

# Advisory Council on Alzheimer's Research, Care, and Services

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Tuesday, January 17, 2012  
9:30am



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## Draft Framework Overview

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Helen Lamont



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# Challenges

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- There are no pharmacological or other interventions to definitively prevent, treat, or cure the disease.
- Improved care quality is needed.
- Family members and other informal caregivers, who take on the responsibility of caring for a loved one with AD, need support.
- Stigmas and misconceptions associated with AD are widespread and profoundly impact the care provided to and the isolation felt by people with AD and their families.
- Progress should be coordinated and tracked.



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# Goals

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1. Prevent and Effectively Treat Alzheimer's Disease by 2025.
2. Optimize Care Quality and Efficiency.
3. Expand Patient and Family Support.
4. Enhance Public Awareness and Engagement.
5. Track Progress and Drive Improvement.



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# Proposed Actions to Achieve Goals 4 and 5

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## Strategy 4.A: Educate the public about Alzheimer's disease

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- Design a national education and outreach campaign
- Conduct a national education and outreach campaign on Alzheimer's disease



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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

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- Convene leaders from State and local governments
- Continue to convene Federal partners



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Strategy 5.A: Enhance HHS' ability to track progress

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- Identify major policy research needs
- Identify needed changes or additions to data



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## Strategy 5.B: Monitor progress on the National Plan

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- Track plan progress
- Update the National Plan annually



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## Feedback on Framework and Goals 4 and 5

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Advisory Council



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# Proposed Actions to Achieve Goal 3

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Cindy Padilla



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## Strategy 3.A: Ensure receipt of culturally sensitive education, training, and support materials

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- Identify culturally sensitive materials and training
- Distribute materials to caregivers
- Utilize informatics for caregivers and persons with AD



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### Strategy 3.B: Enable family caregivers to continue to provide care while maintaining their own health and well-being

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- Identify unmet service needs
- Review the state of the art of evidence-based interventions that can be delivered by community-based organizations
- Develop and disseminate evidence-based interventions for people with Alzheimer’s disease and their caregivers
- Expand implementation of effective caregiver interventions
- Support caregivers in crisis and emergency situations



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### Strategy 3.C: Assist families in planning for future long-term care needs

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- Examine awareness of long-term care needs and options to identify barriers to planning
- Expand long-term care awareness efforts



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## Strategy 3.D: Maintain the dignity, safety and rights of people with Alzheimer's disease

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- Educate legal professionals about working with people with Alzheimer's disease
- Monitor, report and reduce use of anti-psychotic agents for persons with Alzheimer's disease in nursing facilities



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## Feedback on Goal 3

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Long-Term Services and Supports  
Subcommittee  
David Hoffman



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# Proposed Actions to Achieve Goal 2

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Shari Ling



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## Strategy 2.A: Build a workforce with the skills to provide high-quality care

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- Collect and disseminate dementia-specific guidelines and curricula for all provider groups across the care spectrum
- Strengthen the direct-care workforce
- Strengthen the State aging workforce
- Support State and local policies



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## Strategy 2.B: Ensure timely and accurate diagnosis

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- Link the public to diagnostic and treatment services
- Identify and disseminate appropriate assessment tools for use in the Medicare Annual Wellness Visit



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## Strategy 2.C: Educate and support patients and families upon diagnosis

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- Educate physicians and healthcare providers about accessing long-term care
- Enhance assistance for people with AD and their caregivers to plan for care needs



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## Strategy 2.D: Identify and implement high-quality dementia care guidelines and measures across care settings

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- Explore dementia care guidelines and measures



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## Strategy 2.E: Ensure that people with AD experience safe and effective transitions between care settings and systems

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- Implement and evaluate new care models to support effective care transitions for patients with Alzheimer's disease
- Develop an AD-specific toolkit on care transitions



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## Strategy 2.F: Advance coordinated and integrated health and long-term care services and supports for individuals living with AD

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- Review evidence on effectiveness of care coordination models for people with Alzheimer’s disease
- Implement and evaluate care coordination models



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## Strategy 2.G: Improve care for populations disproportionately affected by Alzheimer’s disease

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- Create a taskforce to improve care for these specific populations



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# Feedback on Goal 2

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Clinical Care Subcommittee  
Laurel Coleman



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# Proposed Actions to Achieve Goal 1

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Richard Hodes



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## Strategy 1.A: Identify research priorities and milestones

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- Hold an international Alzheimer's disease research summit to identify priorities, milestones, and a timeline (May 2012)
- Solicit public and private input regarding Alzheimer's disease
- Convene a scientific workshop on other dementias in 2013



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## Strategy 1.B: Enhance scientific research aimed at preventing and treating Alzheimer's disease

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- Expand research to identify the molecular and cellular mechanisms underlying Alzheimer's disease, and translate this information into potential targets for intervention
- Continue genetic epidemiologic research to identify risk and protective factors for Alzheimer's disease.
- Increase enrollment in clinical trials and other clinical research through community, national, and international outreach
- Continue clinical trials on the most promising pharmacologic interventions
- Continue clinical trials on the most promising lifestyle interventions



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## Strategy 1.C: Accelerate efforts to identify early and presymptomatic stages of Alzheimer's disease

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- Identify imaging and biomarkers to monitor disease progression
- Maximize collaboration among Federal agencies and with the private sector



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## Strategy 1.D: Coordinate research with international public and private entities

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- Inventory Alzheimer's disease research investments and use a research ontology framework to analyze research portfolio information
- Expand international outreach



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# Feedback on Goal 1

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Research Subcommittee  
Jennifer Manly



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# Public Input

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To provide input on the National Plan, please  
email [napa@hhs.gov](mailto:napa@hhs.gov)



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