

Strategies and milestones for Alzheimer's patient and caregiver support outlined

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The National Alzheimer's Project Act (NAPA) was signed into law in 2011. Over the past five years milestones have been identified to meet the plan's biomedical research goal. However, similar milestones have not been created for the goals on patient care and caregiver support.

Now, the Alzheimer's Association National Plan Care and Support Milestone Workgroup has developed and recommended milestones for patient and caregiver support and outlined achievement strategies.

Among the strategies for attainment of patient care milestones:

- build a workforce with the skills to provide high-quality care
- ensure timely and accurate diagnosis
- educate and support people with Alzheimer's disease and their families on diagnosis
- identify high-quality dementia care guidelines and measures across care settings

Among the strategies for attainment of caregiver support milestones:

- ensure receipt of culturally sensitive education, training, support materials
- enable family caregivers to continue to provide care while maintaining their own health and well-being
- assist families in planning for future care needs
- maintain the dignity and rights of people with Alzheimer's

disease

- Assess and address the housing needs of people with Alzheimer's disease

Milestones include equipping and requiring clinicians to disclose cognitive status to people with clinically consequential cognitive impairment, building upon on existing efforts to reduce inappropriate use of antipsychotics and other psychotropic drugs, and enhancing care coordination.

An estimated 5.4 million Americans currently are living with Alzheimer's disease. Total payments for the care of people with Alzheimer's and other dementias are projected to be \$236 billion in 2016, of which nearly 70 percent will be paid by Medicare and Medicaid.

By 2050, as many as 16 million Americans will have Alzheimer's disease. Unless prevention therapy or actual treatment is developed in the coming decades, total costs of care could reach an estimated \$1.1 trillion in 2050. The workgroup notes that perhaps even more daunting than the costs of care is the burden on individuals and families.

"Alzheimer's takes a large toll on both individuals and family members who care for them," said Alzheimer Association workgroup member Malaz Boustani, M.D., MPH, associate director of the Indiana University Center for Aging Research, Regenstrief Institute investigator, and founder of the Center for Health Innovation and Implementation Science. Dr. Boustani has developed the Healthy Aging Brain Care model, which focuses on older adults with dementia, depression, and delirium. "It's time for the state and federal government as well as health care systems to optimize brain care."

To develop strategies and milestones the workgroup identified best

practices in the care of individuals with Alzheimer's and the support of unpaid caregivers. The experts also studied published state Alzheimer's plans and dementia plans from other countries.

"The Alzheimer's Association's National Plan Care and Support Milestones Workgroup has created the first-ever, single, comprehensive listing of all the public policies needed to create an ideal care and support system for people with Alzheimer's and their families," said Matthew Baumgart, senior director of public policy for the Alzheimer's Association, who served as the lead staff member for the workgroup. "It is crucial that while we invest in more research to find preventions and treatments, we do not forget those who are living with the disease. These care and [support](#) milestones should serve as a call to action to all levels of government."

Provided by Indiana University

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