

After the diagnosis

Family physicians have an important role in identifying caregiver problems and providing direct and ongoing support to caregivers in their day-to-day responsibilities⁹.

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.

Referral to the Alzheimer Society for support and services

After the diagnosis, it is crucial to link the person with dementia to support services early in the disease course. The Alzheimer Society offers support, information and education sessions to individuals with dementia and their families. Studies demonstrate that modest psychosocial interventions combined with drug therapy are practical and can pay handsome dividends in reducing caregiver depression¹⁰. Past studies have shown that caregiver health, especially their mental health, is critical to enabling people with Alzheimer's disease to continue living in their own homes. Therefore, improving the mental health of caregivers not only benefits caregivers directly, but it has important implications for people with Alzheimer's disease and for our healthcare system.

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

¹⁰ Mittelman M., *Caregiver Health: Combining treatment approaches to further reduce depression.* American Journal of Geriatric Psychiatry, 16 (2008), 893-904.

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.

Visit our Physician's Corner

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 Physician's Corner 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 **Physician's Corner** 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 advocates for people living with Alzheimer's disease and related dementias across Canada. The Society believes everyone living with these diseases should have access to treatments and supports that enhance their quality of life.

The Alzheimer Society is the leading and only nationwide not-for-profit health organization dedicated to helping people affected by Alzheimer's disease and related dementias. The Society has numerous resources and support programs for people living with the disease, their family and caregivers. The Society also funds research into the causes and cure for the disease, and into improved methods of caregiving.

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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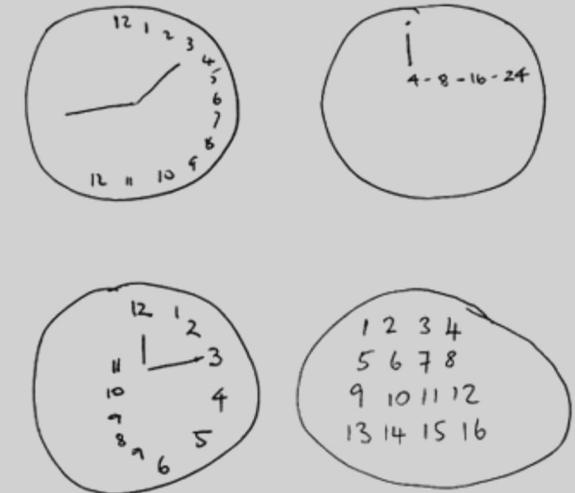
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Alzheimer's disease and related dementias

The importance of early diagnosis



Clock drawing test result indicative of dementia. (Institute of Psychiatry, London, UK)



Key Facts

Alzheimer's disease and related dementias

- Alzheimer's disease is the leading form of dementia and represents **63%** of all dementias.
- Vascular Dementia is the second most common form and accounts for **20%** of all dementias.
- Related 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 Profile¹

- As of 2010, over **500,000** Canadians live with dementia and an estimated **70,000** are under **65**.
- By 2015, with baby boomers reaching the age of 65, cases could jump by up to **50%**.
- Incidence is at more than **100,000** new cases a year, i.e. a new case every **5 minutes**.
- Unpaid family caregiving is estimated at more than **230 million hours** a year.
- **40 to 75%** of caregivers develop psychological illnesses due to their caregiving role.
- As of 2010, the total economic burden of dementia is **\$20 billion** per year.

Gender specific indicators

Women represent:

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

¹ *Rising Tide: The Impact of Dementia on Canadian Society*. Alzheimer Society of Canada, 2009.

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 approaches².

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 effort³.

Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties to name a few⁴.

Early detection of dementia provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future⁵ which can reduce the heavy societal costs associated with institutionalization⁶.

² Feldman H, et al., *Diagnosis and treatment of dementia*. Canadian Medical Association Journal, 178 (March 2008), 825-36.

³ Ibid.

⁴ 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.

⁵ 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.

⁶ 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

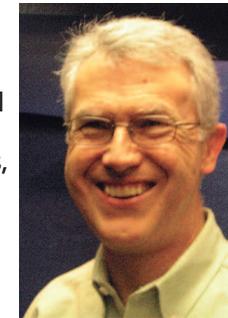
In 2007, Jim Mann, a former airline employee who had traveled the world, froze in the middle of a small regional airport in the United States. He had no idea where he was, or what to do next.

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, Director, Alzheimer Society of Canada Board.

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 distress⁷.

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*⁸, available for download from our Physician's Corner at www.alzheimer.ca.

A dignified diagnosis

The process for diagnostic disclosure for people with cognitive impairment or dementia must begin as soon as the possibility of cognitive impairment is suspected.

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 Physician's Corner at www.alzheimer.ca.

⁷ McAiney, C.A. et al., *First Link: Strengthening primary care partnerships for dementia support*. Canadian Journal of Community Mental Health, 27 (2008).

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