

Policy changes urgently needed as millions to start receiving early label of Alzheimer's

April 8 2014

How will we, as individuals, and a society, live with brains at risk for Alzheimer's disease dementia? As part of *Health Affairs'* April issue, a theme issue focusing on Alzheimer's, a neurodegenerative disease ethicist and clinician with the Perelman School of Medicine at the University of Pennsylvania offers keen observations to help navigate ethically-charged points on the course of the disease progression.

"The new concept of Alzheimer's disease, as a spectrum of diseases ranging from people with pathological biomarkers but no symptoms, to those with [advanced dementia](#), raises many ethical and policy-related questions for individuals and society as to how we will live with Alzheimer's disease" notes Jason Karlawish, MD, professor of Medicine, Medical Ethics and Health Policy and associate director of the Penn Memory Center. "Unlike other diseases of aging, where people learn they are at a higher risk or in the process of developing symptoms that could precipitate an acute and obvious event, such as a stroke, heart attack or hip fracture, society has not prepared or adjusted for someone to be labeled as 'likely to have Alzheimer's disease [dementia](#)' at some time in the future."

One in three seniors dies with Alzheimer's or another dementia and more than 15 million family and friends serve as caregivers to those with the disease, making Alzheimer's the most expensive condition in the United States. It affects an individual's ability to make decisions and perform daily tasks, such as taking medications safely. The progressive, untreatable illness affects not only patients, but caregivers as well.

Progress in diagnostics and studies to develop prevention treatments may, in the coming years, expand the diagnosis to include persons who are asymptomatic but at risk of developing dementia caused by Alzheimer's disease.

Dr. Karlawish offers suggestions for society and individuals to adapt and prepare:

- Prepare legal, banking and financial service providers to be able to competently assess an individual's decision-making ability. Studies show that Alzheimer's patients - even at mild and moderate stages of the disease - often believe they are more capable at making decisions than their caregivers and physicians see. While patients may be able to express a choice, they may have impairments in their ability to understand and appreciate how an intervention could impact them.
- Caregivers of Alzheimer's patients should be offered or even prescribed to attend caregiver training, just as nutritional consultations and education are part of routine diabetes care.
- Electronic Medical Records (EMRs) should be modified to provide access to caregivers and record their roles.
- Hospice care should be aligned with goals of care for patients with advanced dementia, rather than waiting until the last 6-months of life as currently required for insurance coverage.
- Prediction models and treatment algorithms will need to be developed as "biomarker positive" people are identified to have a brain at risk before symptoms emerge.
- Legal reforms should be sought to minimize discrimination in employment and insurability as people are deemed at risk in pre-clinical stages.

"Whether as patients or as caregivers, we all have Alzheimer's disease," says Karlawish. "The question we must engage with is, How should we

live with it?"

Dr. Karlawish's work is supported by a Robert Wood Johnson Foundation Investigator Award in Health Policy Research and the Marian S. Ware Alzheimer's Disease Program.

Provided by University of Pennsylvania School of Medicine

Citation: Policy changes urgently needed as millions to start receiving early label of Alzheimer's (2014, April 8) retrieved 26 April 2024 from <https://medicalxpress.com/news/2014-04-policy-urgently-millions-early-alzheimer.html>

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