



FOCUS ON DEMENTIA-FRIENDLY RESEARCH

Research is constantly evolving, and with complex diseases such as dementia, there is a growing need for people with the lived experience to offer their insights into the disease. While there are exciting opportunities for people living with dementia to be involved in research studies, it's important to have all the information you need prior to participating in a study.

This issue of *Insight* provides tips on participating in research. People living with dementia share their thoughts, including an interview with Mario Gregorio and personal reflections from Jim Mann, long-time advocates, who participate in the B.C. Leadership Group for People Living with Dementia.

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PEOPLE LIVING WITH DEMENTIA SHARE THEIR THOUGHTS

We asked people around the province who are living with dementia to share their thoughts on research participation. Here's what they had to say:

What might help you decide whether it might be a good idea to participate in a study?

- "Past experience."
- "Talking to other people with dementia."
- "Asking the Alzheimer Society of B.C."
- "Asking other participants, or past participants."
- "The doctor has recommended it."
- "It's from a reputable research group."



How can researchers make their studies more dementia friendly?

- "Be kind/nice to us."
- "Don't ask questions too quickly."
- "Ask the person with dementia what they need."
- "Answer **our** questions to you as a researcher."
- "Work from our knowledge and awareness of our diagnosis."
- "Allow adequate time."

What are some things to consider when participating in a research study?

- "Ask ahead of time."
- "There is an adverse reaction during the study."
- "Focus on dementia."
- "The researchers are doing things properly, in stages."

REFLECTING ON RESEARCH PARTICIPATION

Mario Gregorio is a familiar face at the Alzheimer Society of B.C. Since 2014, he has been a member of the B.C. Leadership Group of People Living with Dementia. He worked for TELUS, a telecommunications company, for 27 years and was a project coordinator and data analyst for ten years before he retired. A year after he retired, he was diagnosed with dementia.

Mario immigrated to Canada from the Philippines in the early 1970s. He graduated from the Lyceum of the Philippines where he was awarded degrees in Bachelor of Arts and Bachelor of Science in Journalism. Recently, Mario shared his thoughts about volunteering and participating in research as a person living with dementia.

Why do you think it's important to participate in research?

There is a great need for people who have been diagnosed with dementia to participate in ongoing research. It gives me a sense of accomplishment and great satisfaction in having contributed my share in finding a cure. It might not benefit me now, but somehow in the future, it will help others on the journey.



Mario Gregorio

What kind of research did you participate in?

I participated in a study that looked at the use of diet to promote wellness. The researcher investigated what type of food I eat as well as how I prepare and consume food to achieve the goal of losing weight and at the same time prevent my existing medical condition from deteriorating. I submitted my plan of eliminating processed foods made from sugar, salt, flour and oil and of drastically reducing my consumption of animal products like meat, dairy, eggs and milk.

The researcher suggested that following this method of nutrition might cause a deficiency in vitamin B12.

We talked about adding seafood to augment my diet. I followed this regimen for almost two years, showing encouraging results every six months, with remarkable changes to my A1C test for diabetes and weight loss. There were also marked improvements in other health areas.

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What were some of the highlights of being a participant?

Most research does not give direct benefits to participants. It is the feeling of being involved in an activity that could benefit other people that makes it rewarding.

Is there anything about the research that you felt the researchers could have done differently?

I wish they could have asked participants about their sense of accomplishment in participating. Although I realize there are rigid guidelines for the research, one cannot help feeling like a guinea pig with no concern from the researcher about the personhood of the participants. Sometimes one gets the feeling that the questions are geared toward a specific ethnicity, that of the white population, and does not take into account the multi ethnicity of participants. Thus one may not be able to capture a true picture.



Do you have any tips for people living with dementia interested in participating in research?

Dementia is one of the major diseases that researchers have not found a cure for. I believe that as soon as a person is diagnosed, they should sign up and participate. This creates a pool of talent that the medical profession can access as they search for prevention and hopefully a cure for dementia.



"As a person living with dementia, I get the feeling of satisfaction of lending a hand in the search for a cure for dementia."

THINGS TO CONSIDER BEFORE PARTICIPATING IN A STUDY

There is a lot of exciting research happening on dementia, providing many unique opportunities for participation. While participating in research is a great way of being involved, it is important to be well informed about a study and ensure you have a positive experience. Here are some factors to take into consideration prior to participating.

Informed consent

Informed consent is when a person provides their consent to participate in a study, confirming that they are aware of the nature of the study and the consequences of participating.

Ability to provide informed consent

Even though a person's ability to make informed decisions will be affected as Alzheimer's disease progresses, this does not at all mean that the person must stop making decisions.

The person can provide informed consent as long as the following three criteria are met:

- The person is able to understand the nature of the study
- The consequences of participating are understood
- The person acknowledges alternative choices

If a person has consented to participate in a study, the agreement to participate must be reconfirmed throughout the process.

Process of providing informed consent

Once a person's ability to agree to participate has been determined, the process of providing informed consent can begin. Before the person agrees to participate, the researcher must explain the consent process.

This involves:

- Providing a full description of the study including the risks and benefits involved
- Clarifying what is required of the participant
- Discussing the rights of the participant
- Answering any questions about the study

At this point, if you feel confident in going through with the study, you will be asked to sign a consent form.



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Signing this form does not mean that you are obligated to complete the study. You are free to withdraw from the study at any time without having to give a reason. Ensure that you ask questions about anything you are unsure of.

Check with your health-care provider

Before making a decision to participate, it's always a good idea to check with your doctor to see if you are able to participate in a study.

The safety and ethics of the research

The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* governs research conducted by universities and university-affiliated hospitals involving human subjects in Canada.

This policy statement was created by the federal government research organizations that fund research involving human subjects in Canada. It sets out standards and procedures for conducting safe and ethical research and describes the consent process. Each study must be reviewed and approved, in advance, by an ethics review board or committee. This body is also responsible for monitoring the research process to ensure that it follows the *Tri-Council Policy Statement's* requirements. These requirements include obtaining and maintaining informed consent for all research.



For more information on the *Tri-Council Policy Statement*, please visit alzbc.org/2GdKnhC

Inability to provide consent

When a person living with dementia becomes unable to provide informed consent, it must be sought from a substitute decision maker. The substitute decision maker can be appointed by the person or by the courts. For more information on substitute decision makers in B.C., please contact People's Law School at www.peopleslawschool.ca

Source

alzbc.org/2rFDkK6

Please visit a post-secondary institution, if you would like more information on how the Research Ethics Board ensures studies follow the Tri-Council Policy Statement.

MY THOUGHTS ON THE BIOMEDICAL PANEL

Jim Mann is a member of the B.C. Leadership Group of People Living with Dementia and a long-time advocate and volunteer for people living with the disease. Recently, he wrote on his experience participating in a biomedical panel and lending his voice as a person living with dementia into the proceedings.

For two days in February I had an experience I will forever treasure. I heard 19 researchers talk about tau, oligomers, blood-brain barriers, microglia and amyloid beta. And I heard about various research methods and tools of the trade. It was exhausting!

Let me explain.

The Alzheimer Society Research Program (ASRP) provides funding for both quality-of-life and biomedical research streams through the Alzheimer Society of Canada, the provincial Alzheimer Societies, partners and donors. To assess applications for funding from researchers, the Society convenes Peer Review Panels for both streams that include a person living with dementia as the Community Representative.

And this year I had the honour to be invited to the biomedical panel. Not having a science background, I was surprised to be invited but, on reflection, I think that's a benefit. I wasn't there to adjudicate the various applications and determine the legitimacy of their plan and budget, which was the researchers' role. I was there to ask questions, add a thought or two when appropriate, and inject the voice of 'lived experience' into the proceedings.

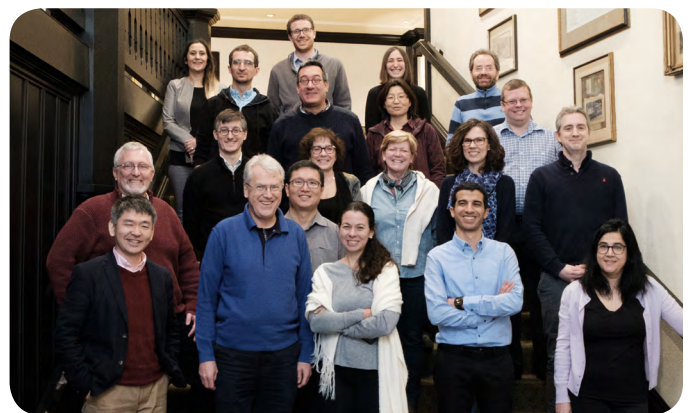
Was I the biggest proponent of biomedical research? To be honest, no. I think I only saw it as looking for a cure, full-stop. But through this experience I learned some biomedical efforts are, yes, looking for a cure, but other research focuses on improving "the lives of the 564,000 Canadians affected by

dementia." And that is definitely the exciting part.

There were more than 150 applications that were reviewed and many generated great discussion around the table with researchers debating applicants' intent, their methods, relevancy, and if their stated outcome was legitimate. I heard the voices of dedicated researchers who, themselves, are working diligently to make discoveries around dementia for the benefit of those of us living with dementia and those who have not yet been diagnosed.

It is a huge challenge but I think the Canadian researchers that I met and heard are all up to the task.

For more information on participating in research, visit alzbc.org/2GcAfFT



Jim Mann at the biomedical panel

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CONTRIBUTE

We welcome contributions, such as personal stories, photography or original poems, from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

- Email Insight@alzheimerbc.org
- Call 604-681-6530 or toll-free 1-800-667-3742
- Mail to the Alzheimer Society of B.C., care of *Insight*:
300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

CALL THE FIRST LINK® DEMENTIA HELPLINE

A confidential, province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, health-care providers and the general public.

- Phone 1-800-936-6033
Lower Mainland: 604-681-8651
Monday to Friday, 9 a.m. to 4 p.m.
- Email supportline@alzheimerbc.org

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