

Detailed Survey Findings

Alzheimer Awareness Month - January 2012
Let's face it! Get the facts. Know for sure.

Early diagnosis, earlier intervention, better treatment

About the survey:

In October 2011 the Alzheimer Society commissioned a nationally representative online survey to determine how long people wait after noticing symptoms before seeing a doctor; their reasons for not seeking a diagnosis and their awareness of the benefits of an early diagnosis.

958 Canadian caregivers of people living with Alzheimer's disease or other dementia responded to the survey. Participants were between the ages of 45 and 65 and were evenly split between males and females. The survey focused on their knowledge of the warning signs of dementia and their willingness to seek a diagnosis.

Survey objectives:

- ✓ How long do people wait after seeing symptoms before seeking a diagnosis?
- ✓ Why don't people seek a diagnosis sooner?
- ✓ What is the pathway to reaching a diagnosis?
- ✓ Do they know the benefits of early diagnosis?
- ✓ Do they wish diagnosis had happened earlier?
- ✓ What kinds of supports or services are recommended and are proven helpful?

Survey respondents:

Respondents who completed the survey self-screened to fit criteria:

- Have a family member who has/had Alzheimer's disease or other dementia
- Have fairly detailed knowledge of process to get diagnosis

Survey accuracy:

- All tests of statistical significance within and between samples of the survey results were conducted at the 90% confidence level.

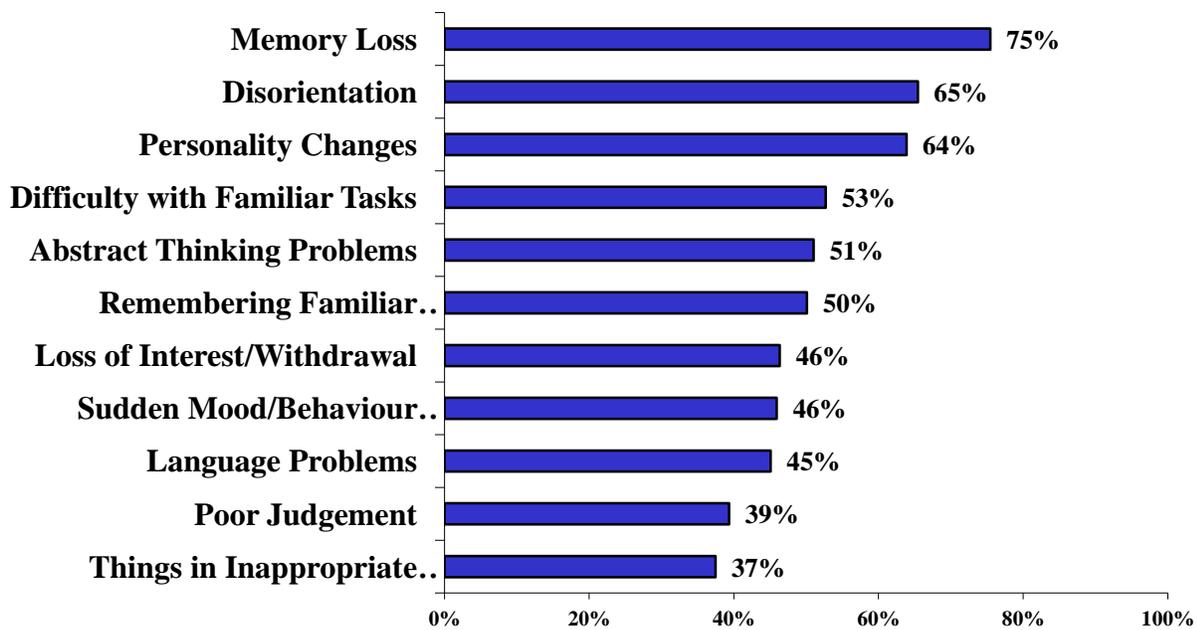
Key findings:

1) Treatment Gap:

Canadians are missing out on treatment and medications for Alzheimer's disease and other dementias because of their low awareness of early signs and symptoms. The lack of early detection and treatment denies opportunities for improving the quality of life for millions of people with dementia around the world, their families and caregivers.

The three highest mentions from respondents on the early symptoms that their family member exhibited :

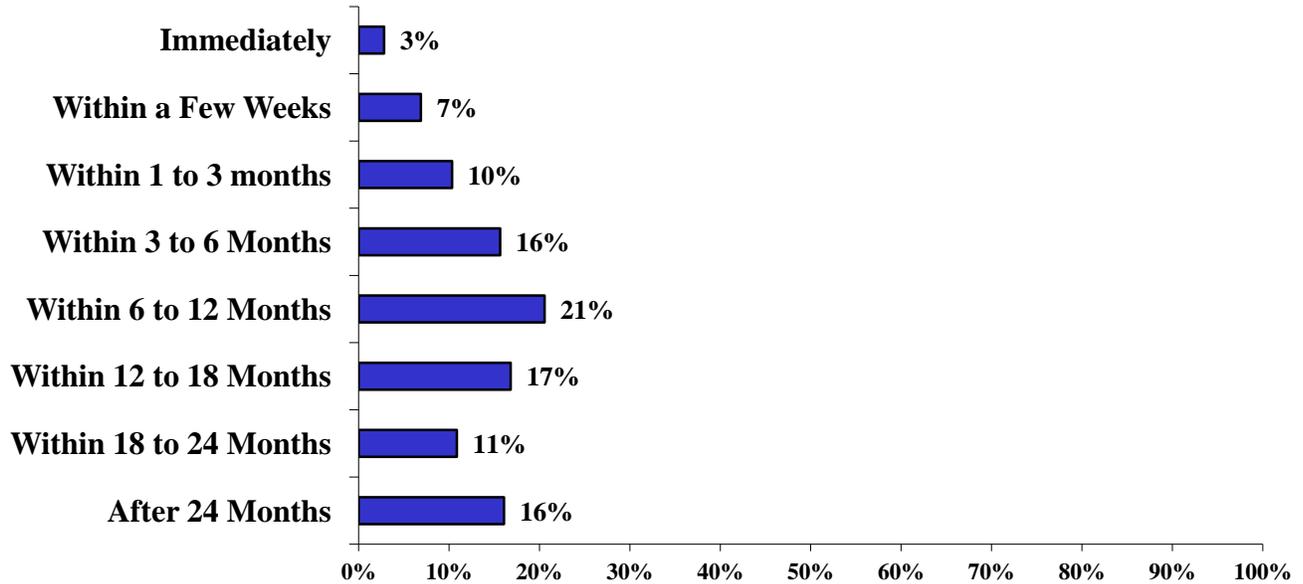
1. **Frequent memory loss** that affects day-to-day function – like continually forgetting where they put things, or what they were doing or why they were doing it. (75%)
2. **Disorientation of time and place**, including getting lost even in familiar places, or not knowing what month or year it is. (65%)
3. **Changes in personality** or acting out of character – like becoming suspicious, fearful, or confused. (64%)



2) Delay in seeing a doctor:

Almost half (44 %) of respondents lived a year or more with dementia symptoms before seeing a family doctor because they thought these were just part of “old age.”

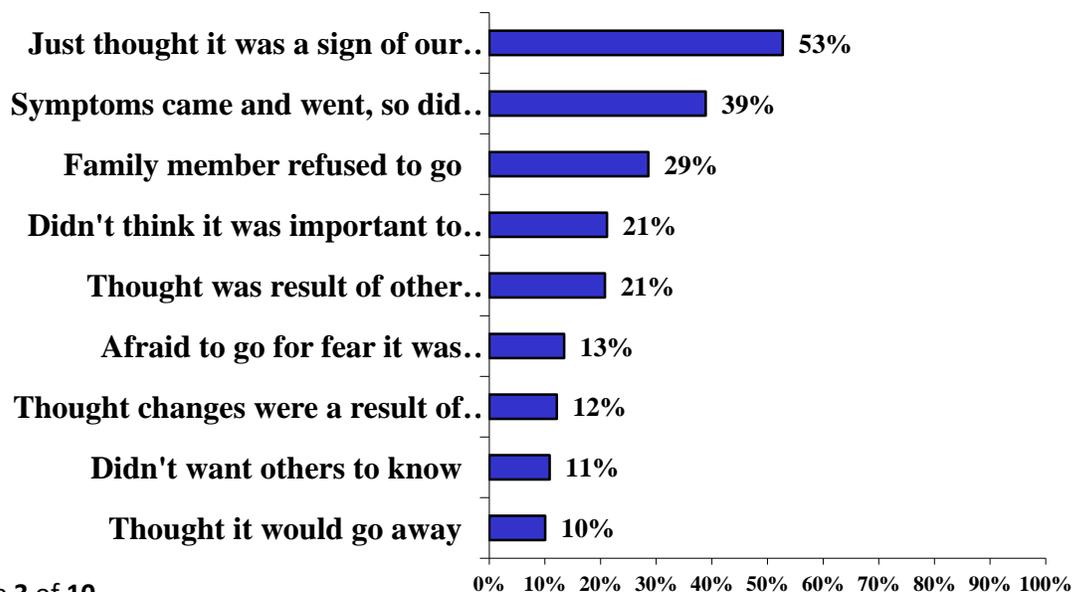
- Of these, 16% waited two years to see a doctor.



Why delay seeking a diagnosis?

Respondents who delayed seeking diagnosis beyond 3 months were asked to indicate from a prompted list all the reasons why they didn't go sooner.

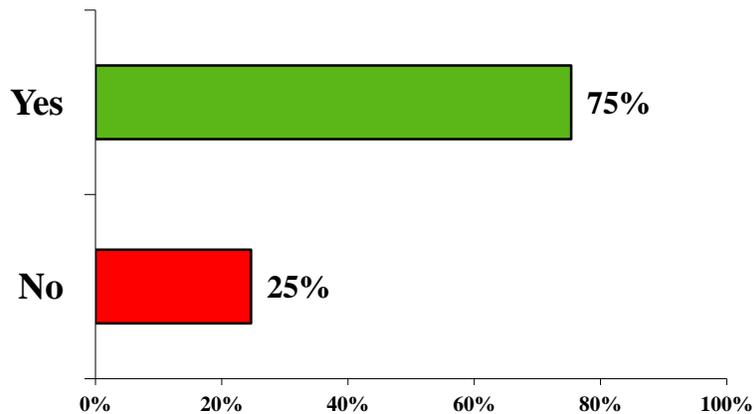
- Over 50% listed “just thought it was a sign of our family member getting older”
- Close to 40% listed “symptoms came and went, so did not take it seriously” as one of the reasons,
- Close to 30% listed “family member refused to go”.



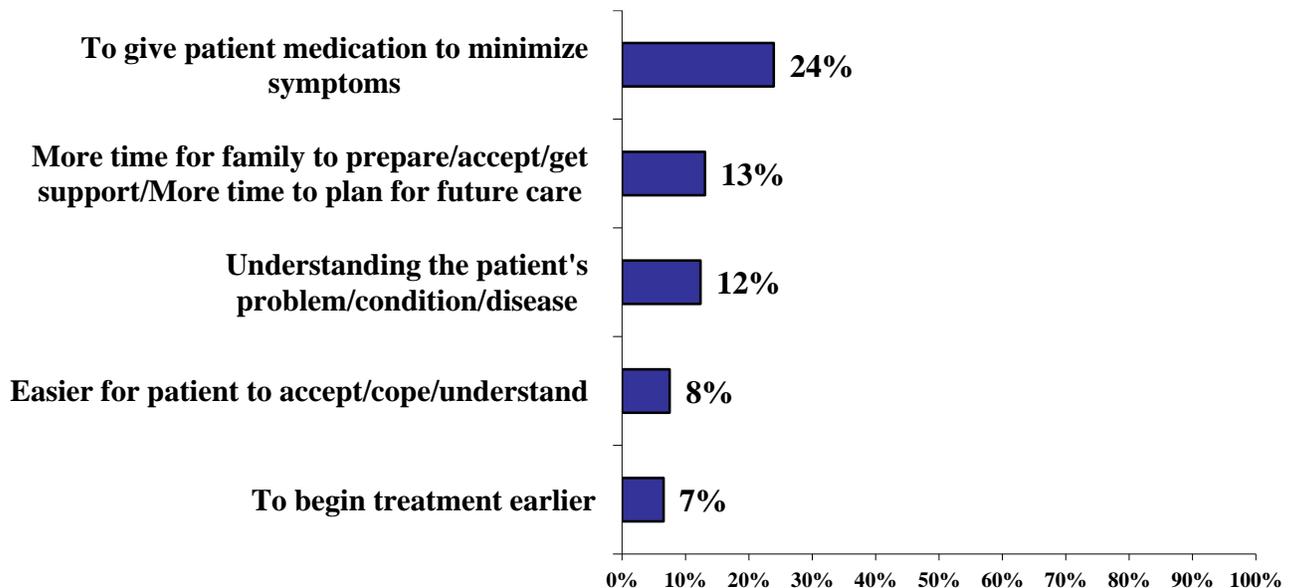
3) Benefits of early diagnosis

Early diagnosis of dementia helps people get care, support and medications faster so they live better with dementia and make important decisions about their future medical, financial and legal needs.

- Given the experience that they've gone through with their family member and what they've learned in the process, in hindsight **three-quarters of all respondents wish that their family member had been diagnosed sooner with Alzheimer's disease or another dementia.**



- By far, the highest percent of mentions as the most important reason why these respondents wish that their family member had been diagnosed sooner was **“to give patient medication to minimize symptoms” (24% of mentions).**

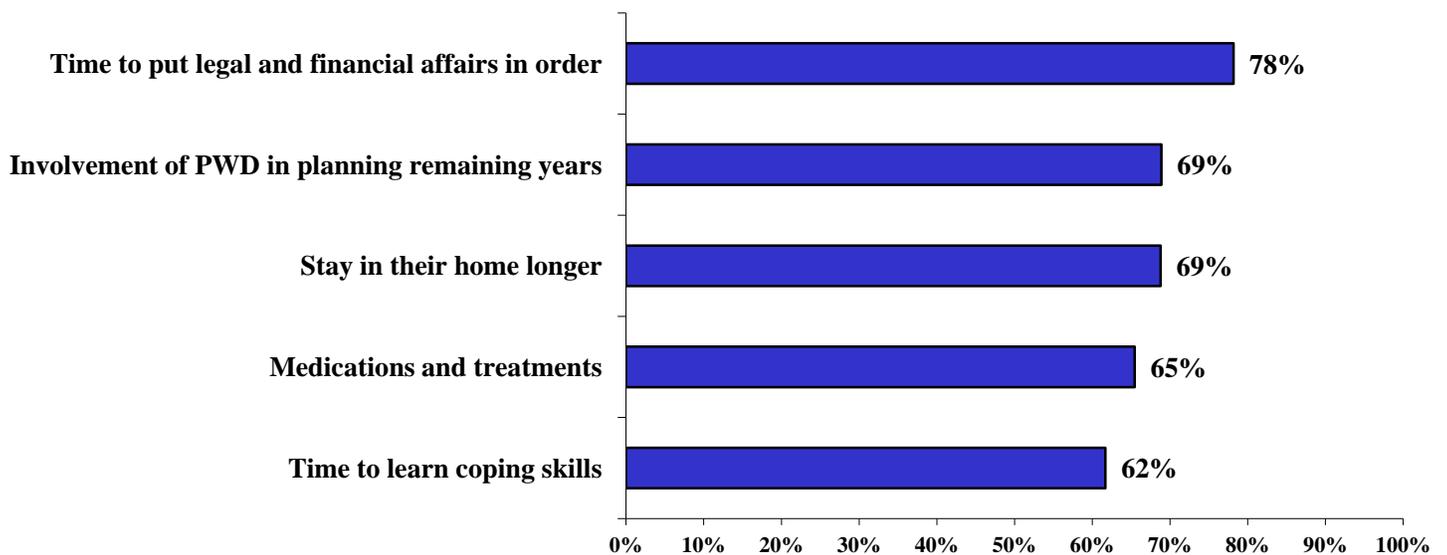


4) Awareness of the benefits of early diagnosis

- 60% said they were aware of the benefits (from a prompted list)
- Same order of benefit as 2010 survey conducted by the Alzheimer Society of Canada 45-65 (general public)

When asked about the benefits of early diagnosis

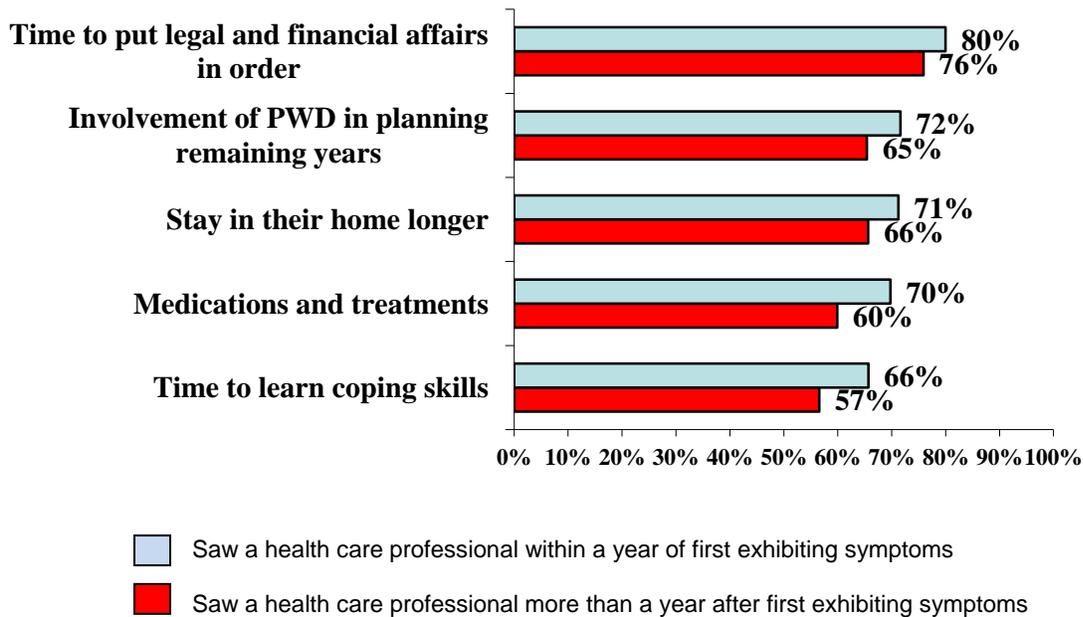
- 78 per cent said it would help with putting legal and financial matters in order.
- 69 per cent said it would help keep the person with dementia at home longer, and allow the person to be more active in key decision-making.
- 62 per cent said it would improve their ability to cope with the disease.



5) Awareness = Action

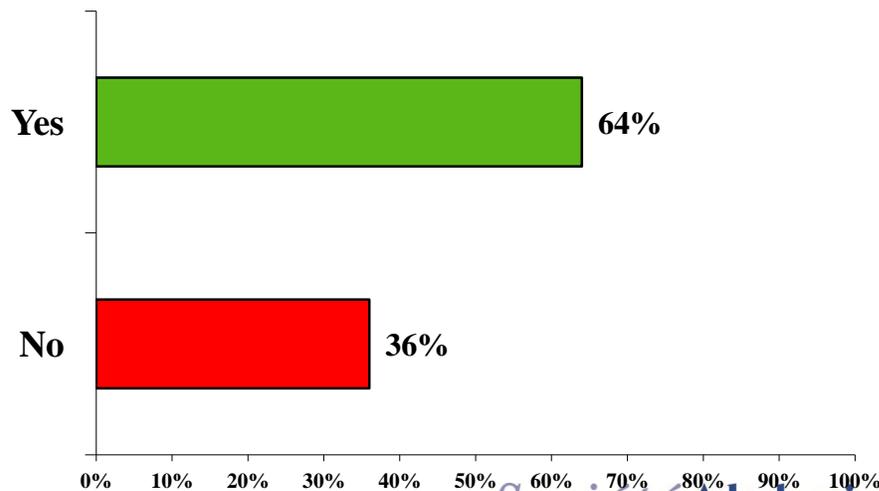
Respondents who knew the benefits of early diagnosis saw their doctor sooner

- Aided awareness of 4 of these 5 benefits is higher among those respondents whose family member saw a health care professional within a year of first exhibiting early symptoms, compared to those who waited longer before going. (Directionally higher for the 5th) (Note: this is correlation, not specifically causality, although it can be implied.)

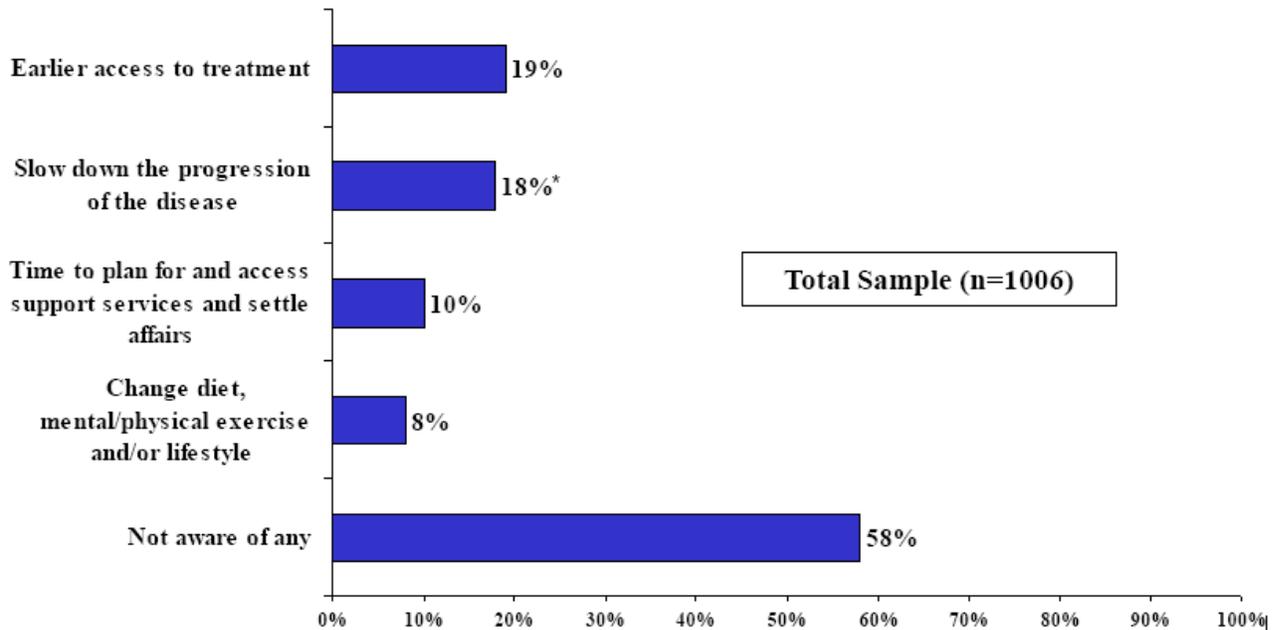


More evidence:

- A 2010 Alzheimer Society of Canada survey found that almost two-thirds of respondents, who initially said they would NOT go to their family doctor right away if they had possible early signs of Alzheimer's changed their mind after completing the survey.

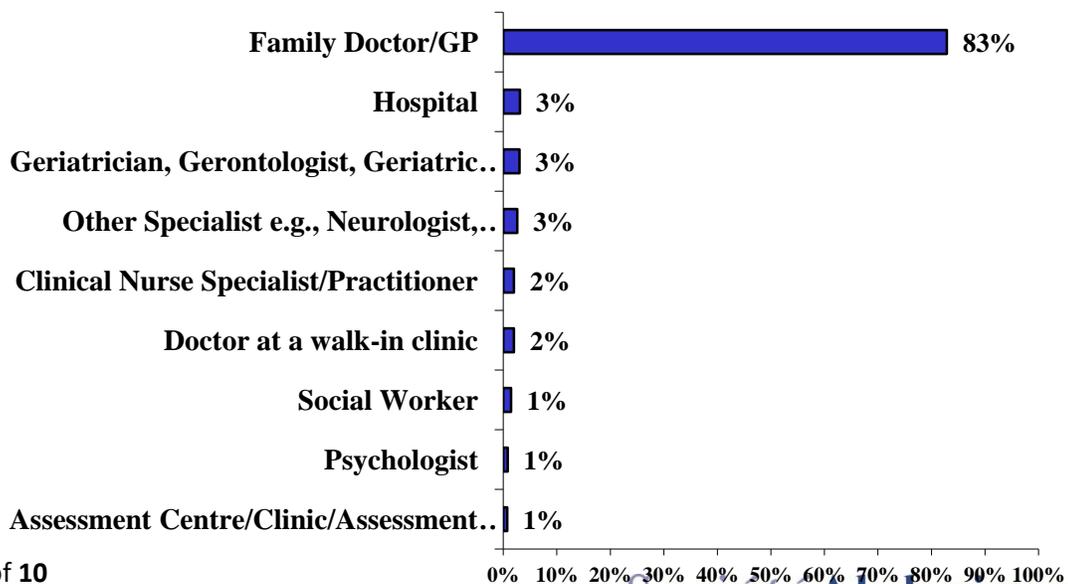


- Unaided, the highest per cent of mentions as the most important reasons for seeking diagnosis had to do with benefits:
 - Treatments available do slow progression
 - Time to plan
 - Earlier treatments and better outcomes

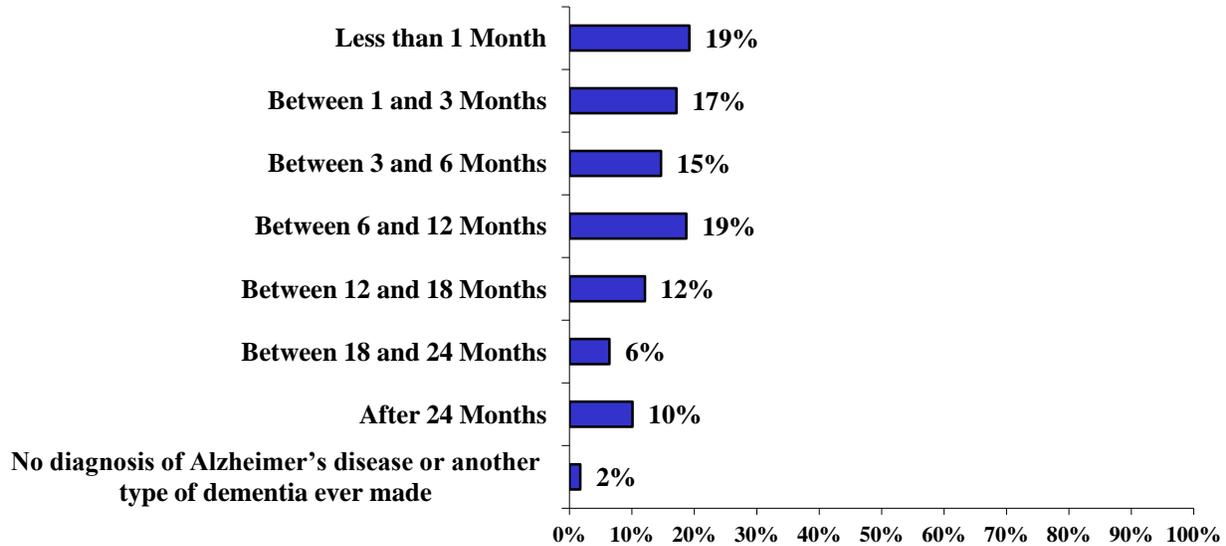


6) Where do people go to get a diagnosis?

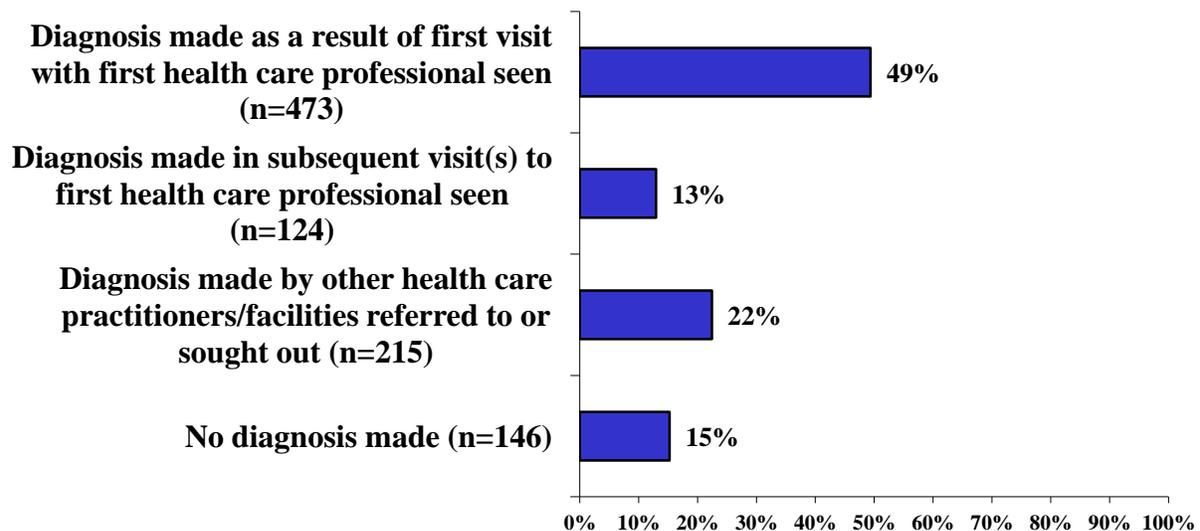
- The vast majority (83%) of all respondents said their family member first saw a family doctor/GP about these symptoms.



- 51% said it took 6 months or less from first appointment with the first health-care professional to diagnosis
- 29% said it took a year or more, and 10% said it took more than 2 years.



- Close to two-thirds of all respondents said that the first health-care professional made a diagnosis (62%).
- Just over 20% said that the first diagnosis was made by other health-care practitioners/facilities referred to or sought out.
- 15% said that no diagnosis was ever made.



7) Satisfaction with diagnosis:

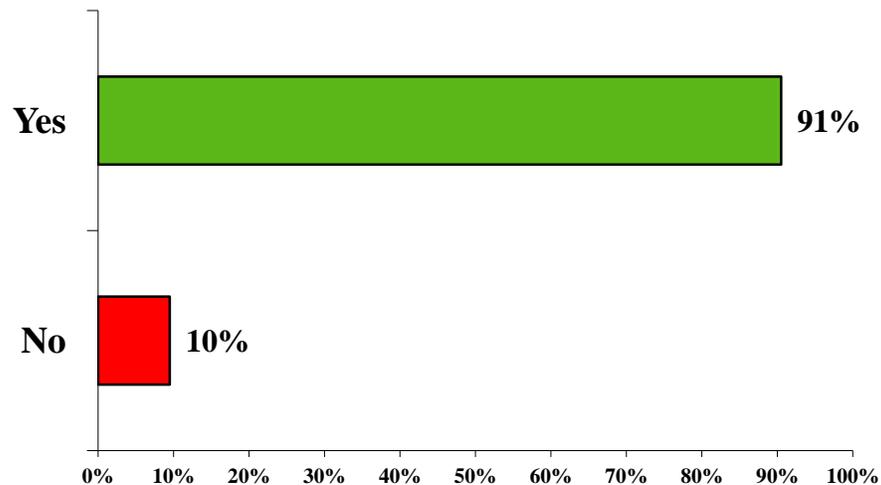
- Across all dimensions, level of confidence/satisfaction is positively correlated with whether or not this first health care practitioner made a diagnosis, how quickly he/she did, and if there were follow-up visit(s) to confirm the initial diagnosis made as a result of the first visit.

	Diagnosis made as a result of first visit, and VISITED AGAIN for sole purpose of confirming initial diagnosis (n= 265)		Diagnosis made as a result of first visit, and did NOT VISIT AGAIN for sole purpose of confirming initial diagnosis (n= 208)		Diagnosis made in subsequent visits (n = 124)		No diagnosis made (n= 361)	
	Top 2 box	Bottom 2 box	Top 2 box	Bottom 2 box	Top 2 box	Bottom 2 box	Top 2 box	Bottom 2 box
a) Confidence in the diagnosis ¹	92%	3%	88%*	6%	62%	23%*	N/A	N/A
b) Caring manner	87%*	6%	80%	12%*	73%*	19%*	55%	29%*
c) Helpfulness, especially advice or information	82%*	9%	70%*	15%*	58%*	25%*	44%	38%*
d) Time it took to get a diagnosis or referral	89%*	5%	80%*	8%	54%	36%	56%	33%*

8) Satisfaction with the Alzheimer Society

An early diagnosis means those affected can take advantage of Alzheimer Society information services and support programs earlier in the disease process. Those referred to the Alzheimer Society by their health-care provider were highly satisfied with the programs and support.

- 91% of all respondents said that, prior to this survey, they have contacted or corresponded with the Alzheimer Society, visited its website, received information from the Society, donated to the Society, or been involved with the Society in some other way.



Summary:

With its landmark report *Rising Tide: the Impact of Dementia on Canadian Society* in 2010, the Alzheimer Society issued a wake-up call about the escalating prevalence of Alzheimer's disease and dementia and the rising economic and social costs to Canada's health-care system and Canadian families.

Early detection is one solution to minimize this trend. Yet too many Canadians are not taking advantage of early treatment and support services or the chance to make key decisions about their future medical, financial and legal needs because they are diagnosed in the later stages of the disease, if at all.

The survey clearly calls for greater promotion of the early signs of dementia and the benefits of early detection to break down barriers such as fear, ignorance and stigma.

Greater awareness also is critical to bridge the gap between available services and treatment to live better and more independently with the disease and plan for the future.

The Alzheimer Society encourages Canadians to take advantage of practical information and other support services it offers in more than 150 communities across the country.

The Society is also working with the College of Family Physicians of Canada (CFPC) to build on awareness as well as physicians' capacity to diagnose and treat through greater collaboration and integration of health and community partnerships.