Support Volunteer Bulletin

Summer 2021

Annual research publication now available

Research is key to changing the present and future for people affected by dementia. The Alzheimer Society of B.C. is committed to fostering a vibrant dementia research community here in B.C. As part of this work, the Society produces "A focus on research," an annual research publication.

This publication summarizes the biggest developments in dementia research, both locally and internationally, over the past year and helps to bridge the gap between research and the community. Examples of stories highlighted include the impact of COVID-19 on brain health and the positive impact of an intergenerational choir on the rate of cognitive decline in people living with dementia.

The publication is also a great resource for anyone interested in dementia research, whether they are living with dementia, a caregiver, a health-care provider, a student or an interested member of the public. Please feel welcome to share this publication with your network.


Alzheimer Society BRITISH COLUMBIA

Spring 2021

A focus on research

Improving the present and changing the future for people affected by dementia

The past year has been difficult for many, particularly people living with dementia and their families, as the COVID-19 pandemic has disrupted routines and created new challenges. Despite this, dementia researchers have persevered and continue to discover ways to improve the lives of people living with the disease and caregivers. At the Alzheimer Society of B.C., we are committed to supporting this critical work and are encouraged to see the important progress made over the past year.

The Society helps ensure people affected by dementia are not alone, by educating and mobilizing a broader community of care around them, and supporting valuable research into the disease and people living with it. We are moving towards our mission by:

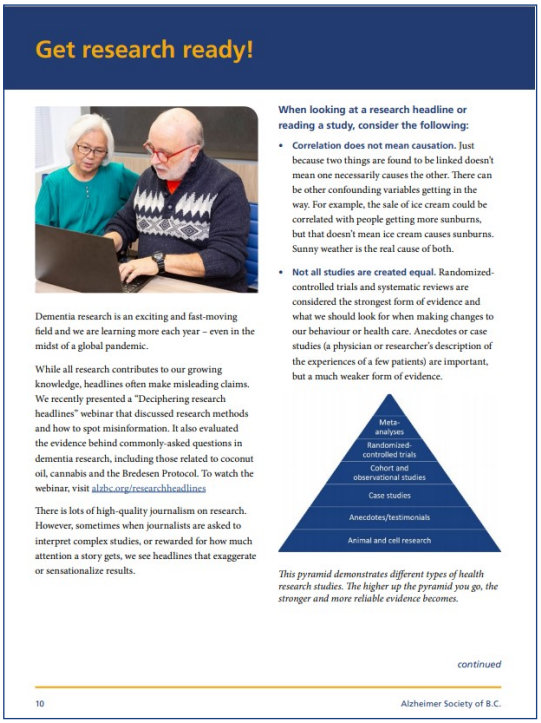
Investing in researchers, both nationally and here in B.C. These investments allow researchers to conduct and mobilize research to improve quality of life, investigate causes and search for effective treatments and cures.

Partnering with the dementia research community on projects to advance research here in B.C. and share knowledge.

Providing reliable and comprehensive information on dementia research through our website, webinars, newsletters and publications such as this one.

In this publication:

Inside preview


Get research ready!

When looking at a research headline or reading a study, consider the following:

- **Correlation does not mean causation.** Just because two things are found to be linked doesn't mean one necessarily causes the other. There can be other confounding variables getting in the way. For example, the sale of ice cream could be correlated with people getting more sunburns, but that doesn't mean ice cream causes sunburns. Sunny weather is the real cause of both.
- **Not all studies are created equal.** Randomized-controlled trials and systematic reviews are considered the strongest form of evidence and what we should look for when making changes to our behaviour or health care. Anecdotes or case studies (a physician or researcher's description of the experiences of a few patients) are important, but a much weaker form of evidence.

Dementia research is an exciting and fast-moving field and we are learning more each year – even in the midst of a global pandemic.

While all research contributes to our growing knowledge, headlines often make misleading claims. We recently presented a "Deciphering research headlines" webinar that discussed research methods and how to spot misinformation. It also evaluated the evidence behind commonly-asked questions in dementia research, including those related to coconut oil, cannabis and the Bredesen Protocol. To watch the webinar, visit alzbc.org/researchheadlines

There is lots of high-quality journalism on research. However, sometimes when journalists are asked to interpret complex studies, or rewarded for how much attention a story gets, we see headlines that exaggerate or sensationalize results.

Meta-analyses
Randomized-controlled trials
Cohort and observational studies
Case studies
Anecdotes/testimonials
Animal and cell research

This pyramid demonstrates different types of health research studies. The higher up the pyramid you go, the stronger and more reliable evidence becomes.

continued

10 Alzheimer Society of B.C.

Topics in this year's "A focus on research" include:

- Tips on how to effectively read about research and navigate headlines.
- The biggest dementia research news stories of the year.
- A spotlight on quality-of-life research here in B.C.
- A profile of dementia researcher Elyn Rowe.
- The how and why of participating in research.

Read the 2021 "A focus on research" publication here.

IN THIS ISSUE

Alzheimer Society BRITISH COLUMBIA

Minds in Motion® Online

We are now in the midst of our third full eight-week series of Minds in Motion® online and have continued to expand the number of programs available as our registration grows. Our last full series saw a total of 201 people living with dementia and care partners registered.

The feedback received from participants has been very positive, with 100% of participants who responded to our last post-series survey reporting that they would recommend Minds in Motion® online to others. Below are some quotes from participants about their experience in the program:

- *"We enjoy all of the activities and like the variety in the games half. We actually interact more with the other participants in the smaller groups on-line than in larger groups at the recreation centre."*
- *"In this time of COVID, this is my most frequent interaction with other people."*
- *"I like how my husband DOES DO the exercise as it focuses on him! That also goes for facilitators speaking his name... focusing on him. He feels important!"*
- *"As a caregiver, I find it's about quality of life. Having this program gives the participants a sense of belonging and I'm not alone. Also gives them something to look forward to. I just want to thank all the staff at Alzheimer [Society] for their respectful and caring approach."*

Minds in Motion® online is a weekly 90-minute fitness and social activity program for people experiencing early symptoms of dementia to attend with a care partner.

Each series runs for 8 weeks and provides an opportunity for participants to connect with others living with dementia while enjoying physical and social activities.

In our last series, we also welcomed seven volunteers into our new Minds in Motion® online facilitator position. The mix of existing support group facilitators and Minds in Motion® assistants have been a wonderful addition to the program. While we are currently working through some technical issues, we look forward to welcoming more volunteers into Minds in Motion® online once they're resolved. Until then, we want to extend our sincerest "thank you!" to the seven volunteers who have joined us in this new volunteer role.

Virtual early-stage groups

We are happy to announce that as of May, we are now offering virtual groups for people living with early symptoms of dementia. We have two types of groups available:

- **Coffee & chat groups** provide an opportunity for people living with early symptoms of dementia to socialize, share experiences, laugh and enjoy the company of others who are living the dementia experience. Participants are invited to make themselves comfortable, grab a cup of coffee or tea and join us virtually to say 'hello.'
- **Early-stage support groups** provide a place for people living with early symptoms of dementia to come together with others also living the dementia experience and discuss the impact of the disease, share stories, experiences, and learn from one another about how to live well with dementia.

All groups meet online every two weeks for one hour in Microsoft Teams. We also have one group specifically for those who prefer to join by telephone. For group members who are new to Teams, we offer practice sessions twice a week to provide support with any issues downloading the Teams app and connecting to a meeting. As with all of our virtual programs, we encourage anyone who is interested and would like to register to call the First Link® Dementia Helpline at **1-800-936-6033.**

While this program is still new, we have received great feedback from group members who have joined us about the opportunity to connect with others in a similar situation. We look forward to sharing more with you about this program in our next issue of the Support Volunteer Bulletin.

Update on virtual caregiver support groups

The option to join online or by telephone.

Starting in April, we piloted a video option in our virtual caregiver support groups in response to requests from group members for this feature. In May, we moved all of our 28 caregiver support groups into Microsoft Teams, allowing group members the option to join their support group with video, or to call in over the telephone. So far, the feedback we have received about this transition has been very positive, and we have enjoyed seeing the faces of those joining us each month.

Expanding our offering of specialized groups.

As this virtual program has grown, so has our ability to offer more specialized groups as they are requested by caregivers. For example, we now have groups in Cantonese and Mandarin; for caregivers of persons living in long-term care; for caregivers of a person living with young onset dementia, behavioural-variant Frontotemporal dementia, dementia with Lewy bodies; adult children caregivers; and for LGBTQ+ caregivers or caregivers of a person living with dementia who identifies as LGBTQ+.

Welcoming volunteers back into caregiver support groups.

Now that our virtual caregiver support group program is well established, and we have smoothed out many of the wrinkles that come with launching a new virtual program, we are excited to finally be able to welcome volunteers back to the groups.

On June 8, 16 support group facilitator volunteers joined us for an online virtual training. The training provided an overview of Microsoft Teams—our platform for hosting our virtual programming; reviewed facilitator roles; and the differences between facilitating online versus in-person. We used breakout rooms to have engaging discussions about strategies for responding to potentially challenging scenarios that may arise in a virtual setting. We want to extend our appreciation to those who joined us; we greatly enjoyed the chance to reconnect with you and look forward to engaging you in caregiver support groups once again.

Support group facilitator training to be offered virtually in September 2021.

We are very excited to announce that we will be offering our full support group facilitator training online in September 2021. Due to the COVID pandemic, we had to cancel our last full two-day training, which was scheduled for March 2020 in downtown Vancouver. We will be reaching out to those who had registered for that training, to notify you of the dates of the virtual training in September. We are also exploring the possibility of offering a “refresher” training for any support group facilitators who would like to review facilitation techniques and modes of responding before returning to their in-person support group.

If you are interested in “refresher” facilitator training, please email your interest to Sarah at seveneshen@alzheimerbc.org.

Restarting in-person programs.

It has been a long year and we have missed you, and I have no doubt that group members have missed you too. While we are very encouraged by the idea of resuming our in-person programming, it will require careful consideration including the health and safety of our clients, staff and volunteers. Our ‘restart’ will include a combination of in-person and virtual programs that will be offered across the province. We don’t have confirmed dates for resuming in-person programs at this time, but we will keep you updated regularly.

Tips for navigating difficult dialogue

In a support group, as in life, some conversations are more challenging than others. It is natural to want to "fix" the situation and to try to steer heavy emotions towards those that are lighter. However, a large part of supporting families affected by dementia is acknowledging the heavy emotions and letting them be expressed, felt and validated. Sometimes, the hardest conversations are those that offer the most opportunities for growth and learning. It's important to let these conversations happen in a healthy way. So how do we navigate these difficult conversations and "go there" in a way that is healthy for the group?

Be genuine.

Proceed with an authentic desire to understand where the person is coming from and what might be giving rise to the emotions you're observing. If we have already passed a judgement on what might be going on for the person, we miss the opportunity to gain a deeper understanding of the full picture. For example, a group member shares her frustration about the care staff not brushing her mom's hair when she comes to visit.

While there may be a myriad of reasons for why this is, consider what else might be going on for the group member. What does her body language and tone of voice tell you?

What, on the surface, may appear to be a critical or negative statement about the quality of care being provided, is often an expression of grief or guilt triggered by the changes that they are witnessing in their family member. It is important to provide a safe space for group members to explore these thoughts and the feelings behind them.

Listen, listen, then listen some more.

You have likely heard us say at the Society, "If you go the whole group without hardly saying anything, you have a healthy group." Pay attention to how much you're speaking—whether this is in a group setting or a one-on-one conversation. This is not to say you cannot interject—we still need to make sure the dialogue stays within the realm of respectful and productive—but ensure you give the person the proper space they need to feel heard, and that you genuinely care about what they are sharing.

Use open questions to dig deeper.

Open questions help us to gain a better understanding of where a person is coming from. For example, "What do you think about…," "You mentioned…," "Tell me more about…," or "What's it like for you when…" Continuing with our example above, some probing questions you might ask to better understand the group member's experience include:

* **What do you think about** the reasons why the care staff might not be brushing her hair regularly? *Or,* **what do you think about** the care staff's rationale for not brushing her hair regularly?
* **What's it like for you when** you see your mum with unkempt hair?
* **Tell me more about** what feelings get stirred up for you when you see your mum with her hair not brushed?

Try to avoid asking "why" questions.

"Why" questions often come across as judgmental, despite our best intentions. For example, "Why did you say that to the care aid?" may cause the group member to feel like you are judging how they responded as wrong, whereas, "Tell me more about how you felt when you were speaking to the care aid" helps the group to understand the experience of the person without judging their response as right or wrong. This question also allows you to bring other group members into the discussion, reiterating to the group that they are not alone in their shared experience. For example, "Who else has felt this way when interacting with a care aid? What was that experience like for you?"

> *"Who else has felt this way when…"*
>
> *"What was that experience like for you?"*

Listen to their heart and head.

Not literally—but listen to what the person is sharing. Are they speaking from their heart or their head? For example, a group member shares his frustration with the group that he no longer has a sexual relationship with his wife, who has been living with Alzheimer's disease for eight years. He asks the group directly, "When did you stop having sex with your spouse?" The group is silent, and several group members appear uncomfortable.

* Is this group member speaking from his head or his heart? His head is trying to understand what is logical or 'normal' for his situation while his heart is expressing loneliness and the change in intimacy with his spouse.
* Before you respond, consider who your audience is. Is your group a mix of spouses and adult children? Or spouses only? The topic of sexuality and dementia may still be relevant to some adult children whose parent displays uninhibited behaviours (e.g., making sexual comments or sexual advances), as it may help them better understand the loneliness and loss that faces a spousal caregiver. However, for some adult children, the topic may not be relevant to their situation or they may feel uncomfortable discussing the topic in relation to their parent.

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As the facilitator, it is important that we do not make assumptions as to who in the group may or may not benefit from the discussion. It is also important to pay close attention to our own non-verbal communication; if we are noticeably uncomfortable proceeding with a topic, that may resonate with the group and prevent further discussion.

* Start by validating the experience for the group member and then ask the group how they would like to proceed.

  "Ron, it sounds like this has been a profound loss for you. Dementia can affect sexuality and intimacy in many ways, and we all have a need to feel loved and connected to one another. It is normal and healthy to address these feelings and to grieve this loss. This topic is an important one, but it can also be sensitive, and perhaps instead of sharing personal details regarding our intimate relationships, we can discuss how we might cope with these changes and ways we can continue to stay connected and feel loved despite dementia. Is everyone comfortable having this conversation?"

* Pay close attention to any non-verbal cues that group members are uncomfortable. If you feel the safety of the group would be compromised by proceeding, consider suggesting that you discuss the topic for a set amount of time before moving on; or ask Ron if he would be okay with having a one-to-one discussion with a staff member outside of the group.

  "Ron, I can see that this is really weighing on you. Is it OK if I ask a staff member to give you a call this week to discuss your situation further?"

Sometimes, we think we are speaking from our head when our heart has taken over, steering the dialogue in a more passionate direction than intended. Try to balance questions that ask about what people "think" about a situation with how they "feel" about it. This can help you to understand what the person believes and why they feel that way. Remember, as much as we want to have all the answers and be able to take away the challenges faced by the group members, in theses moments, validation is often what is needed.

> *Balance questions that ask about what people "think" about a situation with how they "feel" about it.*

Know when it's enough.

While the person engaging in the difficult dialogue, or the group, may have been on board with "going there" at the beginning of the conversation, it is important to pay attention to any signs of changes in energy as the conversation progresses. You might notice through changes in body language or intonation, group members becoming emotional, losing interest or becoming frustrated. Remember that not all difficult dialogue needs to be or can be resolved in one meeting. The seeds for reflection have been planted and may give rise to new learnings at the next meeting or one-to-one. A follow up email can also be sent out directing group members to additional resources on a given subject if appropriate.

THANK YOU VOLUNTEERS!

Weekly dementia education webinars

Learn about dementia from anywhere by participating in one of our live one-hour webinars. All you need is a computer, tablet or phone! You can sign up for upcoming webinars in advance to receive a reminder, or review our recorded videos on a range of different themes related to living with dementia.

You can also subscribe to receive regular webinar updates.

What's coming up

Activities for warmer weather

Wednesday, June 30, 2 p.m.

As the weather warms up and we move outside, explore the benefits of meaningful activities for families affected by dementia.

Focus on behaviour: Delusions, hallucinations and visual mistakes

Wednesday, July 7, 2 p.m.

Explore strategies for responding to delusions, hallucinations and visual mistakes caused by dementia.

How to support a friend who has dementia or is a caregiver

Wednesday, July 14, 2 p.m.

Practical tips on how to offer support to a person living with dementia, their caregiver or family. For the general public.

Research ready (*researcher to be announced closer to the date)*

Wednesday, July 21, 2 p.m.

Join a local researcher for updates on new developments in dementia-related research.

Travelling with a person living with dementia

Wednesday, July 28, 2 p.m.

Challenges, safety concerns and strategies when travelling with dementia.

Accessing services during COVID-19

Wednesday, August 4, 2 p.m.

Learn strategies for navigating changes in accessing services and how to get the most out of your interactions with care providers.

Planning for health-care, legal and financial decisions

Wednesday, August 11, 2 p.m.

Plan now, before dementia affects the ability to communicate. Learn how to begin early legal, health-care and financial planning to prepare for your future.

***Please note that the webinar schedule is subject to change. Visit: alzbc.org/webinars for the most up-to-date schedule and information on how to register.**