

A focus on research 2020: A year in review



There are currently an estimated 70,000 people living with dementia in B.C. In Canada, almost half a million people are living with dementia and this number is expected to double in the next 15 years. The Society's vision is a world without dementia; to achieve this, we champion dementia-friendly research, invest in research, act as a knowledge source and work to bridge research and the community.

Over the past year, we worked to advance dementia research in a variety of ways, from contributing to the national Alzheimer Society Research Program to establishing a new B.C. Fellow in Clinical Dementia. We attended conferences nationally and internationally and collaborated with researchers and people affected by dementia to share knowledge and champion dementia-friendly research.

Research is key to changing the future for people affected by dementia. We hope this year's edition of *A focus on research* will give you a deeper understanding of dementia research, more confidence when reading about research in the news, and perhaps even inspire you to consider participating in research.

Read on to learn about this year in dementia research, including:

- **Tips on how to become a better consumer of research news (Page 2).**
- **The year's biggest stories in dementia research (Page 4).**
- **An interview with Doug Campbell, a person living with dementia who participates in research (Page 6).**
- **Studies currently recruiting participants (Page 9).**

Become research ready!

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, the research we hear about may not always tell the whole story, so it's important to read research news carefully.



To increase your research literacy, keep these questions in mind when reading about research:

What is the source?

Anyone can write an article on a website, but credible research is always published in peer-reviewed journals (publications reviewed by experts in the same field).

Examples of good sources are a government website or a scientific journal. If it's a news article, there should be a link to the original source. A not-so-credible source could be a website written by someone who doesn't have relevant qualifications, such as a blog post about dementia treatments by a personal trainer.

Who did the research?

Legitimate research articles always state the names of the researchers, the organization they work for and where the study was originally published. Just because a researcher is a doctor, or another kind of medical professional, does not automatically mean that the research is reliable. An example of a reliable researcher would be a professor at the University of British Columbia who specializes in neuroscience.

Dementia research is also a fast-moving field — reliable information is generally less than five years old.

Does the study provide correlational or causal evidence?

This is perhaps the most important question, yet it is often reported incorrectly in the news. Correlational evidence (meaning two factors are related in some way, not that one causes the other) is based on observation. If a study is “observational” or references a “case study” it might indicate a new area to be studied but it can't claim anything about the effects of a treatment.

To give a hypothetical example, suppose a study observed that people who drink coffee are more likely to develop dementia than people who do not drink coffee. This does not necessarily mean that drinking coffee causes dementia. It could instead mean that people who do not drink coffee also exercise regularly, eat well and have an overall healthier lifestyle, which reduces their risk of developing dementia.

Causation (for example, proving that a drug is effective in reducing the number of people who develop Alzheimer's disease) is much more difficult to establish. Only highly rigorous experimental research designs can support these strong conclusions.

continued

Become research ready, cont'd

When it comes to developing a new treatment, it can take about eight to 10 years after human studies first begin before your doctor is able to prescribe it.

How many people are in the study?

The higher the number of participants in the study, the more likely the results can be generalized to the larger community. For example, a study done with 10 people who have been diagnosed with dementia cannot represent all people living with the dementia.

When studies have more participants, it also means it is more likely the results are real, not just due to random chance. There is no exact number of participants that you should look for but, in general, studies of a few hundred participants tend to be more reliable.

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 are not always replicated when the same study is done in humans.

Who funded the study?

If the organization that funded the study has something to gain from the results (for example, having a medication approved or a product endorsed), the results may be biased and justify an additional level of caution when interpreting. Reputable journals require authors to declare any conflicts of interest. This section can be found at the end of any article right before the citations.

How do the researchers talk about their results?

Reliable researchers avoid words like “cure” or “prove” because science is rarely that definitive, especially early on. Instead, they should talk about their results as being evidence for something or suggesting a relationship.

A red flag is very specific instructions or recommendations such as “our study shows that taking 85 milligrams of this supplement three times a day will prevent dementia.”

Have other studies found similar results?

One study is rarely enough to confirm a breakthrough. When many studies are complete, researchers can draw conclusions from a combined body of knowledge. When a researcher talks about the results of many studies all together, it is called a “meta-analysis.”

Be cautious of vague and sweeping conclusions, such as: “Everyone should supplement their diet with coconut oil.”

How to weed out bad information online

Many people go online to seek out medical information on preventing diseases, such as Alzheimer’s disease, but how do we determine what information is trustworthy?

Dr. Julie Robillard, Assistant Professor of Neurology at the University of British Columbia, shares five tips on how to find the highest quality of information online: alzbc.org/RobillardTips

Biggest dementia research stories of the year

Aducanumab



In March 2019, the biotechnology company Biogen announced that it was discontinuing its Phase 3 trials for aducanumab – a drug designed to slow

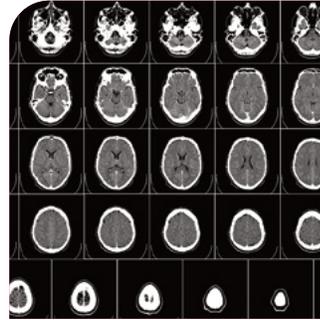
cognitive decline in people living with mild cognitive impairment and early-stage Alzheimer’s disease – when early results suggested they were not likely to be successful.

However, after analyzing more results, Biogen discovered that aducanumab helped lessen a decline of cognitive skills within a subset of patients when the drug was given at higher doses. As a result, Biogen will seek regulatory approval from the U.S. Food and Drug Administration in 2020. This is the first step in making this new drug publicly available. While this is an exciting development, we need to be aware that filing for regulatory approval does not automatically mean aducanumab will be publicly available in Canada. Biogen will first need to file for approval of the drug through Health Canada. It can take at least a year to review applications for new drugs.

To learn more:

- Visit Biogen’s website dedicated to information about the drug at biogenalzheimers.com.
- Watch an interview with Canadian researcher, Dr. Simon Duchesne, who provides more context to the announcement at alzbc.org/DrDuchesne.

Blood-brain barrier and neuroinflammation



The blood-brain barrier is a layer of protective cells that wrap around blood vessels in the brain. This barrier helps protect the brain from toxic substances or infections as only

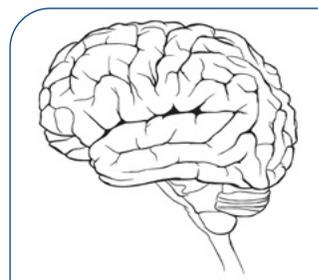
molecules of a certain type and size can move from the blood, past the barrier into the brain.

This past year, multiple studies have found evidence suggesting that the blood-brain barrier weakens with age, and especially with dementia. This potentially leads to infectious agents and other toxic particles entering the brain, having effects such as the loss of synapses (connections between brain cells). This has opened new areas of research, specifically in the diagnosis and treatment of dementia.

To learn more:

- Read the U.S. National Institutes of Health report on using the blood-brain barrier to test for dementia at alzbc.org/NIHblood-brain.

Focused ultrasound



Canadian researchers have found that it may be possible to use a focused ultrasound to briefly open the blood-brain barrier and allow drugs directly into the brain.

A major challenge for any drug aimed at treating dementia is getting it to its destination in the brain.

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Biggest dementia research stories of the year, cont'd

This would be hugely valuable as it may improve the effectiveness of drugs aimed at treating different types of dementia.

Some research has also suggested that simply opening the blood-brain barrier for short periods of time may also improve memory and other symptoms for people living with Alzheimer's disease.

To learn more:

- Read Sunnybrook Health Sciences Centre's Q&A about the work being currently done on focused ultrasounds and dementia at alzbc.org/SHSCblood-brain.

Risk reduction



There has been much research this past year devoted to understanding how to reduce the risk of developing dementia. Risk factors that increase your likelihood of

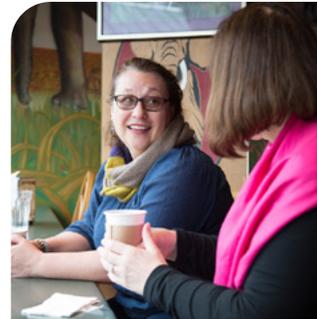
getting a disease are characteristics of your lifestyle, environment and genetic background. Risk factors are not causes of the disease on their own. Instead, they represent an increased chance — not a certainty — that a disease such as dementia will develop.

The World Health Organization (WHO) recently released a report with a detailed breakdown of the most effective risk reduction strategies. It showed that managing modifiable risk factors (risk factors that you can control) can delay or slow onset or progression of dementia. Some of the modifiable risk factors identified in the report include being physically active, not smoking, managing your weight, and remaining socially engaged.

To learn more:

- Read the WHO report, *Risk reduction of cognitive decline and dementia*, available at alzbc.org/WHO-risk-report.
- Access a high-level summary of the report, as reported by the Fisher Center for Alzheimer's Research Foundation, at alzbc.org/risk-report-summary.

Gender and dementia



Much research over the years has been devoted to why women are more likely to develop dementia than men. Theories range from hormonal differences to the simple fact that the

biggest risk factor for dementia is age and women tend to live longer than men.

However, this year research suggested some important new theories regarding gender and dementia. These areas of study include:

- Increased brain connectivity in women, which makes it easier for toxic protein molecules to spread (including the protein tau, which plays a role in the development of Alzheimer's disease).
- Genetic factors.
- Differences in levels of daily and lifetime social interaction.

To learn more:

- Read Alzheimer's Disease International's 2015 report *Women and dementia: A global research review* at www.alz.co.uk/women-and-dementia.

My experience participating in clinical research: An interview with Doug Campbell



Doug Campbell is a research participant and the 2020 honouree at Penticton's IG Wealth Management Walk for Alzheimer's. Doug, originally

from Calgary, now lives with his wife Bev in Summerland, B.C. Recently, he shared his experiences living with dementia and participating in dementia research.

Q: When did your experience with dementia begin?

Minor forgetfulness started sometime in early 2015. It was just little things, like forgetting to pick up the milk or bread on the way home. It was so minor that it didn't seem important, almost like I was not paying attention. When you forget something, you get stressed and then you get frustrated. The more stress and the more frustration that I acquired, the more I would forget. Since then, my memory has slowly, slowly declined.

Q: How have you been involved with dementia research?

I was part of Biogen's clinical trial for aducanumab for two years. I saw the study advertised so I talked to the researchers and indicated I was interested in taking part. They got me to do a bunch of memory tests, then sent me for doctor assessments and blood work to see if I was qualified and to confirm the diagnosis.

Q: What did you have to do as part of the study?

It was a double-blind study, so neither the researchers or the participants were aware of whether we received the placebo (inactive drug) or the real drug for the sake of the research. Though I suspected I had the drug because I experienced

some of the side-effects they warned us about.

Throughout the two years of taking the drug, they also did memory testing, doctor's assessments, blood work and brain scans.

Q: What was the experience like for you?

The experience was good for me. The people who were running the study were really first class. They made me feel at home and not marginalized because I had a disability. It was disappointing when I found out that the study was suspended because I felt like it was doing some good for me, but overall it was a good experience. Now that they've reanalyzed the results of the study (see Page 4), I've already spoken to the people who did the study and will hopefully be involved again.

Q: Why do you think dementia research is important?

Research on any disease is important and especially dementia because so many people are affected and there's no cure in sight. It affects so many people and all their families. It's throughout the world and it's progressing.

Q: What would you say to someone considering participating in a research project?

I would try and convince them to participate because without the volunteers, the research is not going to progress. It also provides an insight into the disease and helps you understand more. If you can participate a little bit and do some good, they will hopefully find something. Even if it's not a total cure, it's really cool to be a part of something like that. Without volunteers, it will be that many more years before the research community finds something. It's simple in my mind. Encouraging people to participate in these things is paramount. Unfortunately, volunteers are hard to come by, but I hope they stand up.

Clinical trials: Dispelling the myths

Clinical trials are vital to discovering new treatments and cures. However, many trials struggle to find enough participants. 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. Therefore, we already know a lot about how safe the drug is and the effects it might have.

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.

Do you have questions about participating in research?

- Download our full brochure on participating in research at alzbc.org/research-guide
- Email research@alzheimerbc.org
- Call 1-800-667-3742

Myth

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

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.

Myth

Researchers will treat you like a guinea pig.

In Canada, the Tri-Council Policy Statement strictly regulates research involving humans and outlines protections for participants, including participants in clinical trials. Studies must also be approved by a research ethics board. In the majority of cases, study participants report receiving excellent care and enjoy the experience.



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

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

What is quality-of-life research and why does it matter?

Doctors in white coats, blood tests, pills, MRIs. These are the things that we often think of when someone is talking about “research.”

These traditional ideas and images all fall into the category of “biomedical research.” Biomedical research focuses on the genetic and environmental causes of diseases and looks at ways to treat or prevent them. For example, a researcher studying how the protein amyloid beta builds up in the brain and how this might lead to Alzheimer’s disease is conducting biomedical research.

Biomedical research is very important, but it is not the only kind of research!

The other main category of dementia research is “quality-of-life research.”

Quality-of-life research seeks to find ways to improve life for people affected by dementia. There are many different areas that fall under this umbrella, including:

- Understanding what daily challenges people living with dementia and their caregivers face.
- Finding non-pharmaceutical ways to manage symptoms.
- Learning how to help people affected by dementia access and navigate the health-care system.
- Identifying how the health-care system itself can be improved.

Quality-of-life research sheds light on the differing experiences of people living with dementia depending on their culture, ethnicity, gender or sexuality. It has led to the development of evidence-based support groups, reminiscence and sensory therapies, person-centred care and dementia-specific hospital units.

Some research interventions are found to impact both the quality of life and physical well-being of people affected by dementia. For example, Voices in Motion is a multi-generational choir that started as a research project in January 2018 at the University of Victoria. The choir (pictured below) brings together adults experiencing memory loss, their family members, care partners, high school students and other members of the community. Research on the effects of the choir has shown that participation in the choir led to:

- Reduced levels of stress, anxiety and depression for both the person living with dementia and their family members.
- Modest gains in memory function for people living with dementia, with much larger gains observed from caregivers.
- Significant improvement in episodic memory (the recall of details from long-term memory) for both people living with dementia as well as their family caregivers.

Many people may dismiss quality-of-life research as not ‘real’ research or think that participating in a study that doesn’t include a new drug or high-tech machine won’t be useful, but quality-of-life research is essential to changing the experiences of people affected by dementia. The Voices in Motion Choir is just one example of this reality. Learn more about the choir at alzbc.org/VIM.



Participating 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.

Check with your primary care provider to see if it's a good fit for you before participating in research. For questions to consider before participating, see the Alzheimer Society of Canada's guide to participating in research at alzbc.org/research-guide and our webpage dedicated to the topic at alzbc.org/research-participation-BC.

Studies currently recruiting participants from B.C.:

The possible benefits of familiar music, poetry and/or stories for adults experiencing some cognitive decline (University of British Columbia)

- **Purpose:** To learn if listening to music, poems, and/or stories that delight a listener might also improve cognitive skills and mood.
- **Looking for:** Adults 45 years and older who are experiencing some forgetfulness or attention-wandering and are feeling a bit down.
- **Details:** Participation is free. No travel required; the researchers can come to you! If you participate, you'll receive an audio player (free) to keep that contains songs, poems, stories, plays or scriptures that you choose and enjoy!
- **Contact:** 604-822-7404 or music_study@devcogneuro.com
- **Recruiting until:** June 2020

The Canary study: Investigating whether speech and eye movements are early markers of cognitive health issues (University of British Columbia)

- **Purpose:** To investigate the relationship between eye movement, speech and cognition. It uses machine learning to predict cognitive impairment.
- **Looking for:** People who do not have a diagnosis of dementia.
- **Contact:** canary.study@ubc.ca or 604-822-0768
- **Recruiting until:** December 31, 2021

Companion and service dogs for people living with dementia (Université Laval)

- **Purpose:** To learn about the impact of companion (pet) and service dogs.
- **Looking for:** People living with mild to moderate dementia and their caregiver who either 1) have been living with a companion dog for at least one year 2) have been living with a service dog for at least one year or 3) have made the decision not to have a dog.
- **Details:** Involves a 45 minute phone interview and a 15 minute online questionnaire for the caregiver. All participants will receive \$25 in appreciation of their time.
- **Contact:** frederic.dumont@cirris.ulaval.ca or 418-529-9141 extension 6033
- **Recruiting until:** August 31, 2020

For more studies recruiting participants:

- Visit the Alzheimer Society of B.C.'s website at alzbc.org/research-participation-BC
- Visit the Alzheimer Society Research Portal at alzbc.org/research-portal
- Visit Vancouver Coastal Health Research Institute's website at alzbc.org/VCHRI

The Alzheimer Society Research Program B.C. recipients

The Alzheimer Society of B.C. is a proud contributor to the Alzheimer Society Research Program, a collaborative initiative between Alzheimer Societies across Canada, partners and generous donors. Since its inception in 1989, the program has funded over \$59 million in grants and awards, supporting vital biomedical and quality-of-life research aimed at finding ways to prevent, diagnose and treat dementia, as well as improve the lives of people living with dementia and their caregivers.

The program funds dementia research driven by basic science, with a focus on:



Biomedical research

- Understanding the brain
- Diagnosis
- Prevention
- Treatment and cures



Quality-of-life research

- Risk factors
- Physical support
- Caregiving

To date, 76 projects in British Columbia have received over \$6 million in funding. In 2019-20, three B.C. researchers were awarded funding through the ASRP.

Ashleigh Parker

University of Victoria

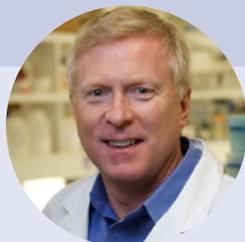


Project: *Identification of earlier biomarkers for Alzheimer's disease: A neuroimaging study of individuals with subjective cognitive decline*

“My research will impact individuals at risk of developing dementia in the future as my research aims to identify early changes in the brain that are associated with Alzheimer's disease.”

Gordon Francis

University of British Columbia



Project: *The role of smooth muscle cell metabolism of amyloid beta in cerebral amyloid angiopathy*

“Our research will lead to a better understanding of how amyloid beta is deposited in the blood vessels of the brain. It is our hope that this new knowledge will provide insight for ways to prevent or reduce the accumulation of plaques in the brain, ultimately reducing the incidence of Alzheimer's and other dementias.”

Nathan Lewis

University of Victoria



Project: *Examining the protective effects of lifelong cognitive engagement on cognitive trajectories and risk of conversion to dementia*

“The proposed research could help direct future interventions aimed at delaying onset of cognitive decline in those at risk for dementia. Engagement in cognitively-stimulating activities is a simple, cost-effective intervention target that may be undertaken by individuals at almost any age or functional ability and could be combined with existing medical treatments aimed at slowing the progression of dementia.”

“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

Research glossary

It's important to understand the language used to share information about research. The following is a list of commonly-used research terms.

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 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.”

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.

Sample: The small number of people from the population that takes part in the study.

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.

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FIRST LINK® DEMENTIA HELPLINE

The First Link® Dementia Helpline provides people living with dementia, their caregivers, health-care providers and the general public with information and guidance on dementia and memory loss.

Learn more: alzbc.org/fldhl

English: 1-800-936-6033 (Monday to Friday, 9 a.m. to 8 p.m.)

Cantonese and Mandarin: 1-833-674-5007 (Monday to Friday, 9 a.m. to 4 p.m.)

Punjabi: 1-833-674-5003 (Monday to Friday, 9 a.m. to 4 p.m.)

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