

## After the diagnosis

### Referral to the Alzheimer Society for support and services

People diagnosed with dementia, their families and the healthcare providers who support them all recognize that early access to ongoing, reliable support and information is critical when living with the many challenges that dementia brings.

To address this need, the Alzheimer Society developed First Link®, a referral program for physicians, health and community services providers that connects individuals and their families to learning, services and support as early as possible in the disease process.

### Family physicians have an important role in identifying caregiver problems and providing direct and ongoing support to caregivers in their day-to-day responsibilities<sup>9</sup>.

Invariably, patients and families want to know about the progression of the disease, risk factors, and available treatments.

As a family physician, you can:

- Ensure regular follow-up visits to assess their physical and emotional health and coping skills;
- Provide further communication about the diagnosis and information during the whole course of the disease, particularly when dealing with challenging symptoms;
- Assist caregivers in mobilizing family and friends;
- Facilitate referrals to appropriate services and resources.

<sup>9</sup> Cohen C.A., *Caregivers for people with dementia. What is the family physician's role?* Canadian Family Physician, 46 (2000), 376-80.

## Canadian consensus on the diagnosis and treatment of dementia

Experts in neurology, geriatric medicine, geriatric psychiatry, neuropsychology and family practice developed evidence-based recommendations to help improve medical practice and dementia care in Canada. You can review these recommendations at: [www.cccdt.ca](http://www.cccdt.ca).

### On our website For healthcare professionals

Dementia management is not the sole responsibility of health practitioners. The Alzheimer Society offers helpful peer-reviewed literature, as well as professional and community resources.

Our website provides updated information on:

- Recommended cognitive screening tests;
- Questions to ask when cognitive impairment is suspected;
- Principles of a dignified diagnosis;
- Alzheimer's disease progression series;
- Tools and resources for post-diagnosis follow-up;
- Recent articles on dementia;
- Useful websites.

For more information, visit our  
**For healthcare professionals section**  
at [www.alzheimer.ca](http://www.alzheimer.ca).

The Alzheimer Society strongly recommends that people who are concerned about their memory and cognitive health see their family physician. Those who do not have a family doctor should contact their local Alzheimer Society to learn more about the disease, and how to find resources for appropriate diagnosis, treatment and care within their community.

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias.

Active in communities right across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

For more information, contact your local Alzheimer Society or visit our website at [www.alzheimer.ca](http://www.alzheimer.ca)

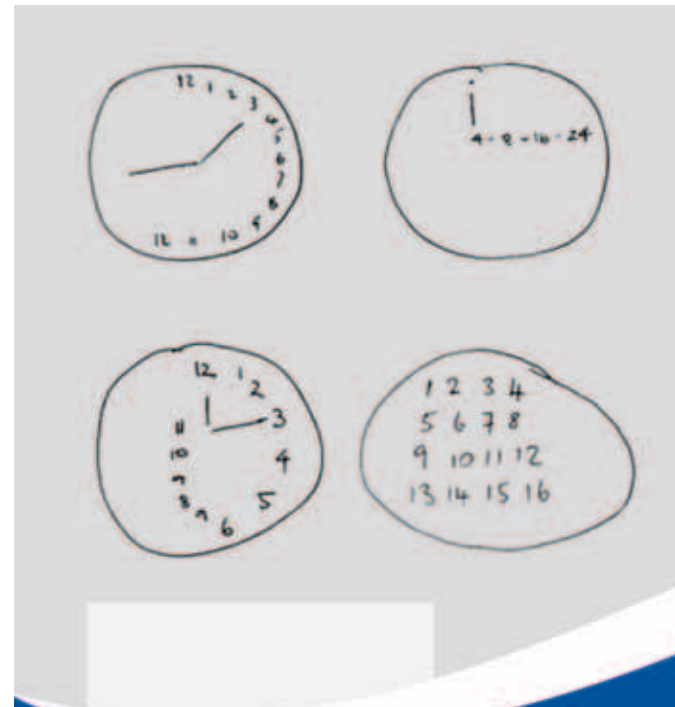
**Help for today. Hope for tomorrow...**

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# Alzheimer Society

Alzheimer's disease

## The importance of early diagnosis



## About Dementia

### Alzheimer's disease and other dementias

- Alzheimer's disease and vascular dementia are two common forms of dementia.
- There are many other dementias including Lewy body dementia, frontotemporal dementia (including Pick's disease), Creutzfeldt-Jakob disease and mixed dementia.

### Dementia numbers in Canada<sup>1</sup>

- 564,000 Canadians are living with dementia right now
- 65% of Canadians over the age of 65 who have dementia are women
- 25,000 new cases of dementia are diagnosed each year in Canada
- 937,000 Canadians will be living with dementia in 15 years
- The average family physician in Canada has 30 to 40 patients with dementia
- \$10.4 billion is spent by Canadians annually to care for people with dementia
- Smoking increases the risk of having dementia by 45%

<sup>1</sup> Alzheimer Society of Canada, 2016

## Encouraging early diagnosis

### Benefits of early diagnosis

- Early diagnosis allows people with dementia and their families to receive timely practical information, advice and support. Only through receiving a diagnosis can they access available drug and non-drug therapies that may improve their cognition and enhance their quality of life<sup>2</sup>.
- Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalization. Some of these interventions may be more effective when started earlier in the disease course<sup>3</sup>.
- Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties to name a few<sup>4</sup>.
- Early detection of dementia provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future<sup>5</sup> which can reduce the heavy societal costs associated with institutionalization<sup>6</sup>.

<sup>2</sup> Prince, M., Bryce, R., Ferri, C., *World Alzheimer report 2011: the benefits of early diagnosis and intervention*. Alzheimer's Disease International (2011).

<sup>3</sup> Ibid.

<sup>4</sup> Woods, R.T. et al., *Dementia: Issues in early recognition and intervention in primary care*. Journal of the Royal Society of Medicine, 96 (2003), 320-24.

<sup>5</sup> Leifer, B.P., *Early diagnosis of Alzheimer's disease: Clinical and economic benefits*. Journal of the American Geriatrics Society, 51 (2003), 281-88.

<sup>6</sup> McAiney, C.A. et al., *First Link: Strengthening primary care partnerships for dementia support*. Canadian Journal of Community Mental Health, 27 (2008).

## The story of Jim Mann



Jim Mann  
Former Board Member,  
Alzheimer Society  
of Canada.

In 2007, Jim Mann, a former airline employee who had traveled the world, froze in the middle of a small regional airport. He had no idea where he was, or what to do next.

After a few tests, Jim's doctor told him he had dementia. After more rigorous testing, he was diagnosed with Alzheimer's disease, a common form of dementia. He was 58 years old.

Jim was lucky. He had been seeing the same doctor for years. When he described his symptoms, the doctor knew they were unusual for Jim. When he went for more extensive testing, however, one specialist questioned the diagnosis, saying, "You don't look like you have Alzheimer's disease".

"I wasn't sure how I was supposed to look", says Jim. "Since then, I've been told I'm too young, too healthy, too capable to have the disease. It can be a hidden illness for years, but when you have it, the impact is unquestionable."

He recommends being persistent to get the answers needed. "When you know something is wrong, it's important to push until you are satisfied. The answer may be frightening, but it's better to have a diagnosis, find out what help is available and have time to plan for the future with family members and caregivers".

While rare, 16,000 Canadians under the age of 65 are living with dementia. These individuals face additional challenges as they may still be in the work force, have considerable financial commitments and dependent children. A timely diagnosis of young onset dementia is an important prerequisite for beginning adequate treatment, planning for the future, and accessing support services appropriate for that age group.

Source: *Prevalence and Monetary Costs of Dementia in Canada*, Alzheimer Society of Canada (2016).

## Assessing patients with dementia

### Early detection of cognitive impairment

Although primary care physicians are in an ideal position to diagnose dementia, cognitive impairment is often unrecognized by family physicians. Many barriers to recognition have been identified, such as lack of knowledge about dementia, lack of symptom recognition and belief that early detection increases patient and caregiver distress<sup>7</sup>.

The major hurdles to diagnosing dementia in family practice are:

- the complexity of the diagnostic process;
- physicians' lack of familiarity with dementia screening;
- the pressures of time (the diagnostic process can require multiple visits to complete);
- the lack of general conviction that an accurate diagnosis of dementia warrants the requisite effort<sup>7</sup>.

To address these challenges, Drs. Masellis and Black developed a tool outlining questions to help family physicians detect early signs of dementia entitled Questions to ask when dementia is suspected<sup>8</sup>, available for download from our *For healthcare professionals* section at [www.alzheimer.ca](http://www.alzheimer.ca).

### A dignified diagnosis

It is the right of all to receive a dignified diagnosis. People with dementia wrote a statement entitled The principles of a dignified diagnosis about their experience of receiving a diagnosis and how to make it better. Although this document was initially intended for people with Alzheimer's disease, the principles of a dignified diagnosis are helpful in the diagnosis of all forms of dementia.

The statement *Principles of a dignified diagnosis* is available for download from our *For healthcare professionals* section at [www.alzheimer.ca](http://www.alzheimer.ca).

<sup>7</sup> Feldman H, et al., *Diagnosis and treatment of dementia*. Canadian Medical Association Journal, 178 (March 2008), 825-36.

<sup>8</sup> Masellis, M., Black, S.E., *Assessing patients complaining of memory impairment*. Geriatrics & Aging, 11 (2008).