

Opening a DOOR to Collaborative Research



Alzheimer Society
BRITISH COLUMBIA

Health
Design
Lab.

Your experience and voice matter in research.
Join us in the dementia research community as partners and collaborators!

This is an invitation from a community of advocates and researchers living with dementia. We welcome you to participate and collaborate in research projects that value your experience and expertise.

In dementia research, there is a growing emphasis on generating meaningful research collaborations with people with lived experiences of dementia. Your experience and expertise are most important! This is to ensure that dementia research is designed to effectively represent and benefit those living with dementia.

“We have a hunger for support and a hunger for community.”

- Research advocate with lived experience of dementia

So often with a dementia diagnosis, we lose community as we lose our voice. Participating in research can provide a meaningful experience. It can be socially and emotionally stimulating.

It's an opportunity to share our experiences and have our voices heard to make a difference in the lives of those affected by dementia.



Types of research

Dementia research is the process of systematically investigating questions associated with the diagnosis of dementia. Most importantly, dementia research is people powered – not just by researchers conducting studies, but also by people with lived experience.

To be a part of dementia research, you can be involved in two types of research:

Quality-of-life research: looks at ways to improve the lives of people living with dementia and caregivers.

Examples of Quality-of-life research questions:

- How can we improve hospital visits for people living with dementia?
- How can art help combat stigma?

Biomedical research: includes studies investigating the causes, treatments, and possible cures for dementia.

Examples of Biomedical research questions:

- What are some treatments to stop, slow or prevent Alzheimer's disease?

Things to remember

“You get to exercise your power by participating in research!” - Research advocate with lived experience of dementia

- Research is regulated and follows ethical guidelines to ensure the safety and comfort of those participating in research.
- Many research projects are not related to drugs or clinical trials. You can be involved in research in many other ways like, in focus groups, completing surveys, or being involved in research teams to shape how research is conducted and applied.
- You can also participate in qualitative arts, design and theatre-based research.
- Being involved in dementia research can introduce you to a larger support community. It can be an enriching experience that brings you confidence in your experiences and voice.
- Researchers have a lot to learn from your experience and expertise of living with dementia and how to engage with the dementia community
- Research can be a reciprocal process for researchers and research partners living with dementia. Research can bring a feeling of fulfillment, productivity, and joy for everyone involved.

What your involvement could look like

You can be involved in dementia research in many ways and during different research phases!

How you wish to contribute to research can help you best choose which research projects you want to be involved in. You can be involved in:

1. Building Teams, Setting goals

You can shape research priorities by helping researchers identify problems and gaps that are most important to you. Your insights can ensure that research is designed to make participants feel safe and comfortable.

2. Preparation and Training

You can share your experiences of living with dementia to better help researchers anticipate risks and benefits of research and other ethical considerations.

You can also support training researchers and facilitators.

3. Data Gathering and Data Analysis

You can help design, facilitate or participate in focus groups, interviews, completing surveys, testing medical interventions and more.

You can also be a part of research teams as a facilitator and help with data gathering activities.

4. Sharing and Communication of Data

You can jointly present research or co-host events to share research findings and outcomes.

You can help develop strategies on how to bring research back to those most affected by dementia.

“ I am Myrna Norman, a research advocate and a researcher who also lives with dementia. I have been a research partner on a four-year research project, Reducing Stigma and Promoting Social Inclusion: Putting Social Citizenship into Practice.

This project focuses on the co-creation of knowledge to reduce the stigma and discrimination experienced by people living with dementia.

This research project brought together 15 of my peers living with dementia for a monthly gathering to talk about our experiences with dementia and the possible actions to be taken to flip stigma on its ears. Throughout the project I felt heard, and my experiences and expertise mattered. My peers and I felt like equals to the researchers and professors involved. The project did not create a distinction between us and them.

We all had a wonderful bonding experience.

We had so much to share with each other and didn't want these conversations and collaborations to end. As part of the focus group conversations, we talked about things that were important to us or things that we felt were hurtful and discriminating. The researchers heard us and together we created a tool-kit to help people living with dementia, their caregivers and researchers take action against stigma and discrimination.



How can you be involved

Call Alzheimer Society of B.C. at 604-681-6530.