



DEMENTIA VENTURES

Learnings on Engaging with People with Lived Experience



Roundtable Takeaways

On May 25th, the Building Capacity Project Team met with Westside Seniors Hub Partners, the Northwest Dementia Working Group, and Flipping Stigma Action Group members for a special Roundtable discussion about engaging people with dementia **using the Action Group's Flipping Stigma toolkit as an entry point.** Dementia Ventures are initiatives of the Hub Partners participating in The Building Capacity Project.

The Building Capacity Project, a Public Health Agency of Canada funded cross-Canada initiative, aims to enable people with dementia to **participate in community life as full social citizens.** The project is a partnership between researchers at the University of British Columbia and Lakehead University, and their community partners: members of the Westside Seniors Hub in Vancouver and the Northwest Dementia Working Group in Thunder Bay, a coalition of people with lived experience, care partners, and researchers. Through Dementia Ventures, Hub Partners are implementing various programming initiatives that seek to create opportunities for active involvement of people with dementia, such as a virtual memory café, a buddy program, and outdoor activities.

The Flipping Stigma toolkit is just one of many powerful initiatives with which they've been involved. The online toolkit, **co-designed by researchers and an Action Group of people with dementia,** identifies common examples of stigma and discrimination experienced by people with dementia, and offers pragmatic suggestions for how to respond. The event gave community partners **a chance to think through what stigma looks and feels like,** and how they might use this toolkit in their contexts to increase awareness and contribute to a more dementia friendly culture that features active involvement of people with lived experience in planning and implementing new initiatives.

This document offers highlights from the discussion where Flipping Stigma Action Group members and Northwest Dementia Working Group members shared powerful insights based on their lived experience, and community leaders had the opportunity to ask questions and **think strategically about engaging people with lived experience** into their organizations, and also about using the toolkit in their contexts.

Questions Asked by Partners

On engagement:

- What's the best way to really **connect, engage, and partner with people with lived experience?**
- How do we engage in cross cultural conversations about dementia?

On program advertisement and promotion, and attendee recruitment:

- How do we advertise programs in a way that makes people aware they're going to be inclusive of people with dementia without using language that is in any way condescending, stigmatizing or discriminatory?
- From an engagement perspective, what are the **pros and cons of making programs inclusive** versus making them specifically for people with dementia?

On addressing conflict or difference:

- How should we deal with situations in our programs** where stigma is very strong and family members will not tell their loved ones who have dementia about their own diagnosis?
- What are some of the resources that **support cultural expectations** around who should be talking about dementia? For example: in some communities, there's a sense that people want to hear from "experts" as opposed to "people with lived expertise". How to broach that?
- How do we **have conversations with people we know personally,** in our families or social groups, who might be showing signs of early-stage dementia?

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-We have Action Group members here today who are confident about attending events, groups and activities. But what about those in the community who aren't that confident yet? How do we phrase things so care partners are convinced attendance is a good idea? And **how do we support shifting the dynamic** when care partners are treating their loved one with dementia as incapable?

On practical issues:

-There is inevitably a mourning period after someone receives a dementia diagnosis, both for the person diagnosed and for their loved ones. There's fear, sorrow, and grief. As care partners or family members, **should we be putting our fear and sorrow to the side** because it needs to be about something else? How do we go about doing this?

-How do we create an advisory group comprised of people with lived experience, and include these voices in our programming and planning?

Insights from Action Committee Members

"We're just like you. If I noticed an acquaintance dealing with something that concerned or worried me, I'd probably ask them about it directly. Until that person with dementia has reached the end stage, **they still have so much understanding.**" -Myrna

"There's a bit of discomfort sometimes when I'm in a social setting with a group of people and they're having a nice rolling conversation. They know I have dementia. They're comfortable with that. But I don't want to rain on them by asking them to slow down." -Granville

"Many people believe what they're told by doctors. They told me I was no longer competent. That was 22 years ago. So, for anybody living with dementia, **sometimes you need to tell the doctor where to go.**" -Bill

"If you're blessed enough to have lucidity, it's almost an obstacle to the other person actually believing you have dementia. When I speak of writing my novel, people say, 'How can you do that? You can't have dementia and be coherent enough to write a novel.' So, we really have to fight not only for ourselves as people but sometimes for our very humanity to get people to understand we are still all there." -Granville

"When I was first diagnosed, I didn't want to do anything. But **luckily my family kept pushing me.**" -Lynn

"I'm having a great deal more success with getting people out [to events] when I ensure that they know there will be others with dementia present. So they feel less awkward about the invitation." -Myrna

"One thing we do in Thunder Bay is offer coffee and cookies. That gets people socializing at their tables and the next thing you know, those who have been reluctant to go are eager to come back the next time. They've had a good time associating with people with a similar diagnosis and are realizing if those people can participate, so can they." -Bill



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“Nobody has a label coming through the door.” -Lois

“If a care partner continues to make the person they care for feel like a patient, then the person is made to feel sick and they act like they’re sick. If the care partner gives them more autonomy, they will have more autonomy.” -Lynn

“We’ve found that at the Dementia Café, the people there don’t talk to the care partner, they talk directly to the person with the diagnosis which is great.” -Bill

“The greatest fear for us all is passing on, and fear is the first thing people experience when they learn of someone they love being diagnosed. It’s also the first thing people try to deny. Fear is the gift and the curse of having dementia. It puts you in the role of having to educate people about their own fear, and you have to start by educating yourself.” -Granville

“You have to find your sense of self, and trust within yourself despite what society is telling you. That’s your first job. And that is where everyone here can help by giving support and a lack of judgment. Non-judgment builds trust and by not judging yourself, you can then impart that non-judgment to those around you. Take that fear and make it a reason to grow rather than scream.” -Granville

“Sharing the toolkit [with my church congregation] helped me feel brave. I could be more open with my friends. I felt included, understood, heard, listened to and not ashamed that I have dementia.” -Lester

“And bravery feeds upon itself. People talk to [Lester] more respectfully now. We shared Lester’s diagnosis with friends who’d said, ‘no, you don’t have dementia.’ And now they’re coming to the Alzheimer Society Walk and cheering us on.” -Cindy (Lester’s partner)

“When I was diagnosed, what pulled me out of my depression was the fact that I had no choice but to feed my horses. I had a reason to carry on. So, get out there, get active, keep at it.” -Bill

Implementing the Toolkit, Engaging People with Dementia in your Context

The toolkit is a great conversation starter, and encourages people with dementia to build confidence and competence to advocate for themselves and others. “To advocate is to educate,” one Action Group member said. And through further education, we all win.

Thoughts on implementing the toolkit in specific contexts:

Partners said they’d use the toolkit in a variety of ways:

- in small group discussions as a way of testing interest in organizing wider church seminars
- in their newsletters and printed off as documents to hand out at local neighbourhood fairs
- for training not only volunteers but also community centre staff
- for using as a way into conversations with anybody who has family members with dementia or just wants to learn how to communicate better



BUILDING CAPACITY PROJECT



Westside
Seniors Hub



Lakehead
UNIVERSITY

Centre for
Education and Research
on Aging & Health

CRPD Centre for Research on
Personhood in Dementia



NORTH WEST
Dementia
WORKING GROUP

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Thoughts on engaging with the material:

The toolkit has the potential to dig into issues coming up for families around diagnosis and ongoing care including **families in denial** that their family member has dementia or families who have decided not to tell the person with dementia about their diagnosis. It's also **effective as a self-advocacy piece**, offering amazing opportunities for people to learn directly from those with lived experience, put themselves in their shoes and get a deeper sense of how they could better support, encourage, and see people with dementia as independent citizens with a **wealth of capability**.

The toolkit can be used as a **means for building connections and relationships**. Community centres and similar public spaces can promote it as a resource that facilitates wider, more powerful **connections in community that would break down stigma** on a systemic level.

The toolkit works like a **roadmap for empathy and shifting perspectives** towards a more empowering approach: seeing dementia-inclusive programming not as the end goal to which we're all working, but as a support system along the journey that lifts up those with lived experience and gives them **the power to direct their own process**.

Resources

Westside Seniors Hub
westsideseniorshub.org

The Building Capacity Project
buildingcapacityproject.com

The Flipping Stigma on its Ear Toolkit
flippingstigma.com

The Northwest Dementia Working Group
cerah.lakeheadu.ca/knowledge-translation/committees-collaborations-networks/

The Northwest Dementia Working Group Dementia Friendly Language Guide
buildingcapacityproject.com/_files/ugd/252a19_e06e5dfe02d04727aa862a9cc31c81c1.pdf

Alzheimer Society of BC
alzheimer.ca/bc/en

Dementia Dialogue
dementiadialogue.ca

Thank you all so much for joining us in this important conversation. We are eternally grateful for your ideas, your open-mindedness, your contributions, and your work in community.