TOUGH ISSUES

Communicating the Diagnosis

BACKGROUND

A diagnosis of Alzheimer's disease or other dementia may take a long time. People experience different symptoms. One person may have memory problems, another may have language difficulties, or changes in personality or behaviour. Also, some people may not be aware or may not let others know that they are having difficulties. It takes time to conduct a thorough assessment to determine if a person's symptoms are caused by Alzheimer's disease or other dementias.

Alzheimer *Society*

THE ISSUES

For people with dementia:

The right to know: People with dementia are often not told their diagnosis. Withholding this information may prevent the person from:

- receiving treatment for symptoms;
- understanding the cause of the symptoms;
- learning more about their diagnosed condition;
- seeking and obtaining support and practical help;
- planning for the future.

People with severe symptoms may not understand the diagnosis or its implications but the information will be useful and necessary to caregivers.

For caregivers:

Protecting the person by withholding information: Caregivers are often uncertain how the person will react to the information. They often fear the person will not be able to cope with the diagnosis or may harm themselves. These concerns may cause them to ask the person's physician to withhold the diagnosis.

For health-care professionals:

Protecting the person by withholding information: Many doctors consider communicating the diagnosis of Alzheimer's disease or other dementia as one of their most difficult tasks. They may fear that delivery of the news will jeopardize their relationship with the person. Or they may find themselves in a situation where some caregivers want to tell the person the diagnosis and others do not. Also, they may choose to withhold the diagnosis, out of fear that the person may not be able to cope.

PREFERRED CHOICE

Sensitive communication of the diagnosis

People with dementia and their families need to be informed sensitively about the diagnosis. This includes providing them with information about:

- how symptoms will affect the person in the future;
- what treatment options are available;
- where to find support.

This will help individuals and caregivers understand better the reasons for the changes the person is experiencing, the progression of the dementia and the need to plan for the future. This planning can include:

- discussion of the person's future health-care wishes;
- arrangements for the management of financial and personal affairs;
- honest and open discussion of the person's experience;
- proper consideration of treatment and support options, such as medications, community programs, support groups, counselling and education programs.

If a person has explicitly expressed the wish to their doctor and caregivers not to know the cause of the symptoms, the request should be honoured.

HOW MIGHT THE DIAGNOSIS BE COMMUNICATED?

Because of the time it takes to complete an assessment, doctors and members of the health-care team have an opportunity to use this time to set the stage for communicating the diagnosis.

Early in the assessment, people who will be present when the person is told the diagnosis can be identified. For some people, this may be a spouse, partner, adult child or a good friend. Some people may prefer to go alone, however, they should be encouraged to bring with them someone who can help understand, record and remember what is being said. Once identified, these people and the person who is being diagnosed can be informed of the assessment process and the possible reactions to the diagnosis. Issues can be identified and a plan put in place for the time when the person will be told the diagnosis. This plan might include who will be present, and where and when the communication of the diagnosis will take place.

The communication of the diagnosis might occur in a doctor's or specialist's office, or in a specialized clinical setting. If a team of health-care professionals was involved in determining the diagnosis, the caregiver meeting should include members of that team, but not too many people. Where possible, the doctor whom the individual and caregivers view as the most credible source of information should be the one to share the news of the diagnosis.

The doctor should take into account the individual's and caregiver's prior knowledge and how they perceive the problems. The doctor also needs to be aware of the impact the diagnosis can have on the person and caregiver relationships.

The diagnosis should be communicated directly to the person, allowing sufficient time for the doctor to answer questions and address concerns. Communication will be aided by:

- making sure the environment is as quiet as possible;
- making eye contact, for example, by sitting facing the person;
- speaking slowly and clearly, using simple words and short sentences;
- giving one message at a time, and not including too many thoughts or ideas at once;
- taking time for the person to understand the information and respond to it.

A written summary of the issues discussed during the communication of the diagnosis can be useful because people may not understand all of the information nor remember the details.

AFTER COMMUNICATING THE DIAGNOSIS

Not all information can be absorbed during the first meeting, so follow-up sessions are recommended. These sessions can be used to discuss the diagnosis further, talk about its implications, and provide advice about available treatment and support options. People with dementia and their caregivers are encouraged to write down any questions they may have for future doctor's appointments.

Communication of the diagnosis may be met with different responses from the person and caregivers. Responses may include: this is what was suspected all along; relief at learning that dementia could account for the changes; depression; anger; denial.

As a result of the communication of the diagnosis, the person and their caregivers should come to understand that:

- The diagnosis does not change who the person is. The individual is still the same person as before receiving the diagnosis.
- Cognitive problems, such as, problems with memory, concentration, language and judgment, are not normal. They are the result of changes in the way the brain functions.
- While dementia cannot be cured, treatment options are available. Also, changes to the person's environment may assist the person in adapting to changing or lost abilities.
- Expectations for the future are uncertain, so future plans should be discussed as soon as possible after the diagnosis.

- The person with dementia and their caregivers are not alone. Support programs are available. These programs include support groups, online and telephone support, and respite or relief. People can contact their local Alzheimer Society for information about support programs in their community.
- There are health-care professionals who are knowledgeable about dementia and can provide help throughout the progression.
- Referral to specialized services and programs may be appropriate for symptom management, support, participation in research or genetic testing (if the family history warrants it).

Once the diagnosis has been communicated, it will take time for the person and their caregivers to come to terms with it. Sharing the diagnosis with family and friends with whom one is comfortable can assist in widening the circle of support.

IF THE DIAGNOSIS IS MILD COGNITIVE IMPAIRMENT

For people with mild cognitive impairment, an Alzheimer diagnosis may not be immediately possible. Nevertheless, people with mild cognitive impairment are at an increased risk of having further cognitive problems and of developing Alzheimer's disease in the future. Regular follow-ups are important to ensure that an accurate diagnosis can be made.

IN CLOSING...

Communicating a diagnosis is difficult even for the most experienced doctor. For caregivers, fear that the sharing of such a diagnosis will have devastating effects on the individual may prevent the communication of the diagnosis from happening. Despite these concerns, it is vital that people with dementia and their caregivers be sensitively informed about the diagnosis. They should also be reassured that, whatever changes, the individual is still the same person inside. Knowledge of the diagnosis will help people be directed to appropriate treatment, care and support, and develop plans for the future.

RESOURCES:

Alzheimer Society of Canada. Getting a diagnosis. alzheimer.ca/gettingadiagnosis

Alzheimer Society of Canada. The stages of Alzheimer's disease. alzheimer.ca/stages

Alzheimer Society of Canada. Principles for a dignified diagnosis. alzheimer.ca/sites/default/files/documents/tipsheet_dignified_diagnosis_2012_e.pdf

Ismail et. al. (2020). Recommendations of the 5th Canadian Consensus Conference on the diagnosis and treatment of dementia. Alzheimers Dement. 2020 Aug; 16(8). 1182–1195. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7984031/

Alzheimer *Society*

Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8
National office: 1-800-616-8816 Information and Referrals: 1-855-705-4636 (INFO)
E-mail: info@alzheimer.ca Website: alzheimer.ca
Facebook: facebook.com/AlzheimerCanada Twitter: twitter.com/AlzCanada