An 'F' for Online Dementia Tests

If you're concerned about Alzheimer's disease, see a neurologist.

BY GINA SHAW

o you often forget important appointments, family occasions, or holidays?

Do you have trouble managing finances?

Do you sometimes have trouble finding words or finishing sentences?

If you answered yes to all three of these questions, you might have Alzheimer's disease.

And you might not.

Unfortunately, if you enter "Do I have Alzheimer's disease?" into Google or other online search engines, some of the websites that come up claim you can determine whether or not you have dementia by answering a few simple questions, like the ones above, from a home computer.

Many such online tests for Alzheimer's disease (AD) are available. AD is one of the most common causes of dementia, but it isn't the only cause. Dementia can also be caused by problems with blood flow to the brain (vascular dementia), frontotemporal degeneration (a disorder of the brain's frontal lobes that causes personality changes, impaired language skills, and movement problems), Parkinson's disease, and many other conditions.

Some of the websites containing online dementia tests look more legitimate and professional than others. But even the best ones aren't very good, accord-

ing to new research presented at the Alzheimer's Association International Conference in July. (See bit. ly/16QYwwH for more about the conference.)

Julie Robillard, Ph.D., a researcher at the National Core for Neuroethics at the University of British Columbia, put together an "The likelihood that you'll find a **good test for dementia** online is very low."



expert panel of physicians, psychologists, and ethicists to review 16 different online tests that claim to screen for AD. They scored the tests in three main categories: ethical factors such as informed consent (a clear explanation of the implications and consequences of taking the test), scientific validity and reliability (whether or not the test was well designed and likely to yield accurate, repeatable results), and ease of use. In each category, the tests were scored on a scale from 1 (very poor) to 10 (excellent).

The result: everybody flunked. "The tests were consistently poor across all

measures," says Dr. Robillard. "There weren't any outliers, such as a small group that was really good. The likelihood that you'll find a good test for dementia online is very low. It's not about finding the right one: it's about not using them at all."

All 16 of the tests scored either poor or

very poor on ethical grounds. Many had no confidentiality policies at all or didn't explain them well. Others failed to disclose commercial conflicts of interest. Some worded their outcomes unethically or inappropriately—in other words, the test may be set up so that no matter how a person responds, the "results" point to a diagnosis of dementia.

Most of the tests didn't fare any better when it came to accuracy. Three-fourths (12 of the 16) scored poor or very poor on scientific validity and reliability. In other words, they were not useful for the diagnosis of AD.

The tests did, however, appear relatively easy to use by older people, with most of them scoring "fair" in that category. But is it really a good thing if an unethical, inaccurate test is easy to use?

TRYING TO SELL YOU SOMETHING

"These websites range from the well intentioned to the nefarious," says Clinton Wright, M.D., director of the Evelyn McKnight Brain Institute at the University of Florida and a member of the American Academy of Neurology (AAN).



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Dr. Robillard did not disclose the names of the 16 tests reviewed or the websites hosting them, and she has no

plans to do so, she says. But a quick online search for "Alzheimer's test" brings up several. One of the more obviously predatory ones is linked to a supplement company whose 21-question test only asks two questions about memory. The remainder of the test asks what you put into and onto your body. For example, it asks, do you eat sugar or table salt, drink tap water, use deodorant, cook in metal pans, and take antioxidant supplements?

Taking the test with multiple different answer combinations almost always yields the same result: you have a moderate risk for AD. To protect yourself, the website then advises, you should immediately start taking three different supplements daily plus take a test for toxic metal and mineral contamination. Of course, you can order those supplements and that mineral test directly from their website.

Not all websites claiming to offer screening tests for AD and dementia have such an obvious agenda. Still, Drs. Robillard and Wright recommend steering clear even of the ones that seem to be well intentioned. "No regulations or governing bodies exist to help you determine if any of these tests are valid," Dr. Wright says.

Individuals who are concerned about AD and dementia are particularly vulnerable to claims made by online tests. And while you can't take a blood sugar or cardiac stress test on the Internet, many people think memory is easy to assess with just a few questions. "People imagine that just by asking you to remember certain images, or a series of words, you can find out if your memory is working well or not," says Dr. Robillard. Not true, she emphasizes.

ONLINE TESTS COMPOUND STRESS

"Sometimes, people post on our Facebook page that they took a

memory test online and didn't do well. But that doesn't mean they have dementia," says Rick Phelps, a former paramedic who was diagnosed with AD in 2010 and founded Memory People, a Facebook-based AD and memory impairment support group. "We tell our members not to use those tests. Just taking a test like that causes stress, and stress can make memory problems worse. People may think they're even worse off than they are."

Occasionally, someone will try to post to the Memory People Facebook page touting an online test. "We don't allow that," Phelps declares. "We have members—both caregivers and patients—who will do just about anything to find out more about their condition. We won't let people use our site to try to make money."

Diagnosing dementia involves many factors. It includes a complete physical and neurologic examination, blood and urine tests, brain imaging (such as magnetic resonance imaging [MRI] and computed tomography [CT] scans), and a thorough discussion of a person's medical history and symptoms. This should all be done by team of qualified medical profes-

sionals, usually including a neurologist and a neuropsychologist. Neuropsychologists are psychologists who study the relationship between the brain and behavior. They are experts in conducting specialized interviews with patients and families, as well as conducting detailed tests of mental function, including thinking ability, recent and past memory, vocabulary, judgment, and attention span.

Some websites offer reliable information about AD and dementia, but they don't imply that an online test can be used for diagnosis. "You can look up information about memory problems on any number of respected websites, such as the Alzheimer's Association website (alz.org)," says Dr. Wright. "They don't offer tests, but they do provide lists of warning signs and symptoms—and then, they direct you to a trained professional who can help separate true memory problems that could be associated with dementia from just typical, normal age-related changes or other issues, such as depression."

"It's perfectly legitimate for people to look for health information online," agrees Dr. Robillard. "There are a number of valuable resources out there with high-quality information. We aren't saying that people should stay away from online health content. But you should definitely steer clear of anything that claims to be a diagnostic test for AD."

FOR MORE INFORMATION

- For a complete collection of *Neurology Now* articles on Alzheimer's disease and dementia, go to **bit.ly/zG4P7z**.
- For Neurology Today coverage of Alzheimer's disease and dementia, go to bit.ly/MumrWy.
- ► For the *Neurology* Patient Pages, which are critical reviews of ground-breaking discoveries in neurologic research written especially for patients and their families along with links to additional informational resources on neurological diseases, go to **bit.ly/idosAJv** and browse for "Alzheimer's disease" and "dementia."