



COMOX VALLEY DEMENTIA CARE WORKSHOP

REPORT ON WHAT WE HEARD

NOVEMBER 2023



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Research BC**
BC SUPPORT UNIT

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Executive summary

With the overarching goal of building a rapidly learning health system with a focus on care and supports for people living with dementia in the Comox Valley, the BC SUPPORT Unit invited persons with dementia – including caregivers, families, friends – researchers and health system leadership to come together to identify priority areas of improvement in dementia care for the Comox Valley. The Comox Valley has one of the largest populations of seniors in British Columbia. Statistically, the community is older than the BC average by about 7 years. Looking ahead, the 75+ age group is set to triple over the next 18 to 20 years. These numbers will place significant pressure on our communities and the healthcare system. To better support the unique needs and priorities of the Comox Valley, we require innovative solutions that can be addressed, in part, by [Patient-Oriented Research](#).

On September 13th the [Comox Valley Community Foundation](#), [Comox Valley Healthcare Foundation](#), [Island Health's Research Department](#), its embedded [BC SUPPORT Unit Island Centre](#) and members of the Comox Valley community held a workshop that explored how health researchers, health care providers, and community can work together to support the growing number of people affected by dementia in the Comox Valley.

Speakers at the event focused on the need for community-based dementia care approaches to be a collaborative effort. An overview of current research in the Comox Valley was provided, in addition to introducing attendees to patient and community engagement in health research. Small and large group dialogues focused on dreaming about the ideal future state of dementia care in the Comox Valley and identifying priority areas that will inform future research. 57 attendees voted for their top areas, which included staying at home longer, caregiver supports and respite, dementia-friendly communities, and navigating supports and services.

While **staying at home longer** was voted a top priority, attendees explained that choice, autonomy and support systems (including financial) are key components for the group. Various supports were discussed including day programs, transportation, housing options, home supports and others. **Caregiver supports and respite** were also identified as key priorities: early caregiver education and training, access to respite beds (emergency and long term respite), different styles (level of care-dependent) adult day programs, and more staff, reduced waitlists for programs and services were all deemed important. Conversations about **dementia-friendly communities** focused on: education & awareness, community engagement & building on existing community supports, infrastructure & research, and stigma & transportation. **Navigating Supports** highlighted the need to coordinate *current* dementia care resources (a regularly updated registry/website), educating general practitioners about available resources, nursing student placements in community, transportation and better access to services.

The Comox Valley-specific community priorities will form the foundation POR projects in 2024-25. The grant and graduate fellowship awards will be administered and supported by the Island Health Research Department and its embedded BC SUPPORT Unit. Applications will be community and peer-reviewed. All successful teams will submit their projects for Human Research Ethics Board Review.

Context and background

Comox Valley Dementia Care Priority Setting

A significant portion of Vancouver Island's population is over the age of 65, therefore research on aging and seniors' health is a growing and much needed area of medical research. As the population within our region ages, research in the health field has increasingly focused on the wellness of individuals who reside in long-term care homes or who can be cared for as they 'age in place' in the community. Aging is also a risk factor for a variety of health diseases and conditions including neurodegenerative diseases such as dementia and Alzheimer Disease, many forms of cancer, and metabolic disease/type II diabetes which have become much more prevalent in recent years.² A growing aging population, age-related health conditions that impact quality of life, and increased demands on our health system, all require innovative approaches and research to better support healthy aging, mental and cognitive health as well as caregiver wellness within our communities.

This project seeks to build capacity for Patient-Oriented Research (POR) on dementia care in the Comox Valley. *It optimizes local value by focusing on research priorities identified by members of the community, and provides opportunities for seniors and their families, caregivers and friends to benefit from partnering in research studies.* Grant and fellowship funding will support research in community-identified priority areas conducted by multidisciplinary teams that engage community members as equal partners. Our multidisciplinary approach also ensures that all key stakeholders are involved in bringing knowledge learned from these studies full-circle to inform how future care is provided in the Valley.

Patient-Oriented Research

The Canadian Institutes of Health Research (CIHR) created [Canada's Strategy for Patient-Oriented Research \(SPOR\)](#) to better address the health needs of our communities by ensuring the meaningful engagement of patients (people with lived and living experience of the health care system, PWLLE), their caregivers, and families in the research process. POR seeks to create opportunities to shift from doing research "on" or "for" patients and instead "by" and "with" patients. What this shift looks like is that Patients/PWLLE integrate into the research team as team members (*not research participants*) and have the opportunity to meaningfully contribute to parts of, or the full research cycle, including research priority setting, project conceptualization, ethics, data gathering and analysis, knowledge dissemination and research evidence implementation. This engagement helps to ensure that research studies focus on patient-identified priorities and ultimately leads to better patient outcomes and healthier communities. The adoption of the POR approach aligns with our [National Dementia Strategy: Together we Aspire](#), and will ensure that the research outcomes will be meaningful to the aging community of the Comox Valley.

Local Context

An Aging Population in the Comox Valley

The Comox Valley is a wonderful place to age and grow old. Many agree it's *the* place to settle and slow down. In fact, the Comox Valley has one of the most senior populations in British Columbia. Statistically, the community is older than the BC average by about 7 years. Looking ahead, the number of people who are 60 years of age and older is growing and it is growing fast. The greatest growth is expected in the 75+ age group. On northern Vancouver Island, this age group is set to triple over the next 18 to 20 years. These numbers will place significant pressure on our communities and the healthcare system and at the same time provide significant opportunity to promote POR and innovation activities within this target population.

Aging Research in the Comox Valley

There is a breadth of knowledge and expertise in aging research and health system services from across Vancouver Island, however the Comox Valley's lack of proximity to major research and innovation hubs (the University of Victoria's (UVIC) [Institute of Aging & Lifelong Health](#); the [Neil and Susan Manning Cognitive Health Initiative](#) (CHI, an Island Health-University of British Columbia -UVIC partnership); Vancouver Island University and the many embedded research collaborations) represent not just a geographical distance, but rather a functional distance that the work proposed aims to bridge.

There are also opportunities to implement evidence from current local research, with a focus on intergenerational connections. For example, Dr. Debra Sheets and team (UVIC) study the impact of choir singing ([Voices in Motion](#)) on the cognitive, physical and mental well-being of people living with dementia and has recently published on their findings. Studying the facilitators and barriers of establishing meaningful, impactful intergenerational programs and spaces in long-term care can add value to the community and the new & innovative Providence Living at The Views.

There is also room for further research around innovative local programs to improve cognitive health for people with dementia. Through a donation to the Comox Valley Healthcare Foundation, Island Health's Comox Valley Geriatric Specialty Services Clinic was able to introduce cognitive stimulation therapy (CST), a treatment program that uses activities such as physical games, music, reminiscence and implicit learning in a small group setting with people living with dementia. Prior to this project, no such treatment options were available in the Comox Valley despite the pressing need. Occupational Therapist [Alison Ritchie and team](#) received the Island Health Gold Evidence-to-Practice Award for leading this work and the team is eager to conduct further research to better understand the cognitive, social and behavioural impacts of CST.

The Team

The Island Health Research Department and its embedded BC SUPPORT Unit Vancouver Island Centre support POR across the Island and build multidisciplinary teams including researchers, clinicians, PWLLE, caregivers, friends, family and decision makers to co-design and conduct research. The teams' expertise and the established community, academic and health system networks help to enable and sustain multidisciplinary POR collaborations in the Comox Valley.

Engagement goal and objectives

Engagement Goal

In fall 2023, the team engaged people with lived and living experience of dementia- including family members, caregivers and friends in a facilitated discussion that identified community priorities for dementia care in the Comox Valley. The workshop brought together health researchers, healthcare providers, and community to support the growing number of people affected by dementia, and was designed to inform future POR on this topic.

Community and Engagement Objectives

There were four Comox Valley **community objectives** supported by the Robert and Florence Medical Research Funds. The workshop specifically focused on Objectives 1 and 2.

1. Pinpointing community and health system gaps/barriers to aging and dementia care and identify research priorities and questions that matter to the aging population of the Comox Valley.

2. Connecting the Comox Valley to research and clinical expertise from across the Island (North Island College, Vancouver Island University, University of Victoria, Island Health, the Rural Coordination Centre of BC...).
3. Building and enabling POR teams that address research questions that matter to the aging and dementia community of the Comox Valley.
4. Building cross-island collaborations and develop the foundation for a Dementia/Aging Research Network in the Valley.

To address Objectives 1 and 2 the **workshop engagement objectives** detail who will be engaged (stakeholder), at what level of the International Association for Public Participation (IAP2) Spectrum, and for what result (outcome/output).

1. To **Inform** all participants about local and island-wide dementia focused research and health system initiatives.
Outcome: There is shared understanding of local and island-wide dementia focused research and health system initiatives.
2. To **Involve** all attendees in understanding how research evidence can be used to support quality dementia care initiatives.
Outcome: There is shared understanding of how research can support local quality dementia care initiatives.
3. To **Involve** all attendees in understanding how people with lived/living experience can contribute to care improvement initiatives, specifically research activities
Outcome: There is shared understanding of how PWLLE can contribute to the care improvement initiatives, specifically research activities
4. To **Involve** all attendees in understanding the challenges and impacts experienced by persons living with dementia in the Comox Valley.
Outcome: There is shared understanding of the challenges
5. To **Involve** all attendees in dreaming of an ideal future state of dementia care in the Comox Valley
Output: There is list of ideal future state ideas of dementia care in the Comox Valley
6. To **Involve** all attendees in identifying priority areas for future dementia care improvement initiatives (including research, QI, health systems improvement activities)
Output: A list of priority areas for improvement initiatives

Engagement Approach

The request for broad engagement support was brought forward to the British Columbia **S**upport for **P**eople & **P**atient-**O**riented **R**esearch & **T**rials (BC SUPPORT) Unit Vancouver Island Centre embedded within the Island Health Research Department. There was a collective interest in: A. Co-identifying Comox Valley community priorities in dementia care; B. Building POR capacity in dementia care, and C: Facilitating networking and connecting the Comox Valley with research and clinical expertise from across the Island including stakeholders from North Island College, Vancouver Island University, the University of Victoria, Island Health, Providence Health, the Rural Coordination Centre of BC and many other relevant Comox Valley community organizations. The team collectively decided that a local, in-person workshop presented the best engagement approach.

The team also wanted to ensure that their approach to the workshop design was accurately reflecting the lived experiences, concerns, and needs of people with lived experience of dementia- including family members, caregivers and friends. The workshop organizing committee included lived experience and the learning from a broad group of PWLLE and community members was prioritized. PWLLE and community members represented 56% of the workshop attendees, the other 44% included researchers, healthcare staff and decision makers (see table below).

Upholding guiding principles from Canada’s Strategy for Patient-Oriented Research (SPOR), including inclusiveness, support, mutual respect, and co-building, has been forefront for the team. The engagement work was built on these guiding principles and incorporated best practices in patient and public engagement from leading organizations like the IAP2.

Engagement technique

In-person Workshop

The organizing committee decided that an in-person workshop is the best engagement technique to bring multidisciplinary stakeholders together to have a conversation about dementia care priorities in the Comox Valley. A total of 59 attendees, composed of local PWLLE, community, cross-Island healthcare staff and decision makers, and researchers were invited to participate in the day. Attendees were seated as part of seven facilitated tables with 7-8 multidisciplinary stakeholders (see Appendix B for the poster and agenda of the day).

PWLLE of Dementia	Researchers	Healthcare Staff	Community
26	11 (4 are healthcare staff)	15	7

PWLLE of dementia and community were strongly represented with 33 attendees. Researchers and healthcare staff added up to a total of 26 attendees. There was some overlap between researchers and healthcare staff as some healthcare staff also conducted research. Overall there was a relatively well balanced distribution of PWLLE, community, researchers and healthcare staff.

Setting the Scene

The day started with setting the scene. **Hereditary Chief Donna Mitchell** opened the workshop and grounded the day on the unceded territory of the Comox First Nation. **Max Jajszczok** (Executive Director Operations and Rural and Remote Strategy- Island Health) welcomed attendees and provided the local health system dementia care context. **Dr. Amy Salmon** (Associate Director, Centre for Advancing Health Outcomes, UBC) shared her current research that focusses on an evaluation of Providence Living at the

Views and a new long term care model that moves away from institutionalized, medicalized models of care toward relational/community models. **Alison Ritchie, Laurel Steed, and Kyle Hillman** are Island Health Occupational Therapists from the Comox Valley Geriatric Specialty Services Team and presented their work on Cognitive Stimulation Therapy for people living with mild to moderate dementia on Northern Vancouver Island. **Dr. Mariko Sakamoto** from the School of Nursing at the University of Victoria talked about her community-based participatory research with people living with dementia. Together, the short presentations provided common ground for attendees, and set the stage for facilitated discussions to follow.

Dreaming Big

For the first facilitated discussion, attendees were asked to **dream big**. Each table generated ideas of the ideal future state for dementia care in the Comox Valley. Table facilitators used the Alzheimer Society's 10 Dementia Research Priorities and/or Canada's Dementia Strategy as guides to stimulate conversation. Attendees were reminded that there are no right or wrong ideas. No level of expertise was needed to dream big and generate ideas of the **ideal future state** for dementia care. In the last 10 minutes of the facilitated discussions each table was asked to identify the **top three priority areas** that need improvement in order to achieve the ideal future state of dementia care in the Comox Valley.

Voting

Each table facilitator summarized the top three areas for improvement identified by the table discussions and posted them on the wall for attendee review and voting. **Attendees voted for their top priority areas** over lunch. Four overarching priority areas were identified (See Key Priorities: What We Heard). The lead facilitator reviewed the four overarching themes with attendees and encouraged attendees to choose the priority area they would like to discuss further.

Achieving the Future State

In groups, participants **identified collective action** that could move us closer to the future state. Table facilitators encouraged each person to talk about how their role could inform/support improvement in that area. For example, researchers could discuss how health research could help move us closer to the ideal future state; people with lived/living experience could share how they could help (partnering on research; helping mobilize knowledge etc.)

Key Priorities: What We Heard

1. Staying at Home Longer

27 attendees identified **staying at home longer as a top priority***.

- Important note by group: It is not always about staying home longer, it is about **choice/autonomy** and what people want - having the supports (often financial) in place for choice
- Day Programs
 - decrease barriers
 - safe, accessible place to go
 - respite for caregivers
- Build communities that include safe places that are accommodating
- Strategies for avoiding social isolation
- Navigation Facilitator – help provide options and come up with plans

- Early conversations of risk (personal risk) so family is aware of what people want (like advance directives convos – worth having even pre-diagnosis)
- Early access to diagnosis and treatment options
- Mobile Day Programs - better access for rural community members
- Indigenous Elders – perspectives of traditional knowledge and supports
- Transportation – especially for rural
- Safe places and supports for caregivers
- Progression planning for the home support journey
- Appropriate housing options – supports for this from social workers, etc.
- Housing crisis
 - one level living
 - intergenerational options
- People with lived experience know best what the barriers and issues are – ask them!

** Note: There is some overlap with themes from Individualized Care.*

2. Caregiver Supports and Respite

23 attendees identified **caregiver supports and respite as a top priority.**

- Caregiver education
- Immediate training (Alzheimer’s Society) for caregivers of newly diagnosed folks (to understand experience of their loved one)
- Earlier support for caregivers
- More daily programs
- Reduced waitlists for programs and services
- Access to immediate/emergency respite
- Longer term respite supports (i.e., full day)
- More respite beds
- More staff
- Varied supports for caregivers – individualized
- Support to visit loved ones
 - Transportation
 - Emotional support
- During Covid individualized programming increased engagement (in LTC)
- Different styles of ADPs
 - Level of care needed
 - Different interests
- Meaningful and purposeful programs for people living with dementia

3. Dementia-Friendly Communities

19 people identified **dementia-friendly communities as a top priority.**

- Community engagement
- Sense of belonging, purpose and connection
- Comox Valley (or CU?) Senior Support – bring people to the project/ “house” the project
- \$ and Volunteers

- LOCAL transportation – not just for medical appointments – possibly students
- Educate bus drivers
- Raising awareness – what does “dementia-friendly community “ means
- Need to be clear on what dementia-friendly means
- Marketing campaign (“forget-me-not”) followed up consistently
- Addressing/decreasing stigma
- Learning from PWLLE (e.g. Flipping Stigma project)
- Signage at service facilities “dementia-friendly”
- Engage all 3+ Comox Valley regional districts – communities have buy-in from 3 municipalities
- Commitment and time to build relationships/trust
- Concept of accessibility for everyone
- Have co-PI on CIHR grants as PWLLE
- Alzheimer’s Society – already has project to inform how to become dementia-friendly
- Reimagine housing – “community” instead of segregated
- What is happening in community already – audit services, research studies

4. Navigating Supports

17 people identified **navigating supports as a top priority**. NOTE: overlap with education

- Reach out and coordinate (central system) for coordinating CURRENT resources (have Island Health or Alzheimer’s Society “own” or responsibility for maintaining)
- Include research/other resources in listings
- Have someone responsible for keeping a registry/website/listings up-to-date
- Regularly update Island Health Resource Guide
- Educating GPs so they can support patients and families (re: what’s available)
- Public funded services for translation beyond medical appointments (e.g., recreational activities)
- “Uber” for folks with dementia (with drivers/companions with flexible pick-up/drop-off times and knowledge about how to support someone w/ dementia)
- Create a literal map for the available services, including process and how to access what everyone does (webpage or a navigator/case worker) – include what is funded and what costs \$
- Marketing – creative ways to reach people in the community to let them know about supports
- People who are offering supports to list supports in a central repository
- Access to care worker/navigator early on (before it’s an emergency)
- Equitable access to in-home resources – sliding scale based on income for wellness and stimulation
- Nursing students’ placement in the community (e.g., driving companion for people with dementia)
- Integrating programs (Cognitive Simulation Therapy in adult day program)
- “Matchmaking” service between volunteers to connect with people w/ dementia who have common interests
- Investment (public \$, not for-profit) in services to provide better access to services

5 .Individualized Care

17 people identified individualized care as a top priority.

6 .Education

15 people identified education as a top priority.

7 .Access to Clinical Trials

5 people identified access to clinical trials as a top priority

The top 4 community priorities will form the foundation for grant and fellowship applications in 2024.

Next Steps

Dissemination

How will people's input be used?

Following the in-person priority setting workshop, the BC SUPPORT Unit Vancouver Island Centre compiled a summary of the input shared in the form of this report. The report will be distributed to network participants, health professionals, researchers, community members, patient partners, research users and any interested stakeholders to provide lived experience input and guidance that will inform Comox Valley-specific POR grant calls and fellowships.

Building capacity

Comox Valley Aging/Dementia-Specific POR Grant Call and Graduate Student Fellowships: As part of our commitment to facilitating research relationships between patients, researchers, healthcare providers, decision-makers and other stakeholders, we will provide awards to support research teams and graduate students conducting POR in alignment with the research priorities identified in the Comox Valley POR workshop. The grant and graduate fellowship awards will be administered and supported by the Island Health Research Department and its embedded BC SUPPORT Unit. All successful teams are required to submit their projects for Human Research Ethics Board Review. The **POR Grant** seeks to support Comox Valley-focussed POR teams in preparing for future substantive (e.g., federal or international funding competitions) POR grant applications with a focus on dementia care. The award will help POR teams pilot and test the feasibility of their research project and make their future grant applications stronger. The **POR Graduate Student Fellowships** will provide students with training and support in the principles and practice of POR, create opportunities for collaboration, and build capacity for POR in dementia care.

Informing implementation

One of the many goals of this engagement work is to inform research design and eventually program design, including implementation, in health care settings. Although program design and implementation are further down the road, collaborating and keeping Island Health leadership and decision makers informed are key components of the work done to date and future work to come.

Acknowledgements

Thank you to all of the individuals who took the time to share their feedback. We are also very grateful to the Comox Valley Community Foundation who made a generous contribution from the Robert and Florence Filberg Fund, held at the Vancouver Foundation, and facilitated by the Comox Valley Healthcare Foundation. These funds enabled the community dialogue and will support grant and fellowship opportunities targeted at the priority areas identified by attendees. Stay tuned for these opportunities in 2024!

Contact information

BC SUPPORT Unit Vancouver Island Centre
islandcentre@islandhealth.ca

Appendix A: Fast Feedback

What worked well?

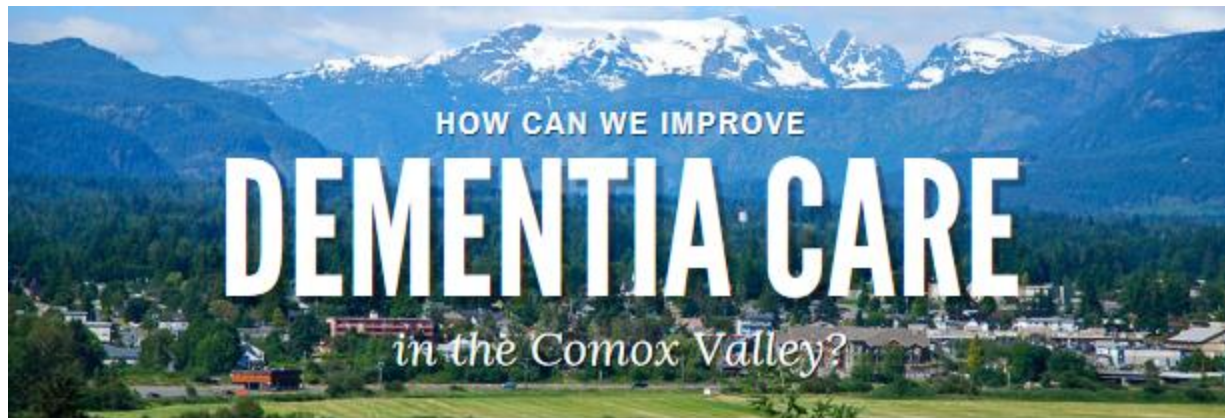
- Structure of the activities
- The process was seamless - very well planned
- I enjoyed how collaborative the workshop was
- Loved small groups - Both I was in had great facilitators and involvement of people with lived experience.
- All
- Collaborating ideas from a variety of communities. Fast paced - well thought out day with a wide variety of people/knowledge/experience
- Small group work (table discussions)
- Nux and energy of participants, meeting friends and colleagues. Gives me hope!
- Diversity of participation
- Round table discussions, information
- Discussion groups
- Well respected and informed speakers
- Well done! Everyone! Perfect!
- The flow – information
- The flow - information, convene, brainstorm with direction
- Facilitation
- Great flow, groups were well facilitated
- Working at small tables/groups
- The variety of engaging activities
- Small groups
- Short presentations. Group discussions with facilitator. Plan to follow up and commitment to move forward.
- Inclusion of diverse background of participants with pt/resident/partners
- Workshops and CST summary
- Great communication. Lots of facilitators.

What could be improved?

- Would have liked to see Indigenous ways of knowing incorporated into the discussion
- the language may have been too technical for many of the participants
- I can't think of anything. Thanks!
- More information on latest medical research, "Boots on the Ground" action to actually help.
- Rep from political party
- more time spent on ACTION and INNOVATION
- More information of what to expect about dementia patients
- Can't think of anything
- More time!
- Nothing! Well done
- Hearing from Alzheimers Society about what they can offer
- Nothing!
- It was really great - also with the food!
- Would have liked a little more time in the last breakout group

- More info about what comes next
- more of these
- Longer time in the groups
- Nothing. Well done!
- Not an improvement, but I would love to hear what research initiatives may come from this work
- I felt the intros were too long

Appendix B: Workshop Poster and Agenda



We invite people with lived experience of dementia - including family members and friends - to join the conversation!

LEARN

about dementia research and care happening here!

DREAM

what the future of dementia care could look like!

VOTE

for the most important ways to improve care!

This workshop will explore how health researchers, health care providers, and community can work together to support the growing number of people affected by dementia in the Comox Valley. Your voice matters!

SEPTEMBER 13, 2023

10:00 AM - 2:30 PM
Doors open at 9:30 am.
Lunch provided.

THE FILBERG CENTRE

411 Anderton Avenue,
Courtenay BC
V9N 6C8

FREE EVENT!

Space is limited.

Please contact us to register:

ISLANDCENTRE@ISLANDHEALTH.CA | 250-713-7553



9:30 AM Registration and coffee

10:00 AM Welcome

10:30 AM Guest Talks



Amy Salmon, PhD
 Centre for Advancing
 Health Outcomes, UBC



Comox Valley Geriatric
 Specialty Services Team,
 Island Health



Mariko Sakamoto, PhD
 School of Nursing, UVic

11:00 AM Break

11:20 AM Table Conversations

- Meet each other!
- Dreaming about the Ideal Future State of Dementia Care in the Comox Valley

12:30 PM Lunch

- Cast your vote! Help identify the top priorities for improving dementia care in the Comox Valley

1:20 PM Action Focused Conversations

- Small group discussions based on priority areas

2:20 PM Closing Remarks