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Dementia Survey

Final Report

Prepared for the Public Health Agency of Canada

Supplier: EKOS RESEARCH ASSOCIATES INC.

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Date: October 2020

This public opinion research report presents the results of an online survey conducted by EKOS Research Associates Inc. on behalf of the Public Health Agency of Canada. The research study was conducted with 4,207 Canadians 18 or older, between March 16 and April 30, 2020.

Cette publication est aussi disponible en français sous le titre : Sondage sur la démence.

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EXECUTIVE SUMMARY

A. BACKGROUND AND OBJECTIVES

Dementia is an umbrella term used to describe a set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities. These abilities include: memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. Prevention of dementia, eliminating stigma and supporting dementia-inclusive communities are key objectives of the awareness raising initiatives through the Public Health Agency of Canada's Dementia Strategic Fund. Growing evidence and recent guidance has suggested that up to one third of dementia cases could be prevented by addressing nine risk factors: lower levels of early life education; hypertension; obesity; hearing loss; smoking; depression; physical inactivity; diabetes; and social isolation¹. In addition, stigma and a lack of understanding about dementia have been raised by people living with dementia and caregivers as significant barriers to receiving early and timely diagnosis, quality care, and the ability to engage meaningfully in one's community. With a growing and aging population, the number of Canadians living with dementia is expected to increase in future decades². Creating safe, supportive and inclusive communities across Canada for people living with dementia and caregivers is essential to improving quality of life.

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, released in June 2019, identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers. To inform initiatives taken to support the strategy's national objectives and provide data to support annual reports to Parliament on the national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, public opinion research (POR) is required to gather information on Canadians' awareness, knowledge, perceptions and attitudes regarding dementia. The primary objective of the research is to establish a national baseline with regard to Canadians' awareness, attitudes, perceptions and behaviours related to dementia.

¹ Livingston, G et al. Dementia prevention, intervention, and care. The Lancet Commissions. 2017; [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31363-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6/fulltext)

² Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system. Government of Canada. 2017; publications.gc.ca/collections/collection_2018/aspc-phac/HP35-84-2017-eng.pdf

B. METHODOLOGY

The survey is comprised of 4,207 completed cases of Canadians, 18 years of age and older, including 938 caregivers (defined as someone who provides unpaid care and support to someone living with dementia), 802 Canadians who identify as members of Black (260), Hispanic (South American) (133), Southeast (212) and South Asian (214) ethnic groups, and 587 Indigenous peoples.

The survey sample was randomly selected from the *Probit* panel, which is assembled using a random digit dial (RDD) process for sampling from a blended land-line cell-phone frame, which provides full coverage of Canadians with telephone access. The distribution of the recruitment process is meant to mirror the actual population in Canada (as defined by Statistics Canada). As such, our more than 80,000 active member panel can be considered representative of the general public in Canada (meaning that the incidence of a given target population within our panel very closely resembles the public at large) and margins of error can be applied. Ten percent of the sample was collected with cell phone only sample. Fifteen percent were collected by trained, bilingual interviewers, while the majority were collected through online self-administration. Additional cases were collected among ethnic target groups using a random digit dial (RDD) sample frame from key communities with considerably higher than average representation of these segments with the population. An interactive voice response (IVR) system was used to find in-scope households as efficiently as possible for this portion of the sample.

The interview length averaged 15 minutes online and 21 minutes by telephone, and was collected between March 16 and April 30, 2020, following extensive testing online and by telephone, in both languages. The rate of participation was 20% (22% online and 17% by telephone). Details on the rate of participation can be found in Appendix A and the questionnaire is provided in Appendix B.

This randomly recruited probability sample carries with it a margin of error of +/-1.5%. The margin of error for each of the target groups is between 2.5% and 7.0%. Results are weighted to population proportions for region, age, gender, education, and Indigenous/ethnic status. Chi-square tests were used to compare subgroups to the remaining sample (e.g., Ontario vs. the rest of Canada; 65 years old and over vs. the rest of Canada; women vs. men; weighted data used when relevant).

C. KEY FINDINGS

Knowledge

Over eight-in-ten Canadians believe that dementia is having a moderate to significant impact in Canada today. While only one-quarter feel they are highly knowledgeable about dementia, a large majority are able to correctly identify common signs and symptoms of dementia, including impaired or reduced judgement, changes in mood, behaviour or personality, misplacing things, and difficulty in managing daily tasks.

Fully three-quarters of Canadians believe there are things people can do to reduce the risk of dementia. A similar number feel that dementia is not an inevitable or normal part of aging. Two-thirds inaccurately trust that there are effective treatments generally that can delay the onset of symptoms and slow the progress of dementia. The majority of Canadians are able to correctly identify at least one or more risk factors linked to increased chances of developing dementia such as loneliness and social isolation, harmful alcohol use, lack of physical activity, having had a stroke, a diet lacking in nutrition, and sleep disruption. Nearly half believe that exposure to toxic chemicals is linked to increased propensity of developing dementia although there is weak evidence for this and it is not a risk factor commonly referenced. Only thirty-seven percent of Canadians correctly identified that people with chronic health conditions (e.g. hypertension, heart disease and diabetes) have a higher risk of developing dementia. Of those who responded “false,” significantly more were older adults.

Attitude and Perceptions

Two-thirds of Canadians worry about the possibility of someone close to them developing dementia, and nearly half worry about developing dementia themselves. In spite of the majority of people believing there are steps that can be taken to mitigate the risk, most Canadians have not taken steps in the past 12 months to reduce their own risk of developing dementia; those over 55 years of age are more likely to have done so.

Over two-thirds of Canadians believe that people living with dementia generally face a lower quality of life than people without dementia. A similar proportion believe that people have negative assumptions about the abilities of people living with dementia. Just under half believe that people living with dementia are sometimes able to continue working for years after the onset of symptoms. Of those who indicated discomfort speaking with a health care provider about an assessment that could lead to a diagnosis of dementia (roughly one-quarter of Canadians), the most common reason (cited by three-quarters) is a fear of facing what lies ahead. Almost six-in-ten fear that a diagnosis would result in others treating them differently. More than

half fear that an assessment might alarm people close to them, and almost as many are afraid that their employer may find out.

At the same time, nearly three-quarters of Canadians report comfort with asking a health care provider for information about dementia symptoms which could lead to obtaining an assessment and diagnosis or having a discussion about their personal risk of developing dementia. Almost two-thirds believe they would feel comfortable telling close family members about a dementia diagnosis; however, only half would be comfortable disclosing the diagnosis to friends, and fewer still said this about telling an employer, neighbours or others in the community.

Half of Canadians described themselves as comfortable interacting with someone living with dementia. Most often, this is because they currently know or have known someone with dementia, or they are generally confident dealing with most situations. Among those who would be uncomfortable (roughly 10% of Canadians), about three-quarters attributed this to uncertainty about how to talk to or support the person living with dementia or worry about how the person would behave or react. More than four-in-ten of those who would feel uncomfortable attributed this to a lack of information about dementia.

Capacity to Care for Persons Living with Dementia

Three-quarters of Canadians report knowing (or have known) someone living with dementia; nearly half of Canadians said they have an extended family member who is living or has lived with dementia. One-fifth have a parent or friend with dementia. Moreover, one-quarter of those who know someone living with dementia have provided unpaid assistance with activities of daily living, and one-fifth have assisted with general health care and monitoring or with financial affairs. Four-in-ten Canadians have provided unpaid assistance to a person they know living with dementia.

For Canadians who have provided unpaid care to a person they know living with dementia, assistance is most frequently provided for another family member or a parent. Within the most recent month at the time of completing the survey (with more than 80% of survey respondents referring to the mid-February to mid-March period just prior to the March 2020 COVID-19 pandemic lockdowns in Canada), one-quarter of caregivers say they spent three hours or less providing unpaid care each week. Just under one in five reported either 3-5 hours/week, or more than 20 hours of care provided each week, and one in four did not provide an estimate. Among those providing an estimate the average number of hours spent providing caregiving responsibilities is 17 (hours) per week. Of those providing care, almost six-in-ten felt they were able to provide the care needed. The remainder felt that a lack of time was a constraint, along with conflicting responsibilities, a lack of support, and a lack of information cited as other barriers.

Among those who have not known or provided care for anyone living with dementia (one-quarter of Canadians), nearly two-thirds feel they would be able to provide frequent unpaid support to a family member or friend living with dementia. The majority attributed this to a desire to do what they could for a person they care about. Half generally reported this is because they feel confident in dealing with all situations, and slightly fewer believe they would have access to sufficient supports and information to assist them in this role. Of those who felt they could not provide support, four-in-ten cited other responsibilities, a lack of time, or a home that is either too small or not appropriately equipped as reasons.

When assessing the level of support in the community provided to people living with dementia, only four-in-ten believe access to health care to be good to excellent. More than one-third believe the quality of health care provided to be good to excellent. Notably, roughly one-fifth to one-quarter indicated they are not aware of the levels of support in their community.

Information Sources

Nearly all Canadians consider health care professionals trustworthy sources of information about dementia. Three-quarters believe scientific books, magazines, and articles to be trustworthy sources, and two-thirds consider provincial or territorial health ministries, or the Government of Canada to be trustworthy sources of information about dementia.

D. NOTE TO READERS

Detailed findings are presented in the sections that follow. Overall results are presented in the main portion of the narrative and are typically supported by graphic or tabular presentation of results. Results for the proportion of respondents in the sample who either said “don’t know” or

did not provide a response may not be indicated in the graphic representation of the results in all cases, particularly where they are not sizable (e.g., 10% or less). Results may also not total to 100% due to rounding.

Bulleted text is also used to point out any statistically and substantively significant differences between sub-groups of respondents. Key demographic patterns of interest are described throughout the report, following a specific order under specific headings (gender, age, province/territory, and groups disproportionately affected by dementia). The latter includes those caring for someone they know who is living with dementia, four ethnic groups for which available evidence suggests a higher than average risk of developing dementia: those of South American, Southeast Asian or South Asian descent or Black Canadians, as well as Indigenous peoples, further sub-divided into First Nations, Métis or Inuit. Other demographic patterns, such as education or income, are also presented where particularly relevant. Only differences that are statistically and substantively different (e.g., five percentage points from the overall mean) are presented.

Details of the methodology and sample characteristics can be found in Appendix A. The programmed survey instrument can be found in Appendix B.

E. CONTRACT VALUE

The contract value for the POR project is \$193,365.37 (including HST).

Supplier Name: EKOS Research Associates

PWGSC Contract Number: 6D016-194055/001/CY

Contract Award Date: Jan 27, 2020

To obtain more information on this study, please e-mail at hc.cpab.por-rop.dgcap.sc@canada.ca

F. POLITICAL NEUTRALITY CERTIFICATION

I hereby certify as Senior Officer of EKOS Research Associates Inc. that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate, or ratings of the performance of a political party or its leaders.

Signed by:



Susan Galley (Vice President)

1. DETAILED FINDINGS

A. SAMPLE CHARACTERISTICS

The table below presents the demographic composition of the survey respondents. As with results throughout the report, results in Table 1 are presented weighted. The questions used in the composition of the (age, gender, region, education, ethnic target groups and Indigenous status) also are presented without weighting in Appendix A.

Table 1: Demographic Table

Demographic	Total
<i>Age</i>	<i>n=4207</i>
18-35	27%
35-44	16%
45-54	18%
55-64	17%
65 up	21%
<i>Gender</i>	<i>n=4207</i>
Male	48%
Female	51%
Prefer to self-identify	1%
<i>Education</i>	<i>n=4205</i>
High School diploma or less	7%
High school completion or equivalent	33%
Registered Apprenticeship or other trades certificate or diploma	5%

Demographic	Total
College, CEGEP or other non-university certificate or diploma	22%
University certificate or diploma below Bachelor's level	7%
Bachelor's degree	15%
Post graduate degree above bachelor's level	10%
Prefer not to answer	1%
<i>Total household income</i>	<i>n=4207</i>
Under \$20,000	9%
Between \$20,000 and \$39,999	14%
Between \$40,000 and \$59,999	14%
Between \$60,000 and \$79,999	13%
Between \$80,000 and \$99,999	12%
Between \$100,000 and \$149,999	17%
\$150,000 or above	11%
Prefer not to answer	11%
<i>Language spoken at home</i>	<i>n=4207</i>
English	72%
French	20%
English and French equally	2%
Other (Please specify):	6%
<i>Region</i>	<i>n=4207</i>
British Columbia	13%
Alberta	11%

Demographic	Total
Saskatchewan	3%
Manitoba	4%
Ontario	38%
Quebec	23%
New Brunswick	2%
Nova Scotia	3%
Prince Edward Island	0% ³
Newfoundland Labrador	2%
Yukon	0%
Northwest Territories	0% ³
Nunavut	0% ³
<i>Belonging to ethnic or cultural groups</i>	<i>n=3867</i>
British	34%
French	24%
Other Western European	11%
Southeast Asian	8%
Eastern European	7%
South Asian	5%
Scandinavian	4%
Southern European	4%
Black Canadians (African, Caribbean)	3%
American	2%
Latin American	2%

Demographic	Total
Arabic	1%
Oceania	1%
Other	2%
None	14%
Prefer not to answer	2%
<i>Indigenous or Aboriginal person</i>	<i>n=4207</i>
Yes	4%
No	92%
Prefer not to answer	1%
<i>First Nations person, Métis, or Inuk</i>	<i>n=596 (Indigenous)</i>
First Nations	54%
Métis	35%
Some indigenous ancestry	4%
Inuk	3%
Prefer not to answer	4%
<i>Living on a reserve or First Nation community for at least 6 months of the year</i>	<i>n=191 (First Nations)</i>
Yes	23%
No	77%

Demographic	Total
<i>Sexual orientation</i>	<i>n=4207</i>
Heterosexual	87%
Bisexual	4%
Gay	3%
Lesbian	1%
Other	1%
Prefer not to answer	5%

* Includes the 3% note as Indigenous in previous question (Belonging to ethnic/cultural group)

Gender

- Higher proportions of those 55 years and older in the sample are women (56% to 58%). Women are also more likely to report lower household incomes (57% of those reporting under \$40,000 are women and only 41% are men). Among sample members living in Nunavut and Quebec, higher than average proportions are women (74% and 57%, respectively).

Age

- According to Statistics Canada, Canadians over 65 years of age are more likely to be retired. This is reflected in more often reported household incomes of \$60,000 or less (29% to 30% of those reporting such incomes are 65 years of age or older), whereas those who are 35 to 55 years of age most often report the highest household incomes (23% to 27% with \$150,00 or higher).
- Those 55 or older are also more likely to report a high school level of education (26% among those 55 to 64 and 31% among those 65 or older). Respondents under 35 are considerably more likely to report post-secondary education (40%).
- There are some age differences across geographic lines, with higher proportions of those 65 or older present among residents of PEI (41%) and Northwest Territories (40%), followed by Newfoundland and Labrador, and Quebec (29% and 27%, respectively). Higher proportions of the Nova Scotia and Ontario sample are under 35 years of age (39% and 32%, respectively).
- Note that, since the education and income are often lower among those 65 or older (and to a lesser extent among those 55 to 64), and those under 45 more often report higher levels

of education and household income, there are a number of sub-group patterns of results where age, education and income follow a predictable pattern. Most often this seems to be driven largely by age, and therefore, only the variation in results by age are reported. **Only in instances where there are variations in results by income and/or education, that are not explainable by the pattern of age cohorts, are such results described in the report.** All sub-group results, however, are available in the companion data tables.

Populations disproportionately affected by dementia

- The study focuses on individuals who are disproportionately affected by dementia along three dimensions.
 - First, respondents who identified themselves as having some responsibility for the care of a person they know who has dementia are examined as a separate sub-group of interest in the study;
 - Second, respondents identifying as belonging to one of four ethnic populations (South American, Southeast Asian, South Asian or Black Canadians) are also examined as separate sub-groups in the study results. Available evidence suggests these four ethnic groups are more likely to be disproportionally affected by dementia, in part due to genetic factors, unequal access to health services, higher risk for other chronic diseases and limited resources in their first language; and,
 - Third, respondents who identified as Indigenous peoples are also examined as a separate sub-group, and further broken down by Indigenous population. Available data suggests Indigenous peoples are at a higher risk for chronic diseases (e.g. diabetes, cardiovascular disease and obesity), which further increases their risk of developing dementia.
- Those identifying as caregivers are more likely to be 55 years of age or older (46%). However, there are no significant gender differences.
- Across the four ethnic groups disproportionally affected by dementia, there is a higher than average proportion of women among Black Canadians in the sample (68%), as well as among those with a South American background (63%). The reverse is true among those of Southeast Asian descent, where 39% are women.
- The educational profile is higher than average among those of (South and Southeast) Asian descent, where approximately half have completed university (48% and 53%, respectively). The household income is lower than average among Black Canadians in the sample, with 53% reporting under \$60,000.
- Among Indigenous Peoples in the sample, just over half (54%) are First Nations people, and one in three (35%) are Métis people. There is a higher than average completion of college/apprenticeship (39%), although a considerably lower than average household income, with 36% reporting less than \$40,000.

Working or volunteering in roles that may require interacting with people living with dementia

Just over one-quarter (26%) of Canadians work in a sector where they may need or may have needed to interact with people living with dementia. Just under a quarter (22%) have volunteered in a sector that may need or may have needed to interact with people living with dementia. Crossing these two, 39% of Canadians may need or may have needed to interact with people living with dementia, either professionally (16%), in a volunteer capacity (12%), or both (10%). Sixty-one percent of Canadians do not need to interact with someone living with dementia in some role.

Table 2: Exposure

Questions and categories	Total
<i>Q19. Do you (or did you) work in a sector where you may need (or may have needed) to interact with people living with dementia?</i>	<i>n=4207</i>
Yes	26%
No	70%
Don't know	3%
<i>Q23. Do you (or did you) volunteer in a sector where you may need (or may have needed) to interact with people living with dementia?</i>	<i>n=4207</i>
Yes	23%
No	75%
Don't know	2%

Gender

- Women are more likely than men to say they volunteer in a capacity that involves interacting with people living with dementia (25%).

Age

- There is a higher than average proportion of individuals working in a sector where they may need to interact with people living with dementia among the under 35 age cohort (31%).

Province/Territory

- There is a higher than average proportion of individuals working in a sector where they may need to interact with people living with dementia among residents of the Yukon (40%), Manitoba (38%) and Newfoundland and Labrador (36%).

Populations disproportionately affected by dementia

- There is a higher than average proportion of individuals working in a sector where they may need to interact with people living with dementia among Black Canadians (38%) and Indigenous peoples (35%), particularly among Métis people (40%).

Education

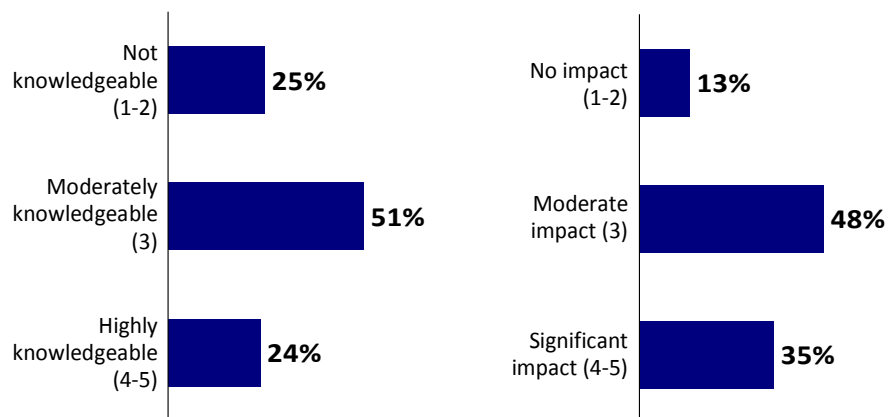
- There is a higher than average proportion of individuals working in a sector where they may need to interact with people living with dementia among those with a college level of education (33%).

B. KNOWLEDGE

Knowledge and Impact of Dementia

One-quarter (24%) of Canadians feel they are highly knowledgeable about dementia, while a similar proportion (25%) say they are not knowledgeable. Over eight-in-ten (83%) believe that dementia is having a moderate to significant impact in Canada today. Only about one-tenth (13%) of Canadians feel that dementia is not having an impact.

Chart 1: Knowledge and Impact of Dementia



Q1. How knowledgeable would you say you are about dementia?

Q2. Overall, how much of an impact do you think dementia is having in Canada today?

Base: 4207

Gender

- Compared with men, a higher proportion of women feel highly knowledgeable (28%) and believe dementia is having a significant impact (41%).

Age

- Canadians over 55 years of age are more likely than others to feel highly knowledgeable about dementia (27% to 28%) and believe dementia is having a significant impact (41%).
- Those under 45 years of age are least likely among the age groups to feel knowledgeable (21%) and believe that dementia is having an impact (18%).

Province/Territory

- Regionally, self-rated knowledge of dementia is highest in the Yukon (44%), PEI (34%) and Quebec (33%). Residents of Nova Scotia (34%) and Ontario (28%) are most likely to say they are not knowledgeable.
- In terms of rated impact of dementia in Canada, residents of the Northwest Territories (56%), along with Newfoundland and Labrador (46%), and PEI (42%) are most likely to rate it as high. Only residents of the Yukon stand out as more likely to indicate no impact (23%).

Populations disproportionately affected by dementia

- Caregivers of people living with dementia are the most likely to feel highly knowledgeable (40%) and that dementia is having a significant impact (48%).
- Indigenous peoples are also more likely to feel highly knowledgeable (31%) about dementia, particularly Inuit people (50%) followed by Métis people (33%). Indigenous peoples (43%) are also more likely to feel dementia is having an impact in Canada today, particularly Inuit people (65%).
- Among the four ethnic groups most affected by dementia, those of South American descent (35%) and Black Canadians (34%) rate themselves as highly knowledgeable. Those of Southeast Asian or South American³ background are the most likely to say their knowledge is little-to-none (33% and 32%, respectively). Those of South American descent are also more likely to rate the impact of dementia as high (46%), while those from a Southeast Asian background are least likely to rate the impact as high (23%).

Education

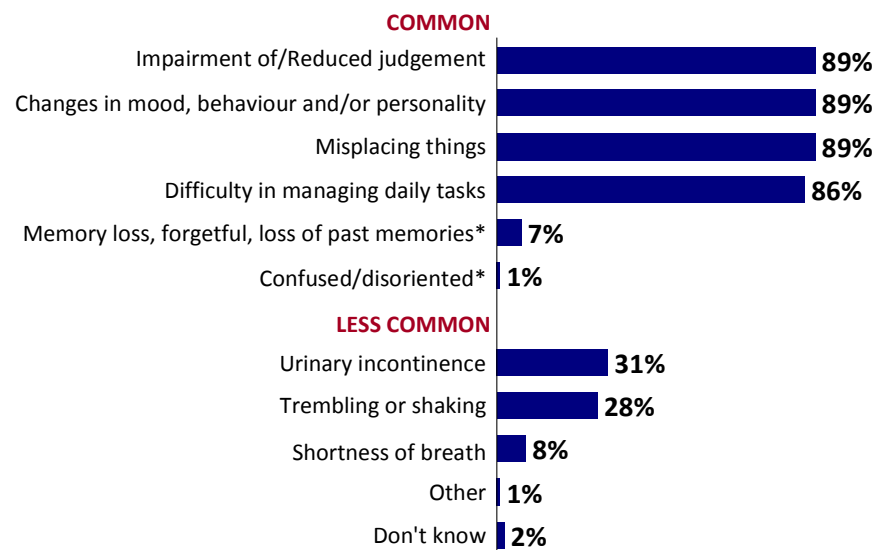
- Contrary to the age pattern described, those with only high school education are least likely to feel knowledgeable (28% not knowledgeable) but more likely to say dementia is having a significant impact (39%).

³ Sampled Canadians of South American descent were more likely than other Canadians to fall on either end of the self-rated knowledge spectrum, with fewer in the moderate category.

Common Signs and Symptoms

Most Canadians correctly identify common signs and symptoms of dementia, most notably impaired or reduced judgement, changes in mood, behaviour or personality, or misplacing things (89% in each case), and difficulty in managing daily tasks (86%). Some signs and symptoms identified by Canadians that are less commonly associated with dementia include urinary incontinence (31%) and trembling or shaking (28%).

Chart 2: Knowledge of Common Signs and Symptoms



Q4. What are the signs and symptoms of dementia as far as you know?

** Indicated by respondents in verbatim responses*

Base: Overall n=4206

Gender

- Women are more likely than men to select urinary incontinence (36%) which is a symptom less commonly associated with dementia.

Age

- Canadians under age 35 are slightly more likely than others to cite each of the common signs and symptoms (88% to 92%), while those over 65 years of age are less likely (82% to 86%).

Province/Territory

- In terms of region, residents of New Brunswick are most likely to point to difficulty managing tasks (91%) as a sign of dementia. Those in Yukon are the most likely to cite misplacing things (97%), as well as changes in mood (96%) and impaired judgement (95%). Misplacing things (94%) and mood changes (93%) are also more likely signs mentioned by Albertans and in Manitoba. Generally, residents of PEI are somewhat more likely to cite symptoms that are not commonly associated with dementia such as urinary incontinence (41%) and trembling or shaking (34%). Those in Yukon or Northwest Territories (50% each) are also more likely to note trembling or shaking.

Populations disproportionately affected by dementia

- Caregivers are more likely to identify common signs (92% to 94%), however, they are also more likely than other Canadians to identify urinary incontinence (37%) as a sign of dementia, although it is uncommon.
- Indigenous peoples are more likely to select urinary incontinence (41%, most notably among Métis people at 48%), or trembling (36%), both symptoms that are less commonly associated with dementia. Inuit people are also more likely than other Canadians to point to shortness of breath (22%) but less likely to select the common signs (difficulty managing daily tasks [55%], changes in mood [64%], impaired judgement [69%], and misplacing things [82%]).
- Common signs are less likely to be chosen by three of the four ethnic groups most affected by dementia: Black Canadians - misplacing things at 84%, difficulty in managing daily tasks at 79%, and impaired judgement at 76%; South Americans - misplacing things at 82% and impaired judgement at 82%; and, those of South Asian descent - changes in mood, behaviour and/or personality at 81%. All four groups select trembling or shaking, which is not a symptom commonly associated with dementia, more than the general population (South America at 45%; South Asia at 38%; Black Canadians at 38%; Southeast Asia at 34%); Black Canadians also select shortness of breath more often, also not a common sign (14%).

Risks and Treatments

Respondents were asked whether a number of statements are true or false. Three-quarters (74%) believe correctly there are things we can do to reduce the risk of developing dementia. Two-thirds (67%) incorrectly believe that there are effective treatments generally that can delay the onset of symptoms and slow the progression of dementia. While more than one-third (37%) perceive accurately that the risk of developing dementia is higher among people with chronic health conditions such as hypertension, heart disease and diabetes, nearly the same proportion (34%) are unsure. One-third (32%) know that some ethnic or cultural groups have a higher risk of developing dementia (as suggested by available evidence), although the same proportion do not believe this to be the case, and a slightly higher proportion are unsure (36%). Relatively few (16%) incorrectly believe dementia to be a normal or inevitable part of aging.

Table 3: Knowledge of Risks and Treatments

For ease of reference, the correct response is flagged with *

To the best of your knowledge, please indicate if each of the following are true or false	Total
<i>Q5b. There are things we can do to reduce the risk of developing dementia</i>	<i>n=4207</i>
True*	74%
False	11%
Don't know	15%
<i>Q5d. Some ethnic/cultural groups have a higher risk of developing dementia</i>	<i>n=4207</i>
True*	32%
False	32%
Don't know	36%
<i>Q5e. The risk of developing dementia is higher among people with chronic health conditions such as hypertension, heart disease, and diabetes</i>	<i>n=4207</i>
True*	37%
False	29%

To the best of your knowledge, please indicate if each of the following are true or false	Total
Don't know	34%
<i>Q5g. Dementia is an inevitable (i.e., normal) part of aging</i>	<i>n=4207</i>
True	16%
False*	76%
Don't know	8%
<i>5h. There are effective treatments that can delay the onset of symptoms and slow the progress of dementia</i>	<i>n=4207</i>
True	67%
False*	13%
Don't know	20%

Gender

- Women are more likely than men to say it false that the risk is higher among people with chronic health conditions (32%), which is incorrect.

Age

- Canadians under 35 years old are more likely to say there are things you can do to reduce risk (79%), that some ethnic groups have a higher risk of developing dementia (42%; also higher among those age 35 to 44 at 36%), and that the risk of developing dementia is higher among those with chronic conditions (44%).
- Canadians who are over 65 are least likely to believe that the risk is higher for some ethnic groups (22%), or that the risk is higher for those with health conditions (33%).

Province/Territory

- Regionally, those in Manitoba (85%), Northwest Territories (81%), New Brunswick (80%) and Saskatchewan (79%) are more likely than those in other regions to say there are things we can do to reduce risk. Residents of Quebec are least likely at 67%.
- Those in Yukon (55%), Manitoba (43%), and Ontario (37%) are more likely to say some ethnic groups have a higher risk of developing dementia. Residents of Quebec (19%), PEI (25%), and Northwest Territories (25%) are least likely.

- Canadians in Nunavut (57%), Saskatchewan (43%), Manitoba (43%), and Ontario (41%) are more likely to believe the risk is higher among those with chronic conditions. Residents of Quebec (26%) are least likely.
- Those in Nunavut (44%), Northwest Territories (28%), Yukon (26%), and Quebec (19%) are more apt to incorrectly feel dementia is a normal part of aging. Residents of Newfoundland and Labrador (10%) and Nova Scotia (8%) are least likely to believe dementia is a normal part of aging.
- Residents of New Brunswick (74%), Newfoundland and Labrador (76%), Northwest Territories (78%) and Manitoba (73%) are more likely to incorrectly believe that there are effective treatments generally that can delay the onset or slow the progression of symptoms. Residents of Nunavut are least likely across Canada (51%) to believe that there are effective treatments.

Populations disproportionately affected by dementia

- Caregivers are more likely than others to say that the risk of developing dementia is higher among those with chronic health conditions (44%).
- Indigenous peoples are more likely than others to believe there is a higher risk of developing dementia among those with a chronic health condition (54%), as well as a higher risk among some ethnic groups disproportionately affected by dementia (39%). First Nations and Metis people also incorrectly believe more often than other Canadians that the onset can be effectively delayed with treatments (74%); however, Inuit people are more likely to believe that there are no effective treatments (29% selected false). Inuit people more often believe incorrectly that dementia is an inevitable part of aging (30%) while Métis are less likely to believe so (7%) compared with other Canadians.
- All four ethnic groups disproportionately affected by dementia are more likely to incorrectly believe that dementia is an inevitable part of aging (Black Canadians at 34%; those of South Americans descent at 28%; and those of South and Southeast Asia descent both at 27%).
- The incorrect belief that there are effective treatments that can delay onset is more prominent among those of South American (75%) and South Asian descent (74%). These two groups are also more likely to believe that the risk is higher among those with chronic health conditions (47% and 50%, respectively). Those of South Asian descent (46%) and Black Canadians (42%) are more likely to believe the risk is higher among some ethnic groups compared with other Canadians.

Income

- Those with household incomes of less than \$40,000 are more likely to incorrectly believe there is nothing we can do to reduce the risk of developing dementia (16%) and that dementia is an inevitable part of aging (24%). They are also more likely to correctly indicate that some ethnic groups have a higher risk of developing dementia (40%) and that the risk is higher among those with chronic health conditions (37%).

- Canadians with a household income of \$100,000 or higher are less likely to believe that dementia is a normal part of aging (80% select false).
- Canadians with household incomes of \$150,000 or higher are more likely to indicate that some ethnic groups have a higher risk of developing dementia (39%). They are also less likely to believe that people with chronic health conditions have an increased risk (23% select false), which is incorrect.

Education

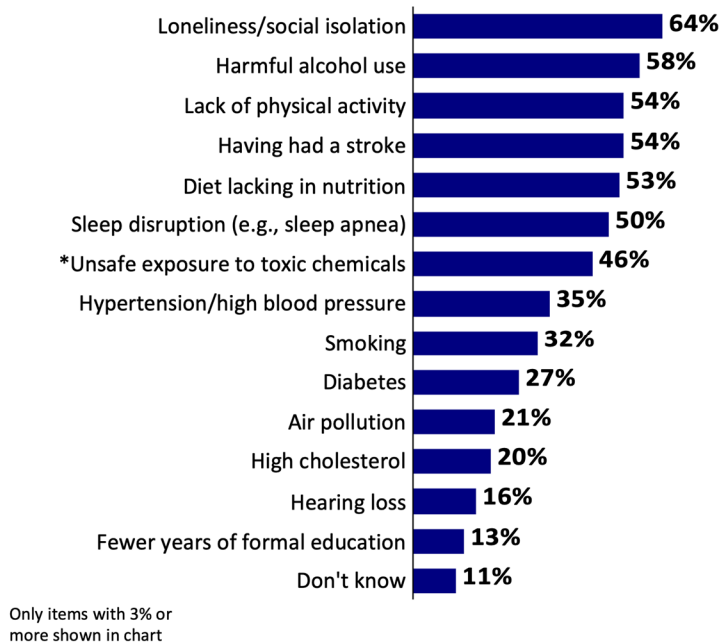
- Those with a university education are more likely to say there are things we can do to reduce risk (85%), some ethnic groups have a higher risk (37%), and the risk is higher among those with chronic conditions (45%). They are less likely to believe that dementia is inevitable (80% indicate it is false).
- For most of the statements in this section of the survey, those with a university education are more likely to accurately identify true and false statements while those with up to a high school education are least likely: there are things that can be done to reduce the risk (85% vs. 67%, respectively), some ethnic groups have a higher risk (37% vs. 29%), those with a chronic health condition have a higher risk (45% vs. 32%), and that dementia is an inevitable part of aging (13% vs 19%).

Risk Factors

Respondents were asked about their knowledge of risk factors linked to dementia. Many Canadians correctly believe that factors such as loneliness and social isolation (64%), harmful alcohol use (58%), lack of physical activity (54%), having had a stroke (54%), a diet lacking in nutrition (53%), and sleep disruption (50%) are linked to increased chances of developing dementia.

Just under half (46%), however, also believe that exposure to toxic chemicals increases the propensity of developing dementia, which is not strongly substantiated by the evidence and is not commonly linked with dementia; this group, however, also selected one or more correct factors. About one-third of Canadians perceive correctly that hypertension or high blood pressure (35%) or smoking (32%) increases the chances of developing dementia. Slightly fewer say that diabetes (27%), air pollution (21%), or high cholesterol (20%) increases the likelihood. Just over one-tenth believe that hearing loss (16%) or fewer years of formal education (13%) can increase the risk of developing dementia. Eleven percent are unsure of any factors that increase the chances of developing dementia, meaning that 89% of Canadians can correctly identify at least one or more risk factors.

Chart 3: Knowledge of Risk Factors



Q6. From what you know or have heard, which of the following increases your chances of developing dementia? (*multiple responses accepted*)

* Not strongly linked in evidence to dementia.

Base: n=4207

Gender

- There are no substantive differences between men and women in terms of identifying risk factors for dementia.

Age

- Canadians under the age of 35 years are more likely to correctly point to alcohol use (67%), a stroke (66%), sleep disruption (61%), and a lack of physical activity (60%) and nutrition (58%) as contributors. They are also more likely, however, to incorrectly select exposure to toxic chemicals (55%) as a risk factor commonly linked to developing dementia.
- Those who are 55 to 64 are more likely than average to identify lack of physical activity (58%) and sleep disruption (54%) as contributors. In addition, they are also more likely to point to smoking (38%) and high cholesterol (25%) as contributors. They are least likely to select a history of a stroke as a risk factor (46%) and exposure to toxic chemicals (41%).
- Canadians 65 years of age or older are less likely to select the following correct risk factors: harmful alcohol use (50%), diet lacking in nutrition (46%), having had a stroke (45%), and sleep disruption (38%).

Province/Territory

- Regionally, residents of the Yukon (78%), Northwest Territories (75%), and Quebec (71%) are more likely to identify loneliness as a factor in increasing chances of dementia.
- Residents of Northwest Territories (76%), Yukon (75%), Quebec (66%), and Manitoba (64%) are more apt to cite harmful alcohol use as a contributor.
- Those in Yukon (75%), Nunavut (67%), PEI (64%), and Manitoba (61%) are more apt to believe lack of physical activity is a risk factor.
- Canadians in Northwest Territories (71%) and Nunavut (65%) are more likely to say having had a stroke increases the chances of developing dementia.
- Yukon (70%), Nunavut (66%), PEI (63%), Saskatchewan (61%), Alberta (60%), and Manitoba (60%) are more apt to identify a diet lacking in nutrition as a contributor.
- Residents of Northwest Territories (62%) are much more likely than others to see smoking as a contributor.
- Aside from the bullets above, residents of Quebec are less likely to select most of the risk factors, notably lack of physical activity (48%), a diet lacking in nutrition (42%), high blood pressure (24%), diabetes (22%), and high cholesterol (14%).

Populations disproportionately affected by dementia

- Caregivers are more likely to select most risk factors including loneliness or isolation (70%), a stroke (64%), lack of physical activity (63%), poor nutrition (61%), and sleep disruption (57%). They are also more likely to identify hypertension (41%), smoking (40%), diabetes (36%), high cholesterol (27%), and hearing loss (21%).
- Those in the four key ethnic groups (particularly those from South America and South Asia, followed by Black Canadians) and Indigenous peoples are more likely to select nearly all risk factors.

Education

- In general, those with post-secondary education select more risk factors while those with high school education select less. Notably, university educated respondents are more likely to select a lack of physical activity (62%), high blood pressure (40%), and fewer years of formal education (19%); those with college education are more likely to select harmful alcohol use (64%) and incorrectly select exposure to toxic chemicals (51%); those with up to high school education are less likely to select harmful alcohol use (52%), lack of physical activity (49%), and exposure to toxic chemicals (41%).

Income

- Loneliness is more often identified as a risk factor among those with the lowest household income (69% among those with \$40,000 or less). In addition, this segment is more likely than others to point to air pollution (26%). Smoking is most often identified as a contributor among those reporting household incomes between \$40,000 and \$60,000 (38%). Sleep

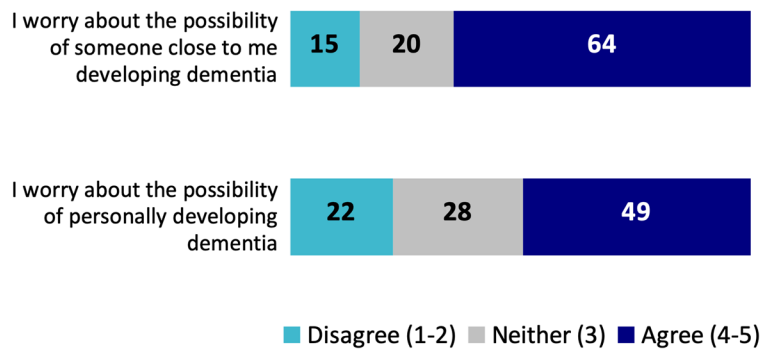
disruption is flagged as a contributor for those with a household income between \$80,000 and \$100,000 (55%). Unsafe exposure to toxic chemicals is selected less often by those with a household income of \$100,000 to \$150,000 (40%). Those in the highest household income range (over \$150,000) select loneliness (56%), sleep disruption (45%), and air pollution (16%) less often.

C. ATTITUDES & PERCEPTIONS (CONCERN, RISK, STIGMA, COMFORT)

Concern About Developing Dementia

Two-thirds (64%) of Canadians indicated they worry about the possibility of someone close to them developing dementia. Fewer (49%) worry about the possibility of personally developing dementia.

Chart 4: Concern about Developing Dementia



Q7ab. To what extent do you agree or disagree with the following...?

Base: n=4207

Gender

- There are no substantive differences between men and women on these measures.

Age

- Canadians between the ages of 55 and 64 are more likely to worry about developing dementia (55%).
- Those under 35, on the other hand, are the most likely age cohort to worry about someone they know developing dementia (73%), whereas this is least likely among those 65 or older (50%).

Province/Territory

- Regionally, concern for personally developing dementia is more prominent in Newfoundland and Labrador (61%) followed by New Brunswick (56%) and Saskatchewan (54%). Residents of Quebec (41%), Northwest Territories (39%), and Yukon (30%) are less likely to be personally concerned.
- Concern for others is also more prominent among residents of Newfoundland and Labrador (75%), as well as those living in New Brunswick (72%), and Alberta (69%). Those in Quebec (58%) and Yukon (37%) are less likely to worry about someone close to them developing dementia.

Populations disproportionately affected by dementia

- Caregivers are more likely than others to be personally concerned about developing dementia (59%), as well as being concerned for others (71%).
- There are no substantively different patterns among Indigenous peoples in their responses on these measures.
- Individuals of Southeast Asian descent (40%) and Black Canadians (36%) are least likely to express worry about personally developing dementia. Black Canadians are also less likely to be concerned about others they know developing dementia (57%).

Taking Steps to Reduce the Risk of Developing Dementia

Most Canadians (70%) have not taken steps in the past 12 months to reduce their own risk of developing dementia while just over one in five (22%) said they have (Q8).

Gender

- Women are more likely to take steps to reduce their risk of developing dementia than men (26% compared with 19% among men).

Age

- Canadians between the ages of 55 and 64 are the most likely to have taken steps (34%), followed by those 65 or older (27%), while those under 45 are least likely to have done so (15% to 16%).

Province/Territory

- Regionally, Manitoba residents are most likely to have taken steps (34%), followed by those living in Newfoundland and Labrador (30%), PEI (29%), and British Columbia (29%). In contrast, residents of Quebec are much less likely to take steps (18%). In Nunavut, most respondents indicated *not* taking steps (82%).

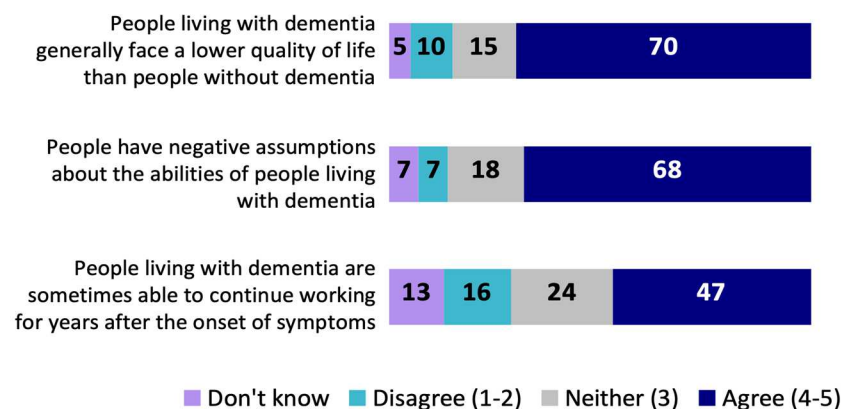
Populations disproportionately affected by dementia

- Caregivers are more likely than others to have taken steps (35%).
- Indigenous peoples are also somewhat more likely than others to have taken steps (28%), although this is more prominent among Métis people (31%), and far less likely among Inuit respondents (6%).
- Each of the four disproportionately affected ethnic groups (28%-34%) are more likely to have taken steps than other Canadians, with those of South American descent (34%) standing out more prominently.

Stigma

Over two-thirds agree with the perception that people living with dementia generally face a lower quality of life than people without dementia (70%). The same proportion agree with the perception that people have negative assumptions about the abilities of people living with dementia (68%). Just under half (47%) agree with the view that people living with dementia are sometimes able to continue working for years after the onset of symptoms.

Chart 5: Perceptions of People Living with Dementia



Q9abc. To what extent do you agree or disagree with the following...?

Base: n=4207

Gender

- Men are more likely to agree with the view that people living with dementia can work for years after the onset of symptoms (51% compared with 43% of women), and that people living with dementia have a lower quality of life (73% versus 66% among women).

Age

- Canadians under 35 years of age are more likely to agree with the view that people living with dementia can work for years after the onset of symptoms (52%), people have negative assumptions about the abilities of people living with dementia (73%), and that people living with dementia have a lower quality of life (74%).

Province/Territory

- Regionally, residents of Nunavut (80%), Saskatchewan (78%), PEI (75%), and Nova Scotia (74%) more often agree with the view that people have negative assumptions about the abilities of people living with dementia.
- In terms of the perception of a lower quality of life, no one province or territory stands out, with the exception of residents of Nunavut who are least likely to agree (23%).
- Residents of Quebec (63%) and Northwest Territories (57%) are least likely to agree with the view that people living with dementia generally face a lower quality of life than people without dementia. Residents of Nunavut are more likely than other residents to disagree (23%) with this view.
- Residents of the Yukon (60%) are more likely to agree with the view that people living with dementia are sometimes able to work years after the onset of dementia. This is followed by residents of Alberta (53%). Residents of Quebec (38%) are least likely to agree. Those living in the Northwest Territories (25%) and New Brunswick (22%) are more likely to *disagree* with this view compared with others.

Populations disproportionately affected by dementia

- Caregivers are more likely than others to agree with the view that people have negative assumptions about the abilities of people living with dementia (73%), and to a lesser extent with the view that those living with dementia can continue to work for years after the onset (51%). They are least likely to agree with the view that someone living with dementia faces a lower quality of life (65%).
- Indigenous peoples are more likely than others to agree with the view that people have negative assumptions about the abilities of people living with dementia (77%; particularly true among First Nations and Inuit people at 79% and 80%, respectively). Métis people (77%) are more likely than other Indigenous peoples, and other Canadians, to agree with the view that people living with dementia generally face a lower quality of life.
- Those of South American (79%) and South Asian (76%) background are more likely than other Canadians to agree with the view that someone living with dementia faces a lower quality of life; a sentiment least often shared by Black Canadians (56%). Those of South Asian (61%) and Southeast Asian (60%) descent are least likely to agree with the view that people have negative assumptions about people living with dementia.

- Those of South American descent (26% agree) and Black Canadians (25% disagree) are least likely to believe that people living with dementia can continue to work for years after the onset of dementia.

Comfort Level with Dementia

Respondents were asked how comfortable they would be interacting with someone living with dementia and the reasons behind their answers. Half (50%) of Canadians say they are comfortable interacting with someone living with dementia. Most often, this is because they currently know or have known someone living with dementia (61%). Just over half also indicate the reasons is that they are generally confident dealing with most situations (57%). Over one-quarter (28%) are comfortable because they have information on supporting people living with dementia. For those who are uncomfortable interacting with someone with dementia, about three-quarters say it is because they are not sure how to talk to or support the person (76%). A slightly smaller proportion indicate that they are worried about how the person would behave or react (70%). More than four in ten (42%) feel they do not have enough information about dementia while 30% attribute their discomfort to never having known someone with dementia.

Table 4: Comfort Level Interacting with People Living with Dementia and Reasons Why

Questions and categories	Total
<i>Q10. How comfortable would you feel interacting with someone living with dementia?</i>	<i>n=4207</i>
Not comfortable (1-2)	12%
Moderately (3)	34%
Comfortable (4-5)	50%
Don't know	4%
<i>Q10a. Why would you feel comfortable interacting with someone living with dementia? (multiple responses accepted)</i>	<i>n=3647</i>
Currently know or have known people with dementia	61%
Generally confident in dealing with most situations	57%
Have information on supporting people with dementia	28%

Questions and categories	Total
*They deserve respect/kindness, empathy/understanding/compassion for people, want to help those in need	6%
*Current or previous work/volunteering/training in field or related field	3%
*Family/loved one	1%
Other	3%
Don't know	5%
<i>Q10b. Why would you feel uncomfortable interacting with someone living with dementia? (multiple responses accepted)</i>	<i>n=421</i>
Not sure how to talk to or support/help the person	76%
Worried about or unsure of how the person will behave/react	70%
Don't have enough information about dementia	42%
I have never known anyone with dementia	30%
Other	9%
Don't know	1%

* Not strongly linked in evidence to dementia.

Gender

- Women (56%) are more likely than men (44%) to say they would feel comfortable interacting with someone living with dementia.
- Women are more likely to cite knowing someone living with dementia (64%) as a key reason for feeling comfortable interacting with someone living with dementia.
- Men are more likely to say they are not sure how to talk to or support a person living with dementia (80%) as their main reason for their discomfort.

Age

- Although there are no notable significant differences in comfort levels across age cohorts, Canadians aged 45 years and older are more likely to say they are comfortable because they know someone with dementia (66% to 69%).
- Those under 35 years are more likely than older age groups to say they are uncomfortable because they have never known someone living with dementia (50%). Those aged 45 to 64 years more often than other age groups point to insufficient information about dementia as a reason for their discomfort (54% to 57%). Canadians 65 years of age or older are least likely to select any of the reasons provided (I have never known anyone with dementia [21%]; don't have enough information [26%]; worried about how the person will behave [59%]; not sure how to support the person [68%]).

Province/Territory

- Regionally, comfort interacting with those living with dementia is more prominent among residents of the Yukon (65%), followed by Alberta (57%) and British Columbia (56%). Residents of Nunavut expressed the greatest discomfort (23%).
- Residents of PEI (78%), Northwest Territories (77%), Saskatchewan (74%) and Alberta (73%) are the most likely to say they are comfortable because they have known someone with dementia. Those in the Northwest Territories (73%), the Yukon (70%), and New Brunswick (63%) are more likely than others to point to a general comfort with most situations. Having information about dementia is the most prominent reason provided in Nunavut (46%) compared with other parts of the country, followed by PEI (41%) and Manitoba (37%). Residents of Quebec are least likely to select any of the reasons provided (have information on supporting people living with dementia [24%]; currently know or have known someone living with dementia [52%]; and generally confident in dealing with most situations [52%]).
- Concern about how a person living with dementia will behave or react is more often cited as a reason for discomfort by residents of Alberta (86%) and British Columbia (84%). Residents of Ontario are more likely than others across the country to say their discomfort is linked to never having known a person living with dementia (38%). Residents of Quebec (51%) are more likely to indicate it is because they do not have enough information about dementia.

Populations disproportionately affected by dementia

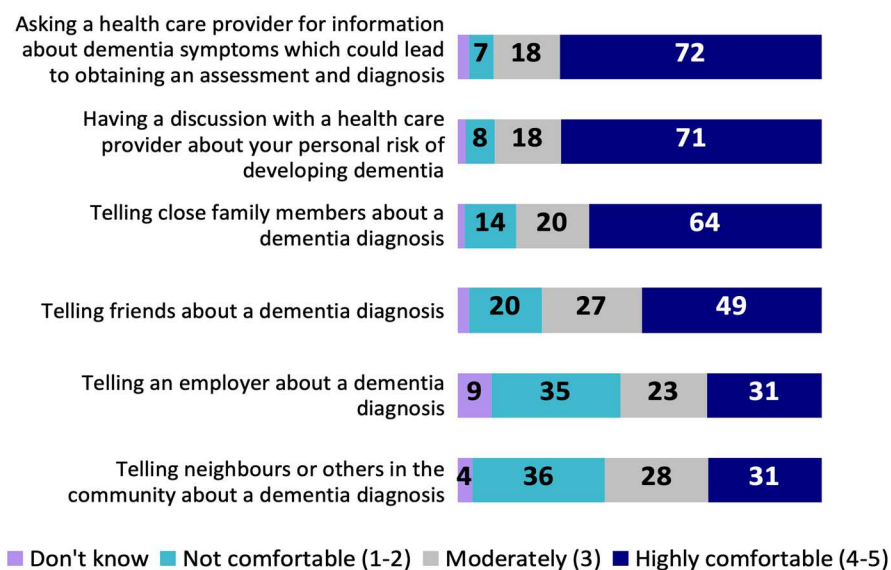
- Caregivers are much more likely to feel comfortable (74%), and to say it is because they have known someone living with dementia (88%). They also are more likely to feel they have the information they need on supporting someone living with dementia (40%). At the same time, the relatively few caregivers expressing discomfort are more likely than others to say they are uncomfortable because they are worried about or unsure how the person living with dementia will behave or react (86%).
- Among Indigenous peoples, Inuit respondents expressed a greater discomfort interacting with a person living with dementia (32%). Among those comfortable, Métis people are more

- likely than others to point to sufficient information about supporting someone with dementia as a reason (35%).
- Those of Southeast Asian (32%), South American (41%) and South Asian (43%) descent are less likely to be comfortable than other Canadians. Of respondents that are comfortable, those of South Asian (50%) and Southeast Asian (51%) descent are less likely than others to point to knowing someone with dementia as a reason; while more often pointing to having sufficient information (39% among South Americans, and 38% among South Asians). Black Canadians (40%) are also more likely to point to having sufficient information.

Dealing with a Dementia Diagnosis

To understand how Canadians feel about seeking and sharing news about a dementia diagnosis, they were asked about their comfort in speaking to different types of people. Nearly three-quarters of Canadians report comfort with asking a health care provider for information about dementia symptoms which could lead to obtaining an assessment and diagnosis (72%) or having a discussion with a health care provider about their personal risk of developing dementia (71%). Almost two-thirds (64%) believe they would feel comfortable telling close family members about a dementia diagnosis; however, only half (49%) would feel comfortable disclosing the diagnosis to friends. Far fewer would feel comfortable telling an employer (31%) or neighbours or others in the community (31%).

Chart 6: Seeking and Sharing Information About a Dementia Diagnosis



Q16a-e. How comfortable would you be with each of the following...?

Base: n=4207

Gender

- There are no substantive differences between men and women in comfort levels.

Age

- In general, discomfort over telling an employer about a dementia diagnosis decreases with age: Those who are 45 to 64 are the most likely to be comfortable with telling an employer (37%), while those under 45 are the least likely to be comfortable (41% to 47% are not comfortable).
- There were no substantive age differences for telling close family members.
- As for telling friends or neighbours, Canadians who are 55 to 64 are also the most likely to be comfortable about telling friends (55%), and neighbours (35%). Those 65 years and older are less likely than younger cohorts to indicate they are comfortable telling friends (44%) but more likely to be comfortable telling neighbours (35%). Those under 45 are relatively unconcerned about telling neighbours (40% to 42% are not concerned).

Province/Territory

- Regional levels of comfort are very mixed, although some regions tend to cluster together as either comfortable or uncomfortable in most cases. Only Ontario residents have no significant differences from the average in any of the scenarios posed.
- The regions that show a higher level of comfort are: Yukon having a discussion with a health care provider (88%), asking for more information (90%), and telling close family (85%), friends (8% not uncomfortable), and neighbours (42%); PEI with telling close family members (73%), friends (13% are uncomfortable), and neighbours (38%); Newfoundland and British Columbia with having a discussion with a health care provider (2% not uncomfortable, 76% comfortable, respectively); Saskatchewan with telling a close family member (69%).
- The regions that show a lower level of comfort are: Northwest Territories in all settings (having a discussion with a health care provider (57%), asking for more information (63%), and telling an employer (45% uncomfortable), close family member (44%), friends (40%), and neighbours (21%)); Manitoba with telling an employer (25%), close family members (20% uncomfortable), friends (28% uncomfortable), and neighbours (43% uncomfortable); Nova Scotia with having a discussion with a health care provider (13% uncomfortable), asking for more information (13% uncomfortable), and telling an employer (43% uncomfortable) or friends (27% uncomfortable); Alberta with telling an employer, friends or neighbours (40% uncomfortable, 25% uncomfortable, and 42% uncomfortable, respectively).
- The regions with varying levels of comfort are: Quebec with reduced comfort discussing with a health care provider (67%) but higher levels of comfort telling an employer (30% uncomfortable) or friends (55%); and, Nunavut with reduced comfort telling friends (39%) but more comfort asking for information (81%) and telling an employer (52%).

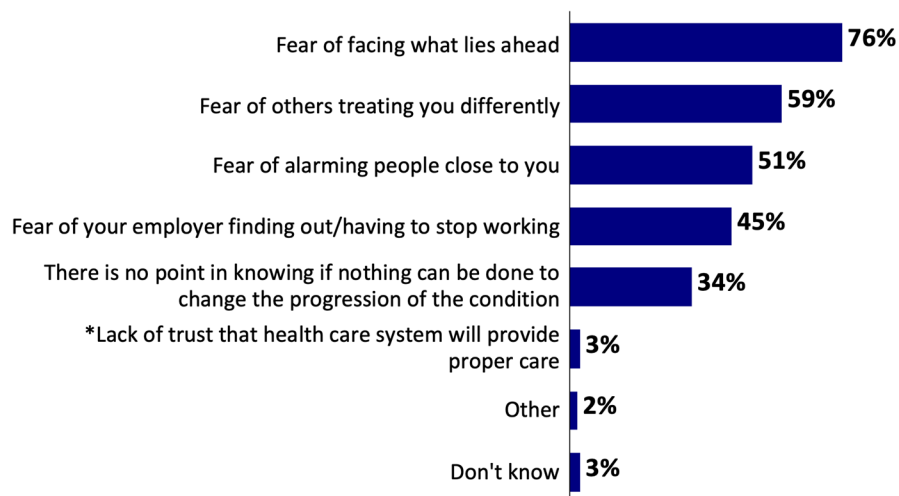
Populations disproportionately affected by dementia

- Caregivers are more comfortable than the general population with the idea of telling neighbours about a diagnosis (38%).
- Indigenous peoples tend to be uncomfortable with most of the scenarios. Métis have a greater likelihood of being uncomfortable having a discussion with a health care provider and telling an employer, friend or neighbour (uncomfortable: 13%, 42%, 30%, and 48%, respectively). For Inuit people, the numbers are small so caution is advised when interpreting the results; however, given that their pattern is similar to Métis people, it is worth noting that they are less comfortable with the idea of having a discussion with a health care provider, asking for more information, or telling close family members or friends (uncomfortable: 16%, 26%, 27%, and 29%, respectively). First Nations are less likely to be comfortable with the idea of asking for more information (67%) and telling close family members (19% uncomfortable), although more comfortable telling an employer (39%).
- Two of the four key ethnic groups report increased comfort in the different settings compared to the rest of the population: Black Canadians in all settings - having a discussion with a health care provider (3% uncomfortable), asking for information, and telling an employer, close family member, friends or neighbours (79%, 45%, 73%, 57%, and 36%, respectively); and, those of South Asian descent are more comfortable with the idea of having a discussion with a health care provider, asking for more information, and telling an employer (77%, 78%, and 40%, respectively).
- Latin Americans show the opposite tendency: more are uncomfortable with the idea of having a discussion with a health care provider, asking for information, and telling friends (uncomfortable: 18%, 14%, and 29%).

Hesitancy in Seeking a Dementia Diagnosis

For the 8% who indicated discomfort with the idea of speaking to a health care provider about an assessment that could lead to a diagnosis of dementia, the most common reason is a fear of facing what lies ahead, cited by three-quarters (76%). Almost six in ten (59%) cited the reason of fear that a diagnosis would result in others treating them differently. Over half (51%) fear that an assessment might alarm people close to them. Just under half (45%) are afraid that their employer may find out and they would have to stop working. About one-third (34%) feel there is no point in knowing if nothing can be done to change the progression of the condition.

Chart 7: Reasons for Avoiding Seeking a Diagnosis



Q16g. Why would you be uncomfortable speaking to a health care provider about an assessment that could lead to a diagnosis of dementia? (*multiple responses accepted*)

** Indicated by respondents in verbatim responses.*

Base: n=283; uncomfortable speaking with a health care provider about assessment leading to diagnosis of dementia

Gender

- Men expressing discomfort with the idea of seeking or speaking about a diagnosis are more likely than women to cite their reasons as being treated differently (65% versus 51% among women), and fear of their employer finding out and/or having to stop working (53% versus 31%).

Age

- Canadians 65 or older who are uncomfortable speaking to a health care provider about an assessment that could lead to a diagnosis of dementia are more likely than younger age cohorts to have concerns about being treated differently (73%). Those who are 45 to 54 are more likely than other age groups to fear their employer finding out (70%).

Province/Territory

- Regionally, residents of Ontario report a greater fear of what lies ahead (89%) as a reason for discomfort.

Populations disproportionately affected by dementia

- Due to the small sample size of this question, there are too few respondents to reveal statistical differences in the populations disproportionately affected by dementia (i.e., caregivers, Indigenous peoples, and the four key ethnic groups).

Income and Education

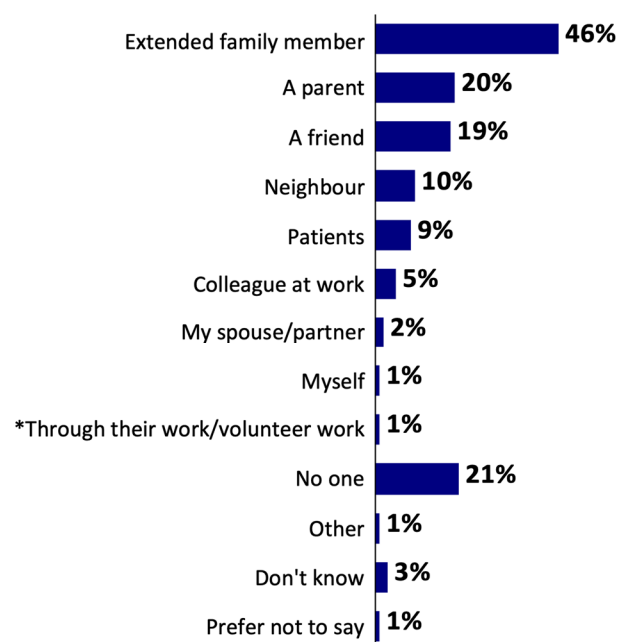
- Of the reasons for discomfort, believing there is no point in knowing if nothing can be done is comparatively stronger among those with household incomes of less than \$40,000 and those with a high school education compared with other segments of Canadians.

D. CAPACITY TO CARE FOR PERSONS LIVING WITH DEMENTIA

Personal Connection to Someone Living with Dementia

Three-in-four Canadians (75%) report knowing someone who is living or has lived with dementia. Nearly half (46%) have an extended family member who is living or has lived with dementia. One-fifth know a parent (20%) or a friend (19%) with dementia. One-tenth cite a neighbour (10%) or a patient (9%).

Chart 8: Personal Connection



Q11. Who do you know (if anyone) that is living/has lived with dementia?
(multiple responses accepted)

** Indicated by respondents in verbatim responses*

Base: n=4074

Gender

- Results do not vary substantively by gender.

Age

- Canadians age 55 years and older are more likely to know a parent (30% to 32%) or a friend (28% to 29%) living with dementia. Those over age 65 are particularly more likely than the rest of the population to have a spouse who is living or has lived with dementia (7%). Those under age 45 are more likely to say they know an extended family member (54% to 56%).

Province/Territory

- Residents of Alberta are more likely than those in other regions to know an extended family member (59%), along with those in PEI (58%) or Newfoundland and Labrador (55%). Those in Northwest Territories (48%), PEI (37%), British Columbia (28%), and Newfoundland and Labrador (29%) are more likely to know a friend. Canadians in the Yukon (27%) or Quebec (25%) are more likely to say they have a parent living/has lived with dementia. Residents of Northwest Territories (29%), Manitoba (17%) or Nova Scotia (18%) are more likely than those in other regions to know a neighbour who is living/has lived with dementia. Residents of the latter two provinces are also more likely to report knowing patients that are living with dementia (17%). Yukon residents are more likely to indicate having (or had) a spouse (7%) or that they (6%) are living with dementia.
- Residents of Nunavut (44%) are more likely to say they don't know anyone living with (or have lived with) dementia.

Populations disproportionately affected by dementia

- Compared with the overall average across all Canadians, caregivers are much more likely to cite an extended family member (60%), a parent (47%), friend (27%), patients (15%) or a spouse (6%) as someone they know who is living (or has lived) with dementia.
- Respondents from the four ethnic groups most affected by dementia more often than average say they do not know anyone who is living or has lived with dementia (30% to 34%).
- Indigenous peoples are more likely than the general population to know an extended family member (52%), a friend (25%), or neighbour (15%) who is living (or has lived) with dementia. Among Indigenous respondents, Métis people and First Nations are more likely to know a neighbour (21%) and friend (26%), respectively.

Experience with Caregiving

An unpaid caregiver may do a range of things for someone living with dementia. One-quarter of those who know someone living with dementia have assisted with activities of daily living (24%). One-fifth have assisted with general health care and monitoring (19%) or with financial affairs (17%). Six in ten (61%) Canadians who know someone living with dementia, however, have not provided any assistance to a person living with dementia.

Assistance is most frequently provided for another family member (43%) or a parent (40%). Just over one-tenth (14%) provide assistance to a close friend, while less than one-tenth have provided care for an acquaintance (9%) or neighbour (7%).

Within the most recent month (where more than 80% of cases were referring to the mid-February to mid-March period - just prior to the March 2020 COVID-19 pandemic lockdowns in Canada), caregivers spend on average 17 hours per week providing care. One-quarter (24%) of caregivers said they spend less than three hours each week, while 16% spend three to five hours per week, and 10% spend six to ten hours weekly. Nearly one-fifth (18%) spend 20 hours or more a week providing assistance. Note, however, that just over one-quarter of those who assist or have assisted people living with dementia did not specify the weekly number of hours they spent caregiving (28%).

Table 5: Current Personal Caregiving

Questions and categories	Total
<i>Q12. An unpaid caregiver may do a range of things to care for someone living with dementia. Have you done any of the following in the last 5 years for a person living with dementia, without getting paid? (multiple responses accepted)</i>	<i>n=3465 (know someone)</i>
Assisted with activities of daily living	24%
General health care and health monitoring	19%
Assisted with financial affairs	17%
*Visiting, social/emotional support	4%
Other types of care	3%

Questions and categories	Total
None of these - no assistance to a person living with dementia	61%
Don't know	2%
Prefer not to answer	1%
<i>Q12a. For whom have you provided the unpaid care? (multiple responses accepted)</i>	<i>n=1418 (caregivers)</i>
Another family member	43%
A parent	40%
A close friend	14%
An acquaintance	9%
Neighbour	7%
My spouse/partner	5%
*A patient from work/volunteering they do	3%
Other	2%
Don't know	1%
Prefer not to answer	2%
<i>Q12b. Thinking of the most recent month you provided unpaid care to someone living with dementia, what would you say is the average number of hours per week you provided the unpaid care?</i>	<i>n=1418 (caregivers)</i>
<3 hours	24%
3-5 hours	16%
6-10 hours	10%
11-19 hours	4%
20+ hours	18%
Average spent per week	17 hours

Questions and categories	Total
Don't know	24%
Prefer not to answer	4%

* Indicated by respondents in verbatim responses

Gender

- Women (28%) are more likely than men (21%) to have assisted with activities of daily living such as cooking, cleaning, bathing or dressing. Women are also more likely to have provided unpaid care for a parent (45% vs. 35%).
- Women also typically provide more hours of care, reporting an average of 22 hours per week, while men report an average of 12 hours per week (30%).

Age

- Those aged 55-64 years are more likely to have assisted with daily activities (32%) or general health care and health monitoring (24%). Canadians over age 55 (22% to 23%) are more likely to have assisted with financial affairs. Those under 35 years of age are least likely to have provided any kind of assistance (66% do not).
- Caregivers under age 45 are more likely to have provided care to another family member (55% to 72%) while those ages 45-54 are more apt to have provided care for a parent (50% to 60%). Caregivers who are 65 and over are more likely to have provided care for a close friend (19%) or a spouse (17%).
- Caregivers who are 35 to 44 provide the fewest hours of care per week (8 hours on average), while those ages 55-64 report the highest number of hours (25 hours per week on average).

Province/Territory

- Residents of Nunavut (47%) and British Columbia (31%) are more likely than those in other regions to have assisted in daily activities. Residents of Alberta and Saskatchewan are more likely to help with financial affairs (22%); the latter are more likely to also assist with general health care and health monitoring (25%).
- Caring for a family member other than a partner or parent is more common in Nunavut (74%) and Newfoundland and Labrador (55%) than it is elsewhere in Canada. Caregivers in British Columbia are more likely to have provided care to a close friend (23%); also true among those in the Yukon (23%) or Northwest Territories (30%). Those in Manitoba (17%), Nova Scotia (16%), PEI (15%), or Newfoundland and Labrador (13%) are more likely to have cared for a neighbour.

- The average time spent on caregiving responsibilities is lowest in Quebec (12 hours on average per week).

Populations disproportionately affected by dementia

- As could be expected, caregivers are considerably more likely to report having done all unpaid activities (assisting with financial affairs [48%]; general health care and monitoring [52%]; and assisting with activities of daily living [70%]).
- Indigenous peoples are more likely to have assisted in daily living (35%), general health care (35%), and assisted with financial affairs (22%). Among these respondents, Métis people are particularly likely to assist with daily living (40%); Inuit people are particularly likely to have assisted with general health care (41%).
- Indigenous peoples are more apt to say they provided care for another family member (49%), a close friend (24%), an acquaintance (14%) or a neighbour (12%). Among Indigenous respondents, Métis people are more likely to have provided care for another family member (57%), while First Nations people are more apt to have provided care for a close friend (29%). Indigenous caregivers also report a higher number of average hours spent per week (24 hours/week), particularly Metis people (33 hours/week).
- Black Canadians are more likely than others to have assisted with daily activities (32%); they more often report assisting a close friend (25%), neighbour (17%), acquaintance (15%), or spouse/partner (11%). Those with South Asian descent more often assist with general health care (27%) than average. This segment is also more likely to report assisting a family member other than a partner or parent (55%). Those of Southeast Asian descent are more likely to help a close friend (26%), although the number of hours spent is lower than average (11 hours/week).

Income and Education

- Those earning less than \$40,000 annually are more likely to have provided care for a close friend (23%) or to an acquaintance (20%). Those with the highest income (\$150,000+ at 53%) or lowest amount of formal education (high school at 48%) are more likely to provide care to a parent. Those with the lowest education and in the \$60,000 to \$80,000 income range reported the fewest average number of hours per week (21 and 29 hours/week, respectively).

Caring for Someone Living with Dementia

Over half (57%) of those who have provided care agree they felt they were able to provide the care needed. In terms of reasons for those who felt unable to provide the care needed, a lack of time was cited most frequently (48%), followed by having other responsibilities (44%), a lack of support (38%), and a lack of information (30%). About one-quarter say they are generally not good in these kinds of situations (25%) or were concerned about finances (24%).

Table 6: Comfort with Caregiving, Reasons

Questions and categories	Total
<i>Q12c. I felt that I was able to/could provide the care needed for someone living with dementia.</i>	<i>n=1418</i>
Disagree (1-2)	16%
Neither (3)	23%
Agree (4-5)	57%
Don't know	3%
Prefer not to answer	1%
<i>Q12d. (21% who disagreed with above) As an unpaid caregiver to someone living with dementia, why did you feel unable to provide the care needed for someone living with dementia? (multiple responses accepted)</i>	<i>n=273 Those feeling unable to provide care</i>
I didn't have enough time	48%
I had other responsibilities	44%
I didn't have enough support	38%
I didn't have enough information	30%
I'm generally not good in those kinds of situations	25%
I was concerned about finances	24%
I was concerned about my own health	17%
I didn't have the space needed	14%

*Distance	10%
*Was not primary caregiver/not in charge	8%
Other	13%
Don't know	3%

** Indicated by respondents in verbatim responses*

Gender

- Women (61%) are more likely to agree that they were able to provide the care needed.
- Men are more likely to point to a lack of time (58%), that they have other responsibilities (51%), not having enough information (39%), that they are generally not good in those kinds of situations (39%), or concerns about finances (32%) as reasons for feeling unable to provide care.

Age

- Canadians age 55-64 are more likely to agree (74%), while those age 35-54 are more likely to disagree (23 to 25%) that they were able to provide care.
- Those under age 35 are more likely to select the following reasons for not feeling able: I didn't have enough time at 58%; I had other responsibilities at 51%; I didn't have enough information at 39%; I'm generally not good in those kinds of situations at 39%; I was concerned about finances at 32%; and, I didn't have the space needed at 9%.

Province/Territory

- Regionally, those living in Nunavut are most likely to say they were able to provide care (81%). Most likely to disagree are residents of PEI (26%), Yukon (26%) and Manitoba (25%), as well as British Columbia (21%). The regions did not differ in their reasons.

Populations disproportionately affected by dementia

- Results among caregivers are essentially the same as found in the broader public with the exception of a lower proportion pointing to a lack time (42%) or lack of information (24%) as key reasons for inability to provide support.
- Indigenous peoples are more likely to disagree that they were able to provide care (21% disagree). They are also more apt to cite that this is because of lack of time (68%), information (55%), or support (54%).
- The four ethnic populations did not differ from average.

Education

- Those with a high school diploma are more likely to agree (65%) they were able to provide the care.

Potential Capacity for Caregiving

Among those with no experience with dementia (i.e., have not known anyone living with dementia or have not provided care for someone with dementia), 61% feel they would be able to provide frequent unpaid support to a family member or friend living with dementia. Among those who feel they could provide support, most (86%) indicate that it is because they would do what they can for a person they care about. About half say it is because they generally feel confident in dealing with all situations (51%), or that they believe they would have access to supports and information (47%). Of those who would not be able to provide support, four in ten say it is because they have other responsibilities (41%), do not have the time (39%), or their home is too small or not appropriately equipped (38%).

Table 7: Personal Ability/Willingness, Reasons

Questions and categories	Total
<i>Q13. Generally speaking, would you be able to provide frequent unpaid support (e.g., acting as a caregiver) to a family member or friend living with dementia?</i>	<i>n=2765 (no experience with dementia)</i>
Yes	61%
No	25%
Don't know	14%
<i>Q13a. Which of the following best describes your reasons for not being able to provide frequent unpaid support to a family member or friend living with dementia? (multiple responses accepted)</i>	<i>n=681</i>
I have other responsibilities	41%
I don't have the time	39%
My home is too small / not properly equipped	38%
I'm concerned about financial implications	32%

Questions and categories	Total
I don't know what would be needed	32%
I'm concerned about the impact on my own health	30%
I'm generally not good in those kinds of situations	27%
*Have a physical disability/chronic illness/mobility issue themselves	6%
*Distance	4%
Other	5%
Don't know	1%
Prefer not to answer	1%
<i>Q13b. Which of the following best describes your reasons for being able to provide frequent unpaid support to a family member or friend living with dementia? (multiple responses accepted)</i>	<i>n=1713</i>
I care about this person so I will do what I can	86%
I'm generally confident in dealing with all situations	51%
I believe I would have access to sufficient supports and information	47%
I know others who have done this who could advise me	35%
I have had experience providing care to someone living with chronic conditions	24%
*Have the time/flexible with time	3%
Other	2%
Don't know	1%

** Indicated by respondents in verbatim responses*

Gender

- Men are more likely to say they would not be able to provide unpaid support because they do not know what would be needed (39%), or that they are not generally good in these kinds of situations (34%). Women are more likely to say that they could not assist because of concerns for their own health (38%).
- Women are more likely to say they would be able to provide support because they have had experience providing care to someone living with chronic conditions (30%).

Age

- Those 55 to 64 years old (67%), along with those under age 35 (66%), are more likely to say they would be able to provide frequent unpaid support. Canadians age 35 to 44 (54%), and over 65 years (53%) are less likely to say they would be able, compared with other age cohorts.
- For those unable to support a person living with dementia, younger Canadians (under age 44) are more likely to say they do not have the time (52% to 65%) or have other responsibilities (52% to 53%). Those under 35 specifically are also more likely to say their home is too small or they are not properly equipped (47%), they are concerned about the financial implications (43%), or they do not know what would be needed (42%). The 55 to 64 age group is also more likely to point to financial constraints (52%), or inadequate home or equipment (52%), generally not being good with these types of situations (50%) and/or a lack of knowledge about needs (48%). Those age 65 and over are more likely to be concerned about the impact on their own health (50%).
- For those able to provide support, younger Canadians (under age 35) are more likely to say they would help because they are generally confident in all situations (61%) or believe they would have access to support and information (58%). Those aged 55 to 64 are more likely to say they would help because they care about the person and would do what they can (91%).

Province/Territory

- Residents more likely to feel unable to provide frequent unpaid support are in Nova Scotia (50%), Yukon (44%), Northwest Territories (42%), and Nunavut (35%). One in three PEI residents (36%) also said they would not be able to provide care.
- Residents of Quebec are more apt than those in other regions to say the reason for not being able to provide support would be that they are generally not good in those kinds of situations (42%). Residents of British Columbia are more likely than others to say that it is because they do not know what would be needed (42%). Having other responsibilities is more often cited as an issue in Saskatchewan (58%), while those in PEI are more likely than others to point to a concern for personal health (59%) or lack of time (56%). Significantly more Ontario residents select financial implication concerns (37%).
- Concern for the person is more often a reason to be able to provide support among residents of Manitoba (93%), who also often say they are generally confident with these

types of situations (63%), and they know others who could advise them (49%). Another 35% of Manitoba residents said they have had past experience in this capacity. Residents of British Columbia are more likely to say the reason for being able is that they would have supports to draw on (57%). Those in Alberta cite confidence in dealing with all situations (59%). Those living in PEI are more likely than others to say they are confident (62%), they know others who could advise them (54%) and they have had past experience (38%). Residents of the Yukon also stand out in their confidence as well as having supports and information to draw on (82% in each case), while those living in Nunavut most often said they could assist because they care about the person (99%) or they could draw on others who could advise them (60%).

Populations disproportionately affected by dementia

- For the four ethnic groups most affected by dementia, their concerns about potentially being a caregiver did not differ from the average. For those that feel they could be a caregiver, Black Canadians select more of the reasons provided (they care about the person so they'll do what they can [93%], they believe they'll have access to the information they need [61%] as well as support from others with experience [48%], and that they have experience being a caregiver [35%]). Those of South American and South Asian descent are more likely to select having access to supports (72%) and caring about this person (93%), respectively.
- Indigenous peoples are less likely than other Canadians to say they would be able to provide support (48%); this is particularly true among Inuit respondents (38%). Among those who feel they could assist, confidence is often the reason (69%); particularly among Metis people (76%).

Income

- Those with household incomes of less than \$40,000 are less likely to feel they would potentially be able to provide frequent support (31%), more often saying the reasons are that they are concerned about their own health (45%), or do not know what to do in these situations (39%). Lack of time is more often selected as a reason among those reporting the highest household incomes (53% to 54% among those reporting \$100,000 or above).
- For those that feel they would be able to provide unpaid care, Canadians within the lowest income range (less than \$40,000) are more likely to indicate that they have experience providing care (30%) while those with the highest incomes more often point to confidence (62%).

Education

- Canadians with a university education are more likely to say the reasons for not taking on a caregiver role are because they have other responsibilities (56%), do not have the time (54%), their home is too small or not equipped (45%), or concerns over finances (38%).

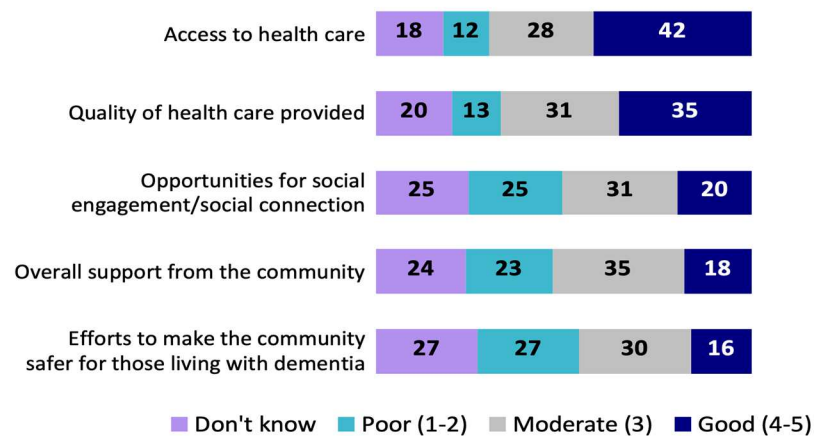
Those with a high school diploma are more likely to say they are generally not good in these kinds of situations (38%).

- Among those who feel they would be able to provide support, those with a university education are more likely to say this is because they have access to the supports and information they need (57%).

Perception of Community Support for those Living with Dementia

Respondents were asked to rate the level of support in their communities for people living with dementia. Only four in ten (42%) rated **access** to health care as good to excellent. Over one-third (35%) believe that the **quality** of health care provided is good to excellent. One-fifth rate the opportunities for social engagement as good (20%), or the overall support from the community (18%). Fewer (16%) rate as good the efforts to make the community safer for those living with dementia. Notable, roughly one-fifth to one-quarter indicated they are not aware of the levels of support in their community.

Chart 9: Support in Community



Q15a-e. From what you know or have heard, how would you rate the level of support in your community that is provided to people living with dementia in each of the following areas...?

Base: n=4207

Gender

- Results do not vary by gender.

Age

- Canadians age 55 – 64 are more likely to rate the quality of health care provided (41%) and opportunities for social engagement or connection (25%) within their community as good.
- The youngest Canadians (less than 35 years old) are more likely to indicate the opportunities for social engagement are poor (32%). Canadians aged 35 to 44 rate the overall support from the community as poor (30%).
- As age increases, the general trend is for increasing approval of the efforts to make the community safer for those living with dementia: from 31% poor for those in the youngest age group (under 35 years old) to 33%, 30%, 22%, and 20% poor for each of the following age groups (35-44, 45-54, 55-64, and 65 years and older, respectively).

Province/Territory

- Regionally, those in Northwest Territories (72%) or PEI (61%) are more likely to rate access to health care as good. PEI (59%), along with those in the Yukon (50%), Nunavut (49%) and Northwest Territories (43%) are more likely to rate quality of health care provided as good. Residents of each of the Territories are also more likely to rate opportunities for social engagement (32 to 35%) and overall support from the community (35 to 37%) as good. Those in Newfoundland and Labrador (30%) and PEI (27%) are also more likely to rate overall support from the community as good. Canadians in PEI (28%) and Northwest Territories (28%) are more likely to rate efforts to make the community safer for those living with dementia as good.

Populations disproportionately affected by dementia

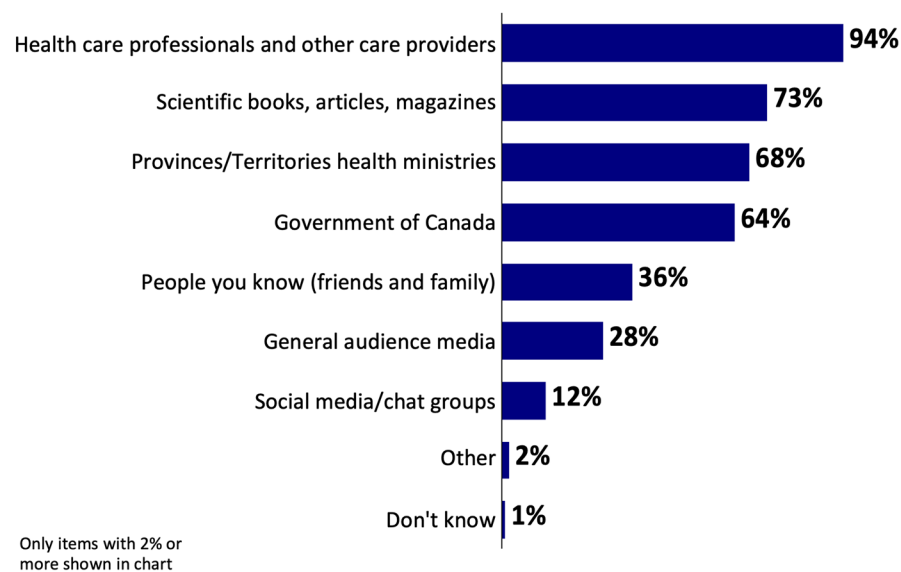
- Caregivers are polarized (e.g., more likely to have more at the high and low end of the rating scale) compared to the general population for all five support mechanisms.
- Black Canadians are more likely to rate all five support mechanisms as good: the access (55%) and quality of health care provided (43%), opportunities for social engagement (37%), overall support from the community (31%), and efforts to make the community safer (29%) as good. South Asian Canadians view the overall support from the community (24%) and efforts to make the community safer (22%) as good.
- More negative views are seen within those of Southeast Asian and Latin American descent. For all community supports listed, Southeast Asian Canadians have fewer ratings of good: access to health care (33%), quality of health care (20%), opportunities for socialization (13%), overall support (10%), and efforts to make the community safer (11%). Those of Latin American descent are more likely to rate the quality of health care provided (significantly more chose 'poor' at 21%) and opportunities for social engagement (significantly fewer chose 'good' at 11%) poorly.
- Indigenous peoples, as a whole, are more likely to rate all support mechanisms as poor: access to health care (18%), quality of health care provided (19%), opportunities for social engagement (34%), overall support from the community (30%), and efforts to make the

community safer for those living with dementia (35%). Interestingly, of the three Indigenous groups, only Inuit peoples provided higher ratings for all support mechanisms but there are signs of polarization: access to care (55%), quality of care (31% poor but 54% excellent), opportunities for socialization (39% poor but 40% excellent), overall support from the community (67%), and efforts to make the community safer (46%). Métis peoples were more likely than average to rate access to and quality of health care (23% and 24% respectively) as poor.

E. INFORMATION SOURCES

Nearly all (94%) Canadians consider health care professionals trustworthy sources of information about dementia. Other trustworthy sources include scientific books, magazines and articles (73%), provincial or territorial health ministries (68%), or the Government of Canada (64%). Over one-third (36%) would trust people they know.

Chart 10: Trusted Sources of Information about Dementia



Q18. What would you consider to be trustworthy sources of information about dementia? (*multiple responses accepted*)

Base: n=4207

Gender

- Results do not vary substantively between genders.

Age

- Canadians under the age of 35 years are more likely than other Canadians to trust scientific books and magazines (84%), the Government of Canada (79%), or provincial or territorial health ministries (79%). Those aged 45-64 are more likely to trust health care professionals (97%).
- Those who are 55 to 64 and 65 or older are less likely to trust scientific sources (66% and 62% respectively), Government of Canada (60% and 49% respectively), and provincial/territorial health ministries (64% and 59% respectively). The oldest Canadians (65 years and older) are less likely to trust health care professionals or other care providers although trust is still high (89%).

Province/Territory

- Regionally, those in Newfoundland and Labrador (99%) and Yukon (99%) are more likely to trust health care professionals. Canadians in Saskatchewan (81%), Quebec (79%) and Manitoba (79%) are more likely to trust scientific books and articles. Those in the northern regions are more likely to trust people they know (62% to 76%). Those in Yukon (90%), Northwest Territories (85%), PEI (80%), and Quebec (73%) are more likely to trust their Provincial or Territorial health ministries. More residents in Yukon (87%), Northwest Territories (83%), and PEI (78%) have trust in the Government of Canada.

Populations disproportionately affected by dementia

- Results for caregivers do not vary substantively from the general population.
- Of those among the ethnic groups most affected by dementia, all groups are more likely to consider the Government of Canada to be a trustworthy source (South Asian at 80%; Southeast Asian and Black Canadians at 78%; and, South American at 74%). Three of the four groups have more trust in provincial/territorial governments, social media, and general audience media (respectively: South Asian at 79%, 18%, 38%; Southeast Asian at 78%, 17%, 45%; and, Black Canadians at 75%, 28%, 41%). Of the remaining sources, the notable increases in trust are seen with those of Southeast Asian descent for scientific sources (79%) and Black Canadians for people they know (57%).
- Indigenous peoples have lower trust in provincial/territorial health ministries (63%). First Nations and Inuit peoples have more trust in people they know (42% and 48%, respectively) and social media (18% and 40%, respectively); Métis people have less trust in these same sources (24% and 7%, respectively).

Income

- Those with less than \$40,000 income are more likely to trust people they know (42%), general media (34%) or social media (17%).

APPENDICES

A. METHODOLOGICAL DETAILS

The summary section of this report (Sub-heading B – Methodology) described the *Probit* panel source used for more than 90% of the sample, with a small sub-set of ethnic respondents obtained from a targeted RDD sample source. As previously outlined the survey was collected between March 16 and April 30, with a questionnaire length averaging 15 minutes online and 21 minutes by phone.

As shown below the average response rate overall across the 4,207 cases is 19%. It is 22% among *Probit* ample members who completed the survey online. A total of 10,723 records were sampled to receive an email invitation to the survey, of which 85 bounced as undeliverable, leaving a valid sample of 10,637. Of these records, 2,346 were completed and 22 were found to be out of scope (i.e., ineligible). These two combined (2,346 plus 22) are divided by the function sample of 10,637 to obtained the 22.3% response rate.

The response rate is 16.8% across cases completed by telephone, including 26.5% among *Probit* panel members who completed the survey by telephone and 7% among those through RDD, including the cases dialled by the IVR. Following are the call outcomes.

Outcome	Probit	RDD
Total	3,885	131,134
Invalid	266	26,412
Valid Sample	3,619	104,722
Non-responding	2,297	45,876
Refusal	351	51,350
Partial complete	12	121
Total non-response	2,660	97,347
Ineligible/quota filled	10	6,463
Complete	949	912
Response rate	26.5%	7.0%

As indicated in Sample Characteristics on page 10, all results in the report are presented as weighted percentages. Following are the unweighted percentages of the sample within each sample segments, within the variables used to create the weight.

Table 8: Unweighted Sample Distribution in Variables used in Weight

Demographic	Total
<i>Age</i>	<i>n=4207</i>
18-35	19%
35-44	16%
45-54	18%
55-64	22%
65 up	25%
<i>Gender</i>	<i>n=4207</i>
Male	48%
Female	51%
Prefer to self-identify	1%
<i>Region</i>	<i>n=4207</i>
British Columbia	10%
Alberta	8%
Saskatchewan	7%
Manitoba	7%
Ontario	18%
Quebec	12%
New Brunswick	7%
Nova Scotia	8%
Prince Edward Island	6%

Demographic	Total
Newfoundland Labrador	6%
Yukon	4%
Northwest Territories	4%
Nunavut	2%
<i>Education</i>	<i>n=4205</i>
High School diploma or less	5%
High school completion or equivalent	20%
Registered Apprenticeship or other trades certificate or diploma	5%
College, CEGEP or other non-university certificate or diploma	20%
University certificate or diploma below Bachelor's level	7%
Bachelor's degree	25%
Post graduate degree above bachelor's level	18%
Prefer not to answer	1%
<i>Belonging to ethnic or cultural groups</i>	<i>n=3867</i>
Southeast Asian	5%
South Asian	5%
Black Canadians (African, Caribbean)	6%
Latin American	3%
Indigenous	14%

B. SURVEY QUESTIONNAIRE

WINTRO

WEB INTRO

Thank you for agreeing to participate in this study. The survey will take approximately 15 minutes to complete. All responses will be grouped, and no survey results will be attributed to any individual. Your answers will be kept entirely confidential.

A few reminders before beginning...

On each screen, after selecting your answer, click on the "Next" button at the bottom of the screen to move forward in the survey.

If you leave the survey before completing it, you can return to the survey URL later, and you will be returned to the page where you left off. Your answers up to that point in the survey will be saved.

If you have any questions about how to complete the survey, please call Probit at 866.211.8881 or send an email to online@probit.ca. Thank you in advance for your cooperation.

QAGEX

In what year were you born?

Year:	77
Prefer not to answer	99

QGENDR

With which gender do you identify?

Male	1
Female	2
Prefer to self-identify (Please specify):	77
Prefer not to answer	99

QAGEY

May we place your age into one of the following general age categories?

Under 18	1
18-24 years	2
25-34 years	3
35-44 years	4
45-54 years	5
55-64 years	6
65 years or older	7
Prefer not to answer	99

Q1

How knowledgeable would you say you are about dementia?

1 Not at all knowledgeable	1
2	2
3 Moderately knowledgeable	3
4	4
5 Very knowledgeable	5
Prefer not to answer	99

Q2

Overall, how much of an impact do you think dementia is having in Canada today?

1 Not at all an impact	1
2	2
3 A moderate impact	3
4	4
5 A very large impact	5
Don't know	99

Q4

What are the signs and symptoms of dementia as far as you know?

Please read each item in the list and select each one that applies

Difficulty in managing daily tasks (e.g., bathing and dressing, washing dishes)	1
Impairment of/Reduced judgement (recognition of danger, rules of driving, financial)	2
Changes in mood, behaviour and/or personality	4
Urinary incontinence	5
Shortness of breath	6
Trembling or shaking	7
Misplacing things (e.g., putting things in strange places)	9
Other (Please specify):	77
Don't know	99

PQ5

To the best of your knowledge, please indicate if each of the following are true or false:

Q5B

There are things we can do to reduce the risk of developing dementia

True	1
False	2
Don't know	99

Q5D

Some ethnic/cultural groups have a higher risk of developing dementia

True	1
False	2
Don't know	99

Q5E

The risk of developing dementia is higher among people with chronic health conditions such as hypertension, heart disease, and diabetes

True	1
False	2
Don't know	99

Q5G

Dementia is an inevitable (i.e., normal) part of aging

True	1
False	2
Don't know	99

Q5H

There are effective treatments that can delay the onset of symptoms and slow the progress of dementia

True	1
False	2
Don't know	99

Q6

From what you know or have heard, which of the following increases your chances of developing dementia?

Please read each item in the list and select each one that applies

Hypertension/high blood pressure	1
Harmful alcohol use	2
Lack of physical activity	3
Diet lacking in nutrition	4
Sleep disruption (e.g., sleep apnea)	5
Smoking	6
Diabetes	7
Having had a stroke	8
High cholesterol	9
Loneliness/social isolation	10
Fewer years of formal education	11
Air pollution	12
Hearing loss	13
Unsafe exposure to toxic chemicals	14
Other (Please specify):	77
Don't know	99

PQ7

To what extent do you agree or disagree with the following...?

Q7A

I worry about the possibility of personally developing dementia

Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	99

Q7B

I worry about the possibility of someone close to me developing dementia

Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	99

Q8

In the last 12 months, have you taken any steps to specifically reduce your own risk for developing dementia?

Yes	1
No	2
Don't know	99

Q8A

If... Q8 = 1

What steps did you take/are you taking?

List up to 3:

List/describe steps	77
Don't know	99

PQ9

To what extent do you agree or disagree with the following...?

Q9A

People have negative assumptions about the abilities of people living with dementia

Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	99

Q9B

People living with dementia are sometimes able to continue working for years after the onset of symptoms

Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	99

Q9C

People living with dementia generally face a lower quality of life than people without dementia

Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	99

Q10

How comfortable would you feel interacting with someone living with dementia?

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q10A

If... Q10 = 3 or Q10 = 4 or Q10 = 5

Why would you feel comfortable interacting with someone living with dementia?

Please read each item in the list and select each one that applies

Currently know or have known people with dementia	1
Have information on supporting people with dementia	2
Generally confident in dealing with most situations	3
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q10B

If... Q10 = 1 or Q10 = 2

Why would you feel uncomfortable interacting with someone living with dementia?

Please read each item in the list and select each one that applies

Worried about or unsure of how the person will behave/react	3
Not sure how to talk to or support/help the person	4
I have never known anyone with dementia	5
Don't have enough information about dementia	6
Other (Please specify):	77

Don't know	99
Prefer not to answer	98

Q11

If... Q10B not = 5

Who do you know (if anyone) that is living/has lived with dementia?

Please read each item in the list and select each one that applies

Myself	2
My spouse/partner	3
A parent	4
Extended family member	5
A friend	6
Neighbour	8
Colleague at work	9
Patients	10
No one	1
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q12

If... Q10B not = 5 or Q11 not = 1

An unpaid caregiver may do a range of things to care for someone living with dementia. Have you done any of the following in the last 5 years for a person living with dementia, without getting paid?

Please read each item in the list and select each one that applies

Assisted with financial affairs	1
Assisted with activities of daily living (e.g., cooking, cleaning, bathing or dressing)	2
General health care and health monitoring (e.g., overseeing medication usage or help administering medication, setting up appointments)	6
Other types of care (Please specify):	77
None of these – no assistance to a person living with dementia	98
Don't know	97
Prefer not to answer	99

Q12A

If... Q12 = 1 or Q12 = 2 or Q12 = 3 or Q12 = 4 or Q12 = 5 or Q12 = 6 or Q12 = 77

For whom have you provided the unpaid care?

Please read each item in the list and select each one that applies

My spouse/partner	1
A parent	2
Another family member	3
A close friend	4
An acquaintance	5
Neighbour	6
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q12B

If... Q12 = 1 or Q12 = 2 or Q12 = 3 or Q12 = 4 or Q12 = 5 or Q12 = 6 or Q12 = 77

Thinking of the most recent month you provided unpaid care to someone living with dementia, what would you say is the average number of hours per week you provided the unpaid care?

Hours	1
Don't know	98
Prefer not to answer	99

Q12C

If... Q12 = 1 or Q12 = 2 or Q12 = 3 or Q12 = 4 or Q12 = 5 or Q12 = 6 or Q12 = 77

To what extent do you agree or disagree with the following statement: I felt that I was able to provide the care needed for someone living with dementia. Being "able" generally means responding to their needs in a satisfactory and timely manner, such as assistance with medical needs, emotional support, and/or assuring safety.

1 Strongly Disagree	1
2	2
3 Neither	3
4	4
5 Strongly Agree	5
Don't know	98
Prefer not to answer	99

Q12D

If... Q12C = 1 or Q12C = 2

As an unpaid caregiver to someone living with dementia, why did you feel unable to provide the care needed for someone living with dementia?

Please read each item in the list and select each one that applies

I didn't have enough information	1
I'm generally not good in those kinds of situations	2
I didn't have enough time	3
I didn't have enough support	4
I was concerned about finances	5
I was concerned about my own health	6
I didn't have the space needed	7
I had other responsibilities	8
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q13

If... Q10B = 5 or Q11 = 1 or Q12 = 97 or Q12 = 98 or Q12 = 99

Generally speaking, would you be able to provide frequent unpaid support (e.g., acting as a caregiver) to a family member or friend living with dementia? This is most commonly 1-3 hours per week.

Being "able" generally means responding to their needs in a satisfactory and timely manner, such as assistance with medical needs, emotional support, and/or assuring safety.

Yes	1
-----	---

No	2
Don't know	98
Prefer not to answer	99

Q13A

If... Q13 = 2

Which of the following best describes your reasons for not being able to provide frequent unpaid support to a family member or friend living with dementia?

Please read each item in the list and select each one that applies

I don't know what would be needed	1
I'm generally not good in those kinds of situations	2
I don't have the time	3
I'm concerned about financial implications	4
I'm concerned about the impact on my own health	5
My home is too small / not properly equipped	6
I have other responsibilities	7
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q13B

If... Q13 = 1

Which of the following best describes your reasons for being able to provide frequent unpaid support to a family member or friend living with dementia?

Please read each item in the list and select each one that applies

I have had experience providing care to someone living with chronic conditions	1
I believe I would have access to sufficient supports and information	2
I'm generally confident in dealing with all situations	3
I know others who have done this who could advise me	4
I care about this person so I will do what I can	5
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

PQ15

From what you know or have heard, how would you rate the level of support in your community that is provided to people living with dementia in each of the following areas:

Q15A

Access to health care

1 Poor	1
2	2
3 Moderate	3
4	4
5 Excellent	5
Don't know	99

Q15B

Quality of health care provided

1 Poor	1
2	2
3 Moderate	3
4	4
5 Excellent	5
Don't know	99

Q15C

Opportunities for social engagement / social connection

1 Poor	1
2	2
3 Moderate	3
4	4
5 Excellent	5
Don't know	99

Q15D

Overall support from the community

1 Poor	1
2	2
3 Moderate	3
4	4
5 Excellent	5
Don't know	99

Q15E

Efforts to make the community safer for those living with dementia

1 Poor	1
2	2
3 Moderate	3
4	4
5 Excellent	5
Don't know	99

PQ16

How comfortable would you be with each of the following...?

Q16A

Having a discussion with a health care provider about your personal risk of developing dementia

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16B

Asking a health care provider for information about dementia symptoms which could lead to obtaining an assessment and diagnosis

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16C

Telling an employer about a dementia diagnosis

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16D

Telling close family members about a dementia diagnosis

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16E

Telling friends about a dementia diagnosis

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16F

Telling neighbours or others in the community about a dementia diagnosis

1 Not at all comfortable	1
2	2
3 Moderately comfortable	3
4	4
5 Very comfortable	5
Don't know	98
Prefer not to answer	99

Q16G

If... Q16B = 1 or Q16B = 2

Why would you be uncomfortable speaking to a health care provider about an assessment that could lead to a diagnosis of dementia?

Please read each item in the list and select each one that applies

Fear of facing what lies ahead	1
Fear of alarming people close to you	2
Fear of others treating you differently	3
Fear of your employer finding out/having to stop working	4
There is no point in knowing if nothing can be done to change the progression of the condition	5
Other (Please specify):	77
Don't know	98
Prefer not to answer	99

Q18

What would you consider to be trustworthy sources of information about dementia?

Please read each item in the list and select each one that applies

General audience media (television, radio, newspapers)	1
Scientific books, articles, magazines	2
Social media/chat groups	3
Health care professionals and other care providers	5
People you know (friends and family)	7
Government of Canada	9
Provinces/Territories health ministries	10
Other (Please specify):	77
Don't know	99

DEMIN

These last few questions will be used for statistical purposes only.

Q19

Do you (or did you) work in a sector where you may need (or may have needed) to interact with people living with dementia?

Yes	1
No	2
Don't know	98
Prefer not to answer	99

Q20

If... Q19 = 1

Which sector do you work (or have you worked) in?

Health care	1
Retail	2
Public transportation	3
Financial services	4
Food services	5
Law enforcement	6
Property management	7

Social worker	8
Other (Please specify):	77
Prefer not to answer	99

Q21

If... Q19 = 2 or Q19 = 98 or Q19 = 99

Do you work as a health care provider, in any capacity?

Yes	1
No	2
Prefer not to answer	99

Q22

If... Q20 = 1 or Q21 = 1

What is (or was) your role?

Physician	1
Nurse	2
Nurse Practitioner	3
Pharmacist	4
Personal support worker	5
Specialist (e.g., dietician, psychologist/counsellor, psychiatrist)	6
Researcher	7
Therapist (occupational therapist, physiotherapist, massage therapist, etc.)	8
Other (Please specify):	77
Prefer not to answer	99

Q23

Do you (or did you) volunteer in a sector where you may need (or may have needed) to interact with people living with dementia?

Yes	1
No	2
Don't know	98
Prefer not to answer	99

QEDUC

What is the highest level of schooling that you have completed?

Grade 8 or less	1
Some high school	2
High School diploma or equivalent	3
Registered Apprenticeship or other trades certificate or diploma	4
College, CEGEP or other non-university certificate or diploma	5
University certificate or diploma below Bachelor's level	6
Bachelor's degree	7
Post graduate degree above bachelor's level	8
Prefer not to answer	99

QINC

Which of the following categories best describes your total household income? That is, the total income of all persons in your household, before taxes?

Under \$20,000	1
Between \$20,000 and \$39,999	2
Between \$40,000 and \$59,999	3
Between \$60,000 and \$79,999	4
Between \$80,000 and \$99,999	5
Between \$100,000 and \$149,999	6
\$150,000 or above	7
Prefer not to answer	99

QLANG

What language do you speak most often at home?

English	1
French	2
English and French equally	3
Other (Please specify):	77
Prefer not to answer	99

QETHN

Other than Canadian, to which ethnic or cultural groups do you consider yourself to belong?

British (e.g., English, Scottish, Irish, Welsh, etc.)	1
French (includes Quebecois, Franco-Ontarian, Franco-Manitoban, Acadian, etc.)	2
Other Western European (e.g., German, Dutch, etc.)	3
Scandinavian (e.g., Swedish, Finnish, Danish, Norwegian, etc.)	4
Eastern European (e.g., Polish, Russian, Czechoslovakian, Ukrainian, etc.)	5
Southern European (e.g., Italian, Greek, Spanish, etc.)	6
Arabic (e.g., Egyptian, Lebanese, etc.)	7
West Asian (e.g., Afghani, Iranian, etc.)	8
South Asian (e.g., Pakistani, Indian, Sri Lankan, etc.)	9
Southeast Asian (e.g., Chinese, Vietnamese, Korean, etc.)	10
Oceania (e.g., Australian, Kiwi, Polynesian, etc.)	11
Latin American (e.g., Mexican, Brazilian, Chilean, etc.)	12
Aboriginal/Indigenous (e.g., Ojibway, Iroquois, Cree, etc.)	13
American (general mention)	14
African (e.g., Nigerian, Somali, etc.)	15
Other (Please specify):	77
None	98
Prefer not to answer	99

Q24

If... QETHN not = 13

Do you consider yourself to be an Indigenous or Aboriginal person?

Yes	1
No	2
Prefer not to answer	99

Q25

If... QETHN = 13 or Q24 = 1

Which of the following best describes you? Are you a First Nations person, Métis, or Inuk?

First Nations	1
Métis	2
Inuk	3
Other (Please specify):	77
Prefer not to answer	99

Q26

If... Q25 = 1

Do you live on a reserve or First Nation community for at least 6 months of the year?

Yes	1
No	2
Prefer not to answer	99

Q27

What is your sexual orientation?

Heterosexual	1
QGENDR = 2	
Lesbian	2
Gay	3
Bisexual	4
Other (Please specify):	77
Prefer not to answer	99

QPOST

What are the first three characters of your postal code?

Please specify:	77
Prefer not to answer	99

QPROV

If... QPOST = 99

What province or territory do you live in?

British Columbia	1
Alberta	2
Saskatchewan	3
Manitoba	4
Ontario	5
Quebec	6
New Brunswick	7
Nova Scotia	8
Prince Edward Island	9
Newfoundland	10
Yukon	11
Northwest Territories	12
Nunavut	13
Prefer not to answer	99

THNK

Thank you very much for taking the time to complete this survey.

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