

# What to Do About Dementia?

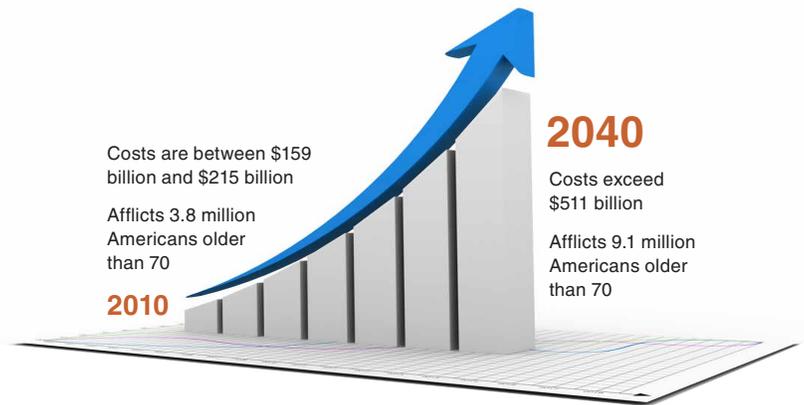
## Policy Options for Crucial Long-Term Care

Millions of Americans already struggle with dementia, a degenerative cognitive condition that costs the United States billions of dollars annually, more than cancer or heart disease. As the nation's population grows grayer, these numbers will only soar. RAND researchers have developed a national blueprint to help decisionmakers improve long-term services and supports that are crucial for those with dementia and those who care for them.



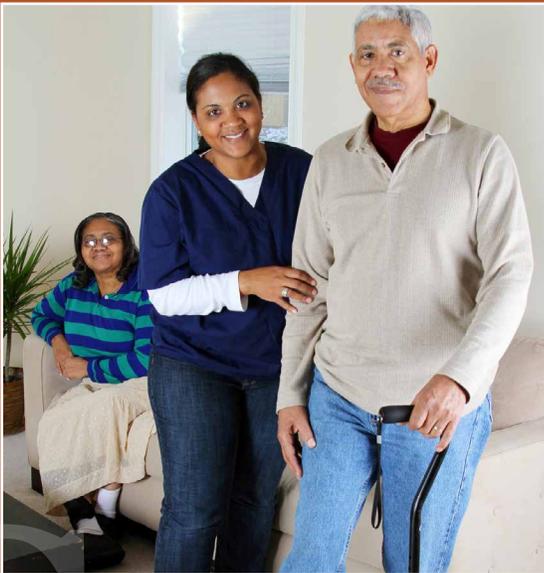
## What Is Dementia?

Dementia is a debilitating condition that tends to afflict older, sicker, and less-educated Americans. Caring for these elderly loved ones becomes ever more demanding, stressful, time-consuming, labor-intensive, heartbreaking, and costly as this condition—which also includes Alzheimer’s disease—progresses. This means that long-term services and supports are critical.



### Costs and Number of People Afflicted Will Soar

## Promote high-quality care centered on individuals and families



- 1 Establish centers-of-excellence models for residential dementia care through life’s end.
- 2 Minimize transitions and improve coordination of care transitions across settings and stages of dementia.
- 3 Expand financial incentives for bundled home, community, and institutional services.
- 4 Establish cross-setting teams for those with dementia, focusing on returning them to their communities.
- 5 Encourage use of quality measurement to ensure that assessment tools get used for those with dementia and their family caregivers.
- 6 Identify those with dementia, jointly with family caregivers.
- 7 Standardize complementary assessment tools for those with dementia and their family caregivers.
- 8 Create new and disseminate existing dementia best practices and training programs for formal caregivers.
- 9 Provide specialized geriatric training during schooling for direct-care professionals.

## The Research Story

After Michael Hurd, director of RAND’s Center on the Study of Aging, published landmark research estimating the extraordinary monetary costs of dementia in coming decades, Michael Rich, RAND’s president and CEO, challenged the RAND community to answer the question: “What can be done about this?” With funding from a generous gift by Charles J. Zwick, a longtime RAND benefactor and onetime RAND trustee, RAND senior behavioral scientist Regina A. Shih put together a team with Thomas W. Concannon, Jodi L. Liu, and Esther M. Friedman. They interviewed key representatives of national, state, and local stakeholder groups. Their views, combined with research on existing national dementia and long-term-care reports, were evaluated to identify policy options with the greatest impact on improving dementia long-term care. Coordination of several policy options together may be necessary to ensure effectiveness.

## Critical Services and Supports

Long-term services and supports for dementia include daily assistance with the basics of living—getting dressed, fed, bathed, and driven around, as well as help with health maintenance. Earlier RAND research estimates these services and supports—and not direct medical attention—comprise the greatest cost in dementia care. The burden for providing this continuing, progressive assistance often falls heaviest on spouses, families, and other loved ones—with women, in particular, reducing their paying work or leaving jobs to provide care.

Further, there are large and growing challenges in this caregiving field—with dementia services, information, training, and financing. For middle-class Americans, dealing with the costs can be particularly daunting.

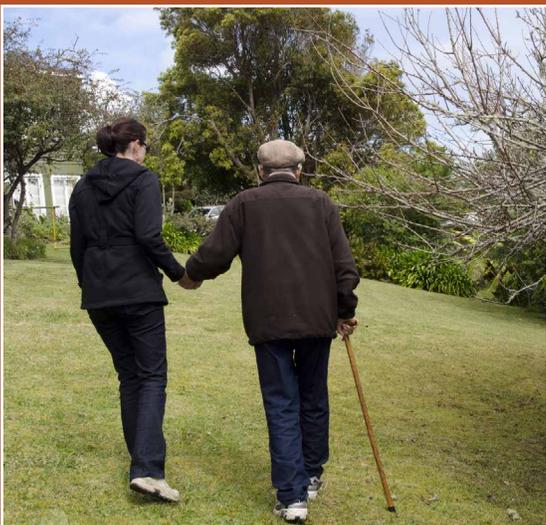
### Increase public awareness and improve early detection of dementia



- 1 Create specialized outreach and education programs about dementia for the public, professional services organizations, and those experiencing younger-onset dementia.
- 2 Encourage providers to use cognitive assessment tools for early detection and recognition of this condition.

# Awareness

### Improve access to long-term services and supports



- 1 Establish new and expand home- and community-based services.
- 2 Integrate web- and other technology-based services.
- 3 Improve existing and create new incentives for the direct-care workforce.
- 4 Expand nurse-delegation laws in all states.
- 5 Broaden Medicaid home- and community-based services waiver programs, self-directed services, and states' infrastructures.
- 6 Include home- and community-based services and managed care in state Medicaid plans.
- 7 Refine Medicare post-acute care and hospice benefits.

# Access

**Life expectancies have increased so that it is possible for two generations within one family to be living with dementia at the same time.**

## Call to Action

This study seeks to serve as a foundation for patients, families, payers, providers, researchers, decisionmakers, and others dealing with dementia to prioritize, plan, implement, and evaluate policy changes to improve long-term dementia care. RAND researchers also identified areas in which more study would be beneficial, including applied research on delivery of dementia long-term services and supports, costs and quality of dementia care under nurse-delegation programs, long-term services and supports financing solutions for the U.S. government and those with dementia, impact of Medicare reforms on dementia care, and uptake of private long-term care insurance and consumers' understanding of Health Insurance Portability and Accountability Act tax incentives.

### Provide better support for family caregivers



- 1 Provide families and volunteer groups with dementia-specific training and information on resources.
- 2 Offer tax incentives to promote family caregiving.
- 3 Expand financial compensation programs to family caregivers.
- 4 Expand family-friendly workplace policies.

# Support

### Reduce dementia's cost burden on individuals and families



- 1 Link private long-term care insurance to health insurance.
  - 2 Create a national voluntary opt-out long-term care insurance program through public-private partnership.
- or —
- 3 Adopt a national single-payer long-term care insurance system.

# Cost

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#### HEADQUARTERS CAMPUS

1776 Main Street, P.O. Box 2138  
Santa Monica, California  
90407-2138  
TEL 310.393.0411  
FAX 310.393.4818

This research brief describes work done jointly in RAND Health and RAND Labor and Population and documented in *Improving Dementia Long-Term Care: A Policy Blueprint*, RR-597, 2014 (available at [www.rand.org/t/RR597](http://www.rand.org/t/RR597)) by Regina A. Shih, Thomas W. Concannon, Jodi L. Liu, and Esther M. Friedman, which resulted from the RAND Corporation's Investment in People and Ideas program. Support for this program is provided, in part, by the generosity of RAND's donors and by the fees earned on client-funded research. The RAND Corporation is a nonprofit research institution that helps improve policy and decisionmaking through research and analysis. RAND's publications do not necessarily reflect the opinions of its research sponsors.



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