

# Dementia diagnosis brings relief, not depression

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When it comes to a diagnosis of Alzheimer's disease, what you don't know may not kill you, but knowing the truth as soon as possible appears to be the better approach — one that may improve the emotional well-being of both patients and their caregivers, suggests new research from Washington University in St. Louis.

Medical advances have made it possible to diagnose Alzheimer's at very early stages, but a 2004 review of research found about half of all physicians were still reluctant to inform patients of an Alzheimer's diagnosis. While many physicians fear a dementia diagnosis would only further upset an already troubled patient, this follow-up study found quite the opposite.

"We undertook this study because we wanted there to be some data out there that addressed this question and that we could show to physicians and say, 'Most of the people don't get depressed, upset and suicidal. So, this fear that you have about telling them and disturbing them is probably not legitimate for most people,'" says Brian Carpenter, Ph.D., associate professor of psychology in Arts & Sciences at Washington University.

The study, published in the current *Journal of the American Geriatrics Society*, is co-authored by Carpenter and colleagues in the Division of Biostatistics, the Department of Neurology and the Alzheimer's Disease Research Center at the University's School of Medicine.

In their study, they followed 90 individuals and their caregivers as they came to the Alzheimer's Disease Research Center for an evaluation. Sixty-nine percent eventually got a diagnosis of Alzheimer's disease, but no significant changes in depression were noted and anxiety decreased substantially.

"The major finding is that both patients and their families feel relief, not increased anxiety, upon learning the diagnosis," says study co-author John C. Morris, M.D., the Harvey A. and Dorismae Hacker Friedman Distinguished Professor of Neurology and director of the Alzheimer's Disease Research Center.

"Nobody wants to hear the diagnosis of Alzheimer's disease, but even that is preferable to recognizing there's a problem and not knowing what it is. At least having the diagnosis allows people to make plans for the future, including treatment as appropriate."

One reason an Alzheimer's diagnosis can be comforting to both family members and patients, suggests Carpenter, is that it provides an explanation for what's been going on with the patient. Caregivers, he notes, are often quick to attribute symptoms of dementia to the person, rather than the disease, and patients wonder if they are going "crazy." This study confirms that most patients, regardless of their degree of impairment, tend to experience a sense of relief after getting their diagnosis.

Patients in this 2007 study came from the Alzheimer's Disease Research Center at Washington University. Individuals calling the Center were informed of the study and could choose to participate. Subjects were then interviewed prior to their appointment at the Center and questioned about their mood, family history and expectations for their upcoming exam. After extensive neurological examination, a diagnosis was delivered to the patients and their caregivers and videotaped for the

purposes of the study. Patients and caregivers were then called two days after their appointment and asked the same questions about mood, anxiety, and the results of their diagnosis. This study is one of the first where caregivers have also been asked about mood and emotions. "In this current study, we were interested in gauging psychological reactions shortly after receiving the diagnosis," Carpenter says. "That's why we did the follow-up phone call within a couple of days of their evaluation." Most clinical practice guidelines instruct physicians to tell patients when they suspect Alzheimer's or dementia.

"It's just taking awhile for the clinicians to catch up," says Carpenter.

Carpenter thinks that the number of physicians not telling their patients has gone down since the 2004 study due to a greater public awareness about Alzheimer's.

"We're probably where we were at 10 or 15 years ago with cancer. Years ago when people had cancer their doctors didn't tell them. But we know now that that's improper, and that everybody needs to know if they have cancer. We're going to get there with Alzheimer's disease. [People] are not aware that when you tell the person they're not going to have some sort of catastrophic emotional reaction. The word will get out eventually," says Carpenter.

And there is good reason to spread the word. Earlier diagnoses allow for earlier intervention to delay the effects of Alzheimer's and dementia. Medications currently on the market can delay symptoms in a minor way, in some patients, and may delay institutionalization.

"There are some real practical and financial advantages of even these small incremental gains that we're getting from the medications now. If you can get an extra three to six months in your own house before you have to go to a nursing home, that's a big deal," says Carpenter.

And perhaps more importantly, providing a diagnosis as early as possible gives people a chance to prepare for what is coming."They know that things are going to get worse rather than better and they know that there's going to come a time when they're not going to be able to do the things they can do now, says Carpenter. "They can get ready for what's coming and we can connect them to support services. We can get their family ready ...so they'll be better prepared."

Source: Washington University in St. Louis

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