

Social Inclusion and Dementia Supportive Communities

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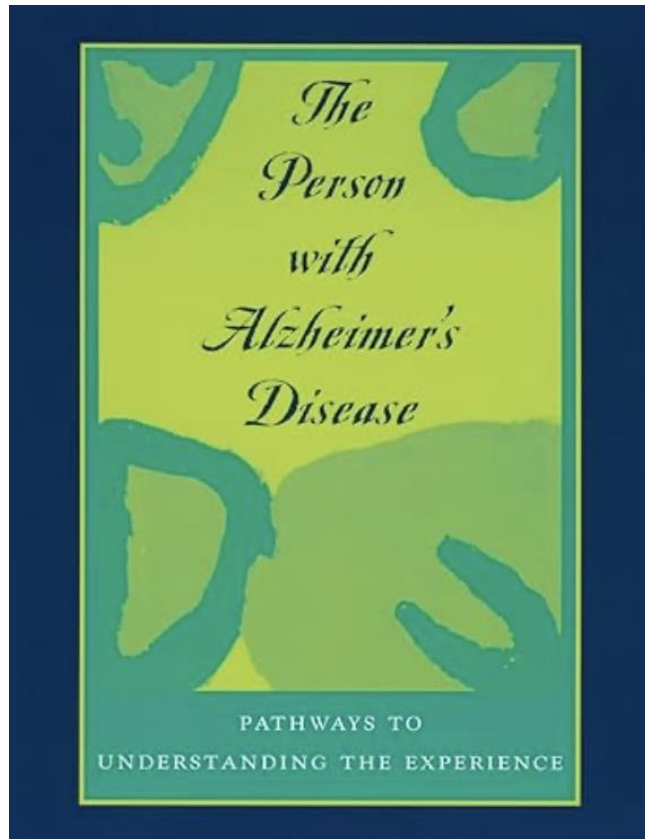


Making connections



- Listening matters
- Don't be afraid to ask questions
- Stay curious

What is it like to have dementia?



- *I Can't Remember*
- *I Worry about Getting Lost*
- *Everything is More Difficult*
- *I'm Sort of Oblivious*
- *Conversations Don't Always Fall Into Place*

Phinney, A. (2002) Living with the symptoms of Alzheimer's disease. In P.B. Harris (Ed.), *The person with Alzheimer's disease: pathways to understanding the experience*. pp. 49-70. Baltimore, MD: The Johns Hopkins University Press.

Example

I used to sort of sit back and let it go, you know, but now I have to concentrate. They may ask me a question, so I better listen and know what they are talking about. This just occurred to me, you know, that they're talking to him and him. They are going to ask me, and I wouldn't even know what the subject is that they were discussing would be...

So I just stand back and listen... I can't really join in here... I would sound kind of foolish if I say something that has no relation to what they've been talking about.

INTERVIEWER: So you would be worried that you would embarrass yourself?

Yeah. Or embarrass them too. They're friends, so I'm a little leery.

What is meaningful activity?



What is meaningful activity?

- Physical activity
- Creative activity
- Social activity
- Autonomy and agency
My brain is not so good but the body still works!
- Pleasure and enjoyment
I can express joy and happiness... it's one of the most wonderful things
- Connection and belonging
You feel like you're wanted

Activities for improving quality of life

- Get your body moving (outdoors if at all possible).
- Find ways to express your imagination.
- Hang out with other people (even if you are an introvert).

What can we do to make opportunities like this available for everyone?

Taking it to the community level



“A *mycorrhizal network* is an underground network found in forests and other plant communities... that connects individual plants together.”

Taking it to the community level



“Dementia is not a single person issue. It’s a family, it’s a neighborhood, it’s a community issue.”

- How can research create change?
- How can this research be led by people with dementia and their communities?

Taking it to the community level

Flipping Stigma Project

Participatory Action Research

Work with people with dementia to reduce stigma and promote social inclusion

→ Developed a toolkit for raising awareness, education and training

Building Capacity Project

Asset-based Community Development

Work with community organizations to build capacity to support involvement of people with dementia

→ Developed and implemented new dementia initiatives

Building Capacity Project

- Dementia Ventures (2019-2023) was an initiative of Vancouver's Westside Seniors Hub whose **community partners** (mostly non-profit neighbourhood-based groups) worked together with our **research team** and an **action group** of people with dementia to imagine and realize new opportunities for social connection.
- Drawing on principles of **asset-based community development**, different kinds of programs were created over the life of the project, including...
 - Memory cafes
 - Butterfly gardens
 - Community dialogues

Building Capacity Project

- As part of our developmental evaluation, at the end of the project Andréa Monteiro conducted interviews with community leaders, program staff, volunteers, and people with dementia.
- Sam Pineda created a short documentary based on these interviews. The film highlights the strengths these groups have leveraged to create new narratives about dementia, and what they have learned about how to put these narratives into action.

LOVE



What did we learn?

- Being ready for change
- Needing to address stigma
- Working with (not for) people with dementia
- Working in a community's own language
- The role of the university as project backer

Who is doing this work?

- Flipping Stigma Action Group
- Northwest Dementia Working Group
- A.S.K. Friendship Society
- Dunbar Residents Association
- Kitsilano Neighbourhood House
- South Granville Seniors Centre
- West Point Grey United Church
- Building Capacity Research Team
- Westside Seniors Hub

New Ways to Connect

Purple Angels

- The Purple Angels is a support and activity group for people living with dementia and their families.
- It was founded and is led by a person living with dementia.
- Activities include educational discussions, outings to cultural and social destinations, and seasonal celebrations like Oktoberfest and Christmas in July.
- New groups are forming!



Dementia Co-Creation Academy



We are proudly and purposefully living WELL with dementia because

We Know, We Connect, We Belong, We Create, We Impact



Happy Memories Café

- South Granville Seniors Centre has taken on several programs and initiatives to support social engagement for people living with dementia.
- Most notable is the **Happy Memories Café** that creates a space where both people with dementia and their loved ones can meet to socialize, learn, and have fun together.
- Program activities evolve based on the ongoing feedback of participating members, e.g. group discussions, music, poetry, and the arts.
- The cafés are growing, and now include a Spanish speaking group.



Memory Buddy Program

- Pairing community members with people living with dementia to get together once or twice a week for an activity they both enjoy.
- These connections create new memories and relationships while also giving care partners some respite.
- Volunteer requirements include compassion, empathy, and a willingness to be flexible. Kitsilano Neighbourhood House provides all the training.



BECOME A MEMORY BUDDY

Are you looking for a meaningful volunteer opportunity to help people living with dementia?

To spend meaningful time with community members living with dementia, raise awareness, support caregivers, create a dementia-friendly environment, and connect people to resources

A Memory Buddy volunteer will support a person with lived experience of dementia or dealing with memory loss for one or two hours per week, based on shared decision-making to create new opportunities, and to connect and learn from each other.

Requirements


- Compassionate and empathetic
- Training and support provided by staff
- Flexible schedule based on volunteer and participant's availability

For more information:
Braelyn Dillon
BraelynD@kitshouse.org
604-736-3588 Ext. 600

Fall & Spring intakes open NOW!

Program established in 2023

BUILDING CAPACITY PROJECT



Take home messages

Reframing dementia as a shared experience

- *“Dementia is not a single person issue. It’s a family, it’s a neighborhood, it’s a community issue.”*

Growing confidence

- *“I know how to talk to them, and that, I mean, that’s beautiful.”*

Centering joy

- *“Bringing some joy, creativity, and art is so important. Please don’t make boring programs !”*

Making Connections

“Our drum therapist, was connected to us through one of our members living with dementia. Amazing.”

Resources

FLIPPING STIGMA TOOLKIT

flippingstigma.com

- Includes a link to the *Flipping Dementia Stigma: An Action Group's Guide*

BUILDING CAPACITY RESOURCES

buildingcapacityproject.com

- Includes a link to the *KT Portfolio*
- Building Capacity Action Guide - soon to be released!