

Safeguards needed to prevent discrimination of early Alzheimer's patients in the workplace

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The changing tide of Alzheimer's diagnosis presents new challenges to the public, physicians and lawmakers: if you could find out your Alzheimer's risk, would you want to know? How should doctors tell you your risk? And what does it mean for the many newly diagnosed Americans still in the workplace?

Despite the emergence of [new tools](#) that can diagnose Alzheimer's earlier, no effective interventions have been identified to stop the progression of the disease. A new report from the Perelman School of Medicine at the University of Pennsylvania tackles the ethical and logistical challenges of safely and effectively communicating a diagnosis of pre-clinical Alzheimer's disease in light of the gulf between diagnosis and treatment. The study appears in the October 11 print edition of [Neurology](#).

Alzheimer's disease is among the most feared diseases of aging. The disease has been known for its role in [memory loss](#) and other clinical symptoms. But increasingly, patients learn they have the disease before symptoms start impacting their ability to function in daily life.

"We need to develop systems now, to navigate the challenges of a pre-clinical Alzheimer's diagnosis," said Jason Karlawish, MD, Professor of Medicine and [Medical Ethics](#), author of the paper and leading voice on the ethics of Alzheimer's. "It's only a matter of time before we are able

identify Alzheimer's before the patient is ill, like we've done with cholesterol and [heart disease](#). Given the unique nature of this disease, which strips people of their independence as the disease progresses, [safeguards](#) are needed to protect those at [high risk](#) or with a pre-clinical diagnosis."

On the individual level, people strongly differ in their desire to know their risk and will react differently to a high Alzheimer's [risk score](#) or diagnosis in the early stages of the disease. In some cases, biomarker test results can be harmful; patients may develop anxiety or serious depression. To safely and effectively communicate a diagnosis of pre-clinical Alzheimer's disease, Dr. Karlawish recommends that researchers and clinicians track the emotional and physical impact of a pre-clinical diagnosis, then develop and disseminate best practices.

When an effective Alzheimer's therapy or intervention is found, a process will be necessary to ensure the patients who stand to benefit most are prioritized accordingly. Both prognostic and predictive evidence should be gauged against not only an individual's risk but the entire population at risk, especially if failure to intervene could cause large numbers of people to be impacted by any disease progression. A "National Alzheimer's Education Program" is proposed, to address how to translate research results into clinical practice for those with pre-clinical disease.

"The Alzheimer's disease label does not equate to disability," said Dr. Karlawish. In order to ensure that patients' daily lives (i.e. driving, financial planning, work status) aren't negatively or prematurely limited, laws and policies need to be revised to prevent stigma, discrimination and, when patients do suffer disability, exploitation.

"The discovery of pre-clinical Alzheimer's disease may be how we prevent the tsunami of Alzheimer's disease dementia, but we must not

drown in the challenges created by our own discovery," warned Dr. Karlawish.

Provided by University of Pennsylvania School of Medicine

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