

Barriers to Quality End of Life Care for People with Dementia

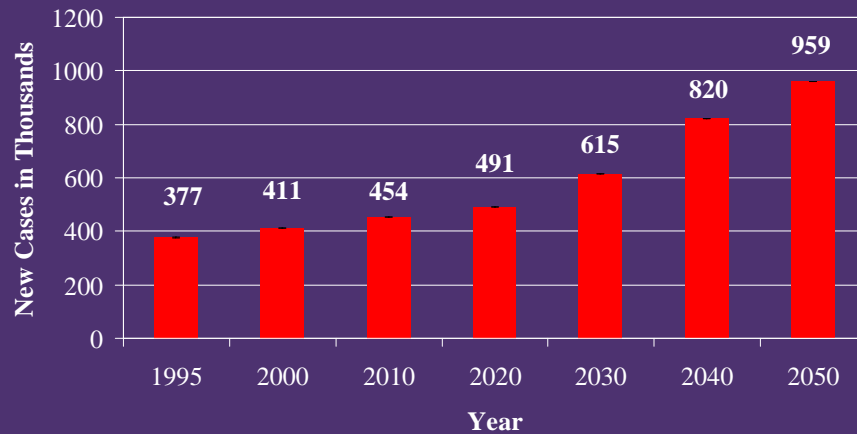
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Alliance for Health Care Reform Briefing
on End of Life Care
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Alzheimer's Disease (AD) Prevalence

- 5 million+ people in the U.S. have Alzheimer's disease
 - 4.9 million people over age 65
 - 200,000 - 500,000 people < 65 with early onset Alzheimer's and other dementias
- Someone develops Alzheimer's every 72 seconds

Estimated Number Of New Alzheimer Cases (In Thousands)



Source: Hebert et al. (2001). Alzheimer's Disease and Associated Disorders, 15(4), 169-173.

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Alzheimer's Disease a *Leading* Cause of Death

Centers for Disease Control reported
mortality rates (2004):

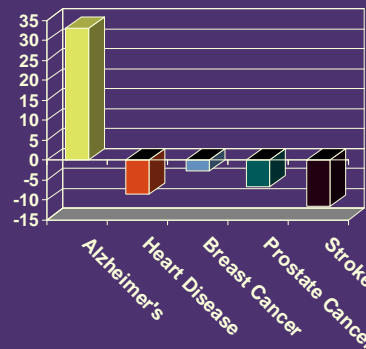
- Alzheimer's is the 5th leading cause of death for people 65+
- 7th leading caused of death for all ages

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Mortality Rates for Alzheimer's and other Leading Causes of Death (2000-2004)

Deaths attributed to:

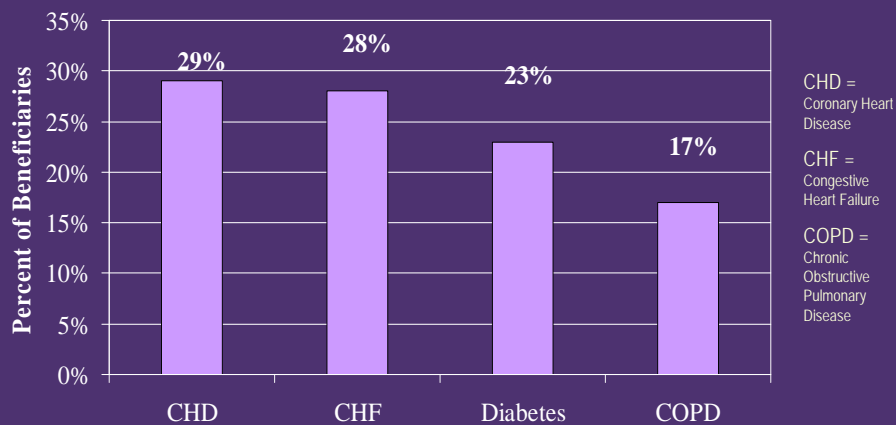
- Alzheimer's - up 33%
- Heart Disease - down 8%
- Breast Cancer - down 2.6%
- Prostate Cancer - down 6.3%
- Stroke - down 10.4%



Source: U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, Mortality Data From the National Vital Statistics System.

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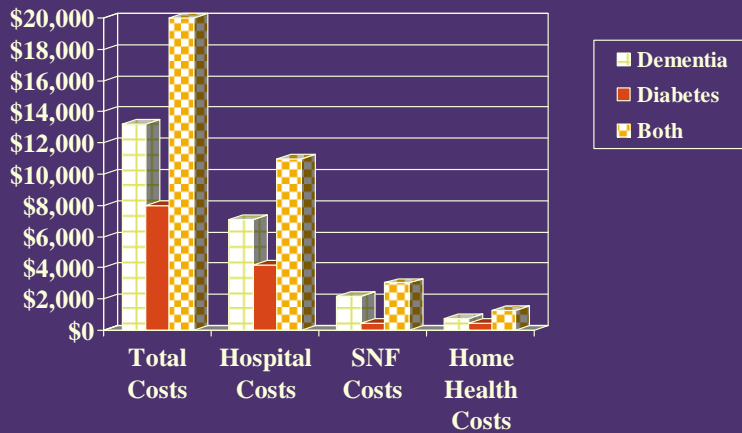
Percent of Beneficiaries with Dementia Having Selected Co-Existing Conditions, 2000



Source: Centers for Medicare & Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

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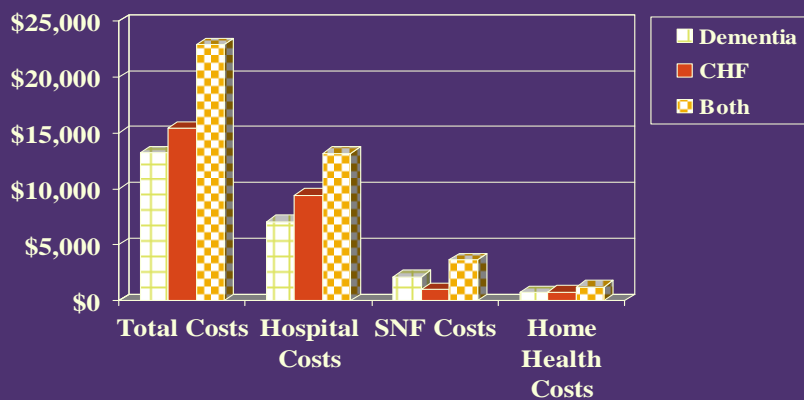
Average Medicare Costs for People with Reported Dementia, Diabetes, or Both, 2000



Source: Centers for Medicare & Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

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Average Medicare Costs for People with Reported Dementia, Congestive Heart Failure (CHF), or Both, 2000



Source: Centers for Medicare & Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

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Late Stage Dementia Issues

- Dementia leads to complete dependence (e.g., incontinence, inability to swallow) and death.
- Individual's inability to make decisions or communicate means loss of control over care decisions.
- Many families, providers, and professionals do not understand the progression and severity of dementia.
- Dementia caregivers experience the most stress and get little relief.

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End of Life Settings

- 67% of dementia-related deaths occur in nursing homes.
- Frequent transfers between nursing homes & hospitals.
- Hospice underused but growing for Alzheimer's Disease population
 - In 2000, AD = 6.3% of hospice pop with average length of stay of 44.9 days
 - In 2005, AD = 9.5% of hospice pop with average length of stay of 72.4 days

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Policy Barriers and Solutions: Management

- **Barrier:** Ineffective management of dementia care
 - Inappropriate transfers (financial incentives)
 - Inadequate physician payment for time required
 - Aggressive interventions vs palliative care
 - Diagnosis and orders not following the person
- **Solution:** Appropriate physician office payment for assessment and chronic care management

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Policy Barriers and Solutions: Access

- **Barrier:** Inadequate access to palliative care
 - Hospice medical eligibility criteria
 - Duration of benefit
- **Solutions:** Alternative hospice medical eligibility criteria and palliative care benefit

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Policy Barriers and Solutions: CMS Concerns

- **Barrier:** CMS concern about hospice use
 - Increasing use by people with dementia
 - Hospice and nursing homes may duplicate services.
- **Solution:** CMS collect data on use of hospice and review use by setting

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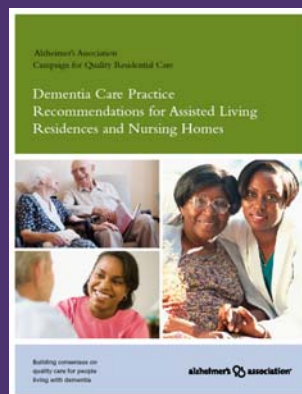
Policy Barriers and Solutions: Knowledge

- **Barrier:** Consumers and providers' inadequate knowledge about the progression and terminal nature of dementia
- **Solutions:** Education & training
 - Medical training
 - Consumer education
 - Nursing and nurse aide training

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Policy/Practice Actions

- The Geriatric Assessment & Chronic Care Coordination Act - S 1340/ HR 2244 (Lincoln Bill)
- CMS review of use of Medicare hospice benefit
- State and federal training requirements
- Dementia care practice recommendations.



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Alzheimer's Association Resources

- *End of Life Care for People with Dementia in Residential Care Settings* (http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp)
- *Barriers to Quality End of Life Care for People with Dementia in Residential Care* (in packet)
- Dementia care practice recommendations on end of life care (August 2007)

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