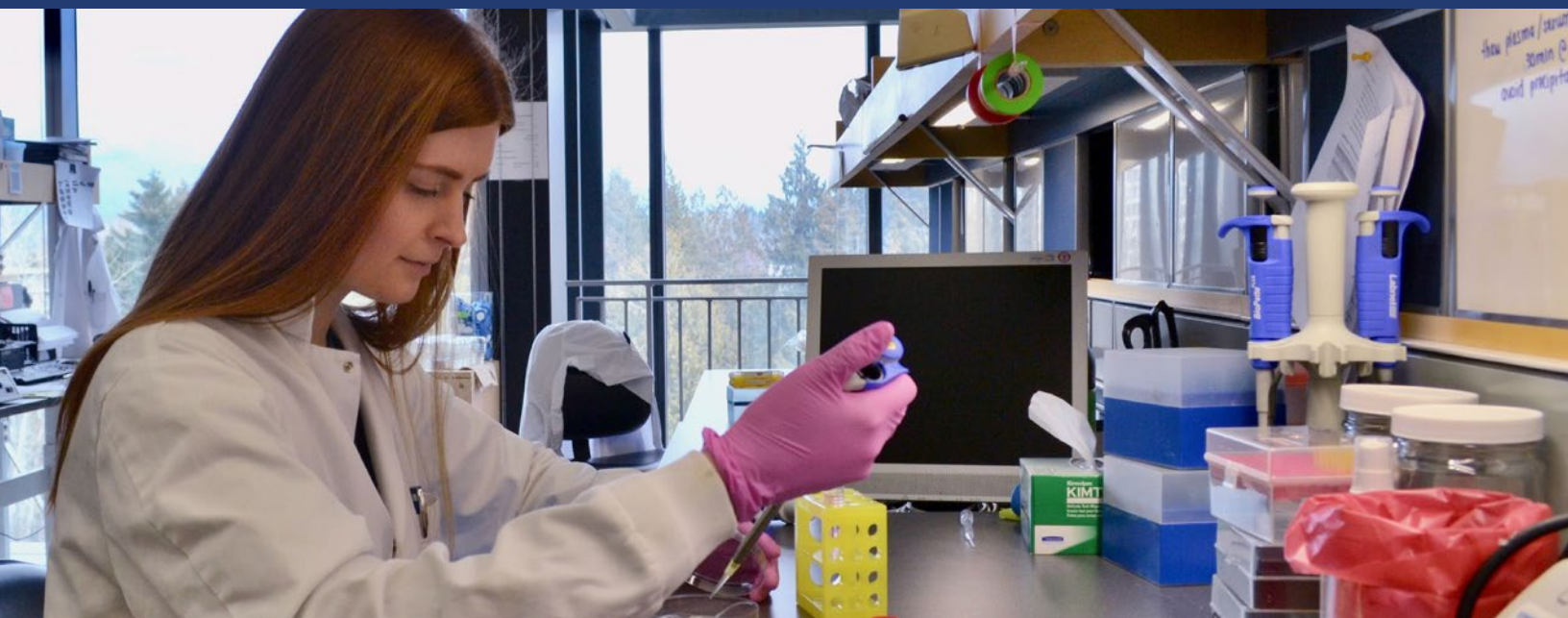


# A focus on research



## 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:

The biggest dementia research stories of the year [Page 3](#)  
Researcher profile: Elyn Rowe [Page 6](#)

A guide to participating in research [Page 8](#)  
Tips for reading research headlines [Page 10](#)

# Spotlight on quality-of-life research



There are many different types of dementia research and many ways to categorize them. Most often, a main distinction can be made between “biomedical” and “quality-of-life” research. Biomedical research includes studies investigating the causes, treatments and possible cures for dementia. Quality-of-life research looks at ways to improve the lives of people living with dementia and caregivers.

“While the search for a cure continues, quality-of-life research addresses the todays and tomorrows for those of us living with a dementia diagnosis. What helps us stay connected, increases our confidence, encourages socialization is what quality-of-life research uncovers.”  
– Jim Mann, dementia advocate

Quality-of-life research can help us answer questions like: How can we improve hospital visits for people living with dementia? How can art help combat stigma? And how can we make community services more accessible?

Quality-of-life research is often overlooked because biomedical research and the excitement of potential treatments or causes tend to attract the most media attention. Yet this type of research accounts for some of the most innovative and valuable work currently happening here in B.C., nationally and internationally.

Recent quality-of-life research projects the Alzheimer Society of B.C. has supported include:



**Art Making Space** – This project, led by Dr. Gloria Puurveen, included interviews and art workshops to learn from people living with dementia and care partners about what it means to live well with dementia to the end of life. The incredible results of the project, including art pieces and videos, are exhibited at [artmakingspace.com](http://artmakingspace.com)



**SWAN tool** – Researchers from Simon Fraser University are currently developing the SWAN (Stakeholders Walkability/ Wheelability Audit in Neighbourhoods) tool in collaboration with people affected by dementia. This tool will allow communities to evaluate the accessibility of neighbourhoods and identify specific ways to make communities more dementia friendly.



**Voices in Motion** – In 2017, Dr. Debra Sheets and her research team conducted a study on the effects of participating in an intergenerational choir composed of people living with dementia, their caregivers and high school students. They found that participating in the choir significantly decreased both the rate of cognitive decline in people living with dementia and caregivers’ distress levels. The choir has now become a non-profit organization and expanded online. Learn more at [voicesinmotionchoirs.org](http://voicesinmotionchoirs.org)

Participating in quality-of-life research can also be an enjoyable and meaningful way to connect with the community after a diagnosis of dementia. For more information about participating in research, see [page 8](#) of this publication.

# Biggest dementia research stories of the year

## Dementia risk reduction



While there is no way to guarantee that a person won't develop dementia, researchers have discovered there are many modifiable risk factors that significantly

reduce the risk. Modifiable risk factors are things you can change, such as increasing your physical activity levels or treating hearing loss. In 2017, the medical journal *The Lancet* released a “Commission on dementia prevention, intervention and care” and identified nine such risk factors for developing dementia. In 2020, they updated this commission and added three new recommendations: limiting excessive alcohol consumption, preventing traumatic brain injuries and reducing exposure to air pollution. There are several large studies currently investigating the value of targeting multiple modifiable risk factors for dementia at once, including “CAN-Thumbs Up,” a Canadian study announced in 2020.

### For more information:

*The Lancet's* 2020 update to the “Commission on dementia prevention, intervention and care” at [alzbc.org/lancet2020](http://alzbc.org/lancet2020)

Our web page on dementia risk factors at [alzbc.org/riskfactors](http://alzbc.org/riskfactors)

## Early diagnosis and blood tests



A blood test for Alzheimer's disease or other forms of dementia has been a long-held goal in the dementia

research community and this past year there has been significant progress made towards reaching it.

Multiple research teams, using different methods, published results of blood tests that seem to be as effective as current diagnostic standards such as brain imaging like MRI or PET scans. Some of the tests may even be able to detect Alzheimer's disease before symptoms appear and one is now available for health-care providers in the U.S. and Europe, though it is still some time away from being available in Canada. A blood test would provide access to earlier and more accurate diagnosis for people living with dementia and would be invaluable in both clinical and research settings.

### For more information:

*New York Times* coverage of the history and current advances in blood tests for Alzheimer's disease at [alzbc.org/NYTests](http://alzbc.org/NYTests)

Our pamphlet on the importance of early diagnosis at [alzbc.org/earlydiagnosis](http://alzbc.org/earlydiagnosis)

## COVID-19 and brain health

The COVID-19 pandemic has been particularly challenging for people living with dementia and



caregivers. Research has shown that people living with dementia are more likely to become infected with the virus and experience worse

health outcomes than others who contract the disease. People living with dementia also suffer the worst consequences of social isolation and distancing requirements. Additionally, we have also known for some time that respiratory infections can increase the risk of developing dementia. To this end, a major international study has been launched to investigate

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# Biggest dementia research stories of the year, cont'd

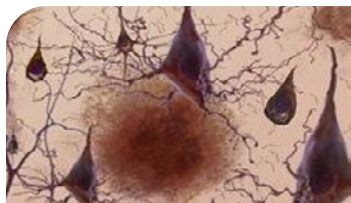
the long-term effects of COVID-19 on brain health in the coming years. This has been a difficult time, but this study may provide valuable insight into the causes of dementia and thus indicate areas for potential treatments.

## For more information:

An opinion column published by the *CBC*, analyzing the social effects of the pandemic on people living with dementia at [alzbc.org/CBCcolumn](https://www.alzbc.org/CBCcolumn)

The journal article that launched the global COVID-19 and brain health study at [alzbc.org/studyimpetus](https://www.alzbc.org/studyimpetus)

## Anti-amyloid drugs



Amyloid beta is a protein found in the brain. In Alzheimer's disease, this protein forms "plaques" that are

thought to potentially be the cause of symptoms. The pharmaceutical company Biogen is studying a drug called aducanumab that clears amyloid from the brain. Aducanumab has been in and out of the news for the past few years as Biogen halted clinical trials, resumed them and then sought approval from the US regulatory body, the Food and Drug Administration (FDA). It is unclear whether the drug will be approved; however, the FDA will deliver its decision by the beginning of June 2021. If successful, Biogen will then apply for Health Canada approval. There are also currently many other anti-amyloid drugs in development, including Eli Lilly's donanemab, which recently showed positive results from a Phase II trial. While no new drugs for Alzheimer's disease have been

approved, research is ongoing and we expect to see more results this year.

## For more information:

Alzheimer's Disease International webinar on aducanumab at [alzbc.org/ADIaducanumab](https://www.alzbc.org/ADIaducanumab)

Alzheimer's Association web page on treatment horizons at [alzbc.org/treatmenthorizon](https://www.alzbc.org/treatmenthorizon)

## Mental health and dementia



Recent research has highlighted the complex relationship between mental health and dementia. Depression is very common in people

living with dementia and it can exacerbate dementia symptoms. Depression is also a well-documented risk factor for developing dementia later in life. In the past year, research also emerged suggesting that anxiety may be a risk factor for progression from mild cognitive impairment to dementia and earlier dementia onset. While more research is needed on the connections between mental health and dementia, these developments remind us of the importance of acknowledging and treating the mental health concerns of older adults and people living with dementia.

## For more information:

The Conversation's article on the complex connection between depression and dementia at [alzbc.org/theconversation](https://www.alzbc.org/theconversation)

Our web page on supporting mental health at [alzbc.org/mentalhealth](https://www.alzbc.org/mentalhealth)

# Meet the 2020 Alzheimer Society Research Program B.C. recipients!

The Alzheimer Society of B.C. is a proud contributor to the Alzheimer Society Research Program (ASRP). The ASRP is a national partnership between Alzheimer Societies across Canada and one of Canada's most innovative hubs for dementia research. Since 1989, the ASRP has funded over \$64 million in grants and awards within the field of dementia research across Canada.

**In 2020, four researchers from B.C. received funding from the program in the areas of: cause, improving care for people affected by dementia and diagnosis and detection.**

## Elyn Rowe

University of British Columbia



**Project:** Peripheral ApoE: Overlooked in the context of Alzheimer's disease?

"While realistically, my research is lab based and may be years away from entering the clinic, it will further the understanding of the most prominent genetic risk factor for Alzheimer disease from a new perspective."

## Mirza Faisal Beg

Simon Fraser University



**Project:** Genetic correlates of Alzheimer's disease subtypes

"Our research will generate tools that take precise measurements of the brain, which will help doctors better diagnose, treat and manage people living with dementia."

## Kishore Rajaram Seetharaman

Simon Fraser University



**Project:** Improving outdoor navigation of persons with dementia through supportive environmental design: A participatory action research approach

"My research will highlight the role that the outdoor environment, more specifically, the built environment, can play in helping people living with dementia to enhance their quality of life."

## Thalia Field

University of British Columbia



**Project:** CANARY: Clinical dAta, NATural language pRocessing and eYe tracking for dementia risk stratification

Dr. Field's research focuses on a new method of diagnosing dementia to streamline the ways clinical trials identify eligible participants. Her work aims to make research participation more comfortable for people living with dementia.

# Lab life: A conversation with dementia researcher Elyn Rowe



*PhD student Elyn Rowe uses the centrifuge in Dr. Cheryl Wellington's lab at UBC.*

## **Elyn Rowe has always been interested in solving problems.**

Growing up in North Bay, Ontario, she loved to catch caterpillars with her scientist father and watch as they changed into butterflies. A general interest in science was further focused when Elyn volunteered at a long-term care home and witnessed the impact of dementia on individuals and families. From this early experience, she became determined to pursue dementia research.

Elyn is now a PhD student in Dr. Cheryl Wellington's lab at the University of British Columbia, where she is investigating the role of cholesterol in Alzheimer's disease.

Most of us know cholesterol is bad for our health, but not everyone is aware that there are actually multiple forms of cholesterol. Low-density lipoproteins, also known as "bad" cholesterol, get deposited inside of our blood vessels and can cause blockages that can lead to heart attacks or strokes. In contrast, high-density lipoproteins (HDL, or "good" cholesterol) clear bad cholesterol deposits from blood vessels, reduce inflammation and help our blood vessels constrict or dilate as needed.

"So many people focus on the things we see in the brain in Alzheimer's disease, like amyloid beta or tau," Elyn says. "When I saw that targeting amyloid wasn't having much success, I wanted to take a different approach. Blood vessels are so important in the brain; they supply the oxygen and nutrients that the brain needs and clear its waste, but they often get overlooked in Alzheimer's disease research."

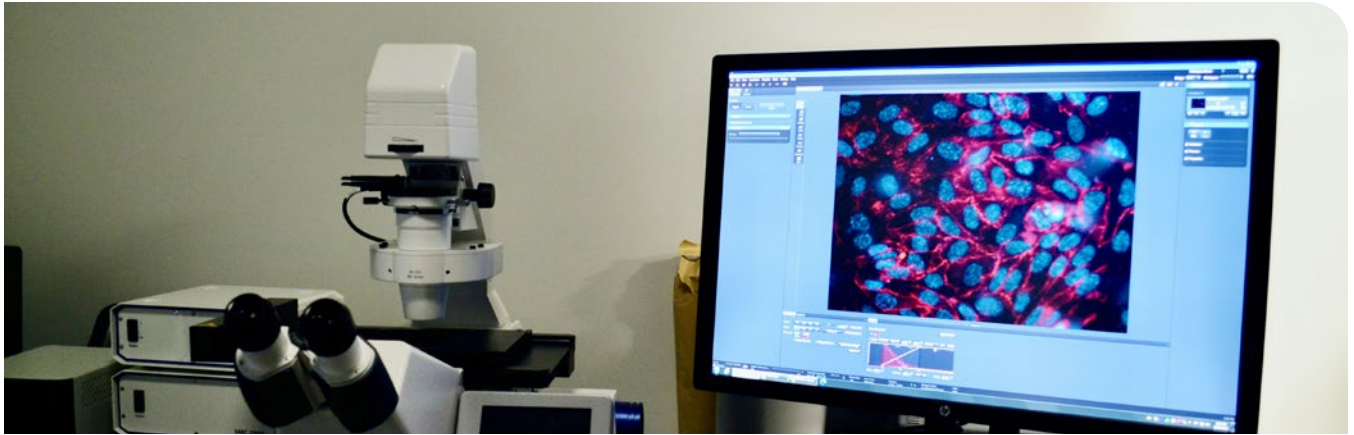
Over the next few years, Elyn will be studying a type of "good" cholesterol that carries a protein called Apolipoprotein E (APOE). The protein is made from the APOE gene, which we all have but, depending on the type, can increase or decrease your risk of developing Alzheimer's disease. Elyn plans to investigate whether this type of "good" cholesterol has protective functions in brain blood vessels. If we can find out how this particle works, we may be able to intervene and develop treatments for Alzheimer's disease.



*A cell model, sometimes called a "brain in a dish," is used to study how good cholesterol behaves in the brain.*

*continued*

# Lab life: A conversation with dementia researcher Elyn Rowe, cont'd



*This is an image of Elyn's cell model under the microscope. The red lines around the cells are called "tight junctions" and show that the model is accurately simulating blood vessels in the brain.*

To find out whether this type of cholesterol might help protect against Alzheimer's disease, Elyn's project has two main components: Studying how this specific type of "good" cholesterol functions in the brain and measuring it in blood samples from people living with Alzheimer's and a control group. She's hopeful this second part of her work might give us a new way to diagnose or predict who may be at risk of developing Alzheimer's disease.

On any given day, you'll find Elyn in the lab isolating "good" cholesterol from blood plasma with a machine called a centrifuge, or carefully testing protein coatings on her cell model to see if it accurately simulates real blood vessels.

"It can be tiring spending day after day pipetting different liquids into tubes, but it's all worth it when I can look through a microscope and see the cells in my model are acting the way they would in the brain," she says, describing a recent success.

Elyn is also passionate about science communication. As an undergraduate student at Carleton University, she was frustrated by the inaccessibility of science, both for the public and researchers. So she

helped create the podcast *AMiNDR: A Month in Neurodegenerative Disease Research*. In it, she and colleagues from around the world sort and summarize the thousands of studies published each month on Alzheimer's disease to help researchers stay up to date.

"It's really hard to keep up," Elyn says. "This podcast allows Alzheimer's researchers to stay connected to the work being done on a global scale."

While Elyn's research is likely years away from identifying potential treatments, she's passionate about improving the lives of people living with Alzheimer's disease and is up for the challenge.

"Research is about problem solving. There's one big problem you're trying to figure out and then many little consecutive problems along the way, but every year we develop better techniques and learn more."

**Elyn recently discussed the cardiovascular risk factors for dementia in an Alzheimer Society of B.C. "Research ready" webinar. You can watch it here: [alzbc.org/elyn](http://alzbc.org/elyn)**



# The how, why and where of participating in dementia research



Dementia research is people powered – not just by the researchers conducting studies, but also by people with lived experience.

Research changes both the present and the future. Participating in research can provide hope for oneself and for others affected by dementia. It's an opportunity to share your experiences and have your voice heard. It's also a great way to stay engaged and make a difference in your community.

One of the most significant discoveries in Alzheimer's disease research occurred in England in 1980 when a teacher named Carol Jennings had multiple people in her family diagnosed with Alzheimer's disease in a short period of time. Carol realized that this was an unlikely occurrence and contacted researchers at University College London. This led to a long-term partnership between researchers and members of the Jennings family. In 1991, based on the research conducted on Carol's family, a genetic cause of Alzheimer's disease was discovered. The fact that these genes affected the production of amyloid beta

in the brain set us on the path research is still on today: targeting amyloid to modify the course of the disease. While we now know that most cases of Alzheimer's disease are not caused strictly by genetics, Carol's commitment and partnership with researchers profoundly shaped the world of dementia research and continues to do so today.

Whether a research project is focused on new ways to diagnose dementia, how to improve emergency room experiences for people living with dementia, or the benefits of art for reducing stigma, people with lived experience are experts in dementia and are an essential part of the research process. If you are interested in participating in dementia research, read on to learn about the studies currently seeking participants. Many studies have adapted their research methods to allow virtual participation.

## Studies currently recruiting participants from B.C.

### Driving self-management (University of British Columbia)

- **Purpose:** To develop a driving self-management program.
- **Looking for:** People living with dementia who have retired or are thinking of retiring from driving AND care partners of people living with dementia who have retired or are considering retiring from driving.
- **Details:** 20-minute online survey about your experiences transitioning away from driving.
- **Contact:** [ariel.hung@alumni.ubc.ca](mailto:ariel.hung@alumni.ubc.ca) or 778-990-6179

*continued*



# The how, why and where of participating in dementia research, cont'd

## CANARY study (University of British Columbia)

- **Purpose:** To develop a new way to diagnose individuals living with pre-symptomatic Alzheimer's disease.
- **Looking for:** People living with mild cognitive impairment or subjective memory complaints AND people over 70 who are interested in being part of a control group.
- **Details:** 30-45 minute in-person visit to UBC, in which participants will complete a brief cognitive test and a speech and eye-tracking assessment.
- **Contact:** [canary.study@ubc.ca](mailto:canary.study@ubc.ca) or 604-401-5180

## Social Co-creation of Robotic Aging Technologies (University of British Columbia)

- **Purpose:** To gain a better understanding of attitudes towards pet-like social robots.
- **Looking for:** People over the age of 50, people living with dementia AND care partners of people living with dementia.
- **Details:** 20-minute online survey which involves reading and answering questions about pet-like robots. Compensation is provided.
- **Contact:** Dr. Jill Dosso at [jill.dosso@ubc.ca](mailto:jill.dosso@ubc.ca) or visit [bit.ly/UBCrobot](http://bit.ly/UBCrobot)

## Dementia Study (Egale Canada)

- **Purpose:** To better understand the unique experiences and needs of LGBTQI2S people living with dementia.
- **Looking for:** People who identify as lesbian, gay, bisexual, transgender, queer, intersex and/ or Two-Spirit, who are living with dementia AND people who provide unpaid care for an LGBTQI2S person living with dementia.

- **Details:** 30-minute introductory phone call and a virtual two-hour focus group with other participants. All participants will receive a \$50 Amazon gift card.
- **Contact:** [dementiastudy@egale.ca](mailto:dementiastudy@egale.ca) or visit [egale.ca/Dementia-Study](http://egale.ca/Dementia-Study)

## Knowledge Implementation for Scale-up, Spread and Sustainability of Assistive Technologies (KISS-AT) (University of Victoria)

- **Purpose:** To improve access to assistive technologies for older adults.
- **Looking for:** Older adults who use, or want to use, any form of assistive technology (like hearing aids, mobility scooters, apps that help with memory, etc.)
- **Details:** One-hour phone interview about your experiences with assistive technology.
- **Contact:** Dr. Gord Miller at [kissat@uvic.ca](mailto:kissat@uvic.ca) or 250-893-5869

## To find more studies looking for participants in B.C.,

- Register on the REACH BC platform which matches people with projects based on interest and eligibility at [alzbc.org/REACH](http://alzbc.org/REACH)
- Browse the current studies at the UBC Clinic for Alzheimer Disease and Related Disorders at [alzbc.org/UBCstudies](http://alzbc.org/UBCstudies)
- Contact us at [research@alzheimerbc.org](mailto:research@alzheimerbc.org)

For considerations about participating in research, see the Alzheimer Society's guide at [alzbc.org/research-guide](http://alzbc.org/research-guide)

# Get research ready!



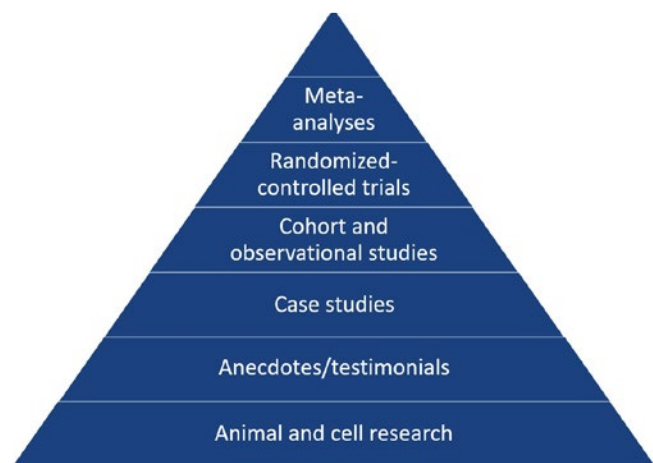
Dementia research is an exciting and fast-moving field and we are learning more each year – even in the midst of a global pandemic.

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](http://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.

**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.



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

*continued*

# Get research ready! cont'd

- **The larger the sample size, the better.** In studies with small numbers of participants, results can sometimes occur by random chance. Large sample sizes help avoid this.
- **Studies done on animals or cells don't always generalize to humans.**
- **One study is just one study.** It's very common for a study to conclude that "more research is needed" and it's always important for results to be repeated by follow-up studies.

**It can be challenging to understand the meaning of new dementia research and sort out reliable information from misinformation. However, here are some steps to follow:**

- **Do an initial gut check.** Does it feel like the headline is informative, or is it seeking to cause an emotional reaction in the reader? Does it sound too good to be true?
- **Look beyond the headline.** Headlines can be oversimplified or exaggerated to grab attention. Read through the full text of the news story to get a more complete understanding.
- **Consider the source.** Does the source appear reputable? Is the author or associated organization listed? Does the website have any academic affiliations? Is it subject to peer review (for example, in an academic journal)? Does the website identify the original sources of the information?
- **Check out the author.** Do a quick Google search. What are their credentials? Do they have qualifications to speak on this subject? For example, it's good news if the source you're reading is a doctor or a professor at a university, but it's still

good to check what their area of expertise is. Do they appear to have any conflicts of interest? That is to say: do they stand to gain financially in any way through the information they're sharing?

- **Cross reference with other sources.** Do a search of the topic and see if other sources support the findings.
- **When possible, read the original, full-text research article.** Many online news stories will link to the source.
- **Consult the experts.** Connect with your family doctor, researchers or other health-care professionals you trust.

## **To keep building your research literacy:**

- Watch our Dementia Research 101 webinar with Dr. Julie Robillard at [alzbc.org/dementia101](https://alzbc.org/dementia101)
- Read the tips included in the 2020 "A focus on research" at [alzbc.org/researchfocus2020](https://alzbc.org/researchfocus2020)

The Alzheimer Society of B.C. is committed to bridging research and the community, demystifying the research process and helping people affected by dementia and researchers meaningfully work together.

The past year has been a challenging one, but researchers have adapted, and our knowledge has grown. We look forward to continuing to support and nurture a vibrant dementia research community here in B.C.

**To learn more about how the Alzheimer Society of B.C. supports research or read our past editions of "A focus on research," see our web page at [alzbc.org/BCresearch](https://alzbc.org/BCresearch)**

# Alzheimer Society

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Website: [www.alzheimerbc.org](http://www.alzheimerbc.org)

## 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 Punjabi-language support 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 [alzbc.org/fldhl](http://alzbc.org/fldhl)

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