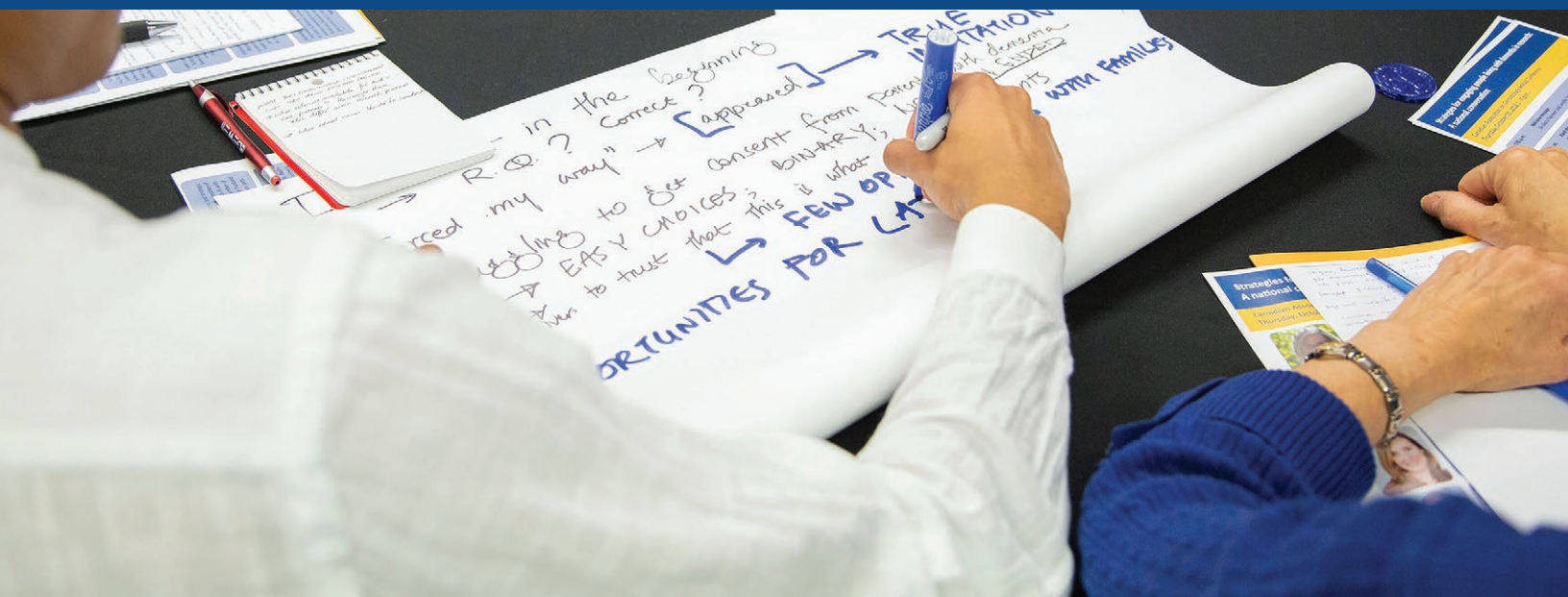


A focus on research



There is currently no cure for Alzheimer's disease or other dementias. By 2031, if nothing changes, 1.4 million Canadians will be living with dementia. Research is key to changing this story.

The Alzheimer Society of B.C.'s vision is a world without dementia. To achieve this vision, we champion dementia-friendly research — studies that ensure people affected by dementia are meaningfully and respectfully included in the work. We are dedicated to supporting research through funding as well as acting as a knowledge source and bridge between researchers and the broader community.

We support biomedical and quality of life research, through our contributions to the national Alzheimer Society Research Program — which to date has funded over \$53 million in awards, including \$4 million for 54 projects in B.C. — and through additional work with studies led by local research partners. We are committed to fostering new research in B.C. by

supporting, partnering with and directly funding local researchers. The Ralph Fisher and Alzheimer Society of B.C. Professorship in Alzheimer Disease Research, which is a collaboration with UBC, is one good example of how we also invest in people.

Read on for highlights from the last year in dementia research, including:

- **An exploration of dementia-friendly research (page 2).**
- **Dementia research headlines of the year (page 5).**
- **An interview with researcher Tomiko Yoneda (page 7).**
- **A guide to clinical trials (page 8).**
- **Ways to get involved in research (page 9).**

While reading, if you're unsure about what something means, please refer to the research glossary on page 11 which contains definitions of some common research terms.

Exploring dementia-friendly research

There is currently a cultural shift occurring in the world of health research. In 2011, the Canadian Institutes of Health Research launched the Strategy for Patient-Oriented Research, grounded in the view that health research needs to focus more on what is considered important by patients. Patient engagement is now becoming a top research priority throughout Canada.

People living with dementia have historically been excluded from research and, despite this new surge in patient engagement, are still largely excluded. This exclusion is generally the result of beliefs that people living with dementia are unsuitable to participate or partner in research because they are unable to understand research processes and give proper consent. This is, of course, not true. People living with dementia and their care partners are experts in the lived experience of dementia and have important perspectives to contribute to the research community.

An estimated 70,000 British Columbians are currently living with dementia and it has never been more critical to engage them in research. However,

It is important to remember that research is more than just drugs. At our October 2018 event on dementia-friendly research, we heard from researchers studying a variety of areas, including how to help people living with dementia improve their quality of life and observational studies on the experiences of caregivers.



Dr. Lillian Hung, post-doctoral fellow and professor Habib Chaudhury from SFU Gerontology brainstorm ideas on dementia-friendly research.

there are many challenges that must be overcome to reach this goal. It is necessary to move beyond patient-oriented research to dementia-friendly research, to include people living with dementia not only as participants in research, but to welcome them as advisors, partners and collaborators in the research process. This shift will both benefit people living with dementia and their caregivers as well as improve the quality of dementia research.

In October 2018 the Alzheimer Society of B.C. hosted “Strategies for engaging people with dementia in research: Facilitating a national conversation,” in partnership with the UBC Centre for Research on Personhood in Dementia. The session was held as a pre-conference workshop at the Canadian Association on Gerontology’s Annual Conference in Vancouver. It was a lively event that brought together researchers, people living with dementia, care partners, students, health leaders and other key stakeholders from around the country to start important conversations about dementia-friendly research.

Dementia-friendly research practices

Participants and panelists representing a range of backgrounds — including research, law, health care and people with lived experience — took part in a series of moderated discussions. In the end, they noted the following key points as important for conducting dementia-friendly research:

- Combat stigma.
- Educate research ethics boards on the unique needs and abilities of people living with dementia.
- Meaningfully work with people affected by dementia on research questions from the start of the research process.
- Ensure that inclusion of people living with dementia goes beyond simply being symbolic or tokenistic.
- Create research designs that are flexible and that can meet the changing realities of someone living with dementia and allow for their continued participation throughout the study in a respectful way.
- Use accessible research methods that don't solely depend on written or verbal communications.
- Use easy-to-understand, person-centred language and avoid jargon and acronyms.
- Give knowledge back to the community at the end of the research process.

The workshop was a wonderful gathering of perspectives and generated many important next steps. The Society is committed to promoting dementia-friendly research and supporting people affected by dementia and researchers to feel more confident and able to engage in research with each other. This is an exciting time in dementia research and we are so pleased to be moving towards a more dementia-friendly future.

Thanks to all who participated, including our panelists: Mario Gregorio and Jim Mann from the Society's Leadership Group of People Living with Dementia; Krista James, Director of the Canadian Centre for Elder Law; Dr. Alison Phinney, Co-Director of the UBC Centre for Research on Personhood in Dementia; Dr. Gloria Puurveen from the W. Maurice Young Centre for Applied Ethics at UBC; Dr. Heather Cooke from the UBC School of

Nursing; Dr. Elaine Wiersma, Director of Lakehead University's Centre for Education and Research on Aging & Health; Dr. Robin Hsiung from the UBC Clinic for Alzheimer's Disease and Related Disorders; and Dr. Larry Mroz, Research Navigator and Patient Engagement Coordinator at the BC SUPPORT Unit.



The session's panelists gather together for a group photo.

Becoming research savvy

It can seem like we're constantly hearing about new and exciting breakthroughs in dementia research. All research helps contribute to our growing knowledge about dementia. However, it's important to be critical when we read about research as some articles or studies may not always tell the whole story.



Here are some questions to keep in mind:

- **What is the source?** Anyone can write an article on a website, but credible research is always published in scientific magazines and peer-reviewed journals (reviewed by experts in that field).
- **Who did the research?** Legitimate research articles always state the names of the researchers, their credentials and when the study was done. It is important to note that the fact that the researcher is a doctor does not automatically mean that the research is reliable.
- **What kind of study is it?** There are many types of studies. A true experiment contains an intervention (for example, a new drug) and controls for variables (such as health conditions) so that the results will indicate the effect of the intervention. If a study is “observational” or references a “case study” it can’t claim anything about the effects of a treatment.
- **How many people are in the study?** The more people in a study, the more likely the results will be real and therefore the treatment will be effective. For example, a study with only 20 participants may suggest a promising direction but it is not a good basis for a treatment.
- **Is it an animal or human study?** Research is often conducted on animals before humans to determine the effects of a treatment. However, promising results in an animal study do not always appear when the same study is done on humans.
- **Who funded the study?** If the organization that funded the study has something to gain from the results (like having a medication approved or a product endorsed) the results may be biased and warrant an additional level of caution when interpreting.
- **Are there other studies that have found similar results?** One study is rarely enough to confirm a new breakthrough. When many studies are complete, researchers can draw conclusions from a combined body of knowledge. When a researcher is talking about the results of many studies all together it is called a “meta-analysis.”

There is a lot of exciting dementia research emerging and being a smart research news consumer helps move our knowledge forward.

Dementia research headlines of the year

Dementia prevention



While there is still no way to ensure that you do not develop dementia, more and more research into risk reduction is being done. According to *The Lancet's* 2017 commission (an in-depth

report) on dementia prevention, intervention and care, an estimated 35 per cent of dementia cases could potentially be preventable by managing nine risk factors that include hearing loss, social isolation and depression. Meanwhile, a Finnish trial, abbreviated as the FINGER study, explored the effects of various lifestyle interventions — from managing vascular (heart) risk factors, nutritional guidance and physical exercise. It showed such encouraging results that it is currently being replicated in seven countries.

Recommended reading:

The Lancet 2017 commission on dementia prevention, intervention and care. <https://alzbc.org/lancet>

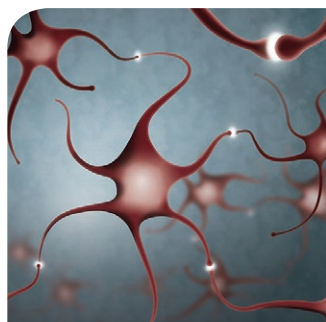
The FINGER worldwide website.

<https://alzbc.org/FINGER>

The Society's web page on brain health.

<https://alzbc.org/brain>

Amyloid



Since Alzheimer's disease has been discovered, the main focus of research has been on the protein amyloid-beta (also known as β -amyloid peptide or A β). Because the "amyloid cascade

hypothesis" suggests the presence of amyloid-beta in the brain causes the degeneration seen in Alzheimer's disease, the majority of drug trials in recent years have focused on clearing amyloid from the brain. Though these trials were successful at clearing amyloid, they were unsuccessful at improving cognition or stopping brain degeneration. As a result, many researchers have turned to other areas of exploration, including tau or neuroinflammation, to search for treatments. However, researchers are still exploring the connection to amyloid: they are testing treatments earlier in the progression of the disease to try to prevent amyloid from forming; they are targeting its most toxic form (amyloid-oligomers); and they are testing higher doses.

Recommended reading:

Anti-amyloid- β monoclonal antibodies for Alzheimer's disease: Pitfalls and promise (2018).

<https://alzbc.org/amyloid>

Second look at BAN2401 data still positive (2018).

ALZforum article. <https://alzbc.org/BAN2401>

Blood tests



A blood test for dementia would allow earlier and more accessible diagnosis which would potentially improve both the lives of people living with dementia and research into the disease. Many

researchers are searching for reliable blood-based biomarkers of dementia. Such biomarkers currently being studied include amyloid, tau and the protein neurofilament light chain, known as NfL. We are still years away from seeing these blood tests available to the public, but exciting research into biomarkers continues, including here in B.C.

continued

Research headlines, cont'd

Recommended reading:

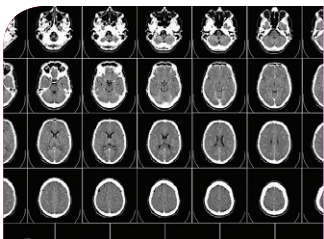
The changing definition of Alzheimer's disease and the role of biomarkers (2019).

<https://alzbc.org/cohen-webinar> Brainxchange webinar.

The Society's web page on getting a diagnosis and the benefits of early diagnosis.

<https://alzbc.org/diagnosis>

Neuroinflammation



Many researchers are now exploring the link between brain inflammation and dementia. In recent years, several

observational studies have suggested there is a correlation (a relationship or connection) between inflammation in the brain and different forms of dementia, though it remains unclear what the relationship is. Recent research has investigated inflammation both as the cause of degeneration and as the result of factors such as sleep disturbances, depression and bacterial infections. It is important to note that clinical trials have not shown any benefit to taking non-steroidal anti-inflammatories (NSAIDs), such as ibuprofen.

Recommended reading:

A new angle on Alzheimer's disease: The inflammation connection (2018). <https://alzbc.org/inflammation>

Expert blog post on the Bright Focus Foundation website.

Inflammatory markers and the risk of dementia and Alzheimer's disease: A meta-analysis (2018).

<https://alzbc.org/inflammation-meta-analysis>

Psychosocial interventions



Research means far more than just drug trials. There is a growing body of research exploring how psychosocial interventions can improve quality of life

for people living with dementia and their caregivers.

This is a diverse field that includes person-centred interventions, using technology (such as robotic animals), better long-term care design and coping strategies for people affected by dementia. Research has shown that psychosocial interventions are often just as effective as pharmacological (drug) interventions for managing the responsive behaviours that sometimes arise with dementia.

Recommended reading:

Psychosocial interventions for people with dementia: A synthesis of systematic reviews (2018).

<https://alzbc.org/psychosocial>

Psychosocial research in dementia: Past, present and future (2019). <https://alzbc.org/brodaty-webinar> Brainxchange webinar.

Tomiko Yoneda on her work and the future of dementia research



Tomiko Yoneda is currently obtaining her PhD in Psychology, focusing on lifespan health and development, from the University of Victoria. She has previously volunteered with the Alzheimer Society of B.C. on the First Link® Dementia Helpline and later received funding from the Alzheimer Society Research Program for her work. The Alzheimer Society of B.C. was also thrilled to welcome Tomiko as a speaker at our 2019 *Victoria Breakfast to Remember*, presented by Trillium Boutique Senior Living.

Q: When did your interest in dementia begin?

During my undergraduate degree, I volunteered at the Oak Bay Lodge. The experience was fascinating and personally really moving. It inspired me to pursue research investigating quality of life in healthy older adults. When I started volunteering at the Alzheimer Society of B.C., my research interests quickly shifted to cognitive decline and dementia.

Q: Why do you think dementia research is important?

There's not yet a cure for dementia but, at some point, there will be and that will happen through research. There's also lots of research showing the progression of dementia may be slowed through healthier lifestyles. Research that can increase understanding of these factors is really important and has the opportunity to make a big difference in the lives of Canadians.

Q: What would you like people to know about dementia research?

Participating in research studies is a huge contribution and can have a significant impact on the state of knowledge! Dementia is a

tricky research area, especially as funding has historically been very limited. Research is also negatively affected by the stigma associated with dementia. I think it's important for everyone, including younger generations, to know more about dementia and how their own health decisions will affect their quality of life as they age.

Q: What is your current research project?

I'm working on several projects right now. All of my projects are related to risk reduction and prediction of cognitive decline and dementia. Specifically, I'm studying the relationship between cognition and blood pressure variability; personality change before a diagnosis; and the importance of maintaining physical activity into older adulthood. Previous research shows that hypertension is associated with cognitive decline and dementia, but recent research is showing that blood pressure that goes up and down quite a bit may further exacerbate the risk of cognitive decline and dementia by negatively impacting the blood circuitry in the brain.

continued

Tomiko Yoneda, cont'd

Q: What do you hope to achieve with this research?

There is a lot of research showing that progression to dementia can be slowed by adherence to a healthy lifestyle, but I don't think that information is as public as it should be. I'm really excited about my project focusing on maintaining physical activity into older adulthood. My results are showing that engaging in the minimum recommendations of physical activity (150 minutes of moderate activity per week), can increase life expectancy for an older adult by almost four years.

The last few years have also seen a push for increased "knowledge mobilization," which means making research results more understandable for the general public. I believe researchers have a responsibility to

use our research to improve quality of life and presenting information in an understandable and usable way will ultimately make research much more meaningful.

Q: What does this mean for people who are living with dementia and their caregivers?

I think that the push for knowledge mobilization can reduce stigma around the disease and highlight ways to stay healthier, longer (which is where my research is focused). Also, although every individual living with dementia, and their family members, has a unique experience, many experiences are also shared and research, like mine, combined with knowledge mobilization can increase awareness of those shared experiences and help families feel less isolated.

Clinical trials: Dispelling the myths

Clinical trials are vital to discovering new treatments and cures. However, many trials struggle to find enough participants. In his 2018 article (<https://alzbc.org/gates>) Bill Gates identified low participation in trials as a key roadblock towards advancing dementia research. Taking part in clinical trials can seem complicated, scary and inconvenient, but it doesn't have to be. The following are common myths about clinical trials¹:

Myth

You will have to take a drug that no one knows anything about.

Before clinical trials take place, drugs go through rigorous testing in laboratory conditions before they are approved for testing on people. Very often, drugs tested in clinical trials have also already been used to treat other conditions and we already know a lot about how safe the drug is and the effects it might have.

Myth

Researchers will treat you like a guinea pig.

In Canada, the Tri-Council Policy Statement (TCPS) strictly regulates research involving humans and outlines protections for participants, including participants in clinical trials. To run, a study will also have to be approved by a research ethics board. In the majority of cases, volunteers find they receive excellent care and enjoy the experience.

Myth

There is no point taking part in a clinical trial if you are given a placebo.

Clinical trials often need two groups of volunteers:

- The active group that receives the drug or intervention.
- The control group that receives a placebo or doesn't take part in the intervention.

Having both groups allows researchers to compare the two and understand the true benefit of the drug or intervention. The control group is equally as important as the active group. In some trials, if the drug or intervention proves successful, the control group will also be offered the treatment once it is approved.

Myth

Once you sign on the dotted line, you have to take part in a clinical trial.

Informed consent is an essential part of participating in a clinical trial, but it's important to remember that you have the right to leave the trial at any point and do not have to give a reason for doing so.

¹*Adapted, with permission, from the Alzheimer's Society in the UK,*

alzheimers.org.uk/5-clinical-trial-myths



Participating in research



"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." – Ellen Allen, family caregiver and B.C. Leadership Group of Caregivers member

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.

Before participating in research, it is always important to check with your primary care provider to see if it's a good fit for you. For considerations to make before participating, see the Alzheimer Society of Canada's guide to participating in research and our web page dedicated to the topic.

The following studies are currently recruiting participants from B.C.

Help us improve First Link®

The Alzheimer Society of B.C. is committed to offering the highest quality services that also meet the needs of the people receiving them. To ensure this, the Society has contracted researchers at the University of British Columbia to evaluate all First Link® dementia support services (support calls, dementia education, support groups and Minds in Motion®). Your feedback is valuable and will help improve services for other British Columbians affected by dementia. If you would like to give feedback and be a part of this research project, visit <https://alzbc.org/FL-evaluation> to sign up and be contacted by our external research partners.

A medium chain triglyceride intervention for Alzheimer's disease (University of British Columbia)

- Looking for: People living with mild to moderate Alzheimer's disease, with a care partner able to participate with them.
- Contact: Penny Slack at 604-822-6379 or pslack@mail.ubc.ca

Shared decision-making about living well with dementia to the end of life (University of British Columbia)

- Looking for: Anyone living with dementia in the community.
- Contact: Dr. Gloria Puurveen at 604-822-4150 or gloria.puurveen@ubc.ca

Brothers and sisters caring for a parent living with dementia (University of Toronto, online study)

- Looking for: Brother-sister pairs who are caring for a parent living with dementia at home.
- Contact: Jennifer Machon at 416-978-5694 or jennifer.machon@mail.utoronto.ca

For more studies recruiting participants, visit our "Participating in Research" web page at <https://alzbc.org/participate>, check with your local hospital or health-science centre or contact your health-care provider (e.g. family physician or specialist).

Research glossary

Active/experimental group Many studies separate participants into at least two groups. The active (or “experimental”) group will receive the intervention being examined (for example, a new drug).

Case study A study based on a very small number of participants who are studied in detail. This can be a starting point for research but generally cannot reveal anything about cause and effect.

Control group This is the group in a study that will be compared to the “active/experimental” group. The group may receive a placebo (e.g. a sugar pill), the normal treatment for the condition being studied or no intervention at all. This group is essential to ensure that the intervention being tested has an effect and that it is better than the established treatment.

Correlation This means that two factors are related in some way. It does not mean that one of them causes the other; more research is needed to make that link. For example, a study may show that there is a relationship between exercise and dementia, but we do not know what the relationship between them is.

Dependent variable This is how researchers measure the effects of the independent variable (defined below). For example, a score on the Mini-Mental State Exam (MMSE) or happiness level could be dependent variables.

Double-blind study This means that neither the participants nor the researchers know if a participant is in the active group or control group during the study. This ensures that the results aren’t influenced by the researchers treating participants in the two groups differently.

Experiment A research design used to establish a cause-and-effect relationship between an intervention (for example, a drug) and a result (for example, improvement in symptoms).

Hypothesis This is what the researchers are testing in their study. It can generally be stated in one sentence. For example, “Walking a mile every day will make you happier.”

Independent variable This is what is being tested in a study, such as a drug or intervention. It should be the only difference between the experimental and control groups.

Population The entire group being considered in a study, for example “people living with dementia.” A sample is the small number of people from the population of interest that actually take part in the study.

Randomized controlled trial (RCT) This is considered the gold standard for any kind of treatment. It is a type of experiment in which people are chosen at random to receive an intervention or a placebo.

Significance If results are statistically significant (often just called “significant”), this means the results have passed specific mathematical tests the researchers have put them through. It doesn’t necessarily mean the treatment works, or has a large effect, but rather that it is unlikely that the result occurred due to random chance.

Alzheimer Society

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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 4 p.m. For information and support in Punjabi, call 1-833-674-5003 and in Cantonese or Mandarin, call 1-833-674-5007. Learn more: <https://alzbc.org/fldhl>

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