, average Medicare costs per beneficiary for hospital care for beneficiaries with CHF and AD or another dementia were $13,178 in 2000, compared with $9441 for beneficiaries with CHF but no AD or other dementia.[3]

Costs to Individuals and Their Families

Although Medicare covers most hospital and other healthcare services for older people with AD and other dementias, individuals and their families still incur high out-of-pocket expenditures for Medicare premiums, deductibles, copayments, and other healthcare costs that are not covered by Medicare.

According to an AARP analysis, Medicare beneficiaries aged 65 and over spent an average of $3455 (22%) of their average income on health care in 2003. About 45% of those expenditures were for Medicare Part B premiums, private Medicare plans (such as HMOs), and private supplemental insurance.[8]

Out-of-pocket expenditures for health care and LTC are higher, on average, for older people with AD 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 $1350 for people with no dementia and $2150 for people with mild or moderate dementia, an increase of $800.[9] For people with severe dementia, average out-of-pocket expenditures were $3010 in 1995, an increase of $1660 from the average for people with no dementia. The study found that the $1660 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.[9] The increase over 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.[9]

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 (see the July/August issue of *ALC*, page 36; www.assistedlivingconsult.com/issues/04-04/alc78-Alzheimers-721.pdf). 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 (AL) 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 AL 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 AL averaging $3000 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 LTC insurance is only an option for those healthy and wealthy enough to purchase policies before developing dementia.

Use of Long-term Care Services by Setting

Seventy percent of people with AD and other dementias are living at home at any one time.[10] Most of these people receive unpaid help from family members and friends. Many also receive paid home and community services, especially as their AD 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 1 daily activity found that[11]:

- 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 3 or more daily activities) were also cognitively impaired.

Eventually, many people with dementia enter AL 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 LTC settings.[10]

Those with dementia represent about one-quarter of elderly users of home care services and about half of users of adult day center services, AL residences, 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.[12]
- At least half of the elderly participants in adult day center services have AD or another dementia.[13,14]
- Estimates from various studies indicate that 45% to 67% of AL residents have AD or another dementia.[15] The most recent study (2003) of disease severity shows that about 60% of AL residents with dementia were in the moderate or severe stages of the disease.[15]
- 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.[16] In June 2007, 46.4% of all nursing home residents had a diagnosis of AD or another dementia in their nursing home record.[17]

- Nursing home Alzheimer's Special Care Units had 90,285 beds in June 2007.[18] 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.

Costs to Individuals and Their Families

Although Medicaid covers some LTC costs, families coping with dementia often incur considerable costs in caring for a person with AD or another dementia. Costs are high for care at home or in an adult day center, AL 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.[19]
- Adult day center services cost an average of $61 per day in 2007.[19]
- The average monthly cost for a private, 1-bedroom unit in an AL residence was $2969 or $35,628 a year in 2007. Assisted living residences that provide specialized dementia care often charge additional monthly fees averaging $1110 for that care.[20]
- The average daily cost for a private room in a nursing home was $213 in 2007 or $77,745 a year.[20]
- Medicare beneficiaries aged 65 and older paid 37% of the cost of their nursing home care out of pocket in 2002.[21] US National Health Expenditure Accounts show that consumers' out-of-pocket payments funded 26% of all spending on nursing homes in 2006.[22]

Affordability of Long-Term Care

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

- Detailed income and asset data are not available for those with AD or other dementias, but the median income for all women aged 65 or older in 2005 was $12,495; for men, it was $21,784.[23] 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, AL, 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.[24] Fifty-seven percent of seniors 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.

Medicaid Coverage

Medicaid covers nursing home care and various LTC 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 because 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 LTC expenses on their own.

- Twenty-nine percent of Medicare beneficiaries aged 65 and older with AD or other dementias were also Medicaid beneficiaries in 2000.[10] Of that total, about half were nursing home residents, and the rest lived in the community.
- Among nursing home residents with AD and other dementias, 51% relied on Medicaid to help pay for their nursing home care in 2000.[10]
- 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 AD will increase rapidly, from $21 billion in 2005 to $38 billion in 2025.[1]
- Among older people with AD and other dementias who were living in the community in 2000, 18% relied on Medicaid to help pay for their care.[10] 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.

Long-term Care Insurance

In 2002, about 6 million people had LTC insurance policies, which paid out $1.4 billion for services for people who filed claims in that year.[25] Private health and LTC insurance policies funded only about 7% of national LTC spending in 2004.[26] However, LTC 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 LTC insurance policies for the first time during 2003, 2004, or 2005 shows that about two-thirds of persons filing claims for care in AL (63%) and nursing homes (64%) had cognitive impairment.[27] The figure was 28% for those filing claims for paid home care.

Use and Costs of Hospice Care

People who are dying from demen-

tia generally are bed-bound and cannot carry out any daily activities without help. They may stop eating and drinking and most likely cannot say that they are in pain. One study showed that hospital patients with AD often had untreated or undertreated pain.[28] Palliative care is a service designed to relieve such symptoms, and the Medicare hospice benefit is one way to fund that care.

Use of Hospice Services

Hospices specialize in pain management, comfort care, spiritual services, and bereavement for families. Individuals can receive hospice in their homes, AL 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.[29]

Consistent with the general population, people dying with dementia underuse hospice. A study investigated hospice referral in people aged 65 and over 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.[30] 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% of all hospice admissions in 2006.[31,32]
- Medicare data from the Centers for Medicare & Medicaid show that AD and senile dementia are among the top 10 diagnoses for beneficiaries receiving hospice services. Alzheimer's is number 5 and senile dementia number 8.[33]
- The number of Medicare beneficiaries receiving hospice due to AD 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.[33]

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

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