Public Health Agency of Canada
Agence de la santé publique du Canada

Quality of Life and Dementia Qualitative and Quantitative Research

Final Report

Prepared for The Public Health Agency of Canada

Supplier name: Earnscliffe Strategy Group
Contract number: 6D016-204011/001/CY
Contract value: $188,810.90 (including HST)
Award date: December 14, 2020
Delivery date: August 5, 2021

Registration number: POR 081-20
For more information on this report, please contact Health Canada at:
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Ce rapport est aussi disponible en français.

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August 2021

This public opinion research report presents the results of focus groups conducted by Earnscliffe Strategy Group on behalf of the Public Health Agency of Canada. The research was conducted from January 12 to June 3, 2021.

Cette publication est aussi disponible en français sous le titre : Démence et qualité de vie

For more information on this report, please contact Health Canada at: hc.cpab.por-rop.dgcap.sc@canada.ca or at:

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Catalogue Number: H14-375/2021E-PDF

International Standard Book Number (ISBN): 978-0-660-39840-2

Related publications (registration number: POR 081-20)

Démence et qualité de vie (Final Report, French) ISBN 978-0-660-39841-9

TABLE OF CONTENTS

EXECUTIVE SUMMARY

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to the Public Health Agency of Canada (PHAC) summarizing the results of a two-phased qualitative and quantitative research project exploring quality of life and dementia.

Previous public opinion research conducted in 2019-20 indicated that two out of three Canadians agree that people have negative assumptions about the abilities of people living with dementia. To support implementation of the national dementia strategy, PHAC sought to build on this research to further inform work towards the strategy's priorities of eliminating stigma associated with dementia; promoting measures that create safe and supportive dementia-inclusive communities; and addressing the importance of access to quality care for those living with dementia. The findings from the research will be used to help inform program development and other initiatives undertaken by PHAC and others working on dementia related initiatives. Further, the research findings will be used to validate key components of quality of life for people living with dementia in a Canadian context to inform efforts intended to improve the quality of life. These findings will support annual reporting on the national dementia strategy and inform other efforts to track progress on improving the quality of life of people living with dementia, which is one of the strategy's national objectives.

The purpose of the research is to gain a first-hand Canadian perspective on the key components that constitute quality of life for people living with dementia, drawing on lived experience. The contract value for this project was $188,810.90 including HST.

To meet the objectives of the research, Earnscliffe conducted a two-phased qualitative and quantitative research approach. To complete both phases of this research and with the intent of reaching as diverse a group of people living with dementia as possible, a creative sampling approach that involved leveraging our quantitative research partner, Leger's, proprietary online panel to canvass for people living with and/or caregivers of people living with dementia was used. The majority of those living with dementia (interview participants and survey respondents) were referred by their caregiver.

As the sample was drawn from an online panel, and the sample universe is not known, it was not possible to set quotas to ensure representativeness. Although efforts were made to balance for gender and region, Leger's panel does not include any panelists in Canada's territories and therefore there were no completions (either qualitative or quantitative) with northern Canadians. Because most interview participants and survey respondents were identified through their caregiver, this may have introduced bias in the research.

The first qualitative phase involved a series of 40 in-depth interviews with people living with dementia and/or their caregiver. The interviews were conducted between January 12 and February 12, 2021. The interviews were approximately 45 minutes in length. Interviewees were offered the option to complete the interview by telephone or video conference. Please refer to the Qualitative Methodology Report in Appendix B for distribution of interviews across target group, region, and completion mode (i.e., telephone or video conference).

The second phase involved a quantitative survey, conducted online or by telephone according to the respondent's preference, of 556 people living with dementia and/or their caregiver. Of those, 51 were people living with dementia who completed the survey on their own; 190 were people living with dementia who completed the survey with the help of their caregiver; and, 315 were caregivers who completed the survey on behalf of the people living with dementia for whom they cared. In the tables throughout the report, 8 caregivers from the total of 556 were not included as they did not identify whether or not they were current or former caregivers.

The original survey was conducted from March 4-23, 2021 in English and in French, and took an average of 10 minutes to complete. Following the completion of the data collection, demographic results were found to be not necessarily consistent with what is known about people living with dementia (e.g., participants were younger in age). A hypothesis was made that in some cases the caregiver aiding the person living with dementia had answered the demographic questions about themselves instead of the person living with dementia. To confirm the integrity of the results and to gather the proper demographic information, PHAC in consultation with Earnscliffe, made the decision to return to the sample with a follow up survey. The return to sample (RTS) survey was conducted from May 13-June 3, 2021 in English and French, and was completed by 481 people living with dementia and/or their caregiver from the first survey. A full description of the data cleaning process and reconciliation of original and RTS data has been provided in Quantitative Methodology Report in Appendix E.

It is important to note, when reading the qualitative findings, that qualitative research is a form of scientific, social, policy, and public opinion research. In-depth interview research is designed to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved, the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

The key findings from the research are presented below. Please note a glossary of terms can be found in the Qualitative Methodology Report in Appendix B that explains the generalizations and interpretations of qualitative terms used throughout the report.

Overall Quality of Life

Self-Assessment of Quality of Life

- The survey revealed that while the majority (55%) of people living with dementia rate their quality of life as at least good, there is clearly a bell curve distribution with most responses dividing between fair (31%) and good (34%) and smaller proportions describing it as better than good (very good or excellent) (21%) or poor (13%).
- During the qualitative in-depth interviews, while most interviewees struggled to define quality of life from a conceptual perspective, they were able to provide an assessment of their own quality of life. Beyond the necessities of life (i.e., food, water, shelter), the most important aspect of quality of life for people living with dementia was being with or spending time with (depending on their own personal circumstances) family or loved ones. Those living alone (because they were capable of caring for themselves) also tended to think they had a generally good quality of life, especially because they had the freedom to do what they wanted, when they wanted.

Current Life Satisfaction Overall

- The survey revealed that many (39%) people living with dementia offer a neutral assessment of their current life satisfaction, saying they are neither satisfied nor dissatisfied with their life as a whole right now; but more describe themselves as satisfied (35%) than dissatisfied (24%).
- The majority of interviewees indicated that they currently live at home with a spouse/partner or close family member (their primary caregiver). A few currently live at home alone while three indicated that they live in a group home, long-term care facility or hospital setting.
- Most interviewees were generally very happy and comfortable where they live. When asked to describe the source of that comfort and joy, most tended to speak of the proximity of family and loved ones and the comfort of familiar surroundings and the security (peace of mind) that it provides. In addition to these factors, those currently living alone often pointed to the freedom of being able to do what they wanted, when they wanted, and having the ability to continue doing that.
- The few interviewees who were dissatisfied with their current living situation were either isolated from family and friends, did not have the financial means to live in a more desirable neighbourhood, or were not able to enjoy the outdoors as much as they would like.

Factors Impacting Quality of Life

- Survey respondents were asked to select which aspects most impact their quality of life from a list of fourteen different values and to offer any that they value that did not appear on the list. Approximately half of respondents in the survey say that good physical health (51%), having frequent support and visits with family and friends (51%), feeling comfortable in their surroundings (51%), good mental health (48%), being able to stay in their home as long as possible (48%), and being independent in daily living needs (47%) have the most impact on quality of life.
- Slightly fewer respondents in the survey believe that having a sense of purpose (45%), living with loved ones (43%), not having to worry about money (42%), being able to move around their community (41%), and making decisions about one’s own healthcare (41%) have the most impact on quality of life.
- Among the factors reviewed in the survey, being able to be close to nature or enjoy the outdoors (35%), feeling a sense of belonging in one’s community (27%), and being able to participate in religious or spiritual activities (21%) are the least likely to impact quality of life.
- Qualitative interviewees were asked to define quality of life (unprompted). While not common to all, especially given individual circumstances and/or stage of dementia, the more common factors that emerged that seemed to most positively impact their quality of life, included: family, health, safety and security, financial stability, freedom, having goals, having tasks to complete, being outdoors or in nature, food/enjoying a good meal, faith/religion, pets, hobbies or activities to participate in, sleep/naps, running errands, and travel.

Rating Specific Aspects of Life

- Survey respondents were then asked to rate their own quality of life on eleven different measures. When survey respondents were asked to rate aspects of their own quality of life (or that of the person living with dementia that they were responding on behalf of), the most positively rated aspects (percent excellent or very good) are relationship with family and friends (42%), access to health services (35%) and finances (29%). Roughly one in five respondents give excellent or very good ratings for their ability to live independently (22%), sleep (20%), and ability to spend time outdoors or in nature (20%). Of the quality of life factors examined in the survey, along with physical health (17%) and mental health (16%), those related to autonomy tend to be the lowest rated, including the ability to: move around freely in their community (16%), socialize with others (15%) and engage in hobbies and leisure (14%).

- The factors that seemed to most negatively impact the quality of life of interviewees tended to revolve around dementia symptoms, including: the loss of memory/vocabulary, hallucinations/altered sense of reality, lack of mobility/dexterity, lack of energy, and lack of focus. These symptoms were often described as hindering their ability to do the things that most positively impact their quality of life. However, it is important to reinforce that this perspective was often provided by the caregiver; the person living with dementia was often unaware of these symptoms or the impact it has on their abilities.

Experiences Impacting Quality of Life

- Investigating the experiences of people living with dementia over the past year during the COVID-19 pandemic (March 2020 to May/June 2021 at the time of the survey) in the survey finds that the majority (87%) identify having had negative feelings or experiences. In the past year, over half of people living with dementia felt isolated (59%), sad (55%), or anxious (54%) for an extended period of time. Half of people living with dementia have felt helpless related to a loss of independence (49%) and approximately one-third have felt ashamed or embarrassed about their symptoms (35%).
- The survey revealed that the majority (85%) of people living with dementia have also experienced challenges or difficulties in the past year. Over half (53%) have had difficulty communicating their needs to others, and four in ten (39%) had people talk to their caregiver rather than to them even though they were present. There are a variety of other negative experiences identified by significant proportions of people living with dementia, including:
  - Approximately one-third of people living with dementia have:
    - been excluded from decisions about health care or finances that affect them (35%);
    - encountered people who focused on things they can no longer do instead of the things they can (33%); and,
    - had difficultly navigating a public space (31%).
  - Approximately one-quarter of people living with dementia have:
    - heard people make negative comments about their ability to do things (26%);
    - experienced a transition in care such as moving between health care settings (26%);
    - had support group meetings or activities cancelled (26%); and,
    - been unable to go where they needed to or wanted due to accessibility issues (24%).

Ease of Discussing Dementia Diagnosis

- The survey revealed that one-quarter (25%) of people living with dementia are comfortable talking about their dementia diagnosis and symptoms with those outside of their close circle, and only 6% say they are very comfortable doing so. The same amount of people living with dementia are neutral (26%), while 43% are uncomfortable talking about it.
- In the qualitative interviews, a few had refrained from sharing the news of their diagnosis with members of their family and/or friends. When probed, more often than not, this decision was generally made by those with early onset dementia, whose symptoms were not yet discernable, and a desire not to burden anyone unnecessarily. A few of these same people had refrained from sharing the news with their employers for fear of being penalized.
- With regards to any perceptible changes in family and/or friends' behaviour upon learning of their dementia diagnosis, interviewee experiences varied, although most felt that their interactions had not changed at all or had in fact improved.

The COVID-19 Pandemic

Awareness of the COVID-19 Pandemic

- The survey revealed that the vast majority (91%) of people living with dementia report that they have heard, read, or seen something about the COVID-19 pandemic.
- The qualitative interviews revealed that despite having some general awareness of COVID-19, some people living with dementia may not have a true understanding of the nature and/or severity of the pandemic, as some caregivers reminded the person living with dementia during the interview about public health restrictions to prompt awareness of the pandemic.

Impact of COVID-19

- The vast majority of people living with dementia feel COVID-19 has had a negative impact on their quality of life (84%), including one-third (32%) who describe the effect as very negative. Few say that COVID-19 has had no noticeable impact (14%), and almost none (2%) describe the impact as positive.
- In addition to the disruption of certain services, many (about half of) interviewees described having a hard time with the public health restrictions with respect to the inability to get together with family and friends or do the things they used to do; while for a smaller number (some interviewees), this pandemic period has not proven to be much different than their previous day to day (i.e., staying at home).
- For some interviewees, the disruption of services was particularly problematic. Some mentioned missing the support group meetings/activities and religious services they attended regularly. Mostly, they missed the opportunity these activities provided to socialize in a comfortable setting. A few also mentioned needing to adapt to video or telephone appointments and feeling uncomfortable with digital technology.

Change in Frequency of Contact Since COVID-19

- Among the vast majority of participants in the survey who were aware of COVID-19 and have an unpaid caregiver, seven in ten (69%) say they do not see their caregiver any less as a result of the pandemic, while 23% that say they see their unpaid caregiver more. Almost one-third (31%) say the pandemic has caused them to see their unpaid caregiver less often.
- Participants in the in-depth interviews spoke about the impact of having less physical contact with people in their lives. In fact, the most important change during the pandemic seemed to be the lack of physical contact and in-person visits. The impact of this was different depending on the situation. For some, the lack of physical contact was depressing and isolating. However, for most, it was not all that noticeable because they were living with family and still seeing family members regularly at a distance and/or talking regularly on the telephone or on video calls.

Caregiving and Support

Types of Care Providers

- The majority (62%) of people living with dementia have an unpaid caregiver, while half as many (31%) have a care provider who is paid by the healthcare system, and less than one-quarter (22%) have a care provider who they pay themselves or is paid by someone in their household.
- The majority of participants in the qualitative interviews do not pay out of pocket for additional support. Those who do not personally pay for a care provider either did not have the means to do so

or did not feel their dementia was at a stage that required that level of care yet. Of the few who have a paid care provider, a few were on the receiving end of provincial government support in the form of a personal care worker. Often the support provided by these personal care workers included administering medications, personal care, meal preparation, and/or general supervision/companionship.

- Those at the receiving end of external support (i.e., care provider to help with medication, personal hygiene, physical exercise) felt that it was extremely helpful; especially the caregivers for whom this support provided them with a regular respite during the week. For the person living with dementia, it was a pleasant distraction and an opportunity to socialize.
- In terms of community support, most generally felt that they had what they needed. In fact, when asked what is making it difficult for them to stay engaged/involved, most were unable to list any resources they thought were lacking.
- Community support needs differed significantly based on individual circumstance and/or severity of dementia. For example, some people living with dementia who live alone explained that they live in an urban community setting deliberately to ensure they have ready access to the community supports they need. Others, who live with their caregivers, explained that they had chosen to move to a more rural setting so that they could live away from the hustle and bustle of urban life and be closer to nature.

Types of Professional Care Providers

- Among those who have a paid caregiver, more than two-thirds (69%) say they have a personal support worker, while almost half say they have a nurse (47%) and/or a doctor (43%) as part of their ongoing care. Less than one in five (17%) have a developmental service worker.
- Over half (55%) of people living with dementia who have paid care providers have at least one that provides care for them in their own home.
- When interviewees were asked if they were aware of any services or benefits available to assist people living with dementia, responses were split. Those aware of services recalled receiving help or introductory information from the Alzheimer Society although many had not followed through and reached out. Other supports that were mentioned included the availability of doctors, nurses and personal care workers, although some had difficulty navigating the provincial health care systems to access these services. Few, if any, spoke of federal and/or provincial benefits available to them. One or two mentioned insurance and/or tax relief but details were vague.

Knowledge of Paid Care Providers

- The majority (72%) of survey respondents feel that their paid caregivers are very knowledgeable or somewhat knowledgeable about supporting people living with dementia. However, one in five (22%) say their paid caregiver is not knowledgeable.

Tasks Performed by Paid Care Providers and Unpaid Caregivers

- The survey revealed that tor those who have them, over the past year, paid caregivers have most commonly been helping with activities of daily living (76%) and general health care and health monitoring (72%); less so with house maintenance (40%), transportation (29%), or financial affairs (16%).
- The variety of support being provided by unpaid caregivers is much broader than is typically being provided by paid caregivers. Caregivers are about as likely as paid caregivers to be providing assistance with activities of daily living (69%) and general health care (78%), but are far more likely to be assisting with transportation (74%), financial affairs (72%), and house maintenance (69%).

Relationship to Unpaid Caregivers

- The survey revealed that of the people living with dementia who have unpaid caregivers, the most common relationship type is a child (66%). Less common relationships include spouse (26%), grandchild (10%), child-in-law (10%), or a friend (10%).
- When asked to describe their relationship with their caregivers in the survey, the majority of qualitative participants conveyed an overwhelming sense of appreciation and gratitude to have these people in their lives to support and care for them. Quite often, this question elicited a lot of laughter especially when the person living with dementia described the occurrence of "trying" moments in addition to all of the "good" moments.
- When asked whether they had a support system of family or friends (beyond their unpaid caregivers), responses seemed to vary widely based on individual circumstances and severity of dementia. Those with early onset dementia and those living with their caregiver(s) spoke of having fairly strong networks of family and friends with whom they were in regular contact. Some at more advanced stages of dementia spoke of having some contact with close family but limited friend networks.

Frequency of Contact with Unpaid Caregivers

- Prior to COVID-19, the majority of people living with dementia in the survey (67%) say they interacted daily with their unpaid caregivers. Most of the remaining respondents (29%) say they interacted with these caregivers at least once per week.
- People living with dementia who are not aware of COVID-19 have a similar experience with their unpaid caregivers as those who are aware of COVID-19 in terms of frequency. Two-thirds (67%) interact with their unpaid caregiver daily.

Research Firm: Earnscliffe Strategy Group (Earnscliffe)
Contract Number: 6D016-204011/001/CY
Contract award date: December 14, 2020

I hereby certify as a Representative of Earnscliffe Strategy Group that the final 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: Date: August 5, 2021

Stephanie Constable
Principal, Earnscliffe

INTRODUCTION

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to the Public Health Agency of Canada (PHAC) summarizing the results of the two-phased qualitative and quantitative research project exploring quality of life and dementia.

Previous public opinion research conducted in 2019-20 indicated that two out of three Canadians agree with the perception that people have negative assumptions about the abilities of people living with dementia. To support implementation of the national dementia strategy, PHAC sought to build on this research to further inform work towards the strategy's priorities of eliminating stigma associated with dementia; promoting measures that create safe and supportive dementia-inclusive communities; and addressing the importance of access to quality care for those living with dementia. The findings from the research will be used to help inform program development and other initiatives undertaken by PHAC and others working on dementia related initiatives.

The objectives of the research were to gain a first-hand Canadian perspective on the key components that constitute quality of life for people living with dementia by drawing on lived experience. Further, the specific research objectives included, but were not limited to:

- Identify perceived and actual key components of quality of life and explore how these would be prioritized in terms of importance.
- Determine perceived barriers to, and enablers of, optimal quality of life and explore their relative impact on quality of life.
- Explore topics including components that contribute to quality of life, such as:
    - Care: carer characteristics, person living with dementia/carer relationship, level of care provided
    - Care setting/living arrangements (community, care homes, assisted living facilities, etc.)
    - Quality of dementia-specific care such as timeliness of diagnosis and availability of supports (e.g., day care or respite care)
    - Management of comorbidities (with consideration for polypharmacy)
    - Connectedness to others/feelings of belonging (inclusion)
    - Relationships (together vs. alone)
    - Wellness perspective (well vs. ill)
    - Sense of place (located vs. unsettled)
    - Happiness and sadness
    - Self-esteem
    - Independence/control in one's daily life
    - Experiences of stigma
    - Experienced quality of care
    - Physical symptoms
    - Cognitive symptoms

Findings from the research will be used to validate key components of quality of life for people living with dementia in the Canadian context, as well as support and improve the quality of life of those living with dementia. The research will also be used to inform program development and other initiatives undertaken by PHAC, including annual reporting to Parliament on the national dementia strategy.

To meet these objectives, Earnscliffe conducted a two-phased qualitative and quantitative research approach. To complete both phases of this research and with the intent of reaching as diverse a group of people living with dementia as possible, a creative sampling approach that involved leveraging our quantitative research partner, Leger's, proprietary online panel to canvass for people living with and/or caregivers of people living with dementia was used. The majority of those living with dementia (interview participants and survey respondents) were referred by their caregiver.

As the sample was drawn from an online panel, and the sample universe is not known, it was not possible to set quotas to ensure representativeness. Although efforts were made to balance for gender and region, Leger's panel does not include any panelists in Canada's territories and therefore there were no completions (either qualitative or quantitative) with northern Canadians. Because most interview participants and survey respondents were identified through their caregiver, this may have introduced bias in the research.

The first qualitative phase involved a series of 40 in-depth interviews with people living with dementia and/or their caregiver (using the Interview Guide found in Appendix D). The interviews were conducted between January 12 and February 12, 2021. The interviews were approximately 45 minutes in length. Interviewees were offered the option to complete the interview by telephone or video conference. Participants were offered a $125 honorarium to thank them for their time. Information about the interview design, methodology, and sampling approach has been provided in the Qualitative Methodology Report in Appendix B.

The second phase of research was a quantitative survey (questionnaire found in Appendix G), conducted online or by telephone according to the respondent's preference, of 556 people living with dementia and/or their caregiver. Of those, 51 were people living with dementia who completed the survey on their own, 190 were people living with dementia who completed the survey with the help of their caregiver; and, 315 were caregivers who completed the survey on behalf of the people living with dementia for whom they cared. In the tables below, 8 caregivers from the total of 556 were not included as they did not identify whether or not they were current or former caregivers.

The original survey was conducted from March 4-23, 2021 in English and in French, and was an average of 10 minutes long. Following the completion of the data collection, demographic results were not necessarily consistent with what is known about people living with dementia (e.g., some were younger in age than might have been expected). A hypothesis was made that in some cases, the caregiver aiding the person living with dementia had answered the demographic questions about themselves instead of the person living with dementia. To confirm the integrity of the results and to gather the proper demographic information, PHAC in consultation with Earnscliffe, made the decision to return to the sample with a follow up survey. The return to sample (RTS) survey was conducted from May 13 to June 3, 2021 in English and French, and was completed by 481 people living with dementia and/or their caregiver from the first survey. A full description of the data cleaning process and reconciliation of original and RTS data, and RTS questionnaire have been provided in the Quantitative Methodology Report (Appendix E) and Return to Sample Questionnaire (Appendix H) sections.

DETAILED FINDINGS

This report presents the combined results of both the qualitative and quantitative phases of research. The report is divided into three sections: Overall Quality of Life; the COVID-19 Pandemic; and Caregiving and Support. The majority of the results are informed by the quantitative online survey with nuanced findings informed by the qualitative in-depth interviews (indented sections within the body of the report).

The quantitative findings focus primarily on the differences across the target segments: people living with dementia answering the survey on their own (PLWD only), people living with dementia and their caregiver (PLWD+), current caregivers providing care to a person living with dementia (Current CG alone), former caregivers who previously, but no longer, provide care to a person living with dementia during the COVID-19 pandemic (Former CG during COVID-19), and former caregivers who previously, but no longer, provide care to a person living with dementia before the COVID-19 pandemic and within the last five (Former CG before COVID-19). Bolded survey results indicate that the result of the demographic group mentioned is significantly higher (at the 95% confidence interval) than the result found in other subgroups discussed in the same analysis, including the comparisons made between the columns in each table (as identified using letters A through F). The Z–test was used to determine the significance of the results. Percentages may not add up to 100% due to rounding. Details about the survey design, methodology, and sampling approach may be found in the Quantitative Methodology Report in Appendix E.

The qualitative findings, except where specifically identified, represent the combined results across the various target groups. The only noticeable differences seemed to more highly correlate with age and/or severity of dementia. The individuals with whom we spoke had a diverse range of cognitive abilities. Most (32/39) interviews included the assistance of a caregiver though the level of caregiver involvement ranged widely from one interview to another. Furthermore, individual circumstances ranged widely, which suggests the opportunities for quality of life improvement as well as the measures required to catalyze improvements also widely varies. Quotations (in *italics*) used throughout the report were selected in order to bring the analysis to life and provide typical verbatim commentary from participants across the various groups. Details about the interview design, methodology, and sampling approach may be found in the Qualitative Methodology Report in Appendix B.

It is also important to note that qualitative research is a form of scientific, social, policy, and public opinion research. In-depth interview research is designed to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved, the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

Overall Quality of Life

The following section explores self-assessment of overall quality of life and life satisfaction as well as identification of components of quality of life, including the factors that contribute to and negatively affect quality of life. This section, informed by lived experience, also explores how people living with dementia rate specific factors related to quality of life, along with the challenges and difficulties that people living with dementia may or may not face; as well as, understanding how comfortable people living with dementia are discussing their dementia diagnosis.

Self-Assessment of Quality of Life

While the self-assessed quality of life for people living with dementia varies from excellent to poor, the majority (55%) of people living with dementia rate their quality of life as at least good (i.e., good, very good, or excellent). There is a bell curve distribution with most responses dividing between fair (31%) and good (34%) and smaller proportions describing it as better than good (21% rating it 4 or 5) or worse than fair (13% rating it 1 or 2).

Among the target segments, people living with dementia doing the survey on their own are more likely to say that their quality of life is excellent or very good (**35%**). Conversely, the poorest self-assessment of quality of life comes from former caregivers before COVID-19, with one in five (**19%**) indicating that the quality of life of the people living with dementia is poor. Both current caregivers and former caregivers before COVID-19 are more likely than people living with dementia doing the survey on their own to say that the quality of life of the person living with dementia is fair or poor (**48%** and **46%** respectively, compared to 30%).

Table A1. Q4: How would you rate your quality of life?

Rating Quality of Life	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
Excellent	4%	10%	2%	4%	2%	6%
Very good	17%	25%	15%	17%	19%	16%
Good	34%	35%	39%	31%	36%	29%
Fair	31%	22%	**35% B**	33%	30%	27%
Poor	13%	8%	9%	15%	9%	**19% BC**
Prefer not to answer	1%	0%	0%	0%	4%	3%

Base: All respondents.

Important demographic differences include:

- People living with dementia who do not have a caregiver are significantly more likely than people living with dementia who have any type of caregiver to say their quality of life is excellent or very good (**44%**). At various points in this report, this segment stands apart and one plausible explanation is that the independence they have causes their experiences, perspectives, and motivations to contrast somewhat with those who require or have more support.

Qualitative Insights: Overall Quality of Life

Most interviewees struggled to define quality of life, although the factors that contribute to a good quality of life came out at different points over the course of the interview. Most participants defined quality of life by providing their assessment of their quality of life. Findings indicated that people living with dementia are pleased to be with family/ loved ones so long as they had the necessities of life (e.g., food, water, shelter). Those living alone (because they were still capable of caring for themselves), also tended to think they had a generally good quality of life especially because they had the freedom to do what they wanted, when they wanted. A few participants alluded to the idea of relativity when talking about quality of life (i.e., considering the circumstances of their condition).

"I would say probably happiness is maybe one of the first things that I think is important in the quality of life. Whatever provides happiness is important." ~ Person living with dementia and their caregiver

"I would say on a scale of 1 to 10, her quality of life, given what she's dealing with, is a 9.5." ~ Person living with dementia and their caregiver

"I would say for mine, anyways, my quality [of life] is poor. I'm depressed all the time. I don't do nothing. I just sit around watching TV all day." ~ Person living with dementia

Current Overall Life Satisfaction

Respondents rated their satisfaction with their life as a whole right now, on a scale of 0 to 10, where 0 represents very dissatisfied and 10 represents very satisfied. Among those who responded, more describe themselves as satisfied (greater than 6; 36%) than dissatisfied (less than 4; 24%). Many (39%) people living with dementia offer a neutral assessment (rating of 4 to 6) of their current life satisfaction, saying they are neither satisfied nor dissatisfied with their life as a whole right now. Furthermore, among all respondents, the average rating of overall life satisfaction is 5.2 out of 10.

Table A2. Q5: Using a scale of 0 to 10, where 0 means "very dissatisfied" and 10 means "very satisfied", how do you feel about your life as a whole right now?

Overall Life Satisfaction	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
Very satisfied (8-10)	17%	24%	13%	16%	15%	22%
Satisfied (7)	19%	14%	21%	21%	17%	16%
Neutral (4-6)	39%	47%	44%	36%	45%	29%
Dissatisfied (3)	8%	6%	9%	8%	9%	9%
Very dissatisfied (0-2)	15%	10%	14%	19%	9%	19%
Mean	5.2	5.7	5.1	5.1	5.2	5.3
Prefer not to answer	2%	0%	0%	0%	4%	5%

Base: All respondents.

Important demographic differences include:

- People living with dementia who do not have a caregiver are significantly more likely than people living with dementia who have any type of caregiver to give satisfaction rating between 8 and 10 of their life overall (**38%**). The average rating among people living with dementia who do not have a caregiver is also significantly higher, at **6.3** out of 10.
- Conversely, people living with dementia who have both paid and unpaid caregivers are more likely to give a rating of 0 to 2 (**22%**) than those who have a caregiver paid for by the healthcare system (16%) or no caregiver (8%).

Qualitative Insights: Satisfaction with Surroundings

The majority of interviewees indicated that they currently live at home with a spouse/partner or close family member who were usually their primary caregiver. A few respondents, typically younger in age or with early onset dementia, currently live at home alone while three indicated that they live in a group home, long-term care facility or hospital setting.

Most were generally very happy and comfortable where they live. When asked to describe the source of that comfort and joy, most spoke of the proximity to family and loved ones and the comfort of familiar surroundings and the security (peace of mind) that provides. In addition to these dimensions, those currently living alone (whether at home or those in a group home or long-term care facility) often pointed to the freedom of being able to do what they wanted, when they wanted, and having the ability to continue doing that.

“For me, we're both comfortable. We don't have any worries other than the dementia.” ~ Person living with dementia and their caregiver

“Of course, we have a lot of neighbors that we're close to, and you can chat with them. And … that makes a huge difference.” ~ Person living with dementia and their caregiver

Those dissatisfied with their current living situation (approximately four interviewees) were either isolated from family and friends, did not have the financial means to live in a more desirable neighbourhood, or were not able to enjoy the outdoors as much as they would like.

“Our quality of life is pretty good, except for the fact of, you know, the frustration of the communication. Yeah... I mean, that's the main thing right there is trying to find the words that you want to say.” ~ Person living with dementia and their caregiver

Factors Impacting Quality of Life

To get a general sense of what factors impact quality of life in the current moment, respondents were asked to review a list of fourteen factors that may have an impact on their quality of life and select those that have the most impact. If any factors were missing from the list, respondents were asked to identify them. Approximately half of respondents say that good physical health (51%), having frequent support and visits with family and friends (51%), feeling comfortable in their surroundings (51%), having good mental health (48%), being able to stay in their home as long as possible (48%), and being independent in activities of daily living (47%) have the most impact on quality of life. Slightly fewer respondents believe that having a sense of purpose (45%), living with loved ones (43%), not having to worry about money (42%), being able to move around their community (41%), and making decisions about their own healthcare (41%) have the most impact on their quality of life. Among the factors reviewed, being able to be close to nature or enjoy the outdoors (35%), feeling a sense of belonging in one's community (27%), and being able to participate in religious or spiritual activities (21%) are less commonly identified.

Looking at the target groups, people living with dementia doing the survey on their own tend to identify fewer factors as having an impact on their quality of life compared to other groups for most of the factors identified.

For people living with dementia doing the survey on their own, the most impactful factors are good physical health (37%), being able to stay in their own home (33%), being independent in their daily living needs (33%), making their own healthcare decisions (33%), and feeling like they belong to a community (31%), while the other groups have rankings that more closely resembles the overall ranking (displayed in the table). Note that having good physical health and having comfortable surroundings are among the top five impactful factors for all target groups.

Table A1. Q6. Thinking of your life right now, which of the following most impact your quality of life? If there is something that is missing, please provide that answer.

Impact on Quality of Life	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
Good physical health	51%	37%	52%	**57% B**	55%	51%
Having frequent -- that is, weekly or more often -- support and visits with family and friends	51%	27%	**55% B**	**62% BF**	**57% B**	**45% B**
Feeling comfortable in my surroundings	51%	27%	**51% B**	**60% B**	**51% B**	**53% B**
Good mental health	48%	27%	**51% B**	**51% B**	**51% B**	**49% B**
Being able to stay in my own home as long as possible	48%	33%	**51% B**	**57% BE**	40%	**49% B**
Being independent in my daily living needs such as preparing my own food, laundry, or shopping	47%	33%	**51% BE**	47%	34%	**53% BE**
Having a sense of purpose, that my life is useful	45%	29%	44%	**48% B**	42%	**51% B**
Living with loved ones such as family and friends	43%	27%	**44% B**	**44% B**	**51% B**	**45% B**
Not having to worry about money	42%	29%	44%	**46% B**	43%	44%
Being able to move around my community as much as I want or need	41%	29%	**47% B**	38%	38%	43%
Making my own decisions about my health care	41%	33%	40%	42%	40%	45%
Being able to be close to nature or enjoying the outdoors	35%	16%	**41% B**	**31% B**	28%	**40% B**
Feeling like I belong to a community	27%	31%	30%	24%	25%	24%
Being able to participate in religious or spiritual activities	21%	14%	25%	22%	21%	19%
Other	1%	0%	1%	0%	2%	2%
Prefer not to answer	2%	0%	0%	0%	4%	5%

Base: All respondents.

Important demographic differences include:

- People living with dementia who do not have a caregiver are more likely to say that having good mental health (**61%**), and not having to worry about money (**59%**) are major factors compared to people living with dementia who have a caregiver.

- Respondents in Manitoba/Saskatchewan are more likely to say that feeling a sense of belonging to a community has an impact on their quality of life (**48%**) than those in Atlantic Canada (14%), Quebec (19%), and Alberta (25%).
- Compared to those from urban areas, respondents in rural/remote communities are less likely to indicate that feeling like they belong to a community has an impact on their quality of life (13%).
- Respondents who have not graduated from high school are less likely to indicate that belonging to a community has an impact on their quality of life (19%) than respondents who have higher levels of education (including those who have graduated high school (**31%**), have attended college or university (**28%**) and have attended post-graduate studies (**38%**)). The same is true of Francophone respondents (18%) compared to English respondents (**31%**).
- People living with dementia aged 85 years or older are more likely to say that having frequent support and visits from family and friends has an impact on their quality of life (**61%**) compared to people living with dementia who are younger than 85 years.

Qualitative Insights: Factors Impacting Quality of Life

While not common to all, especially given individual circumstances and/or severity of dementia, the factors that seemed to most positively impact the quality of life of people living with dementia, included: family; health (including mental health and self-confidence); safety/security; financial stability; freedom; having goals (sense of accomplishment and sense they are contributing to the community); natural space/outdoors (either to look out the window at trees, birds, wildlife and people or to enjoy walks and nature); food (e.g., enjoying a good meal and meal preparation); faith/religion; pets; activities (e.g., television watching, reading, and puzzles/crosswords/games); sleep/naps; running errands like shopping or doing the groceries; and, travel.

"Quality of life revolves around grandchildren, seeing family." ~ Person living with dementia and their caregiver

"But I think I read somewhere that 99% of people polled do not want to go into institutionalized care, they want to remain in home. So, I'm a big proponent for that. See how tech and a little bit of assistance from a family member can keep somebody healthy and happy in their house." ~ Person living with dementia and their caregiver

"The positive things include that he still has contact with people. He has a niece, she's very, very concerned about him. She phones every Sunday to see how he's doing." ~ Person living with dementia and their caregiver

Rating Specific Aspects of Life

Respondents were then asked to rate eleven different aspects of their lives (or that of the person living with dementia that they were responding on behalf of); by providing a rating of excellent, very good, good, fair, or poor. This question provides a rating of actual experience related to some of the factors identified as having the most impact on quality of life (previous question). The table below shows the most highly rated results (i.e., excellent, and very good) overall and by the target groups. The most positively rated factors are the relationship with family and friends (42%), access to health services (35%) and finances (29%). Roughly one in five respondents give excellent or very good ratings for the ability to live independently (22%), sleep (20%), and the ability to spend time outdoors or in nature (20%). Of the quality of life factors included, along with physical health (17%) and mental health (16%), those related to autonomy tend to be rated the lowest, including the ability to: move around freely in their community (16%), socialize with others (15%) and engage in hobbies and leisure (14%).

There are a few significant differences among the target groups. People living with dementia who did the survey on their own are more likely to give ratings of excellent or very good to the following factors: their ability to live independently (**27%**), freely move in their community (**25%**), and socialize with others (**22%**), when compared to former caregivers during COVID-19. Current caregivers are more likely to give higher ratings for access to the health services they need (**46%**, compared to people living with dementia who did the survey on their own and people living with dementia who did the survey with a caregiver), finances (**39%**, compared to people living with dementia who did the survey with their caregiver), and the ability to move freely in their community (**19%**, compared to former caregivers during COVID-19). Compared to former caregivers during COVID-19, former caregivers before COVID-19 give higher ratings for the ability to live independently (**25%**) and freely in their community (**18%**).

Table A4. Q7-Q17- How would you rate each of the following? **[Percent Excellent or Very Good]**

Rating Different Aspects of Life	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
Relationship with family or friends	42%	45%	38%	46%	38%	44%
Access to the health services you need to support your health	35%	25%	31%	**46% BC**	38%	34%
Finances	29%	25%	25%	**39% C**	28%	27%
Ability to live independently	22%	**27% E**	22%	22%	11%	**25% E**
Sleep	20%	27%	19%	24%	21%	16%
Ability to spend time outdoors or in nature	20%	27%	18%	22%	15%	19%
Physical health	17%	24%	13%	22%	15%	16%
Ability to freely move around your community	16%	**25% E**	14%	**19% E**	8%	**18% E**
Mental health	16%	20%	16%	18%	17%	14%
Ability to socialize or spend time with other people	15%	**22% E**	14%	16%	8%	16%
Ability to engage in your favourite hobbies and leisure activities	14%	20%	15%	14%	13%	11%

Base: All respondents.

Important demographic differences include:

- People living with dementia who do not have a caregiver rate most factors higher than those who do have a caregiver, including: ability to live independently (**52%**), ability to freely move around the community (**42%**), ability to spend time outdoors (**39%**), sleep (**33%**), physical health (**33%**), mental health (**33%**), ability to socialize with others (**23%**), and ability to engage in hobbies and leisure (**23%**).
- People living with dementia under 55 years of age give lower ratings for access to health services (14%) and finances (10%).
- People living with dementia 85 years or older give lower ratings for ability to: live independently (12%), spend time outdoors (11%), and freely move around their community (9%).
- Compared to other regions, those in Manitoba/Saskatchewan are less likely to say their sleep is excellent or very good (at 7%).
- Respondents in Alberta rate mental health and ability to engage in hobbies and leisure higher than those in other regions (**28%** and **23%**, respectively).
- Francophone respondents are more likely to rate their relationship with friends and family as excellent or very good (**51%**) compared to English respondents (38%).
- College/university graduates rate their ability to live independently (**28%**) higher than respondents with less education.
- The ability to live independently is rated as excellent or very good more frequently by people living with dementia who live at home alone (at **35%**) than those who do not.

Qualitative Insights: Negative Ratings Impacting Quality of Life

Bearing in mind the current situation for most respondents (i.e., living with a caregiver), the factors that seemed to most negatively impact their quality of life tended to revolve around the loss of memory/vocabulary, hallucinations/altered sense of reality, lack of mobility/dexterity, lack of energy, and lack of focus. These symptoms were often described as hindering their ability to do the things that most positively impact their quality of life. However, it is important to note that this perspective was often provided by the caregiver that lived with the person living with dementia, as the person living with dementia was often unaware of these symptoms or the impact they had on their abilities.

“And I'm kind of worried more about the future, you know, naturally with progression of the disease. Additional care will be sort of probably required at some point.” ~ Person living with dementia and their caregiver

“The lack of community, I guess, is the thing that detracted me most from my quality of life.” ~ Person living with dementia and their caregiver

Experiences Impacting Quality of Life

Investigating the experiences of people living with dementia over the past year during the COVID-19 pandemic finds that the majority (87%) identify having had negative feelings (for two weeks or more at a time) or experiences. In the past year, over half of people living with dementia felt isolated (59%), sad (55%), or anxious (54%) for an extended period of time. Half of people living with dementia have felt helpless related to a loss of independence (49%) and approximately one-third have felt ashamed or embarrassed about their symptoms (35%).

People living with dementia who did the survey with their caregiver are the most likely to identify any negative feelings (**92%**). When compared to people living with dementia who did the survey on their own, people living with dementia who did the survey with their caregiver are more likely to experience feeling isolated (**65%**) or sad (**60%**). Former caregivers during COVID-19 and former caregivers before COVID-19 are the most likely to indicate that they have not experienced any of the experiences investigated (**19%** and **15%**, respectively). Lastly, people living with dementia who did the survey on their own are less likely than all target groups to have experienced feeling sad time in the past year (37%).

> *"I think I think it's changed gradually over the 10 years, but I noticed other people pulling away from my mom more than the other way around. And then my mom just, you know, that became very isolating." ~ Person living with dementia and their caregiver*

Table A6. Q18. In the last year, did you experience any of the following for an extended period of time (that is, for 2 weeks or more at a time)?

Experiences Impacting Quality of Life	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
ANY	87%	90%	**92% EF**	**89% F**	77%	80%
Feeling isolated	59%	47%	**65% B**	59%	62%	55%
Feeling sad	55%	37%	**60% B**	**56% B**	**57% B**	**56% B**
Feeling anxious	54%	51%	58%	58%	43%	53%
Feeling helpless, related to a loss of independence	49%	49%	55%	43%	53%	45%
Feeling ashamed or embarrassed about my symptoms	35%	37%	35%	37%	30%	32%
None of the above	11%	10%	7%	10%	**19% C**	**15% C**
Prefer not to say	2%	0%	1%	1%	4%	**5% CD**

Base: All respondents.

Important demographic differences include:

- People living with dementia who do not have any caregiver are less likely to have experienced any of the feelings investigated (69%) compared to people living with dementia who have a caregiver (both paid and unpaid; **90%**).
- Francophone people living with dementia are more likely to have felt anxious (**62%**) or sad (**62%**) in the past year.
- Compared to people living with dementia whose spouse or child is a caregiver, people living with dementia who have a friend that is a caregiver are more likely to report feeling anxious in the past year (**74%**).

The majority of people living with dementia (85%) have also experienced challenges/difficult experiences in the past year. Over half have had difficulty communicating their needs to others (53%) and four in ten had people talk to their caregiver rather than to them even though they were present (39%). There are a variety of other negative experiences identified by significant proportions of people living with dementia. One-third of people living with dementia have: been excluded from decisions about health care or finances that affect them (35%), encountered people who focused on things they can no longer do instead of the things they can (33%), or had difficultly navigating a public space (31%). One-quarter of people living with dementia have: heard people make negative comments about their ability to do things (26%), experienced a transition in care such as moving between health care settings (26%), had support group meetings or activities cancelled (26%), or had been unable to go where they needed to or wanted due to accessibility issues (24%).

Looking at the target groups, people living with dementia who did the survey on their own and people with dementia who did the survey with their caregiver are more likely to have experienced at least one of the difficult experiences illustrated in the past year, at **96%** and **93%**, respectively. Current caregivers are less likely to indicate that the person living with dementia experienced an occasion where they were not able to go where they wanted to go due to an accessibility issue (14%). Former caregivers, both during (**51%**) and before COVID-19 (**42%**), are more likely than people living with dementia who did the survey on their own to say the person living with dementia had experienced someone talking to their caregiver instead of them despite being present. Nearly half of former caregivers during COVID-19 say the person living with dementia experienced a transition in the past year (**45%**). Note that an assumption has been made that former caregivers before COVID-19 referred to their final year of caregiving when responding to this question.

Table 2. Q19. In the last year, have you experienced any of the following?

Experiences Impacting Quality of Life	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
ANY	85%	**96% DEF**	**93% DF**	82%	85%	75%
Had difficulty communicating my needs to others	53%	49%	54%	60%	57%	49%
Had people talk to my caregiver rather than to me even though I was present	39%	27%	38%	35%	**51% B**	**42% B**
Been excluded from decisions about health care or finances that affect me	35%	25%	34%	32%	36%	40%
Encountered people who focused on things I can no longer do instead of the things I can	33%	31%	34%	30%	28%	35%
Had difficultly navigating a public space such as a grocery store, bus or train station	31%	18%	**38% B**	30%	26%	29%
Heard people make negative comments about my ability to do things	26%	31%	27%	24%	23%	24%
Experienced a transition in care such as moving between health care settings	26%	20%	20%	26%	**45% BCDF**	27%
Had support group meetings or activities cancelled	26%	25%	26%	30%	30%	20%
Been unable to go where I needed to or wanted due to accessibility issues such as a lack of wheelchair accessible transportation	24%	**31% D**	**29% D**	14%	21%	**25% D**
None of the above	15%	4%	7%	**18% BC**	**15% B**	**25% BC**

Base: All respondents.

Important demographic differences include:

- Compared to people living with dementia who have a caregiver, people living with dementia who do not have a caregiver are less likely to have experienced any and all of the difficult experiences illustrated. Over half of people living with dementia without a caregiver have not experienced the situations being asked (**52%**), compared to 2%-10% for people living with dementia who do have a caregiver.

- People living with dementia aged 85 years or older are more likely than people living with dementia under the age of 85 years to have experienced someone talking to their caregiver instead of them despite being present (**49%**).
- When compared to people living with dementia aged 65-84, people living with dementia aged 85 years or older are more likely to have experienced being excluded from decisions about their healthcare and finances (**42%**).
- Fewer people living with dementia in Quebec have experienced any one of the difficult experiences identified in the past year (**79%**), when compared to people living with dementia in Ontario (**88%**), Manitoba/Saskatchewan (**93%**) and British Columbia (**94%**).
- English people living with dementia (**88%**) are more likely to have experienced at least one of the difficult experiences in the past year than Francophone people living with dementia (80%).
- People living with dementia who live in an institution or care home are more likely to have experienced a transition in care within the past year (**40%**).
- People living with dementia who were diagnosed at age 55 years or younger are more likely to have experienced: encountering people who focus on the things they can no longer do (**46%**), hearing people make negative comments about their ability (**39%**) and being unable to go where they want/need to due to accessibility issues (**38%**).

Ease of Discussing Dementia Diagnosis

One-quarter of people living with dementia (25%) are comfortable talking about their dementia diagnosis and symptoms with those outside of their close circle, and only 6% say they are very comfortable doing so. A similar amount of people living with dementia are neutral (26%), while 43% are uncomfortable talking about it.

Looking at the target groups, people living with dementia who did the survey on their own are more likely to be comfortable talking about their diagnosis (**53%**) than any other group, while 12% of people living with dementia who did the survey on their own say they are very comfortable doing so.

Table 3. Q20: Would you say you are very comfortable, comfortable, neither comfortable nor uncomfortable, uncomfortable or very uncomfortable talking about your dementia diagnosis and symptoms with those who are not part of your close circle such as employers, community members, etc.?

Comfort Discussing Dementia Diagnosis/Symptoms	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
Very comfortable	6%	**12% E**	5%	7%	2%	**8% E**
Comfortable	18%	**41% CDEF**	**21% F**	**18% F**	15%	8%
Neither	26%	18%	26%	23%	28%	29%
Uncomfortable	22%	18%	25%	23%	23%	19%
Very uncomfortable	21%	12%	21%	20%	23%	**25% B**
Prefer not to say	6%	0%	2%	**9% C**	9%	**10% C**

Base: All respondents.

Those more likely to say they are comfortable discussing their diagnosis:

- People living with dementia who have a College/University education (**34%**).
- English people living with dementia (**32%**).

Those less likely to say they are comfortable discussing their diagnosis:

- People living with dementia aged 85 years or older (15%).
- People living with dementia in Quebec (14%).

Qualitative Insights: Discussing One's Diagnosis

In keeping with the quantitative results that show a level of discomfort with discussing a dementia diagnosis, a few interviewees mentioned that they refrained from sharing the news of their diagnosis with members of their family and/or friends. When probed, more often than not it tended to be a person with early onset dementia whose symptoms were not yet discernable and a desire not to burden anyone unnecessarily. A few of these same people had refrained from sharing the news with their employers for fear of being penalized.

With regards to any perceptible changes in family and/or friends' behaviour upon learning of the diagnosis, experiences varied although most felt that their interactions had not changed at all or had in fact improved. Some spoke of having family or friends take a more active interest in their well-being with more frequent interactions including regular phone calls to check in. A few who witnessed adverse changes in behaviour, spoke of people distancing themselves.

"It's hard to tell people but we did because it was becoming more obvious that something wasn't quite right." ~ Person living with dementia and their caregiver

> *"We have purposely kept it quiet. I feel that you can't help start to act differently. I don't want friends to suddenly be looking for problems or whatever. So, I have just told my sister and a close friend because I need that support. But I have asked everybody to keep quiet. I don't think there's any need to know until other people notice something." ~ Person living with dementia and their caregiver*
>
> *"It does bother me to think that I have dementia. I have prided myself on being a reasonably intelligent, straightforward, man." ~ Person living with dementia and their caregiver*

Section B: The COVID-19 Pandemic

The COVID-19 pandemic had impacted Canadians for over a year as of the timing of the fieldwork for this project, which made understanding how the pandemic has impacted people living with dementia important to having a contextual understanding of quality of life, both before and since COVID-19. This chapter outlines overall level of awareness of the pandemic, as well as how, if at all, it has impacted people living with dementia and the frequency of care they receive.

Awareness of the COVID-19 Pandemic

The vast majority (91%) of people living with dementia have heard or read something about the COVID-19 pandemic. However, people living with dementia who did the survey on their own are less likely to say they have read or heard anything about COVID-19 (80%).

Table B1. Q21: Have you read or heard anything about the COVID-19 pandemic?

Awareness of the COVID-19 Pandemic	Total n=402 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=0 (F)
Yes	91%	80%	**93% B**	**93% B**	91%	-
No	7%	12%	6%	5%	9%	-
Prefer not to answer	2%	8%	1%	2%	0%	-

Base: All respondents, except those for were former caregivers ending before COVID-19.

Those more likely to have heard or read about COVID-19:

- People living with dementia who have a post-graduate education (**100%**).
- Those in Atlantic Canada (**100%**), when compared to those in Quebec (89%) or Ontario (90%).

Those less likely to have heard or read about COVID-19:

- People living with dementia aged 85 years or older (**86%**).

Qualitative Insights: Awareness of the COVID-19 Pandemic

General awareness and understanding of the nature and/or severity of the COVID-19 pandemic including social distancing restrictions were not broadly understood by those living with dementia. For example, some caregivers recounted needing to remind the person living with dementia about the reasons for restrictions.

"We do talk about it. I explained to her why people aren't coming. Why I can't take her to a restaurant. Why we don't go shopping. But that knowledge falls off the pile." ~ Person living with dementia and their caregiver

"And he keeps forgetting that there is a pandemic and he'll say, let's go to the pub for lunch." ~ Person living with dementia and their caregiver

Impact of the COVID-19 Pandemic

The vast majority of people living with dementia feel COVID-19 has had a negative impact on their quality of life (84%), including one-third (32%) who describe the effect as very negative. Few say that COVID-19 has had no noticeable impact (14%), and only 2% describe the impact as positive.

Table B2. Q22: What has been the impact of the COVID-19 pandemic on your quality of life?

Impact of the COVID-19 Pandemic	Total n=367 (A)	PLWD only n=41 (B)	PLWD+ n=177 (C)	Current CG alone n=93 (D)	Former CG during COVID-19 n=48 (E)	Former CG before COVID-19 n=0 (F)
A very positive impact	0%	0%	1%	0%	0%	-
A somewhat positive impact	2%	2%	3%	0%	2%	-
No noticeable impact	14%	12%	12%	15%	15%	-
A somewhat negative impact	51%	54%	49%	58%	46%	-
A very negative impact	32%	32%	34%	27%	38%	-
Prefer not to answer	1%	0%	1%	0%	0%	-

Base: Those aware of COVID-19.

There are no significant demographic differences in the results.

Qualitative Insights: Impact of the COVID-19 Pandemic

Except for the disruption of certain services, the perceived impact of the COVID-19 pandemic on the lives of people living with dementia is much the same as that on anyone else. Many described having a hard time with the restrictions as they can no longer get together with family and friends or do the things they used to do (e.g., run errands, go out for dinner, go to movies); while for others who prefer to stay at home, this period has not proven to be much different than their normal day to day.

For some, the disruption of some services was particularly problematic. Some mentioned missing the regular support group meetings/activities and church services they attended. For the most part, they missed the opportunity these provided to socialize in a setting that was comfortable. A few also mentioned the move to video or telephone appointments (i.e., medical appointments) and a discomfort online.

Some caregivers also seemed to be having a harder time balancing priorities and caring for those living with dementia during the pandemic with the added responsibility due to the fact the external supports (and outlets) they had come to rely on were not available to them.

"I think the most benefit we get is from friends and family being able to visit them. And right now, that's restricted. I mean, our granddaughter won't come into our house, even with a mask, because she doesn't want to give us the virus." ~ Person living with dementia and their caregiver

"And we don't have any problems with COVID. The only thing that was missed is the weekly dinner." ~ Person living with dementia and their caregiver

"So, you know, the dementia is making her world smaller. COVID has made it even smaller. But we're trying to keep her in her home and the world is opening as big as possible using technology." ~ Current caregiver

Change in Frequency of Contact Since COVID-19

Of those who are aware of COVID-19 and have an unpaid caregiver, seven in ten (69%) say they do not see their caregiver any less as a result of the pandemic and 23% say they see their unpaid caregiver more. Conversely, almost one-third (31%) say the pandemic has caused them to see their unpaid caregiver less often.

People living with dementia who did the survey on their own are more likely to report no change in the frequency of contact with their unpaid caregiver due to the pandemic (**69%**), whereas former caregivers during COVID-19 are more likely to indicate they saw their loved one with dementia less often (**47%**). Current caregivers are more likely to report seeing their loved one with dementia more often (**35%**).

Table B3. Q31: Has COVID-19 changed how often you interact with or are in contact with your unpaid caregiver?

Impact of the COVID-19 Pandemic on Caregiver Interactions/Contact	Total n=248 (A)	PLWD only n=16 (B)	PLWD+ n=133 (C)	Current CG alone n=62 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=0 (F)
I see them more often	23%	13%	18%	**35% BC**	20%	-
I see them less often	31%	19%	31%	24%	**47% BD**	-
No change, I see them the same amount	46%	**69% DE**	50%	40%	33%	-
Prefer not to answer	0%	0%	1%	0%	0%	-

Base: Those aware of COVID-19 and have an unpaid caregiver. Note: Be aware of the small sample sizes.

Those more likely to see their unpaid caregiver less often:

- People living with dementia who live in an institution or care home (**60%**).
- Francophone people living with dementia (**39%**).

Qualitative Insights: Change in Frequency due to the COVID-19 Pandemic

While only three in ten people living with dementia report seeing their unpaid caregiver less due to COVID-19, participants in the in-depth interviews spoke about the impact of having less physical contact with people in their lives. In fact, the most important change since the pandemic seemed to be the decrease in physical contact and in-person visits. The impact of this was different depending on the situation. For some, the lack of physical contact was depressing and isolating. For others, it was not all that noticeable because they were living with family and still seeing family members regularly at a distance and/or talking regularly on the telephone or on video calls.

"They wouldn't let me in to see you [at the hospital]. I couldn't talk to you on the phone. So, when I finally came in, you were pretty lonely. You told me you were sad. You had no visitors. So, because she broke a hip during COVID, her quality of life suffered greatly during that time, you know, it was difficult. I visited her every day when I was able." ~ Current caregiver

"It has changed. I think, you know, initially when COVID hit and things went into lockdown. You know, trying to restructure was really quite challenging. It was lucky, I think, that we were going into spring. But what I feel is [he] became a bit more withdrawn initially, and he wasn't talking to as many people and things like that." ~ Person living with dementia and their caregiver

Section C: Caregiving and Support

This chapter focuses on the relationship people living with dementia have with caregivers, including understanding the different types of care providers, what, if any, assistance people living with dementia get with a variety of tasks, and the frequency of care received. Understanding what differences exist, if any, between paid and unpaid caregivers among these factors is also undertaken.

Types of Care Providers

The majority (62%) of people living with dementia have an unpaid caregiver, while half as many (31%) have a caregiver who is paid by the healthcare system, and less than one-quarter (22%) have a caregiver who is paid by themselves.

Looking at the target groups, people living with dementia who did the survey on their own are less likely to have an unpaid caregiver (37%), compared to people living with dementia who did the survey with their caregiver (**75%**), current caregivers (**68%**), and former caregivers during COVID-19 (**62%**).

Table C1. Q23. Do you have someone who provides regular care to you where you live?

Caregiving Support	Total n=556 (A)	PLWD only n=51 (B)	PLWD+ n=190 (C)	Current CG alone n=100 (D)	Former CG during COVID-19 n=53 (E)	Former CG before COVID-19 n=154 (F)
An unpaid caregiver such as a spouse, child, or close friend	62%	37%	**75% BF**	**68% BF**	**62% B**	49%
A care provider who is paid by the health care system	31%	39%	27%	29%	42%	31%
A care provider who is paid by me or someone in my household or family	22%	27%	21%	22%	25%	22%
None of the above	12%	10%	4%	**11% C**	11%	**21% BCD**
Prefer not to answer	1%	2%	1%	2%	0%	3%

Base: All respondents.

Important demographic differences include:

- People living with dementia who live in a private home alone are less likely to have a paid caregiver (13%).

Qualitative Insights: Types of Care Providers

Mirroring the quantitative findings, in-depth interview found that the majority of participants do not pay out of pocket for additional support. Of those who do not, many either did not have the means to do so or did not feel their dementia was at a stage that required that level of care yet. Of the few who do have external support, a number were on the receiving end of provincial government support in the form of a personal care worker. More often than not, the support provided by these personal care workers included administering medications, personal care (bathing, grooming, etc.), meal preparation, and/or general supervision/companionship.

Those at the receiving end of this support felt that it was extremely helpful; especially the caregivers for whom this support provided them with a regular respite during the week. For the person living with dementia, it was a pleasant distraction and an opportunity to socialize.

In terms of community support, most generally felt that they had what they needed. In fact, when asked what is making it difficult for them to stay engaged or involved, most were unable to list any resources they thought were lacking.

Again, community support needs differed significantly based on individual circumstance and/or severity of dementia. For example, some people living with dementia who live alone explained that they live in an urban community setting deliberately to ensure they have ready access to the community supports they need (i.e., public transportation and amenities nearby). Others, who live with their caregivers, explained that they had chosen to move to a more rural setting so that they could live away from the hustle and bustle of urban life and be closer to nature.

"Someone in the house all the time. Glen comes at night, and Imelda comes in the afternoon. And Sammy comes in the morning. Yeah. So, there's different people that come and go." ~ Person living with dementia and their caregiver

"We're pretty proud of the fact that we can…manage, you know?" ~ Person living with dementia

Types of Professional Care Providers

Among those who have a caregiver, more than two-thirds (69%) say they have personal support worker, while almost half say they have a nurse (47%) and/or a doctor (43%) as part of their ongoing care. Less than one in five (17%) have a developmental service worker.

People living with dementia who did the survey on their own are the least likely to have a personal support worker (47%) and former caregivers during COVID-19 are the least likely to have a developmental service worker (3%). Former caregivers before COVID-19 are more likely to have a nurse (**58%**) than people living with dementia who did the survey with their caregiver (41%) and current caregivers (40%).

Table 4. Q24. What type of care providers do you currently have as part of your ongoing care?

Types of Care Providers	Total n=264 (A)	PLWD only n=30 (B)	PLWD+ n=80 (C)	Current CG alone n=48 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=74 (F)
Personal support worker	69%	47%	**70% B**	**79% B**	63%	**74% B**
Nurse	47%	43%	41%	40%	50%	**58% CD**
Doctor	43%	37%	45%	42%	50%	42%
Developmental service worker	17%	10%	**19% E**	**25% E**	3%	**19% E**
Family/friends	6%	0%	5%	6%	13%	5%
Staff at seniors' residence	3%	0%	3%	2%	0%	7%
Other	3%	0%	0%	6%	7%	4%
Prefer not to answer	2%	0%	1%	0%	7%	4%
No response	5%	3%	8%	6%	3%	1%

Base: Those with a caregiver.

Important demographic differences include:

- People living with dementia who have a caregiver in Manitoba/Saskatchewan are less likely to have a personal support worker (44%) or a doctor (17%) as part of their ongoing care, compared to other regions.
- Those who have a caregiver paid for by the healthcare system are more likely to have a developmental service worker (**20%**) than those who have unpaid caregivers or caregivers paid by other means.

Qualitative Insights: Types of Professional Care Providers

When asked if they were aware of any services or benefits available to assist people living with dementia, responses were split pretty evenly. Those aware of services recalled receiving help or introductory information from the Alzheimer Society although many had not followed through and reached out (yet). Other supports that were mentioned included the availability of doctors, nurses and personal care workers although some had difficulty navigating the provincial health care systems to access these services. Few spoke of federal and/or provincial benefits available to them. One or two mentioned insurance and/or tax relief but details were vague.

"I think the Alzheimer Society was very, and has been very good. They were very supportive. Very helpful." ~ Person living with dementia and their caregiver

"We actually have …government provided home care twice a day, in the morning, and in the evening. They're here anywhere from 5 to 30 minutes" ~ Person living with dementia and their caregiver

> *"The support from [a] home care perspective is phenomenal." ~ Person living with dementia and their caregiver*

In-home Care by Paid Providers

Over half (55%) of people living with dementia who have a paid caregiver have at least one that provides care for them in their own home.

Table C3. Q25: Do any of your paid care providers provide care for you in your home?

In-home Paid Care Providers	Total n=264 (A)	PLWD only n=30 (B)	PLWD+ n=80 (C)	Current CG alone n=48 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=74 (F)
Yes	55%	50%	59%	65%	50%	49%
No	38%	30%	34%	29%	47%	**49% D**
Prefer not to answer	2%	**17% F**	0%	0%	0%	1%
No response	5%	3%	8%	6%	3%	1%

Base: Those with a caregiver.

Those less likely to have a paid caregiver who provides care in their home:

- People living with dementia aged 85 or older and have a caregiver (42%).
- Francophone people living with dementia who have a caregiver (37%).
- People living with dementia whose caregiver is paid for by the healthcare system (47%).
- People living with dementia who live in an institution or care home (34%).

Tasks Performed by Paid Care Providers

For those who have them, over the past year, paid caregivers who provide care in the home of people living with dementia have most commonly been helping with activities of daily living (76%), general healthcare and health monitoring (72%); and less so with house maintenance (40%), transportation (29%), or financial affairs (16%).

People living with dementia who did the survey with their caregiver are more likely to have paid a caregiver who helps with transportation (**36%**, compared to former caregivers before COVID-19) and financial affairs (**26%** compared to former caregivers). Current caregivers are more likely to have paid caregivers that assist with activities of daily living (**90%**) when compared to people living with dementia who did the survey with a caregiver (70%).

Table 5. Q26. Do any of your paid care providers help you with any of the following?

Paid Care Provider Assistance	Total n=144 (A)	PLWD only n=15 (B)	PLWD+ n=47 (C)	Current CG alone n=31 (D)	Former CG during COVID-19 n=15 (E)	Former CG before COVID-19 n=36 (F)
Assist with activities of daily living such as cooking, cleaning, bathing, or dressing	76%	67%	70%	**90% C**	73%	78%
General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	72%	60%	72%	68%	80%	78%
House maintenance or outdoor work	40%	47%	30%	39%	47%	50%
Transportation	29%	40%	**36% F**	29%	27%	17%
Assist with financial affairs	16%	20%	**26% EF**	16%	7%	6%
Other	1%	0%	2%	0%	0%	0%

Base: Those with a caregiver in their home. Note: Be aware of the small sample sizes.

Important demographic differences include:

- People living with dementia aged 75-84 and 85 years or older are less likely to have paid caregivers that assist with transportation (12% and 20%, respectively).
- People living with dementia who have not graduated from high school are less likely to have paid caregivers that assist with transportation (13%).
- People living with dementia who have a caregiver paid for by the healthcare system are less likely to have help with daily living activities (69%).
- Those with a College/University degree are more likely to get assistance with their finances from their paid caregiver(s) **(32%)**.
- Those who have caregiver paid for by themselves are more likely to have assistance with house maintenance and outdoor work (**51%**).
- People living with dementia who have a friend that is a caregiver are more likely to have assistance with general health care and health monitoring (**92%**) and house maintenance and outdoor work (**75%**).
- Those who received their dementia diagnosis at 55 years of age or younger are more likely to have assistance with transportation from their paid caregiver (**58%**).

Knowledge of Paid Care Providers

The majority of people living with dementia with a caregiver (72%) feel that their paid caregivers are very knowledgeable (36%) or somewhat knowledgeable (36%). However, one in five (22%) say their paid caregiver is not knowledgeable.

Current caregivers (**46%**) and former caregivers during COVID-19 (**53%**), compared to people living with dementia who did the survey on their own (20%) and people living with dementia who did the survey with their caregiver (31%), are more likely to say the paid caregiver(s) are very knowledgeable.

Table 6. Q27: How knowledgeable do you feel the paid care providers you have are about supporting people living with dementia?

Knowledge of Paid Care Providers	Total n=264 (A)	PLWD only n=30 (B)	PLWD+ n=80 (C)	Current CG alone n=48 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=74 (F)
Very knowledgeable	36%	20%	31%	**46% B**	**53% BC**	36%
Somewhat knowledgeable	36%	37%	38%	38%	20%	**39% E**
A little knowledgeable	19%	27%	20%	10%	17%	19%
Not at all knowledgeable	3%	13%	1%	0%	7%	3%
Prefer not to answer	1%	0%	3%	0%	0%	1%
No response	5%	3%	8%	6%	3%	1%

Base: Those with a caregiver.

Those more likely to say their paid care provider is very knowledgeable:

- People living with dementia in Atlantic Canada (**75%**).

Relationship to Unpaid Caregivers

Unpaid caregivers of people living with dementia are most commonly their child (66%). Less common relationships include spouse (26%), grandchild (10%), child-in-law (10%), or a friend (10%).

People living with dementia who did the survey on their own are significantly more likely to have a spouse act as a caregiver (**74%**) compared to all other target groups, and conversely, are less likely to have a child act as a caregiver (32%). Current caregivers are the most likely to have a caregiver that is their child (**81%**). One quarter of former caregivers during COVID-19 say their child-in-law is their caregiver (**24%**).

Table C6. Q28. What is your relationship with your unpaid caregiver or caregivers? The caregiver is your…

Relationship with Unpaid Caregiver(s)	Total n=345 (A)	PLWD only n=19 (B)	PLWD+ n=142 (C)	Current CG alone n=68 (D)	Former CG during COVID-19 n=33 (E)	Former CG before COVID-19 n=76 (F)
Child	66%	32%	**65% B**	**81% BCF**	**67% B**	**63% B**
Spouse	26%	**74% CDEF**	21%	19%	27%	30%
Grandchild	10%	0%	12%	9%	12%	12%
Child-in-law	10%	5%	7%	12%	**24% BC**	9%
Friend	10%	16%	**11% E**	6%	3%	9%
Family	3%	0%	4%	0%	6%	1%
Sibling	1%	0%	1%	3%	0%	0%
Other	1%	0%	1%	0%	0%	1%
Prefer not to answer	1%	0%	0%	0%	0%	3%

Base: Those with an unpaid caregiver. Note: Be aware of the small sample sizes.

Important demographic differences include:

- People living with dementia aged 85 years or older are less likely to have a caregiver that is their spouse (13%).
- Those who live in a rural/remote area are less likely to have a caregiver who is their child (43%).
- Those with high school education or less are more likely to have their child act as their caregiver (some high school: **73%**; graduated high school: **72%**).

Qualitative Insights: Unpaid Caregivers and Support

When asked to describe their relationship with their caregivers, the majority conveyed an overwhelming sense of appreciation and gratitude to those who support and care for them. Quite often, this particular question elicited a lot of laughter, especially when the person living with dementia described the occurrence of "trying" moments in addition to all of the "good" moments.

When asked whether they had family or friends nearby, responses seemed to vary widely based on individual circumstances and severity of dementia. Those with young onset dementia and those living with their caregiver(s) spoke of having fairly strong networks of family and friends with whom they were in regular contact (mostly by phone or video, depending on their technical abilities). Some with more advanced stages of dementia spoke of having some contact with close family, but limited friend networks – a trait many of these respondents had before their dementia diagnosis. A few interviewees described friends/neighbours pulling away from them following their diagnosis.

> *"Not so much anymore since we've been retired. We have contact with my siblings who live in Kingston and Toronto. I don't have a lot of friends." ~ Person living with dementia and their caregiver*
>
> *"The best thing they could possibly do for patients, especially for people who take care of their own at home as long as possible, is I think we need more education as to the severity of the disease and the unpredictability of it all. I think if I would have known a lot more about dementia, let's say two years ago, I would have been better prepared to give [her] a better quality." ~ Person living with dementia and their caregiver*

Frequency of Contact with Unpaid Caregivers Prior to COVID-19

Recognizing that the pandemic has certainly impacted the access to care and/or services of unpaid caregivers (due to public health restrictions, etc.), the survey sought to measure the kind of activities caregivers were providing before the pandemic. To do this, people living with dementia who are aware of COVID-19 and have an unpaid caregiver were asked about their interactions with their caregivers before the pandemic.

Prior to COVID-19, the majority of people living with dementia (67%) say they interacted daily with their unpaid caregivers. Most of the remaining (29%) say they interacted with their caregivers at least once per week.

Table C7. Q30: Prior to the COVID-19 pandemic, on average, how often did you interact with or were in contact with your unpaid caregiver, whether in person, by phone, text, email, video chat, etc.?

Pre-COVID-19 Pandemic Contact with Unpaid Caregiver	Total n=248 (A)	PLWD only n=16 (B)	PLWD+ n=133 (C)	Current CG alone n=62 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=0 (F)
Daily	67%	75%	68%	63%	73%	-
At least once a week	29%	19%	27%	37%	23%	-
At least once a month	2%	0%	2%	0%	3%	-
Less than once a month	1%	6%	1%	0%	0%	-
Prefer not to answer	1%	0%	2%	0%	0%	-

Base: Those aware of COVID-19 and have an unpaid caregiver. Note: Be aware of the small sample sizes.

Those more likely to interact with unpaid caregiver daily have a:

- Caregiver that is the person living with dementia's spouse (**80%**).

Tasks Performed by Unpaid Caregiver Prior to COVID-19

The variety of support being provided by unpaid caregivers is much broader than is typically being provided by paid caregivers. Unpaid caregivers are about as likely as paid care providers to provide assistance with daily living (69%) and general health care (78%), but are far more likely to assist with transportation (74%), financial affairs (72%), and house maintenance (69%).

Looking at the target groups, people living with dementia who did the survey on their own are more likely than current caregivers to have unpaid caregivers who help with activities with daily living (**88%** versus 61%). People living with dementia who did the survey with a caregiver are more likely than people living with dementia who did the survey on their own to have assistance with transportation from their unpaid caregiver (**77%** versus 50%). People living with dementia who did the survey with a caregiver are more likely than current caregivers to indicate the person living with dementia has assistance with house maintenance or outdoor work (**74%** versus 60%).

Table C8. Q29. Prior to the COVID-19 pandemic, did your unpaid caregiver help you with any of the following?

Tasks Performed by Unpaid Caregiver	Total n=248 (A)	PLWD only n=16 (B)	PLWD+ n=133 (C)	Current CG alone n=62 (D)	Former CG during COVID-19 n=30 (E)	Former CG before COVID-19 n=0 (F)
General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	78%	56%	80%	79%	83%	-
Transportation	74%	50%	**77% B**	76%	73%	-
Assisted with financial affairs	72%	56%	75%	73%	70%	-
Assisted with activities of daily living such as cooking, cleaning, bathing, or dressing	69%	**88% D**	71%	61%	67%	-
House maintenance or outdoor work	69%	69%	**74% D**	60%	60%	-
Errands / Shopping	1%	0%	2%	0%	0%	-
Company / Conversation	1%	0%	1%	2%	0%	-
Other	1%	0%	1%	2%	0%	-
None / Nothing	1%	0%	2%	0%	0%	-
Prefer not to answer	1%	0%	2%	2%	0%	-

Base: Those aware of COVID-19 and have an unpaid caregiver. Note: Be aware of the small sample sizes.

Important demographic differences include:

- English people living with dementia are more likely to have assistance from their unpaid caregiver(s) with daily living activities (**76%**) and house maintenance/outdoor work (**74%**).

Unaware of COVID-19: Tasks Performed by Unpaid Care Providers

The people living with dementia who were not aware of COVID-19 (n=18) were asked to identify which tasks their unpaid caregivers performed. While the proportions are different from the results reported above, likely due to the limited sample size, the majority of people living with dementia have unpaid caregivers assist with the tasks described below.

Table C9. Q32. Has your unpaid caregiver helped you with any of the following?

Tasks Performed by Unpaid Caregiver	Total n=18 (A)	PLWD only n=2 (B)	PLWD+ n=9 (C)	Current CG alone n=4 (D)	Former CG during COVID-19 n=3 (E)	Former CG before COVID-19 n=0 (F)
Assisted with financial affairs	83%	100%	89%	100%	33%	-
General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	78%	50%	78%	75%	100%	-
Transportation	67%	0%	78%	75%	67%	-
Assisted with activities of daily living such as cooking, cleaning, bathing, or dressing	67%	50%	67%	75%	67%	-
House maintenance or outdoor work	50%	0%	44%	75%	67%	-
Other	6%	0%	11%	0%	0%	-

Base: Those unaware of COVID-19 and have an unpaid caregiver. Note: Be aware of the small sample sizes.

There are no significant demographic differences among comparison groups.

Unaware of COVID-19: Frequency of Contact with Unpaid Caregiver

People living with dementia who are not aware of COVID-19 are just as frequently in contact with their unpaid caregivers as those who are aware of COVID-19. Two-thirds (67%) of people living with dementia who are unaware of the COVID-19 pandemic interact with their unpaid caregiver daily.

Table C10. Q33: On average, how often do you interact with or are in contact with your unpaid caregiver, whether in person, by phone, text, email, video chat, etc.?

Frequency of Contact with Unpaid Caregiver	Total n=18 (A)	PLWD only n=2 (B)	PLWD+ n=9 (C)	Current CG alone n=4 (D)	Former CG during COVID-19 n=3 (E)	Former CG before COVID-19 n=0 (F)
Daily	67%	50%	56%	75%	100%	-
At least once a week	17%	0%	33%	0%	0%	-
At least once a month	17%	50%	11%	25%	0%	-
Less than once a month	0%	0%	0%	0%	0%	-
Prefer not to answer	0%	0%	0%	0%	0%	-

Base: Those unaware of COVID-19 and have an unpaid caregiver. Note: Be aware of the small sample sizes.

There are no significant demographic differences among comparison groups.

CONCLUSIONS

Taken together, the qualitative and quantitative phases of research undertaken in this study provided a wealth of information on the lived experience of people living with dementia. The research findings will help in developing informed dementia related programs and initiatives to help improve the quality of life of those living with dementia. Previous public opinion research undertaken by the Public Health Agency of Canada in 2020 indicated that two in three Canadians believe that people living with dementia generally face a lower quality of life than those without dementia. The findings from this research show that a majority of people living with dementia describe their quality of life as good or better (55% combined saying excellent, very good or good) and slightly less than half rating it as less than good (44% combined saying fair or poor). Exploring overall life satisfaction with people living with dementia mirrors these findings, with the average rating landing squarely in the middle (approximately five on a ten-point scale).

Both phases of the research suggest that defining quality of life is difficult for a person living with dementia particularly on an unaided basis and understanding what drives quality of life generally can be hard to pinpoint especially as it varies person to person. The most commonly identified factors having an important impact on the quality of life for people living with dementia (for all respondents, especially when a caregiver is responding on their behalf) are having good health (physical and mental), receiving support and frequent visits from family and friends, and being comfortable and independent (ideally, in one's own home). While the self-assessment ratings for different aspects of their lives are highest for the relationship with family or friends and access to necessary health services, fewer than half of all respondents would rate those as very good or excellent. The qualitative and quantitative findings consistently found that people living with dementia rate their ability to participate in hobbies/leisure activities and socialize with other people as the lowest aspects of their quality of life.

These low ratings are, at least in part, exacerbated by the COVID-19 pandemic. Most people living with dementia are aware of the pandemic, however, the interviews revealed that level of awareness and understanding is likely lower than what is demonstrated by the quantitative exercise. During the interviews, caregivers on multiple occasions reminded the people living with dementia that they were living in a pandemic.

Regardless of their awareness of the pandemic, the impact of it is being felt by people living with dementia, as with other Canadians. There is a segment of this target group who has not noticed much of an impact and have expressed in interviews that some things remain consistent (e.g., seeing their caregivers the same amount or more). However, the vast majority of people living with dementia participating in this project have experienced a negative impact on their quality of life due to COVID-19.

Beyond the pandemic, people living with dementia report relatively high levels of negative feelings and experiences, some of which may be related to dementia-related stigma. Over half of people living with dementia experience feeling isolated, sad, or anxious, and the vast majority have experienced at least one negative feeling for an extended period in the past year (March 2020 to May/June 2021 at the time of the survey). Furthermore, in the last year, over half of people living with dementia have had difficulty communicating their needs, and many have had people talk to their caregiver instead of to them, been excluded from decisions about their health or finances, or encountered people who focus on the things they can no longer do. While these feelings and experiences were not directly linked to how a person living with dementia assessed their quality of life, finding a way to reduce these feelings and experiences could be expected to have a positive impact on the life of a person living with dementia. Perhaps consistent with these feelings and experiences, one-quarter of people living with dementia are comfortable (including 8% who are very comfortable) with discussing their diagnosis or symptoms outside of their close circle, and a few interviewees indicated they have not told some people in their lives.

For most people living with dementia participating in this project, that close circle includes unpaid and/or paid caregivers. The majority of people living with dementia have an unpaid caregiver that is most commonly their child or spouse. Half of people living with dementia have a paid caregiver, most commonly a personal support worker, and just a little over one in ten (12%) have no caregiver. Unpaid and paid caregivers most commonly assist with activities of daily living, like cooking, cleaning, and bathing; and general healthcare needs and health monitoring. Less commonly performed by paid caregivers, unpaid caregivers regularly assist the person living with dementia with transportation, financial matters, and house maintenance and outdoor work. People living with dementia express a great deal of gratitude for their caregivers, and so it appears that the care being provided is not a negative factor affecting their quality of life. This appears to be true for both unpaid and paid caregivers; in fact, most people living with dementia believe their paid caregivers are knowledgeable about supporting people living with dementia.

APPENDIX A: PANEL RECRUIT SCREENER

PHASE 1: QUALITATIVE RESEARCH (40 IN-DEPTH INTERVIEWS) **January 12-26, 2021**

- Either by telephone or video depending on participant preference
- Approximately 30-40 minutes in length
- People living with dementia, including early onset dementia, and those living in home settings as well as facility-based settings (AIM FOR MIX)
- If needed, family/friend caregivers may be involved in assisting the interviewee
- Using family/friend caregivers as proxies should be explored only after extensive efforts are made to recruit direct participation by the person living with dementia (PLWD) and if needed to enable recruitment from a variety of settings
- In English or French depending on interviewee's preference

PHASE 2: QUANTITATIVE RESEARCH (500 CANADIANS) **February 10-March 31, 2021**

- Either online, by telephone or videoconference depending on participant preference
- Approximately 15 minutes in length
- People living with dementia, including early onset dementia, and those living in home settings as well as facility-based settings (AIM FOR MIX)
- If needed, family/friend caregivers may be involved in assisting the interviewee
- In English or French depending on interviewee's preference

	Overall Incidence	Interview Targets	Survey Targets
Male	49.9%	20	249
Female	50.1%	20	251
Atlantic Canada	5.6%	2	28
Quebec	27.5%	11	138
Ontario	37.7%	15	189
Manitoba/Saskatchewan	6.5%	4	32
Alberta	9.9%	3	49
British Columbia	12.8%	5	64
TOTAL		40	500

Respondent's name:
Respondent's phone number: (cell)
Respondent's phone number: (work)
Respondent's email:

Interviewer:
Date:
Validated:

Earnscliffe Strategy Group, a national public opinion research firm has been engaged to conduct a research project on behalf of the Government of Canada on issues of importance to Canadians. This project is being conducted on behalf of Health Canada and the Public Health Agency of Canada, more specifically. We are looking for people who would be willing to participate.

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. Participants will receive an honorarium for their participation.

But before we invite you to participate, we need to ask you a few questions to ensure that we get a good mix and variety of people. This survey will take about 5 minutes to complete and is voluntary and completely confidential. Your responses to this survey will be kept entirely anonymous and any information you provide will be administered in accordance with the Privacy Act and other applicable privacy laws.

Do you wish to continue?
Yes
No

1. (DO NOT ASK – RECORD SEX)

Male	1
Female	2

2. In what year were you born?

[INSERT YEAR. IF YOUNGER THAN 18 YEARS OR PREFER NOT TO SAY, *TERMINATE]

3. Which province or territory do you live in?

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

4. Do you, or does anyone in your family or household, work in any of the following areas?

Advertising or market research	1
The media (i.e. TV, radio, newspapers)	2
A public relations company	3
An online media company or as a blog writer	4
The federal, provincial or municipal government in marketing, advertising, public opinion research, media relations, and/or communications	5
None of the above	7
Prefer not to answer	9

IF SELECT ANY OF THE ABOVE, NOT ELIGIBLE: Thank you for your willingness to take part in this survey, but you do not meet the eligibility requirements of this study.

IF SELECTED "NONE OF THE ABOVE", ELIGIBLE: Thank you, let's begin the survey.

5. Which of the following have you, or anyone within your close family/friend circle, ever been diagnosed with? (PLEASE SELECT ALL THAT APPLY)

- **Hypertension**: *Individuals with high blood pressure have hypertension. High blood pressure is systolic blood pressure at or above 140 mmHg or diastolic blood pressure at or above 90 mmHg.* 1
- **Dementia**: *Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.* 2
- **Depression**: *Major depression is a clinical term used by psychiatrists to define a time period that lasts more than two months in which a person feels worthless and hopeless.* 3
- **Diabetes**: *Diabetes is a chronic condition that stems from the body's inability to sufficiently produce and/or properly use insulin which the body needs to use sugar as an energy source.* 4
- **High cholesterol**: *Blood cholesterol is a natural fat. Your liver makes about 80% of the cholesterol in your body. The rest comes from animal-based foods or drinks. High cholesterol has no symptoms. Only a blood test can detect high cholesterol.* 5
- **Heart disease**: *Also known as ischemic heart disease or coronary heart disease, heart disease refers to the buildup of plaque in the heart's arteries that could lead to a heart attack, stroke, heart failure, or death.* 6
- **Insomnia**: *Insomnia is predominantly characterized by dissatisfaction with sleep and difficulties initiating or maintaining sleep, along with substantial distress and impairments of daytime functioning.* 7
- **Obesity**: *Overweight and obesity are defined as abnormal or excessive fat accumulation that presents a risk to health. A body mass index (BMI) over 25 is considered overweight, and over 30 is obese.* 8
- None of the above 9

6. Have you, or anyone within your close family/friend circle, ever provided care and/or assistance to a person living with any of the following in the last 5 years? (PLEASE SELECT ALL THAT APPLY)

   Care can include assistance with financial affairs, activities of daily living (ex. cooking, cleaning) and general health care/health monitoring (ex. helping administer medication or scheduling medical appointments).

- **Hypertension**: *Individuals with high blood pressure have hypertension. High blood pressure is systolic blood pressure at or above 140 mmHg or diastolic blood pressure at or above 90 mmHg.* 1
- **Dementia**: *Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease,*

vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias. 2

- **Depression**: *Major depression is a clinical term used by psychiatrists to define a time period that lasts more than two months in which a person feels worthless and hopeless.* 3
- **Diabetes**: *Diabetes is a chronic condition that stems from the body's inability to sufficiently produce and/or properly use insulin which the body needs to use sugar as an energy source.* 4
- **High cholesterol**: *Blood cholesterol is a natural fat. Your liver makes about 80% of the cholesterol in your body. The rest comes from animal-based foods or drinks. High cholesterol has no symptoms. Only a blood test can detect high cholesterol.* 5
- **Heart disease**: *Also known as ischemic heart disease or coronary heart disease, heart disease refers to the buildup of plaque in the heart's arteries that could lead to a heart attack, stroke, heart failure, or death.* 6
- **Insomnia**: *Insomnia is predominantly characterized by dissatisfaction with sleep and difficulties initiating or maintaining sleep, along with substantial distress and impairments of daytime functioning.* 7
- **Obesity**: *Overweight and obesity are defined as abnormal or excessive fat accumulation that presents a risk to health. A body mass index (BMI) over 25 is considered overweight, and over 30 is obese.* 8
- None of the above 9

[IF RESPONDENT SELECTED "DEMENTIA" IN EITHER Q5 OR Q6, PLEASE CONTINUE. IF NOT, PLEASE THANK AND TERMINATE: Thank you for your willingness to take part in this survey, but you do not meet the eligibility requirements of this study.]

[IF SELECTED "DEMENTIA" AT EITHER Q5 OR Q6]
As part of the national dementia strategy, Health Canada and the Public Health Agency of Canada would like to build on existing research to continue to work towards their goals of: eliminating stigma associated with dementia; promoting measures that create safe and supportive dementia inclusive communities; and, addressing the importance of access to quality care for those living with dementia.

Health Canada and the Public Health Agency of Canada have retained Earnscliffe Strategy Group to conduct an important research study to better understand the lived experience and perceptions of quality of life of people living with dementia.

The research project will span several months and involves two phases of research; participation in both phases is NOT mandatory. The first is a series of one-on-one, 40-minute interviews conducted via telephone or video (based on your preference) and led by a research professional. The second is a 15-minute survey to be completed either online, via telephone or videoconference (based on your preference). The questions for both phases would be provided in advance.

To assess your eligibility for this study, we have a few more questions. Do you wish to continue?

Yes
No

7. *[IF SELECTED DEMENTIA AT Q5]* Can you please confirm whether you or a member of your close family/friend circle has been diagnosed with dementia?

I have been diagnosed with dementia	1
A member of my close family/friend circle has been diagnosed with dementia	2

IF "I HAVE BEEN DIAGNOSED WITH DEMENTIA", QUALIFIES AS PERSON LIVING WITH DEMENTIA, CONTINUE TO Q10

8. *[IF "A MEMBER OF MY CLOSE FAMILY/FRIEND CIRCLE HAS BEEN DIAGNOSED WITH DEMENTIA"]* Do you provide care and/or assistance to the member of your household diagnosed with dementia?

Yes	1
No	2

IF YES, QUALIFIES AS A CAREGIVER, CONTINUE TO Q14.
IF NO, ASK: WE WOULD VERY MUCH LIKE TO INCLUDE THE MEMBER OF YOUR CLOSE FAMILY/FRIEND CIRCLE WHO IS LIVING WITH DEMENTIA IN OUR RESEARCH. CAN YOU PLEASE SHARE THIS SURVEY WITH THEM TO DETERMINE THEIR INTEREST IN PARTICIPATING?
[NOTE TO INTERVIEWER]: PLEASE REQUEST FOLLOW-UP CONTACT INFORMATION FOR THE MEMBER OF CLOSE FAMILY/FRIEND CIRCLE LIVING WITH DEMENTIA AND CONDUCT SURVEY FROM BEGINNING.

9. *[IF SELECTED DEMENTIA AT Q6]* Can you please confirm whether you or a member of your close family/friend circle has provided care and/or assistance to a person living with dementia in the last 5 years?

I have provided care and/or assistance to a person living with dementia in the last 5 years	1
A member of my close family/friend circle has provided care and/or assistance to a person living with dementia in the last 5 years	2

IF INDIVIDUAL HAS PROVIDED CARE AND/OR ASSISTANCE TO A PERSON LIVING WITH DEMENTIA, QUALIFIES AS A CAREGIVER, CONTINUE TO Q14.

IF A MEMBER OF CLOSE FAMILY/FRIEND CIRCLE, ASK: WE WOULD VERY MUCH LIKE TO INCLUDE THE PERSON WITHIN YOUR CLOSE FAMILY/FRIEND CIRCLE WHO IS CARING FOR SOMEONE LIVING WITH DEMENTIA IN OUR RESEARCH. CAN YOU PLEASE SHARE THIS SURVEY WITH THEM TO DETERMINE THEIR INTEREST IN PARTICIPATING?
[NOTE TO INTERVIEWER]: PLEASE REQUEST FOLLOW-UP CONTACT INFORMATION FOR THE MEMBER OF CLOSE FAMILY/FRIEND CIRCLE LIVING WITH DEMENTIA AND CONDUCT SURVEY FROM BEGINNING.

FOR THOSE LIVING WITH DEMENTIA [Q7=1]

As mentioned earlier, the research project will span several months and will involve two phases of research. Participation in both phases is NOT mandatory.

10. The in-depth interviews will take place between January 12 and 26, 2021 and will last approximately 40 minutes. The interview will be led by a research professional. Should you wish to participate,

someone will follow up with you to schedule an interview at a date and time that works best for you. You will receive an honorarium of $125 for your time. The questions will be provided in advance. Would you be interested in participating in this phase of research?

Yes	1
No	2

11. [IF NO] We would very much like to include your views in our research. Would you feel more comfortable participating in the interview with assistance from a caregiver or family member?

Yes	1
No	2

12. Would you require any accommodations to participate in the interview?

Yes, please specify	1
No	2

13. The second phase of research will involve a 15-minute survey that will be conducted mid-February through March 2021. You would be offered the option of conducting the survey online, by telephone or videoconference. The questions would be provided in advance. Would you be interested in participating in this phase of research?

Yes	1
No	2

14. [IF NO] We would very much like to include your views in our research. Would you feel more comfortable participating in the survey with assistance from a caregiver or family member?

Yes	1
No [PLEASE THANK AND TERMINATE]	2

15. Would you require any accommodations to participate in the survey?

Yes, please specify	1
No	2

IF YES TO PARTICIPATE INDIVIDUALLY OR WITH THE ASSISTANCE OF A CAREGIVER OR FAMILY MEMBER, PLEASE PROCEED TO Q24.

FOR THOSE CARING OR SUPPORTING SOMEONE LIVING WITH DEMENTIA [Q8=1 OR Q9=1]
We would very much like to include the person living with dementia for whom you provide care and/or assistance in our research.

16. The in-depth interviews will take place between January 12 and 26, 2021 and will last approximately 40 minutes. The interview will be led by a research professional. Should the person living with dementia wish to participate, someone will follow up to schedule an interview at a date and time

that works best. They will receive an honorarium of $125 for their time. The questions would be shared in advance. Would they be interested in participating in this phase of research?

Yes	1
No	2

17. [IF NO] We would very much like to include their views in our research. Do you think they would feel more comfortable participating in the interview with your assistance?

Yes	1
No [PLEASE THANK AND TERMINATE]	2

18. [IF YES] Would you be available to assist the person living with dementia to participate in the interview?

Yes	1
No [PLEASE THANK AND TERMINATE]	2

19. Would they require any accommodations to participate in the interview?

Yes, please specify	1
No	

20. The second phase of research will involve a 15-minute survey that will be conducted mid-February through March 2021. The person living with dementia would be offered the option of conducting the survey online, by telephone or videoconference. The questions would be shared in advance. Would they be interested in participating in this phase of research?

Yes	1
No	

21. [IF NO] We would very much like to include their views in our research. Do you think they would feel more comfortable participating in the survey with your assistance?

Yes	1
No	2

22. [IF YES] Would you be available to assist the person living with dementia to participate in the survey?

Yes	1
No [PLEASE THANK AND TERMINATE]	2

23. Would they require any accommodations to participate in the survey?

Yes, please specify	1
No	2

INVITATION:

24. The interviews will be scheduled by Quality Response, a qualitative market research company that specializes in recruitment of in-depth interviews. So that we can follow-up to schedule an interview, we will need to provide your name, email address, and a contact phone number. This information will not be shared with the Government of Canada department organizing this research. I assure you it will be kept strictly confidential. Can you please confirm your name and contact information for me?

    First name
    Last Name
    Email
    Cell phone number
    Other phone number

If the respondent refuses to give his/her first or last name or phone number, please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the research project. If they still refuse THANK & TERMINATE.

[FOR THOSE INTERESTED IN THE PHASE 2 SURVEY] The second phase of research will involve a 15-minute survey that will be conducted mid-February through March 2021. We will be conducting the survey and will follow up with you at a later date to schedule a date/time and your preference to complete either online, via telephone or videoconference.

APPENDIX B: QUALITATIVE METHODOLOGY REPORT

Methodology

In the initial phase of qualitative research, we conducted forty (40) in-depth interviews between January 12th and February 12th, 2021. Of those interviews, thirty-nine (39) were conducted with people living with dementia; seven (7) participated in the interview alone while 32 participated with the support of a caregiver. Only one interview was conducted with a caregiver alone. In terms of regional representation, interviews were conducted with interviewees in Atlantic Canada (2), Quebec in French (10), Ontario (16), Manitoba (4), Alberta (4), and British Columbia (4). As Leger's panel does not include any panelists from Canada's territories, no interviews were conducted with northern Canadians. Interviewees were offered the choice to complete the interview by telephone or video conference; three (3) interviews were conducted by video while the rest were conducted by telephone. Interviewees (people living with dementia as well as their caregivers) were offered an honorarium of $125 as a thank you for their time.

Recruitment

Participants were recruited using a screening questionnaire (included in Appendix C).

All participants were recruited from our data collection firm, Leger's, proprietary panel. The target groups were people living with dementia and/or their caregivers (current or former). Additionally, we sought a good mix of gender and region though no firm quotas were set.

Moderation

Four interviewers were used to conduct the in-depth interviews: Stephanie Constable (24), Doug Anderson (11), Hilary Martin (3) and Cassie Grenier (2). Stephanie conducted in-depth interviews in English (14) and in French (10) and Doug, Hilary and Cassie conducted in-depth interviews in English.

A note about interpreting qualitative research results

It is important to note that qualitative research is a form of scientific, social, policy, and public opinion research. In-depth interview research is designed to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

Reporting

Except where specifically identified, the findings represent the combined results regardless of target group, location or language (English and French). Quotations used throughout the report are selected on the sole basis of bringing the report to life and providing unique verbatim commentary from the participants.

Glossary of terms

The following is a glossary of terms which explains the generalizations and interpretations of qualitative terms used throughout the report. These phrases are used when groups of participants share a specific point of view and emerging themes can be reported. Unless otherwise stated, it should not be taken to mean that the rest of participants disagreed with the point; rather others either did not comment or did not have a strong opinion on the question.

Generalization	Interpretation
Few	*Few* is used when less than 10% of participants have responded with similar answers.
Several	*Several* is used when fewer than 20% of the participants responded with similar answers.
Some	*Some* is used when more than 20% but significantly fewer than 50% of participants respondents with similar answers.
Many	*Many* is used when nearly 50% of participants responded with similar answers.
Majority/Plurality	*Majority* or *plurality* are used when more than 50% but fewer than 75% of the participants responded with similar answers.
Most	*Most* is used when more than 75% of the participants responded with similar answers.
Vast majority	*Vast majority* is used when nearly all participants responded with similar answers, but several had differing views.
Unanimous/Almost all	*Unanimous* or *almost all* are used when all participants gave similar answers or when the vast majority of participants gave similar answers and the remaining few declined to comment on the issue in question.

APPENDIX C: INTERVIEW SCREENER

PHASE 1: QUALITATIVE RESEARCH (40 IN-DEPTH INTERVIEWS) **January 12-26, 2021**

- In-depth interviews with persons living with dementia
- If needed, family/friend caregivers may be involved in assisting the interviewee
- Interview to be conducted either by telephone or videoconference depending on participant preference
- Approximately 30-40 minutes in length

	Overall Incidence	Interview Targets
Male	49.9%	20
Female	50.1%	20
Atlantic Canada	5.6%	2
Quebec	27.5%	11
Ontario	37.7%	15
Manitoba/Saskatchewan	6.5%	4
Alberta	9.9%	3
British Columbia	12.8%	5
TOTAL		40

Respondent's name:
Respondent's phone number: (cell)
Respondent's phone number: (work)
Respondent's email:

Interviewer:
Date:
Validated:

Hello, my name is ________________ and I'm calling on behalf of Earnscliffe, a national public opinion research firm. We are following up with you regarding a survey you conducted with Legerweb in which you indicated you would be interested in participating in an important research study being conducted on behalf of the Government of Canada.

Health Canada and the Public Health Agency of Canada would like to build on existing research to continue to work towards their goals of: eliminating stigma associated with dementia; promoting measures that create safe and supportive dementia inclusive communities; and, addressing the importance of access to quality care for those living with dementia.
To do so, they have retained Earnscliffe Strategy Group to conduct an important research study that will span several months. We are reaching out regarding the one-on-one, 40-minute interviews led by a research professional. The questions would be provided in advance.

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. But before we schedule an interview, we need to ask you a few questions to ensure that we get a good mix and variety of people. May I ask you a few questions? This will only take about 5 minutes.

Yes	CONTINUE
No	THANK AND TERMINATE

READ TO ALL: "This call may be monitored for quality control and evaluation purposes.
ADDITIONAL CLARIFICATION IF NEEDED:

- To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;
- To assess my (the interviewer) work for performance evaluation;
- To ensure that the questionnaire is accurate/correct;
- If the call is recorded, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all recordings are destroyed after the evaluation.
- The personal information you provide is governed in accordance with the *Privacy Act* and we will only collect the minimum relevant information we need to complete discussion groups.
- Your views, opinions and feedback are personal information. The personal information you provide in this questionnaire will be collected, used, retained and disclosed by Health Canada in accordance with the *Privacy Act* and is being collected under the authority of section 4 of the *Department of Health Act*.
- In addition to protecting your personal information, the *Privacy Act* gives you the right to request access to and to correct your personal information. For more information about these rights, or about our privacy practices, please contact Health Canada's Privacy Management Division at 613-948-1219 or hc.privacy-vie.privee.sc@canada.ca. You also have the right to file a complaint with the Privacy Commissioner of Canada if you think your personal information has been handled improperly.
- Your participation is voluntary and you are free to withdraw, at any time.

S1. Do you or any member of your household work for…

	Yes	**No**
Advertising or market research	1	2
The media (i.e. TV, radio, newspapers)	1	2
A public relations company	1	2
An online media company or as a blog writer	1	2
The government, whether federal, provincial or municipal	1	2
An organization involved in caring for or advocating for persons living with dementia	1	2

IF "YES" TO ANY OF THE ABOVE, THANK AND TERMINATE.

[*NOTE TO INTERVIEWER*: Please refer to the list for participant identification. Each is either a Person Living with Dementia OR a Caregiver of a person living with dementia. Please refer to the questioning for each audience].

PERSONS LIVING WITH DEMENTIA:

S2. Can you please confirm that you have been diagnosed with dementia? Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.

Yes	1
No (Proceed to Q22 for Caregiver)	2

S3. When were you diagnosed with dementia?

Within the past year	1
1-2 years ago	2
3-5 years ago	3
6 or more years ago	4

S4. Which type of dementia were you diagnosed with?

Alzheimer's Disease	1
Vascular dementia	2
Lewy body dementia	3
Frontotemporal dementia	4
Other (i.e., mixed dementias)	5

S5. How would you characterize the disease severity?

Mild	1
Moderate	2
Advanced	3

S6. **DO NOT ASK** – NOTE GENDER

Male	1
Female	2
Prefer not to identify as either male or female	3

S7. Could you please tell me which of the following age categories you fall in to? Are you...

18-24 years	1
25-29 years	2
30-34 years	3
35-44 years	4
45-54 years	5
55-64 years	6
65-74 years	7
75-84 years	8
85-94 years	9
95+ years	10
Prefer not to answer	99

S8. What is your current employment status?

Working full-time	1
Working part-time	2
Self-employed	3
Retired	4
Unemployed	5
Student	6
Other	7
Prefer not to answer	9

S9. Which of the following categories best describes your total household income? That is, the total income of all persons in your household combined, before taxes [READ LIST]?

Under $20,000	1
$20,000 to under $40,000	2
$40,000 to under $60,000	3
$60,000 to under $80,000	4
$80,000 to under $100,000	5
$100,000 to under $150,000	6
$150,000 or more	7
Prefer not to answer	9

S10. What is the highest level of education that you have completed?

Some high school only	1
Completed high school	2
Some college/university	3
Completed college/university	4
Post-graduate studies	5
Prefer not to answer	9

S11. What is your ethnic background? **DO NOT READ** *[GRID] (ENSURE GOOD MIX)*

Caucasian	1
Chinese	2
South Asian (i.e., East Indian, Pakistani, etc.)	3
Black	4
Filipino	5
Latin American	6
Southeast Asian (i.e., Vietnamese, etc.)	7
Arab	8
West Asian (i.e., Iranian, Afghan, etc.)	9
Korean	10
Japanese	11
Indigenous (First Nations, Métis, or Inuit)	12
Other (please specify)	13
Prefer not to answer	9

S12. What is your marital status?

Married	1
Living common law (i.e., two people who live together as a couple but who are not legally married to each other)	2
Never married (not living common law)	3
Separated (not living common law)	4
Divorced (not living common law)	5
Widowed (not living common law)	6
Other	7
Prefer not to answer	9

S13. Do you consider yourself to be…?

Heterosexual (straight)	1
Homosexual (lesbian or gay)	2
Bisexual	3
Other	4
Prefer not to answer	9

INVITATION:

S14. The in-depth interviews will take place between January 12 and 26, 2021 and will last approximately 40 minutes. The interview will be led by a research professional. You would receive an honorarium of $125 for your time. Would you be interested in participating?

Yes	1
No	2

S15. [IF YES AT QS14] Would you prefer to do the interview alone or would you prefer to participate in the interview with the support of a care partner or family member?

Alone	1
With a care partner or family member	2

S16. [IF NO AT QS14] We would very much like to include your views in our research. Would you prefer to participate in the interview with the support of a care partner or family member?

Yes	1	
No	2	THANK AND TERMINATE

S17. Would you prefer to do the interview by telephone or videoconference?

Telephone	1
Videoconference	2

S18. Have you participated in a research interview, discussion or focus group before?

Yes	1	
No	2	SKIP TO S34

S19. When was the last time you participated in a research interview or discussion group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE

S20. How many of these sessions have you attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE

S21. And what was/were the main topic(s) of discussion in those groups?

IF RELATED TO DEMENTIA OR ALZHEIMERS, THANK AND TERMINATE

CARE PARTNER/CAREGIVER:

S22. Can you please confirm that you provide or have provided care and/or assistance to a person living with dementia in the last 5 years? Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.

Care can include assistance with financial affairs, activities of daily living (ex. cooking, cleaning) and general health care/health monitoring (ex. helping administer medication or scheduling medical appointments).

Yes	1
No	2

[IF NO, PLEASE THANK AND TERMINATE]

S23. When was the person you care for diagnosed with dementia?

Within the past year	1
1-2 years ago	2
3-5 years ago	3
6 or more years ago	4

S24. To the best of your knowledge, which type of dementia were they diagnosed with?

Alzheimer’s Disease	1
Vascular dementia	2
Lewy body dementia	3
Frontotemporal dementia	4
Other (i.e. mixed dementias)	5

S25. How would you characterize the severity of the disease?

Mild	1
Moderate	2
Advanced	3

The next series of questions are for analytical purposes. Please answer these, to the best of your ability, about the person for whom you provide care and/or assistance.

S26. Could you please tell me the gender they identify with?

Male	1
Female	2
Prefer not to identify as either male or female	3

S27. Could you please tell me which of the following age categories they fall in to? Are they...

18-24 years	1
25-29 years	2
30-34 years	3
35-44 years	4
45-54 years	5
55-64 years	6
65-74 years	7
75-84 years	8
85-94 years	9
95+ years	10
Don’t know/Prefer not to answer	99

S28. What is their current employment status?

Working full-time	1
Working part-time	2
Self-employed	3
Retired	4
Unemployed	5
Student	6
Other	7
Don’t know/Prefer not to answer	9

S29. Which of the following categories best describes their total household income? That is, the total income of all persons in their household combined, before taxes [READ LIST]?

Under $20,000	1
$20,000 to under $40,000	2
$40,000 to under $60,000	3
$60,000 to under $80,000	4
$80,000 to under $100,000	5
$100,000 to under $150,000	6
$150,000 or more	7
Don’t know/Prefer not to answer	9

S30. What is the highest level of education that they completed?

Some high school only	1
Completed high school	2
Some college/university	3
Completed college/university	4
Post-graduate studies	5
Don’t know/Prefer not to answer	9

S31. What is their ethnic background? **DO NOT READ** *[GRID] (ENSURE GOOD MIX)*

Caucasian	1
Chinese	2
South Asian (i.e., East Indian, Pakistani, etc.)	3
Black	4
Filipino	5
Latin American	6
Southeast Asian (i.e. Vietnamese, etc.)	7
Arab	8
West Asian (i.e. Iranian, Afghan, etc.)	9
Korean	10
Japanese	11
Indigenous (First Nations, Métis, or Inuit)	12
Other (please specify)	13
Don’t know/Prefer not to answer	99

S32. What is their marital status?

Married	1
Living common law (i.e., two people who live together as a couple but who are not legally married to each other)	2
Never married (not living common law)	3
Separated (not living common law)	4
Divorced (not living common law)	5
Widowed (not living common law)	6
Other	7
Don’t know/Prefer not to answer	9

S33. Do you think they consider themselves to be…?

Heterosexual (straight)	1	
Homosexual (lesbian or gay)	2	
Bisexual	3	
Other	4	
Don’t know/Prefer not to answer	9	

INVITATION:

S34. The in-depth interviews will take place between January 12 and 26, 2021 and will last approximately 40 minutes. The interview will be led by a research professional. Interviewees would receive an honorarium of $125 for their time. Do you think the person you care for would be interested in participating? The questions will be provided in advance.

Yes	1	
No	2	

S35. Would they prefer and/or be capable doing the interview alone or do you think they would prefer to participate in the interview with your support?

Alone	1	
With my support	2	

S36. Would they prefer to do the interview by telephone or videoconference?

Telephone	1	
Videoconference	2	

S37. Have you/they participated in a research interview, discussion or focus group before?

Yes	1	
No	2	SKIP TO P1

S38. When was the last time you/they participated in a research interview or discussion group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE

S39. How many of these sessions have you/they attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE

S40. And what was/were the main topic(s) of discussion in those groups?

IF RELATED TO DEMENTIA OR ALZHEIMERS, THANK AND TERMINATE

[ASK ALL]

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing the session moderator with a list of respondents' names and profiles (screener responses) so that they can confirm interviewees. This information will not be shared with the Government of Canada department organizing this research. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	GO TO P1A

We need to provide the session moderator with the names and background of the people participating because only the individuals invited are allowed in the session and the moderator must have this information for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I've explained this, do I have your permission to provide your name and profile to the moderator?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the interview will be produced for research purposes. The recordings will be used only by the research professional to assist in preparing a report on the research findings and will be destroyed once the report is completed.

Do you agree to be recorded for research purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researcher needs this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

P3) Employees from the Government of Canada may observe the interviews (via recording).

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	GO TO P3A

P3a) It is standard qualitative procedure to invite clients, in this case, Government of Canada employees, to observe the research. They will be there simply to hear your opinions first hand although they may take their own notes and confer with the moderator on occasion to discuss whether there are any additional questions to ask the interviewees.

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	THANK & TERMINATE

As I mentioned earlier, the interviews will be approximately 40 minutes and will take place between January 12 and 26, 2021. The questions will be provided in advance.

Can I confirm your contact information so that we can send you the login details for the interview.

We ask that you login a few minutes early to be sure you are able to connect and to test your sound (speaker and microphone). If you require glasses for reading, please make sure you have them handy as well.

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at **[INSERT PHONE NUMBER]** at our office. Please ask for **[NAME].** Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the interview or contact you should there be any changes, can you please confirm your name and contact information for me?

First name
Last Name
Email
Cell phone number
Other phone number

If the respondent refuses to give his/her first or last name, email or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the discussion group. If they still refuse THANK & TERMINATE.

APPENDIX D: INTERVIEW GUIDE

Name:
Date/Time:
Conference Login:
Interview conducted by:

Thank you for agreeing to take part in this research project on behalf of Health Canada and the Public Health Agency of Canada. The research will be used to help the Public Health Agency of Canada develop activities to support and improve the lives of those living with dementia.

As a reminder:

- There are no right or wrong answers, so please speak as openly and frankly about opinions.
- Results are confidential. Your name is anonymous and your views, as well as those of others participating in the research, are compiled into a report that will provide feedback to Health Canada and the Public Health Agency of Canada.
- We will be recording the interview for reporting purposes as it is difficult to take notes and lead the discussion at the same time. With your approval, we would also like to share the recordings with Health Canada and the Public Health Agency of Canada so they can hear your views first hand.
    - Do you approve of us recording the interview?
    - Do you approve of us sharing the recording with Health Canada and the Public Health Agency of Canada?
- The interview will last approximately 45 minutes.

We really appreciate you taking the time to talk with us today and share your experiences. Your views and opinions are extremely important. Feel free to stop me at anytime for a break or if you have any questions at all.

Warm-up/Background (5 minutes)

I would like to begin by asking a few questions to help me better understand your dementia diagnosis and living arrangement.

- When we reached out to invite you to participate in this research, you indicated that you were diagnosed with dementia [insert # of years] years ago and that you were diagnosed with [insert type of dementia].
- Do you have any additional health conditions?
    - If yes, what are they?
    - Do you feel that these additional health conditions are effectively managed?
- Where are you living now – at home alone, at home with a caregiver, in long term care, etc.?
    - Are you happy/comfortable where you live? Why or why not?

Support Systems (15 minutes)

FAMILY/FRIENDS

- Do you have family or friends nearby?
  - How regularly do you talk with/visit with/see them? How do you communicate with them (e.g., face to face, phone calls, video, text, email)?
  - How has your visiting with family and friends changed since the COVID-19 pandemic?
  - How would you describe your circle of family and friends – close, supportive, not too involved?
  - Have your interactions or relationships with family and friends changed since your dementia diagnosis? *[IF YES]* How so?

- Do you have a caregiver? *A caregiver is defined as a person who provides care and support to a person with dementia, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbour or volunteer. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning*.
  - *[IF YES]* What is your relationship to your caregiver?
  - How would you describe your relationship with your caregiver?

PAID SUPPORT

- Do you pay out of pocket for care and support provided by, for example, personal care workers or other health professionals?
  - What types of care and support?
  - How important are these supports to your daily life?

COMMUNITY

- Prior to the COVID-19 pandemic, did you feel that the community that you reside in supports your ability to remain involved/engaged in:
  - Social activities (e.g., clubs, exercise programs, worship services);
  - General activities that you engage in on a daily basis (e.g., grocery shopping, banking, restaurants); and,
  - Mobility/transportation (e.g., ensuring that you can safely get from one place to another)?

    - *[IF YES]* How does it support you?
    - *[IF NO]* What is making it difficult for you to stay engaged?

- Are you aware of any services and benefits available to assist people living with dementia (e.g. support groups, federal/provincial benefits, etc.?

  [IF YES]
  - Do you use any of these? Why or why not?
  - What are they?
  - Have any of these services/benefits been disrupted due to COVID-19 pandemic?
  - What has been the impact of the disruption on your quality of life?

  [IF NO]
  - Have you tried seeking out any services and benefits? Why or Why not?

- If you were working at the time of diagnosis, did you feel that your employer was / is equipped or able to support you in continuing to work as long as you wanted to?
  - *[IF YES]* How did your workplace support you?
  - *[IF NO]* Why do you think your workplace was unable to support you?

Perceptions of Quality of Life (20 minutes)

- How would you define quality of life?
- How would you describe your quality of life before the COVID-19 pandemic (i.e., before March 2020?
- How much has your quality of life changed since the COVID-19 pandemic? In what ways has your quality of life changed?
- Has your own definition of what is important to quality of life changed since being diagnosed with dementia? If yes, in what ways?
- Are there some aspects of your life or routine that you believe you can no longer take part in because of your dementia diagnosis? What are they? Please describe.
- What would you say are the main factors that most **positively** impact your quality of life (e.g. health, family, finances, etc.)?
- What are the main factors that most **negatively** impact your quality of life (e.g. health, family, finances, etc.)?
- Other than a cure or change in your diagnosis, what kinds of changes would make the biggest difference in your quality of life? Why?
  - How would that improve your quality of life?

Conclusion (5 minutes)

This wraps up all of the formal questions I had for you today.

- Before we conclude, do you have any final thoughts and/or advice you would like to pass along?
- Would you be willing to share your contact information with the Public Health Agency of Canada for participation in future work on dementia?

We really appreciate you taking the time to speak with us today. Your input will be very helpful to help the Public Health Agency of Canada develop activities to support and improve the lives of those living with dementia.

APPENDIX E: QUANTITATIVE METHODOLOGY REPORT

Survey Methodology

Earnscliffe Strategy Group's overall approach for this study was to conduct a telephone/videoconference survey of 556 people living with dementia and/or their caregiver. A detailed discussion of the approach used to complete this research is presented below.

Questionnaire Design

The questionnaire for this study was designed by Earnscliffe, in collaboration with PHAC, and provided for fielding to Leger. The survey was offered to respondents in both English and French and completed based on their language preference. Respondents could not skip any of the questions as all questions required a response before continuing to the next question. However, for every question, respondents were provided with the option to explicitly indicate they prefer not to answer.

Sample Design

The sampling plan for the study was designed by Earnscliffe in collaboration with PHAC. The quantitative phase involved an online/telephone survey (chosen by each respondent) of 556 people living with dementia and/or their caregivers. Recruitment for the survey was conducted using our data collection partner, Leger's, proprietary online panel. As this is a hard-to-reach target group, a pre-screening survey was utilized to identify eligible respondents. All respondents were recruited from this collection of pre-screened individuals and all participants in the first wave also took part in the survey. Firm quotas were not set, however, we expected respondents would be a mix of ages and have representation across Canada.

Data Collection

The original telephone/teleconference survey of 556 people living with dementia and/or their caregivers was conducted from March 4th-23rd, 2021 in English and in French. All survey respondents were recruited by Leger using their proprietary online panel. The return to sample survey was conducted with 458 people living with dementia and/or their caregivers from May 13th-June 3rd, 2021, and was conducted in English and in French.

Data Cleaning

A thorough review of the data was undertaken following data collection. While this process is normal, the data was particularly scrutinized due to the sample composition and the complexity of the approach. That is, people living with dementia were a challenging target group to interview in Phase 1 due to varying degrees of understanding and having confidence that the caregivers did indeed respond to the survey as if they were the person living with dementia.

Following the initial survey, demographic results were not necessarily consistent with what is known about people living with dementia (e.g., younger in age). A hypothesis was made that in some cases the caregiver aiding the PLWD had answered the demographic questions about themselves instead of the person living with dementia. To confirm the integrity of the results and to gather the proper demographic information, Health Canada and PHAC in collaboration with Earnscliffe, made the decision to return to the sample (RTS) with a follow up demographic survey.

Once the RTS was complete, Earnscliffe, PHAC reviewed all the data collected a final time. In most cases, the RTS confirmed the hypothesis, and RTS responses were used as the final demographic data. However, in some cases, a determination was made to remove age and age at diagnosis data from the response due to the inability to confirm which responses were valid, or if there were age/diagnosis discrepancies we could not otherwise explain (n=50). For the cases where the original responses were consistent with what is known about the target group and the RTS was anomalous (e.g., a Caregiver answered the RTS questions instead of the person living with dementia as in the original survey), the original demographic data was used instead of the RTS demographic data (n=23). Finally, all respondents from the original survey who did not complete the RTS were included in the final data.

Reporting

Bolded results presented in this report show that the difference between the target groups analysed are significantly higher than results found in other columns in same demographic analysis. In the text of the report, unless otherwise noted, differences highlighted are statistically significant at the 95% confidence level. The statistical test used to determine the significance of the results was the Z-test.

Due to rounding, results may not always add to 100%.

Quality Controls

Leger's panel is actively monitored for quality through a number of approaches (digital fingerprinting, in-survey quality measures, incentive redemption requirements, etc.) to ensure that responses are only collected from legitimate Canadian panel members. For both the initial and return to sample surveys, the survey link is reviewed multiple times before a pre-test is conducted in both languages. The pre-test data is thoroughly reviewed, and any changes are made before another test of the links and full-launch of the survey.

Results

FINAL DISPOSITIONS – PRE-SCREEN SURVEY

A total of 34,484 individuals entered the online survey, of which 1,481 qualified as eligible and completed the survey. The response rate for this survey was 33.6%.

Total Entered Survey	**34,484**
Completed	1,481
Not Qualified/Screen out	32,397
Over quota	0
Suspend/Drop-off	606

Unresolved (U)	**66,431**
Email invitation bounce-backs	474
Email invitations unanswered	65,957

In-scope - Non-responding (IS)	**606**
Non-response from eligible respondents	N/A
Respondent refusals	N/A
Language problem	N/A
Selected respondent not available	N/A
Qualified respondent break-off	606
In-scope - Responding units (R)	**33,878**
Completed surveys disqualified – quota filled	0
Completed surveys disqualified – other reasons	32,397
Completed surveys	1,481
Response Rate = R/(U+IS+R)	33.6%

FINAL DISPOSITIONS – ONLINE/TELEPHONE SURVEY

A total of 1,490 individuals were invited to take part in the online/telephone survey, of which 556 completed the initial survey. All potential respondents had been pre-screened by Leger in advance of the survey to measure feasibility of the data collection. The response rate for this survey was 28.1%.

Total Entered Survey	738
Completed	556
Not Qualified/Screen out	67
Over quota	0
Suspend/Drop-off	115

Unresolved (U)	717
No answer	717
In-scope - Non-responding (IS)	877
Non-response from eligible respondents	717
Respondent refusals	10
Language problem	0
Selected respondent not available	35
Qualified respondent break-off	115

In-scope - Responding units (R)	623
Completed surveys disqualified – quota filled	0
Completed surveys disqualified – other reasons	67
Completed surveys	556
Response Rate = R/(U+IS+R)	28.1%

FINAL DISPOSITIONS – RETURN TO SAMPLE

All 556 survey participants were invited to take part in the return to sample survey, of which 481 completed the survey. The response rate for the return to sample survey was 76.7%.

Total Entered Survey	485
Completed	481
Not Qualified/Screen out	0
Over quota	0
Suspend/Drop-off	4

Unresolved (U)	71
No answer	71
In-scope - Non-responding (IS)	75
Non-response from eligible respondents	71
Respondent refusals	0
Language problem	0
Selected respondent not available	0
Qualified respondent break-off	4
In-scope - Responding units (R)	481
Completed surveys disqualified – quota filled	0
Completed surveys disqualified – other reasons	0
Completed surveys	481
Response Rate = R/(U+IS+R)	76.7%

NONRESPONSE

Respondents for the telephone/videoconference survey were selected from among those who have volunteered to participate in online surveys by joining an online opt-in panel. The notion of nonresponse is more complex than for random probability studies that begin with a sample universe that can, at least theoretically, include the entire population being studied. In such cases, nonresponse can occur at a number of points before being invited to participate in this particular survey, let alone in deciding to answer any particular question within the survey.

MARGIN OF ERROR

Respondents for the telephone/videoconference survey were selected from among those who have volunteered to participate/registered to participate in online surveys. Because the sample is based on those who initially self-selected for participation in the panel, no estimates of sampling error can be calculated. The results of such surveys cannot be described as statistically projectable to the target population. The treatment here of the non-probability sample is aligned with the Standards for the Conduct of Government of Canada Public Opinion Research for online surveys.

SURVEY DURATION

The telephone/videoconference survey took an average of 10 minutes to complete. The return to sample survey took an average of 3 minutes to complete.

APPENDIX F: PRE-SCREEN QUESTIONNAIRE

1. GENDER

Male	1
Female	2
Prefer not to identify as either male or female	3

2. In what year were you born?

[INSERT YEAR. IF YOUNGER THAN 18 YEARS (born 2002 or earlier) OR PREFER NOT TO SAY, *TERMINATE]

3. Which province or territory do you live in?

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

4. Do you, or does anyone in your family or household, work in any of the following areas?

Advertising or market research	1
The media (i.e. TV, radio, newspapers)	2
A public relations company	3
An online media company or as a blog writer	4
The federal, provincial or municipal government in marketing, advertising, public opinion research, media relations, and/or communications	5
An organization involved in caring for or advocating for persons living with dementia	6
None of the above	7
Prefer not to answer	9

IF SELECT ANY OF THE ABOVE, NOT ELIGIBLE: Thank you for your willingness to take part in this survey, but you do not meet the eligibility requirements of this study.

5. Which of the following, if any, have you ever been diagnosed with? (PLEASE SELECT ALL THAT APPLY)

- **Hypertension**: *Individuals with high blood pressure have hypertension. High blood pressure is systolic blood pressure at or above 140 mmHg or diastolic blood pressure at or above 90 mmHg.* 1
- **Dementia**: *Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.* 2
- **Depression**: *Major depression is a clinical term used by psychiatrists to define a time period that lasts more than two months in which a person feels worthless and hopeless.* 3
- **Diabetes:** Diabetes is a chronic condition that stems from the body's inability to sufficiently produce and/or properly use insulin which the body needs to use sugar as an energy source. 4
- **High cholesterol**: *Blood cholesterol is a natural fat. Your liver makes about 80% of the cholesterol in your body. The rest comes from animal-based foods or drinks. High cholesterol has no symptoms. Only a blood test can detect high cholesterol.* 5
- **Heart disease**: *Also known as ischemic heart disease or coronary heart disease, heart disease refers to the buildup of plaque in the heart's arteries that could lead to a heart attack, stroke, heart failure, or death.* 6
- **Insomnia**: *Insomnia is predominantly characterized by dissatisfaction with sleep and difficulties initiating or maintaining sleep, along with substantial distress and impairments of daytime functioning.* 7
- **Obesity**: *Overweight and obesity are defined as abnormal or excessive fat accumulation that presents a risk to health. A body mass index (BMI) over 25 is considered overweight, and over 30 is obese.* 8
- None of the above 9

6. **(SKIP IF '2' is selected in Q5)** Have you ever provided care and/or assistance to a friend or family member living with any of the following **within the last 5 years**? (PLEASE SELECT ALL THAT APPLY)

Care can include assistance with financial affairs, activities of daily living (ex. cooking, cleaning) and general health care/health monitoring (ex. helping administer medication or scheduling medical appointments).

- **Hypertension**: *Individuals with high blood pressure have hypertension. High blood pressure is systolic blood pressure at or above 140 mmHg or diastolic blood pressure at or above 90 mmHg.* 1
- **Dementia**: *Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.* 2
- **Depression**: *Major depression is a clinical term used by psychiatrists to define a time period that lasts more than two months in which a person feels worthless and hopeless.* 3

- **Diabetes**: *Diabetes is a chronic condition that stems from the body's inability to sufficiently produce and/or properly use insulin which the body needs to use sugar as an energy source.* 4
- **High cholesterol**: *Blood cholesterol is a natural fat. Your liver makes about 80% of the cholesterol in your body. The rest comes from animal-based foods or drinks. High cholesterol has no symptoms. Only a blood test can detect high cholesterol.* 5
- **Heart disease**: *Also known as ischemic heart disease or coronary heart disease, heart disease refers to the buildup of plaque in the heart's arteries that could lead to a heart attack, stroke, heart failure, or death.* 6
- **Insomnia**: *Insomnia is predominantly characterized by dissatisfaction with sleep and difficulties initiating or maintaining sleep, along with substantial distress and impairments of daytime functioning.* 7
- **Obesity**: *Overweight and obesity are defined as abnormal or excessive fat accumulation that presents a risk to health. A body mass index (BMI) over 25 is considered overweight, and over 30 is obese.* 8
- None of the above 9

[IF RESPONDENT SELECTED "DEMENTIA" IN EITHER Q5 OR Q6, PLEASE CONTINUE. IF NOT, PLEASE THANK AND TERMINATE: Thank you for your willingness to take part in this survey, but you do not meet the eligibility requirements of this study.]

Q7 and Q8 ONLY FOR THOSE LIVING WITH DEMENTIA [Q5=DEMENTIA]

7. We are contacting you today as part of a research project on behalf of the Government of Canada to invite you to participate in a 15-minute survey that will aim to help better understand the lived experience and perceptions of the quality of life of people with dementia. You will be offered the option of conducting the survey either online, by telephone or videoconference. Would you be interested in participating?

Yes	1
No	

8. (IF NO at Q7) We would very much like to include your views in our research. Would you feel more comfortable participating in the survey with assistance from a caregiver or family member?

Yes	1
No – terminate	2

Q9, Q10, Q11 and Q12 ONLY FOR THOSE CARING OR SUPPORTING SOMEONE LIVING WITH DEMENTIA [Q6=DEMENTIA]

9. We are contacting you today as part of a research project on behalf of the Government of Canada to invite you to participate in a 15-minute survey that will aim to help better understand the lived experience and perceptions of the quality of life of people with dementia. You will be offered the option of conducting the survey either online, by telephone or videoconference. Would you be interested in participating?

   Yes
   No – terminate

10. What is your relationship to the person living with dementia for whom you provide(d) care?
    Parent / In-laws
    Spouse/Significant other
    Grandparent
    Aunt/Uncle
    Sibling
    Friend
    Other; please specify ________

11. Due to the nature of this study and the impact the results will have on the quality of life of those living with dementia, it would add great value to the research if the person living with dementia for whom you provide care participates in this survey with you. Would it be possible for both you and the person living with dementia to complete the survey together?

    Yes
    No

12. (IF NO at Q11) Thank you for your interest in participation, we will conduct the survey with you alone. For information purposes, can you explain why you will not be able to participate with the person living with dementia? OPEN END

13. Thank you for your time and your interest in participating in this important research study! Can you confirm if you prefer to conduct the survey online, by telephone or videoconference?

    Online: *Completed via a link sent to your email address much like this survey*
    Telephone: *An interviewer from our call centre will conduct the survey over the phone with you*
    Videoconference: *An interviewer will conduct the survey using an application (Zoom, Microsoft Teams, etc.) where you will be able to see the person you are speaking with and they will see you; a webcam is required for this method*

14. Would you like to receive the questionnaire in advance to prepare for your interview?

    Yes
    No

15. (IF ONLINE IN Q13) Can you please confirm your first name, last name, and email address in order for us to send you the invitation to participate in the survey?

    First name
    Last name
    Email
    Email confirm

16. (IF TELEPHONE OR VIDEOCONFERENCE in Q13) Can you please confirm your first name, last name and telephone number where we can reach you for the survey?

    First name
    Last name
    Phone number
    Phone confirm

17. Thank you for your interest in this study! We would like you to please confirm the following information: (terminate if no to any of the below)

    IF PERSON LIVING WITH DEMENTIA
    I have been diagnosed and am currently living with dementia Yes/No
    I am willing to participate in a 15-minute survey (pipe in either: online, by telephone, on videoconference, based on Q13) Yes/No
    (IF Q8 = yes) I will take part in the survey with the assistance from a caregiver or family member Yes/No
    The personal information I provided is correct: (Pipe in information from Q14 or Q15) Yes/No

    IF CAREGIVER
    I am currently, or have provided care within the last 5 years, to someone living with dementia outside of a work setting Yes/No
    I am willing to participate in a 15-minute survey (pipe in either: online, by telephone, on videoconference, based on Q13) Yes/No
    (IF Q11 = yes) I will take part in the survey **together** with the person living with dementia Yes/No
    The personal information I provided is correct: (Pipe in information from Q14 or Q15) Yes/No

ONLINE IN Q13: Thank you for agreeing to participate in this study! You will receive an email with the link to participate in the coming weeks.

TELEPHONE IN Q13: Thank you for agreeing to participate in this study! An interviewer will be calling you in the coming weeks to conduct your telephone survey!

VIDEOCONFERENCING IN Q13: Thank you for agreeing to participate in this study! An interviewer will be calling you in the coming weeks to schedule a time to conduct the survey!

APPENDIX G: ONLINE QUESTIONNAIRE

Email Invitation

LA VERSION FRANÇAISE SUIT

Earnscliffe Strategy Group, in collaboration with Leger Marketing, has been hired to administer a survey on behalf of the Government of Canada. The purpose of the study is to better understand the factors that contribute to the quality of life of Canadians living with dementia informed by lived experience.

This survey will take about 15 minutes to complete. Your participation in the study is voluntary and completely confidential. All your answers will remain anonymous and will be combined with responses from all other respondents.

If you have any questions about the survey or if you encounter any difficulties, please email [INSERT EMAIL CONTACT].

To begin, please click on the link below.
[URL]

Online Introduction

Background information

This research is being conducted by Earnscliffe Strategy Group, a Canadian public opinion research firm on behalf of Health Canada and the Public Health Agency of Canada (PHAC).

The research will be used to help the Public Health Agency of Canada develop and support activities that improve the lives of those living with dementia.

How does the survey work?

- You are being asked to offer your opinions and experiences.
- We anticipate that the survey will take 15 minutes to complete.
- Your participation in the survey is completely voluntary.
- Your responses are confidential.
- Your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada.

What about your personal information?

- The personal information you provide to Health Canada (HC) and the Public Health Agency of Canada (PHAC) is governed in accordance with the Privacy Act and is being collected under the authority of section 4 of the Department of Health Act in accordance with the Treasury Board Directive on Privacy Practices. We only collect the information we need to conduct the research project.
- **Purpose of collection**: We require your personal information such as demographic information to better understand the topic of the research. However, your responses are always combined with the responses of others for analysis and reporting; you will never be identified.
- **For more information:** This personal information collection is described in the standard personal information bank Public Communications – PSU 914, in Info Source, available online at infosource.gc.ca.

- **Your rights under the *Privacy Act*:** In addition to protecting your personal information, the *Privacy Act* gives you the right to request access to and correction of your personal information. For more information about these rights, or about our privacy practices, please contact Health Canada at privacy-vie.privee@hc-sc.gc.ca. You also have the right to file a complaint with the Privacy Commissioner of Canada if you think your personal information has been handled improperly.

What happens after the online survey?
The final report written by Earnscliffe Strategy Group will be available to the public from Library and Archives Canada (http://www.bac-lac.gc.ca/).

If you have any questions about the survey, you may contact Earnscliffe at research@earnscliffe.ca or PHAC at phac.phacdementiapolicyaspcpolitiquessurlademence.aspc@canada.ca.
Your help is greatly appreciated, and we look forward to receiving your feedback.

[CONTINUE TO Q1]

Telephone/Video Introduction

Background information
This research is being conducted by Earnscliffe Strategy Group, a Canadian public opinion research firm on behalf of Health Canada and the Public Health Agency of Canada (PHAC).

The research will be used to help the Public Health Agency of Canada develop and support activities to improve the lives of those living with dementia.

Your participation in the study is voluntary and completely confidential. All your answers will remain anonymous and will be combined with responses from all other respondents.

May we begin?

[CONTINUE TO Q1]

Streaming

Please note that all questions should be answered from the perspective of a person living with dementia, even if the respondent is someone helping the person living with dementia to respond or responding independently on their behalf.

INTERVIEWER NOTE: When necessary, remind participants of the need for the responses to be from the perspective of the person living with dementia.

1. Which of the following applies?

I am a person living with dementia	ASSIGN TO PLWD
I am helping a person living with dementia complete this survey	ASSIGN TO PLWD+
I am doing this survey without the presence of a person living with dementia	ASSIGN TO CAREGIVER

2. [CAREGIVERS ONLY] Which of the following applies?

I am a caregiver currently providing care to a person living with dementia	1
I am a former caregiver who has provided care to a person living with dementia within the last 5 years	2
I am a former caregiver who provided care to a person living with dementia over five years ago	3

IF OPTION 3 THANK AND TERMINATE

3. [FORMER CAREGIVERS ONLY] Which of the following applies?

I was a caregiver for a person living with dementia during the period of the COVID-19 pandemic ASK COVID Qs
My caregiving for a person living with dementia ended before the COVID-19 pandemic SKIP COVID Qs

FOR PLWD+ AND CAREGIVER ONLY DISPLAY: The rest of the questions in this survey are designed to be answered by a person living with dementia. Throughout the survey, the term “you” refers to a person living with dementia, not a caregiver. Please ensure that the responses provided come directly from the person living with dementia, not the caregiver, whenever possible. When this is not possible, please ensure the response reflects the perspective of the person living with dementia to the best of your ability.

Section 1: Defining Quality of Life

4. How would you rate your quality of life?

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Prefer not to answer	98

5. Using a scale of 0 to 10, where 0 means "very dissatisfied" and 10 means "very satisfied", how do you feel about your life as a whole right now?

Very dissatisfied	0
	1
	2
	3
	4
	5
	6
	7
	8
	9
Very satisfied	10
Prefer not to answer	98

Different people value things in different ways. In other words, some people think some things are important that others may not. The next few questions explore what you value and what is important to you.

6. Thinking of your life right now, which of the following most impact your quality of life? If there is something that is missing, please provide that answer. [RANDOMIZE. SELECT ALL, ADD ONE SPECIFIED “OTHER”.]

Good physical health	1
Good mental health	2
Having frequent -- that is, weekly or more often -- support and visits with family and friends	3
Feeling like I belong to a community	4
Having a sense of purpose, that my life is useful	5
Feeling comfortable in my surroundings	6
Being able to stay in my own home as long as possible	7
Being independent in my daily living needs such as preparing my own food, laundry, or shopping	8
Being able to participate in religious or spiritual activities	9
Living with loved ones such as family and friends	10
Being able to be close to nature or enjoying the outdoors	11
Making my own decisions about my health care	12
Not having to worry about money	13
Being able to move around my community as much as I want or need	14
Other (Please specify)	15
Prefer not to answer	98

How would you rate each of the following? [RANDOMIZE]

7. Your physical health
8. Your mental health
9. Your access to the health services you need to support your health
10. Your relationship with family or friends
11. Your sleep
12. Your finances
13. Your ability to engage in your favourite hobbies and leisure activities
14. Your ability to live independently
15. Your ability to freely move around your community
16. Your ability to spend time outdoors or in nature
17. Your ability to socialize or spend time with other people

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Prefer not to say	98

18. In the last year, did you experience any of the following for an extended period of time (that is, for 2 weeks or more at a time)? [RANDOMIZE. SELECT ALL THAT APPLY.]

Feeling anxious	1
Feeling sad	2
Feeling helpless, related to a loss of independence	3
Feeling ashamed or embarrassed about my symptoms	4
Feeling isolated	5
None of the above	6
Prefer not to say	98

19. In the last year, have you experienced any of the following. [RANDOMIZE. SELECT ALL THAT APPLY.]

Experienced a transition in care such as moving between health care settings	1
Heard people make negative comments about my ability to do things	2
Had people talk to my caregiver rather than to me even though I was present	3
Had support group meetings or activities cancelled	4
Been excluded from decisions about health care or finances that affect me	5
Encountered people who focused on things I can no longer do instead of the things I can	6
Been unable to go where I needed to or wanted due to accessibility issues such as a lack of wheelchair accessible transportation	7
Had difficultly navigating a public space such as a grocery store, bus or train station	8
Had difficulty communicating my needs to others	9
None of the above	98

20. Would you say you are very comfortable, comfortable, neither comfortable nor uncomfortable, uncomfortable or very uncomfortable talking about your dementia diagnosis and symptoms with those who are not part of your close circle such as employers, community members, etc.?

Very comfortable	1
Comfortable	2
Neither	3
Uncomfortable	4
Very uncomfortable	5
Prefer not to say	98

Section 2: The COVID-19 pandemic

21. Have you read or heard anything about the COVID-19 pandemic?

Yes	1
No	2
Prefer not to answer	98

22. [IF AWARE OF COVID] What has been the impact of the COVID-19 pandemic on your quality of life?

A very negative impact	1
A somewhat negative impact	2
No noticeable impact	3
A somewhat positive impact	4
A very positive impact	5
Prefer not to answer	98

Section 3: Caregiving

The next few questions use the terms care provider and caregiver. A **care provider** is a person who provides care and support to a person with dementia, in a paid or unpaid role. Includes, but is not limited to, the following groups: caregivers, developmental service workers, first responders, health professionals and personal care workers.

A **caregiver** is defined as a person who provides care and support to a person with dementia, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbour or volunteer. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning.

23. Do you have someone who provides regular care to you where you live? [SELECT ALL THAT APPLY]

A care provider who is paid by me or someone in my household or family	1
A care provider who is paid by the health care system	2
An unpaid caregiver such as a spouse, child, or close friend	3
Prefer not to answer	98

24. [FOR THOSE WITH A CARE PROVIDER] What type of care providers do you currently have as part of your ongoing care? [SELECT ALL THAT APPLY]

Doctor	1
Nurse	2
Personal support worker	3
Developmental service worker	4
Other (SPECIFY)	5
Prefer not to answer	98

25. [FOR THOSE WITH A CARE PROVIDER] Do any of your paid care providers provide care for you in your home? [SELECT ALL THAT APPLY]

Yes	1
No	2
Prefer not to answer	98

26. [IF YES AT Q25] Do any of your paid care providers help you with any of the following? [RANDOMIZE. SELECT ALL THAT APPLY.]

General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	1
Assisted with activities of daily living such as cooking, cleaning, bathing, or dressing	2
House maintenance or outdoor work	3
Transportation	4
Assisted with financial affairs	5
Other (please specify)	6
Prefer not to answer	98

27. [FOR THOSE WITH A CARE PROVIDER] How knowledgeable do you feel the paid care providers you have are about supporting people living with dementia

Not at all knowledgeable	1
A little knowledgeable	2
Somewhat knowledgeable	3
Very knowledgeable	4
Prefer not to answer	98

[IF NO CAREGIVER OR CARE PROVIDER INDICATED AT Q23, SKIP TO Q34]

28. [FOR THOSE WITH UNPAID CAREGIVER] What is your relationship with your unpaid caregiver or caregivers. The caregiver is your… [SELECT ALL THAT APPLY.]

Spouse	1
Child	2
Child-in-law	3
Friend	4
Other (please specify)	5
Prefer not to answer	98

29. [IF AWARE OF COVID AND HAVE UNPAID CAREGIVER] Prior to the COVID-19 pandemic, did your unpaid caregiver help you with any of the following? [RANDOMIZE. SELECT ALL THAT APPLY.]

General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	1
Assisted with activities of daily living such as cooking, cleaning, bathing, or dressing	2
House maintenance or outdoor work	3
Transportation	4
Assisted with financial affairs	5
Other (please specify)	6
Prefer not to answer	98

30. [IF AWARE OF COVID AND HAVE UNPAID CAREGIVER] Prior to the COVID-19 pandemic, on average, how often did you interact with or were in contact with your unpaid caregiver, whether in person, by phone, text, email, video chat, etc.?

Daily	1
At least once a week	2
At least once a month	3
Less than once a month	4
Prefer not to answer	98

31. [IF AWARE OF COVID AND HAVE UNPAID CAREGIVER] Has COVID-19 changed how often you interact with or are in contact with your unpaid caregiver?

I see them more often	1
I see them less often	2
No change, I see them the same amount	3
Other (please explain)	4
Prefer not to answer	98

32. [IF UNAWARE OF COVID AND HAVE UNPAID CAREGIVER] Has your unpaid caregiver helped you with any of the following? [RANDOMIZE. SELECT ALL THAT APPLY.]

General health care and health monitoring such as overseeing medication usage or help administering medication or setting up appointments	1
Assisted with activities of daily living such as cooking, cleaning, bathing, or dressing	2
House maintenance or outdoor work	3
Transportation	4
Assisted with financial affairs	5
Other (please specify)	6
Prefer not to answer	98

33. [IF UNAWARE OF COVID AND HAVE UNPAID CAREGIVER] On average, how often do you interact with or are in contact with your unpaid caregiver, whether in person, by phone, text, email, video chat, etc.?

Daily	1
At least once a week	2
At least once a month	3
Less than once a month	4
Prefer not to answer	98

Demographics

The last few questions are strictly for statistical purposes. All of your answers are completely confidential.

FOR PLWD+ AND CAREGIVER ONLY DISPLAY: The questions in this survey are designed to be answered by a person living with dementia. Throughout the survey, the term “you” refers to a person living with dementia, not a caregiver. Please ensure that the responses provided come directly from the person living with dementia, not the caregiver, whenever possible. When this is not possible, please ensure the response reflects the perspective of the person living with dementia to the best of your ability.

34. Which of the following best describes where you reside?

In a private household by myself	1
In a private household with at least one other person	2
In supportive housing providing minimal to moderate support or care, such as homemaking or personal care	3
In an institution or care home providing moderate to advanced care such as hospital, nursing home, long term care, group home	4
Other (specify)	97
Prefer not to answer	98

35. What is your gender?

Male	1
Female	2
Other	3
Prefer not to answer	98

36. In what year were you born?

[INSERT YEAR]

[IF RESPONDENT DOES NOT PROVIDE BIRTH YEAR, ASK:] Which of the following age categories do you belong to?

Under 55	0
55-64	1
65-74	2
75-84	3
85+	4
Prefer not to answer	98

37. In what year were you diagnosed with dementia?
[INSERT YEAR]

[IF RESPONDENT DOES NOT PROVIDE DIAGNOSIS YEAR, ASK:] Roughly how many years ago did you receive your dementia diagnosis?

Within the past year	1
About 1 to 3 years ago	2
About 4 or 5 years ago	3
More than 5 years ago	4
Prefer not to answer	98
Don’t know	99

38. Which of the following provinces or territories do you live in?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13

39. What is the language you speak most often at home?

English	1
French	2
Other (SPECIFY)	3
Prefer not to answer	98

40. What is the highest level of education that you have completed?

Less than a high school diploma or equivalent	1
High school diploma or equivalent	2
Post-secondary such as college, university, apprenticeship, trades certificate or diploma	3
Post-graduate degree such as a Masters, PhD, LLB, or MD	4
Other (specify)	97
Prefer not to answer	98

41. How would you describe the type of community you live in?

Large urban population centre, that is, it has a population 100,000 or greater	1
Medium urban population centre, that is, it has a population of 30,000 to 99,999	2
Small urban population centre, that is, it has a population of 1,000 to 29,999	3
Rural area, that is, it has a population of less than 1,000	4
Remote area, that is you are isolated from other communities	5
Other (please explain)	6
Prefer not to answer	98

42. Do you have any of the following conditions? [SELECT ALL THAT APPLY]

Cardiovascular disease such as angina, heart attack, stroke or hypertension	1
Diabetes	2
Asthma	3
Hearing Impairment	4
Chronic bronchitis, emphysema or chronic obstructive pulmonary disease or COPD	5
Mental illness such as depression, bipolar disorder, mania or schizophrenia	6
Mobility issues such as from injuries, or arthritis	7
Developmental disability or disorder such as behavioural disorders, or learning disabilities	8
COVID-19	9
Other (please explain)	10
None of the above	11
Prefer not to answer	98

43. Do you identify as any of the following? [SELECT ALL THAT APPLY]

An Indigenous person who is First Nations	1
An Indigenous person who is Métis	2
An Indigenous person who is Inuk (Inuit)	3
A member of an ethno-cultural or a visible minority group	4
A member of the LGBTQ2 community	5
None of the above	11ß
Prefer not to answer	98

44. [IF MEMBER OF ETHNO-CULTURAL OR VISIBLE MINORITY GROUP] Of which ethno-cultural or a visible minority group or groups are you a member? [OPEN-END]

[RESPONSE}	
Prefer not to answer	98

45. Would you be willing to share your contact information with the Public Health Agency of Canada for participation in future work on dementia?

Yes [LEGER FLAG FOR FUTURE]	1
No	2

46. [IF YES TO Q45]

a. Please confirm your first and last name?
b. What is your telephone number beginning with your area code?
c. What is your email address?

[PRE-TEST ONLY ADD QUESTIONS A THRU J]

A. Did you find any aspect of this survey difficult to understand? Y/N
B. [IF A=YES] If so, please describe what you found difficult to understand.
C. Did you find the way in which of the any of the questions in this survey were asked made it difficult for you to provide your answer? Y/N
D. [IF C=YES] If so, please describe the issue with how the question was asked.
E. Did you experience any difficulties with the language? Y/N
F. [IF E=YES] If so, please describe any difficulties you had with the language.
G. Did you find any terms used within the survey confusing? Y/N
H. [IF G=YES] If so, please describe the terms you found confusing.
I. Did you encounter any other issues during the course of this survey that you would like us to be aware of? Y/N
J. [IF I=YES] If so, what are they?

This concludes the survey. Thank you for your participation!
Looking for information about living with dementia?
Visit https://www.canada.ca/dementia

APPENDIX H: RETURN TO SAMPLE QUESTIONNAIRE

A few weeks ago, you completed a survey on dementia on behalf of the Government of Canada. It appears that the demographic section at the end of the questionnaire may have confused some respondents and in order to make sure all of our information is correct, we would like you to please answer those again. These questions are asked strictly for statistical purposes. All of your answers are completely confidential.

1. [ASK ALL] Regardless of whether you completed this survey from your own perspective, helped someone else complete the survey or answered on behalf of someone, please indicate whether you personally have ever been diagnosed with dementia.

Yes, I have personally been diagnosed as having dementia	1
No, I have not personally ever been diagnosed as having dementia	2

[FOR THOSE WHO HAVE NOT BEEN DIAGNOSED AS HAVING DEMENTIA DISPLAY: When we originally had you complete the survey, we asked for the demographic profile of the person living with dementia. For the next several questions, we would like to get **<u>your</u>** profile – **<u>not</u>** the person living with dementia.]

2. [ASK ALL] Which of the following best describes where you reside?

In a private household by myself	1
In a private household with at least one other person	2
In supportive housing providing minimal to moderate support or care, such as homemaking or personal care	3
In an institution or care home providing moderate to advanced care such as hospital, nursing home, long term care, group home	4
Other (specify)	97
Prefer not to answer	98

3. [ASK ALL] What is your gender?

Male	1
Female	2
Other	3
Prefer not to answer	98

4. [ASK ALL] In which of the following age categories do you belong?

Under 55	0
55-64	1
65-74	2
75-84	3
85+	4
Prefer not to answer	98

5. [ASK ONLY THOSE WITH DEMENTIA] In which of the following age categories did you belong to when you received your dementia diagnosis?

Under 55	1
55-64	2
65-74	3
75-84	4
85+	98
Prefer not to answer	99

6. [ASK ALL] In which of the following provinces or territories do you live?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13

7. [ASK ALL] What is the language you speak most often at home?

English	1
French	2
Other (SPECIFY)	3
Prefer not to answer	98

8. [ASK ALL] What is the highest level of education that you have completed?

Less than a high school diploma or equivalent	1
High school diploma or equivalent	2
Post-secondary such as college, university, apprenticeship, trades certificate or diploma	3
Post-graduate degree such as a Masters, PhD, LLB, or MD	4
Other (specify)	97
Prefer not to answer	98

9. [ASK ALL] How would you describe the type of community you in which you live?

Large urban population centre, that is, it has a population 100,000 or greater	1
Medium urban population centre, that is, it has a population of 30,000 to 99,999	2
Small urban population centre, that is, it has a population of 1,000 to 29,999	3
Rural area, that is, it has a population of less than 1,000	4
Remote area, that is you are isolated from other communities	5
Other (please explain)	6
Prefer not to answer	98

10. [ASK ALL] Do you have any of the following conditions? [SELECT ALL THAT APPLY]

Cardiovascular disease such as angina, heart attack, stroke or hypertension	1
Diabetes	2
Asthma	3
Hearing Impairment	4
Chronic bronchitis, emphysema or chronic obstructive pulmonary disease or COPD	5
Mental illness such as depression, bipolar disorder, mania or schizophrenia	6
Mobility issues such as from injuries, or arthritis	7
Developmental disability or disorder such as behavioural disorders, or learning disabilities	8
COVID-19	9
Other (please explain)	10
None of the above	11
Prefer not to answer	98

11. [ASK ALL] Do you identify as any of the following? [SELECT ALL THAT APPLY]

An Indigenous person who is First Nations	1
An Indigenous person who is Métis	2
An Indigenous person who is Inuk (Inuit)	3
A member of an ethno-cultural or a visible minority group	4
A member of the LGBTQ2 community	5
None of the above	11ß
Prefer not to answer	98

12. [IF MEMBER OF ETHNO-CULTURAL OR VISIBLE MINORITY GROUP] Of which ethno-cultural or a visible minority group or groups are you a member? [OPEN-END]

[RESPONSE}	
Prefer not to answer	98

[THE REMAINING QUESTIONS ARE ONLY FOR THOSE WHO HAVE NOT BEEN DIAGNOSED WITH DEMENTIA.]

Now, please answer the same profile questions, but this time, please provide the responses describing the person living with dementia whom you helped complete the survey or for whom you had provided care in the past.

13. [ASK IF NOT DIAGNOSED WITH DEMENTIA] Which of the following best describes where the person living with dementia resides or last resided?

In a private household by themselves	1
In a private household with at least one other person	2
In supportive housing providing minimal to moderate support or care, such as homemaking or personal care	3
In an institution or care home providing moderate to advanced care such as hospital, nursing home, long term care, group home	4
Other (specify)	97
Prefer not to answer	98

14. [ASK IF NOT DIAGNOSED WITH DEMENTIA] What is or was the gender of the person living with dementia?

Male	1
Female	2
Other	3
Prefer not to answer	98

15. [ASK IF NOT DIAGNOSED WITH DEMENTIA] In which of the following age categories does/did the person living with dementia belong?

Under 55	0
55-64	1
65-74	2
75-84	3
85+	4
Prefer not to answer	98

16. [ASK IF NOT DIAGNOSED WITH DEMENTIA] In which of the following age categories did the person living with dementia for whom you care(d) for belong when they received their dementia diagnosis?

Under 55	0
55-64	1
65-74	2
75-84	3
85+	4
Prefer not to answer	98

17. [ASK IF NOT DIAGNOSED WITH DEMENTIA] In which of the following provinces or territories does/did the person living with dementia live?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13

18. [ASK IF NOT DIAGNOSED WITH DEMENTIA] What is the language the person living with dementia speaks/spoke most often at home?

English	1
French	2
Other (SPECIFY)	3
Prefer not to answer	98

19. [ASK IF NOT DIAGNOSED WITH DEMENTIA] What is the highest level of education that the person living with dementia completed?

Less than a high school diploma or equivalent	1
High school diploma or equivalent	2
Post-secondary such as college, university, apprenticeship, trades certificate or diploma	3
Post-graduate degree such as a Masters, PhD, LLB, or MD	4
Other (specify)	97
Prefer not to answer	98

20. [ASK IF NOT DIAGNOSED WITH DEMENTIA] How would you describe the type of community in which the person living with dementia lives/lived in?

Large urban population centre, that is, it has a population 100,000 or greater	1
Medium urban population centre, that is, it has a population of 30,000 to 99,999	2
Small urban population centre, that is, it has a population of 1,000 to 29,999	3
Rural area, that is, it has a population of less than 1,000	4
Remote area, that is you are isolated from other communities	5
Other (please explain)	6
Prefer not to answer	98

21. [ASK IF NOT DIAGNOSED WITH DEMENTIA] Does/did the person living with dementia have any of the following conditions? [SELECT ALL THAT APPLY]

Cardiovascular disease such as angina, heart attack, stroke or hypertension	1
Diabetes	2
Asthma	3
Hearing Impairment	4
Chronic bronchitis, emphysema or chronic obstructive pulmonary disease or COPD	5
Mental illness such as depression, bipolar disorder, mania or schizophrenia	6
Mobility issues such as from injuries, or arthritis	7
Developmental disability or disorder such as behavioural disorders, or learning disabilities	8
COVID-19	9
Other (please explain)	10
None of the above	11
Prefer not to answer	98

22. [ASK IF NOT DIAGNOSED WITH DEMENTIA] Does/did the person living with dementia identify as any of the following? [SELECT ALL THAT APPLY]

An Indigenous person who is First Nations	1
An Indigenous person who is Métis	2
An Indigenous person who is Inuk (Inuit)	3
A member of an ethno-cultural or a visible minority group	4
A member of the LGBTQ2 community	5
None of the above	11
Prefer not to answer	98

23. [ASK IF NOT DIAGNOSED WITH DEMENTIA AND IF MEMBER OF ETHNO-CULTURAL OR VISIBLE MINORITY GROUP] Of which ethno-cultural or a visible minority group or groups is/was the person living with dementia a member? [OPEN-END]

[RESPONSE}	
Prefer not to answer	98