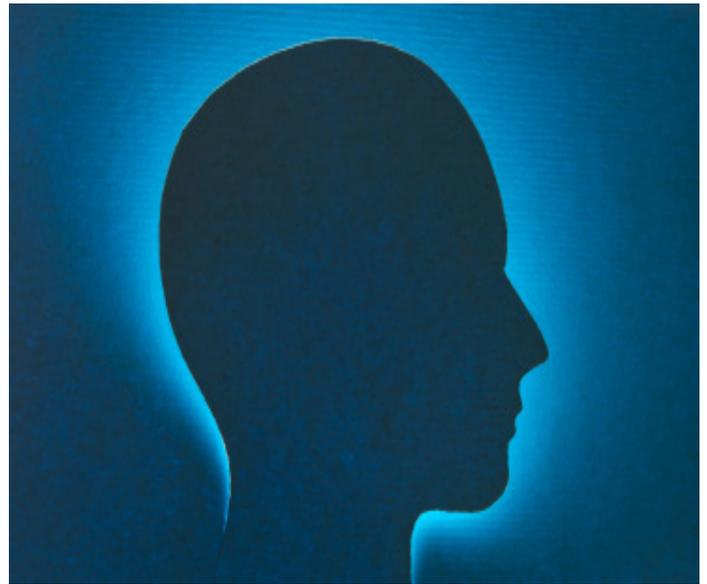


Fall 2016

A FOCUS ON RESEARCH



The vision of the Alzheimer Society of B.C. is to create a world without Alzheimer's disease and other dementias, something we know can only be achieved through research. This handout provides a variety of interesting information related to research, including:

- Highlights from the 2016 Alzheimer's Association International Conference, the world's largest forum for the dementia research community ([page 2](#)).
- Tips on how to think critically about research you hear about in the news or read online ([page 4](#)).
- An interview with Dr. Sharon Koehn, a recent grant recipient of the Alzheimer Society Research Program ([page 6](#)).
- A research partnership between a PhD student and a person with dementia ([page 7](#)).

DEMENTIA RESEARCH IN B.C.: BOOMER LIFE PODCAST

The Alzheimer Society of B.C. partners with CISL 650am for a monthly episode of Boomer Life, a lifestyle show focused on issues faced by the baby boomer generation.

The March 2016 episode focused on research being done into the causes of and possible treatments for Alzheimer's disease and other dementias. Guest speakers included researchers Dr. Mari DeMarco and Dr. Cheryl Wellington from the University of British Columbia. Scientific Advisor to the Alzheimer Society of Canada, Dr. Larry Chambers, also phoned in to talk about the state of research in Canada and about the Alzheimer Society Research Program.

To listen to the full episode visit <http://ow.ly/9icf304fQXu>.

2016 ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE

The 2016 Alzheimer's Association International Conference® (AAIC®) was hosted this year in Toronto, Canada. Researchers, clinicians, health-care providers and students from over 70 countries gathered to network and discuss the latest dementia theories, discoveries and study results.

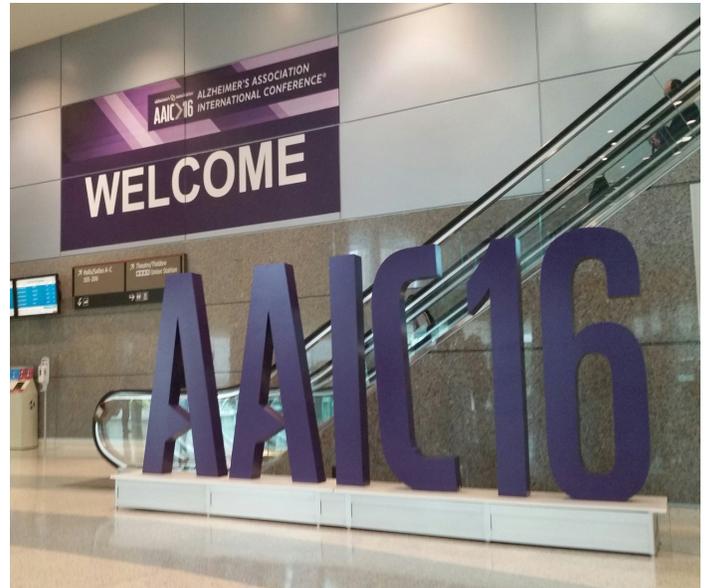
Below, we share some research highlights from the conference.

FORMAL EDUCATION AND COMPLEX WORK MAY REDUCE THE NEGATIVE EFFECTS OF BAD DIET AND CEREBROVASCULAR DISEASE ON COGNITION

Researchers presented new data that suggests that people whose work requires complex thinking and/or activities are better able to withstand the onset of Alzheimer's disease. Results suggest that working with people, rather than data or physical things, contributed the most to the protective effect.

Of course, this is just one lifestyle factor that may help reduce a person's risk of developing dementia. There are other healthy lifestyle choices, such as following a healthy diet, being physically active and reducing stress, that may help reduce the risk of getting the disease and help keep our brains as healthy as possible as we age.

"It is becoming increasingly clear that in addition to searching for pharmacological treatments, we need to address lifestyle factors to better treat and ultimately prevent Alzheimer's disease and other dementias," said Maria C. Carrillo, Alzheimer's Association chief science officer.



The 2016 AAIC had over 90 sessions, 1,700 posters and 475 presentations discussing the latest in dementia studies.

COGNITIVE TRAINING MAY PROTECT AGAINST THE ONSET OF DEMENTIA

Cognitive training for maintaining brain health is a growing area of interest, particularly as it may complement or be an alternative to drug therapies in delaying the onset of cognitive decline. A group of researchers found that speed-of-processing training may reduce the risk of developing cognitive decline or dementia over time.

The scientists say this is the first time a cognitive training intervention has been shown to protect against dementia in a large, randomized, controlled trial. The researchers would now like to get a better understanding on what exactly is the right amount of cognitive training to get the optimal benefits.

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SMELL AND EYE TESTS ONE STEP CLOSER FOR DETECTION OF MEMORY DECLINE AND DEMENTIA

The potential to use smell and eye tests to detect cognitive impairment and Alzheimer's disease at an early stage was supported by four studies presented at the AAIC.

Two of the studies evaluated odor identification as an early predictor of cognitive decline. Two other studies reported the potential of non-invasive imaging of the eye as early testing for Alzheimer's disease.

Today, it is only possible to clinically detect Alzheimer's disease relatively late in its development when significant brain damage has already occurred.

"Using other biomarkers of Alzheimer's disease to detect the disease at an earlier stage – which have the potential to be lower-cost and non-invasive – could lead to dramatic improvements in early detection and management of the disease," shared Heather Snyder, Alzheimer's Association director of medical and scientific operations.

MILD BEHAVIOURAL IMPAIRMENT AND CHECKLIST OF SYMPTOMS COULD SUPPORT EARLIER DEMENTIA DIAGNOSIS

A new condition or patient status, known as Mild Behavioural Impairment (MBI), was introduced at this year's AAIC. MBI may be a sign of neurodegeneration and progression to mild cognitive impairment or dementia.

Researchers also proposed a new MBI checklist that looks at five categories of behavioural symptoms, and which may eventually help



Dementia advocate Jim Mann, Joanne Bracken and Joanne Michael present their research on meaningful engagement of people with dementia.

clinicians capture changes in behaviour that signal the beginnings of neurodegeneration.

"While memory loss is a hallmark of Alzheimer's disease, early symptoms such as anxiety, confusion and disorientation are often more common, troubling and obvious to family members," said Maria C. Carrillo, chief science officer for the Alzheimer's Association. "By looking beyond memory-related issues to closely evaluate the behavioural issues included in the checklist, physicians could reach a more efficient and accurate diagnosis, sooner."

For more information about the AAIC, including press releases, video highlights and more visit www.alz.org/aaic/pressroom.asp.

Source: Alzheimer's Association International Conference. (2016). News Reports from the Alzheimer's Association International Conference® 2016 [Press release].

READING ABOUT RESEARCH: THINGS TO KEEP IN MIND

It seems like we hear about a new study that reports exciting progress in dementia research almost every week. We hear about these “break-throughs” on the internet, in newspapers and magazines. However, the reports on these studies may not tell the whole story. So how do you know what to believe?

It is important to be critical when you read or hear about new research. There are several things to keep in mind when thinking about how reliable a study may be.

Here we share information to help you understand and interpret the results of research studies:

WHAT IS THE SOURCE? Anyone with an opinion can write an article on a web page, but credible research is published in scientific magazines or peer-reviewed journals (publications reviewed by professionals working in the same field).

A good source could be a government web page or scientific magazine. A not so credible source could be a popular magazine or website written by someone with no relevant qualifications.

WHO DID THE RESEARCH? Legitimate research articles always state the name of the researchers, their credentials, the organization where they work, when the research was done and where the research study was originally published.

A reliable study would likely come from researchers who are associated with a respected organization or educational institution and have experience in the area they are writing about. For example, a trustworthy researcher could be a professor from the University of British Columbia who specializes



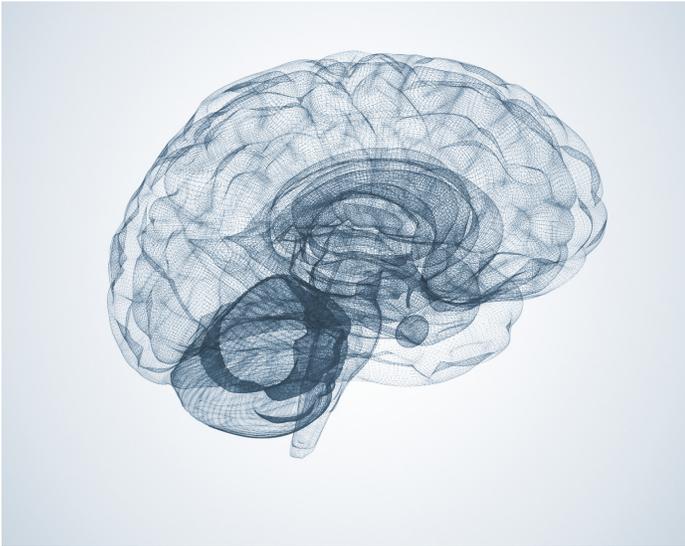
in brain research. A less credible person could be a celebrity who does not have medical or research training.

IS IT AN ANIMAL OR HUMAN STUDY? There are various steps involved in developing an effective treatment for a disease. For example, when developing a drug, laboratory tests are first carried out with a variety of small animals, such as mice, to determine the effects of the drug. However, testing something using animals does not mean that the same results will be found when the same test is conducted with humans.

The media may widely report on a study that is promising, but only in the early stages of testing on animals. If the study has not moved to testing in humans, these results may be exciting, but years of more studies are required before this could be determined effective or ineffective as a possible treatment.

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HOW MANY PEOPLE ARE IN THE STUDY? The higher the number of participants in a clinical study, the more likely the results will represent the larger population being studied. For example, a study done with only 10 people who have a diagnosis of Alzheimer's disease cannot claim to represent all people living with the disease. It may, however, suggest a potential direction for future research.

WHO FUNDED THE STUDY? If the organization that funds the study has something to gain or lose from the results (like having a product or medication approved or rejected), there is more potential for

bias. Researchers or companies may be tempted to omit negative results or even exaggerate findings. For example, a supplement company may endorse turmeric as a "miracle cure" even though their claim is based on a faulty study or no study at all. Often, if it sounds too good to be true, it probably is. Note that a reputable journal requires authors to declare any conflicts of interest.

ARE THERE OTHER STUDIES THAT SUPPORT THE RESULTS? One experiment is rarely enough. Many studies are needed on one topic to know we can trust the results. When enough studies have been done, researchers can combine all of these results to look for patterns and draw conclusions.

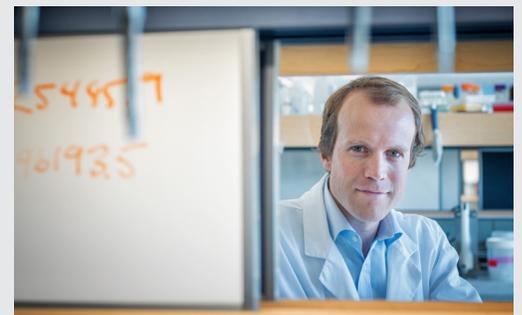
HOW TO WEED OUT BAD INFORMATION ONLINE

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 from the University of British Columbia shares five tips on how to find the highest quality of information online. To watch visit www.youtube.com/watch?v=Godg90AY-JA0.

DEMENTIA RESEARCH UPDATE 2016

Are you interested in hearing about an update in clinical research? In a previously recorded tele-workshop, Dr. Haakon Nygaard from the University of British Columbia's Centre for Brain Health reviews some of the exciting scientific progress being made in Alzheimer's disease research and its potential future clinical directions.



To view the recording visit www.youtube.com/watch?v=D3k5uV7tzCY.

Q&A WITH DR. SHARON KOEHN

Dr. Sharon Koehn is a clinical research professor in the Department of Gerontology at Simon Fraser University and a research associate at Providence Health Care. Sharon received a Quality of Life grant from the Alzheimer Society Research Program (ASRP) for her study “Building trust to facilitate access to dementia care for immigrant older adults: The role of the multicultural services sector.”

Recently, Sharon sat down with the Alzheimer Society of B.C. to discuss her research.

Q: WHAT HAS INSPIRED YOUR RESEARCH WITH ETHNOCULTURAL MINORITY SENIORS WHO ARE LIVING WITH DEMENTIA?

A: I have been doing research with immigrant older adults for 20 some years. My training is as a medical anthropologist so I have always been interested in ethnocultural minorities’ conceptions of health and illness and how they approach healing and healthcare.

I also had research opportunities that introduced me to dementia, but another important piece is that in 2000, I discovered that my grandmother had dementia. That was a very difficult thing as I was raised by my grandparents. The personal connection has deepened my interest in studying dementia.

Q: WHAT IMPACT DO YOU HOPE YOUR RESEARCH WILL HAVE FOR PEOPLE AFFECTED BY DEMENTIA?

A: I hope my research will determine barriers to services that ethnocultural minority seniors face and how we can overcome them. There are barriers that come from their cultural perceptions of health and illness, but there are also structural



barriers that exist. We know, for example, that Punjabi people get dementia at similar rates as everyone else, but they are not showing up and using dementia resources.

We also hope to find out what the general understanding of dementia is in the populations we are studying. When you have dementia, or your spouse or parent has dementia, what has your journey been like? We would like to understand what services and information are available and who the individuals trust for information.

Q: AS A DEMENTIA RESEARCHER WHY DO YOU THINK QUALITY OF LIFE RESEARCH IS IMPORTANT?

A: At this point in time we don’t have the cure. We have drugs that can help with the symptoms, but at this moment, and probably for a while, we are going to see people affected by this disease. We know that when we provide people with support, especially caregivers, that’s incredibly important. If we don’t do that, we make the people living with dementia really vulnerable too. They become vulnerable to abuse, neglect and

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insufficient care. We need to find as many ways as possible to support the people who are providing the majority of support.

Q: WHAT DID IT MEAN TO YOU TO RECEIVE A QUALITY OF LIFE GRANT FROM THE ASRP?

A: I was really excited to receive the grant. I think it is extremely important funding right now, particularly because it is focusing on quality of life. Also, immigrant older adults are often not prioritized because they are deemed to be too small a population, despite the fact that they make up about 1/3 of the older population in B.C. Funding for this research from the ASRP is incredibly important in terms of being able to get something like this done.

The Alzheimer Society of B.C. would like to congratulate British Columbian researchers Dr. Jennifer Baumbusch from the University of British Columbia, Dr. Myeong Jin Ju from Simon Fraser University and Dr. Holly Tuokko from the University of Victoria who also received funding from the ASRP.

The Alzheimer Society Research Program (ASRP) is a collaborative initiative of the provincial Alzheimer Societies, the Alzheimer Society of Canada, partners and our valuable donors who support research directed at both eradicating dementia and improving the lives of those affected by it. To learn more about the ASRP, visit www.alzheimer.ca/bc/Research.

WORKING TOGETHER TO CO-CREATE A DEMENTIA-FRIENDLY ENVIRONMENT IN A HOSPITAL

People with dementia, caregivers and family members can participate in dementia research in many ways. PhD candidate Lillian Hung and dementia advocate Jim Mann, share their positive experience collaborating on a valuable research study focused on improving the lives of people with dementia in the acute care environment.

LILLIAN HUNG, PHD STUDENT, SCHOOL OF NURSING, UNIVERSITY OF BRITISH COLUMBIA

The acute hospital setting can be a stressful environment for people with dementia. My PhD research, titled "Person-Centred Care in Acute Hospital" focuses on creating solutions in the physical and social environments to improve the care experience of people with dementia who are patients in a hospital.



PhD student Lillian Hung (left) and dementia advocate, Jim Mann.

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The ultimate goal is to co-create a dementia-friendly environment in a medical unit at Vancouver General Hospital (VGH). By working with patients, families, staff and hospital staff leaders, and reviewing best evidence in dementia design, I was able to identify practical design solutions (Table 1) and create a proposal to carry out these changes.

To ensure that the voices of people living with dementia were included in this research, I invited Jim Mann to be an advisor for my study. Jim used his expertise to provide input and tips on interviewing people with dementia, ensuring consent forms were clearly written and developing practical educational resources.

Jim also helped deliver a workshop to 50 staff at VGH. He eloquently explained how environmental features, like lighting and clocks, could considerably affect a person with dementia's ability to understand and function. He also shared

**TABLE 1:
TEN POSSIBLE DESIGN SOLUTIONS TO MAKE
A HOSPITAL WARD DEMENTIA-FRIENDLY**

1. Non-institutional seating arrangements
2. Multiple small sitting areas
3. Fun colours
4. Adaptable lighting
5. Turn dead ends into sitting areas
6. De-centralized nursing station
7. De-clutter
8. Create a dining room as a social space
9. Wayfinding through art and technology
10. Focal points of interest

that small details in care approaches, such as calling the person by name, slowing down and avoiding multi-tasking can make a big difference.

I am deeply grateful for his generous support, first-hand insight and expert knowledge about dementia. I will continue to work closely with Jim to ensure the experiences of people living with dementia continue to inform this research.

JIM MANN, DEMENTIA ADVOCATE

There are so many positive and progressive outcome possibilities from Lillian's research and to be a part of it has been a wonderful and challenging experience for me.

I was honoured to speak to some Vancouver General Hospital staff – including nurses, aides, occupational therapists and physiotherapists – about caring for people living with dementia in an acute care setting. The feedback was very positive! I have never worked so closely with a researcher, so I'm learning a lot at the same time as I am hopefully having an impact in an acute care ward.

PARTICIPATING IN RESEARCH

Many people affected by dementia are participating in research. They take comfort and find hope in being able to help increase our understanding of the disease and its effects.

If you are interested in being involved in research, visit the Society's [Participating in Research webpage](#) or call the First Link® Dementia Helpline at 1-800-936-6033 for more information.

CELEBRATING **35** YEARS

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