

# Dementia-Friendly Canada

A national initiative to build dementia-friendly communities



Financial contribution from



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**Dementia-Friendly  
CANADA**

# Acknowledgements

The Dementia-Friendly Canada project is a partnership between the Alzheimer Societies of Canada, British Columbia, Saskatchewan, Manitoba and Ontario to leverage their individual successes in creating dementia-friendly communities to have a truly nation-wide impact.



It is critical that the everything we do as part of the Dementia-Friendly Canada project is guided by the voices of people with lived experience. Therefore, we are extremely grateful to the individuals from across the country – people living with dementia, care partners and community professionals – who participated in our focus groups.

This project has been generously funded by the Government of Canada, administered by the Public Health Agency of Canada. We applaud the Government of Canada for recognizing the impact of dementia, as well as its commitment to support and improve the lives of people living with dementia and their caregivers.

*Financial contribution from*



The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

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# Brief reflections from the national project manager

The Alzheimer Society is committed to building a world where people living with dementia, their care partners and families feel included, acknowledged and supported – a truly dementia-friendly Canada. But we can't do it alone, it will take a dramatic shift in our culture to support people affected by dementia – it will take a movement.

The Dementia-Friendly Canada project is an integral part of the movement we are creating. The project is a partnership between the Alzheimer Societies of Canada, British Columbia, Saskatchewan, Manitoba and Ontario intended to foster the creation of dementia-friendly communities across the country.

There are more than 500,000 Canadians living with dementia and we know that approximately 60 per cent of these individuals still live in their communities. They visit libraries and recreation facilities, enjoy restaurants and stores, and access public transportation. However, according to a Leger-led online survey conducted by the Alzheimer Society of Canada, 46 per cent of Canadians said that they would feel ashamed or embarrassed if they had dementia and 61 per cent felt they would face discrimination of some kind.

In order to build a dementia-friendly Canada, we need to move away from fear and denial of the illness, towards awareness and understanding. In a dementia-friendly community, each community member is educated about dementia and knows that a person living with dementia may sometimes experience the world differently. To achieve our vision, the project will provide educational opportunities for the general public and professionals working in the community to mobilize them to champion dementia-friendly principles wherever they go.

The Alzheimer Society is committed to having the voices of people with lived experience guiding this work. That is why we are so thankful to the individuals – people living with dementia, care partners and community professionals – who took part in our focus groups to help define what a dementia-friendly community is to them and to help us shape the vision for the project.



Heather Cowie, M.A.

National Project Manager, Dementia-Friendly Communities

# Executive summary

## What is the Dementia-Friendly Canada project?

The National Strategy for Alzheimer's Disease and Other Dementias Act was passed in 2017, requiring the federal Minister of Health to spearhead the creation of a national dementia strategy. As part of the work to make this a reality, the Public Health Agency of Canada provided funding to organizations who support and improve the lives of people living with dementia and their caregivers. The Dementia-Friendly Canada project is a partnership between the Alzheimer Societies of Canada, British Columbia, Saskatchewan, Manitoba and Ontario and is intended to leverage their individual successes in creating dementia-friendly communities to have a truly nation-wide impact.

A dementia-friendly community is a place where people living with dementia, their families and care partners feel included and supported. While creating dementia-friendly communities, individuals and organizations should focus on both physical and social environments to ensure they are accessible. To help achieve this, the project develops and provides educational resources (e.g., online-based training modules) for the general public and professionals working in the community to empower

them to champion dementia-friendly principles in their places of employment, neighborhoods and beyond.

## What have we learned thus far?

It is important that everything we do as part of the Dementia-Friendly Canada project be guided by the voices of people with lived experience. Therefore, in each of the partnering provinces in February and March of 2020 the project hosted focus groups with people living with dementia, care partners and targeted professional groups including recreation, libraries, retail, restaurants and public transportation. Participants were asked to share their views, beliefs and experiences on key characteristics that define a dementia-friendly community; to identify topics that dementia-friendly education should cover; and to suggest effective strategies, tools and resources for fostering dementia-friendly communities. In-depth qualitative analysis of the focus-group transcripts identified four central themes that will be used to guide the project:

- **Accessibility:** Participants emphasized the importance of communities being accessible in the sense of being both physically and emotionally safe as well as inclusive.

- **Education:** Dementia-friendly communities must incorporate opportunities for education on dementia, with the goal of increasing understanding about the disease and empathy for the people affected by it within communities.
- **Communication:** People living with dementia need communities to place more emphasis on stronger communication channels in order for them to feel visible, heard and understood. Some examples of this include ensuring signage in community spaces is clear and having clarity about resources and services that are available to people living with dementia.
- **Championing:** Participants described feeling a sense of responsibility, ownership and value in being a part of advocacy work. They also emphasized their ability to challenge and decrease stigma in their communities through this work.

## How will this information be used?

Findings from this project, including detailed insights from the focus group discussions, will be critical for informing the development of tools, education and programming that will allow for the growth of dementia-friendly communities across the country. The resources developed as part of this initiative will be targeted at professionals working in sectors including recreation, library, public transportation, retail and restaurant service sectors, as well as members of the general public.

# What is a dementia-friendly community?

Over 500,000 Canadians are currently living with dementia, with this number projected to double in the next decade. Dementia can have an impact on our families, neighbours, workplaces and entire communities. Given the increasing prevalence of dementia, we must act now in order to foster the creation of dementia-friendly communities in Canada.

## What is a dementia-friendly community?

In brief, dementia-friendly communities are environments (e.g. cities, neighborhoods, service locales including grocery stores and the library, government offices, groups such as book clubs or service organizations, etc.) where people living with dementia are included, acknowledged and supported. Dementia-friendly communities are defined by their physical and social characteristics. Dementia-friendly physical environments, for example, employ effective signage and do not overwhelm a person's visual or auditory senses. Dementia-friendly social environments employ staff trained in effective communication and provision of support for people living with dementia. Fostering dementia-friendly communities requires that all individuals within these environments have an awareness and understanding of dementia so that people with lived experience continue to be included and respected as members of the community. Many individuals living with

dementia, as well as their care partners, report barriers to feeling included in their communities; the stigma of dementia often results in them withdrawing from community interaction, resulting in a diminished quality of life and loss of personal connections.

*"A dementia-friendly community means that my partner and myself can carry out our daily activities with fewer barriers, and less stigma [than] we might have otherwise experienced as a result of her condition"*

*– Care partner, Ontario*

# Creating dementia-friendly communities in Canada



## Accessibility

Dementia-friendly communities should be safe and inclusive in both the physical and social environment.

## Communication

Community members know how to interact with people living with dementia, to ensure their voices are heard. They also know how to implement supports, like clear signage, in order to make their community dementia friendly.



## Education

To increase understanding and empathy dementia-friendly communities must include opportunities for dementia education.



## Championing

People living with dementia and their care partners act as a "champion" in educational work, advocacy, story sharing, supporting others and creating change.



# Four central themes guiding the Dementia-Friendly Canada project

In February and March 2020, the Dementia-Friendly Canada project sought to engage key stakeholders in focus group conversations about dementia-friendly communities. Participants included people living with dementia, care partners and individuals working in relevant professional sectors including recreation, libraries, retail, restaurants and public transportation. Participants were asked to share their views, beliefs and personal experiences on key characteristics that define a dementia-friendly community; identify topics that dementia-friendly education should cover; and suggest effective strategies, tools and resources for fostering dementia-friendly communities.

From over 22 hours of focus-group discussion, hosted in the four partnering provinces (British Columbia, Saskatchewan, Manitoba and Ontario), thematic analysis identified four central themes: Accessibility, Education, Communication, and Championing. The following report summarizes each theme, with the goal of using these themes to guide the work being done as part of the Dementia-Friendly Canada project.

The following word cloud represents the frequency with which focus-group participants identified key terms that capture what it means for a community to be dementia friendly. Words in larger font size were identified more frequently across all provinces and participant groups (individuals with lived experience, care partners and professionals).



# Methods underlying the Dementia-Friendly Canada project

## Scope of project

The Dementia-Friendly Canada project is a partnership between the Alzheimer Societies of Canada, British Columbia, Saskatchewan, Manitoba and Ontario and is intended to foster the creation of dementia-friendly communities across Canada. To achieve this goal, the project provides education opportunities for the general public and professionals working in the community to mobilize them to champion dementia-friendly principles wherever they go.

It is critical that everything we do as part of the Dementia-Friendly Canada project is guided by the voices of people with lived experience. We are also committed to building tools and resources that stem from best practices and can be easily utilized across the country. These guiding principles play a key role in achieving each of the project's three main goals:

1. Train Canada's workforce to be dementia friendly.
2. Promote and educate the general public about dementia through awareness campaigns and resources.
3. Achieve sustainability and ensure growth of the Dementia-Friendly Canada project across the country.

In order to achieve these goals, the Dementia-Friendly Canada project will create tools, education and programming that will allow for the development

of dementia-friendly communities across Canada. Visit [alzheimer.ca/dementiafriendlycanada](http://alzheimer.ca/dementiafriendlycanada) to learn more.

## Methods

### Establishing the working group

The Dementia-Friendly Canada working group is led by the National Project Manager and consists of dementia-friendly communities' experts from each of the partnering provinces (British Columbia, Saskatchewan, Manitoba and Ontario).

### Establishing the scientific advisory panel

The Dementia-Friendly Canada project has partnered with Dr. Stuart MacDonald and his team at the University of Victoria (UVic) to support the project evaluation. Comprised of faculty and graduate student expertise from Nursing, Psychology and Sociology, this UVic research team has explored select lifestyle interventions (e.g., social singing) and engaged lifestyle (e.g., social connectedness) to improve the psychological, physical and cognitive health of individuals and families experiencing the dementia journey. The research team's recent findings underscore the agency that we all have in fostering dementia-friendly communities, and the powerful impact that such efforts can have on quality of life for people living with dementia as well as their families, care partners and friends.

## Developing the focus group questions

The focus groups undertaken in 2020 were intended to inform the Dementia-Friendly Canada project. Questions were created in order to learn more about what a dementia-friendly community means to all focus group participants, including people living with dementia, care partners and professionals. Questions touched upon a number of themes, including:

### Motivation and Personal Meaning

- What brought you to today's focus group?
- What does a dementia-friendly community mean to you?
- Please share three words that best describe the Dementia-Friendly Canada project.

### Personal Experience

- Please share stories and examples from your personal experience based on today's topic "dementia-friendly communities."

### Education and Resources

- What topics should dementia-friendly education cover?
- What resources would be beneficial for your learning?
- Instituting Change
- What are some ways you could champion dementia-friendly communities?
- What are some tools and resources that would help you in championing dementia-friendly communities?

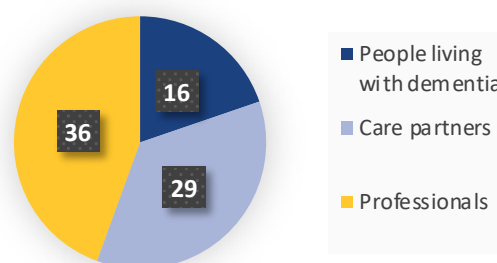
## Engaging people living with dementia, care partners and professionals

### Inviting focus group participants

To ensure that the Dementia-Friendly Canada project was guided by the vital voices of all key stakeholders, we invited people living with dementia, care partners and professionals from specific target sectors – recreation, library, public transportation, retail and restaurant – to participate in focus groups. These moderated discussion sessions explored stakeholder viewpoints concerning what a dementia-friendly community means to them.

A total of 81 individuals participated in the focus group sessions across all provinces: individuals self-identified as people living with dementia, care partners, and professionals from one of the target sectors (see Figure 1).

Figure 1: Focus group participants



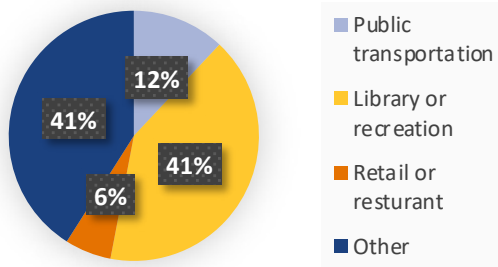
A subset of 55 individuals provided detailed demographic information (see Table 1).

Table 1: Demographics

> age 50 years	70%
> age 70 years	25%
Female	71%
Living in urban contexts	87%
Bilingual (French and English)	9%

Professional sector participants included individuals from public transportation, library or recreation, as well as service industry professionals (including retail and restaurant), with 41% identifying another sector (see Figure 2).

**Figure 2: Professional focus group participants**



## Data collection

### Structure of the focus groups

#### Similarities and differences across jurisdictions

In February and March of 2020, we held 12 in-person and online focus groups with people living with dementia, care partners and professionals from the project's target sectors in order to help gather some initial feedback, as well as generate additional information to guide and inform the project's future work. The structure of each focus group differed slightly based upon factors including context, capacity and group preference. Individual focus group sessions were held for people living with dementia in British Columbia; for care partners in British Columbia and Manitoba; and for professionals in British Columbia, Ontario, Saskatchewan, and the Northwest Territories. Combined focus group sessions for people living with dementia and care partners were held in British Columbia, Manitoba and

Saskatchewan, with Ontario hosting an in-person and online session for all three groups (people living with dementia, care partners and professionals).

## Data analysis

### Transcription

Of the 12 focus group sessions, all but two were recorded and subsequently transcribed, ensuring anonymity of participants. We were unable to include transcript data from one of the Manitoba focus groups as not all individuals attending the session provided informed consent for the audio recording. Similarly, transcript data from the Northwest Territories had to be excluded due to systematic differences in the size and composition of the focus group, as well as technical difficulties impacting audio quality during the recording of the focus-group session. In these instances, key themes were summarized by staff who attended the focus-group discussions. However, important handwritten feedback from participants of the Northwest Territories focus group was also received in regards to what a dementia-friendly community means to them, and we will use these notes to inform the Dementia-Friendly Canada project (e.g., recommended dementia-friendly resources for libraries).

In total, over 22 hours of audio recordings were transcribed encompassing all focus group content. All transcripts were reviewed, with any identifying information redacted. The final transcripts were subsequently shared with the research team for thematic data analysis.

## Thematic analysis

The focus group transcripts were uploaded into the software program, NVivo Version 12 (2018), where a trained Research Assistant read through each transcript and highlighted sections of participants' contributions which appeared relevant and important to the study. An example of this process is summarized below:

*R2: My name s [name, R2]. I have been diagnosed for a few – quite a few years now with frontal temporal dementia and atypical Parkinson-ism. I've been a passionate advocate for people in the early stage of the disease mostly, and have done that locally, nationally, and internationally. My father - he passed away last year - was diagnosed with Lewie Body Dementia, and my mother*

Through this process, these highlighted sections of the transcripts were grouped together into codes, to document similarities and differences among provinces and groups of participants (i.e., people living with dementia, care partners, professionals). Codes represented distinct characteristics or aspects that participants used to describe a dementia-friendly community. An example of a list of codes can be found in the NVivo screenshot to the right:



For each code, representative sections of text could be identified. For example, the B.C. Advocacy code has 23 text references that were identified in the transcripts (i.e., 23 quotations represent this code). The following represents an example of a statement linked to the B.C. Advocacy code:

*you know I've - I wanna be of help where I can. And I'm here to serve and advocate and help make change for people that don't often, or may not as often, have a voice when they shift.*

The aggregate thematic analysis was based upon data compiled from four provinces (British Columbia, Manitoba, Ontario and Saskatchewan). Coded statements were thematically grouped into categories according to shared meaning. For initial purposes, we conducted an open thematic analysis (i.e., a bottom-up/data driven identification of themes). Specifically, after all transcripts had been coded, the focus group transcripts were carefully inspected again to ensure that all relevant content was accurately coded. During the process of coding, the trained research assistant identified key similarities throughout the codes and noted how some codes appeared to connect to others. These observations underwent a review process, and as the research assistant further developed these connections, themes emerged which could help to categorize the data clearly. Through this process, four central themes were identified: *Accessibility, Education, Communication and Championing*. These identified themes are expanded upon in detail in a forthcoming section (*Key Dementia-Friendly Themes Identified and Representative Quotations*) of the report.

# Key findings

## Brief synopsis of findings

### Step 1: Establish the Working Group and Scientific Advising Panel



The Alzheimer Society of Canada, in partnership with the Alzheimer Societies of B.C., Saskatchewan, Manitoba, Ontario – and with the support of the Alzheimer Society of Alberta & Northwest Territories – contributed to the Dementia-Friendly Canada focus groups, along with a scientific advisory panel from the University of Victoria.

### Step 2: Develop Focus Group Questions



Questions were developed to probe the meaning of a dementia-friendly community, referencing central themes including: motivation and personal meaning, instituting change, education and resources, and personal experience.

### Step 3: Focus Group Data Collection



Twelve focus groups were held in locations across Canada for people living with dementia, care partners and professionals.

### Step 4: Transcription



Twenty-two hours of focus group recordings were transcribed for a number of key questions on “what makes a community dementia-friendly?”

### Step 5: Qualitative Data Analysis



Using NVivo software, an open-ended, thematic data analysis was conducted on over 1300 coded statements and 275 keywords, yielding four central themes: Accessibility, Education, Communication and Championing.

### Step 6: Knowledge Mobilization



To foster the growth of dementia-friendly communities across the country, findings will be used to develop tools, education and programming, with developed resources targeting professionals working in recreation, library, public transportation, retail and restaurant service sectors, as well as the general public.

## Dementia-Friendly themes identified and representative quotations

### Theme One: Accessibility

#### Overview of theme

One of the most common concerns across focus groups centered around the theme of accessibility. For many participants with lived experience, the onset of dementia meant that their views of community shifted and navigating their communities felt different. In some cases, this meant that new challenges arose for both the person living with dementia and their care partner. The theme of accessibility is of particular importance for several reasons: (1) it underscores that a lack of access often means that a person living with dementia is unable to actively engage in their community; and (2) it serves as a reminder that safety, mobility and inclusion must be at the forefront of community planning.

#### Highlights

The theme of accessibility, in both the physical and social environment, was one of the most common concerns identified across all focus groups.

#### In the physical environment:

- Participants highlighted specific challenges in recreation centers, libraries, restaurants and retail spaces; such as noisy environments, confusing store layouts and challenging payment methods.

*“Restaurants are too loud today and I find that they get louder and louder every time. They are also full of people, so I believe people with dementia will get very confused now at a restaurant because there is too much stimulus.”*

– Care Partner, Manitoba

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*“The grocery store’s a challenge because the layout makes you weave through the jungle of groceries.”*

– Participant, British Columbia

- Many participants also avoided public transportation largely due to fears around people living with dementia getting lost in their communities, coupled with concerns of a lack of understanding from public or transportation staff to aid them.

#### In the social environment:

- Participants highlighted concerns that a lack of understanding from staff in these locations could result in poor communication which could lead to challenging situations and ultimately limit their ability to access these spaces. And in the case of transit, focus group participants worried that a lack of understanding meant staff may not be able to properly help a person who is lost or disoriented.
- Participants described the need to feel supported, accepted and included in their communities.
- Participants often noted that a dementia-friendly community should be inclusive for everyone, not just for people living with dementia.

*"[The Library] is a real community hub. They must have looked at the community and thought about what can they offer, it's so diverse – it's a workspace, it's a social space, there's a coffee shop. The books are almost secondary to what they do there now. It's incredible."*

*– Participant, Ontario*

Participants also identified that physical, financial and emotional safety are key aspects of an accessible and inclusive dementia-friendly community. Changes around accessibility must be rooted in safety and inclusivity. While some of these aspects of accessibility (e.g., financial safety) are outside the scope of the current project's objectives, these points are of value as they may impact work being done in other areas of the Alzheimer Society, as well as future work being done within dementia-friendly communities.

### **Detailed assessment of accessibility and related subthemes**

Through the thematic analysis, several accessibility challenges were identified. The following overview addresses the idea of safety in more detail and describes the importance of a dementia-friendly community being centered around inclusivity and accessibility.

#### **Navigation, mobility, and/or access**

Community spaces often felt inaccessible to people living with dementia for a variety of reasons. In some cases, such as retail locations or grocery stores, a confusing store layout, noisy environment, and at times misunderstanding staff, led to disorientation, frustration, or confusion

for participants living with dementia. Care partners emphasized the amount of planning that often went into trips to these locations. This type of "strategizing" included choosing locations that were known to be quiet or have familiar staff, describing the location to their partner ahead of time, preparing for unexpected challenges, and at times, going into the store earlier to explain to the staff that their partner was living with dementia and that the interaction may be different than with other customers. Quite often, the individual living with dementia completely avoided these spaces, even if their care partner could attend with them. Solutions to these concerns that were raised are framed around education and communication – points that are described in greater detail in the following subthemes.

*"She wants a new outfit, how am I going to accomplish that? You can't just go to the GAP, where the music is pounding away."*

*– Care partner, British Columbia*

#### **Transportation**

Another challenge around accessibility raised across the focus groups came down to transportation for people living with dementia. Finding ways to move around one's community could be challenging and again, many participants completely avoided public transit due to concerns around confusing routes, cold bus shelters, unreliable scheduling or communication, and ultimately, a fear of getting lost. Care partners and people living with dementia expressed deep-rooted fear around getting lost, and compounding this fear was the concern that transit staff,



police, or community members would be unable or unwilling to safely support an individual in distress. For people who did rely on public transit, clear routes were relied upon and individuals only used one or two routes consistently. For example, to go from home to the library and back, when they and their care partner could be assured that the route was unlikely to change. Other forms of transport for some participants included walking or bike riding. Often, the individuals living with dementia relied quite heavily on their care partner to transport them around their community. Therefore, a dementia-friendly community must incorporate ways to boost mobility that are reliable and most importantly, safe.

*“Getting lost is one of the most traumatic things for both the person and the caregiver.”*  
– Focus group participant, Saskatchewan

## Safety

### Physical safety

Safety was identified as a defining feature of a dementia-friendly community. Participants raised the need for their communities to be safer and feel less restrictive. From a physical standpoint, safety included the ability to move around without getting lost, without fearing physical threat, and to feel as though confrontations would be unlikely to escalate into physical violence as some participants had experienced. Care partners referenced the concern that their partner may unintentionally escalate a situation while in the community alone, and that the response from others could be physically threatening. As mentioned,

getting lost in the community was referenced as extremely traumatic for both the individual with dementia and the care partner. Beyond these concerns, other spaces lacked physical accessibility, with some individuals mentioning that spaces with too many stairs could be a challenge or public spaces with limited seating could make it challenging if the person living with dementia needed breaks during their outings.

*“Our Mom could navigate the bus from close by here, across the river, three busses, two transfers, get there, visit, come out the building, get to the bus, come home. Now I wouldn’t think she could find the bus stop at the corner street.”*

– Care Partner, Manitoba

### Emotional safety

Another aspect of safety raised in the focus groups revolved around the idea of emotional safety. Participants described the need to feel supported, accepted, and included in their communities. Participants often noted that a dementia-friendly community should be inclusive for everyone, not just for people living with dementia. Inclusivity included more understanding around the challenges of aging, a stronger recognition of how dementia support looks different for different cultural groups (e.g., in terms of language accessibility for English as a Second Language speakers, or cultural distinctions regarding dementia care), and a recognition that lowering accessibility barriers would aid multiple groups and individuals. Furthermore, participants described a dementia-friendly community as creating an environment where people

living with dementia experienced freedom of restriction, and in this, their overall well-being could markedly increase. This suggests that by aligning communities with many of the values presented in this report, a greater sense of emotional well-being and sense of safety could emerge.

*“Always taking into consideration if mom were to go roaming, is she safe? And will people know [about her dementia]? Will she be not only safe physically but emotionally safe. Like, if she has an anxiety attack is that an okay place for her to do that?”*

*– Focus group participant, Saskatchewan*

### **Financial safety**

Finally, financial safety was also raised by participants as critical for individuals living with dementia. Discussion around this issue included concern that people living with dementia were much more susceptible to financial fraud issues and that many individuals with little support may be experiencing confusion when paying for items or bills. While solutions were limited around these issues, knowledge on behalf of banking staff was suggested as a potential way to recognize warning signs around dementia and financial insecurity. As noted earlier, while financial safety falls outside the scope of the current project directives, this information may be impactful to other projects/programs at the Alzheimer Society, as well as highlight future areas of work within dementia-friendly communities initiatives.

## **Theme Two: Education**

### **Overview of theme**

Participants raised education as a critical tool for creating and maintaining a dementia-friendly community. Education is noted as a tool because participants often described education as a process, in which educational content, programs, or media could be utilized in order to spread information or awareness of dementia. Participants centered the need for empathy and understanding in communities, desiring for members of their community to exercise patience, reflection and engagement when interacting with individuals who have dementia, or may exhibit signs of dementia. In order to access and promote higher levels of empathy, participants suggested finding ways to share educational content with groups within communities. Groups identified included staff working in the public sector who are more likely to engage with individuals living with dementia, such as transit workers, recreational centre staff, and front-facing restaurant, bank and retail staff. Other groups included youth and those who are in the age-range most likely to experience the onset of dementia symptoms. This last group was identified because many participants noted having little understanding or awareness of dementia upon diagnosis. This created challenges in recognizing early signs or symptoms, accepting their diagnosis, preparing for life with dementia and sharing their experience with friends or family. Therefore, incorporating education

into community planning may allow individuals with dementia to be better understood, and in turn, allow others to recognize early signs or symptoms and feel empowered in seeking medical or social support. While this later group (i.e., youth) are outside the current project's scope, this highlights a need that the Alzheimer Society may be able to address through other projects/programs, or future dementia-friendly communities work. Through education, awareness and understanding about dementia can be shared widely within the community, with the corresponding benefit of reducing stigma.

### Highlights

- Participants discussed education as an important way to create and maintain a dementia-friendly community.
- Participants often described education as a process, in which educational content, programs, and/or media could be used to spread information and awareness about dementia.
- Participants focused on the need for empathy and understanding in communities and a want for members of their community to exercise patience, reflection and engagement when interacting with people living with dementia.
- Participants often discussed experiencing high levels of stigmatization.
- Participants expressed that the most important hallmark of educational programming is that it is rooted in lived experience and shares stories

that portray an accurate portrayal of situations and events.

*"I think a dementia-friendly community would mean that people's default would be to be curious."*

*– Focus group participant, Saskatchewan*

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*"...we have a man on our street who is living with dementia at home with his wife. One morning my daughter was on the school bus heading out and she noticed that he was out and about, and it probably wasn't normal. So, she called home and my husband was able to call the wife, and sure enough he got out of the house without her knowing. So, my daughter became a young advocate. She felt great about it. She made a difference. But if she hadn't been aware of this, she wouldn't have thought to call. I teach them not to be bystanders."*

*– Focus group participant, Ontario*

### Detailed assessment of education and related subthemes

As anticipated, the thematic analysis process identified education as a recurrent theme across groups and jurisdictions. The following synopsis of theme two findings elaborates upon education-related subthemes including stigma, understanding, awareness and educational content, and describes the general importance of education as a foundational element in fostering creation of dementia-friendly communities.

#### Stigma

Participants often discussed experiencing high levels of stigmatization around dementia. This included being viewed

as “invisible, incapable, scary, or misunderstood.” Participants told many stories about situations when customer service representatives didn’t understand that a person was living with dementia (or what that meant), and instead viewed them as rude or challenging. Representations of dementia and Alzheimer’s disease in media were raised as often creating or reinforcing ideas around dementia that could be damaging for people living with it. Participants were aware that dementia was often viewed as an illness nobody wanted to have, or that dialogue around dementia was not publicly available. Therefore, interrupting this narrative was essential for participants. They felt that if messaging, media, and public awareness campaigns shared a more accurate depiction of dementia, there was an opportunity to promote a stronger sense of community.

*“People are mistreating this person because they think something’s wrong or that they’re mean but meanwhile this person is living with dementia. Like our Mom looks normal...but I mean...she struggles.”*

– Care partner, Manitoba

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*“We have grandchildren, five all under the age of nine. It could be that my children don’t explain it [dementia] well enough, but I find that our grandchildren are a little patronizing. They know that it’s, I mean, they’ve heard it’s an illness. But I don’t feel that they have the understanding that would include respect for his illness.”*

– Focus group participant, Saskatchewan

## **Understanding and awareness**

Participants felt that providing key community facilities, such as restaurants, recreation centres, libraries, schools and public transit operations with educational programs around dementia would be a good step in spreading awareness. Participants recognized that these facilities may have limited training material, time and budgets to distribute dementia-friendly material to their staff. However, participants recognized these challenges as being a reason to provide shorter content, to make it more widely available such as on social media, and to spread awareness through education as a key goal in advocacy work.

*“One of the things that would be great is to develop content and make a lot of these pieces shareable. Using social media as an example, I can take that clip, share it with my community of friends, because it may be a scenario that they’ve either been exposed to and never known how to respond.”*

– Focus group participant, B.C.

## **Education as a tool**

Participants had key ideas on how the educational content could be most effective and their ideas were widely consistent across different geographical groups as well as in regards to any audience who may be receiving the education. The most important hallmark of an educational program was that it is rooted in lived experience. Participants felt strongly that accurate portrayals of dementia are largely missing from both public awareness and educational campaigns. Creating content that is

developed from lived experiences and stories from either people living with dementia or their care partners, is recommended to promote a greater sense of empathy in others in their community. For example, participants suggested constructing role-playing activities or videos of the experiences a person with dementia may have in a noisy store environment with a confusing layout. Another example included showing a care partner providing support to an individual with dementia in a restaurant setting, where there may be unique challenges such as a confusing menu or encountering staff with little knowledge of the illness.

*“Really, it’s that not necessarily just looking at age as dementia being a senior’s disease. Looking at mom, she’s very very fit, very agile, very able to do things. But she has lost all functioning of toileting, hygiene, feeding, dressing and speaking. But to see her walking in the neighbourhood, you would never know. So, she just looks like somebody who’s still of working age, but can’t work. So, I guess from that it would be to not see age as a defining factor of dementia.”*  
– Care Partner, Saskatchewan

It is important to note that participants often acknowledged that the solutions to the challenges faced in public settings may be unclear not only to the staff at the facility, but also to the person living with dementia or care partner themselves. One care partner noted how their mother who lives with dementia may forget what she ordered for lunch at a restaurant and become disappointed or frustrated when the food is delivered to the table. In that scenario, the care partner acknowledged

that the ideal solution was not necessarily for the restaurant to take ownership of changing the meal or pushing his mother to eat the food that was first ordered. Rather, the goal of educational content in showing examples such as this is to bring more awareness to staff and facilities of the underlying disease (and accompanying symptoms) that is influencing the situation and to encourage staff to reflect upon how they may respond. This may help in eliminating hostility, awkwardness, or pressure that many care partners or people living with dementia experience in public settings in their communities. Further, it allows individuals to pause and consider what they would do in the scenario, and may spark changes in behaviour when out in the community.

*“I wasn’t there, but my husband went out for dinner with his family, and his Dad had to order the meal off the menu and then the waitress brought the meal and he was like, “I didn’t order that. What’s that?” She’s, “Well, you did order.” “That? I would never order that.”*  
– Care Partner, Manitoba

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*“We went to the store and I would say, “He has dementia.” And I assumed they knew what that meant, and I assumed they knew how to treat him. And I’m just thinking, if someone came into where I work before this started, would I know how to treat them? But I assumed because I told them that they would automatically put in this professional dementia gear and know what to do.”*  
– Care Partner, Manitoba

## Theme Three: Communication

### Overview of theme

A dementia-friendly community must be centered on having open and clear channels of communication. Participants from all groups often raised how challenges in their current communities were rooted in misunderstandings due to communication, or how challenges around communication kept them from actively participating in their communities to the extent they may wish to. Ideas around communication can be broken into two areas; (1) a desire for those living with dementia to have the means to communicate, and (2) how communities could adapt their communication to contribute to a more dementia-friendly community.

### Highlights

Communication emerged as an important piece of what makes a community dementia friendly.

- Many participant's stories of frustration often came down to challenges around communication
  - participants discussed how misunderstandings and communication challenges often kept them from actively participating in their communities to the extent they wanted to.
  - it was discussed that community members need to learn how to adapt their communication to contribute to a more dementia-friendly community

– for example communication may look different for different people, and there may be more patience needed when speaking to a person living with dementia.

*"I didn't realize how powerful a smile was."*  
– Care partner, Saskatchewan

- An emphasis on the importance of people living with dementia to have a voice and be visible, heard and understood also came out of the focus groups.
  - participants living with dementia often described feeling that they had very little voice in community planning, or in sharing information and/or awareness around dementia.
  - this was particularly highlighted when participants described the value of this project and how beneficial they felt their contributions could be. Highlighting that dementia-friendly communities should not move forward without consultation and inclusion of those living with dementia.
- There was also a lack of clear communication in the built environment. Barriers in accessibility were often rooted in lack of communication. Participants consistently raised the challenges of signage in community spaces such as grocery stores, retail locations, recreation centres, and transit vehicles as a challenge to their ability to enter those spaces

*“Maybe we need to have Handi-transit be more accessible to people with dementia. Just because they don’t have a physical disability, why can’t they use Handi-transit where it’s a little safer. I mean, it’s not the greatest service but it is better than trying to get on a public bus.”*

– Care partner, Manitoba

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*“I had to find a place where I could feel comfortable. And I had nowhere to start. I had no idea where to go . I could have gone and played cards at the Seniors’ Centre, but I wasn’t old enough yet and I didn’t fit in any group and so I was really lost. And so I started out by just simply walking. I was walking in from my car in a parking lot, and smiling at people and saying hi to people I didn’t know because I was at such a low point in my life I needed some support, and I didn’t know where to get it.”*

– Focus group participant, Saskatchewan

### **Detailed assessment of communication and related subthemes**

#### **Communication in the social environment**

Participants living with dementia described often feeling as though they had very little voice in community planning, or in sharing information or awareness around dementia and Alzheimer’s disease. Participants described feeling as though they were often spoken for, or that their voices were rarely incorporated into conversations of how to make changes in dementia awareness. This was particularly highlighted when participants described the value of this study and how beneficial they felt their contributions could be to the project. Therefore, research around

dementia and further efforts to develop stronger dementia-friendly communities should not move forward without consultation and inclusion of those living with dementia. Beyond this, attempts to break down stigmatization in communities must include the recognition that people living with dementia often do not feel seen in their communities, as barriers exist that make it challenging for them to have access to many spaces in their community (as previously discussed in relation to the Accessibility theme). Many participants living with dementia and care partners described needing community members to recognize that communication may look different for different people, and there may be more patience necessary in communicating with people living with dementia. Suggestions were raised around creating ways to communicate to other community members that an individual may be facing unique challenges in an interaction due to dementia. Creating more spaces where people living with dementia could communicate their needs, become more visible, and be subsequently understood would promote a more dementia-friendly space.

#### **Communication in the physical environment**

Beyond interactional challenges in community spaces, the physical environment of facilities could be more clearly communicated in order to create more dementia-friendly spaces in a community. Participants consistently raised the challenges of signage in community spaces such as grocery stores, retail locations, recreation centres, and transit

vehicles as a challenge to their ability to enter those spaces. For example, many participants described the challenges of planning a route on public transit due to differences between the signage at bus stops or stations, online schedules, and word-of-mouth from staff or drivers. If routes changed, these changes were not always clearly communicated in a way that someone living with dementia may readily understand or be able to quickly make the necessary adaptations. Other examples included signage for public washrooms that used unique symbols as opposed to standardized labels, or menus at restaurants which used play on words to describe items. Grocery store layouts were noted to change without clear signage, or payment methods such as card machines did not follow standardized symbols, making it more challenging for some participants with dementia to even access these spaces. Also, some programming in recreational centres that may be specifically targeted towards people living with dementia, such as music programs or support groups, were sometimes confusingly communicated as to the registration process or other details such as location or timing of the groups. Many of these subtle forms of communication were not easily understood by individuals living with dementia and resulted in an inability to participate in their communities. Therefore, a focus on clear and consistent communication should be at the core of dementia-friendly community planning, with an added emphasis on listening to and amplifying the voices of people living with dementia in these processes.

*“And one thing - clear signage. Quite often the recreation facilities can be big, so you walk in, and so that you don't feel overwhelmed by it. Because that's one of the things, one of the sensations I get is that overwhelming. Like, okay, whoa, where do I go, what do I do?”*

*– Focus group participant, Saskatchewan*

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*“I really echo what [other participant] had said in that you know, mom doesn't have the language to be able to communicate what she would want from the community. And so we have to speak on her behalf, and it feels like, it's double-edged. It feels - like, we want to but we also feel there's a weight to that because we want to represent mom and give her the best voice possible, and then we hope that we're capturing her heart and soul and what she would want, but we're also making the assumption that we're doing that. And so it's you know, I didn't bring mom today because she doesn't have the language to communicate anymore. And so she would just, I think find it more frustrating to be able to have the thoughts in her mind and not be able to express them.”*

*– Focus group participant, Saskatchewan*

## **Theme Four: Championing**

### **Overview of theme**

Having champions, in terms of advocacy, support and determination to effect positive change, represents another cornerstone of creating dementia-friendly communities. The theme of championing was identified across all focus groups (persons with lived experience, care partners, and professionals alike), with



people living with dementia in particular emphasizing the importance of sharing knowledge and stories in order to generate a movement toward improving awareness and available support across contexts (e.g., transit, libraries, grocery stores) that are regularly used within their communities. Many participants noted that being a part of these focus groups aligned with their overall goal of sharing their story in order to aid others experiencing dementia and creating change around awareness and support, including contributing to making their communities more dementia friendly. Moreover, participants also acknowledged that, in previous generations, people living with dementia were inclined to hide their diagnosis, were less involved in activism. Participants emphasized how this constructed dementia as an illness no one wanted to get, and that this cycle created more fear around speaking out publicly when one was diagnosed. As a consequence, current focus-group participants with lived experience often reported that they were generationally the first group to work towards promoting more dementia awareness, and were much less afraid to publicly acknowledge and live with their diagnosis.

*"I think we're the trailblazers because the generation before us, when they were diagnosed, they just stayed at home and you didn't see them again. Whereas we're out and about and we want to stay out and about."*

*– Person living with dementia,  
British Columbia*

*"I talk about it openly because I now believe we need to talk openly about what we have. And not be scared of it. Like people might frown at me, but I really don't care. I just talk. [laughs] I'm getting really good at it."*

*– Person living with dementia, Saskatchewan*

## Highlights

- The idea of championing refers to people living with dementia and their care partners acting as a "champion" in educational work, advocacy, story sharing, supporting others and creating change.
- Participants described a sense of responsibility, ownership and value in being a part of work that raises awareness and provides an opportunity to challenge stigma, stereotypes, or their own feelings of inadequacy.

*"It [the diagnosis] came out of the blue for us, it shouldn't have but it did. First of all we told his brother and sister. And it was very interesting to see how people back away. Family back away. People who love me back away. The most support we get are from my friends."*

*– Focus group participant, Saskatchewan*

- A number of informative quotes, directly from people living with dementia, speak volumes about the theme of championing.

*"I think it'd be really helpful, for those of us that are able to do it, is to go into these places and tell them what it's like to have dementia and how they might help us."*

*– Person living with dementia,  
British Columbia*

- Dementia-related resources may be improved upon by being more diverse, specifically culturally and in regards to the targeted age groups.
- Discussions centered on the need for more funding, more resources and further connections.

### **Detailed assessment of championing and related subthemes**

Key facets of championing summarized in this section include the availability of dementia-friendly resources and programming, as well as reflections on the core characteristics required to be a champion for one's own community.

### **Dementia-Friendly resources and programming**

Participants were aware that this work was important and that they benefited from research and social supports around dementia. They spoke of dementia-related programming that was available in their respective communities which they participated in and how in these settings, they were able to build community or participate in activities that aided them socially, emotionally and physically. Within the focus groups, participants built off of each other's stories and experiences, finding commonality and creating a rapport that often led to laughter and humour being shared. Participants mentioned that the experience of a diagnosis of dementia can feel isolating and confusing, but that creating these types of spaces where they could share and rely on others for support or information was beneficial. Care partners built similar rapport over the course of

the focus groups and could also relate to each other's experiences. In some cases, care partners described needing their own spaces for social support or community building in order to reduce their stress. These findings suggest that a dementia-friendly community allows for individuals to develop their identity as a person living with dementia in a holistic way, which can include, but does not require, being a champion for the experience and is inclusive in supporting care partner's experiences.

*"When I think of recreation centres, I think specifically of physical exercise, but I have also learned from the various stories I've heard - people living with dementia, they like to talk and exercise their brain by talking about serious things. Philosophical things. And about what's happening to them. And almost like a support group but even just like a social interaction group, not always around exercise. So maybe thinking about a little wider about the types of programs that are offered."*

*– Focus group participant, Ontario*

### **On being a champion**

In these discussions, participants provided critical feedback on some of the resources available to them in their communities that were centered on dementia advocacy. Most of this feedback however, was positive in nature and suggested that if resources are available, individuals living with dementia will utilize them. Participants often noted that broadly in this area, more funding is required and that more awareness needs to be raised around resources available, as many individuals may not be aware of the social

supports available to them after receiving a diagnosis. However, critiques were raised that the supports currently available may not be as culturally diverse as needed, and should be as inclusive to individuals of all ages living with dementia, suggesting that a younger demographic may not feel as welcome. Beyond this, participants noted that a greater amount of dementia resources may be possible if they were to boost their connections in the community.

Participants sometimes made suggestions around different types of groups or individuals in their communities they could connect with that may aid in raising funding, or providing more programming, suggesting that networking is a core aspect to raising awareness around dementia.

# Next steps

The Alzheimer Society is committed to having the voices of people with lived experience guiding the Dementia-Friendly Canada project. The findings from these focus groups have helped shaped the vision for the project and have been critical in the development of tools, education and programming that will allow for the growth of dementia-friendly communities across the country. The following is an overview of many of the ways these project findings have been instrumental to this work.

- Launching an awareness campaign to promote the Dementia-Friendly Canada initiative and dementia-friendly values across the country.
  - Focus group participants highlighted the importance of awareness when it comes to reducing stigma and educating the general public about dementia.
- Developing tools such as video clips and a social media kit that can facilitate the championing of dementia-friendly communities.
  - Championship was a central, recurring theme in the focus groups and individuals wanted ways to promote dementia friendly communities within their personal networks.
- Developing our online education to fit the needs of community-based professionals.
  - Participants highlighted the need for short and easily accessible education. Our new online course, *Building dementia-friendly communities*, will consist of four modules, each approximately 10 to 20 minutes in length that participants can stop and start as needed, allowing them to fit the course into their daily responsibilities.
- Incorporating stories, quotes and recommendations directly into online education, awareness materials and other resources being developed as part of the program.
  - Focus group participants emphasized that education and awareness should be grounded in lived experiences and stories.
- Creating and sharing video clips that provide dementia-friendly communication strategies through scenario-based learning.
  - Interactive and engaging elements, such as videos, were highlighted as an important educational tool.

- Continued engagement of people living with dementia, their care partners and community-based professionals.
  - Participants highlighted how important it was for people living with dementia to be involved in the development of dementia-friendly communities, and the project is committed to ongoing consultation. For example, we are working with people living with dementia, their care partners and community-based professionals to gather feedback on the resources currently in development (e.g. online education, job-aids and scripts).
- Providing resources in English, French and Mandarin.
  - Participants highlighted the need for resources in other languages. As such, we are committed to translating all of our resources to French and Mandarin in order to further outreach.
- Expanding our reach across the country by partnering and sharing resources with Alzheimer Societies across the country to create a truly dementia-friendly Canada.

As referenced earlier in the report, the focus group findings also highlighted areas outside the scope of the current project, including the importance of financial safety and the need for educational programs targeted at youth. These points will be shared with relevant staff as they highlight opportunities for work in other areas of the Alzheimer Society, as well as a potential for future work in the development of dementia-friendly communities.

We all have a roll to play in the development of dementia-friendly communities. The Dementia-Friendly Canada project is so thankful to the individuals (people living with dementia, care partners and community professionals) who took the time to participate in the focus groups, and shared their views, beliefs and experiences that have helped shape the vision for the project.