



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canada

Emergency Preparedness and Response in Canada for People Living with Dementia

Final Report

Prepared for the Public Health Agency of Canada

Prepared by Narrative Research

Call-Up Number: CW2340840

Requisition Reference Number: 6D016-23-5125

Contracted Value: \$119,661.35

Contract Date: 2023-12-07

Delivery Date: 2024-02-26

POR number: 100-23

For more information, please contact: cpab_por-rop_dgcap@hc-sc.gc.ca

Ce rapport est aussi disponible en français

Emergency Preparedness and Response in Canada for People Living with Dementia

Final Report

Prepared for the Public Health Agency of Canada

Supplier Name: Narrative Research

February 2024

This public opinion research report presents the results of online focus groups/dyads and in-depth interviews conducted by Narrative Research on behalf of Health Canada and the Public Health Agency of Canada to better understand the current state of emergency preparedness and response guidance and the adequacy of measures to protect and support people living with dementia during emergency situations, with a particular focus on how to better prepare for future climate-related emergency situations. The research included a total of 25 online focus groups of various sizes, two dyad and 11 in-depth interviews conducted from January 25th to February 23rd, 2024, divided into the following categories: people living with dementia who confirmed their ability to participate, unpaid caregivers to people living with dementia, and paid care providers who care for and interact, either directly or indirectly, with people living with dementia in a professional capacity, including paid care and support personnel, first responders, and government/logistical planners. Good geographic coverage was achieved across Canada and various community sizes were represented, including large urban, small/medium size urban, and rural areas.

Cette publication est aussi disponible en français sous le titre :

Préparation et réponse aux situations d'urgence au Canada pour les personnes atteintes de démence

This publication may be reproduced for non-commercial purposes only. Prior written permission must be obtained from Health Canada. For more information on this report, please contact Health Canada at: cpab_por-rop_dgcap@hc-sc.gc.ca

Catalogue Number:

H14-621/2024E-PDF

International Standard Book Number (ISBN):

978-0-660-72308-2

Related publications (registration number: POR-100-23):

Catalogue Number H14-621/2024F-PDF (Final Report, French)

International Standard Book Number (ISBN): 978-0-660-72309-9

© His Majesty the King in Right of Canada, as represented by the Minister of Health, 2024

Table of Contents

	Page
Executive Summary.....	1
Introduction	7
Research Methodology	9
Research Findings	13
Personal Experiences with Climate-Related Emergencies	13
Impacts of Climate-Related Emergencies.....	16
Challenges and Needs During Climate-Related Emergencies	19
Tools and Resources	31
Conclusions	41
Direction	44
Appendices:	
Appendix A – Recruitment Screener	
Appendix B – Moderator’s Guides	



Executive Summary

Narrative Research Inc.

Call-Up Number: CW2340840

Requisition Reference Number: 6D016-23-5125

POR Registration Number: 100-23

Contract Award Date: 2023-12-07

Contracted Value: \$119,661.35

Background and Research Methodology

Extreme weather events are becoming more common in Canada. While this type of emergency situation can have a significant impact on anyone, it can be especially difficult for those living with dementia. The main objective of this research is to better understand the current state of emergency guidance and the adequacy of information-based measures such as training and tools to protect and support people living with dementia during climate-related emergencies.

More specifically, the research objectives are to:

- Understand the unique needs of people living with dementia and family / friend caregivers during and after emergencies.
- Gather the nature of experiences of people living with dementia and family / friend caregivers during and after emergencies, including types of challenges.
- Understand the impact of emergencies on people living with dementia including on quality of life both during and after the emergency.
- Identify resources and tools needed to protect and support the quality of life of people living with dementia during emergencies and gather assessments of their availability and effectiveness.

To achieve these objectives, a qualitative research approach was undertaken with the fieldwork conducted from January 25th to February 23rd, 2024. While the initial research plan included 28 online focus groups of various sizes, low participation rate in select audiences led to the final methodology including a combination of online focus groups, dyads (e.g. small focus group with two participants), and in-depth interviews. Specifically, the research entailed a total of 25 online focus groups across four regions including the East (ON/NB/NS/PE/NL/NU); West (MB/SK/AB/BC/YT/NT); West/Central (ON/MB/SK/AB/BC/YT/NT); and Quebec, along with two dyads and 11 in-depth interviews.

Five target audiences were included in the research, namely people living with dementia, unpaid caregivers (often friends and family), paid care providers (personal care workers, health aides, and professional care providers), first responders (including emergency responders), as well as representatives from government or community organizations and emergency response planners or logistical experts (referred to as Government/Logistical Planners in this report). Good geographic



coverage was achieved across Canada and various community sizes were represented, including large urban, small/medium urban, rural, and mixed urban, and rural areas.

Sessions were held in English with the exception of those in Quebec, which were conducted in French. Participation incentives ranged from \$150 to \$200 based on the target audience (i.e., professional care providers and people living with dementia each received \$200, while all remaining audiences each received \$150). Across all groups, a total of 171 individuals were recruited and 150 participated. One additional participant had technical issues and could not take part in the sessions but still received remuneration. Focus group length ranged from one to two hours, while the dyad and in-depth interviews lasted between 30 minutes and one hour.

The following table presents the breakdown of sessions by audience, community size, and language, in addition to the number of recruited participants per session.

Number of Online Focus Groups, Dyads and In-depth Interviews (IDIs)									
Audience	Large Urban	Large/ Medium Urban	Small/ Medium Urban	Small Urban/ Rural	Rural	Mixed Urban	Total Sessions	Total Recruits	Total Participants
	English	English	English	English	English	French			
Unpaid Caregivers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	49	45
Paid Care Providers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	48	42
First Responders	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group Quebec	5 Groups 3 IDIs	32	28
Government/ Logistical Planners	n/a	1 Group East 1 Group West	n/a	1 Dyad East 1 Group West	n/a	1 Group Quebec	4 Groups 1 Dyad 5 IDIs	27	24
People Living with Dementia	1 Dyad West	n/a	1 Mini Group East	n/a	1 IDI West/ Central	2 IDIs Quebec (French) 1 Mini Group Mixed Locations (English)	2 Mini Group 1 Dyad 3 IDIs	15	11
TOTAL							25 groups 2 dyads 11 IDIs	171	150



All participants were recruited per the specifications for the Government of Canada. Recruitment was conducted through qualitative panels stored on Canadian servers, with follow up calls to confirm the details provided and to ensure quotas were met. A referral recruitment approach was also accepted for harder-to-reach populations, following industry guidelines to ensure no participant from the same household took part in the study, and to ensure no participants knew each other in the same group.

Those currently employed in, or retired from a sensitive occupation, or who have others in their household in this situation, were excluded from the research. These sectors included marketing, marketing research, public relations, advertising, media, web development, and provincial/territorial or federal positions related to health care. All focus group participants had access to either a computer or tablet with high-speed internet and equipped with a webcam, or a smartphone, to take part in the session.

This report presents the findings from the study. Caution must be exercised when interpreting the results, as qualitative research is exploratory and cannot infer causality. Results cannot be attributed to the overall population under study.

Political Neutrality Certification

I hereby certify as a Representative of Narrative Research that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Directive on the Management of Communications. 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 _____

Margaret Brigley, CEO & Partner | Narrative Research

Date: February 26, 2024



Key Findings

The following provides key highlights from the research:

Personal Experience with Climate-Related Emergencies

Research findings suggest that during and after a climate-related emergency, people living with dementia experienced a wide range of unique challenges and corresponding needs, all of which are intrinsically linked to the condition itself. Most notably, people living with dementia face challenges related to their cognitive ability in responding to the emergency situation appropriately. While symptoms can vary significantly across individuals, many may be unable to gauge that a crisis is occurring or the severity of the crisis and the nature of implications for them personally. With a disruption in their regular routine and potential challenges being able to communicate with others and to understand information and guidance, an individual living with dementia may be much less able to cope with a climate-related emergency than others.

During times of evacuation, additional challenges may include a reluctance/hesitation to leave a familiar environment, little clarity on what to pack, a lack of urgency or understanding of the severity for why evacuation is needed, and in what timeframe an action is needed. Moving a person living with dementia to a new location also presents further challenges, most notably related to placement in an unfamiliar and potentially unsafe environment. Surroundings, contacts, and activities that are unfamiliar may present a serious test to a person living with dementia's ability to adapt to the situation and maintain current functional abilities.

Needs Identification Related to Climate-Related Emergencies – People Living with Dementia

The wide range of unique challenges experienced by those living with dementia highlight a variety of corresponding needs for the provision of care when faced with a climate-related emergency. The primary needs of those living with dementia during an emergency revolve around ensuring continuity of care, which is dependent upon ready access to current information to direct their care. This includes, but is not limited to, a clear baseline of their condition, medication listings, key contact information, and strategies to calm or support the individual when needed. In addition, people living with dementia having access to ongoing contact from primary care providers (paid or unpaid) is deemed paramount in their care provision. Throughout the emergency, there is a need for patience, reassurance and ongoing support. Clear, simple messaging is also needed to guide their actions, ideally supported by visual cues.

Needs Identification Related to Climate-Related Emergencies - Unpaid Caregivers

In addition to the significant challenges facing those living with dementia during a climate-related emergency, unpaid dementia caregivers face a range of unique challenges. Across participants, there was general agreement that unpaid caregivers often have difficulty coping with the responsibilities of providing care in the context of this type of emergency and need guidance on how to respond to the changing and increased needs of people living with dementia. Directions for preparedness are needed,



as is information on how to provide care during an emergency, such as the importance of checking in during the duration of the emergency. Unpaid caregivers may be overwhelmed and often exhibit ‘burn out’ as a result of their extended provision of unpaid care to a person living with dementia during a climate-related emergency. They are typically unaware of what resources or supports are available to assist them, as well as what financial programs might be accessible for them during and after such an emergency.

Some unpaid caregivers expressed a need for more direct physical aid, beyond just guidance. During a climate-related emergency, some had experienced staffing issues at facilities, whereby family / friend caregivers were relied upon when there were not enough paid staff to meet needs.

Impact of Climate-Related Emergency Events

Across participants, climate-related emergencies were thought to have an impact on people living with dementia, although the extent was unclear. There was a belief that the situation could be vastly different across individuals living with dementia depending on the type and severity of climate-related emergencies, their past experiences, the range and severity of symptoms experienced, their living conditions during the emergency, and the strength of their support networks. The situation of each person was considered unique and can be difficult to plan for. Nonetheless, the perception was that in many instances, climate-related emergencies can disrupt routines and cause heightened stress for people living with dementia, thus resulting in sudden worsening of their symptoms and/or exaggerated responsive behaviours. Elevated levels of stress were also reported by unpaid caregivers who have to react to the impact of the climate-related emergency on themselves in addition to increasing their support for the person they care for.

An additional impact of climate-related emergency events on people living with dementia was nutritional or other health-related factors, especially among those who live alone. This included eating expired foods during power outages, experiencing mould during floods, or forgetting to eat or drink.

Identification of Tools and Resources

There was limited awareness of existing tools and resources to support people living with dementia and unpaid caregivers during climate-related emergencies. In fact, most of the participants included in the research reported relying on their personal judgement or experiences to inform their interactions with people living with dementia. Paid care providers and first responders reported relying on training or a support network provided by their employer, although nothing specifically designed for responding to the needs of people living with dementia during climate-related emergencies is currently available. The Alzheimer Society of Canada was commonly cited as a good source of support for people living with dementia and unpaid caregivers, although it was not generally thought of as a source for providing climate-related emergency-specific resources or resources for other participants (e.g., first responders and health care professionals). Tools and resources from other sources were far less often cited and tended to be community- or province-specific.



Although few tools are currently relied upon by people living with dementia and unpaid caregivers to prepare for climate-related emergencies, there was interest in additional information and support. Most notably, it was believed that unpaid caregivers play a significant role during climate-related emergencies and should be properly informed and supported in this role.

There was a desire among unpaid caregivers for information to guide interactions with people living with dementia during emergencies, including such things as understanding how climate-related emergencies may impact people living with dementia, the signs to look for when keeping them safe and healthy during the event, how to communicate with them based on different scenarios, actions to take and avoid, where to go, who to call for assistance, and what to include in an emergency kit. Suggestions were also made to develop outreach tools to support people living with dementia and caregivers during a climate-related emergency. Examples given included a secure, centralized national vulnerable person registry to be accessed only by emergency responders or other professionals in appropriate circumstances, and a portal that centralizes information and resources of interest.

In developing tools and information specific to people living with dementia, it was felt that a multi-mode approach should be considered to allow adaptation to the breadth of dementia symptoms that exist. While online and print copies may be of use to unpaid caregivers and some people living with dementia, there was also an expressed need for short, focused videos in different languages, as well as other visual tools, and audio formats. Interactive workshops or discussion groups were believed to be of use to unpaid caregivers as they provide an opportunity for discussions with peers.

A variety of other suggestions were provided, including:

- In-person check-ins by paid health professionals with people living with dementia during the emergency.
- Raising awareness of unpaid caregivers' mental health and providing support resources for them.
- Sending regular weather reports to supportive and long-term care facilities so they can prepare for the impact of climate-related emergencies ahead of time.
- Having a hotline available that families can call to get information quickly, to avoid calling 911.
- Encouraging long-term care homes to develop climate-specific emergency preparedness plans and keep regularly updated records related to people living with dementia.
- Encouraging communities to set up a coordinated climate-related emergency response team/plan specific to people living with dementia.
- Making it easier for paid care providers and first responders to access the medical records of people living with dementia during emergencies.
- Encouraging municipalities to establish an evacuation protocol that is specific to people living with dementia.
- Ensuring long-term care homes conduct regular inspections and evacuation drills.



Introduction

Context

Dementia has an increasingly significant impact on Canadians, with close to 477,000 Canadians aged 65 years and older living with diagnosed dementia as of March 31, 2021. As this number only includes those with a formal diagnosis and aged 65 years and older, the number of people living with dementia in Canada may be higher. Moreover, with a growing and aging population, the number of Canadians living with dementia is expected to increase in future decades although the rate of growth may be influenced by a decline in the rate of newly diagnosed cases as well as prevalence in people aged 65 and older over the past several years when controlling for age.

In June 2019, Canada's national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released. It supports the vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood and effectively treated. The strategy identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers.

As part of the national objective focused on quality of life, Canada's dementia strategy encourages progress on creating dementia-inclusive communities, ensuring access to quality care, improving support for family/friend caregivers, including through access to resources and supports, and building the capacity of care providers, including through improved access to and adoption of evidence-based and culturally appropriate guidelines for standards of care. These priorities also apply to broad public emergency events, such as those that are climate-related (e.g., extreme heat or cold events, forest fire / wildfires, severe air pollution (including wildfire smoke), flooding with heavy rain and snow, heavy ice storms, severe winds, hurricanes, or tornados) with the goal of protecting and improving the quality of life of people living with dementia and caregivers during and following such events, and supporting preparedness for future such events.

Stakeholder engagement and previous public opinion research (POR) projects have highlighted a gap in guidance related to support for people living with dementia in times of emergencies. In addition, the experiences and lessons learned in the past few years during the COVID-19 pandemic and a series of climate-related emergencies have highlighted that people living with this condition are at particular risk and have unique challenges during such emergencies. People living with dementia are at increased risk during climate-related emergencies. According to a 2021 Lancet policy brief, people living in Canada with pre-existing medical conditions such as dementia face structural barriers such as frequent social isolation, less access to energy-efficient and heat-resilient housing, as well as less access to green spaces



and public transport which can all exacerbate climate-health inequities¹². As such, there is a recognized need for resources related to emergency response and preparedness that are tailored for people living with dementia.

Objectives

The primary purpose of the research is to better understand the current state of emergency preparedness and response guidance and the adequacy of measures such as training and tools to protect and support people living with dementia during and after emergency situations, with a particular focus on climate-related emergency situations, and to support preparedness for future events. Note that for the purposes of this project, emergencies were considered to be those that have a broad public / community impact. Individual, isolated emergencies (e.g., heart attack) were outside the scope of this study.

Specific research objectives include:

- Understand the unique needs of people living with dementia and family / friend caregivers during and after emergencies.
- Gather the nature of experiences of people living with dementia and family / friend caregivers during and after emergencies, including types of challenges.
- Understand the impact of emergencies on people living with dementia including on quality of life both during and after the emergency.
- Identify resources and tools needed to protect and support quality of life of people living with dementia during emergencies and gather assessments of their availability and effectiveness.

This report presents the findings of the research. It includes a description of the detailed methodology used and the detailed findings of the online focus groups, dyads, and in-depth interview discussions. The working documents are appended to the report, including the recruitment screener (Appendix A) and the moderator's guides (Appendix B).

¹ The Lancet Countdown on Health and Climate Change: Policy Brief for Canada. December 2020.
<https://policybase.cma.ca/viewer?file=%2Fmedia%2FPolicyPDF%2FPD21-01.pdf#page=1>

² The Lancet Countdown on Health and Climate Change: Policy Brief for Canada. October 2021,
https://www.cpha.ca/sites/default/files/uploads/advocacy/2021_lancet/2021_Lancet_Countdown_Canada_Policy_Brief_e.pdf



Research Methodology

Target Populations for Participants

The target populations for this research project included people living with dementia who have experienced climate-related emergencies, as well as those who have experienced climate-related emergencies in the context of supporting people living with dementia, either directly (e.g., unpaid caregiver, paid care provider, deployed as part of an emergency response) or indirectly (e.g., work in emergency response planning). Across groups, participants experienced a wide-range of climate-related emergency events (e.g., flooding, extreme heat event, wildfires, severe air pollution due to wildfire smoke, extreme cold event, ice storms, heavy snow, hurricanes).

For the purpose of the study, there were five target populations, namely:

- **Unpaid Caregivers:** Family members, friends, neighbours, and/or volunteers who provide care and support to an individual living with dementia, who are not a paid care professional or personal care worker. This support may include assisting with the activities of daily living and helping with advance care planning. A mix of gender and cultural backgrounds were included.
- **Paid Care Providers:** Paid personal care workers / health care aides (title for this occupation varies by jurisdiction), developmental service workers, and health professionals (including primary care physicians, general practitioners, nurse practitioners, geriatric care specialists, registered nurses, occupational therapists, and pharmacists).
- **First Responders:** Front-line emergency response / emergency preparedness workers, namely first responders (e.g., ambulance, fire, police, military, search and rescue).
- **Government/Logistical Planners:** Includes governments (e.g., front line response at any level of government), community organizations (e.g., public health, emergency services, non-profit organizations providing supplies such as shelter, food, and clothing during emergencies, religious/faith communities), and emergency response planners/logistical experts who may not have direct contact but who need to incorporate/do incorporate considerations for vulnerable populations into their work.
- **People Living with Dementia:** Individuals who have been diagnosed with dementia and who have the capacity to take part in an online group discussion alone or with assistance. Where needed, a caregiver assisted them during the sessions. A mix of gender and cultural backgrounds were included.



Research Approach

Although the research approach initially included 28 online focus groups of various sizes, low participation and difficulty recruiting some of the participants resulted in a revised methodology. Specifically, a total of 25 online focus groups of various sizes, two dyads, and 11 in-depth interviews were conducted. All sessions were conducted from January 25th to February 23rd, 2024. Focus group length ranged from one to two hours, while the dyad and in-depth interviews lasted between 30 minutes and one hour.

Each person living with dementia and paid care providers received an incentive of \$200, while unpaid caregivers, first responders, and government/logistical planners each received an incentive of \$150. In total, 171 individuals were recruited to take part, while 150 attended a session. More specifically, participation totalled 45 unpaid caregivers, 42 paid care providers, 28 first responders, 24 government/logistical planners, and 11 people living with dementia. In addition, one person recruited received an incentive although they did not participate in a session due to experiencing technical difficulties.

All discussions were held in English except in Quebec where the sessions were conducted in French. For the focus groups, all participants had access to a computer, tablet, or smart phone and webcam with high-speed internet to take part in the session. The following table provides an overview of sessions by audience, segment, location, and language.

Number of Online Focus Groups, Dyads, and In-depth Interviews (IDIs)									
Audience	Large Urban	Large/Medium Urban	Small/Medium Urban	Small Urban/Rural	Rural	Mixed Urban	Total Sessions	Total Recruits	Total Participants
	English	English	English	English	English	French			
Unpaid Caregivers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	49	45
Paid Care Providers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	48	42
First Responders	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group Quebec	5 Groups 3 IDIs	32	28
Government / Logistical Planners	n/a	1 Group East 1 Group West	n/a	1 Dyad East 1 Group West	n/a	1 Group Quebec	4 Groups 1 Dyad 5 IDIs	27	24
People Living with Dementia	1 Dyad West	n/a	1 Mini Group East	n/a	1 IDI West/Central	2 IDIs Quebec (Fr) 1 Mini Group Mixed Locations (En)	2 Mini Group 1 Dyad 3 IDIs	15	11
TOTAL							25 groups	171	150
							2 dyads		
							11 IDIs		



Community sizes were defined as follows:

- Large Urban: population of at least 150,000 or more
- Small/Medium Urban: population between 10,000 and 149,999
- Rural: population of less than 10,000 and a minimum of 50km from an urban centre
- Mixed Urban: population of at least 30,000, aiming for some rural

Those with current or past employment in sensitive occupations were excluded from the research, in addition to those who have others in the household in this situation. These sectors included marketing, marketing research, public relations, advertising, media, web development, and provincial or federal positions related to health care. In addition, no more than half of recruits in each group would have attended a group discussion or interview in the past for which they received a sum of money.

All participants were recruited per the specifications for the Government of Canada. Recruitment was conducted through qualitative panels stored on Canadian servers, with follow up calls to confirm the details provided and to ensure quotas were met. A referral recruitment approach was also accepted for harder-to-reach population (e.g., people living with dementia and government/logistical planners), following industry guidelines to ensure no participant from the same household were taking part in the study, and to ensure no participant knew each other in the same group.

Three moderators were involved in this project to accommodate the timeline and language requirements. Sessions were recorded for analysis purposes. An online chat function was also made available for group participants to use in addition to the verbal discussion, or as desired, and the inputs were considered in the analysis of findings.

A number of measures were put in place to enhance accessibility. For people living with dementia, the length of sessions was reduced (i.e., one hour for focus groups, and 30 minutes for a dyad/interview), each focus group session included a small number of participants, and the sessions were scheduled earlier in the day. In addition, an assistant was on hand prior to, and during the session, to help participants with the technology, if required. People living with dementia were also offered the research instruments (i.e., recruitment questionnaire and discussion guide) in advance, giving them an opportunity to prepare for their session.

In addition, during the sessions, the moderators adjusted their facilitation approach when needed. This included restricting unnecessary probing, using simple or familiar language, using shorter, more pointed questions that offer simple choices in response, providing participants sufficient time to respond, speaking slowly, minimizing distractions during the session, and offering reassurance. If responses appeared out of context, moderators would encourage more details or rephrasing and assist in structuring thought processes when required. A number of participants received assistance from a care provider during the focus group.



Context of Qualitative Research

Qualitative discussions are intended as moderator-directed, informal, non-threatening discussions with participants whose characteristics, habits and attitudes are considered relevant to the topic of discussion. The primary benefits of individual or group qualitative discussions are that they allow for in-depth probing with qualifying participants on behavioural habits, usage patterns, perceptions and attitudes related to the subject matter. This type of discussion allows for flexibility in exploring other areas that may be pertinent to the investigation. Qualitative research allows for more complete understanding of the segment in that the thoughts or feelings are expressed in the participants' "own language" and at their "own levels of passion." Qualitative techniques are used in marketing research as a means of developing insight and direction, rather than collecting quantitatively precise data or absolute measures. As such, results are exploratory and cannot infer causation.



Research Findings

Personal Experiences with Climate-Related Emergencies

This research presents findings from discussions with participants across the country and in varying roles. Across locations, research participants had experienced a wide range of different climate-related emergencies including primarily forest fires or wildfires, severe air pollution (most notably from wildfire smoke), floods, heavy rain and snow, ice storms, hurricanes and tornados. Extreme heat and cold were also experienced by many, although it warrants mention that in many parts of the country, coping with such extreme temperatures is now considered typical or normal behaviour rather than an isolated incident. Across locations a variety of individuals and professionals had experienced evacuations as a result of climate-related emergencies.

“The past few years have been wild. We see polar vortexes, with extreme cold of -40C or colder for about 10 days, and that is now happening regularly. And then we have high smoke index days in the summer, and the heat is exacerbated with that. We have days of +40C or +35C.” - First Responder

The type of experience described by participants varied depending on the nature of the climate-related emergencies they had been involved in and their specific role. The following provides context of those experiences when considering the remainder of this report.

First Responders

Several first responders indicated that they have responded to many emergency calls for people living with dementia during climate-related emergencies. They spoke of extreme heat or cold conditions that have now become more of a normal occurrence, often lasting for an extended period of time. Typical involvement included entering a residence, providing an initial assessment of vital signs, a primary and secondary survey to assess medical and physical health and determine their needs, and then determining course of action. In most instances, transporting individuals to the hospital was the end result.

“In most cases we almost always transport to the hospital. We assess, load, and treat them depending on their vital signs.” - First Responder

During such extreme heat and cold weather alerts, a few first responders noted that their interaction involved search and rescue efforts for people living with dementia. In those instances, their role was primarily checking vitals once the individual was found and ensuring the person living with dementia was transported to a safe location.

“I work with police when people are wandering or lost or looking for a friend. Sometimes in a location where they used to live. In the extreme weather, it is a life and death situation.” First Responder



Paramedics shared experiences where they had been involved in multiple evacuations either of individual (private) homes where a person living with dementia was living with a caregiver or in institutional settings such as long-term care homes, because of the threat of fire, or air quality issues / air filtration system failures, as a result of wildfires.

“We had to evacuate the building. The air quality couldn’t be maintained. We had multiple casualty units that looked like a city bus, which held up to 18 patients.” - First Responder

Others spoke of evacuations required as a result of floods.

“The area [rural community] was flooded and there was an evacuation order for the elder care home. I helped with the transportation to the airport. It was difficult. People don’t like to be displaced from their home.” - First Responder

“A facility had been evacuated, and we were sent to bring them back...We had a converted city bus, there had been six patient treatment centers, and we were bringing people back to their facility. There had to be a 1-1 ratio of paramedics. All the patients were living with dementia, and they wanted them to be with someone at all times.” - First Responder

One police officer expressed frustrations towards unpaid caregivers as a result of his calls to homes where people living with dementia were living alone during times of power outage, or extreme cold.

“Most of my experiences with unpaid caregivers are pretty negative. There is often lots of elder abuse that you see in times of emergency where unpaid caregivers have not been providing the needed levels of care. I’ve seen where individuals living with dementia are on their own, and their furnace hasn’t been on (or serviced) in a long time – during times of extreme cold. Or times where no one checks in on them and they are suffering severe dehydration. I’ve had to arrest unpaid caregivers.” - First Responder

Paid Care Providers

Paid care providers who work in long-term care homes or independent retirement homes spoke of experiences dealing with wildfires, heavy snow fall, or extreme heat or cold events, all of which required residents to stay indoors. This proved especially problematic given the resulting break in normal routines, as well as reduced or no visitation from family. Wildfires were problematic given that air quality was often impacted for an extended period of time (1-2 months).

“Forest fires made it difficult. He [person living with dementia] could not understand why he couldn’t go out. His mood and demeanor changed. He was emotionally damaged.” - Paid Care Provider

“The dementia unit has a secured courtyard that they could go out to. They couldn’t go out and that was distressing for them. A change in their routine meant they were disoriented with the



time of day. Not being able to go outside, we were having flareups of other cognitive declines.” - Paid Care Provider

Several paid care providers experienced an evacuation of their long-term care homes, which lasted a matter of days or weeks. They spoke of having to manage several major factors, such as working with local authorities to relocate people living with dementia, which can include finding a safe and appropriate place for relocation, physical transportation of patients, and separation from unpaid caregivers (who often were also evacuated from the area). In some instances, significant effort was required to connect with unpaid caregivers. Regardless, paid care providers consistently spoke of how an evacuation process was typically reactive, with minimal real-life experiences to guide their efforts.

“I remember a patient was evacuated and her daughter came. If we only had the paperwork, it would have been a problem. It was her daughter who was her advocate. She helped us to manage her mother’s needs. She could tell [us] what her mother needed as her emotions changed.” - Paid Care Provider

“There was one who didn’t have any family. There was such a significant change in living conditions [during the evacuation], which led to their decline.” - Paid Care Provider

“When we had to evacuate during the fires, the nursing home had to be completely evacuated – 60-70 beds. It was total disruption. We had to create a plan in place and make sure their needs were supported as best we could.” - Paid Care Provider

People Living with Dementia

People living with dementia primarily shared experiences related to wildfires, and the resulting smoke and air pollution, which typically lasted about one week, as well as of extreme cold or heat. While some relocated to live with friends and family in locations outside immediate danger, several indicated that they chose to remain in their home.

“I have bad lungs. The forest fires caused me lots of discomfort, but I couldn’t get away. I had to be near my heart doctor.” - Person living with dementia

“The air was really bad. I have breathing problems, so I went to a friend’s house 15km away and stayed there for a week.” - Person living with dementia

A few others spoke of experiencing extended power outages (2-3 days), where they stayed in place.



Unpaid Caregivers

Unpaid caregivers typically spoke of the experiences of those living with dementia who they cared for, rather than their own personal experiences. These experiences typically involved forest fires, extreme cold, extreme heat, severe snow fall or power outages. Their involvement primarily included visiting the person living with dementia during the climate-related emergency, when possible, staying in contact with the long-term care home (when applicable), maintaining stability and routine, or ensuring that the person they care for who is living with dementia is transported to a safe place, when appropriate.

Government / Planners

Those involved in planning or executing emergency responses during climate-related emergencies were typically involved in many aspects related to an emergency response – including hospitals and long-term care homes – and spoke of personal experience with wildfires, tornados and floods. Their involvement during an emergency involved working with provincial / territorial health authorities and emergency response teams to effectively meet the community’s needs, addressing internal staffing issues, planning appointments and liaising with families, as well as conducting door-to-door safety checks on people living with dementia.

“Last year a wildfire almost came into the town. It resulted in a massive evacuation of our town. I wore multiple hats, including communications, incident command, logistics and working with the evacuation of several facilities, including extended care units. We also had to deal with our homelessness or unhoused in the community – many whom struggle with dementia. It was a real struggle to get them to evacuate, and also to account for them.” – Government/Logistical Planner

“We had to evacuate [a care facility]. There were lots of problems with where to send them. Thankfully, some communities close to us were willing to take them. Caregivers [paid] were also evacuated, and had to deal with their families, so it was a challenge.” – Government/Logistical Planner

Impacts of Climate-Related Emergencies

Impact on People Living with Dementia

Climate-related emergencies were viewed as impacting people living with dementia, notably in a sudden worsening of the symptoms of their condition that may be temporary or permanent.

Severity of Impact

Across participants, climate-related emergency situations were seen as having an impact on people living with dementia with varying severity based on a number of factors including the type of climate-related emergency, the living conditions of people living with dementia, the range and severity of symptoms experienced, their past experiences with climate-related emergencies, and the strength of their support network. A situation that is more commonly experienced and has minimal impact on



someone's living arrangements (e.g., a short stint of extreme cold or an ice storm without power outages) was seen as having less severe impacts on people living with dementia compared to other types of climate-related emergencies with longer durations and a need for displacement (e.g., wildfires). Having experienced past climate-related emergencies is also considered a factor influencing the severity of impacts, with compounding effects for those with multiple experiences.

« Si la personne a déjà vécu une urgence climatique qui l'a marquée, ça va avoir un impact plus grand que quelqu'un qui ne l'a jamais vécu. » (If the person has already experienced a climate emergency that has marked them, it will have a greater impact than someone who has never experienced it.) - Government/Community

A strong support network, whether provided by a supportive care organization, or in the case of people living with dementia who are in their home, paid services, neighbours, and family/friend caregivers, was considered an important consideration in minimizing the impact of climate-related emergencies.

"If they don't have family members or a close network, there is more of an impact. More isolation – they withdraw. It's different from those with interaction." - Paid Care Provider

Emotional Impact

The most common impact that was reported by participants with direct interactions with people living with dementia was a sudden worsening of their symptoms during the climate-related emergency, with lasting impacts for some. In instances where the emergency leads to an environment where anxiety and uncertainty is generalized in the community, it was believed that some people may become increasingly frustrated, leading some to display exaggerated behavioural responses. These reactions were generally seen as temporary and displayed during severe climate-related emergencies that significantly disrupt daily activities or require displacement for extended periods.

« À chaque stress intense, il y a une dégradation de son état. Des fois c'est temporaire mais pas tout le temps. » (With each intense stress, his condition worsens. Sometimes it's temporary but not always.) - Unpaid Caregiver

"There is a significant increase in stress and flareups of other health conditions. Complications of other health conditions. [After the emergency] there is generally a worse health condition overall." - Paid Care Provider

A feeling of being unsafe, or insecurities, may follow once routine is broken.

"Once their routine is broken, it is hard. They feel unsafe and insecure." - Paid Care Provider



Physical Impact

Increased anxiety and frustration often lead to people living with dementia no longer able to perform familiar tasks without assistance and feeling a loss of control over their environment. There is a certain loss of independence, but also a risk to their health if they are no longer able to take care of themselves.

“As soon as there is a level of unpredictability, the control [people living with dementia have] is lost day-to-day. They become agitated and irate because they lose control. They need support to do the daily tasks they used to be able to do before. They need someone with them all the time. They don’t know what’s going on.” - Paid Care Provider

« Ça les sort de leur routine et ils ont des comportements d’anxiété et des troubles du sommeil. Ils ont besoin d’avoir un objet significatif avec eux parce qu’ils sont déstabilisés. » (It takes them out of their routine and they have anxious behaviours and sleep disorders. They need to have a meaningful object with them because they are unsettled.) - First Responder

“With any stress and sudden changes there is a decline. Mentally it is hard when they are displaced or have to move. And they are more prone to falls.” - First Responder

Pressures on settings where people living with dementia live, or rely on for care, during climate-related emergencies can lead to other consequences including the increased possibility of physical injuries and disruptions to regular care activities.

“There is an increased risk for falls and injuries during an emergency. Evacuations, being in unfamiliar environments can easily lead to a chance for a fall.” - Paid Care Provider

“If they need to be confined to their bed during the emergency and they are not used to it there is a bit of resistance. With the lack of staff [to respond promptly] there is a high incidence of falls and injuries [when they try to get out of bed].” - Paid Care Provider

Further it was felt that during emergency events, people living with dementia may face nutritional or other health-related impacts, especially among those who live alone. This included eating expired foods during power outages, experiencing mould during floods, or forgetting to eat or drink.



Impact on Unpaid Caregivers

Elevated stress was seen as the most common impact of climate-related emergencies on unpaid caregivers, given their increased involvement and the need to manage their own personal situation during the emergency.

Climate-related emergencies were also seen as impacting unpaid caregivers, notably in causing them increased stress which sometimes leads to or increases the risk of burnout. As mentioned, in addition to being worried about the person they care for, they also felt the need to allocate more time to support this person, while also managing their own situation during the climate-related emergency. Unpaid caregivers who do not live in the same community as the person they care for experience added stress as they are not able to effectively monitor the state of the situation and how the person living with dementia is coping (e.g., progression of symptoms and changing needs), and have limited ability to promptly intervene if there was a sudden worsening of symptoms.

“They have more stress. They need to be a lot more available to the patient and they are not always able to provide that additional support.” - Paid Care Provider

« Ça cause plus de stress chez la famille parce qu'ils doivent se mobiliser durant l'urgence et donner plus d'accompagnement à la personne [atteinte de démence.] » (It causes more stress for the family because they have to mobilize during the emergency and give more support to the person living with dementia.) - First Responder

Unpaid caregivers can sometimes feel a financial impact of providing care to a person living with dementia, and at times assume costs associated with time off work, travel, care, or emergency-related needs (e.g., purchase of a heater or air conditioner).

Challenges and Needs During Climate-Related Emergencies

Challenges and Needs of People Living with Dementia

Diminished cognitive abilities present significant challenges for those living with dementia during climate-related events, which may also be exacerbated as a result of the emergency. This may increase levels of fear or anxiety and leads to a need for continuity in care, ready access to information, regular contact, and interactions that are based on patience, reassurance, and support.

During and after a climate-related emergency, people living with dementia, as well as their unpaid caregivers, experience a wide range of unique challenges and corresponding needs, all of which are intrinsically linked to the condition itself.

Comprehension

People living with dementia may face challenges related to their ability to understand things they hear and read. Depending on the scope and severity of their symptoms, many may be unable to recognize that there is a crisis ensuing during an emergency. Some people may not fully comprehend what is



happening, why elements in their immediate surrounding might be different, and what the implications might be to them personally. As a result, they may have increased level of fear or anxiety, repeatedly ask the same questions to seek clarity and gain some level of reassurance, or withdraw in their confused state.

“The inability to recognize risk is a big one. Not understanding the risk of cold weather. In our community people are dying from exposure and she does not make the connection that it may happen to her.” - Unpaid Caregiver

“With dementia patients they don’t realize why they can’t breathe as well [during severe air pollution events]. They are panicked because their breathing isn’t as good as it usually is.” - Paid Care Provider

“The challenge is that they are not aware how serious it is. They are not aware of the safety risks. They will not take action to take care of themselves.” - Paid Care Provider

« On aborde le sujet avec eux et on répète, mais [les gens atteints de démence] n’ont pas toujours la capacité de comprendre et la capacité de s’adapter. L’entourage est aussi limité dans son habileté à évaluer la situation. » (We bring up the topic and we repeat the information, but people living with dementia don’t always have the ability to understand and the ability to adapt. The entourage is also limited in their ability to assess the situation.) - First Responder

“There is a lot of fear. They can’t seem to put the puzzle together or understand why I am present, or why the caregiver is so upset. The difficulty in connecting those dots causes much distress. They are overwhelmed with emotions.” - First Responder

Communication

An emergency can be a stressful time for people living with dementia. Comprehension issues discussed above present serious corresponding communication challenges that warrant special consideration. Those living with dementia need clear, simplified messaging, ideally communicated using visual cues or imagery to guide their reactions.

“Rather than having a detailed plan, I’d like to have cue cards or visuals. If I see [a cue] on a picture, if I feel like this picture, then I turn it over and see what to do.” - Person living with dementia

“When I am not as anxious, I would readily absorb the information regarding future planning, rather than during an emergency. I would like to have a list of resources, pointers or a note, [that says]: if this, do that; if this, do that. So I have a clear path. In a stressful situation I may not be able to determine the correct course of action.” - Person living with dementia



“I need clear information on what to do. I used to be able to do things in an hour that now take me 4-6 hours. Time is of the essence. I need to know what to pack in an emergency preparedness bag.” - Person living with dementia

At the same time, having clearly communicated guidelines to direct actions provide a sense of reassurance and important advice that assists during times of emergency.

“... I need help – someone to make sure I’m ready.” - Person living with dementia

“Tell me what to do. I’m not quite sure. Rules are for fools to follow and wise men to be guided by. I like to have the guidance...That would reassure me that I am on the right track.” - Person living with dementia

During a climate-related emergency, the level of communication provided can be especially problematic for persons living with dementia. Excessive or repeated information that highlights the severity of the situation and amplifies a sense of urgency may create increased stress and anxiety, causing further confusion and uncertainty. Similarly, alerts, evacuation orders or visits from uniformed professionals can result in an escalation of response, increased anxiety and sometimes responsive behaviours. During an emergency, those living with dementia and unpaid caregivers typically relied on television and radio for their updates, as well as their phone. The frequency of information, however, was often stress-inducing to some, resulting in some choosing to limit their exposure.

“When my cell phone had an alert on it, that was extremely distressful. I turned it off and froze in the moment. I didn’t know how to react. The repetitive nature of the news and watching the news made me super emotional.” - Person living with dementia

“I didn’t watch TV as much as normal. Every time I did it was talking about the weather. I felt completely isolated and afraid.” - Person living with dementia

“I was sad because of the trees burning down. Watching the firefighters being flown in because there were not enough. It looked like a movie. Towns were being engulfed and not being able to do much.” - Person living with dementia

It was felt that incorporating persons living with dementia into emergency planning as much as possible is key. Where applicable, asking them questions such as what they would like to bring with them if they needed to leave the home (versus telling them they need to leave now), or what to put in an emergency kit, will help to engage and alleviate stress. At long-term care homes, and especially during an evacuation, it was felt that efforts are needed to include the family in the emergency care plan development.

“If you are able to get family support into their inner circle, even in a phone call, it will help. Getting that insight on what will reassure or calm them (like a song) is key.” - Paid Care Provider



“It is important to try to find that line - where it’s not me coming in and taking all of their independence, but instead finding ways to incorporate them into the preparedness.” - Unpaid Caregiver

For some people living with dementia, an inability to absorb the gravity of the details or the overwhelming nature of the message, resulted in increased anxiety and distress or a disassociation from the situation. For others, worry stemmed from an uncertainty of where they could turn if they needed help, resulting in a sense of helplessness.

“I don’t know if I needed anything. But I would have liked a phone number that I could have called in case I needed ambulatory care. I knew from the news that emergency departments were overwhelmed and the last thing I would want to do is add to the load. So, I likely wouldn’t do anything. I wouldn’t bother.” - Person living with dementia

Another specific key challenge mentioned only in English sessions was noted for those whose mother tongue or primary language is not English. People living with dementia are likely to experience a decline in their ability to use a second language as dementia symptoms progress. Several unpaid caregivers indicated that during an emergency the person living with dementia’s ability to converse in or understand English (as their second language) decreased significantly, with an increased dependency on the language of their mother tongue.

“My Dad started speaking Spanish again, which he hadn’t done in years. That was the language of his childhood. We had to speak to him in Spanish.” - Unpaid Caregiver

Consistency and Normalcy

Unpaid caregivers shared numerous instances of how the persons living with dementia they provide care for who live on their own lacked the ability to function as they usually would during a climate-related emergency and had been unable to respond appropriately to conditions related to the emergency. Such examples included not knowing to turn on air conditioning or drink more liquids during times of extreme heat, a lack of awareness that the power had been off for multiple days, even during times of extreme cold, or simply leaving windows open when wildfire smoke was present. Persons living with dementia living on their own also shared examples of confusion.

“I didn’t know how to plan for that in advance. At the beginning I went to the store to look for an air conditioner, but couldn’t figure out what to do when I was in the store aisle. After that, I didn’t go outside. No groceries for over a week.” - Person living with dementia

Some participants living with early or moderate stages of dementia articulated a level of confusion or uncertainty and described a response of disassociation when dealing with an emergency. Others indicated that they were sufficiently prepared for the climate-related emergency and made plans to stay with friends or family.



“It was hard to breath. I went to visit my mother in Montreal for a week.” - Person living with dementia

“When I am faced with a safety situation, I pause and go back to not comprehending. Then I drift off from what is going on. When I come back [to the moment], I am very tired.” - Person living with dementia

“I get concerned and worried and disassociate from the situation. I go to a safe place in my head.” - Person living with dementia

During climate-related emergencies, people living with dementia frequently experience interruptions in visitations from paid care providers, unpaid caregivers, and family members, which create a greater sense of isolation and loneliness. Further, the basic provision of care can be interrupted, such as a lack of home care visitation, cancellation of health-related appointments, or a lack of access to food, basic necessities, or prescriptions. These present additional challenges to coping with the situation.

For some, management of personal hygiene or self-care is also challenged as part of an individual’s response to a climate-related emergency.

“I didn’t shower – it was too hot. I didn’t want to dress in the morning. I was very fatigued. I didn’t have an appetite. I wouldn’t have eaten if my neighbour didn’t drop in.” - Person living with dementia

“I had no energy. I was in bed and dehydrated. I didn’t have the energy to get up and get water. Things that were more dire didn’t seem that way.” - Person living with dementia

Maintaining some state of normalcy or regular routine minimizes the impact of a climate-related emergency on a person living with dementia. The ability to keep a person in their home, whenever possible, was deemed paramount to lessening the progression of their condition, as home is where they feel comfortable and safe. For those living in long-term care, consistency of paid care providers during an emergency helped to lessen the impact of the emergency.

« Ce sont des personnes qui ont besoin de routines mais les routines sont brisées [lors d’urgences climatiques]. Il faut faire de la gestion des émotions au quotidien pour expliquer le bruit, les sacs de sables. » (These are people who need routines, but routines are broken [during climate-related emergencies]. You have to manage emotions on a daily basis to explain the noise, the sandbags.) - Unpaid Caregiver

“We all know each other. Some are more spiritual; some are more responsive to music. You know how to make them feel most at ease because of the relationship. You make sure their culture is respected – and you have an open dialogue.” - Paid Care Provider



Support and Individual Care

People living with dementia who live alone indicated that they need regular contact during an emergency to ensure a continuity of care as well as safety. Having someone (e.g., family member, friend, neighbour, community care) provide frequent and constant in-person check-in and outreach was considered key.

During times of emergency or routine disruption, a person living with dementia may experience increased confusion, frustration, fear, and potential responsive behaviours. Both paid caregivers and unpaid caregivers highlighted a need for reassurance, patience and one-on-one care during such times. Clear and calm communication, including repetition of key instructions or information, can assist the person living with dementia with understanding. The physical presence of those with whom they are familiar is important in efforts to offer reassurance, clarity and minimize withdrawal and isolation. Similarly, when removed from the home, ensuring evacuation settings are safe and conducive to reduced stress (e.g., avoiding large crowds or excessive noise, tailored transportation options) wherever possible is important.

“Keeping them informed and calm is top priority. And then tell them what’s next, what’s going to happen next. A little bit at a time. Making sure that their routine is not disrupted. Each individual needs to be managed one at a time.” - Government/Logistical Planner

“Having empathy and patience is key for people with dementia, anytime. During emergencies but also at other times.” - Government/Logistical Planner

“They [people living with dementia] need someone to take the time with them. The more rushed they are, the more stressed and anxious they will become. We offer them as much patience as possible, knowing that with the emergency, we are adding fuel to the fire. Dementia will progress with stress.” - Paid Care Provider

Familiar activities can provide a sense of reassurance or normalcy during times of confusion. For Indigenous Peoples living with dementia, access to traditional foods was also identified as helpful. Including items or familiar activities in an emergency bag that are familiar and important if a home evacuation is needed (e.g., music, photos, knitting needles, stuffed animal, etc.), may provide comfort and help a person living with dementia to stay calm.

“We use reinforcement tools to keep them calm. Some react to the noise of the alarms so we give them headsets to reduce the background noise.” - Paid Care Provider

Further, those living with dementia in their own home indicated that they need some type of reassurance that they are safe after a climate-related emergency has passed.



“I’d like some assurance that the critical time is now passed, and it is ok to go back to normal. Information and some reassurance that all is ok.” - Person living with dementia

“I need someone reaching out and helping me. When something gets overwhelming, I just disassociate.” - Person living with dementia

Those living with dementia have a strong dependence on routines, and these routines are usually disrupted during times of climate-related emergencies. For many, regular outings, whether it be on their own or through organized activities with others, are fundamental to their successful, day-to-day functioning. During times of emergency, such outings are not able to happen as a result of weather-related factors (e.g., extreme heat, extreme cold, severe snowfall, smoke, floods, etc.), and people living with dementia are forced to stay indoors. This provides a substantial challenge to their regular routine, causing significant confusion and frustration, a sense of isolation, leading to responsive behaviours for some.

“They want to go outside but they don’t understand why they can’t [due to air pollution].” - Paid Care Provider

“With this kind of situation [tornado warning], [people living with dementia] are agitated and they become aggressive. We tried to keep them involved with activities and kept caregivers informed as well. After that incident [the long-term care home] made it protocol that in case of emergency they call for more staff.” - Paid Care Provider

« La compréhension peut être court-circuitée. Pour ces personnes avec la démence, il n’y a pas de situations d’urgence. Elles ne comprennent pas qu’on doit évacuer ou prendre telles mesures. » (Comprehension can be short-circuited. For these people with dementia, there are no emergency situations. They don't understand that we have to evacuate or take such measures.) - Government/Community

Evacuation

During times of evacuation, a variety of additional challenges are presented, including a lack of clarity on what people living with dementia need to take with them, a lack of urgency or understanding of why evacuation is needed, and in what timeframe an action is needed. Evacuating a person living with dementia also presents several further challenges, most notably removing them from familiar surroundings, the risk of large crowds (i.e., an unsafe environment conducive for getting lost), increased noise levels, an unfamiliarity with the people around them, and lack of mobility. The absence of normalcy/continuity in both surroundings and activities presents a serious challenge to a person living with dementia’s ability to cope with the situation and function normally.

“They are not used to the new environment if they need to be moved. We put post-it notes so they know where their items are kept.” - Paid Care Provider



“How do you plan for what you don’t know what’s coming? We would have these conversations around what they like [to bring] if [a climate-related emergency] happened but the problem is they forget. In the moment they don’t recognize the issue, the danger.” - Unpaid Caregiver

“They may not be fully aware of what’s going on but they sense that something is going on. In their behaviours they may be more aggressive towards the PSW or caregivers. Things are not the norm during that time. It may take some time to settle them and get them back.” - Government/Logistical Planner (with direct interaction with people living with dementia)

It was noted that being evacuated from communities can be traumatic for some, especially for those who have previous experience of being removed from communities, such as Indigenous Peoples who experienced the residential school system. Several paid care providers also indicated that emergency events can trigger past traumatic events, which challenges the person’s ability to respond to care and direction.

“We didn’t know she had experienced a house fire as a child. This event triggered that memory and elevated her fear.” - Paid Care Provider

Strategies for Addressing the Needs and Challenges of People Living with Dementia

Strategies shared by participants for addressing the needs and challenges of people living with dementia during a climate-related emergency revolve around first responders and paid care providers adapting personal interactions, seeking unpaid caregivers and family support, and accessing as much information as possible about the situation of each individual.

First responders consistently reported that in order to address challenges they try to slow down their interactions with people living with dementia, reassuring them and providing them with an opportunity, wherever possible, to make some decisions.

“[Rushing] exacerbates their emotional state. I speak more slowly and clearly without being a higher volume. I reassure them that I won’t forget their cane or walker and make them as comfortable as possible. They are very acutely aware when I see a vital sign that is not good. I need to stop myself from [revealing] my sense of urgency. Even though it’s an emergency, I can’t show that. My mantra is slow is smooth and smooth is faster.” - First Responder

“They don’t often have the ability to follow instruction and worry about whether their valuables are safe. We do a lot of reassurance - like, ‘yes we’ve locked the door; your health card is safe.’ The greatest challenge is fear because they have lost control.” - First Responder



During times of emergency, paid care providers underscored the importance of getting family support into the inner circle of the person living with dementia. Such involvement ensures that a health condition baseline is established and understood, that their medical information (such as medication lists) are at the ready, and that there is a shared understanding of what actions or items will reassure the person living with dementia. People living with dementia often have a strong reliance on select close relationships, whether it be established paid care providers, unpaid caregivers, or specific family members. In many cases, these are the only people they readily identify or are comfortable communicating with. These caregivers are often the only people who fully understand the extent of their condition, their individual comprehension ability, and what factors may positively or negatively impact responses.

“When you brought in people [caregivers] who could be there with [the person living with dementia] that changed their whole response to [the evacuation]. Whether someone they knew or a volunteer coming in providing one-on-one support. Knowing there is someone with them.” - Paid Care Provider

Having ready access to current information on a person living with dementia’s health condition (including the state of their symptoms and level of comprehension, medications, current photo, baseline state, etc.) provides an important baseline to direct first responders’ provision of care during an emergency. In addition, having information for key contacts ensures quick access to a direct point of contact for further details as required when providing care. Ideally, it was felt that some type of identification system was needed to ensure that a person’s condition is readily identified to flag where additional in-person check-ins, supervision, and ongoing monitoring of symptoms may be necessary and to guide the efforts of first responders.

“People living with dementia suffer longer because they can’t communicate. We need quicker recognition of their problems. Family members are the best source for information. Information is much better gathered from a third party rather than the individual living with dementia.” - First Responder

As mentioned earlier, a wide range of communications challenges become evident during a time of climate-related emergencies for those living with dementia, whether it be related to the person’s ability to communicate their needs or the extent to which they can effectively comprehend instruction. It was felt by some unpaid caregivers that limiting the amount of information related to the climate-related emergency to what is directly affecting a person living with dementia may alleviate stress resulting from unnecessary information. This was deemed especially important when considering the proximity of the climate-related emergency.

« Quand l’urgence climatique touche directement la personne avec la démence, c’est essentiel de la garder informée, mais sinon, si l’urgence climatique est lointaine, là, je limite l’information que je lui donne. Quand c’est à 20 km, c’est trop loin. » (When the climate emergency directly affects the person with dementia, it is essential to keep



them informed, but otherwise, if the climate emergency is far away, then I limit the information I give them. When it's 20 km away, it's too far.) - Unpaid Caregiver

First responders highlighted that people living with dementia are typically unable to correctly respond to questions or provide accurate cues when they have an urgent need. There is a general inability to accurately describe their personal condition, and accordingly, first responders are heavily reliant on any readily available information, including any information verbally shared by unpaid or paid care providers, the reading of vital signs, evaluating their surroundings, or their own personal experience with non-verbal cues.

"We can't use, or rely on, the pain scale because they can't remember what it [pain level] was... They are often unable to notify us that they need to use the bathroom because of a lack of cognitive cue that they have an urgent need to pee." - First Responder

"Their inability to communicate their needs is a challenge. The severity can vary. Some are in a state where they are nonverbal, and others are non-mobile. [I recall] one patient, he was stable, but not able to communicate and tell you what was bothering him – but he knew something was wrong." - First Responder

"They are slower to process information so as a health care worker it can be a challenge to simplify the information in easy language. There can be information overload, and it can be frustrating for people with dementia. For me, it's a matter of speaking slowly and clearly. I had to be calm with them. I'm looking at their verbal cues and also their body language." - Paid Care Provider

"Our main goal is to treat signs and symptoms – what is in front of us. Sometimes we can't figure it out. It's important for the caregivers, especially unpaid caregivers, to tell us. One example is dehydration. The [person living with dementia] can't communicate that they are too hot and not getting fluid." - First Responder

Challenges and Needs Specific to Unpaid Caregivers

Unpaid caregivers are challenged by a lack of awareness of what needs to be done during a climate-related emergency, an unfamiliarity of available resources, conflicting life interests, and financial constraints.

In addition to the significant challenges facing those living with dementia during a climate-related emergency, unpaid caregivers face a realm of unique challenges. In particular, across participants there was general agreement that unpaid caregivers often have difficulty personally coping with an emergency. Many feel ill equipped to respond to the progressive condition of the person living with dementia generally, lacking information on how to address their changing needs. During times of emergency, they are usually also facing the consequences of the climate-related emergency and



experience challenges effectively balancing their other responsibilities and the needs of the person living with dementia who they provide care.

“There is a lot of uncertainty in knowing where to go to find out information, to know if the reactions [of people living with dementia] are normal. Not knowing where to get resources [is challenging for unpaid caregivers].” - Paid Care Provider

“They are juggling a variety of roles – family, professionally, and caring for their loved ones. I can’t think of a single instance where the caregiver was coping well. They are always suffering caregiver burnout.” - First Responder

“We forget that the unpaid caregiver has their own life and their own things they have to deal with in the midst of taking care of their loved one.” - Government/Logistical Planner

« Dans un moment d'urgence c'est très difficile de penser à mon ami si moi-même j'ai possiblement besoin d'aide. » (In times of emergency, it's very difficult to think of my friend if I myself possibly need help.) - Unpaid Caregiver

Many of the unpaid caregivers who participated noted that they are the sole caregiver for the person living with dementia. In some of these situations, the unpaid caregivers noted that very few other people are recognized or accepted by the person living with dementia and thus their ability to assist with caregiving is limited.

“What happens when I am not there? My husband worked from home so he could deal with mom. But resistance can be an issue. The more you push, the more frustrated [people living with dementia] are going to be and the more they feel stripped of their power.” - Unpaid Caregiver

« Les besoins que cette personne à c'est la prise en charge. Je suis très occupé vu que je suis à temps plein à l'école et à temps partiel au travail, et donc je trouve difficile de pouvoir l'aider dans ces tâches journalières. » (The need that this person has is for someone to take care of them. I'm very busy since I'm full-time at school and part-time at work, so I find it difficult to be able to help him with these day-to-day tasks.) - Unpaid Caregiver

During times of evacuation, immediate actions are sometimes required without any communication to the family. That creates a great deal of uncertainty and worry for the unpaid caregiver.

As with those living with dementia, unpaid caregivers also have specific needs, including:

Education / Information: Unpaid caregivers need guidance on how to care for people living with dementia during an emergency. Details are needed on ways to prepare, how to provide care during an



emergency, the importance of checking in regularly and the person they provide care for in their home whenever possible, as well as understanding implications of such events on the progression of dementia. Many lack familiarity with how to identify or cope with the changing progression of dementia which may be accelerated by a climate-related emergency event.

“They need education on how to help family members living with dementia. They are often mentally worn out. There is no differentiation between work and home. Lots of family members are tired. Their free time is spent caring for others. They are taking care of their own life and someone else’s.” - First Responder

Support / Resource Identification: Unpaid caregivers are overwhelmed and often exhibit ‘burn out’ as a result of the additional demands during a climate-related emergency and their extended provision of unpaid care to a person living with dementia. They face many competing challenges, including their household responsibilities, employment, and limited emotional and financial support. They are typically unaware of what resources are available to assist them (e.g., available in-home care options, support groups, care approaches, etc.), as well as what financial programs might be accessible for them.

“They need financial support, for taking time off work. They need education on the importance of regular home check ins, depending on needs. And they need a place where they can go to get questions answered. Educate them on the disease progression.” - First Responder

Communication: There is a clear need for direct communication with unpaid caregivers on the gravity of the emergency and the necessary course of action. They need to be advised when action is taking place, what the specific action is, and when it is planned for. Also, having advance notification (e.g., an alert) of when an emergency will likely impact the person living with dementia they care for is desired to give them advice of when their action and assistance will be needed. Several paid care providers shared lessons learned during the COVID-19 pandemic relating to communicating with family members during times of emergency.

“COVID taught us a lot. Communicate, communicate, communicate. When we try to soften the information [to family members], it doesn’t really go well.” - Paid Care Provider

“Family members need to be heard. We need to appreciate and hear what they are saying.” - Paid Care Provider



Tools and Resources

Available Tools and Resources to Inform and Guide People Living with Dementia and Unpaid Caregivers

There was limited knowledge of tools and resources available to inform and guide people living with dementia and unpaid caregivers before, during, and after climate-related emergencies.

Across participants and locations, there was a perception that few tools and resources currently exist to inform and guide people living with dementia and help unpaid caregivers address climate-related emergencies.

A number of participants mentioned the Alzheimer Society of Canada as being a useful resource for general information on dementia specifically for people living with dementia and unpaid caregivers. A few unpaid caregivers were under the impression that they offered content specific to climate-related emergencies but that it may be limited. Checklists, information, and tools such as a bracelet system recording medication use, were identified resources currently available from the Alzheimer Society of Canada.

“I am not sure how much is out there that works for [people living with dementia]. The Alzheimer Society has a home safety checklist but depending on where [the people living with dementia] are in the continuum, I’m not sure if any checklist will work for them. The checklist may work for people taking care of them.” - Unpaid Caregiver

“There is probably some support through the Alzheimer Society but I am unsure if there is anything related to weather events.” - Government/Logistical Planner

Accessing health care professionals by dialing 8-1-1 was also identified by just a few participants as a potential source of assistance for people living with dementia and unpaid caregivers. That said, this was not something that is generally looked for.

“The Alzheimer Society advocates how to interact with individuals who are experiencing dementia. If unpaid caregivers are not as equipped with the medical system, 811 is a good resource; they get access to a nurse practitioner.” - Paid Care Provider

Other sources identified by unpaid caregivers and people living with dementia to stay informed on climate-related emergencies include weather reports and news stories. Only a few unpaid caregivers reported that the person they care for has an emergency kit in place, although many participants across audiences identified this as an important tool to prepare in case of any emergency.

“I put together a small kit for myself and for my friend so that we have it already to go in case we need to vacate and that is new [for us]. Even now if he needs to go to the



hospital, he has a kit near the door. He has a necklace that has important information about him. That is helpful. When we need to be rounded up, we would be ready to go.”
- Unpaid Caregiver

Finally, short videos are currently being produced in Alberta on dealing with emergencies in general, directed at the wider public. In addition, the use of medical alert bracelets or necklaces was mentioned by a few unpaid caregivers as a safety mechanism for people living with dementia within their home.

Available Tools and Resources to Assist Paid Care Providers and First Responders with Meeting the Needs of People Living with Dementia

There was limited knowledge of tools and resources available to assist paid care providers, first responders, and other professionals in their roles to respond to the needs of people living with dementia during climate-related emergencies.

Tools

Among paid care providers and first responders, limited specialized tools and resources were identified to assist in responding to the needs of people living with dementia during climate-related emergencies. Paid care providers and first responders generally rely on their work experience and professional training to guide or inform their interactions with people living with dementia during emergencies. Such training, however, was generally not specific to dementia or climate-related emergencies.

“I use my experience, and also information from their [unpaid] caregiver.” - Paid Care Provider

« Je me fie à mon expérience personnelle mais j’ai accès au soutien dont je peux avoir pour soutenir la personne avec de la démence. J’ai une travailleuse sociale et une psychoéducatrice que je peux appeler. Les ressources sont disponibles, mais je me fie surtout à mon expérience personnelle [dans mes interactions avec les personnes atteintes de démence]. » (I rely on my personal experience but I have access to the support I need to support the person with dementia. I have a social worker and a psycho-educator that I can call. The resources are available, but I mostly rely on my personal experience [in my interactions with people living with dementia].) - Paid Care Provider

“We had a course about dementia, but it did not deal with emergency situations. It explained how to care for them and just the basics. You have to adapt the theory you have learned in emergencies.” - First Responder

Further, several first responders knew of the existence of Project Lifesaver, a program in select communities that helps coordinate police response to locate people living with dementia who are lost by using radio technology. A few unpaid caregivers also mentioned the use of tracking devices on the



key ring of someone living with dementia (e.g., Apple Air Tag) linked to their cellular phone as a tool to monitor and track the individual's movements when leaving the home.

RCMP in some communities reported having access to a psychiatric nurse as an available resource to contact as needed on calls. Another resource provided by community paramedics in Ontario's Peel and York regions are health information sheets, posted in the homes of people living with dementia (on the back of the front door) to provide first responders directions for care. Finally, a first responder mentioned the mobile community paramedic services, where paramedics provide drop-in or scheduled care/monitoring to vulnerable people at specified periods.

Of note, the Alzheimer Society of Canada was seldom mentioned as being directed at audiences other than people living with dementia and caregivers, despite information specific to first responders and health care providers being available on its website.

Training

A few participants felt that available training varies depending on if you are in an urban or rural community. It was felt that in larger urban centres budgets are more readily available for training. By contrast, in rural communities first responders do not have access to the same level of training.

"There is no standardized training related to dementia and dealing with emergencies. There should be standardized systems. Right now every emergency service, their own agency develops training. But that doesn't work for rural communities. There should be some type of standardized training for all." - First Responder

"Nothing in any course is specific to climate emergencies – it deals with high stress situations. There are no resources specific to climate emergency. We need to bring awareness to the challenge and add to existing tools." - First Responder

Other training tools were each mentioned by a limited number of participants. A paid care provider recalled a workshop titled Open Focus Care, which was offered by a long-term care home to raise awareness among unpaid caregivers about their own mental health and provide an opportunity to share their experiences with others. A first responder attended a training module offered to police officers titled "L'intervention sociale en contexte de sécurité civile" that provides general information to first responders on addressing crisis situations.

Preparedness

Most paid care providers from supportive housing settings or long-term care homes mentioned that some type of emergency preparedness plan is in place where they work, although none appear specific to climate-related emergencies. Many considered this a direct outcome of the COVID-19 pandemic or from a recent climate-related emergency.



“None of us were ready for COVID. Since then, we have spent a significant time practicing and focusing on preparedness. We learned a lot. We pivoted and changed direction. We have a plan in place, and we are making it a living tool versus something on a shelf. We are actually practicing.” - Paid Care Provider

“Past experience brought community partners together, finding evacuation centers and transportation. We have policies in place. You lean on your experience.” - Paid Care Provider

“We’ve looked at the whole policy and have reviewed it. We have protocols in place – phone trees. Instead of going to the residents, we are now going to family members first, so they can be involved.” - Paid Care Provider

A few government representatives mentioned that some provincial governments have a vulnerable person registry in place, although the extent to which it is effective is unclear. Green Sleeve was mentioned as a resource in Alberta that is kept with individuals. Those over 65 in Alberta have a conversation with their doctor and are given a green sleeve. It includes goals of care, level of resuscitation, etc. People typically post the green sleeve on the fridge. First responders know to look for it. People are encouraged to put their medication list in the sleeve.

Desired Tools and Resources to Inform and Guide People Living with Dementia

Although few tools are currently available to inform and guide people living with dementia before, during, and after climate-related emergencies, there was interest in additional information and support.

Participants recognize the need to be prepared and they provided suggestions on ways people living with dementia could be better prepared and supported to face climate-related emergencies. The following provides a listing of recommended tools and suggestions on the best formats and approaches for these participants.

Information

- Consider offering information specific to people living with dementia in different formats and available through various mediums, such as the provision of checklists and directions on how to develop emergency preparedness kits.

“When you think about dementia, there are all these different kinds of dementia so it’s hard to plan information or tools that would be useful.” - Government/Logistical Planner

“We put a lot of our information about climate emergencies about what is happening on phones, tablets, and computers. We put a lot of faith in those things and a lot of people with dementia do not have access to those things or are no longer able to use them. That is why you are relying on the unpaid caregivers to relay this information.” - Government/Logistical Planner



“I’d like some kind of a checklist of what I need to do. So I can reassure myself I haven’t forgotten something.” - Person living with dementia

- Distribute a telephone list of community resources people living with dementia and unpaid caregivers can contact in case of climate-related emergencies.
- Provide short videos with simple content to explain climate-related emergency situations to people living with dementia.
- Develop a portal that centralizes information and resources for people living with dementia and unpaid caregivers. Such a portal would include a few qualifying questions to ensure information is streamlined to best meet relevant needs.

Tools

- Provide visual cue cards (directed to people living with dementia – e.g. the card has visuals of symptoms on one side and instructions on what to do on the other side).

Preferred Formats and Approaches

- Provide videos for people living with dementia in different languages. This was felt to be important since people living with dementia are more likely to use their mother tongue as their cognitive functions decline.

“With language barriers, we need short videos explaining what is going on. These patients [living with dementia] need it repeated over and over, so having them connect in the video, someone speaking in their language in simple language as well, saying this is what is going on and this is what you should be doing in this situation [would be good]. Especially with the smoke which we are not used to. Heat we have dealt with, but smoke impacted patients. There should be videos for people with dementia, but also videos for caregivers.” - Paid Care Provider

- Use simple language with a reassuring tone.

« On doit sécuriser les gens. Utiliser un vocabulaire simple et rassurant. » (We must reassure people and use a simple and reassuring vocabulary.) - First Responder

Desired Tools and Resources to Inform and Guide Unpaid Caregivers

There was also interest in additional information and support for unpaid caregivers, especially as it was felt that unpaid caregivers play a crucial role in preparing people living with dementia to navigate through climate-related emergencies and cope with the aftermath of an emergency event.

It was widely believed that there is merit in developing an approach tailored to the specific needs of unpaid caregivers during climate-related emergencies. This was felt to be most important given the cognitive and memory impairments experienced by people living with dementia.



« C'est difficile de les préparer à l'avance [les personnes atteintes de démence] mais il faut mettre au courant les proches. » (It's hard to prepare them [people living with dementia] in advance, but you have to let their loved ones know.) - First Responder

"You need to consider the caregiver in the plan. Is the caregiver able to provide the care, or do they have limitations? Do they live close enough that they can provide care?" - Government/Logistical Planner

« Avec les personnes atteintes de démence, c'est plus angoissant qu'autre chose de faire de la planification. Ça va les perturber pendant plusieurs journées. » (With people living with dementia, it's more nerve-wracking than anything else to plan. It's going to disrupt them for several days.) – First Responder

The following provides suggestions of information, tools, and resources that were seen as valuable to unpaid caregivers.

Information

- Provide information on what to do during an emergency, where to go, and who to call for assistance.

"[I would like to have] a plan that if I have to move my friend. Where would I move them to in case of an emergency and who would be there?" - Unpaid Caregiver

« Au lieu de me fier à mes connaissances, j'ai besoin de savoir qui contacter, quoi faire en premier lieu, comment agir avec la personne qui a la démence, quoi dire ou pas dire. J'ai besoin de ressources matérielles aussi; un budget si jamais on doit évacuer vers un hôtel ou quoi que ce soit. » (Instead of relying on my knowledge, I need to know who to contact, what to do in the first place, how to deal with the person living with dementia, what to say or not to say. I need material resources too; a budget if you ever have to evacuate to a hotel or whatever.) - Unpaid Caregiver

- Develop an emergency kit checklist specific to people living with dementia, including the provision of cognitive games, medical equipment/ supplies, familiar clothing and personal items, familiar food/snacks, and medication. This checklist could be provided to people living with dementia and unpaid caregivers.

- Raise caregiver awareness about their own mental health, especially following climate-related emergencies, and provide support resources specific to their needs.

"We need information on caregiver burnout and also respite care and focus about people dealing with it personally." – Paid Care Provider

- Provide a description of the types of climate-related emergencies, their possible impacts on a person living with dementia, and signs to look for when considering changing health conditions related to dementia to keep them safe and healthy. This would support unpaid



caregivers' in identifying actions that may be required prior to, and during the climate-related emergency to keep the person they care for safe and comfortable.

« Il faut informer les aidants naturels de c'est quoi une situation dangereuse. Desfois, on pense que de faire chaud ou froid, c'est normal mais on oublie que ça peut avoir un impact important pour les personnes [atteintes de démence]. » (Caregivers need to be informed about what a dangerous situation is. Sometimes, we think that hot or cold is normal but we forget that it can have a significant impact on people living with dementia.) - First Responder

- Give information on how to prepare for various climate-related emergency situations in the form of scenarios (e.g., suggesting what to do before, and during a wildfire; what to do in the case of an evacuation order).
- Provide advice on how to communicate with people living with dementia during and after a climate-related emergency.
- Provide access to services, including specialized care, that can come to the home during climate-related emergencies.
- Financial support during evacuations (e.g. cost to travel to a hotel).

Tools and Resources

- Offer a dedicated phone number for unpaid caregivers and people living with dementia where questions can be answered.
- Consider the use of AI (artificial intelligence) in the creation of an easily accessible information source that unpaid caregivers can use to direct their questions (ideally phone in).
- Offer support groups for caregivers (in-person or online).
- Develop an alert system (i.e. a cell phone alert) that would provide notice to unpaid caregivers, allowing those who are more vulnerable to have more time to prepare.
- Offer interactive workshops that provide an opportunity for discussion.

"I feel like everything is great in writing, pieces of legislation, toolkits, accessibility is there. But I am a big advocate of face-to-face workshops and having an open dialogue. Even a web meeting; or a video workshop; or in-person. Or even a recorded video." - Paid Care Provider



Desired Tools and Resources to Assist Paid Care Providers and First Responders with Meeting the Needs of People Living With Dementia

Suggestions to support professionals who are responding to the needs of people living with dementia during climate-related emergencies primarily relate to the provision of information on the specific needs of each individual, and access to professional resources.

The following provides a summary of desired information, tools, resources, and training to guide in responding to the needs of people living with dementia during a climate-related emergency.

Information

- Develop a health Information form (similar to Green Sleeve) to provide first responders information specific to the needs of each person living with dementia during climate-related emergencies.
- Introduce a standard door safety sign / decal that can be placed on the main entry doors of homes with people living with dementia to allow first responders to readily identify characteristics of the call and look for relevant information related to the person living with dementia.

“You have alarm stickers on windows, stickers on doors for first responders that identify if a pet is in the house. Why not have a sticker on the door that helps us to identify when someone has dementia?” - First Responder

- Put together information packages for physicians, to be shared with people at the time dementia is diagnosed.
- Provide ongoing weather alerts to supportive or long-term care homes in anticipation of a climate-related emergency, and during the event, to allow them to staff appropriately to support the needs of people living with dementia under their care.
- Make it easier for paid care providers and first responders to access the medical records of people living with dementia, notably in terms of medications they use and their schedules.

“I don’t have access to the full [medical] information on a resident with dementia and because there are vast degrees [of the condition], everyone is different. If I don’t know that person’s history, you are working in blind. Information is key to all of this.” - Paid Care Provider



Tools and Resources

- Develop a national vulnerable person registry and coordination of the provincial or municipal tools that currently exist, for consistency across the country.

“I worry that they would lose the cell phone or did not bring with them. Something is needed to make sure we can find them. Watches or bracelets identifying where they are would be nice. Some kind of GPS tracker.” - Government/Logistical Planner

- Develop an app that provides information on how to respond to the needs of people living with dementia in different scenarios, including different versions for unpaid caregivers and first responders.
- Provide sufficient funding to ensure equitable service delivery within rural and remote communities.
- Have a dedicated phone number to reach a psychiatric nurse or related health care professional with expertise in dementia for first responders to access advice in smaller communities (a direct priority line). This ideally would be available 24/7.
- Consider the importance of incorporating in-person check-ins to assess the situation with people living with dementia and their environment, in addition to connecting with them by telephone during an emergency situation.

« Il faut une présence physique d'un aidant pour constater l'état des lieux [lors d'une urgence climatique]. Par téléphone, les personnes ne sont pas toujours cohérentes. » (It takes a caregiver to assess the situation onsite [during a climate emergency]. On the phone, people are not always coherent.) - Government/Logistical Planner

Training

- Develop a standardized system of training (for all unpaid or paid care providers).
- Add a component concerning vulnerable audiences, that considers the particular needs of people living with dementia, to existing ICS training (Incident Command System – a command system that is taught to all first responders).
- Coordinate the establishment of a pool of unpaid caregivers with basic training who can support hospital staff / volunteers when needed.



Additional Suggestions for Supporting Professionals in their Roles to Respond to the Needs of People Living with Dementia During Climate-Related Emergencies

Increased leadership in coordinating preparedness efforts is desired to support the needs of people living with dementia during climate-related emergencies.

Although not directly related to the development of information, tools, resources or training to respond to the needs of people living with dementia during climate-related emergencies, a number of suggestions warrant consideration.

- Development of specialized teams for people living with dementia, including behavioural specialists, personal support workers, etc.
- Ensure there are enough emergency personnel (including paid care providers) who are familiar with the culture of the north.

“Cannot easily bring supports from outside the north/area because they don’t know the culture / norms.” – Paid Care Provider

- Encourage long-term care homes to prepare an emergency preparedness plan specific to climate-related emergencies.

“We have had heat emergencies and fire emergencies and there isn’t a lot of structure from upper management. Most of the nurses I work with are using common sense. Emergency situation plans are in place but not for climate-related emergencies.” - Paid Care Provider

- Encourage communities to setup an emergency response plan, including pre-determined resources, such as a coordinated emergency response team and resources specific to people living with dementia that unpaid caregivers can rely upon during climate-related emergencies for assistance if they reside in another community. This plan should be talked through ahead of a climate-related emergency to improve efficiency during the event.
- Encourage municipalities to develop evacuation protocols specific to people living with dementia, notably identifying an evaluation site that is adapted to their needs, with proper security measures and supportive resources.

“People are going to be housed in large areas [in case of evacuation] and it will be confusing and chaotic and extremely stress inducing. I would like to see small locations and someone in those locations dedicated on checking on people with needs. Someone reassuring and calm. If I can’t be there to be the reassuring factor, I would like to see someone tasked to deal with those needs.” - Unpaid Caregiver

“... when [sic] you are taking them from one place to the other that place also needs to be safe, safety measures put in place. If [people living with dementia] are in a place they do not know, they are looking to go home. You will need to increase supervision.” - Government/Logistical Planner



Conclusions

The following provides broad conclusions from the summary of research findings.

- ***Diminished cognitive abilities present significant challenges for those living with dementia during a climate-related emergency, which may also be exacerbated as a result of the event. Most notably this involves a lack of comprehension of what is happening and its personal implications, and an inability of some to effectively communicate or absorb information or instruction.***

During and after a climate-related emergency, people living with dementia experience a wide range of unique challenges and corresponding needs, all of which are intrinsically linked to the condition itself. That said, dementia symptoms can differ from one person to the next and can change over time. Depending on their level of cognitive impairment and the severity of their symptoms, some may face challenges with understanding what is happening, and its personal implications, and have difficulties being understood by others. With a disruption in their regular routine, and difficulty in understanding the situation and adapting, an individual's ability to cope with the emergency may be limited.

During times of evacuation, a variety of additional challenges are presented including a lack of clarity on what to pack, a lack of urgency or understanding of why evacuation is needed, and in what timeframe an action is needed. Moving a person living with dementia also presents several further challenges, most notably placement in an unfamiliar and potentially unsafe environment. The absence of normalcy in surroundings, contacts, and activities may present a serious challenge to a person living with dementia's ability to cope with the situation and function effectively.

- ***The needs of those living with dementia revolve around ensuring continuity of care, ready access to information to direct their care, regular contact, and a need for patience, reassurance and support. Clear, simplified messaging is also needed to guide their actions.***

The wide range of unique challenges experienced by those living with dementia highlight a variety of corresponding needs for the provision of care when faced with a climate-related emergency. Most notably, the primary needs of those living with dementia during an emergency revolve around ensuring a continuity in care, which is dependent upon ready access to current information to direct their care. This includes, but is not limited to, a clear baseline of their condition, medication listings, key contact information, and factors of consideration that calm or support the individual. In addition, regular contact from familiar care providers (paid or unpaid) with those living with dementia is deemed paramount in their care provision. Further, the importance of their role in mitigating impacts by providing information and knowing how to best reassure the person living with dementia is vital. Throughout the emergency, there is a need for patience, reassurance, and ongoing support. Clear, simplified messaging is also needed to guide their actions, ideally supported by visual cues.



- ***Unpaid caregivers are challenged by a lack of awareness of what needs to be done during a climate-related emergency, an unfamiliarity of available resources, conflicting responsibilities, and financial constraints.***

There was general agreement that unpaid caregivers often have difficulty coping during climate-related emergencies and need guidance on how to care for people living with dementia during an emergency. Directions for preparedness are needed, as is information on how to provide care during an emergency, such as the importance of checking in regularly. Providing this level of care can have a negative impact on caregiver wellbeing over time. They are also typically unaware of what emergency resources or supports are available to assist them, as well as what financial programs might be accessible for them. Elevated stress was seen as a severe impact of climate-related emergencies on unpaid caregivers, given their increased involvement and the need to manage their own family situation during the emergency.

- ***Climate-related emergencies were viewed as especially impactful for people living with dementia. Notably these events disrupt routines, and exacerbate the symptoms of their condition, as well as cause elevated stress for unpaid caregivers.***

There is widespread recognition that climate-related emergencies are especially impactful for people living with dementia, although how exactly is uncertain to most. The impact is most notable when the event disturbs their routine or the services and assistance they normally receive, leading to increased confusion, frustration, disorganization and a general worsening of their symptoms. That said, it was believed by participants that the impacts can be vastly different depending on the type and severity of climate-related emergency, the past experiences of people living with dementia, the stage of their condition, their living situation during the emergency, and the strength of their support network.

- ***Although few tools are relied upon by people living with dementia and unpaid caregivers right now to prepare for climate-related emergencies, there was interest in additional information and support.***

There was limited awareness of tools and resources available to assist people living with dementia and unpaid caregivers facing climate-related emergencies. Across participants, most relied on personal experiences to guide their interactions with people living with dementia during the emergency. As well, some utilized employer information, professional training, or networks available to paid care providers and first responders. Of the resources available, the Alzheimer Society of Canada was most cited and viewed as providing tailored tools for people living with dementia and unpaid caregivers, though very little specific to climate-related emergencies was known to be available. Other resources were far less commonly identified, with most being community- or province-specific.



There is interest in accessing additional information and resources particularly to assist unpaid caregivers with their role of keeping people living with dementia safe, supported, and informed. Topics of interest include understanding climate-related emergencies and how they may impact people living with dementia in unique ways, including their health; how to keep people living with dementia safe and healthy during the event; tips on how to best communicate with people living with dementia during emergencies; and how to stay prepared as the emergency situation evolves, including who to call and where to go for assistance.

Other types of desired resources and tools that focus on easy access to information were also seen as potentially playing an important role during climate-related emergencies. From the perspectives of first responders and paid care providers, having a national registry for vulnerable people and easy access to centralized information on each individual's health were seen as key ways to improve health care delivery during emergency situations. In addition, having a portal on dementia that provides information about how to prepare for emergencies and interact with, or respond to, various symptoms were seen as valuable resources for all participants.

When developing tools specific to people living with dementia, it was believed that a variety of formats and mediums should be considered to accommodate a diversity of abilities and cultures, in addition to offering the material in different languages with clear and simplified terminology used throughout. Attention should also be paid to developing national protocols or guidelines that can be used by long-term care /settings, municipalities, and provinces to ensure some consistency in the level and type of response.



Direction

These research findings have uncovered many suggestions for how to protect and support people living with dementia during climate-related emergencies and also prepare for future events. Although several suggestions were made throughout the report, the below highlights few key recommendations to be considered:

1. Public education for unpaid caregivers of those living with dementia should be a priority.

Findings confirm that unpaid caregivers are largely unprepared to support people living with dementia during emergency situations. Not only are they unaware of what actions should be taken during times of emergencies to support the person living with dementia, there is also clearly a void in terms of information to direct their efforts. Unpaid caregivers, first responders, and paid care providers confirmed that the actions and involvement of unpaid caregivers are fundamental to the successful continuation of care. Efforts to educate unpaid caregivers are needed through the development information tools (including direction for the development of an emergency kit and how to interact with people living with dementia during emergency situations), and the introduction of appropriate supports to ensure unpaid caregivers' actions are effective during times of climate-related emergencies. They are also best positioned to support people living with dementia, and thus should be made aware of resources specifically developed for them.

2. A process for ensuring care providers have access to current information on the health status of people living with dementia during emergency situations should be implemented.

First responders and paid care providers generally lack current information on the health status of people living with dementia when responding during emergencies. Indeed, it is not clear when or if a call for assistance involves a person living with dementia and the state of their condition or symptoms is often unknown to the first responder, negatively impacting the efficient provision of care and support. Efforts in some provinces (e.g. Green Sleeves in Alberta, and information sheets in areas in Ontario) have been well received by first responders for providing a baseline when addressing the needs of people living with dementia during climate-related emergencies. First responders and those living with dementia would be best served by the development and implementation of a standardized approach that compiles current information and can be readily available in the home.

3. Development of specialized training and/or directed resources for first responders to guide their response to people living with dementia during a climate-related emergency should be considered.

Specific training on how to effectively respond to the needs of those living with dementia during times of emergency is lacking and limited to isolated initiatives. Across the country, first responders generally rely on their lived experiences to direct their actions. The development of standardized training (which could be included in Incident Command System training) would go a long way to guide their efforts. Similarly, there is interest in having an app developed for first



responders that provides direction or suggestions on how to respond to dementia-related situations during an emergency, among other resources. Dedicated access to health care professionals with expertise in dementia would also help support first responders' interactions during an emergency situation.

Appendix A:

Recruitment Screener

Health Canada: Emergency Preparedness Dementia Study Recruitment Screener – Final

Name: _____

Home phone: _____ Work phone: _____ Cell: _____

Email: _____

Community: _____ Province: _____

SECTION 1: Schedule & Specifications

Group	AST	EST	Participant Time	Length (min)	Audience	Language	Moderator
Thursday, January 25, 2024 1, 2024							
1	5:00pm	4:00pm	3:00pm CT/SK/2:00pm MT/1:00pm PT	90	West; First/Emergency Responders; Large/Medium Urban	EN	CP
2	9:00pm	8:00pm	7:00pm CT/SK/6:00pm MT/5:00pm PT	90	West; Unpaid Care; Large Urban	EN	CP
Friday, January 26, 2024							
3	2:00pm	1:00pm	1:00pm ET 2:00pm AT/2:30pm NT	90	East; Professional Care; Large Urban	EN	MB
Monday, January 29, 2024							
4	2:00pm	1:00pm	1:00pm ET/2:00pm AT/2:30pm NT	90	East; Professional Care; Small/Medium Urban	EN	CP
5	3:00pm	2:00pm	2:00pm ET/3:00pm AT/3:30pm NT	90	East; First/Emergency Responders; Large/Medium Urban	EN	MB
6	5:00pm	4:00pm	3:00pm CT/SK/2:00pm MT/1:00pm PT	90	West; Professional Care; Large Urban	EN	CP
7	6:00pm	5:00pm	5:00pm ET/6:00pm AT/6:30pm NT	90	East; Unpaid Care; Small/Medium Urban	EN	MB
Tuesday, January 30, 2024							
8	10:30am	9:30am	9:30am ET/10:30am AT/11:00am NT	90	East; Government/Community; Large/Medium Urban	EN	CP
9	11:00am	10:00am	10:00am ET/11:00am AT/11:30am NT	90	East; Government/Community; Small Urban/Rural	EN	LG
10	1:00pm	12:00pm	11:00am CT/SK/10:00am MT/9:00am PT	90	West; Government/Community; Large/Medium Urban	EN	CP
11	5:00pm	4:00pm	3:00pm CT/SK/2:00pm MT/1:00pm PT	90	West; Professional Care; Small/Medium Urban	EN	LG
12	6:30pm	5:30pm	5:30pm ET/6:30pm AT/7:00pm NT	90	East; Unpaid Care; Large Urban	EN	MB
13	9:00pm	8:00pm	7:00pm CT/SK/6:00pm MT/5:00pm PT	90	West; Unpaid Care; Small/Medium Urban	EN	MB
Wednesday, January 31, 2024							
14	2:00pm	1:00pm	12:00pm CT/SK/11:00am MT/10:00am PT	60	West; PLWD; Large Urban	EN	MB
15	5:00pm	4:00pm	3:00pm CT/SK/2:00pm MT/1:00pm PT	90	West; Professional Care; Rural	EN	MB
16	6:00pm	5:00pm	5:00pm ET/6:00pm AT/6:30pm NT	90	East; Unpaid Care; Rural	EN	LG
17	9:00pm	8:00pm	7:00pm CT/SK/6:00pm MT/5:00pm PT	90	West; Unpaid Care; Rural	EN	LG

Group	AST	EST	Participant Time	Length (min)	Audience	Language	Moderator
Thursday, February 1, 2024							
18	12:00pm	11:00am	11:00am ET	90	Quebec; Government/Community; Mixed Urban	FR	CP
19	3:00pm	2:00pm	2:00pm ET	90	Quebec; Professional Care; Mix Urban	FR	CP
20	7:00pm	6:00pm	6:00pm ET	90	Quebec; Unpaid Care; Mix Urban	FR	CP
21	1:00pm	12:00pm	11:00am CT/SK/10:00am MT/9:00am PT	90	West; Government/Community; Small Urban/Rural	EN	LG
22	2:00pm	1:00pm	1:00pm ET/12:00pm CT/SK/11:00am MT/10:00am PT	60	West/Central; PLWD; Rural	EN	MB
23	3:30pm	2:30pm	2:30pm ET/3:30pm AT/4:00pm NT	90	East; First/Emergency Responders; Small Urban/Rural	EN	LG
24	5:00pm	4:00pm	3:00pm CT/SK/2:00pm MT/1:00pm PT	90	West; First/Emergency Responders; Small Urban/Rural	EN	MB
Monday, February 5, 2024							
25	12:00pm	11:00am	11:00am ET	60	Quebec; PLWD; Mixed Urban	FR	CP
26	11:30am	10:30am	10:30am ET/11:30am AT/12:00pm NT	60	East; PLWD; Small/Medium Urban	EN	MB
27	2:00pm	1:00pm	1:00pm ET/2:00pm AT/2:30pm NT	90	East; Professional Care; Rural	EN	MB
28	2:30pm	1:30pm	1:30pm ET	90	Quebec; First/Emergency Responders; Mixed Urban	FR	CP

Focus Group Segmentation (by audience, market, discussion length, and language)

Audience	Length	Large Urban	Large/Medium Urban	Small/Medium Urban	Small Urban/Rural	Rural	Mixed Urban	Total Groups	Total Recruits
Unpaid Care Provider	Up to 2 h	2 English Groups East / West	n/a	2 English Groups East / West	n/a	2 English Groups East / West	1 French Group Quebec	7	49 (7 per group)
Professional Care Providers: Paid Personal Care Workers / Health Aides / Other Paid Care Providers	Up to 2 h	2 English Groups East / West	n/a	2 English Groups East / West	n/a	2 English Groups East / West	1 French Group Quebec	7	49 (7 per group)
First Responders / Emergency Responders	Up to 2 h	n/a	2 English Groups East / West	n/a	2 English Groups East / West	n/a	1 French Group Quebec	5	35 (7 per group)
Government and Community Organizers / Emergency Response Planners/Logistical Experts	Up to 2 h	n/a	2 English Groups East / West	n/a	2 English Groups East / West	n/a	1 French Group Quebec	5	30 (6 per group)
People living with Dementia	1 h	1 English Mini Group West	n/a	1 English Mini Group East	n/a	1 English Mini Group West/Central	1 French Mini Group Quebec	4 Mini	16 (4 per group)

TOTAL	5	4	5	4	5	5	28	179
--------------	----------	----------	----------	----------	----------	----------	-----------	------------

Specification Summary

- | | |
|---|--|
| <ul style="list-style-type: none"> ● Number of groups: Twenty-eight (28) focus groups in total of various sizes. The distribution of focus groups by length, size, audience, geographic location and language is specified in the table above. ● Community sizes: these are defined as: <ul style="list-style-type: none"> ○ Large Urban (pop. 150,000+) ○ Rural (pop. Less than 10,000 and min. 50km from urban centre) ○ Small/Medium Urban (pop. 10,000-149,999) ○ Mixed Urban (pop. 30,000+) and aim for some rural ● Geography: In each group, include a good mix of provinces/territories within each region and a good mix of locations within Quebec. Regions include: East (ON/NB/NS/PE/NL/NU); West (MB/SK/AB/BC/YT/NT); West/Central (ON/MB/SK/AB/BC/YT/NT); and Quebec. Recruit min 1 per English sessions from the North. ● Recruits: Total of 179 recruits across all groups. ● Audiences: <ul style="list-style-type: none"> ○ Unpaid Care Providers (7 groups; 49 recruits): (family members, friends, neighbours, volunteers) who provide care and support to an individual living with dementia, who is not a paid care professional or personal care worker. This support may include assisting with the activities of daily living and helping with advance care planning. Mix of gender and cultural background. ○ Professional Care Providers (7 groups; 49 recruits): Paid personal care workers / health care aides (title for this occupation varies by jurisdiction). Developmental service workers. Health Professionals (including primary care physicians, general practitioners, nurse practitioners, geriatric care specialists, registered nurses, occupational therapists and pharmacists) ○ First/Emergency Responders (5 groups; 35 recruits): Front-line Emergency Response /emergency preparedness workers who have interacted with PLWD during emergencies, namely first responders (e.g., ambulance, fire, police, military, search & rescue). | <ul style="list-style-type: none"> ● Audiences (continued): <ul style="list-style-type: none"> ○ Government/Community (5 groups; 30 recruits): Includes Government (e.g., front line response at any level of government) and community organizations (e.g., public health, emergency services, non-profit organizations providing supplies such as shelter, food, and clothing during emergencies, religious/faith communities); and Emergency response planners/logistical experts who may not have direct contact but who need to incorporate/do incorporate considerations for vulnerable populations into their work ○ People Living with Dementia (4 mini groups; 16 recruits): Individuals who have been diagnosed with dementia. Only includes individuals who have the capacity to take part in an online group discussion without assistance. Only include those who have experienced a climate-related emergency. It is expected that some, or all of those participants will be accompanied by a caregiver during the focus group. Mix of gender and cultural background. ● Incentive: <ul style="list-style-type: none"> ○ \$150 (Unpaid Care Provider) ○ \$200 (Professional Care Providers) ○ \$150 (First/Emergency Responders) ○ \$150 (Government/Community) – where deemed appropriate ○ \$200 (People Living with Dementia) ● # of participants recruited per group <ul style="list-style-type: none"> ○ Unpaid Care Provider: 7 recruited ○ Professional Care Providers: 7 recruited ○ First/Emergency Responders: 7 recruited ○ Government/Community: 6 recruited ○ People Living with Dementia: 4 recruited ● Length of discussion: <ul style="list-style-type: none"> ○ People living with dementia: 1 hour ○ All other audiences: up to 2 hours |
|---|--|

RECRUITER NOTE - WHEN TERMINATING AN INTERVIEW, SAY: “Thank you very much for your cooperation. We are unable to invite you to participate because we have enough participants who have a similar profile to yours.” RECRUITER NOTE: If a respondent wishes to verify the validity of the study, please contact: Narrative Research: 888-414-1336; focusgroups@narrativeresearch.ca

SECTION A: General Introduction

Hello, my name is _____ and I am calling on behalf of Narrative Research, a national market research company. Would you prefer that I continue in English or French? / Pr  f  rez-vous continuer en fran  ais ou anglais?

RECRUITER NOTE - FOR ENGLISH GROUPS, IF PARTICIPANT WOULD PREFER TO CONTINUE IN FRENCH, PLEASE RESPOND WITH: "Malheureusement, nous recherchons des gens qui parlent anglais pour participer   ces groupes de discussion. Nous vous remercions de votre int  r  t."

Let me assure you that we are not trying to sell you anything. We are conducting market research on behalf of the Government of Canada and are looking for a variety of people to take part in a small online group discussion called focus groups. The focus groups we are recruiting for will be held from <INSERT DATES> and those who qualify and take part in the group discussion will receive a financial incentive.

Participation in this research is voluntary and completely anonymous and confidential. No attempt will be made to sell you anything or change your point of view. The format of the focus group is an informal small group discussion led by a professional moderator. The session is held online on the Zoom platform, and will require the use of a computer or tablet equipped with a microphone, speakers and ideally, a webcam.

Would you have a few minutes right now so I can provide you more information about the study and to find out if you are the type of participant we are looking for? This should take between 5 and 15 minutes, depending on your responses.

Yes 1

No 2 **SCHEDULE CALL BACK IF POSSIBLE & THANK & TERMINATE**

INSTRUCTIONS: If yes continue; if no, thank & terminate

****IF ASKED: The personal information you provide is protected in accordance with the Privacy Act and is being collected under the authority of section 4 of the Department of Health Act. The information you provide will not be linked with your name on any document including the consent form or the discussion form. In addition to protecting your personal information, the Privacy Act gives you the right to request access to and correction of your personal information. You also have the right to file a complaint with the Office of the Privacy Commissioner if you feel your personal information has been handled improperly.***

[IF ONLINE, PROVIDE A LINK TO NARRATIVE RESEARCH'S PRIVACY POLICY AT THE BOTTOM OF EACH PAGE: <https://narrativeresearch.ca/privacy-policy/#politique-de-confidentialit C3%A9>]

[IF BY PHONE: Narrative Research's privacy policy is available upon request. IF ASKED, PROVIDE PRIVACY POLICY LINK BY PHONE OR RECORD EMAIL WHERE IT WILL BE SENT]

This research is registered with the Canadian Research Insights Council Research Verification Service.

[IF NEEDED, SPECIFY: to verify the research, you can visit <https://canadianresearchinsightscouncil.ca/rvs/home/?lang=en>
 The survey registration number is: 20231214-NA352

The purpose of this group discussion is to explore the needs of people living with dementia and unpaid family or friend caregivers, during and after a climate-related emergency and learn more about what is needed to support them during such events.

We are looking to speak with people who have experienced climate-related emergency events within the last few years. This refers to emergency situations such as: extreme heat and cold events, forest fires / wildfires, severe air pollution (including wildfire smoke), floods with heavy rain and snow (e.g, atmospheric rivers, bomb cyclone snowstorms), heavy ice storms, severe winds, hurricanes, and tornadoes AND who are one or more of the following:

- someone living with dementia
- family/friend dementia caregivers (those providing unpaid care)
- first responders and health professionals who have provided assistance during climate emergencies that is likely to have reached and supported people living with dementia and dementia caregivers
- government and community representatives who are involved in providing support resources during climate-related emergencies

Now I have a few questions to see if you are the type of participant we are looking for. This should take between 7 and 10 minutes. Would you like to continue?

- Yes 1
- No 2 **THANK & TERMINATE**

To begin, do you or anyone in your household currently work or have ever worked in any of the following areas?

	Current Work	Past Work
Marketing/Market Research.....	1.....	5
Advertising or Media (TV, Radio, Newspaper).....	2.....	6
Web developer.....	3.....	7
Health-related communications position for the federal or provincial government.....	4.....	8

INSTRUCTIONS: If yes to any of the above, thank & terminate

AUDIENCE PROFILE

We are looking to speak with a variety of people for this study, including people who have been diagnosed with dementia and would be comfortable participating in a focus group. Would there be someone in your household, including you, who has this condition?

- Yes, self 1
 Yes, someone else from household 2
 No 3

INSTRUCTIONS: If yes, self, consider for **PEOPLE LIVING WITH DEMENTIA GROUPS** and continue to **QP3**; if yes, someone else, ask to speak to that person if possible and repeat intro; if no, continue to **QP4** and consider for all other groups

[IF “YES, SELF” AT QA1 – PEOPLE LIVING WITH DEMENTIA] Would you like to take the time to review the list of screening questions before answering them, or would you like to go through the screening questionnaire right now? Note that this is not a test and there are no right or wrong answers to those questions.

- Prefers to review questions1
 Prefers to go through screening questions now ..2

INSTRUCTIONS: If prefers to review questions (code 1), record email and send them the screener questions. Schedule call-back to go through the screener with them. If prefers to go through screening questions now, continue to **QP7**.

We are also looking to speak with someone who is currently interacting with a person or more than one person living with dementia, to provide support and care in either a unpaid or paid capacity. This could include paid or unpaid caregivers, health care providers, social workers, therapists, and first responders, among other types of work. Would that describe your situation or that of someone else in your household?

- Yes, self 1
 Yes, someone else from household 2
 No 3

INSTRUCTIONS: If yes, self (Code 1), consider for **UNPAID CAREGIVER GROUPS** or **PROFESSIONAL CARE GROUPS** or **FIRST/EMERGENCY RESPONDERS** and skip to **QP7**; if yes, someone else (Code 2), ask to speak to that person if possible and repeat intro; if no (Code 3), continue to **QP5**;

If necessary, specify that the type of person we are looking for include unpaid caregivers (friend, relative, neighbour) or paid caregiver (including first responders, healthcare providers, social workers, occupational therapists, developmental service workers and personal care workers among other types of work).

We are also looking to speak with front-line government employees and community organization representatives who deliver response services in emergencies (e.g. providing shelter, food, clothing and other essential resources directly to individuals during emergencies – could include a variety of community organizations such as religious/ faith communities). Would that describe your situation or that of someone else in your household?

- Yes, self 1
 Yes, someone else from household 2
 No 3

INSTRUCTIONS: If yes, self (Code 1), consider for **GOVERNMENT/COMMUNITY GROUPS and continue to **QP7**; if yes, someone else (Code 2), ask to speak to that person if possible and repeat intro; if no (Code 3), continue to **QP6**;**

If necessary, specify that the type of person we are looking for include front line response at any level of government, and community organizations (e.g., public health, emergency services, non-profit organizations providing supplies such as shelter, food, and clothing during emergencies, religious/faith communities).

We are also looking for emergency response planners and logistical experts involved in the development, delivery and / or evaluation of emergency response plans. Would that describe your situation or that of someone else in your household?

- Yes, self 1
 Yes, someone else from household 2
 No 3

INSTRUCTIONS: If yes, self (Code 1) at **QP6, consider for **EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS** and continue to **QP7**; If yes (code 1) to both **P5** and **P6**, prioritize for **EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS GROUPS** continue to **QP7**; if yes, someone else (Code 2), ask to speak to that person if possible and repeat intro; if no (Code 3), thank & terminate.**

[ASK ALL] Within the past five years, have you personally experienced a climate-related emergency situation in your area, such as an extreme heat or cold event, forest fire / wildfire, severe air pollution (including wildfire smoke), flood with heavy rain and snow (e.g. atmospheric rivers, bomb cyclone snowstorms), heavy ice storm, severe winds, hurricane, or tornado?

- Yes 1
 No 2

INSTRUCTIONS: For **PEOPLE LIVING WITH DEMENTIA: If code 1 (yes), continue; if code 2 (no), thank & terminate; **ALL OTHER AUDIENCES**, continue**

P7A. **[ASK IF CODE 1 (YES) AT P7]** What kinds of climate emergency situations have you experienced within the past five years?

- Extreme heat or cold event.....1
- Forest fire / Wildfire.....2
- Severe air pollution (including wildfire smoke)3
- Flood with heavy rain and snow (e.g., atmospheric rivers, bomb cyclone snowstorms) .4
- Heavy ice storm.....5
- Severe winds6
- Hurricane or tornado7
- Other (Please specify: ___)8

INSTRUCTIONS: Aim for a mix in each group

[ASK IF CODE 1 (YES) AT P7] Have you been displaced from your home during one of those climate-related emergency situations? That is, have you been required to leave your home because of the emergency?

- Yes 2
- No 3

INSTRUCTIONS: PLWD GROUPS: aim for min 2 of 4 per group who answer ‘Yes’. Skip to QP11. ALL OTHER GROUPS: Continue

A) [ASK UNPAID CARE; PAID CARE; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY; EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS] Within the past five years, in your role as [insert role discussed above] have you interacted with one or more persons living with dementia during, or immediately after, an extreme heat or cold event, forest fire / wildfire, severe air pollution (including wildfire smoke), flood with heavy rain and snow (e.g, atmospheric rivers, bomb cyclone snowstorms), heavy ice storm, severe winds, hurricane, or tornado?

- Yes 1
- No 2

INSTRUCTIONS:

For **UNPAID CARE GROUPS** all must say ‘yes’, continue to QP9B; if no, thank & terminate;

For **PAID CARE**, and **FIRST/EMERGENCY RESPONDERS**, recruit min 5 of 7 per group who say ‘yes’ and continue to P9B; if ‘no’, ask P9C.

For the; **GOVERNMENT/COMMUNITY; EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS**, recruit min 4 of 6 per group who answer ‘yes’ and continue to P9B; if ‘no’, ask P9C.

P9 B) **[ASK IF CODE 1 (YES) AT P9A]** What kinds of climate emergency situations have those people experienced?

- Extreme heat or cold event.....1
 Forest fire / Wildfire.....2
 Severe air pollution (including wildfire smoke)3
 Flood with heavy rain and snow (e.g., atmospheric rivers, bomb cyclone snowstorms).4
 Heavy ice storm.....5
 Severe winds6
 Hurricane or tornado7
 Other (Please specify: ___)8

INSTRUCTIONS: Aim for a mix in each group; Skip to P10

P9. C) **[IF NO TO P9A AND PAID CARE; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY; EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS]** Within the past five years, have you had to consider the specific needs of people living with dementia in developing or implementing responses for climate-related emergencies?

- Yes 1
 No 2

INSTRUCTIONS: Recruit max 2 per group for PAID CARE; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY; EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS; If no, thank & terminate

[ASK UNPAID CARE; PAID CARE; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY; EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS] Have any of those people been displaced from their homes / living situations during one of those climate-related emergency situations? That is have those people been required to leave the building they are living in because of the emergency?

- Yes 1
 No 2
 Unsure 3

INSTRUCTIONS: Aim for min 2 per group who answer 'yes'; continue to QP11

PARTICIPANT PROFILE

The next two questions will provide us with a profile of who is attending the focus group.

A) [ASK ALL] In which community (town, city or village) and province/territory do you currently live?

Record name of community: _____

Record name of province/territory: _____

INSTRUCTIONS: For GOVERNMENT/COMMUNITY and EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS GROUPS, use QP24 as the geographic marker for recruitment

P11 B) [ASK UNPAID CARE; PAID CARE; FIRST/EMERGENCY RESPONDERS] In which community (town, city or village) and province/territory does the person or people living with dementia with whom you interacted during, or immediately after, a climate-related emergency live?

Record name of community: _____

Record name of province/territory: _____

INSTRUCTIONS: Note geographic breakdown by provinces/territories for English groups and Quebec regions for French groups. Recruit a good mix of locations in each group. Note the community size to align with the focus group breakdown. For English sessions, recruit 1-2 from northern territories in each group.

[ASK ALL] How long have you lived in <INSERT PROVINCE/TERRITORY FROM P11A>?

RECORD # of Years: _____

INSTRUCTIONS: Thank & Terminate if less than 2 years. UNPAID CARE, PAID CARE, and FIRST/EMERGENCY RESPONDERS, continue; PLWD, skip to QP17; GOVERNMENT/COMMUNITY and EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS, skip to QP24.

[ASK UNPAID CAR, PAID CARE and FIRST/EMERGENCY RESPONDERS] Do you currently provide unpaid or paid care or support to a person or more than one person who has been diagnosed with dementia?

Yes 1

No 2

INSTRUCTIONS: If yes, continue; if no, thank & terminate

[ASK UNPAID CAR, PAID CARE and FIRST/EMERGENCY RESPONDERS] Which of the following best describes your role in providing care or assistance?

I interact with people who have been diagnosed with dementia as part of my work or my paid activities 1

I am an unpaid caregiver to a person who has been diagnosed with dementia, providing support in an unpaid capacity..... 2

INSTRUCTIONS: If code 1 (professional), consider for PAID CARE GROUPS; if code 2 (personal, unpaid), consider for UNPAID CARE GROUPS

[ASK UNPAID CAR, PAID CARE and FIRST/EMERGENCY RESPONDERS] How often do you interact with people who have been diagnosed with dementia? Would you say...

Daily..... 1

A few times a month 2

Once a month..... 3

- A few times every year.....4
 Once a year or less5

INSTRUCTIONS: Recruit at least 3 OF 7 per group who answered daily or a few times a month for PAID CARE GROUPS and FIRST/EMERGENCY RESPONDER GROUPS and all 7 in UNPAID CARE GROUPS must be at least once a month. PAID CARE and FIRST/EMERGENCY RESPONDERS, skip to QP23

[ASK UNPAID CARE] What is your relationship with the person or people living with dementia for whom you provide unpaid care or assistance?

- I am a family member of that person/those people..... 1
 I am a friend or acquaintance of that person/those people..... 2
 I am a neighbour of that person/those people..... 3
 Other (Specify: ____) 4

INSTRUCTIONS: Recruit a mix in each UNPAID CARE GROUPS if possible

[ASK PEOPLE LIVING WITH DEMENTIA & UNPAID CARE] In which age group are you?

- Less than 18..... 1
 18-29 2
 30-39 3
 40-49 4
 50-59 5
 60-64 6
 65-69 7
 70-74 8
 75-79 9
 80-85 10
 More than 85 years old 11

[ASK PEOPLE LIVING WITH DEMENTIA & UNPAID CARE] What is your gender?

- Man 1
 Woman; or 2
 Prefer to self-identify (Please specify: ____) 3
 Prefer not to answer 4

INSTRUCTIONS: Aim for a mix of gender in each group. Skip to QP22.

[ASK UNPAID CARE] What is your current employment status?

- Working part-time or full-time, or self-employed 1
 Retired..... 4
 Unemployed..... 5
 Student..... 6

Other (Specify: _____) 7
 DK/NR..... 8

[IF EMPLOYED AT P19] In what sector do you work and what is your current occupation?

Sector: _____
 Occupation: _____

INSTRUCTIONS: Thank & Terminate if similar occupations as in QP1

[IF RETIRED AT P19] In what sector did you last work in before retirement and what was your occupation?

Sector: _____
 Occupation: _____

[ASK PEOPLE LIVING WITH DEMENTIA AND UNPAID CARE] To make sure that we speak to a diversity of people, could you tell me what is your ethnic background? **DO NOT READ – CODE ALL THAT APPLY**

White/European (for example, German, Irish, English, Italian, French, Polish, etc.) 1
 Hispanic, Latino, Spanish (for example, Mexican, Cuban, Salvadoran, Columbian, etc.) 2
 Black or African Canadian (for example, African Canadian, Jamaican, Haitian, Nigerian, Ethiopian, etc.) 3
 East Asian (for example, Chinese, Filipino, Vietnamese, Korean, etc.)..... 4
 South Asian (for example, East Indian, Pakistani, etc.) 5
 Middle Eastern or North African (for example, Lebanese, Iranian, Syrian, Moroccan, Algerian, etc.) 6
 Indigenous (e.g. First Nations, Métis, Inuit) 7
 Other (Specify: ___) 8
 Don't know / No response 9

INSTRUCTIONS: Recruit mix in PEOPLE LIVING WITH DEMENTIA GROUPS and UNPAID CARE GROUPS and skip to SECTION N

[ASK PAID CARE and FIRST/EMERGENCY RESPONDERS] In which capacity or role do you interact with people living with dementia as part of your work or paid activities; that is what type of work do you do?

[CONSIDER FOR FIRST/EMERGENCY RESPONDER GROUPS]

Police officer.....1
 Firefighter.....2
 Paramedic.....3
 Search and rescue4
 Dispatcher5
 Military personnel6

[CONSIDER FOR PAID CARE GROUPS]

Physician.....7

Specialist (psychologist, psychiatrist).....8
 Nurse9
 Geriatric care specialist10
 Pharmacist.....11
 Continuing Care Assistant (CCA)12
 Social worker13
 Therapist (occupational, physio, massage, etc.) ..14
 Dietitian/nutritionist15
 Developmental service worker16
 Paid personal care worker / health care aide17

[FOR ALL]

Other (Specify: ___)99

INSTRUCTIONS: If other, please verify validity with supervisor; Consider others based on the categories identified– recruit mix of employment in each group – limiting the number to 2 for each type of employment identified; Skip to SECTION N

[ASK GOVERNMENT/COMMUNITY and EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS]

Which geographic and jurisdictional scope (e.g. municipal, provincial, regional, national) do you cover as part of your work relevant to response during emergencies?

Record geographic location(s): _____

Choose jurisdictional scope(s):

- Municipal1
- Provincial/territorial2
- Regional3
- National.....4

INSTRUCTIONS: Aim for a mix in each group based on the session geographic scope

[ASK GOVERNMENT/COMMUNITY and EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS] For

which organization or government department do you work?

RECORD NAME: ____

[ASK GOVERNMENT/COMMUNITY and EMERGENCY RESPONSE PLANNERS OR LOGISTICAL EXPERTS]

What is your title and briefly describe the nature of your work related to emergency response.

TITLE: _____

NATURE OF WORK: _____

SECTION N: Netfocus Questions

The focus groups for this project will be conducted online on the Zoom platform and will require the use of a laptop or desktop computer, or a computer tablet, connected to high-speed Internet and equipped with a webcam, a microphone and speakers. **Note that you cannot use a smartphone to access the**

online session. The screen of those electronics is simply too small for the purpose of this research project.

Do you have access to a laptop or desktop computer, or a computer tablet, with high-speed Internet to take part in this focus group? **[MULTIPLE RESPONSES KEEPING CODE 3 EXCLUSIVE]**

Yes, laptop or desktop computer1
 Yes, computer tablet2
 No3

INSTRUCTIONS: If no, thank & terminate

Is the computer or tablet you will use for the focus group equipped with a webcam, a microphone and speakers you will be able to use?

Yes, webcam, microphone, and speakers1
 Yes, microphone and speakers only2
 No3

INSTRUCTIONS: If no, thank & terminate; webcams are not necessary for remote participants

You will need to be in a place that is quiet and free of distractions for the duration of the session. This includes being on your own, without pets, children or other people nearby, and in a quiet room. **An outdoor area, a vehicle, or a public place are NOT acceptable locations.** Are you able to secure a quiet environment without distractions or noises for the duration of the focus group session?

Yes1
 No2

INSTRUCTIONS: If no, thank & terminate

INSTRUCTIONS FOR NF1-NF3 THANK & TERMINATE: Based on your responses, we are unable to invite you to take part in this online focus group, as you do not meet the technical or logistic requirements. We thank you for your interest in this research.

SECTION R: Previous Focus Group Experience Questions

I just have a few more questions...

Have you ever attended a group discussion or interview for which you received a sum of money?

Yes1
 No2

INSTRUCTIONS: If yes, max of half of the recruits in each group; If no, skip to SECTION I: INVITATION

When was the last time you attended a group discussion or interview? _____

How many groups or interviews have you attended in the past 5 years? _____ **MAX 4**

What was the subject(s) of the focus group(s) or interview? _____

SECTION I: Invitation

Based on your responses so far, we would like to invite you to participate in a small group discussion that will be conducted online at <INSERT TIME> on <INSERT DATE>. The session will bring together up to **[PEOPLE LIVING WITH DEMENTIA: 4] [ALL OTHERS: 7]** people and it will last **[INSERT DISCUSSION LENGTH]**. We will send you a link to join the online focus group via Zoom. The purpose is to explore the needs of people living with dementia and unpaid family or friend caregivers, during and after a climate-related emergency, and learn more about what is needed to support them during such events. In appreciation for your time to attend the focus group, you will receive **[INSERT INCENTIVE AMOUNT]** after the session.

1. Are you available and interested in taking part in this focus group?

Yes 1

No 2

INSTRUCTIONS: If no, thank & terminate

2. The discussion in which you will be participating will be video recorded for research purposes only. Be assured that your comments and responses will not be attributed to you and that your name will not be included in the research report. Are you comfortable with the discussion being video recorded?

Yes 1

No 2

INSTRUCTIONS: If no, thank & terminate

3. There may be employees from the Government of Canada who will be listening in on the discussion. They will not be given the last names of participants. Are you comfortable with having observers?

Yes 1

No 2

INSTRUCTIONS: If no, thank & terminate

4. Which of the two official languages, English or French, do you speak most often on a regular basis?
[SINGLE RESPONSE]

English 1

French..... 2

Both equally 3

INSTRUCTIONS: Must answer French (code 2) or both (code 3) for Quebec groups

5. The group discussion will be held [**GROUPS X,X,X in French**] [**ALL OTHER GROUPS: in English**]. Participants may be asked to read simple text, write simple responses and/or review images during the session. Are you able to take part in these activities [**GROUPS X,X,X in French**] [**ALL OTHER GROUPS: in English**] on your own, without assistance?

Yes 1
 No 2
 Unsure 8

INSTRUCTIONS: If “no” or Unsure, thank & terminate

6. [**FOR PEOPLE LIVING WITH DEMENTIA GROUPS**] There will be someone available to assist you with the login process to join the online session. We will also provide you with the list of topics and questions that will be discussed during the focus group ahead of time. There will be a professional facilitator conducting the focus groups, and they will provide ample response time during the session for participants to share their opinions. Are there any other accommodations you may require to ensure you are able to participate in this focus group?

RECORD VERBATIM COMMENT: _____

INSTRUCTIONS: People living with dementia are permitted to have a caregiver or someone to support them during the focus group.

Could we please confirm the email address where we can send you the instructions to log in to the focus group session?

Record email address (and verify): _____.

We will send you by email the log-in instructions at least 1 day in advance of the group. The group discussion will begin promptly at **<TIME>** and will last [**INSERT DISCUSSION LENGTH**]. Please log in on time to ensure that the session is not delayed. If you arrive late, we will not be able to include you in the discussion and will not provide you with the incentive.

As mentioned, we will be pleased to provide everyone who participates with [**INSERT INCENTIVE AMOUNT**], provided by e-Transfer or cheque, as you'd prefer. It takes approximately 5 business days to receive an incentive by e-Transfer or approximately 2-3 weeks following your participation to receive an incentive by cheque.

7. Would you prefer to receive your incentive by e-Transfer or cheque?

e-Transfer 1
 Cheque 2

8. [**IF PREFER TO RECEIVE INCENTIVE BY E-TRANSFER – CODE 1 IN Q17**] Could you please confirm the e-mail address where you would like the e-transfer sent after the focus groups?

Email address: _____

And please confirm the spelling of your name: _____

The e-transfer password will be provided to you via email approximately 3-5 business days following the focus group

9. **[IF PREFER TO RECEIVE INCENTIVE BY CHEQUE – CODE 2 IN Q17]** Could I have the mailing address where you would like the cheque mailed after the focus groups? Note, you can expect to receive your incentive in approximately 2-3 weeks following the group.

Mailing address: _____

City: _____

Province: _____ Postal Code: _____

And please confirm the spelling of your name: _____

10. As these are very small groups and with even one person missing, the overall success of the group may be affected, I would ask that once you have decided to attend that you make every effort to do so. If you are unable to take part in the study, please call _____ (collect) at _____ as soon as possible so a replacement may be found. Please do not arrange for your own replacement.

So that we can call you to remind you about the focus group or contact you should there be any last-minute changes, can you please confirm your name and contact information for me? **[CONFIRM INFORMATION ALREADY COLLECTED AND CHANGE/COMPLETE AS NECESSARY]**

First Name: _____

Last Name: _____

Email: _____

Cell Phone: _____

Home Phone: _____

Work Phone: _____

INSTRUCTIONS: 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 focus group. If they still refuse THANK & TERMINATE.

Thank you for your interest in our study. We look forward to hearing your thoughts and opinions!

Attention Recruiters

1. Check the number of recruited participants per group according to the schedule
2. CHECK QUOTAS
3. Ensure participant has a good speaking (overall responses) ability-If in doubt, DO NOT INVITE
4. Do not put names on profile sheet unless you have a firm commitment.
5. Repeat the date, time and verify email before hanging up.

Confirming – DAY BEFORE GROUP

6. Confirm in person with the participant the day prior to the group– do not leave a message unless necessary

7. Confirm all key qualifying questions
8. Confirm date and time
9. Confirm they have received the login instructions

Appendix B:
Moderator's Guides

Emergency Preparedness Dementia Moderator's Guide – Final

Unpaid and Paid Care Providers; First/Emergency Responders; Government/Community/Logistical Experts

Study Objectives (do not share with participants)

- *Understand the unique needs of people living with dementia and family/friend caregivers during and after emergencies;*
- *Gather the nature of experiences of people living with dementia and family / friend caregivers during and after emergencies, including types of challenges;*
- *Understand the impact of emergencies on people living with dementia including on quality of life both during and after the emergency; and*
- *Identify resources and tools (including type of content) needed to protect and support quality of life of people living with dementia during emergencies and gather assessments of their availability and effectiveness.*

Introduction

15 minutes

- **Welcome:** Introduce self & research firm & role as moderator (keep on time/on topic)
- **Length, Sponsor & Topic:** Groups on behalf of the Public Health Agency of Canada; Federal government is looking to identify needs for people living with dementia and their caregivers during and after climate emergencies.

[**FOR UNPAID CAREGIVERS:** For the next 90 minutes or so, we will discuss your personal experience in relation to the person who you care for.]

[**FOR PAID CAREGIVERS; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY/ LOGISTICAL EXPERTS:** For the next 90 minutes or so, we will discuss your professional experience with these situations, either through direct interactions with people living with dementia or indirect involvement as a function of your work. We will also ask about your experience with those providing unpaid care to people living with dementia, often family and friends, who we will refer to as caregivers.]
- **Break:** I recognize that any discussion that involves the topic of dealing with emergency situations may spur emotions regarding these events, so feel free to step aside during our session if you feel the need. If possible, please use the chat function to let the moderator know that you are stepping aside and when you return.
- **Your Role:** Share your opinions freely and honestly; no prep needed; not testing your knowledge.
- **Process:** All opinions are important; looking to understand minority/majority of opinions; interested in hearing from everyone but participation is voluntary.
- **Logistic:** Video recording for reporting (the recording can be paused during the session if you feel more comfortable sharing your opinion on something without it being recorded – just let me know when this is the case); observation from government employees (listening in but not part of discussion).

- **Confidentiality:** Comments will not be attributed in the study report; no names in reports; answers will not affect dealings with Government of Canada.
- **Participant Introduction:**
 - **[UNPAID CARE PROVIDERS]** You all have one thing in common today: you provide care to someone living with dementia without financial compensation. First, tell us in which community do you live? What's your relationship to the person living with dementia to whom you are providing care? Dementia is an evolving condition where symptoms change over time. Can you briefly describe the current health condition, or dementia symptoms, of the person living with dementia you care for? How long have you been a caregiver to that person? Does that person live in the same community as you do? **[If not: probe on community]**
 - **[PAID CARE PROVIDERS & FIRST/EMERGENCY RESPONDERS]** You all have one thing in common today: as part of your work, you interact or are likely to interact with people living with dementia. First, tell us what is the nature of your work? In which community(ies) do you work? How long have you been doing this type of work? How often do you interact with people living with dementia?
 - **[GOVERNMENT/COMMUNITY/LOGISTICAL EXPERTS]** You all have one thing in common today: part of your work involves either interacting directly with the public (including people living with dementia) to provide assistance during a climate-related emergency; or indirect involvement such as planning and executing emergency responses for such situations. First, tell us what is the nature of your work? What geographic area do you cover as part of your work? How long you have been doing this type of work?

Nature of Personal Experience with Climate Emergency

15 minutes

In recent years, we have had to deal with an increasing number of climate-related emergencies, with many severely disrupting people's daily activities. I am referring to events such as extreme heat or cold; forest fires or wildfires; severe air pollution (including from wildfire smoke); and floods with heavy rain and snow. Or things like atmospheric rivers, bomb cyclones, snowstorms, heavy ice storms, severe winds, hurricanes, or tornadoes.

You've all mentioned having had direct interactions [**FOR GOVERNMENT/COMMUNITY/LOGISTICAL EXPERTS:** or indirect involvement] with someone living with dementia during climate-related emergencies. During our discussion today, I'd like you to reference those experiences as you answer the questions.

To begin, and to provide me with a bit of context:

- Which types of severe climate-related emergency events have you experienced in your role as [an unpaid caregiver / a paid care provider / a first or emergency responder / a government or community representative / an emergency planner]?

- How long did the emergency[ies] last?
- What was your role during the emergency?
 - Did you have direct interaction with the person/people living with dementia during these emergencies? If so, in what ways did you help the person/people living with dementia during that time? If no direct interaction, what was the nature of your involvement?
- Was an evacuation alert or order issued?
 - If yes, was (were) the person/people living with dementia you interacted with evacuated?
 - If yes, were you involved in the evacuation of the person/people living with dementia, or their return to home?
- **[ALL EXCEPT UNPAID CARE]** While we will mostly focus on people living with dementia during our discussion, we are also interested in those who provide unpaid care to people living with dementia, which are often friends and family, and who we will refer to as caregivers for our discussion. During the emergency, did you also have direct interaction with caregivers for people living with dementia?
 - How so?
 - **[If no]** Did you have any other type of involvement with caregivers? What was the nature of your involvement?

Needs Identification

40 minutes

Thinking of those experiences, I'd like your thoughts on the specific needs of people living with dementia.

- Based on your experience, how would you describe the needs of people living with dementia during the emergency?
- From your experience, how were those needs addressed, and by whom?
- What worked well? Why did it work?
- What challenges did you observe the person/people living with dementia experiencing?
 - Which of those, if any, are directly related to an evacuation order? Probe, as needed: either at home pre-evacuation, during transportation to a shelter/host community, or post-evacuation, returning to their community
- What measures were taken to address those challenges? By whom? What was the outcome? What's missing?
- **[UNPAID CARE]** Thinking about the future, if a more significant emergency was to happen – perhaps including evacuation, are there any additional challenges that you think you may have to deal with? What measures would help address those additional challenges in the future?

- **[ALL EXCEPT UNPAID CARE]** Did you notice anything different or unique in terms of the needs and challenges of unpaid caregivers (such as family and friends) during the emergency?

[ASK THOSE WITH DIRECT INTERACTION WITH PLWD DURING EMERGENCY]

Now thinking of yourself and the role you played directly interacting with people living with dementia during a climate-related emergency...

- How comfortable and prepared did you feel in supporting the person/people living with dementia?
- What tools or resources did you draw on to help you?
- What challenges did you personally experience in your role? How did you overcome those challenges, if at all?
- What would have helped you be better prepared for or be supported in your role?
- What are the key lessons from your experience?

[ASK IN ALL GROUPS EXCEPT UNPAID CARE PROVIDERS - THOSE INDIRECTLY INVOLVED WITH PLWD DURING EMERGENCY]

For those who have not directly interacted with a person living with dementia during a climate emergency, but who have worked on emergency preparedness and response activities tailored to their needs...

- In your experience, what has been helpful in addressing the needs of people living with dementia in times of climate-related emergencies? **PROBE, IF NOT MENTIONED:** In terms of processes, responsibilities, involvement, support, resources
- What challenges might there be to addressing those needs?
- What is needed to address or minimize those challenges?
- Is there anything different you would note in what has been helpful in addressing the needs of unpaid caregivers (such as family and friends) in times of climate-related emergencies?

[ASK ALL]

- Other than what we have already discussed, are there any additional important points to consider when supporting people living with dementia for climate-related emergency situations?
 - (e.g. having contact information (including emergency contacts) and/or a designated meeting place for household members if you cannot go home, having photocopies of important documents)
- Anything different or unique thinking just about dementia caregivers (again, those providing unpaid care such as family and friends)?

Impact of Climate Emergency Event**15 minutes**

Experiencing a climate-related emergency has a significant impact on anyone, particularly on people in vulnerable situations, such as people living with dementia.

- What have you observed to be the physical and emotional impacts from climate emergencies on people living with dementia?
 - Is there anything that is notably unique about these impacts for people living with dementia compared to the general population?
- **[FOR THOSE WITH DIRECT INTERACTIONS WITH PLWD]** In responding to these impacts, did you experience or witness any successes or challenges while providing support to those living with dementia that helped with their specific needs?
- **[ALL EXCEPT UNPAID CARE]** Is there anything different you would note about the impact of climate-related emergencies thinking just about caregivers of people living with dementia?
- **[UNPAID CARE ONLY]** What about in terms of physical and emotional impacts of the climate-related emergency on yourself as a caregiver? What helped? What would have helped?

Identification of Tools & Resources**15-20 minutes**

I'd like your thoughts on the information, tools, and resources that inform or guide people living with dementia and caregivers to help them deal with climate emergencies. We are thinking about things like advice and guidance being directly provided to people living with dementia and their caregivers, communication tools for providing advice and updates, and resources such as checklists. Please think of various content, formats, and channels.

[ASK ALL]

- Based on your experience, what type of information, tools, or resources have been most useful in terms of helping people living with dementia and unpaid caregivers to prepare for, navigate through climate-related emergencies and cope with the aftermath of an emergency event? These do not have to be necessarily designed specifically for people living with dementia, but ones you have found to be nonetheless useful to your situation. Why?
 - Which ones are not useful? Why?
- Based on your experience, is it important to tailor these tools for people living with dementia and unpaid caregivers? If so, how?
- Have you had feedback or do you have feedback on whether these tools are:
 - Easy to use? If not, what could be improved?
 - Easy to find? If not, what could be improved?
 - Do you have any other comments on what is missing or gaps?

- **IF NONE MENTIONED:** What information, tools, or resources would you like to have? [IF NEEDED: Suggestions of what to include in an emergency kit for someone living with dementia (e.g., copies of medical documents that indicate the person’s condition and current medications, identification items, favourite personal item/food; etc.); advice on advance preparations in case evacuation / what to do during an evacuation; tips for preventing/managing agitation.]

[ASK PAID CARE PROVIDERS; FIRST/EMERGENCY RESPONDERS; GOVERNMENT/COMMUNITY/LOGISTICAL EXPERTS]

Now this section is going to focus on tools, resources, or supports that you personally have used to assist people living with dementia and caregivers in your role during climate-related emergency events.

- What tools, resources, or supports are available to help ensure that you are well-prepared to interact with and support people living with dementia during an emergency event?
 - Have you had feedback or do you have feedback on whether they:
 - Cover the range of scenarios and needs that you have observed during a climate-related emergency?
 - Are easy to use? If not, what could be improved?
 - Are easy to find? If not, what could be improved?
 - Do you have any other comments on what is missing?
 - **[ALL EXCEPT UNPAID CARE]** What about tools, resources, or supports to help ensure you are well-prepared to interact with and support unpaid caregivers during an emergency event?
- To your knowledge, what is available or what has been done to ensure these tools reflect the specific and unique needs of people living with dementia experiencing climate-related emergencies?
 - What is most useful to you? Why?
 - What should be improved? How?
 - What is missing?
 - **[ALL EXCEPT UNPAID CARE]** What about ensuring these tools reflect the unique needs of unpaid caregivers?
- What specialized training or education have you received to prepare you to address the needs of people living with dementia during an emergency?
 - What is useful?
 - What’s not useful?
 - What’s missing?

[ASK ALL]

Before we conclude our session...

- Any final suggestions for the Public Health Agency of Canada as it looks to better understand the needs for people living with dementia and dementia caregivers during climate-related emergencies and support preparedness for future events?

Thanks & Closure

That concludes our discussion. On behalf of the Government of Canada, thank you for your time and input. We will follow-up by email regarding the incentive distribution. For those interested, once finalized, the report can be accessed through a government agency called Library and Archives Canada. Finally, I have posted on the screen information about resources available to provide support, if needed

Emergency Preparedness Dementia

Moderator's Guide – Final

People Living with Dementia

Study Objectives (do not share with participants)

- *Understand the unique needs of people living with dementia and family/friend caregivers during and after emergencies;*
- *Gather the nature of experiences of people living with dementia and family / friend caregivers during and after emergencies, including types of challenges;*
- *Understand the impact of emergencies on people living with dementia including on quality of life both during and after the emergency; and*
- *Identify resources and tools (including type of content) needed to protect and support quality of life of people living with dementia during emergencies and gather assessments of their availability and effectiveness.*

Introduction

10 minutes

Provide visual cues on the screen during the introduction

- **Welcome:** Introduce self & research firm & role as moderator (keep on time/on topic). Apart from me, there are X people on the call. I will start by explaining what we will do in this session and then you will have an opportunity to introduce yourself before we continue with our discussion.
- **Length, Sponsor & Topic:** Groups on behalf of the Public Health Agency of Canada; Federal government is looking to identify needs for people living with dementia and their caregivers during and after climate emergencies.
- **Length:** Our discussion should last about 60 min. Excuse yourself if needed during the session
- **Your Role:** What you all have in common is that you live with dementia and you have experienced at least one climate emergency within the past five years. We will discuss your personal experience during the climate emergencies you have been through. This is a casual conversation and no preparation is needed. There are no right or wrong answers. All opinions are important and I need to understand when opinions are shared across the group, but also when and how opinions might be different. But know that your participation is voluntary and if questions make you uncomfortable, you do not have to answer them.
- **Break:** I recognize that the discussion today may be emotional at times and if that is the case at any point, feel free to step aside for a moment if you feel the need. If possible, please use the chat function to let me know that you are stepping aside and when you return.
- **Logistic:** Video recording of the discussion for reporting (the recording can be paused during the session if you feel more comfortable sharing your opinion on something without it being recorded – just let me know when this is the case); observation from government (listening in but not part of discussion)
- **Confidentiality:** Comments will not be attributed in the study report; no names in reports; answers will not affect dealings with Government of Canada.
- **Agenda:** We will begin with a short introduction from everyone; then we will discuss your experience with climate emergencies; the impacts these situations had on your daily lives and

how you felt; the information and resources you used to help with your decisions during those times; and if there is anything else you may have needed.

- **Participant Introduction:** In which community do you live? What is your current living situation – do you live in your own home, with someone else, or in supportive housing? [**IF HOME/WITH SOMEONE ELSE:** Who lives with you?] [**IF SUPPORTIVE HOUSING:** What kind of residence is it? What level of care do you receive?]

NOTE FOR MODERATOR: Through their responses, identify in which of category they belong:

- In a private household by myself
- In a private household with at least one other person
- In supportive housing providing minimal to moderate support or care, such as homemaking or personal care
- In a long-term care home providing moderate to advanced care such as hospital, nursing home, long-term care, group home

Nature of Personal Experience With Climate Emergency

10 minutes

THROUGHOUT THE SESSION, MODERATOR ASKING REPETITIVE NATURE QUESTIONS (IN BRACKET AND ITALICS) AS NEEDED BASED ON THE GROUP DYNAMIC; VISUAL CUES SHOWN ON THE SCREEN WHERE POSSIBLE TO AID WITH THE DISCUSSION.

In recent years, there have been an increasing number of climate-related emergencies - like extreme heat or cold, forest fires or wildfires, severe air pollution, and important rain, snow, or wind storms. I am only referring to events that cause significant disruptions to our daily activities.

Share listing on the screen [moderator to read]

- Extreme heat or cold
- Forest fire or wildfire
- Sever air pollution (including from wildfire smoke)
- Floods
- Atmospheric river
- Bomb cyclone
- Snowstorm
- Heavy ice storm
- Sever winds, hurricane, or tornado

Thinking of your own experience...

- What type of severe climate-related emergency events have you recently experienced?
- How long ago was it?
- How long did the emergency[ies] last?
- Did you have to evacuate your home? If so, how long were you away from home? Where did you stay?

Personal Experience Related to the Climate Emergency**15 minutes**

I'd like to talk about your experience during these climate emergencies.

- How did you feel during the emergency? *(What emotions did you go through? How did the situation make you feel?)*
- Did your daily life change during the emergency? *(What changed in your life during the emergency? How were your daily activities or routines impacted?)*
- Were the services or supports you rely on different? Were any unavailable? How were they different? When did things get back to normal?
- Did anything make you feel better/more comfortable/safe during the emergency?
- And what, if anything, about the situation made you anxious or caused you distress?

Information Needs**25 minutes**

Information is important in times of emergencies to be prepared and know what to do.

- Tell me about the information you received during the emergency. Where did it come from? When did you receive it? How was it communicated / in what format?
- How did you use the information? What information was most useful? What was helpful about it? Probe specifically regarding information related to wellbeing vs. safety
- Was information easy or difficult to obtain? How so?
- Was the information easy or difficult to understand? How so?
- **[IF TIME PERMITS]** Was information provided in a timely manner? If not, what could be improved? *(Was information provided when you needed it?)*
- What information or advice was specific to an evacuation order? How useful was it? How did you respond to the evacuation order? Did you experience any challenges when responding to the evacuation order?
- What (other) information would you have liked to receive during the emergency? *(What other information would have been essential for your safety and wellbeing?)*

Now think about the period of time after the climate emergency...

- What was recovery like? How did you feel after the events?
- Did you notice any health impacts resulting from the emergency event? Probe, if not mentioned: things like impact on your health or well-being.
- Did you receive information after the event to help you with the aftermath?
 - What information was more or less helpful to getting back to normal?
- What else, if anything, would you have been useful to know after the emergency?

Apart from information or advice ...

- What other things did you find helpful during or after the emergency? To ensure you stayed safe? Help you to evacuate? Probe, if not mentioned: an emergency supply kit; an emergency exit plan; a designated meeting place; a plan for how household members will

contact one another if they are separated; photocopies of important documents; list of emergency contact numbers

- Who provided those?
- What other tools or resources, if any, would you have liked to have?
- Thinking about the people that helped you during the emergency, what do you think would have better supported them while helping you?

Since the last climate emergency...

- What, if anything, have you done to prepare for similar future events?
- What else would help you better prepare? (*What additional information, tools or resources would help you be better prepared?*)

Before we conclude...

- Do you have any other comments about dealing with a climate emergency? Anything we have not discussed today that is important to mention?

Thanks & Closure

That concludes our discussion. On behalf of the Government of Canada, thank you for your time and input. Once finalized, the report can be accessed through Library and Archives Canada.