

**Online self-assessments for Alzheimer's disease
and other dementias**

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Position of the Alzheimer Society of Canada

- People who are experiencing memory issues accompanied by difficulties in day-to-day activities and skills should contact their health-care provider.
- Alzheimer's disease and other dementias are complex diseases of the brain and qualified health care providers should be involved in diagnosing these conditions.
- Online self-assessments of cognitive health are possibly useful for the screening of Alzheimer's disease and other dementias and may pose risks to users unless completed following the advice of a health provider to do so.
- Scientists have raised ethical concerns with most online self-assessments for the diagnosis or screening of Alzheimer's disease and other dementias.
- The Alzheimer Society provides information, education and support to help people with dementia and their families live as well as possible.

Questions:

- [1] Do online self-assessments accurately diagnose dementia, including Alzheimer's disease?
- [2] Do online self-assessments accurately evaluate a person's risk of developing dementia?
- [3] What are the risks associated with online testing for dementia?
- [4] Which online tools are useful for people who are concerned about dementia?

Background information

Many people who worry about their health or the health of a family member turn to the Internet to find information. A number of websites hosted by universities, for-profit companies, charities and governments offer information about Alzheimer's disease and other dementias. Some of these sites also offer *self-assessments of cognitive health* in the form of tests, quizzes or questionnaires that claim to evaluate whether someone has dementia or is at risk of developing the disease. It can be tempting to take one of these tests to get more information, as they often involve answering only a few questions before getting a result. These tests measure a person's abilities with regards to language, thought, memory, attention, perception, everyday skills, such as driving and planning tasks, or any combination of these. Some tests also evaluate risk factors, which are characteristics that increase the occurrence of dementia in the general population (for example, getting older).

Most online tests claim to either *diagnose* or *screen* for dementia. A *diagnosis* is the process of identifying the nature of the illness that an individual is experiencing. *Screening* means identifying possible elements of the disease in individuals, or not.

[1] Do online self-assessments accurately diagnose dementia, including Alzheimer's disease?

The diagnosis of dementia is a complex process that requires careful medical evaluation and includes many different steps such as establishing a medical history, undergoing both a

physical and neurological exam, as well as mental status testing. There is no single test, online or even at the doctor's office that accurately determines whether someone has dementia.

[2] Do online self-assessments accurately evaluate a person's risk of developing dementia?

Memory screening usually involves giving someone an assessment of cognitive health, which sometimes takes the form of a simple mental status test. These tests usually involve assigning a numbered score that indicates whether a person may have memory problems or whether they're at risk for dementia. More and more studies suggest that screening, whether online or otherwise, is not necessarily useful. Experts have shown that screening may have negative consequences for individuals and can add burden to the healthcare system.

[3] What are the risks associated with online self-assessments for dementia?

Many studies have shown that online health information on a variety of topics is frequently of poor quality. Using incomplete or incorrect information to make health-care decisions can have negative consequences. Information about a person's risk for diseases in particular can be difficult to understand and may cause people to take inappropriate actions (for example, taking medications they don't need). Looking for health information online can also lead to anxiety.

When it comes to online self-assessments of cognitive health, these can result in "false positives" and "false negatives." A "false positive" occurs when a person who doesn't have dementia "fails" or scores poorly on the test. A "false negative" happens when a person who does have dementia "passes" or scores well on the test. It takes time and expertise to correctly assess someone for dementia, and this assessment should only be carried out by a qualified health care provider.

Online self-assessments of cognitive health also present certain ethical issues. For example, some organizations that offer self-assessments are in a position to benefit from the people who use them. This is a conflict of interest. In cases of conflict of interest, the quality of the self-assessments can be jeopardized.

Other concerns include issues around the privacy and confidentiality of the information collected in online self-assessments.

[4] Which online tools are useful for people who are concerned about dementia?

While the Internet offers some valuable information about dementia, it can be difficult to identify which websites provide high quality information and which websites do not. People who are concerned about dementia should ask their health-care provider about reputable online sources of information.

About the Alzheimer Society of Canada

The Alzheimer Society of Canada is the leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society offers help for today through our programs and services, and hope for tomorrow by funding research into the cause, prevention and a cure.

For more information, visit www.alzheimer.ca

Sources

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