Dementia Update: A New National Plan for Alzheimer's Disease Research, Care and Services

June 21, 2012

Featured Speaker

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Caring for people with Alzheimer’s or other dementias will cost the United States $200 billion in 2012, including $140 billion paid by Medicare and Medicaid.

Alzheimer’s: Significant Driver of Health Care Costs

- Medicare payments for an older person with Alzheimer’s and other dementias are nearly 3 times more than for seniors without these conditions.
- Medicaid payments are 19 times higher.

Why is Alzheimer’s such a cost driver?

Nearly 30% of people with Alzheimer’s or another dementia are on both Medicare and Medicaid.

Most people with Alzheimer’s have 1 or more other serious chronic conditions, and dementia complicates the management of other conditions.

A senior with diabetes and Alzheimer’s costs Medicare 81% more than one with diabetes and no Alzheimer’s. An older person with cancer and Alzheimer’s costs Medicare 53% more than one with cancer but no Alzheimer’s.

The number of people with the disease is growing—and fast.

The costs for caring for people with Alzheimer’s and other dementias will soar from $200 billion this year to a projected $1.1 trillion per year by 2050.

This dramatic rise includes a 500% increase in combined Medicare and Medicaid spending and a 400% increase in out-of-pocket spending for families.
An estimated 5.4 million people are living with Alzheimer’s disease today – 5.2 million people age 65 and older and 200,000 under the age of 65 with younger-onset.

Among those 65 and older, 1 in 8 has Alzheimer’s and nearly half of individuals age 85 and older have the disease.

Every 68 seconds, someone develops Alzheimer’s and by 2050 someone will develop the disease every 33 seconds.

If caregivers were the residents of a state – it would be the fifth highest populated state in the country.

- Alzheimer’s is the 6th leading cause of death in the U.S.
- It is the only one among the top 10 causes without a way to prevent, cure, or even slow disease progression. 5 to 15% of all deaths in older people can be attributed to Alzheimer’s disease.

From 2000-2008, Alzheimer’s Disease Deaths Increased 66% while...

Deaths by:

- HIV – declined 29%
- Stroke – declined 20%
- Heart Disease – declined 13%
- Prostate Cancer – declined 8%
- Breast Cancer – declined 3%
- Alzheimer’s disease: INCREASED 66%

Special Report: People with Alzheimer’s & Other Dementias Who Live Alone

- An estimated 800,000 individuals – 1 out of 7 – have Alzheimer’s disease and live alone.
- Up to half of these individuals do not have an identifiable caregiver.
People with Alzheimer’s or another dementia who live alone tend to be:
- older
- female
- less cognitively impaired

People with Alzheimer’s or another dementia who live alone tend to have significant deficiencies:
- managing money
- shopping
- preparing meals
- doing household chores
- managing medications.

Greater Risks for People with Alzheimer’s Who Live Alone Include:
- self-neglect including malnutrition
- untreated medical conditions
- inadequate clothing or housing
- falls
- wandering away from home unattended
- accidental death
- more hospital stays
- higher per person outpatient costs

Advance Planning is Essential for People with Alzheimer’s Who Live Alone

- Advance planning is absolutely critical.
- Begin in the early stages of the disease.
- Allow individuals to:
  - build their care team
  - make legal and financial plans
- Care consultations can also be very helpful for live alones.
- Counsel on:
  - Finances
  - long-term care planning
  - advance directives
  - Assessments of potential safety threats

We Need A Smart Commitment to Alzheimer’s Research

- For every $28,000 Medicare and Medicaid spends on care for individuals with Alzheimer’s and other dementias...
- ...the National Institutes of Health spends only $100 on Alzheimer’s research.
- Today the CDC spends only $2 million total on public health efforts to address dementia.

National Alzheimer’s Project Act Vision Statement

For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer’s disease is a pain they know all too well. Alzheimer’s disease burdens an increasing number of our Nation’s elders and their families, and it is essential that we confront the challenge it poses to our public health.

-- President Barack Obama

National Alzheimer’s Project Act 1-4-11

- Create and maintain an integrated national plan to overcome Alzheimer’s
- Coordinate research and services across all federal agencies
- Accelerate the development of treatments that would prevent, halt, or reverse the disease
- Improve early diagnosis and coordination of care and treatment of the disease
National Alzheimer’s Project Act 1-4-11

- Improve outcomes for ethnic and racial minority populations at higher risk
- Coordinate with international bodies to fight Alzheimer’s globally.
- Create an Advisory Council to review and comment on the national plan and its implementation

Advisory Council Members
http://aspe.hhs.gov/daltcp/napa/#Council

Public
- Chair -- Ronald Petersen, Ph.D., M.D., Mayo Clinic
- 11 members representing:
  - Persons with Alzheimer’s disease
  - Caregivers
  - Providers
  - State government
  - Local government
  - Researchers

Federal Government
- Department of Health and Human Services
- Department of Defense
- National Science Foundation
- Department of Veterans Affairs

Proposed Federal $156 Million Investment

- Investment designed to take immediate action on Alzheimer’s disease without waiting for Congress and support for the National Plan.
- Increasing Alzheimer’s disease research funding. The National Institutes of Health (NIH) immediately dedicated an additional $50 million in FY 2012.
- Sustaining and growing the Alzheimer’s disease research investment. President’s proposed FY 2013 budget has $80 million in new Alzheimer’s disease research funding.
- Congress hasn’t acted on this proposal.

Investment (cont)

- Supporting people with Alzheimer’s disease and their families and educating the public and providers.
- $26 million in FYs 2012 & 2013 to support the goals of the National Plan:
  - Education and outreach: $8.2 million in FY 2012 & 2013
  - Outreach to enhance healthcare providers’ knowledge: $6 million in FY 2012 & 2013
  - Expanded support for people with Alzheimer’s disease and caregivers: $10.5 million in FY 2013
  - Improved data collection and analysis: $1.3 million in FY 2013

Sub-Committees Provide Focus

- Research
- Clinical Care
- Long Term Services and Supports

Draft Plan Development

- Formation of Federal Interagency Workgroup & Advisory Council
- Formal meetings of the Advisory Council and ad hoc meetings of workgroup and subcommittees
- Work to date addresses current programs serving those with Alzheimer’s and their caregivers, possible improvements to programs, and new initiatives.
### Draft of 1st Annual National Alzheimer’s Plan

- National Plan, not just a federal plan.
- Activities include: immediate actions, near term, and longer-range goals
- Requires engagement of public and private sector stakeholders
- Path forward will be contingent on resources, scientific progress, and collaborations
- In subsequent plans, HHS will work with the Advisory Council and stakeholders to add additional actions

### National Alzheimer’s Plan Principles

- Optimize existing resources and improve and coordinate ongoing activities
- Support public-private partnerships in consultation with the Advisory Council
- Transform the way we approach Alzheimer’s disease

### National Alzheimer’s Plan Goals

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

### Goal 1: Prevent and Effectively Treat Alzheimer’s Disease by 2025

- Strategy 1.A: Identify research priorities and milestones
- Strategy 1.B: Expand research aimed at preventing and treating Alzheimer’s disease
- Strategy 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer’s disease –
- Strategy 1.D: Coordinate research with international public and private entities
- Strategy 1.E: Facilitate translation of findings into medical practice and public health programs

### Goal 2: Enhance Care Quality and Efficiency

- Strategy 2.A: Build a workforce with the skills to provide high-quality care
- Strategy 2.B: Ensure timely and accurate diagnosis
- Strategy 2.C: Educate and support people with AD and their families upon diagnosis
- Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings

### Goal 2: Enhance Care Quality and Efficiency

- Strategy 2.E: Explore the effectiveness of new models of care for people with AD
- Strategy 2.F: Ensure that people with AD experience safe and effective transitions between care settings and systems
- Strategy 2.G: Advance coordinated and integrated health and long-term services and supports for individuals living with AD
- Strategy 2.H: Improve care for populations disproportionately affected by Alzheimer’s disease and for populations facing care challenges
Goal 3: Expand Supports for People with Alzheimer’s Disease and Their Families

- Strategy 3.A: Ensure receipt of culturally sensitive education, training, and support materials
- Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being
- Strategy 3.C: Assist families in planning for future care needs
- Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer’s disease
- Strategy 3.E: Assess and address the housing needs of people with AD

Goal 4: Enhance Public Awareness and Engagement

- Strategy 4.A: Educate the public about Alzheimer’s disease
- Strategy 4.B: Work with state and local governments to improve coordination and identify model initiatives to advance Alzheimer’s disease awareness and readiness across the government

Goal 5: Improve Data to Track Progress

- Strategy 5.A: Enhance the federal government’s ability to track progress
- Strategy 5.B: Monitor progress on the National Plan

National Council Recommendations

- Increase initiatives spanning basic, translational, and clinical research
- Research on people with the disease, AND also include study of caregivers
- To address disparities, clinical research studies and activities aimed at translation of research findings into medical practice and to the public should include specific targets for outreach to specific populations

National Council Recommendations

- Expand funding and incentives for health care providers to:
  - become more knowledgeable about dementia
  - encourage individuals to pursue careers in geriatric specialties
- State education and health agencies and others should include key information about AD in all curricula for any profession or career track affecting LTSS
- Redesign Medicare coverage and physicians’ and other health care providers’ reimbursement to:
  - encourage appropriate diagnosis of AD
  - provide care planning to diagnosed individuals and their caregivers

- Assure a robust, dementia-capable system of LTSS is available in every state
- States should ensure that Paraprofessional Caregivers in every venue are adequately trained and compensated.
- The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial)
- HHS should assure that health and related systems funded with federal resources should improve chronic disease treatment and related services for people with AD.
- HHS should develop quality measures and indicators for the comprehensive care and treatment of individuals with AD.
2013 Plan Underway

- Public comments welcome at: http://aspe.hhs.gov/daltcp/napa/
- National Council to reconvene this Summer

New York State Report

- Coordinating Council on Alzheimer’s Disease Services and committees deliberated
- This is the second Report from the Council
- There were significant contributions from the field
- This report includes ground breaking recommendations

NYS Recommendations

- Cognitive screening for everyone age 65+ as part of normal care
- Include key information in all training
- Engage Alzheimer’s Disease Assistance Centers and other partners to develop training
- Explore possibilities for public awareness
- Providers should engage people with dementia and family in advance planning at the earliest opportunity

Resources

- NYS DOH: http://www.health.ny.gov/diseases/conditions/dementia/
- New Federal Site: http://www.alzheimers.gov/
- NAPA: http://aspe.hhs.gov/daltcp/napa/
- Alzheimer’s Association: http://www.alz.org/

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