

Alzheimer's Disease and Related Disorders: The Public Health Call to Action

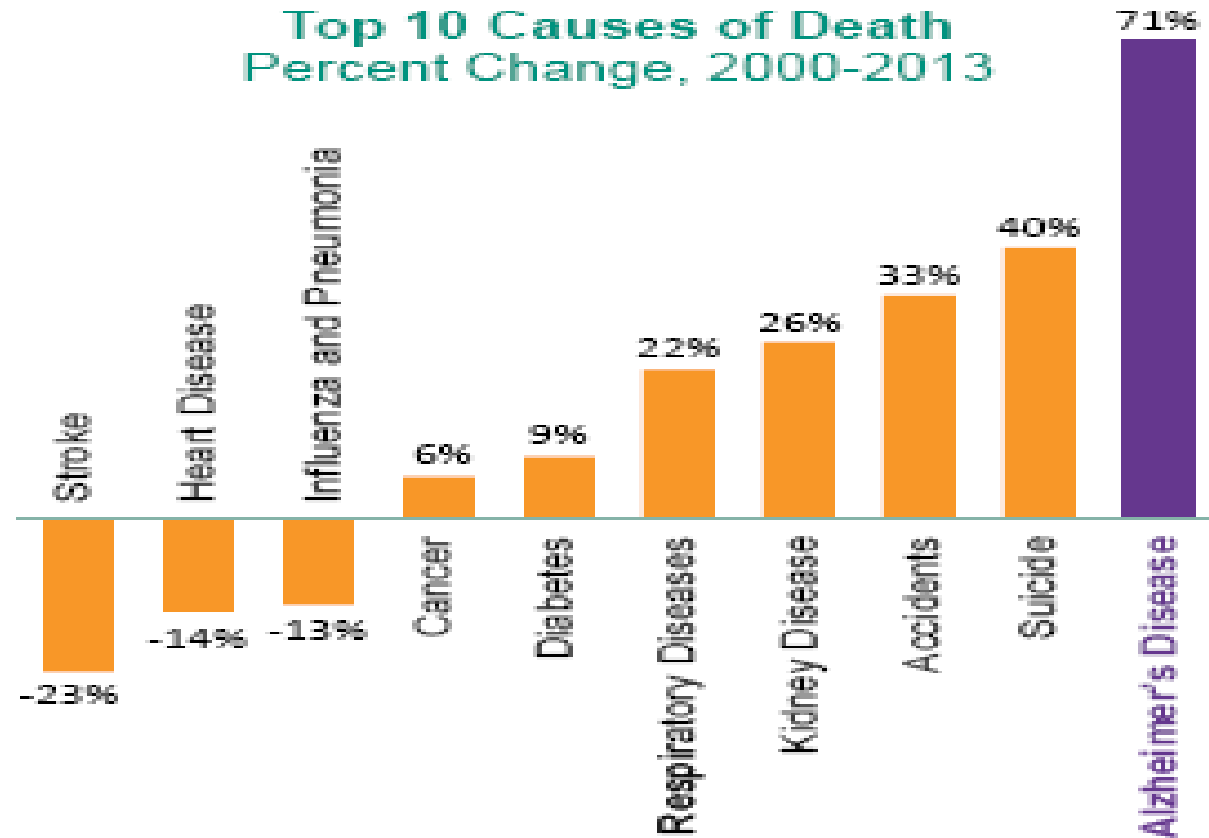
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2015 Alzheimer's Disease Facts and Figures

- Every 67 seconds, an American develops Alzheimer's disease
- 5.3 million Americans live with Alzheimer's
- Alzheimer's is the 6th leading cause of death in the U.S.*
 - 2014 study in Neurology places it as 3rd leading cause of death
- More Americans suffer from Alzheimer's disease than breast cancer and prostate cancer combined
- 1 out of 7 people with Alzheimer's lives alone, making this a community problem
- Baby boomers are entering the age of greatest risk
- 1 in 3 people over the age of 85 have Alzheimer's
- 4% of people with Alzheimer's are under the age of 65.

Alzheimer's Disease: The Escalating Epidemic

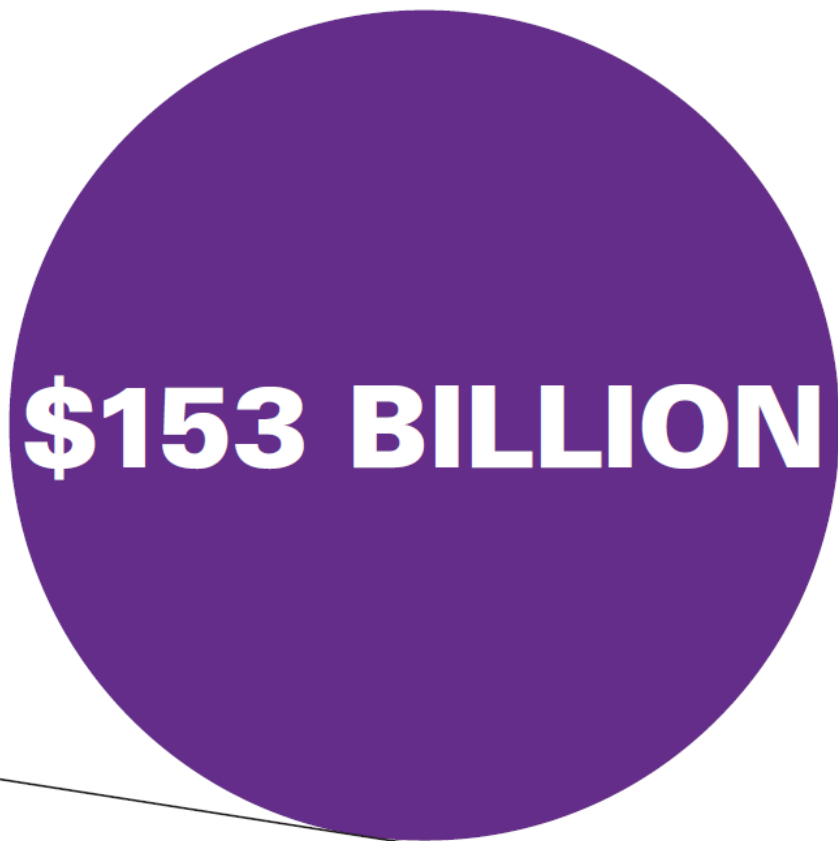


David Satcher, MD
former Director, CDC
former U.S. Surgeon General

Alzheimer's is:
over-taxing state and federal budgets.



Nearly 1 in 5 Medicare dollars
is spent on a person with Alzheimer's



\$586 MILLION

2015 NIH research spending on
finding treatments for Alzheimer's

Source: National Institutes of Health (report.nih.gov/categorical_spending.aspx)

2015 Medicare and Medicaid spending on
caring for people with Alzheimer's

Source: *Changing the Trajectory for Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars.* (alz.org/trajectory)

Cost to Medicare and Medicaid

- Medicare spends nearly **3 times** as much on average for PWD's as for a beneficiary without dementia
- One in every five Medicare dollars is spent on medical care for someone with AD or other dementia
- Medicaid spends nearly **19 times** as much on average for PWD's as for a beneficiary without dementia
- Overall costs to US \$226 Billion projected to increase to 1.1 Trillion in 2050
- The most expensive disease in the United States

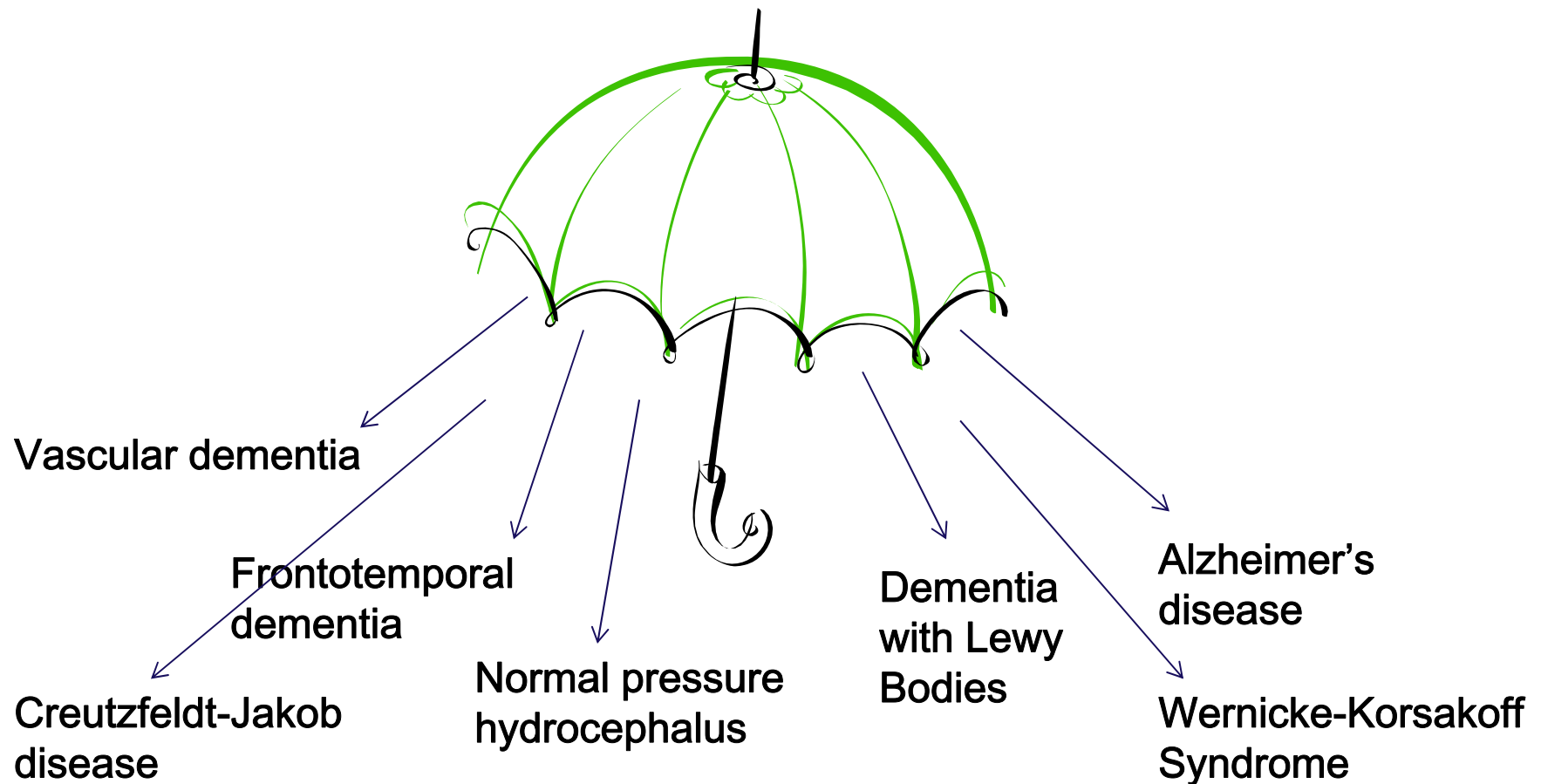
What is Dementia?

An umbrella term for many conditions characterized by similar symptoms:

- Memory loss
- Losses in other cognitive domains (such as judgment, reasoning, language, fluency, orientation, apraxia, agnosia)
- Personality changes
- Impaired judgment and reasoning
- Confusion
- Losses in physical functioning (gait, balance, reflexes, motor planning, etc.)
- Change in ability to manage IADL's (shopping, medication, finances, etc.)
- Eventual dependence on someone else to assist with all ADL's (showering, dressing, toileting, feeding, etc.)

Changes severe enough to affect day-to-day life

What Causes Dementia?



Symptoms of Alzheimer's Disease by Stage

Mild Cognitive Impairment (MCI):

Memory difficulties greater than would be expected for an individual's age and education; some MCI progressed to Alzheimer's disease

Early:

Forgets material just read, loses or misplaces objects, has trouble coming up with just the right word. Has trouble with financial management, daily household chores, doctor's appointments, i.e. Executive Function

Middle:

Asks the same questions over and over, forgets how to use utensils, becomes confused about where they are, begins to wander, is at an increased risk for getting lost, i.e. Has more behavioral symptoms (anxiety and agitation)

Social skills are retained well into the disease. Emotional part of the brain remains intact as well.

Symptoms of Alzheimer's Disease by Stage (cont'd.)

Late Stage:

Unable to communicate with words, becomes incontinent, unable to walk, needs 24-hour care

By age 80, four percent of Americans enter a nursing home. For people with AD, 75% end up in a nursing home by age 80.

On average, 40% of a persons years with AD are spent in the most severe stage of the disease—longer than any other stage

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Special Report: Race, Ethnicity and Alzheimer's Disease

Older African-Americans and Hispanics are considerably more likely than older whites to have Alzheimer's disease and other dementias. (107-108)

- African Americans are about two times more likely to have Alzheimer's and other dementias than whites
- Hispanics are about one and a half more times likely to have Alzheimer's and dementia than whites
- African-Americans and Hispanics are less likely than whites to have a diagnosis of the disease
- There are no known genetic factors that can explain the greater prevalence of Alzheimer's and dementia in African Americans and Hispanics than in whites

What we are learning about managing the risk...

- There are correlations between head trauma, vascular disease and hearing loss and the risk of developing dementia.
- There may be a correlation between heart-healthy and brain-healthy behavior.
 - Manage health factors including body weight, blood pressure, cholesterol and blood sugar
 - Use aerobic exercise to stay physically active
 - Maintain a brain-healthy diet
- Some scientists believe that staying mentally engaged and socially involved is a good defense mechanism.
- There are certain risk factors we cannot control:
 - Age
 - Family history
 - Genetics

Impact on Caregivers

- Emotional Responses
- Anxiety, depression, social isolation
- Stress – higher when compared to other caregivers
- Grief response – chronic sadness, “frozen grief”
- About 1/3 have symptoms of depression
- Comparing PWD with former self is very painful
- Family conflict
- “I feel like I was picked up by a tornado, and thrown around by this disease.”
- “This disease is bigger than you.”
- Worried about finances

Impact on Caregivers

Physical

- Fatigue, reduced immune function, new hypertension and new heart disease.
- More MD visits, more likely to report that health is fair or poor, more emergency room visits and hospitalization.
- Older spousal caregivers might pre-decease the PWD.
- Spousal caregivers at greater risk for dementia themselves.

OPPORTUNITIES FOR GROWTH

“The Deeply Forgetful”

Stephen G. Post, Ph.D.

“People with cognitive disabilities need the sense of safety and peace that love creates; care for them must therefore provide loving attention, which reveals their value to themselves.”

“We must develop a view of personhood that takes into account the emotional, relational, symbolic, and even spiritual capacities of the person.”

“DEBUNKING DESCARTES” – J. Levine

Treatment and Caregiving

- There are some symptom modifying treatments available that will help some people with Alzheimer's, for a period of time. There is no disease modifying treatment yet that will prevent, slow down or stop the disease.
- No new drug in over 10 years.
- In the absence of an effective therapy to prevent, treat or cure Alzheimer's disease and related dementias, the best treatment is superb care.

Key Findings:

- 40% of caregivers spend 40 hours or more per week providing care to a family member or friend with Alzheimer's.
- Two-thirds of respondents missed work in the last year in order to perform caregiving duties, and almost 20% missed the equivalent of over four, full-time work weeks.
- 50% said that services provided in New York City were less than satisfactory or poor.
- A majority of those surveyed encountered barriers to accessing services including affordable quality care.

Crisis for Caregivers

Alzheimer's Disease in New York City

December 2013



Office of the Manhattan
Borough President

Scott M. Stringer
Manhattan Borough President

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New York City Chapter

Alzheimer's Association

ALL services are free of charge for persons with dementia and their families

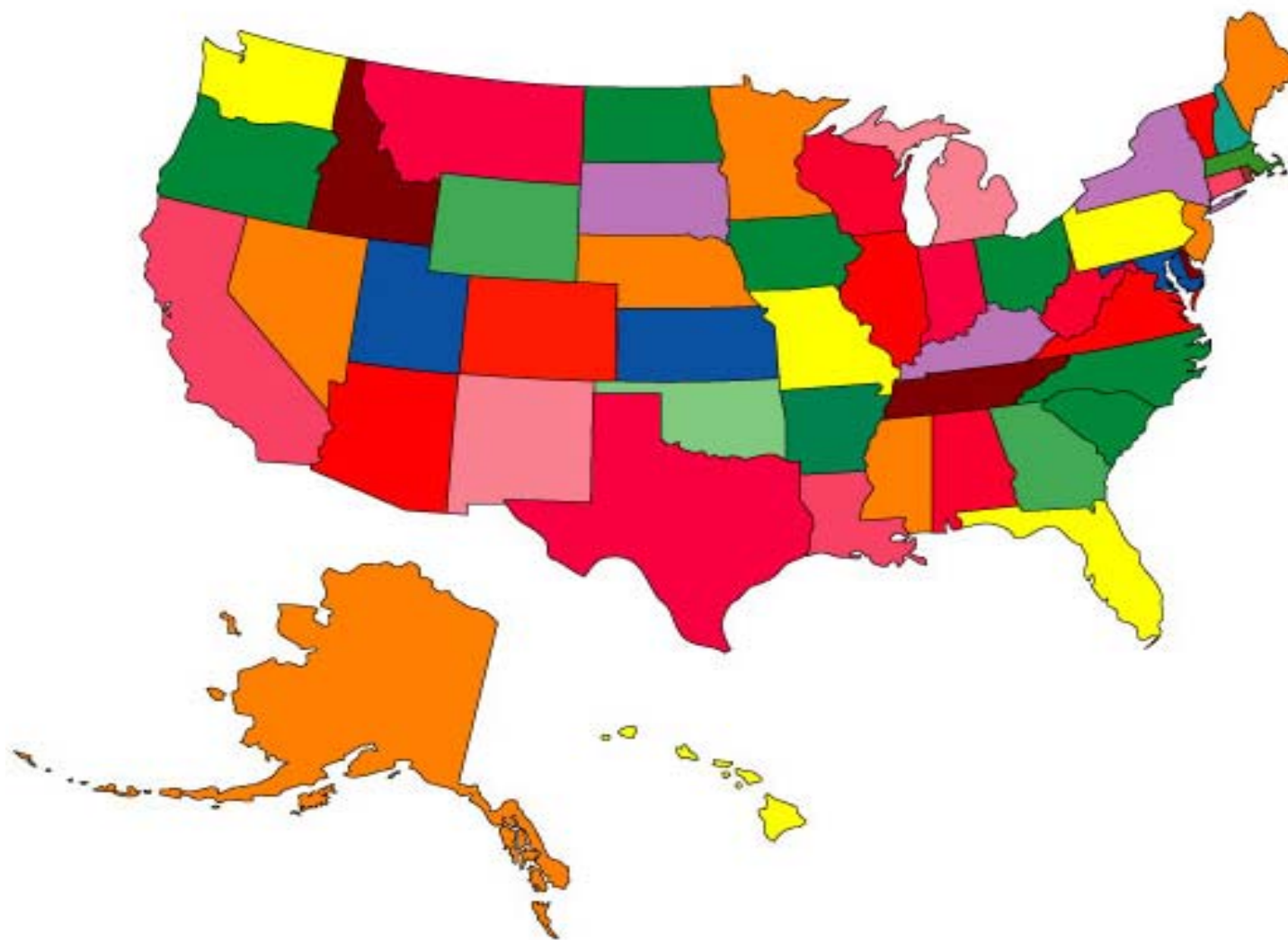
- National Organization with 83 Chapters and over 300 Points of Service
- The largest private funder of research
- The leading organization for care, support, awareness, research and advocacy

Alzheimer's Association New York City Chapter

Local Services for Families and Professionals – all free of charge

- Information and Referral (24-hour helpline 800.272.3900)
- Support Groups: over 110 groups in all five boroughs, run by professionally trained leaders
- Private family and individual Care Consultation
- Education and Training
- MedicAlert®+Alzheimer's Association Safe Return® Program
- Early Stage Services
- Alzheimer's Association TrialMatch
- Alzheimer's & Dementia Caregiver Center (online information and tips)
- Young Professional group, the Junior Committee

Innovative State Initiatives



New York State Funding for Alzheimer's Disease

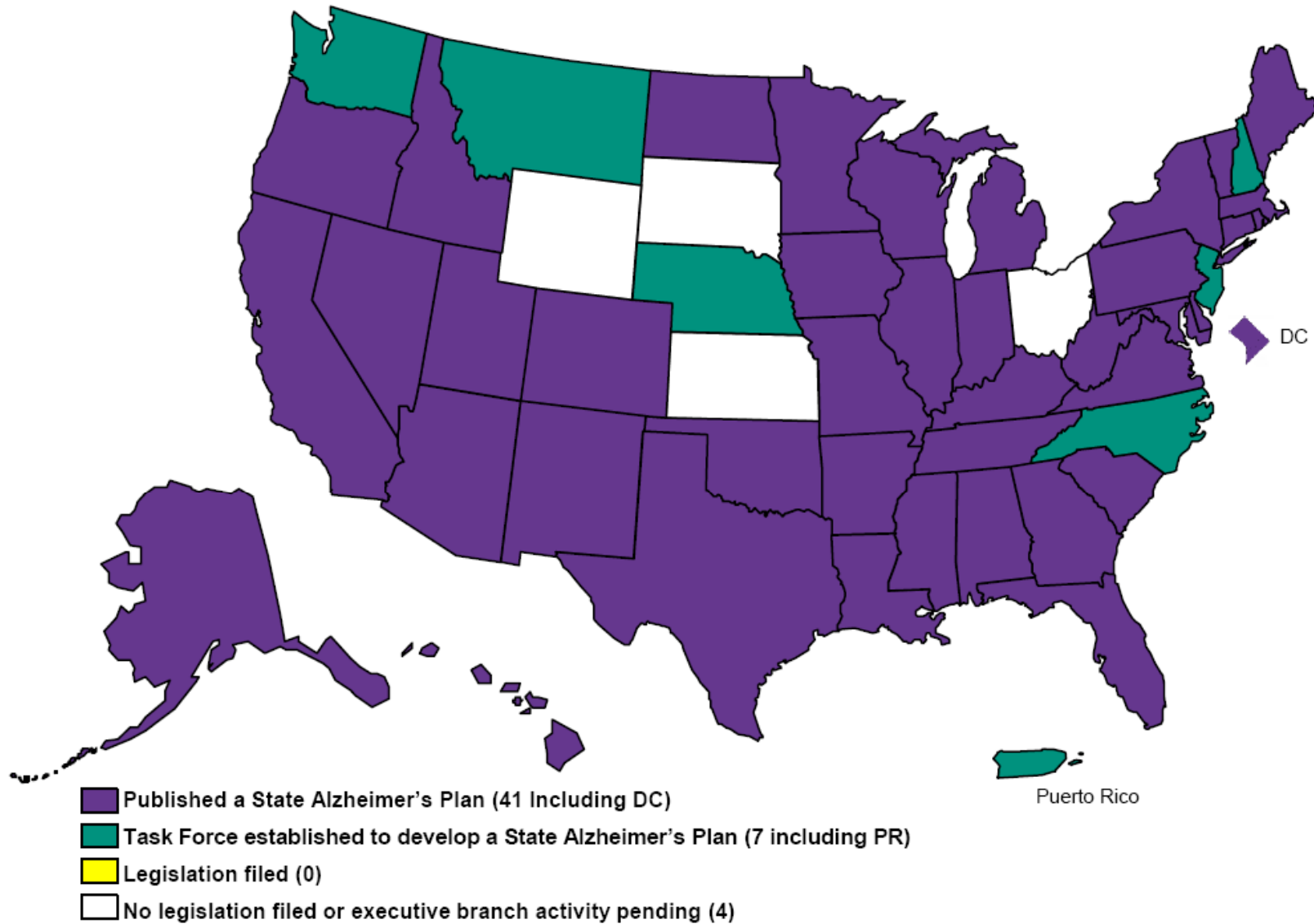
FY2015 State Budget

- Alzheimer's disease care and support services funded at \$1.37 million
 - \$559,000 for Alzheimer's Disease Community Assistance Program
 - \$811,000 for Alzheimer's Disease Assistance Centers

FY2016 State Budget

- Alzheimer's disease care and support services funded at \$25 million
 - \$4 million for Alzheimer's Disease Community Assistance Program
 - \$4 million for Alzheimer's Disease Centers of Excellence
 - \$15 million for respite and caregiver services grants (\$75 M over 5 years)

State Government Alzheimer's Disease Plans



Music & Memory

State Supported Programs

11 States

- Wisconsin
- California
- Ohio
- Texas
- Utah
- Vermont
- West Virginia

Missouri

New Mexico

Illinois

Louisiana

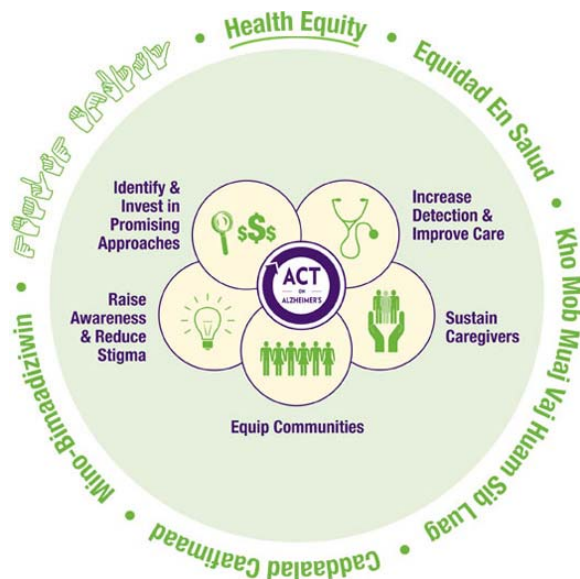
CMP's





Is your community prepared?

Take Action Now!



89,000 Minnesotans age 65+ live with Alzheimer's disease and the number is growing.

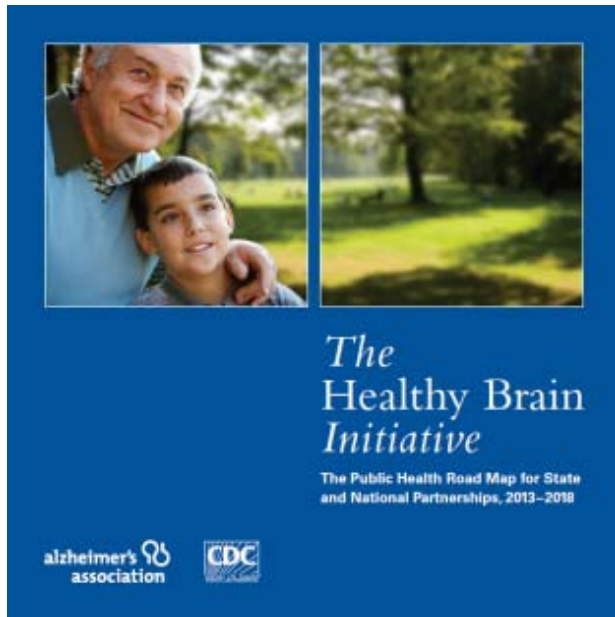
Communities are taking action.

This site provides a toolkit and resources to guide communities in becoming dementia friendly, practice tools to assist professionals in identifying and managing the disease and an economic model of dementia intervention with projected cost savings.

ACT on Alzheimer's is a volunteer-driven collaboration bringing Minnesotans together to create supportive environments for everyone touched by Alzheimer's disease and prepare Minnesota for its impacts.

At a Glance

[Preparing Minnesota Communities \(brochure\)](#)



The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships

23 of 52 (44%) States, DC, and Puerto Rico are implementing one or more road map actions

Looking to hire private home care workers?



DementiaAides.org can help in your search.

alzheimer's  association®

New York City Chapter

24-hour Helpline
800-272-3900

The NYC Chapter of the Alzheimer's Association trains hundreds of home care workers each year through our nationally recognized Dementia Care Training for Professional Caregivers program.

DementiaAides.org provides families looking to hire private home care workers with the opportunity to search and view profiles of graduates of our training program.

Visit [DementiaAides.org](https://www.dementiaaides.org) and begin your search for home care workers today.

A Professional Caregiver's participation in or completion of the Training Program does not constitute a recommendation or endorsement by the Alzheimer's Association, New York City Chapter of the Professional Caregiver's ability, competence, knowledge, quality, timing, legality, or any other aspect whatsoever of the services actually delivered by the Professional Caregiver. Users are urged to conduct their own investigation and research when selecting a Professional Caregiver.

Palliative Care for Advanced Dementia: Why Comfort Matters

A Training and Implementation Program
3 NYC Nursing Homes
based on the Beatitudes Model



Thank You

www.alz.org/nyc

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