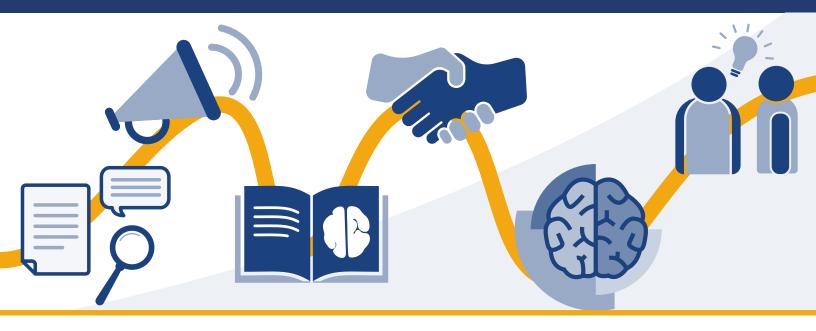
AlzheimerSociety

A focus on research



Advancing dementia research in B.C.

Research is key to helping people affected by dementia to live well today, as well as providing hope for the future. The Alzheimer Society of B.C. champions dementia-friendly research, invests in innovative studies and acts as a bridge between the academic world and the community. We do this to change the conversation, the experience and the future for people affected by dementia.

This edition of *A focus on research* shines a light on the work we've been doing over the last year to advance dementia research. This includes collaborating with provincial and national researchers, partnering with Michael Smith Health Research BC and contributing

to the national Alzheimer Society Research Program (ASRP). We also fund a Professorship in Alzheimer's disease research at the University of British Columbia and a Clinical Fellowship in Cognitive Health at the University of Victoria.

In addition to funding research, we strive to facilitate connections between researchers and community members who are interested in participating in research. We hope *A focus on research* will provide you with insights into what is happening in dementia research, foster confidence in interpreting research news and perhaps even inspire you to consider getting involved in research!

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The power of partnership: Advancing dementia research together

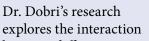
Michael Smith Health Research BC

We're delighted to announce our partnership with Michael Smith Health Research BC (MSHRBC)! At the forefront of impactful research, MSHRBC is dedicated to enhancing the well-being of British Columbians. Our partnership has allowed us to grant three valuable awards to six outstanding researchers. Together we're working to make a positive impact in the world of dementia research.

Research Trainee Awards: Assist post-doctoral fellows in their pursuit of shaping the future of health care.

Dr. Simon DobriSimon Fraser University

Project: Multisensory integration in aging and Alzheimer's disease.



between different senses and brain activity in young and older adults, with and without Alzheimer's disease, to inform strategies and policies for helping people living with Alzheimer's disease lead full, meaningful lives.



Project: Mapping the musical brain in dementia.

Dr. Faber will record the brain data of people

living with dementia while they listen to music to better understand why and how music is engaging and beneficial to people living with dementia.



Convening & Collaborating Awards: Promote knowledge sharing and meaningful collaboration by supporting researchers, trainees and research users on projects that can directly benefit people living with the disease, caregivers, health-care providers and policy makers.

Dr. Mariko Sakamoto

University of Victoria

Project: Dementia-Friendly Communities: Bringing to the fore the perspectives and needs of people living with dementia who live alone.



Together with people living with dementia and designers from Emily Carr University of Art + Design, Dr. Sakamoto will engage people who live alone in co-designing an action plan for future dementia-friendly community planning.

Dr. Juanita-Dawne Bacsu

Thompson Rivers University

Project: Developing a research agenda to address the stigma of dementia in rural communities in interior British Columbia.



Dr. Bacsu's project will bring together researchers and research users to develop a research agenda to explore methods of reducing dementia stigma, specifically in rural interior B.C.

The power of partnership: Advancing dementia research together, cont'd

REACH Awards: Support researchers and research users to extend their "reach" by sharing their work – through events, activities and tools – with the audiences who can use this knowledge to improve health and care for people affected by dementia.

Dr. Lillian Hung Simon Fraser University

Project: Sharing knowledge to connect, collaborate and co-create Dementia-inclusive Spaces for Community Access, Participation, and Engagement (DemSCAPE).



This project showcases the findings from research into how people living with dementia interact with their neighbourhoods and the environmental features that affect their mobility and ability to participate with their wider communities.

Dr. Teresa Liu-AmbroseUniversity of British Columbia

Project: Exercise for healthy aging: Mobilizing knowledge with users and clinicians in B.C.



Dr. Liu-Ambrose's team will hold a public forum to share the latest information on the benefits of exercise on cognitive health and mobility, as well as delivering interactive workshops to help older adults learn how to exercise safely and develop online resources sharing the content of the interactive workshops.

Learn more about the work the DemSCAPE team is doing on Page 11.

The Alzheimer Society Research Program

The Alzheimer Society of B.C. is also a proud contributor to the Alzheimer Society Research Program (ASRP), a national partnership between provincial Alzheimer Societies and the Alzheimer Society of Canada. Since 1989, the ASRP has provided nearly \$73 million for dementia-related research across Canada. To date, 96 projects in British Columbia have received over \$9 million in funding. We are proud to announce that this year, 10 researchers in B.C. were awarded ASRP funding.

The program funds dementia research with a focus on:



Biomedical research

- understanding the brain
- diagnosis
- prevention
- treatment and cure



Quality-of-life research

- risk factors
- physical support
- caregiving

The power of partnership: Advancing dementia research together, cont'd

Jennifer Cooper

University of British Columbia

Doctoral Award

Project: Blood based biomarkers of neurodegeneration across the health spectrum.



Rebeca Hernández Gambo

University of British Columbia

Doctoral Award

Project: Refining exercise prescription to promote cognitive health in mild cognitive impairment: understanding the "what" and "how."



Dr. Khaled Abdelrahman

University of British Columbia

New Investigator Grant

Project: The contribution of metabotropic glutamate receptor 5 (mGluR5) to impaired control of brain blood flow in Alzheimer's disease.



Dr. Michael Adachi

Simon Fraser University

Proof of Concept Grant

Project: Sensors for rapid detection of Alzheimer's disease biomarker proteins.



Dr. Leigh Anne Swayne

University of Victoria

Proof of Concept Grant

Project: Repairing nerve cell connections in Alzheimer's disease.



Madeline Gregory

University of Victoria

Doctoral Award

Project: Exploring resiliency in informal caregivers of people living with dementia.



Dr. Printha Wijesinghe

University of British Columbia

Postdoctoral award

Project: Using tear fluids to assess Alzheimer's disease.



Dr. Brianne Kent

Simon Fraser University

New Investigator Grant

Project: How circadian rhythms affect resilience in Alzheimer's disease.



Dr. Lillian Hung

University of British Columbia

Proof of Concept Grant

Project: Bring joy and happiness to long-term care by co-building an immersive experience program.



Dr. Sriram Subramaniam

University of British Columbia

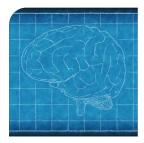
Proof of Concept Grant

Project: Disrupting
GluA1-VCP/p97 as novel
therapeutic intervention to
restore synaptic plasticity in
Alzheimer's disease: a cryo-electron
microscopy (cryo-EM) based approach.



A spotlight on research over the year

Every year the scientific community makes research advancements that are shared through the news. Below are some notable developments that happened over the past year.



Disease-modifying treatments

Amyloid beta is a protein found in the brain. When someone is living with Alzheimer's disease, this

protein forms "plaques" that are thought to potentially be the cause of their symptoms. In the development of recent drug treatments specifically for Alzheimer's disease, synthetic molecules called "monoclonal antibodies" are being designed to target and clear harmful proteins like amyloid beta. Two drugs using this approach that have received significant attention in the past year are lecanemab and donanemab. Both target amyloid beta, but at different stages of build-up.

Lecanemab

On July 6, 2023, the United States Food and Drug Administration granted full approval to lecanemab (brand name Leqembi). The drug is believed to reduce amyloid build-up in the brain and benefit someone's cognition and daily functioning. In the U.S., this drug is only approved for people in the early stages of Alzheimer's disease. It is not designed for people in the moderate or late stages of the disease. It is worth noting that there was a 43 per cent slowing of cognitive decline in males as opposed to just 12 per cent for females, emphasizing the importance of understanding sex-specific responses to drug treatment.

The most common side effects to lecanemab are reactions to its intravenous administration, headache and amyloid related imaging abnormalities (or ARIA).

ARIA refers to side effects including brain swelling and microhemorrhages (i.e., brain bleeds) that are visible on brain scans.

Eisai, the maker of lecanemab, applied for Health Canada approval in May 2023, but it could take another year before the medication is available to Canadians. The Alzheimer Society of B.C. continues to trust and support Health Canada's rigorous assessments of the safety and effectiveness of all drugs related to the treatment of dementia. Lecanemab will not be suitable for everyone. To be effective, lecanemab requires early detection and diagnosis of Alzheimer's disease, which further underscores the importance of continuing to address stigma and ensure more British Columbians have timely access to health-care providers and a diagnosis.

Donanemab

In July 2023, American drug company Eli Lilly shared promising developments from a phase three trial of donanemab. Forty-seven per cent of participants on donanemab – compared to 29 per cent of participants on a placebo – showed no clinical progression of dementia after one year. As with lecanemab, ARIA side effects were noted among study participants.

Donanemab is currently awaiting approval from the U.S. Food and Drug Administration, with approval expected in early 2024. The drug has not yet been submitted to Health Canada for review. Ongoing phase three clinical trials are due to be completed in 2024, 2025 and 2027, but none are being conducted in Canada.

A spotlight on research over the year, cont'd

Additional information

- Currently, four drugs have been approved in Canada for helping to manage the symptoms of Alzheimer's disease: <u>alzbc.org/approved-</u> treatments
- Research connects: Disease-modifying treatments and dementia webinar with Dr. Alex Henri-Bhargava: alzbc.org/AHB-webinar
- Alzheimer Society of Canada resource on general drug approvals in Canada: <u>alzbc.org/ASC-drug-approvals</u>



Feeding the mind for brain health

As we explore the intricacies of brain health, one topic keeps sparking curiosity – the

role our diet plays. Recent research suggests that our diet could be pivotal in reducing our risk of dementia and supporting a healthy aging brain.

A recent U.S. study (Agaral et al., 2023) focused on the Mediterranean and Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diets. The Mediterranean diet emphasizes vegetables, fruits and regular fish intake, while the MIND diet focuses on lower salt intake, leafy green vegetables and berries. Findings highlight that participants who closely followed the Mediterranean or MIND diets had levels of plaques equivalent to people 12 to 18 years younger. In a similar British study, Shannon et al., (2023) found participants who adhered to the Mediterranean diet had up to 23 per cent lower risk of developing dementia.

There are some limitations with these two studies. While they may show certain dietary habits are

associated with lower rates of dementia, they can't prove that these dietary habits directly reduce dementia rates. Participants in both studies self-reported their diet, so it is difficult to know the true quality and quantity of foods people ate. Most participants in both studies were older, white individuals. Further research with more diverse participants is required. For example, looking at diets from diverse communities can enrich understanding and ensure a broader and more authentic representation of various cultural dietary practices.

Despite these limitations, both studies suggest a connection between these diets and better brain health as people age. Research suggests that a healthier diet, which includes regular intake of nutritious foods and is low in processed foods and unhealthy fats, contributes to good health (Health Canada, 2019). Eating a well-balanced, nutritious diet may not only impact our brain health but also our overall well-being. For more tips on following a healthy diet visit: alzbc.org/BrainHealthyTips

The Landmark Study: Reports 1 & 2



Dementia is one of the most pressing health challenges facing Canada's aging population – but its scale and impact

remains uncertain. To address this knowledge gap, the Alzheimer Society of Canada commissioned the Landmark Study. The first two reports have been published, and the third is expected in late 2024. Here we present the highlights:

• In 2022, an estimated 85,800 people were living with dementia in B.C., a number predicted to increase to 247,300 by 2050.

A spotlight on research over the year, cont'd

- In 2022, an estimated 50,400 care partners were providing support. This is projected to increase to 144,900 by 2050.
- In 2020, caregivers in B.C. provided about 61 million hours of unpaid support to people living with dementia each year. By 2050, this is expected to increase to 198 million hours.
- In 2020, an estimated 1,530 Indigenous people were living with dementia. By 2050, a projected 5,900 Indigenous people will live with dementia, an increase of 286 per cent.

- By 2050, one out of every three people who live with dementia in B.C. will be of Asian origin.
- By 2050, there will be 1.7 times as many people assigned female at birth who live with dementia than people assigned male at birth.
- By 2050, more than 6,000 people under the age of 65 will live with dementia.

To read the full reports and learn more about what health-care providers, governments, researchers and people like you can do to change the future of dementia in Canada, visit: alzbc.org/landmark2



Getting involved in research

Research helps improve the ways we understand, treat, diagnose and manage the risk of developing dementia. Participating in research can offer hope for oneself and for others. It can also be a great way to keep active and engaged in the community. If you are living with dementia, have a conversation with your primary care partner about the possibility of participating.

For studies currently recruiting participants:

- Visit the Alzheimer Society Research Portal: <u>alzbc.</u> <u>org/research-portal</u>
- Visit REACH BC: <u>reachbc.ca/studies</u>
- Visit Vancouver Coastal Health Research Institute: alzbc.org/VCHRI

 Check with your local hospital, health centre or health-care provider (family physician or specialist).

Do you have questions about participating in research?

- Visit: <u>alzbc.org/research-participation-BC</u>
- Download our brochure on participating in research: <u>alzbc.org/research-guide</u>
- Download the brochure *Opening a door to* collaborative research: alzbc.org/collaborative
- Email: research@alzheimerbc.org
- Call: 1-800-667-3742

"If you are asked to participate in a research project, say yes! Researchers genuinely want to hear our experiences. ... [It] gives me hope that there are people striving to make the system better."

- Caregiver

Shaping the future of dementia care: A conversation with Dr. Shelley Canning

Dr. Shelley Canning (Associate
Professor, University of the
Fraser Valley) is a passionate
advocate for improving
the lives of older adults,
particularly people living with
dementia. Shelley is focused

on teaching and research, where she explores engagement, meaning and quality of life for older adults in care – including people living in the later stages of dementia. Shelley is a recent recipient of an ASRP Proof of Concept Grant for a project called *Implementing a dementia-friendly care approach for cancer patients living with dementia*.

When did your interest in dementia-related research begin?

I have been a nursing professor with a clinical specialty in gerontology for the past 18 years. In this role, I supervise first-year nursing students caring for older adults and people living with dementia in long-term care. These experiences led to my passion for improving dementia care and became the focus for my dissertation research and current research portfolio.

What excites you most about your work?

As a nursing educator, I mentor new students as they begin to form their understanding of the powerful role of nursing within the health-care system. One of my goals is to support students to shed their ageist attitudes and stigmas related to dementia. In the classroom, lab and clinical settings I work hard to role model best practices and to show how dementia-friendly care can make a meaningful difference in the lives of the people they care for. As a nurse researcher, I'm excited to collaborate with colleagues who share the goal of improved understanding and care of people living with dementia. One of my favourite aspects of my work is recruiting undergraduate

nursing students to join my research team, allowing me to mentor them in developing an understanding and passion for research.

Why is your area of research important?

Both my research and my clinical practice have focused on older people and people living with dementia and I recognize that within our ageing population the care of these individuals is becoming increasingly important. However, in addition to the obvious demographic challenges we face, I would also argue that this area of research is important because systemic ageism and dementia stigma challenge us to meet the needs of these people in meaningful ways. Regardless of the numbers, we are neither age-friendly nor dementia-friendly as a health-care system, or more broadly, as a society.

How are you collaborating with people with lived experience in your work?

Our research team is seeking input from people living with diagnoses of both cancer and dementia. We recognize that they can play an invaluable role as members of the team where their subjective experiences and expertise will be important in all aspects of the project.

What do you hope to achieve with this research?

I hope our findings will make a difference to members of the health-care team providing care for cancer patients living with dementia and subsequently improve the care experience for both them and their caregivers. We believe the results from our project will also have the potential to inform and improve dementia-care practices in other care settings.

If you'd like to participate or learn more about this study, email Shelley.Canning@ufv.ca or call 604-855-9813.

Navigating dementia research in the age of (mis)information



Many people go online to seek out medical information on preventing diseases, including dementia. We have more information at our fingertips than we've ever had before. But how do we assess that information — particularly when it comes to health — to ensure it's accurate? It's important to recognize research varies in the quality of evidence that is generated. Not all research is created equal. Read on to explore how to detect fact from fiction when it comes to health information related to dementia.

The importance of peer review

While most of us hear about dementia-related research from the media, those headlines are often based on research published in academic journals as part of the peer review process. Researchers submit a written manuscript to a journal which summarizes their research. The manuscript is then sent out to other academics not involved in the research for review. Typically, reviewers don't know who authored the manuscript and authors don't know who reviewed their work — this is referred to as a "double-blind" review process. Based upon the recommendations of the peer reviewers, the article is either accepted, sent back for revisions or rejected. Peer review is an important step in the research process, serving as a quality check. Peer review typically takes one to six months (or longer).

The CRAAP Test

One way to refine your literacy is to employ what Blakeslee (2004) termed the CRAAP test. This memorable acronym stands for Currency, Relevance, Authority, Accuracy and Purpose.

Currency: How current the information is. **Ask:** *When was the information published or posted?*

Dementia research, particularly biomedical research, can advance considerably in a five-year period; if you're looking at research that was published more than five years ago, you'll want to note whether the information has been revised or updated. However, if you're looking at quality-of-life research, older sources are likely not as problematic. For example, the challenges family caregivers face have been known for a while. Additional research in this area likely refines and adds nuance to what we know, rather than coming up with something entirely new.

Authority: The source of the information. **Ask:** Who did the study? Who wrote the information on the site you are reading?

Ideally, there should be a name, along with information about the researcher's credentials and organizational connections. However, just because someone has a PhD doesn't mean they are qualified to contribute to the field in question. For example, having a PhD in psychology does not necessarily make someone qualified to write with authority on exercise or nutrition.

Accuracy: The reliability, truthfulness and correctness of the content you're reading.

Ask: Where does the information come from?

Is the study from a reputable peer-reviewed journal, like The Lancet, or is it from a predatory journal? These are journals that accept articles for publication,

Navigating dementia research in the age of (mis)information, cont'd

along with authors' fees, without performing promised quality checks for issues such as plagiarism or ethical approval. You can view an updated list of potential predatory journals and publishers here: beallslist.net/#update

Look carefully at the tone of the article; does it use words like "definitely," "reverse," or "cure?" Is the tone more cautious? Better yet, is the advice balanced? Does it discuss limitations and criticisms? Does it encourage you to talk to your doctor or is it dismissive of doctors? If it's the latter, be careful!

Purpose: The reason the information exists. **Ask:** What is its purpose? Is it to inform, teach, entertain or sell?

Be wary of articles disguised as research that attempt to sell a product or service that claims to prevent or treat the disease. While we've made some progress in disease-modifying treatments in the last few years, there is currently no cure for dementia, nor is there anything that can guarantee you will not develop dementia. Ask yourself if there is a conflict of interest. For example, is the author using the information to convince you to buy a product, information or service that you might be able to access elsewhere free of charge? There is a lot of information about dementia available on the internet, much of it from reputable sources and for free. Anytime someone is asking you to pay money for information, a red flag should go up!

Key takeaways

- Engage your CRAAP radar.
- Search out the original article. Type the description or title into Google Scholar. Even if you can't access the entire article, you'll be able to read the summary or abstract.
- Use reputable sources, like the ones we share below, to learn more about dementia research.
- If you have questions, don't hesitate to reach out at research@alzheimerbc.org.

Learn more about dementia-related research

- Stay connected to the Alzheimer Society of B.C.! Register for our ongoing Research connects webinars focusing on research here in B.C.: <u>alzbc.org/research-webinars</u>
- Check-out the Alzheimer Society of Canada's regular research webinars featuring Canadian researchers: <u>alzbc.org/</u> <u>DTC</u>
- Check out EurekAlert! a news-release distribution platform, operated by the non-profit American Association for

- the Advancement of Science. Only news releases that meet EurekAlert!'s longstanding eligibility guidelines are hosted on the website. Type "dementia" into the search bar on the home page and you'll be able to see all the recent news releases related to the topic: eurekalert.org
- Visit "The Conversation," an independent source of news and views from the academic and research community, intended for the public. Type "dementia" into the search bar on the home page to see the recent posts related to dementia: theconversation.com

DemSCAPE: Paving the way for dementiafriendly communities

The Alzheimer Society of B.C. has been engaged as a community partner in a new, multi-year project called DemSCAPE underway at Simon Fraser University (SFU), focused on creating more inclusive and supportive community for people living with dementia. Funded by the Public Health Agency of Canada and the Alzheimer Society of Canada, the project brings together a diverse team of researchers from across the province and includes partnerships with the City of Burnaby and City of Richmond.

DemSCAPE — short for "Dementia-inclusive Streets and Community Access, Participation and Engagement" — seeks to identify key neighbourhood features that impact the mobility of people living with dementia.

Led by SFU's Dr. Habib Chaudhury, the research team engaged with people living with dementia and their care partners from Metro Vancouver and Prince George to learn what makes it easier or harder for people affected by dementia to navigate their surroundings and participate in activities within their neighbourhoods.

Designing Dementia-Friendly Cities: A blueprint for urban living

In January 2023, the DemSCAPE team held a community event in Vancouver. People living with dementia, care partners, community members, researchers and dementia-focused organizations came together to contribute to the development of dementia-inclusive design guidelines for municipalities. Participants' top priorities included:

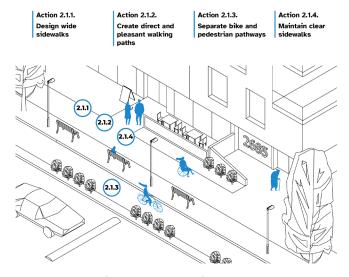
- Improving pedestrian paths and sidewalks.
- Enhancing public toilets.
- Clear and effective signage.

Over the months that followed, the DemSCAPE team joined forces with Happy Cities to create British Columbia's first-ever guide for planning and designing dementia-friendly cities. The guide offers 20 practical strategies to enhance comfort, safety, inclusivity and an overall sense of belonging in our cities. The guidelines are divided into three design categories, each tailored to different stages and sizes of implementation, from neighbourhoods to street design. Within each strategy, actions provide specific examples of how to support people living with dementia through the built environment.

The DemSCAPE initiative has the potential to improve community design, supporting people living with the disease to stay actively engaged with their neighbourhoods and enhance their quality of life, especially as more people choose to age in place.

Additional information

- Project website: alzbc.org/demscape
- Short documentary video: <u>alzbc.org/demscape-video</u>
- Dementia-inclusive planning and design guidelines: alzbc.org/demscape-guide



These actions from the guide focus on street design.

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Contact us

- Online at <u>alzheimerbc.org</u>
- Email research@alzheimerbc.org
- Call 1-800-667-3742
- Mail to

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FIRST LINK® DEMENTIA HELPLINE

If you are living with dementia or have questions about the disease, call the First Link* Dementia Helpline at 1-800-936-6033. The Helpline is available Monday to Friday, 9 a.m. to 8 p.m.

Call 1-833-674-5003 for support in Punjabi, Hindi or Urdu and call 1-833-674-5007 for support in Cantonese or Mandarin (both available Monday to Friday, from 9 a.m. until 4 p.m.). Learn more at <u>alzbc.org/fldhl</u>