



# Dementia Capable Care: How do we get there?

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# The Landscape of Alzheimer's

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Facts

&

Figures

MORE THAN  
**5 MILLION**

AMERICANS ARE LIVING WITH ALZHEIMER'S

**1 IN 3 SENIORS**  
DIES WITH ALZHEIMER'S  
OR ANOTHER DEMENTIA



IN 2015, MORE  
THAN 15 MILLION  
CAREGIVERS  
PROVIDED AN  
ESTIMATED

**18.1 BILLION  
HOURS OF  
UNPAID CARE**

ALZHEIMER'S COSTS CAREGIVERS  
MORE THAN THEIR TIME

FAMILY CAREGIVERS SPEND MORE THAN  
**\$5,000 A YEAR**  
CARING FOR SOMEONE WITH ALZHEIMER'S

FOR SOME FAMILIES THIS MEANS  
**MISSING A VACATION**

BUT FOR OTHERS, IT MAY MEAN  
**GOING HUNGRY**

2016

**EVERY  
66 SECONDS**

SOMEONE IN THE UNITED STATES  
DEVELOPS THE DISEASE



IN 2016, ALZHEIMER'S AND OTHER  
DEMENTIAS WILL COST THE NATION

**\$236 BILLION**

IT  
KILLS  
MORE  
THAN

BREAST AND  
PROSTATE CANCER  
COMBINED

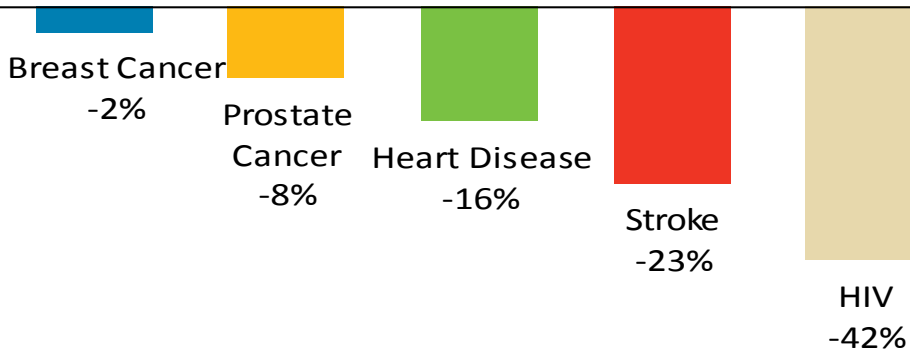


# Alzheimer's on the Rise

- *Change in the # of Deaths: 68%*
- *Between 2000 and 2010*

Alzheimer's  
Disease  
68%

- 6<sup>th</sup> leading cause of death across all ages
- 5<sup>th</sup> leading cause of death for those aged 65 and older
- Only cause of death among the top 10 in America without a way to prevent, cure or even slow its progression.



Based on preliminary 2010

# Pennsylvania



# Number of deaths from Alzheimer's disease in 2013

**3,271**



Medicaid costs of caring for people with Alzheimer's, 2016

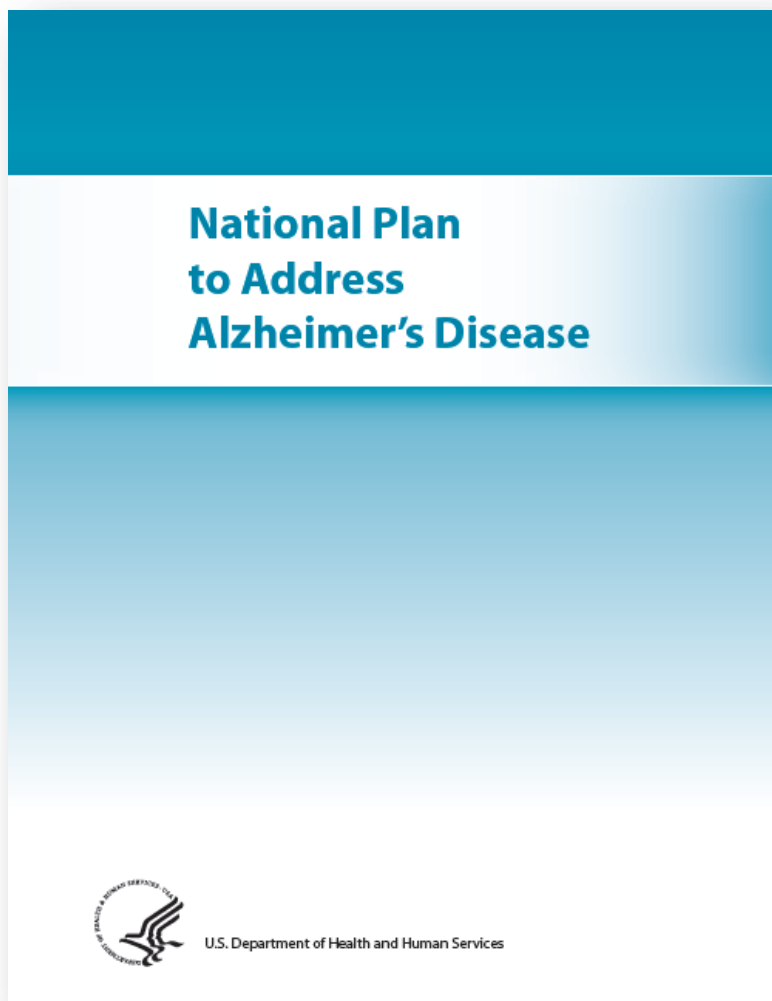
**\$3,209**  
MILLION



Number of Alzheimer's and dementia caregivers, hours of unpaid care, and costs of caregiving

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2013	669,000	762,000,000	\$9,492,000,000	\$456,000,000
2014	671,000	765,000,000	\$9,304,000,000	\$472,000,000
2015	673,000	766,000,000	\$9,390,000,000	\$488,000,000

# Addressing the Epidemic



## Key strategies:

1. Prevent and effectively treat Alzheimer's disease by 2025.
2. Optimize care quality and efficiency.
3. Expand supports for people with Alzheimer's disease and their families.
4. Enhance public awareness and engagement.
5. Track progress and drive improvement.

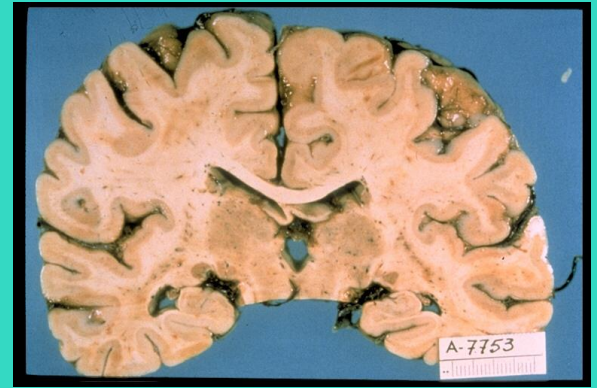
# The Need for Medical and Long-term Services and Supports

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# Alzheimer's disease

- Causes problems with:
  - Memory
  - Thinking
  - Behavior
- Is not a normal part of aging.
- Is the most common form of dementia. Others include:
  - Vascular dementia
  - Mixed dementia
  - Dementia with Lewy bodies
  - Frontotemporal dementia
  - Parkinson's disease
- Its symptoms can vary among individuals.
- Leads to nerve cell death and tissue loss throughout the brain, affecting nearly all its functions, and is therefore progressive.



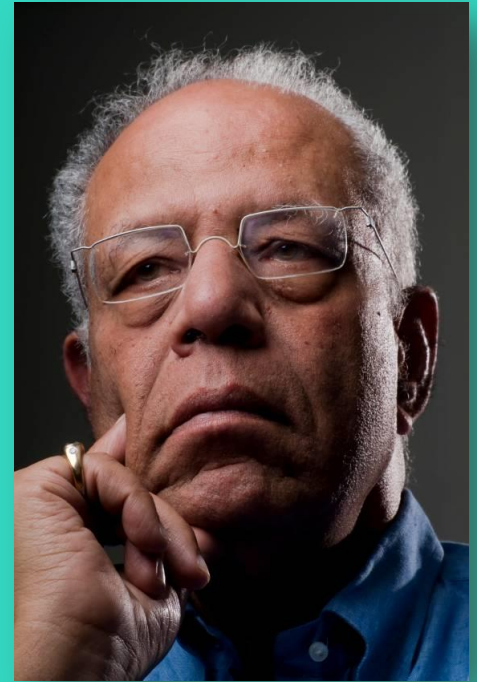
Average  
lifespan post  
DX=8 years





# Alzheimer's disease

- **Has no cure**
- **Requires behavioral and environmental interventions**
  - Are the most effective means of managing the journey
  - Anti-psychotic medications should be a very last resort
- **Current treatment options offer modest help in early stages:**
  - Cholinesterase inhibitors
  - Memantine



# Dementia Capable Communities

\*Adapted from “Dementia-capable States and Communities: the Basics”

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# Model Conditions

Given the impact of dementia on people and communities, service systems that wish to be dementia-capable should consider adopting key aspects of a model proposed by U.S. Administration for Community Living/Administration on Aging:

1. Education
2. Identification
3. Eligibility Criteria & Resource Allocation
4. Person & Family Centered Services
5. Staff Training
6. Quality Assurance
7. Dementia Friendly Communities

# Education

- Risk factors
- Signs of cognitive problems
- Symptom management
- Support programs
- Research opportunities
- Healthy Brain Initiative
  - The Public Health Road Map for State and National Partnerships, 2013–2018

# Public Health Alzheimer's Resource Center

## Healthy People 2020

**Objective 1:** Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis.

**Objective 2:** Reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer's disease and other dementias.



**Goal:** Reduce the morbidity and costs associated with, and maintain or enhance the quality of life for, persons with dementia, including Alzheimer's disease.

# Identification

Need for timely, accurate diagnosis to rule out reversible causes of dementia or conditions that resemble it.

- improves access to medical and support services
- provides an opportunity to make legal, financial and care plans while the affected individual is still capable
- may reduce health care costs by delaying placement in a nursing home

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## Health Care Professionals and Alzheimer's alz.org | hcps

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# Eligibility Criteria & Resource Allocation

...take into account the impact of cognitive disabilities & model dementia-capable service systems recognize:

1. people with dementia use more and different services than people with physical disabilities and
2. rely on caregivers to remain in their communities.

*Research using data from the Health and Retirement Study found that older people with cognitive disabilities who needed help with daily activities **used twice as many hours of paid care** on average as people who had physical disabilities only. People with dementia often need constant supervision and special services due to memory and behavior symptoms. Some states have accommodated these needs.*



# Person & Family Centered Services

- Foundation of good care focuses on *Personalized Needs* of a person with AD in all realms.
  - Psychological
  - Physical
  - Social
  - Safety



# Developing a “new normal”

- **Focus:** retained abilities, strengths, non-pharmacological interventions, goals, preferences, service needs and desired outcomes
- **Attitudes:** Person-first (aka, person-centered); continued meaning in living
- **Behaviors:** brain changes PLUS unmet needs, longstanding traits & habits, environmental influences

Find ways to connect

**Words from a caregiver:**

*“Success means that you have found a way to be happy within the confines of this disease.”*



# Staff Training → Quality Assurance

- Minimum federal requirements for 75 hours inadequate for new CNAs in NHs as resident acuity increases (OIG Nurse Aide Training Report, 2002).
- US federal requirements for CNA initial training much lower than in several countries:
  - 16-22 months for health service helpers/assistants in Denmark
  - 2-3 years for care-workers in the Netherlands (Fujisawa & Colombo, 2009)

## Evidence supports additional training

- Increases job satisfaction (Castle, 2010)
- Reduces turnover (Noel et al., 2000)
- Promotes improved care for residents (Horn et al., 2010; Zheng & Temkin-Greener, 2010).

# Dementia Friendly Communities

This concept goes beyond developing dementia-capable health and long-term services and supports. Dementia friendly communities involve improved customer service at participating agencies and businesses, supportive faith or spiritual communities, emergency services that understand dementia, and suitable transportation and public spaces.

e.g. **ACT on Alzheimer's**, which involves more than 50 partners



Minnesotans working together on the impacts of Alzheimer's

Health care that promotes early diagnosis and uses dementia care best practices along the care continuum

Residential settings that offer memory loss services and supports

Dementia-aware and responsive legal and financial planning

Welcoming and supportive faith communities

Businesses with dementia-informed services and environments for customers and employee caregivers

Dementia-friendly public environments and accessible transportation

Dementia-aware local government services, planning and emergency responses

Supportive options for independent living and meaningful community engagement



THE END OF  
ALZHEIMER'S  
**STARTS**  
WITH YOU

*Thank You!*

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