After the diagnosis

Referral to the Alzheimer Society for support and services

People diagnosed with dementia, their caregivers and the health-care professionals who support them all recognize that early access to ongoing, reliable support and information is critical when living with the many challenges that dementia can bring.

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 caregivers to learning, services and support as early as possible. For more information, visit alzheimer.ca/firstlink.

Physicians have an important role in identifying caregiver challenges and providing direct and ongoing support to caregivers in their day-to-day responsibilities.

People living with dementia and caregivers want to know about the progression of dementia, risk factors, and available treatments.

As a 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 dementia, particularly when managing symptoms;
- Assist caregivers in mobilizing family and friends;
- Facilitate referrals to appropriate services and resources.

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

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.

Information for health-care professionals

Dementia management is not the sole responsibility of health-care professionals. 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
- Communicating a diagnosis
- Tools and resources for post-diagnosis follow-up
- Alzheimer’s disease progression series
- Recent articles on dementia;

For more information, visit our website for health-care professionals at alzheimer.ca/healthcareprofessionals.

Information for health-care professionals

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 alzheimer.ca.
About Dementia
- Alzheimer’s disease and vascular dementia are two common forms of dementia.
- There are many other types of dementia including Lewy body dementia, frontotemporal dementia, Creutzfeldt-Jakob disease and mixed dementia.

Dementia numbers in Canada
- As of 2024, it is estimated that 733,040 people are living with dementia in Canada. By 2030, we can expect this number will reach close to 1 million.
- In 2020, an estimated 61.8% of persons living with dementia (352,000) in Canada were female.
- In 2020, there were 124,000 new cases of dementia diagnosed (10,333 per month).
- For every person in Canada who has dementia diagnosed (10,333 per month).
- In 2020, at least 28,000 people under the age of 65 were living with young onset dementia in Canada. These individuals face additional challenges as they may still be in the workforce, have considerable financial commitments and depend on children.
- Billions of dollars are spent on health-care costs and out-of-pocket individual and caregiver expenses in supporting people living with dementia in Canada.

Benefits of early diagnosis
- Early diagnosis allows people living with dementia and their caregivers to receive timely practical information, advice and support.
- When people receive a diagnosis they can access available drug and non-drug therapies that may improve their cognition and enhance their quality of life.
- Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying a move to long-term care. Some of these interventions may be more effective when started early.
- Undetected dementia places people at risk for delirium, motor vehicle accidents, medication errors and financial difficulties to name a few.
- Early detection of dementia provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future. This can reduce the heavy societal costs associated with dementia care and support.

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. 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. 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.”

In 2020, at least 28,000 people under the age of 65 were living with young onset dementia in Canada. These individuals face additional challenges as they may still be in the workforce, 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.

Assessment
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.

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 assurance that an accurate diagnosis of dementia is worth the effort.

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. This resource available for download at alzheimer.ca/healthcareprofessionals.

A dignified diagnosis
It is the right of all to receive a dignified diagnosis. People living 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 living with Alzheimer’s disease, the principles of a dignified diagnosis are helpful in the diagnosis of all types of dementia.

The Principles of a Dignified Diagnosis is available for download at alzheimer.ca/dignifieddiagnosis.