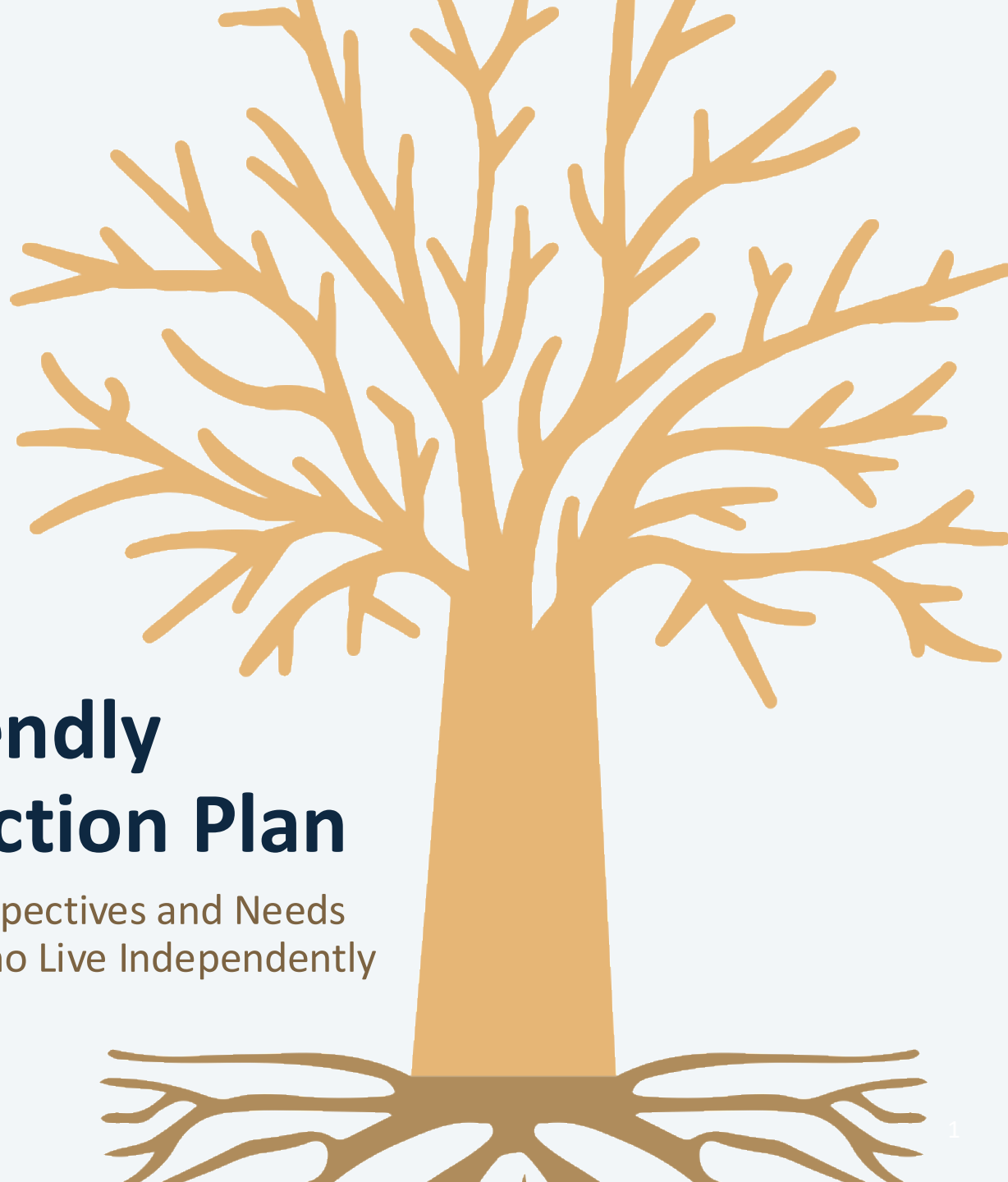


SEPTEMBER 2024

Dementia Friendly Community Action Plan

Bringing to the Fore the Perspectives and Needs
of People with Dementia Who Live Independently



Project Team

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Project Fund

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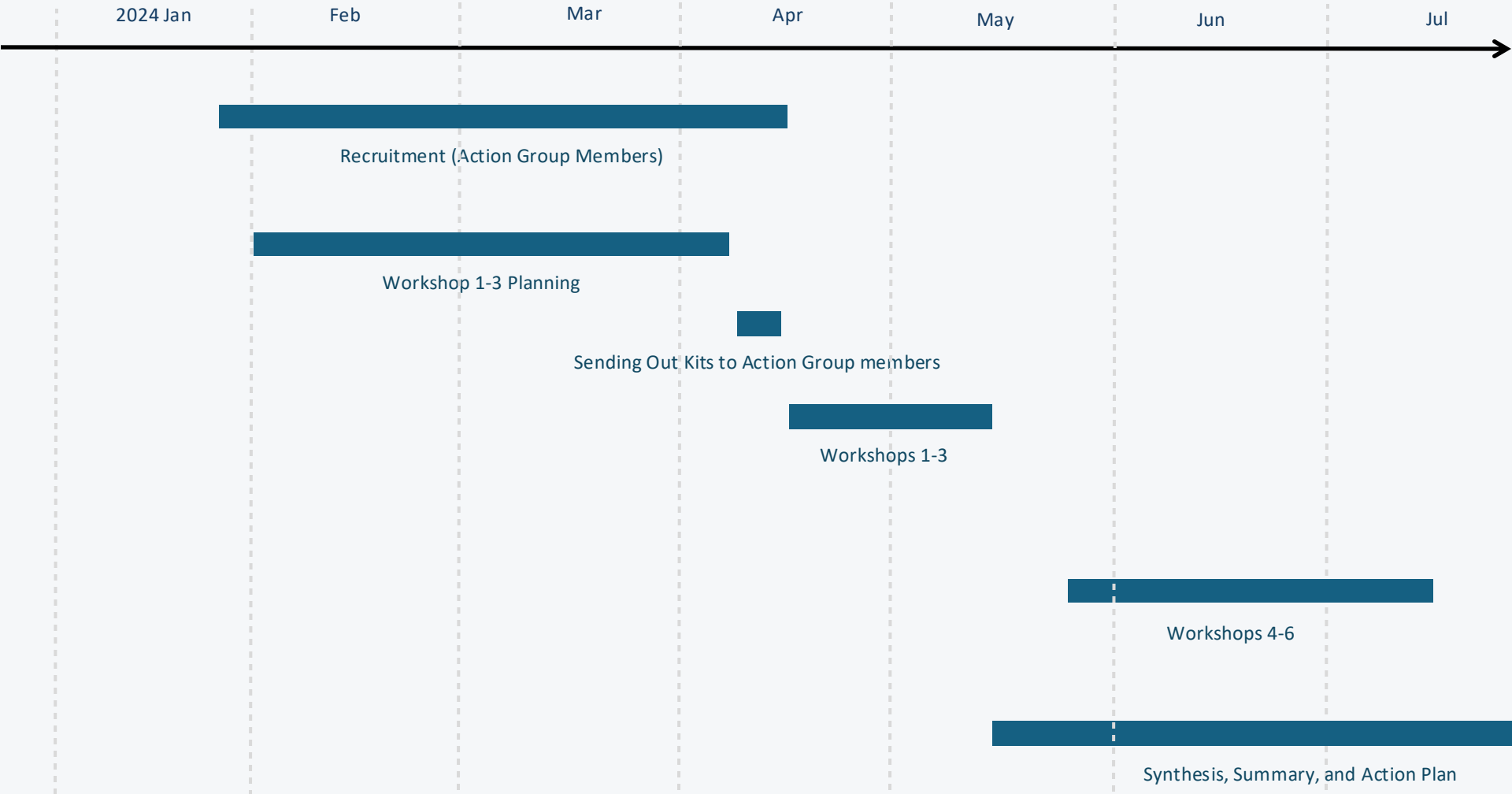
Project Goal

To convene an Action Group of people with dementia who live independently*, and collaborate with them to create an action plan that will lay the groundwork for future planning of Dementia Friendly Communities.

* By *live independently* we refer specifically to people with dementia who are living on their own in the community

Project Timeline

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The Action Group

The Action Group consisted of 8 individuals living with various forms of dementia or neurocognitive challenges from different communities from across BC. This included members joining from the communities of Burnaby, Ladner, Victoria, Sidney, Comox, Salmon Arm, Kamloops, and Williams Lake. This also included 4 men and 4 women who collectively had lived with dementia or neurocognitive challenges for 4 months to 25 years. Given that members came from diverse communities from across the province, the workshop series occurred primarily over Zoom.

Project Approach

Forming and Co-Designing with a
Dementia Friendly Action Group

Workshop Summary

The Health Design Lab, in collaboration with the UVic team, designed and hosted a series of six virtual workshops to engage with the project's Action Group members, people with dementia living independently in various communities in British Columbia.

Workshops were designed to engage and gather action group members' thoughts, ideas, and priorities regarding Dementia Friendly Communities. Our goal was to work together to co-design an Action Plan to inform future Dementia Friendly Community development that included the perspectives of people with dementia who live independently



Planning and Designing

For research purposes and to allow Action Group members from across British Columbia to participate, the workshops were planned to be virtual over Zoom.

Over a period of eight weeks, the team met weekly to iterate multiple ideas and prototypes to plan the first three co-design workshops that focused on connecting with and hearing from the Action Group members. Throughout this process, Lynn Jackson, co-lead of the project with lived experience, was brought in to ensure the workshops were aligned with research objectives.



Workshop Kits

As a result, to enhance engagement, workshop kits were produced and mailed to participants for the first three workshops. The kits were used for individual and synchronous workshop activities, explained in the following pages in this booklet.

Kits included a welcome package, introduction to the research and team, and supplies for workshops 1-3 activities.



Workshops Details

Workshop 1: Diary Collages

April 17, 2024

Workshop 2: Tree Talks
(Grounding and Strength)

April 30, 2024

Workshop 3: Tree Talks (Hopes and
Aspirations)

May 07, 2024

Workshop 4: Synthesis Share Back

May 28, 2024

Workshop 5: Future Research
Objectives and Priorities

June 11, 2024

Workshop 6: Finalizing the Action
Plan as a Team

July 16, 2024

There were a total of eight action group members participating in the workshops. Some members attended all the workshops; however, a few members did some one-on-one (virtual and in-person) sessions with the University of Victoria researchers. It was part of the research's methodology to be flexible with different action group members' needs and include options that made participation more accessible.



Workshop 1 Diary Collages

The purpose of workshop 1 was to introduce the action group members to one another and to the research team, and to create a comfortable, safe environment. In the first workshop, we discussed what *community* and *independence* means.

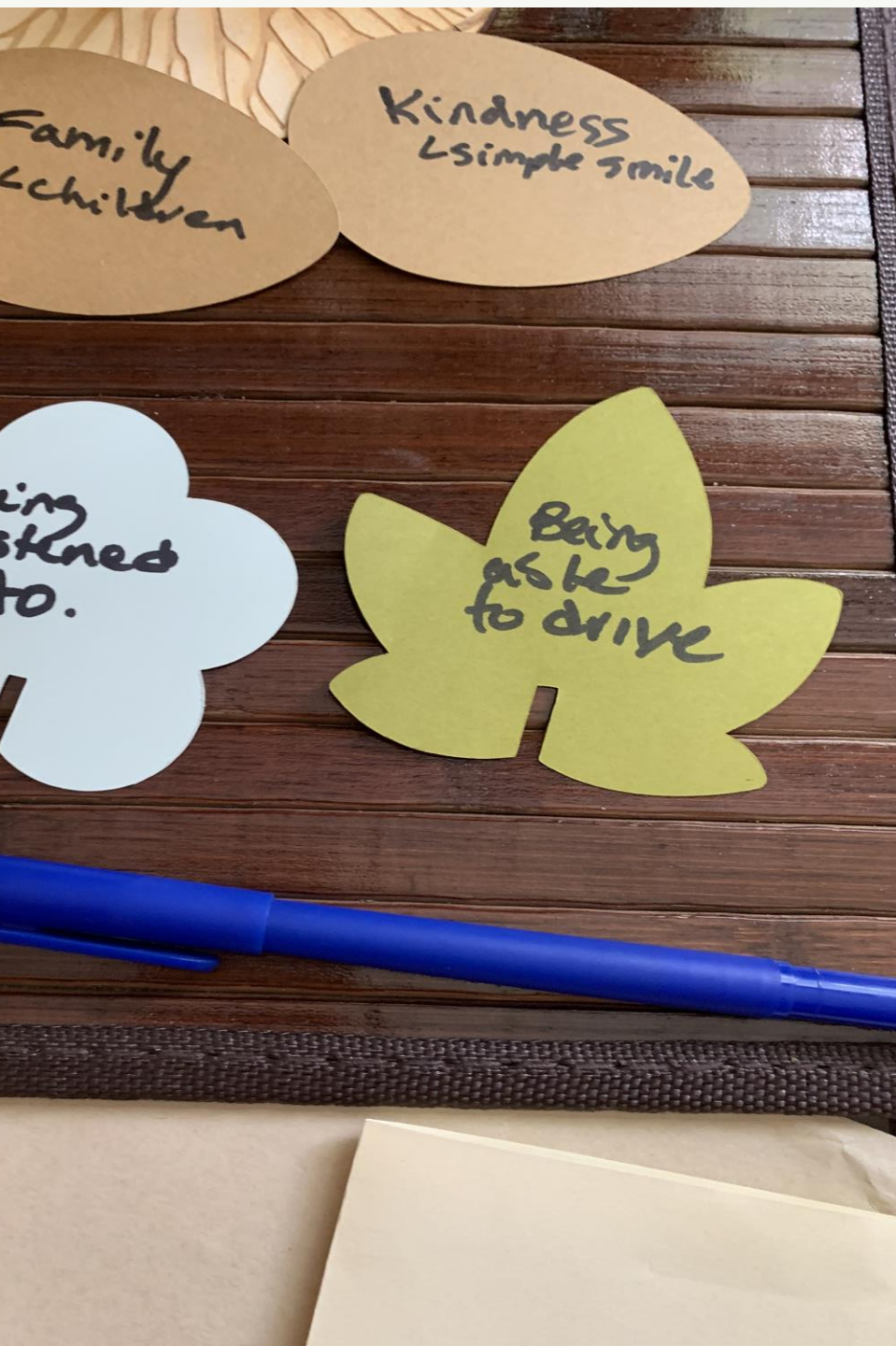
Note that workshops 1-3 were scheduled one week apart from each other.



Workshop 1 - Activity 1 Diary Collages

A couple days prior to the first workshop, action group members were asked to create a diary collage of their daily activities.

In the first half of the workshop, members introduced themselves using their collages.



Workshop 2

Tree Talks (Grounding and Strength)

In this workshop, using a tree as a metaphor, members explored what created a stable foundation in their lives as people with dementia living independently.

Prior to the workshop, members were asked to write their thoughts and ideas on seed and leaf-shaped cards and then assemble their trees.



Activity

Tree Talks: Roots/ Trunk

Members were also to reflect upon the prompts below when writing on the seed and leaf shaped cards (included in the kits):

- Some values important to me are...
- The relationships that provide me with a stable foundation in my life are...
- Things that help me live independently are...
- Some of the challenges I experience while living independently are ...

During the workshop, members shared their answers to each prompt through conversation and storytelling.



Workshop 3

Tree Talks (Hopes and Aspirations)

This workshop was a continuation of the second workshop, engaging members through the tree activity. Together we explored their hopes and aspirations for future Dementia Friendly Communities.

Their hopes and aspirations were represented by flower-shaped cards which they wrote on and affixed to the branches.



Activity

Tree Talks: Flowers

As with workshop 2, members were asked to reflect upon the prompts below and write down some thoughts on the flower cards.

- The things and actions that make me feel understood are ...
- To maintain my independence in the future, I envision ...

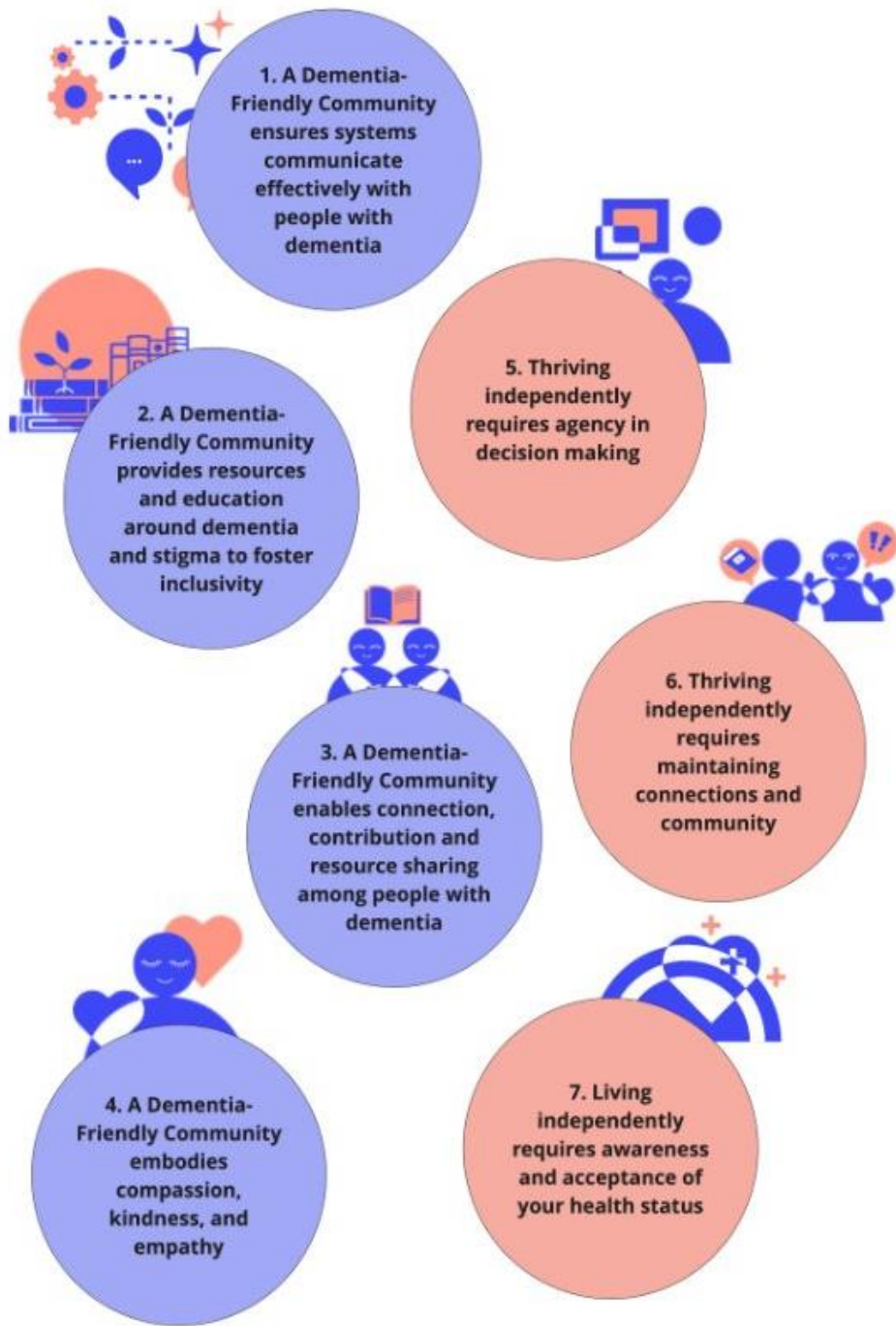
Workshop 4 Synthesis Share Back

Throughout the first three workshops, two research assistants in attendance recorded verbatim notes, capturing action group members' reflections and contributions to the workshop discussions. All the workshops were recorded, and transcripts were created.

The research team analyzed the collected data to create initial themes capturing the main ideas discussed throughout the first three co-design workshops.

In workshop four, these initial themes were shared with members for discussion and feedback.





Workshop 5

Refining the Themes

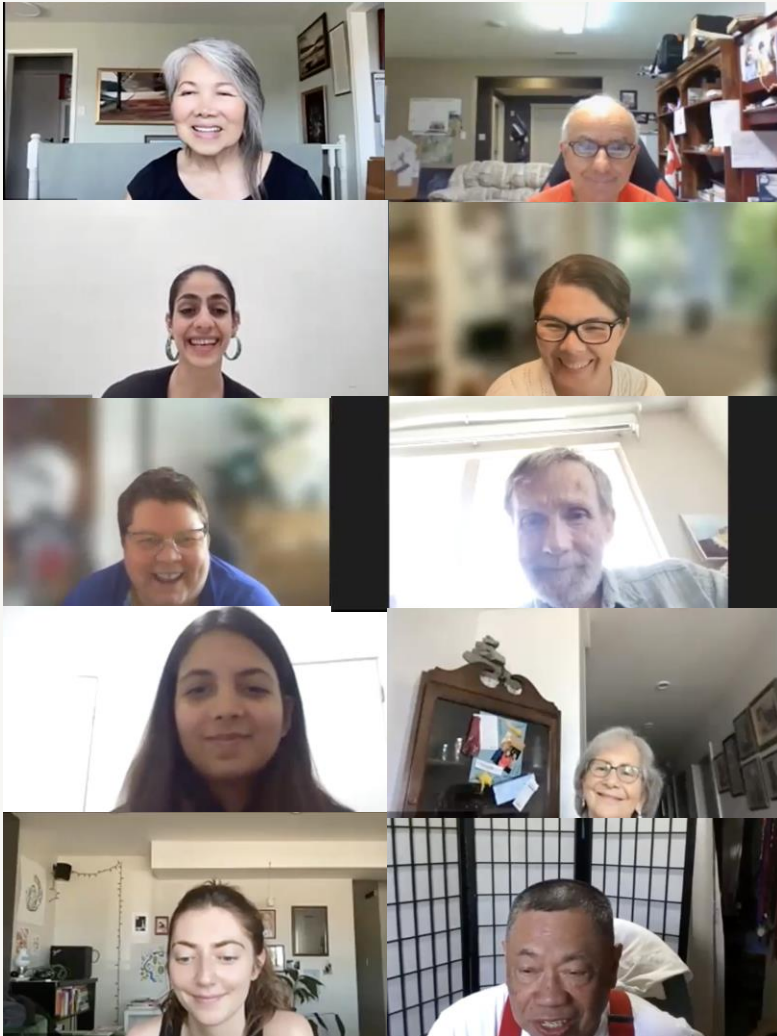
During workshop 5, the research team provided Action Group members with revised theme statements and explored the interconnected relationships amongst the themes.

Themes were divided into two categories that initially created seven statements overall (this later became eight themes). The two categories included:

Category 1: A Dementia Friendly Community...

Category 2: Thriving independently...

During this workshop, language and terminology that did not resonate with members was discussed and refined. For example, members did not like the word *agency* as it was felt to be too academic in nature – and later iterations of the Action Plan include "Being involved in making your own decisions" rather than *agency*.



Workshop 5

Future Research Objectives and Priorities

During workshop 5, the research team also engaged with members to discuss what they considered priorities for future research focused on people with dementia who live independently.

Action Group members identified the following as priorities:

- There needs to be more opportunities for others to listen and learn from people with lived experience. One member suggested that videos could be created that showcase people living well with dementia
- Ongoing education for the general public is needed to learn about the experiences and needs of people living with dementia
 - Education materials and resources need to be developed by and in partnership with people with lived experience

2. In a Dementia Friendly Community, information and resources about dementia are easily accessible to the public

In a Dementia Friendly Community, it's imperative that information and resources about dementia are easily accessible. Facilitating widespread awareness can play a pivotal role in dispelling myths, misconceptions, and stigma surrounding dementia, emphasizing its distinction from normal aging and the importance of meaningful support. Information and resources should also recognize the anxiety that those receiving a diagnosis of dementia often face. This recognition, coupled with education on dementia related stigma, can lead to a better understanding of what meaningful support for people with dementia can look like.

One member spoke about the potential for community members to provide support when they are educated about dementia. Action Group members also emphasized the importance of making the community aware of who they are, where they are, and how the community can help, highlighting the need for community engagement and support.



5. In a Dementia Friendly Community, people living with dementia are connected to other people with dementia

In a Dementia Friendly Community, connecting people living with dementia to others who share their experience is essential. Establishing peer support groups and providing resources for individuals with dementia to connect with one another enables them to share valuable information (such as helpful resources, stories of their unique experiences of living with dementia, opportunities for engaging in research), offer mutual support, and build a sense of community.

By forming these relationships, people with dementia can strengthen their support networks, enhance their social and emotional well-being, and feel more integrated into the community. Organizations and community groups can facilitate these connections by organizing regular meetings, social events, and other activities designed to bring people with dementia together.

Everyone in the Action Group emphasized the importance of these connections in maintaining their own sense of purpose and establishing friendships.



Workshop 6

Finalizing the Action Plan as a Team

During the sixth and final group workshop, action group members provided feedback and key edits on the initial draft of the "Action Plan". The Action Plan provides more concrete examples for future action in the development of dementia friendly communities as well as quotes directly from action group members. The Action Plan is informed by the edits and feedback that action group members shared about the synthesis presented during workshops 4 and 5.

The Dementia Friendly Community Action Plan

A full report of the eight key themes developed in the workshop series-presented as an Action Plan for future Dementia Friendly Community Planning.

In this document two main ideas are presented:

1. What people with dementia who live independently need to thrive in community
2. What makes a dementia friendly community based on the sharing of people with dementia who live independently

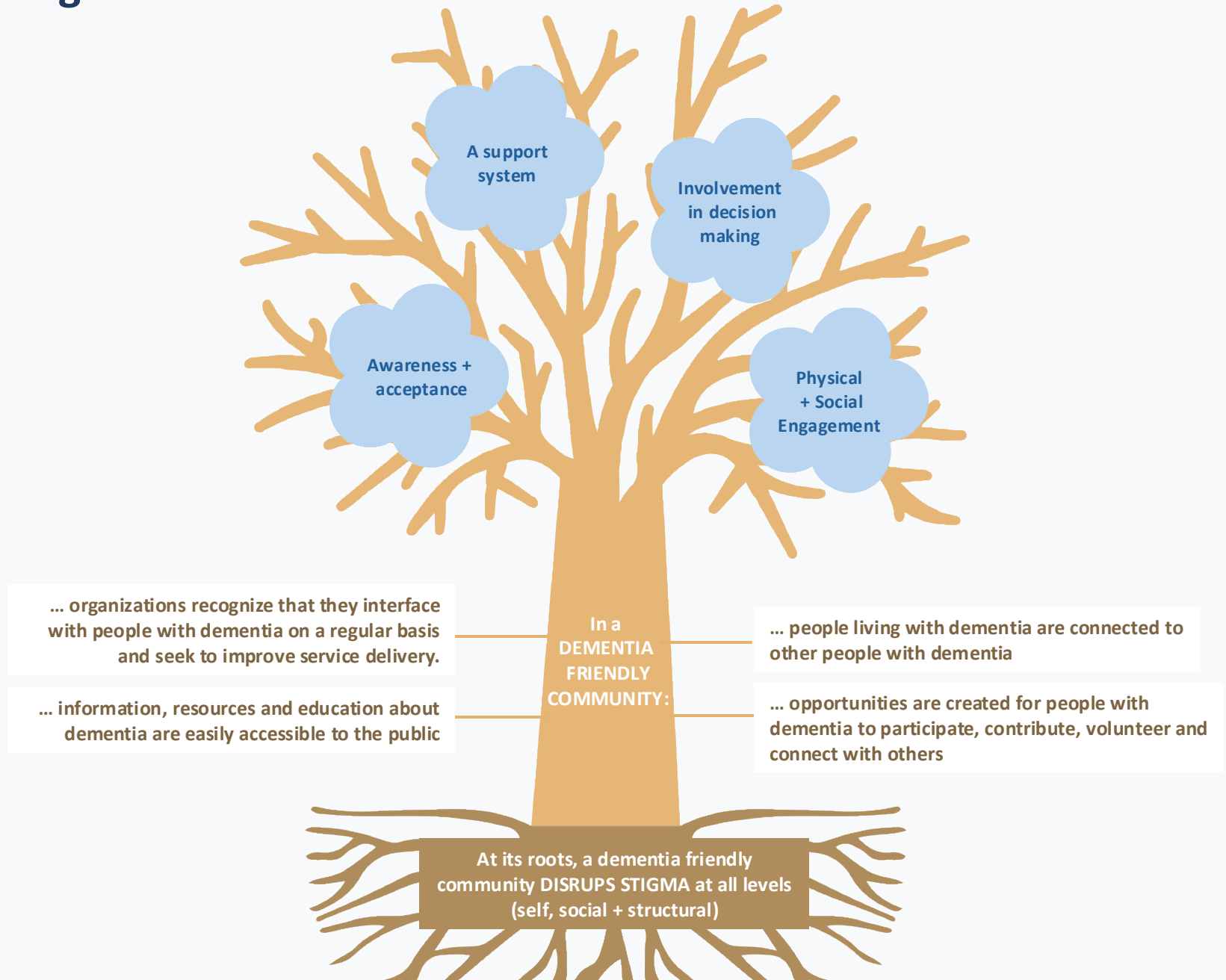
First, we present these ideas in a diagram (tree diagram) and then discuss these ideas separately

**People who live independently* refers to people living with dementia, who also live on their own in the community setting.

Key Insights:

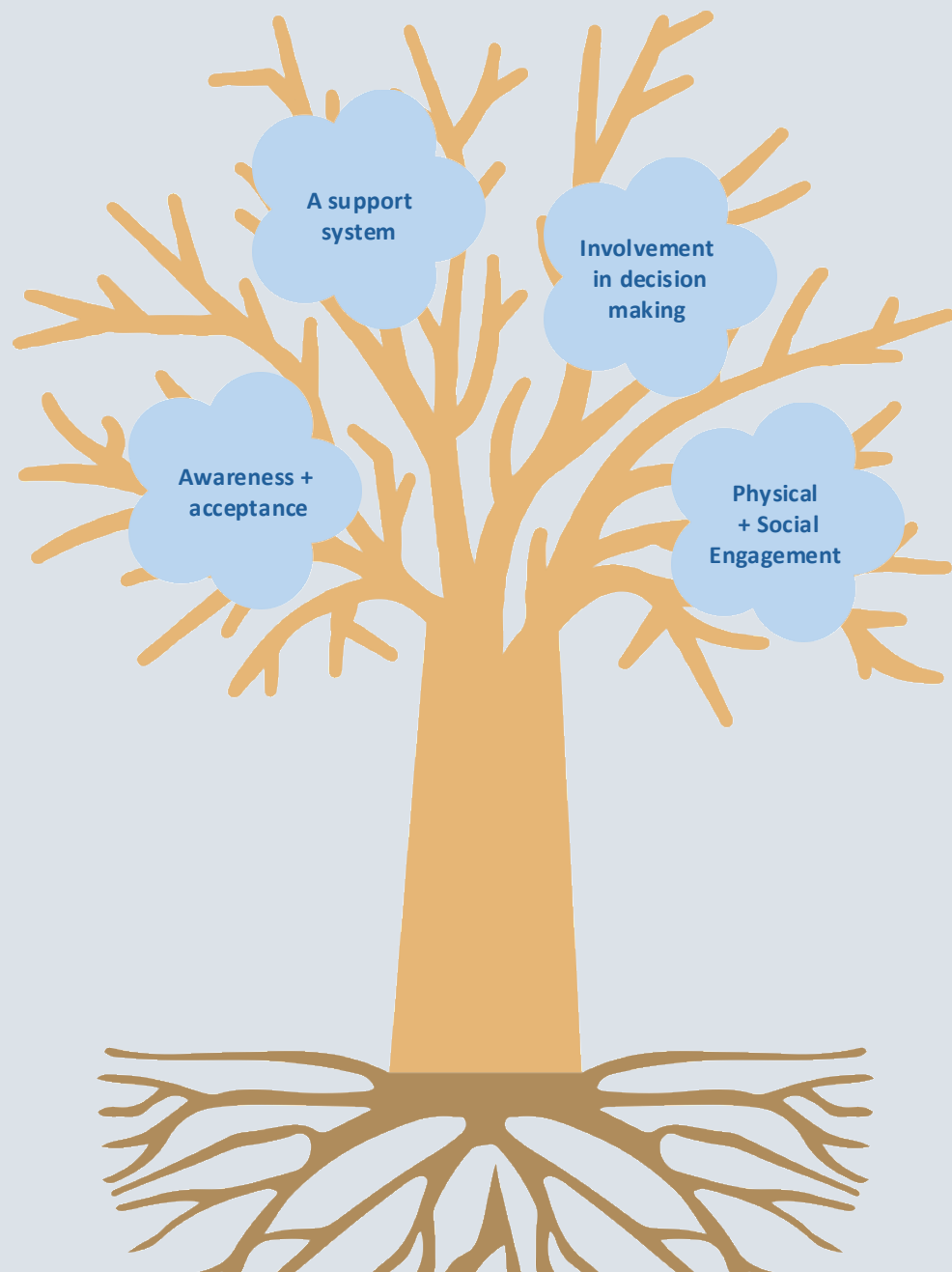
To THRIVE INDEPENDENTLY
people with dementia need:

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Thriving Independently With Dementia

Key Themes According to People
with Dementia Who Live
Independently



A dementia friendly community enables people with dementia to **thrive while living independently**. Based on our conversations with the Action Group, we learned that the following elements are valuable when living with dementia independently:

1. Awareness and acceptance of what it means to live with dementia
2. Establishing and maintaining a support system to meet individual needs
3. Being involved in making your own decisions
4. Being physically and socially active

1. Awareness and acceptance of what it means to live with dementia

It is important for people living independently with dementia to have opportunities and resources to educate themselves about their unique diagnosis and begin to overcome self-stigma. Thriving independently with dementia includes being aware of the changes and challenges that go along with a dementia diagnosis, the common misconceptions related to dementia, as well as activities and skills one is comfortable, willing, and eager to carry out on their own.

For example, an Action Group member described how educating herself about her type of dementia helped her to gain the confidence and willingness to talk openly about her diagnosis to family members and the greater community. This, in turn, helped to ease tension that existed in conversations and interactions with those around her. One member shared how his memory loss sometimes leads him to socially withdraw to avoid having to explain his dementia symptoms to others. Over time, he has become more comfortable disclosing his diagnosis, describing this journey as an "inner process" of self-acceptance and adaptation to his current reality and lifestyle.

1. Awareness and acceptance of what it means to live with dementia

"...When they found out that I was comfortable talking about it, then they became more comfortable about it.... I could teach them about it and what it was. I told them that I might need some help once in a while, I've got these idiosyncrasies that I do or not do, and if you could watch for that. I was really quite open. And that has been a good thing for me and my friends."

This sentiment was articulated clearly by another member, sharing that *"the acceptance of my condition and the comfort in just telling people 'I'm having memory challenges'...that's been the switch for me - being more accepting of my current reality with memory loss and also my comfort level of sharing it with other people."*

"I talked to them...Once you get it out in the open it's easier."

2. Establishing and maintaining a support system to meet individual needs

Thriving independently with dementia involves establishing and maintaining connections and community as a support system to meet individual needs. People with dementia can choose and build their support systems, which can include their family and friends, health practitioners, neighbours, and extended community.

One member explained how he periodically has friends who stay with him and support him with his health. He often has seizures at night and feels supported through a "friendship kind of arrangement" where friends stay at his home at no cost while providing him with information about the length of his seizures and if any other health events occurred that may be of concern.

2. Establishing and maintaining a support system to meet individual needs

Through connection with a hospice network, one Action Group member made a connection with a local peer, and they regularly go for walks in nature where *"...we just share stories with each other and that's a great support...there's no obligation on either side"*.

One member explained how a support system helps him when he has health complications: *"...Periodically, I have friends staying with me... I always have [seizures] at night, while I'm sleeping...so I wake up without any awareness of how long it was and what occurred in terms of falling and so on..."*. *"There's just a friendship kind of arrangement."*

"Living independently for me is supported by a community of people around me who aren't government connected...somebody in the local community in [my] apartment complex may have that knowledge that I can go to... So, living independently is supported by those different...gifts."

"I tell the people at [volunteering space] that I have dementia... I leave things behind [so] I think it's important to let people know and they will be helpful."

3. Being Involved in Making Your Own Decisions

From little decisions to bigger ones, thriving independently involves having autonomy in making choices and actively participating in decision-making on one's own behalf. This can include choosing the individuals that people with dementia surround themselves with (who they want to include in their support system), how they spend their time, how they navigate varying aspects of everyday life, and to who and when they disclose their diagnosis.

For example, an Action Group member mentioned how they decided to travel and live in Mexico for five months when they were diagnosed with dementia. Their story helped other members to recognize that a diagnosis of dementia does not take away the possibility of living a full life. After a diagnosis, one can continue to be in control of their own life – making decisions on their own behalf and making choices that bring them joy.

Key Themes: Thriving Independently with Dementia

3. Being Involved in Making Your Own Decisions

Many members expressed hesitancy about disclosing their diagnosis to family, with some family members suggesting they limit their activities. This hesitation reflects the stigma that often accompanies dementia, and a broader uncertainty about how dementia will be perceived and accommodated within social circles. *"...When I told my siblings [that I had dementia], they said 'big sister, don't say anything, don't say anything to anybody, it's not noticeable yet. It could be normal aging - all of us have some memory loss' ...I really understood that right from the start... by them trying to make me deny or stop me from telling people...the bad reputation... This stigma...that people usually have the words people who are diagnosed with...what we have."*

4. Being physically and socially active

Taking ownership of one's health is important for thriving independently and sustaining one's wellbeing. This means focusing on basic needs such as keeping physically and socially active, establishing routines, maintaining a healthy diet, and connecting to others. Volunteerism was seen as great way to build and maintain social life and connections that can be relied on, while enhancing a sense of purpose, belonging, and support.

For example, members emphasized connecting to nature and the outdoors as a practice and routine in their daily lives. This included growing a garden in their backyard, attending community gardens, or enjoying morning walks and taking pictures of flowers.

As another example, an Action Group Member mentioned how he goes swimming and lifts weights at his community center every day. Another member shared how she enjoys getting involved in different research or community events to have a sense of purpose.

4. Being physically and socially active

"I'd like to meet people all the time. I'll go to exercises and swimming daily with friends."

"Every time I wake up in the morning I need to have a purpose. I will go for a walk, and...I will go to Stanley Park and take a picture of the water, or sometimes...I would like to take a picture of the flowers. That sense of purpose, I think, make(s) my day...purposeful...so that in the end of the day I would sit [at] my computer, download the pictures, and I [say], 'Look at what I did' and start appreciating what I did, and at the same time what Mother Nature has offered...to present me in my...morning walks."

A Dementia Friendly Community

Key Themes According to People with Dementia Who Live Independently



To live independently, people with dementia need to rely on their community for support. Communities should seek to disrupt stigma at all levels (self, social, structural), as addressing the stigma that people with dementia often face can reduce isolation and improve their quality of life.

This is what we learned from Action Group members:

1. In a Dementia Friendly Community, information, resources, and education about dementia are easily accessible to the public
2. In a Dementia Friendly Community, opportunities are created for people with dementia to participate, contribute, volunteer, and connect to others
3. In a Dementia Friendly Community, organizations recognize and understand that they interface with people with dementia on a regular basis and actively seek to improve service delivery
4. In a Dementia Friendly Community, people living with dementia are connected to other people with dementia

1. In a Dementia Friendly Community, information and resources about dementia are easily accessible to the public

In a Dementia Friendly Community, it's imperative that information and resources about dementia are easily accessible. This would include ensuring that resources are provided in multiple languages, and in easy to access online formats with printable versions as an option.

Resources should emphasize widespread awareness, which can play a pivotal role in dispelling myths, misconceptions, and stigma surrounding dementia, highlighting its distinction from normal aging. Information and resources should be created in ways that are sensitive to the anxiety that those receiving a diagnosis of dementia often face. This means that language used in resources is non-stigmatizing, includes the voice of people living with dementia, and offer tangible supports and potential for people to seek a meaningful life following diagnosis. Promoting and seeking out educational resources on dementia related stigma created in partnership with people with lived experience, such as the Flipping Stigma Toolkit (www.flippingstigma.com), can lead to a better understanding of what meaningful support for people with dementia can look like.

2. In a Dementia Friendly Community, opportunities are created for people with dementia to participate, contribute, volunteer and connect with others

Organizations and community groups can consider how to enhance participation by people with dementia in their programming, such as providing opportunities for people with dementia to volunteer in community. This enables people with dementia to continue to be socially and physically active. By engaging in community and participating as volunteers, people with dementia can also strengthen and grow their support system.

People living with dementia are encouraged to reflect on the spaces in their lives where they wish to maintain participation and connection. Certain activities may benefit from some adaptation such as peer support, asking and accepting help from others, expressing one's feelings and anxieties so that such adaptations may occur, and recognizing that living with dementia is a "day by day process".

Additionally, organizations and public spaces such as community centers, public recreational facilities, tennis courts, walking trails, and public pools, need to consider how they can make space in their existing activities and programs for people living with dementia. This could mean enlisting the expertise of peer support networks.

3. In a Dementia Friendly Community, organizations recognize and understand that they interface with people living with dementia on a regular basis and thus, actively seek to improve service delivery

This understanding is essential for adapting approaches to effectively engage and support individuals with dementia. The healthcare system, government agencies, transportation services, financial institutions, and community centers need to prioritize the enhancement of their services, ensuring they are accessible, non-stigmatizing, inclusive, and tailored to the needs of people living with dementia. By prioritizing understanding and responsiveness, these organizations play a crucial role in nurturing a supportive and inclusive community for individuals living with dementia. Education for staff and personnel about the diverse needs and strengths of people living with dementia will go a long way in helping to build dementia friendly communities. It will be important for education sessions to include and be designed around the perspectives of people with dementia.

4. In a Dementia Friendly Community, people living with dementia are connected to other people with dementia

In a Dementia Friendly Community, connecting people living with dementia to others who share their experience is essential. Establishing peer support groups and providing resources for individuals with dementia to connect with one another enables them to share valuable information (such as helpful resources, stories of their unique experiences of living with dementia, opportunities for engaging in research), offer mutual support, and build a sense of community.

By forming these relationships, people with dementia can strengthen their support networks, enhance their social and emotional well-being, and feel more integrated into the community. Organizations and community groups can facilitate these connections by organizing regular meetings, social events, and other activities designed to bring people with dementia together.

Everyone in the Action Group emphasized the importance of these connections in maintaining their own sense of purpose and establishing friendships, collegial and supportive relationships.

Reflections on the Co-Design Process

Team Insights and Self-Reflection

Reflections on the Co-Design Process

- People with Lived Experience were at the core of the planning and analysis process
 - The co-PI is a person living with dementia who has an extensive background in advocacy work and research. All research decisions included her perspective – especially those that concerned the engagement of the Action Group.
 - The development of the Action Plan was an iterative process that involved Action Group members at all stages
- Arts-based activities were used to support connection and discussion
 - Workshop materials were mailed or hand-delivered to all members and prompted members to share examples and stories from their own lives.
 - Images and collage work were used to prompt personal reflection and storytelling
- The co-design and workshopping processes were adaptive and flexible to members' needs
 - We mailed a pre-programmed tablet to an Action Group member who did not have a personal computer.
 - We connected with several Action Group members via phone, text, email, Zoom, and in-person when they were unable to join the group workshops.
 - Each workshop started with a social check-in, allowing time to connect and meld as a group.
- Adaptation is not just methodology – it's an important finding. Dementia friendly communities become reality when they adapt to people's needs.

Reflections on the Co-Design Process

- This project was successful because of the practices we put in place:
 - e.g., One Action Group member met one-on-one with the project PI in-person rather than in the online group format. She was **aware of her own abilities with technology and preference for engaging one-on-one**, and made this known to the project team so that she was still able to participate. This was an **autonomous choice** that was supported and respected by the project team.
 - e.g., As stated in the 4th point of the calls to action, *"In a Dementia Friendly Community, people living with dementia are connected to other people with dementia"*. **This results of this project are built upon the foundation of a group of people living with dementia who became connected to one another**, discussed their experiences, shared knowledge with one another, and formed positive working relationships that led to the creation of this document.
- It was difficult to recruit for this project – it took several months and intense recruitment to build the Action Group.
 - Many of those who participated were already involved in their communities/already thriving.
 - Questions for future research: how do we reach those people living with dementia who are not thriving? How best to reach those who are not connected with other people with dementia or with supportive communit(ies)?

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It was developed by the UVic Dementia Friendly
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and the Sakamoto Lab at the University of Victoria
2024