

After the diagnosis

Referral to the Alzheimer Society for support and services

People diagnosed with dementia, their families and the health-care 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 responsibilities¹⁰.

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.

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.cccdttd.ca.

On our website For health-care 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 health-care professionals section** at 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

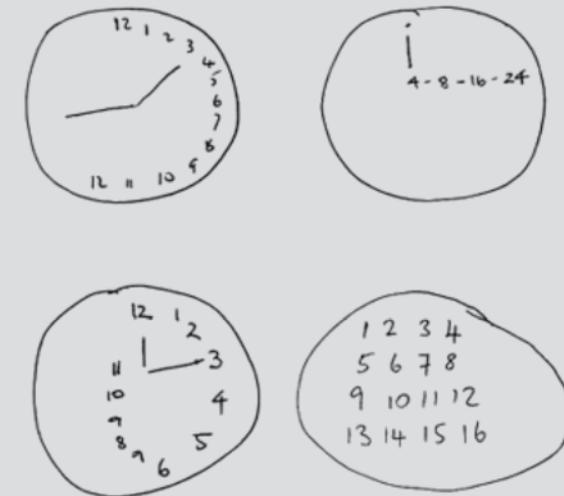
Help for today. Hope for tomorrow...

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Alzheimer Society

Alzheimer's disease

The importance of early diagnosis



¹⁰ Cohen C.A., *Caregivers for people with dementia. What is the family physician's role?* Canadian Family Physician, 46 (2000), 376-80.

Cover: Clock drawing test result indicative of dementia.
Source: Institute of Psychiatry, London, UK

Key Facts

Alzheimer's disease and other dementias¹

- Alzheimer's disease is the leading form of dementia and accounts for 50%-75% of all cases.¹
- Vascular Dementia is the second most common form and accounts for 20%-30% of all cases of dementia.
- Other dementias include Vascular Dementia, Lewy body Dementia, Frontotemporal Dementia (including Pick's Disease), Creutzfeldt-Jakob Disease and mixed dementia (usually Alzheimer's disease combined with Vascular Dementia).

The Canadian Dementia Profile²

- The number of Canadians living with cognitive impairment, including dementia, now stands at 747,000 and is expected to double to 1.4 million by 2031.
- Today, the combined direct (medical) and indirect (lost earnings) costs of dementia total \$33 billion per year. By 2040, this figure is expected to skyrocket to \$293 billion per year.
- In 2011, family caregivers spent 444 million unpaid hours per year looking after someone with dementia, representing \$11 billion in lost income and 227,760 lost full-time equivalent employees in the work force. By 2040, they will be devoting a staggering 1.2 billion unpaid hours per year.

Gender specific indicators

Women represent:

- **72%** of all cases of Alzheimer's disease,
- **47%** of Vascular Dementia cases,
- **62%** of overall dementia cases.

¹ Alzheimer's Disease International, 2013.

² Alzheimer Society of Canada, 2013.

Encouraging early diagnosis

Undetected dementia

Cognitive impairment and dementia are present in about 20% of the elderly population and are consistently rated among the top 3 health concerns of older adults. However, **less than 25% of cases of Alzheimer's disease in Canada are diagnosed** and treated which implies a lack of application of known diagnostic approaches³.

The major hurdles to diagnosing dementia in family practice are:

- the complexity of the diagnostic process;
- physicians' lack of familiarity with cognitive screening;
- the pressures of time (the diagnostic process requires multiple visits to complete); and
- the lack of general conviction that an accurate diagnosis of dementia warrants the requisite effort⁴.

Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties to name a few⁵.

Early detection of dementia provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future⁶ which can reduce the heavy societal costs associated with institutionalization⁷.

³ Feldman H, et al., *Diagnosis and treatment of dementia*. Canadian Medical Association Journal, 178 (March 2008), 825-36.

⁴ Ibid.

⁵ Sternberg, S.A. et al., *Undetected dementia in community dwelling older people: The Canadian Study of Health and Aging*. Journal of the American Geriatrics Society, 48 (2000), 1430-34.

⁶ 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.

⁷ Leifer, B.P., *Early diagnosis of Alzheimer's disease: Clinical and economic benefits*. Journal of the American Geriatrics Society, 51 (2003), 281-88.

The story of Jim Mann

In 2007, Jim Mann, a former airline employee who had traveled the world, froze in the middle of a small regional airport in the United States. 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, the most 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".



Jim Mann,
Board Member,
Alzheimer Society
of Canada.

Despite the changing profile of dementia in Canada, the stereotype persists that Alzheimer's disease strikes only the elderly. Yet we know early detection of dementia is critical as it provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future which can reduce the heavy societal costs associated with institutionalization.

Source: *Rising Tide: The Impact of Dementia on Canadian Society*, Alzheimer Society of Canada, 2009.

Assessing patients with cognitive impairment

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, including lack of time and ability to screen for dementia, lack of knowledge about dementia, lack of symptom recognition and belief that early detection increases patient and caregiver distress⁸.

Dr. Masellis and Dr. Black developed a tool outlining questions to help family physicians detect early signs of dementia entitled *Questions to ask when dementia is suspected*⁹, available for download from our For health-care professionals section at 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 health-care professionals section at www.alzheimer.ca.

⁸ McAiney, C.A. et al., *First Link: Strengthening primary care partnerships for dementia support*. Canadian Journal of Community Mental Health, 27 (2008).

⁹ Masellis, M., Black, S.E., *Assessing patients complaining of memory impairment*. Geriatrics & Aging, 11 (2008).