

# MIND OVER MATTER<sup>®</sup>

**CHEMO  
BRAIN**

**DEMENTIA:  
A FINANCIAL &  
SOCIAL SINKHOLE**

**TOO YOUNG TO CARE**  
THE INVISIBLE POPULATION  
OF CAREGIVERS

**WHEN WORK  
& CAREGIVING  
COLLIDE**

**INTIMATE-PARTNER  
VIOLENCE & TRAUMATIC  
BRAIN INJURY**

**A GROWING HEALTH  
CONCERN FOR  
INDIGENOUS PEOPLE**

Insight into the latest research findings to combat brain aging diseases and what you need to stay **brain healthy longer.**



Women's Brain  
Health Initiative

# With Gratitude

THIS EDITION OF MIND OVER MATTER® WAS MADE POSSIBLE THANKS TO THE ONGOING GENEROUS SUPPORT AND ENCOURAGEMENT OF OUR PARTNERS BRAIN CANADA FOUNDATION AND HEALTH CANADA.

In the two decades since Brain Canada was founded, there has been a real shift from a singular focus on new discoveries aimed at cures, to a broader focus on prevention and translating what we already know into measures we can take to prevent or delay the onset or progression of diseases and disorders. As a result, knowledge translation – the dissemination of research findings to the general population – has become an important focus for many research organizations. Knowledge is empowerment – it allows us to take charge of our own health.

Through our partnership with Women's Brain Health Initiative, Brain Canada is proud to be reaching Canadians with the powerful message about prevention. The evidence-based information presented in Mind Over Matter® promotes not only a healthy brain, but also overall health and well-being. The more we learn about the human system, the more common underlying causes we find across disease and disorder categories.

With this thinking in mind, Brain Canada convened a panel this past February to discuss prevention, as well as sex and gender considerations, across a range of disorders. This panel included representatives from Heart and Stroke Quebec, the Quebec Breast Cancer Foundation, and Women's Brain Health Initiative's Founder and President, Lynn Posluns. While it is not immediately obvious what breast cancer, cardiovascular conditions, and Alzheimer's and dementia might have in common, the panelists concluded that the same healthy lifestyle habits will have benefits across all diseases – eating well, exercising, reducing stress, moderately consuming alcohol, quitting smoking, and sleeping enough. Even for conditions which are not as preventable, like breast cancer, these habits still help reduce risk or, at the very least, improve quality of life.

Beyond common preventative measures, there are also concrete examples of how changes in one part of the body can affect other conditions. For instance, there is constant communication between the gut and the brain. Among other things, there is now evidence to suggest that gut microbiota – the population of different types of microbes living in the intestine – can have an effect on fetal brain development. The microbiome has become one of the fastest growing areas of

biology research and Brain Canada is proud to support this through Canadian Institute for Advanced Research's Humans and the Microbiome program. The program aims to shed new light on broad issues of human health, such as healthy aging, human development and the effects of diet and drug treatments, and delve into how the microbiome has interacted with human evolution and cultural and societal practices.

Recognizing that the brain, and indeed the entire body, are interconnected systems, Brain Canada continues to advocate for breaking down research silos and for increased collaboration among teams of scientists. This will ultimately lead to fully understanding how different elements of the human system interact and how good lifestyle habits can contribute to a healthy mind and healthy body.



*Naomi Azrieli*

Naomi Azrieli  
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Brain Canada  
Foundation

# EDITOR'S LETTER

The mere mention of the words makes me salivate: cakes, cookies, sweet baked goods. For most of my life, desserts made up far too large a proportion of my diet. I admit it: I have not been a healthy eater.

But with age comes greater knowledge, if not wisdom. Since I founded Women's Brain Health Initiative (WBHI) in 2012, I have been fortunate enough to have met many brilliant people and to have learned from their research that even though we face ever-increasing rates of dementia, we can all make choices that help protect our brain health. That includes the choice of our food.

There was an extraordinary study published by *The Lancet* Commission in July 2017. It described dementia as "the greatest global challenge for health and social care in the 21st century." The authors found that more than a third of all dementia cases could be prevented if we eliminate nine potentially modifiable health and lifestyle factors. The study cites some fairly obvious ones, like smoking, lack of exercise, or obesity – all of which we have some control over. There are others, however, that are more challenging, such as hearing loss, social isolation, and poor education, that we need to address as a society. The implications of the Lancet study are profound: reducing the number of Canadians with dementia by one third would mean that hundreds of thousands of people would be spared that debilitating fate.

In this issue of Mind Over Matter®, we explore the relative risks and benefits of two ingestibles that play central roles in the daily lives of many of us: alcohol and coffee. Although the evidence is mixed, I am happy to report that there is some research indicating that a glass of red wine per day (just one glass, not a bottle) can help prevent memory loss and that the antioxidant properties of coffee can help maintain brain health.

In a variant of the theme of taking command of our lives, we also touch on important issues that we all need to consider, including the necessity of preparing for the possibility that at some point in our lives we may find that we are no longer capable of making decisions for ourselves. I had a conversation recently with Toronto-based lawyer Kimberly Whaley and I was shocked to learn that there has been a drastic increase in the number of court

battles over power of attorney documents – often pitting family members against each other in protracted, costly litigation. Our article gives a sobering but essential lesson in the importance of putting our affairs in order.

A diagnosis of dementia is heartbreaking – both for the individual diagnosed and his or her loved ones. In this issue, we share a story about one woman's personal experience with dementia, and in another article we include some useful advice on how to cope with such devastating news.

But let me return to the Lancet study for a note of optimism. I was struck by the quote, "dementia is not an inevitable consequence of aging." I could not agree more. A core element of WBHI's mission is to promote the concept that we all have more control over our cognitive destiny than we realize.

I admit that I still have a weakness for sugar, but I am doing better. Fish, fruits, and vegetables now comprise a larger part of my diet, while red meat is more rarely on my plate. We can all make positive life choices to reduce our risks of dementia and the sooner we start the better. 🍷

**Lynn Posluns**  
Founder and  
President,  
Women's Brain  
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PHOTO: JAVLYN TODD

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### AMY CHAPLICK // CONTRIBUTING EDITOR

Amy is a real estate lawyer at DelZotto, Zorzi LLP, one of Canada's top real estate boutique law firms. "Although many people think of dementia as a disease that affects older adults, the disease begins to impact the brain decades before symptoms are even noticed. WBHI is inspiring a new generation of women to take care of our brain health today, since research shows the earlier you protect your brain, the better the cognitive outcome."



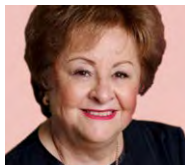
### VITINA BLUMENTHAL // CREATIVE DIRECTOR

Vitina is creative to her core. An adventurous soul with a passion for travel, a healthy lifestyle (especially all things yoga), and sharing her love of mindfulness with others. She runs a wellness travel business, Wanderwell, which focuses on the intersection between well-being and creating unforgettable, transformational experiences. Through WBHI's Young Person's Cabinet, she encourages Millennials to start taking care of their mental and brain health.



### STEPHANIE HAHN // WRITER

Stephanie is a writer and yoga instructor living in Waterloo Region, Ontario. It was through the "gift" of back pain that Stephanie learned to slow down, listen to her body and rediscover the joys of moving. "Writing for this magazine allowed me to merge my love of writing with my love of spreading the word that stress relief is critical for health."



### MARGI OKSNER // WRITER

Margi is the principal of Margi Oksner & Associates, a full service consulting firm that offers strategic, creative, and business planning in the philanthropic sector. "My mother's Alzheimer's journey gave me an insight into this horrific disease and the motivation to help others. Working with WBHI is my way of learning more and sharing that knowledge with others. Thank you Lynn Posluns for the opportunity to do both."



### DILIA NARDUZZI // WRITER

Dilia is a writer and editor living in Hamilton, Ontario. She's been interested in healthy eating and a balanced lifestyle for almost twenty years. She studied gender dynamics while doing graduate work at McMaster University and was really honoured to write for Mind Over Matter®. "I want the medical profession and all women to know that women's bodies require specialized medical care."



### SEAN MALLEN // WRITER

Sean Mallen is a Toronto-based communications consultant, journalist, and writer. His book *Falling For London* is expected to be published by Dundurn Press in the fall of 2018. Having seen family members deal with dementia, he is a strong supporter of the mission of WBHI.



### SUSANNE GAGE // WRITER

Susanne is a marketing/communications agency and events professional, with a solid appreciation for smart thinking. A believer in life balance and healthy body and mind, Susanne is also a passionate advocate for giving back. "As a business woman, wife, mother, daughter and friend, I am inspired by the impact of WBHI and the collaborative opportunities to make a real difference."



### VIVIAN AND KITTY CHAN // ON THE COVER

Committed to overall mental and physical health, Kitty and Viv are honoured to represent the Women's Brain Health community. This dynamic duo builds confidence and strength by advocating for a healthy lifestyle. A relationship built on love and laughter has allowed them to fearlessly pursue their dreams and they hope to be strong ambassadors of Mind Over Matter®.



# BE KIND TO YOURSELF

## Helpful Ways to Stress Less

**H**ave you ever heard a dentist say, “only brush the teeth that you want to keep”? Well, you only have one brain, so the choice is clear – you are best to treat it with all the care you can, if you want to keep it.

One of the biggest contributors impacting brain health is stress. It is therefore critical to not only understand the signs of stress, but also to engage in those practices in your day-to-day life that help minimize the risks that stress can have on the health of the brain.

There are essentially two main types of stress that we experience, each with its own characteristics, symptoms, duration, and treatment approaches. **Acute stress**, which is defined by short periods of stressful stimuli exposure, is beneficial for you. The hormones that induce “stress” in the brain are active during the moment of the stimuli, but do not stay active in the cortex once the stimuli have passed. **Chronic stress**, defined by the continuing release of cortisol-related hormones in the brain, can cause long-term disadvantages, such as changing the ratio of white matter to gray matter in the brain, developing anxiety or symptoms similar to post-traumatic syndrome disorder, and damaging your brain cells. —>

Not surprisingly, then,

**ONGOING STRUGGLES WITH CHRONIC STRESS INCREASES THE LIKELIHOOD FOR NERVE DAMAGE AND CAN HAVE SIGNIFICANT LONG-TERM IMPLICATIONS, CONTRIBUTING TO ALZHEIMER'S DISEASE AND OTHER DEMENTIAS.**

There are countless enjoyable and easy activities that can help improve your brain health, examples of which are set out to the right. It is important to find activities that challenge you, promote concentration, and push you to think creatively and to make quick decisions. For example, try reading a new book not only for joy and pleasure, but also to increase your knowledge of a certain subject matter and to stimulate your imagination. Additionally, when it comes to brain health exercises, consistency is key. In the book, "The Memory Prescription," Dr. Gary Small reports that "doing crossword puzzles four days each week translated into a 47 percent lower risk of dementia compared with once-a-week puzzle solvers. For each day of the week that people exercised their minds, the researchers found nearly a 10 percent reduction in the risk for dementia."

It is also worth considering joining a group for any stress-reducing activities. Not only can that make the activity more enjoyable, but it can also help to reduce feelings of social isolation and depression when working independently on your health. This can range from playing regular games of cards or backgammon with a friend to joining a local bridge group, a book club, or having game nights with your friends at home or at the local community center. Sewing and knitting circles even vary in sizes, as do exercise classes.

Participation in even the simplest stimulation activities can be quite beneficial for your health and should not be underestimated. In fact, Harvard Medical School reports in its article, "12 Ways to Keep Your Brain Young" (January 16, 2018), that through research with both mice and human subjects, "scientists have found that brainy activities stimulate new connections between nerve cells and may even help the brain generate new cells, developing neurological 'plasticity' and building up a functional reserve that provides a hedge against future cell loss."

Notably, dancing is one of the most effective stress-relieving activities, because it uses a variety of different brain functions, encouraging sensory and motion stimulation all at the same time. For example, dancing involves music, emotions, thinking, kinesthetic, and physical touching (if dancing with a partner), especially ballroom dancing. In fact, a study conducted by the Albert Einstein College of Medicine found that taking part in ballroom dancing reduced the risk of Alzheimer's disease by 76% (followed by crossword puzzles at 47%).

### PHYSICAL ACTIVITIES THAT ARE GREAT STRESS RELIEVERS:

- ✔ MEDITATION
- ✔ YOGA
- ✔ SWIMMING
- ✔ EXERCISE (EVERYTHING FROM MILD WALKING TO MORE INTENSIVE CARDIO CLASSES)

### ACTIVITIES THAT ENCOURAGE YOU TO THINK CREATIVELY, USE DEDUCTIVE REASONING AND CRITICAL THINKING SKILLS, AND PROVIDE MENTAL STIMULATION:

- ✔ DANCING
- ✔ READING BOOKS
- ✔ WATCHING A MOVIE
- ✔ JIGSAW PUZZLES
- ✔ CROSSWORD PUZZLES
- ✔ SUDOKO
- ✔ PAINTING OR COLOURING
- ✔ WRITING
- ✔ PLAYING GAMES
- ✔ PLAYING AN INSTRUMENT

### ACTIVITIES THAT CAN HELP IMPROVE YOUR MEMORY:

- ✔ KNITTING, QUILTING, AND SEWING
- ✔ USING COMPUTERS (SUCH AS, DIGITAL PHOTOGRAPHY)
- ✔ PLAYING CARDS
- ✔ LEARNING A FOREIGN LANGUAGE
- ✔ COOKING CLASSES

When choosing an activity to improve your cognitive health, always remember to have fun with it. As the popular inspirational phrase goes, "dance like there is no one watching" - and know that you are not only enjoying yourself, but you are also actively improving your brain health at the same time!

To help encourage better brain health, and support your daily and weekly efforts, enjoy the regular Instagram reminders posted by Women's Brain Health Initiative (@womensbrains). 🧠



# COFFEE AND YOUR BRAIN

## Is it Worth a Second Cup?

Do you drink coffee? Or, maybe the better question is, should you drink coffee? Although the Coffee Association of Canada reports that coffee is the most popular beverage choice amongst adult Canadians over 16 (even more than tap water), many people do not know whether their coffee consumption is beneficial or harmful for their health. In fact, the health effects of coffee are quite controversial amongst the general public and health professionals alike. For years, doctors had warned their patients to avoid drinking coffee because it may increase their risk of heart disease and stunt growth. Experts also worried that coffee had damaging effects on the digestive tract, which could lead to stomach ulcers, heartburn, and other ills.

These concerns emerged from studies conducted decades ago that compared coffee drinkers to non-drinkers on a variety of health measures, including heart problems and mortality.

Coffee drinkers, it seemed, were always worse off. However, those studies did not always take into account that high-risk behaviours, such as cigarette smoking and physical inactivity, tended to be more common amongst heavy coffee drinkers.

Recent research reveals that once the proper adjustments are made for confounding factors, coffee drinkers do not appear to have a higher risk for heart disease or cancer than non-drinkers. On the contrary, recent studies have shown that coffee consumption may have health benefits, including protecting against Parkinson's disease, type 2 diabetes, and liver disease. In June 2016, the World Health Organization announced that regularly drinking coffee may reduce the risk of cancers of the liver and uterine endometrium – a reversal from the organization's position over 25 years ago, when it cautioned that coffee was possibly carcinogenic to humans. —>

Interestingly, mostly because of the general public's concerns around coffee consumption and heart disease, many people, as they age, switch from drinking regular coffee to decaf, while younger individuals (from teenagers to those in their twenties and thirties) drink regular coffee. Dr. Chuanhai Cao of the Byrd Alzheimer's Center & Research Institute at University of South Florida recommends the exact opposite. "I encourage people 50 and older to start drinking coffee," he says, while younger people, "if they like the smell of coffee," should be drinking decaf. As Dr. Cao explains, this is because of coffee's effects on the immune system and how these cohorts are consuming coffee.

## COFFEE BOOSTS IMMUNE SYSTEM

Recent research suggests that coffee's effects can translate into immune system boosters. According to research conducted by Dr. Cao and his colleagues, published in the 2011 issue of *The Journal of Alzheimer's Disease*, an unidentified component of caffeinated coffee synergizes with caffeine to greatly enhance levels of a growth factor known as granulocyte-colony stimulating factor (GCSF). This protein encourages the bone marrow to release stem cells into the bloodstream, effectively increasing functional immune cells, and to take away the harmful beta-amyloid protein - a prime suspect in Alzheimer's disease.

## COFFEE CONSUMPTION AND DEPRESSION

In addition to the correlation between coffee and Alzheimer's disease and other forms of dementia, recent research has suggested that an individual's coffee consumption may alter his or her risk of depression. In one large longitudinal study out of the Harvard School of Public Health, published in the *Archives of Internal Medicine*, the researchers found that depression risk decreased with increased caffeinated coffee consumption amongst women (mean age, 63 years old). This finding was consistent with earlier observations that suicide risk is lower amongst individuals with higher consumption of coffee. Decaffeinated coffee was not associated with depression risk.

In light of the fact that the World Health Organization reports that depression is twice as common in women than men, there is an important gendered component to finding solutions to this disorder. The researchers concluded that further investigations are needed to confirm their findings and to determine whether usual caffeinated coffee consumption may contribute to prevention or treatment of depression.

In the study, increased GCSF levels as a result of caffeinated coffee intake were linked to enhanced memory performance in mice with Alzheimer's-like symptoms. Notably, neither decaffeinated coffee nor caffeine alone had this effect. The body works together as a network - blood, brain, and the immune system - and regular coffee appears to activate "the whole system," explains Dr. Cao. As we age, our immune system's ability to metabolize the amyloid-beta protein decreases, and therefore it accumulates in the brain and causes "toxicity of the neurons." By boosting immune function, "caffeine has the ability to suppress amyloid-beta production." Caffeine easily crosses the blood-brain barrier because its molecule is so small, which is why it perks us up very quickly, but also why it has other effects on the brain itself, like amyloid-beta inhibition.

As we know, one of the biggest risk factors for Alzheimer's disease is aging. Experts have hypothesized that as our immune systems decline with age, our susceptibility to Alzheimer's disease and other dementias increases. Since Alzheimer's disease likely develops for 25 to 30 years before symptoms arise, relying solely upon any kind of drug to counteract the disease will not fix the long-term problem. "Short-term something may work, but long-term, nothing works," observes Dr. Cao. Accordingly, any kind of treatment for these brain diseases has to be able to address or activate the immune system - the body's own protective mechanism. This immune system dynamic is why Dr. Cao says that younger people should not consume caffeinated coffee: "When you're young, your immune system is good so you don't need to keep boosting or activating it."

Even though this study was conducted using mice, the scientists revealed that they have collected clinical evidence of the ability of caffeine/coffee to provide humans with protection against Alzheimer's disease. Other studies involving human subjects have also supported the inverse relationship between caffeine consumption and reduced risk of dementia, including the results of the Canadian Study of Health and Aging, published in 2002. This study analyzed the data of 4,615 subjects (aged 65 and older) and looked at risk factors for developing Alzheimer's disease, such as physical activity, wine consumption, and history of depression, in addition to coffee intake. More recently, research published in *The Journals of Gerontology: Series A* in 2016 sought to investigate the relationship between caffeine intake and incidence of cognitive impairment or probable dementia in women aged 65 and older from The Women's Health Initiative Memory Study (a randomized, controlled clinical trial of postmenopausal hormone therapy that tracked nearly 6,500 women over the course of ten years). The researchers found that the participants who self-reported drinking more than 261 milligrams of caffeine (one average cup of coffee has 94.8 milligrams) were less likely to develop incident dementia. The authors warned, however, that the results were not enough to establish a direct link between higher caffeine consumption and lower incidence of cognitive impairment and dementia.



A study published in the *Journal of Alzheimer's Disease* in 2016 also reported that coffee consumption was significantly associated with a lower risk of dementia. The researchers examined 13,137 Japanese subjects over the age of 65 for nearly six years. Interestingly, the researchers found that the "significant inverse association was more remarkable among women, non-smokers, and non-drinkers."

Research published in *The Journal of Nutrition* in 2014 found that higher caffeine intake "may benefit cognition acutely and even prevent age-related declines in certain cognitive domains, including global cognition, verbal memory, and attention." For this study, researchers used data from the Baltimore Longitudinal Study of Aging, which is the longest running scientific study of human aging in the U.S., according to the National Institute of Aging's website.

### COFFEE AS HERBAL MEDICINE

According to Dr. Cao, coffee is not just a beverage, it is also a "herbal medicine." As is the case with any herbal medicines, the appropriate dosage at the right time is critical. "A lot of people wake up and drink a cup of coffee. That's a bad habit. You have to eat food first and then drink coffee," says Dr. Cao. On an empty stomach, the caffeine "gets into the bloodstream in a short time and accelerates your metabolism rate," which may be the cause of the abnormal response experienced by some coffee drinkers. Consuming coffee in the late afternoon is also problematic because it interferes with the function of melatonin in the brain, which regulates sleep. How much coffee is good for you depends upon your metabolism rate.

Generally speaking, on average, two eight-ounce cups of regular coffee works for most people, notes Dr. Cao. However, this amount will also depend on the strength of the coffee. Dr. Cao and his colleagues are currently working on a standardized coffee formulation so that people will know exactly how much to consume.

### MODERATION IS KEY

Overall, there appears to be little evidence of health risks and some promising evidence of health benefits for adults consuming moderate amounts of coffee. However, some groups, including people with hypertension, may be more vulnerable to the adverse effects of caffeine. As with most things in life, moderation seems to be paramount. Consuming coffee in reasonable amounts just might be one of the easiest things you can do to help protect your brain health. 🌱

### EFFECTS OF CAFFEINE IN THE "OLDEST-OLD"

Research published in 2016 in *Alzheimer Disease & Associated Disorders* examined the data of nearly 600 people aged 90 and over (who did not have dementia at the commencement of the study) to query how lifestyle factors influence the health of this segment of the population. The researchers found that caffeine consumption was one of the few lifestyle factors that may be related to a reduced risk of incident dementia. Participants who consumed 200 milligrams or more per day of caffeine had a 34% lower risk compared with those who consumed less than 50 milligrams per day.

Although cause and effect could not be determined, the authors concluded that their findings could represent a substantial reduction in dementia incidence and warrant further study in other very old individuals. Additionally, like many of the studies that investigate the relationship between coffee consumption and dementia, the authors of the study emphasized that because therapeutic regimens are currently limited, "modification of lifestyle behaviours may offer the only means for disease control."





# UNDER THE INFLUENCE

## Alcohol's Impact on Brain Health

**A**lcohol is a psychoactive substance that is socially accepted and widely consumed in many, but not all, parts of the world. It is estimated that in 2013, 22 million Canadians drank alcohol in the previous year - that is nearly 80% of the population. In 2015 in the U.S., 70.1% of individuals aged 18 years old and over indicated that they consumed alcohol in the past year.

Despite how commonplace alcohol consumption is, it is not a risk-free activity. Drinking is associated with many health problems including increased risk of certain cancers, high blood pressure, heart disease, and diabetes. According to the World Health Organization, approximately 3.3 million deaths (or 5.9% of all global deaths) were attributable to alcohol consumption in 2012.

**CONSUMING ALCOHOL ALSO IMPACTS BRAIN HEALTH SINCE THE BRAIN IS ESPECIALLY VULNERABLE TO ITS TOXIC EFFECTS.**

However, the exact relationship between alcohol and brain health is complex - affected by the total quantity of alcohol consumed, consumption patterns, the age and sex of the drinker, and even possibly genetics - and the relationship is not yet fully understood.

## THE EFFECTS OF LIGHT-TO-MODERATE ALCOHOL CONSUMPTION

There is almost universal agreement that heavy drinking is associated with cognitive impairment, but some studies have suggested that light-to-moderate alcohol consumption may protect against cognitive decline and help lower the risk of dementia. A recent study conducted by Dr. Iben Lundgaard and her colleagues found that low doses of alcohol have a positive effect on brain health. As part of this study, the researchers gave mice low doses of alcohol - 0.5g/kg, the equivalent of 2.6 drinks for a 70kg person - and then observed the impact on their glymphatic pathway function. The glymphatic pathway is a complex system in the brain (for humans, too) that clears wastes and other harmful substances, including amyloid beta and tau proteins, which are both hallmarks of Alzheimer's disease.

The researchers discovered that the low dose of alcohol significantly improved the mice's glymphatic activity, regardless of whether the mice received just one dose of alcohol or chronic exposure over 30 days. This boost in glymphatic function may explain the lowered risk of dementia that has been noted among light alcohol drinkers in other studies. These findings were shared in February 2018 in *Scientific Reports*.

**IT IS IMPORTANT TO NOTE, THOUGH, THAT MANY STUDIES ABOUT THE BENEFITS OF LIGHT-TO-MODERATE DRINKING (LMD) HAD METHODOLOGICAL LIMITATIONS AND MANY OF THE RESEARCHERS WARNED THAT THEIR FINDINGS NEED TO BE INTERPRETED WITH CAUTION.**

For example, Dr. Iben Lundgaard and her colleagues warn that their findings on mice "should not be viewed as a recommendation for alcohol consumption guidelines in humans."

Moreover, research to date on the effects of light-to-moderate alcohol consumption is inconsistent. By way of contrast, a recent U.K. study conducted by Topiwala et al. - published in *The BMJ* in 2017 - casts doubt on any potential claims of a brain health boost from light-to-moderate drinking. The researchers found that moderate drinkers were three times more likely than those who do not drink at all to experience shrinking of the hippocampus, and very light drinking did not offer any protection compared to abstinence.

In an accompanying editorial, Dr. Killian A. Welch, a neuropsychiatrist from the U.K., discussed these findings in the context of the broader research base. In his view, as the intake of alcohol increases, so does the risk to one's health. "Heavy consumption is associated with potentially severe impairments in memory and executive function, but lower quantities in the range many people consider 'normal' can also have adverse consequences for brain health. Because of the uncertainty around any potential benefits, no one should ever start drinking alcohol, even in small amounts, in

"Standard" drink sizes vary from country to country. For instance, in the U.K. a "standard" drink contains 8 grams of alcohol, versus 10 grams in Australia, 13.6 grams in Canada, 14 grams in the U.S., and 19.75 grams in Japan. Additionally, definitions of "high" levels of alcohol consumption could range from 10 "standard" drinks a week to more than 9 "standard" drinks each day.

an attempt to improve brain health," Dr. Welch emphasized.

One of the challenges with conducting research about alcohol consumption is the lack of universal definitions of a "standard" size for a single serving of alcohol and how many servings constitute "light," "moderate" or "heavy" drinking. Consequently, it is difficult to compare results across studies. Yet, Jee Wook Kim and his colleagues attempted to do just that in their review article, published in *Psychiatry Investigation* in 2012. These researchers reviewed studies published between 1971 and 2011 related to alcohol and cognition, specifically in the elderly. They found that studies of the influence of LMD on cognition reported varying results and they referred to the outcomes of those studies as "controversial."

It is possible that the reason why researchers are struggling to determine whether LMD has cognitive benefits or not is because the answer might differ based on certain characteristics or conditions. For example, one study found that alcohol improved cognitive function only in patients with cardiovascular disease or diabetes, while other studies have reported that elderly women experienced the benefits of alcohol, but not men.

**THERE MAY EVEN BE A GENETIC EXPLANATION FOR WHY SOME INDIVIDUALS SEEM TO BE MORE SUSCEPTIBLE TO ALCOHOL-INDUCED NEUROTOXICITY.**

It appears that people with the apolipoprotein E epsilon 4 allele (APOE e4) are more susceptible to the negative effects of alcohol. Dr. Brian Downer and his colleagues in the U.S. reported in *Alcohol and Alcoholism*, published online in September 2013, that "light and moderate alcohol consumption during late life was associated with greater decline in learning and memory among APOE e4 carriers, whereas light and moderate alcohol consumption was associated with an increase in learning and memory among non-APOE e4 carriers."

Age may also play a role in the impact of alcohol on the brain. Older individuals are less able to metabolize alcohol and their brains →

**A PSYCHOACTIVE SUBSTANCE** changes brain function, resulting in temporary alterations to perception, mood, consciousness and/or behaviour.

Apolipoprotein E (APOE) is the gene most commonly associated with late-onset Alzheimer's disease (AD). It has three forms (called alleles):

- » APOE e2 is the least common and appears to reduce the risk of AD;
- » APOE e4 is slightly more common than e2 and appears to increase the risk of AD; and
- » APOE e3 is the most common and does not appear to impact the risk of AD.

are more sensitive to it compared to younger individuals, possibly making the effect of alcohol more potent for seniors - especially with regard to cognition.

## THE EFFECTS OF ALCOHOL MISUSE

Excessive drinking has an immediate neurotoxic effect that impairs cognitive performance and may lead to "blacking out" - a full or partial experience of memory impairment while intoxicated. The impact of high amounts of alcohol on cognitive performance extends well beyond the intoxication period, starting immediately after an episode of drinking during a hangover. Studies have found that people suffering from a hangover (but with alcohol levels at zero) experienced a decline in memory, attention, psychomotor performance and executive function when asked to complete complex tasks.

When a person consumes excessive amounts of alcohol - either through heavy drinking or binge drinking - particularly over a long period of time, the consequences to his or her brain health can be quite severe, affecting both the structure and function of the brain. The umbrella term widely used to describe the range of potential disorders caused by too much alcohol is "alcohol-related brain damage" or "ARBD." It is estimated that ARBD may account for 10% of early-onset dementia and possibly 10%-24% of dementia cases in nursing homes.

Below is a summary of some of the ways excessive drinking has been found to affect brain health.

### **BINGE DRINKING BY ADULTS AGED 65 YEARS AND OLDER NEGATIVELY AFFECTS COGNITIVE FUNCTION AND MEMORY.**

In a study that analyzed data from over 5,000 U.S. adults aged 65 years and older, researchers found that those who reported binge drinking at least twice each month were 2.5 times more likely to experience higher levels of decline in cognitive function and memory over the eight-year study period. Outcomes were similar in women and men. In this study, binge drinking was defined as consuming four or more drinks on one occasion. This research was led by Dr. Iain Lang from University of Exeter in the U.K., and the results were presented at the Alzheimer's Association International Conference 2012 in Vancouver, Canada.

**EXCESSIVE DRINKING IN MIDLIFE SUBSTANTIALLY INCREASES THE RISK OF DEMENTIA LATER IN LIFE.** Researchers in Finland - Tarja Jürvenpää and colleagues - examined data from 554 Finnish twins who provided information about their alcohol consumption at two different times (in 1975 and 1981) and were later assessed for dementia (once they were over the age of 65, between 1999 and 2001). The results indicated that those who reported binge drinking in 1975 (i.e. consumed more than five bottles of beer or a bottle of wine on one occasion at least monthly) were 3.2 times more likely to have dementia when they were over the age of 65. The researchers also found that participants who reported in 1981 that they had passed out at least twice from excessive alcohol in the previous year were 10.5 times more likely to develop dementia later in life. These results were reported in 2005 in *Epidemiology*.

**EXCESSIVE DRINKING CAN LEAD TO A MEMORY DISORDER REFERRED TO AS "KORSAKOFF SYNDROME," WHICH IS CAUSED BY A SEVERE DEFICIENCY OF THIAMINE (VITAMIN B-1).** Alcohol is known to contribute to thiamine deficiency and thiamine is an essential nutrient for brain function. Korsakoff Syndrome makes it difficult to learn new information and remember recent events, and can cause long-term memory gaps. Korsakoff Syndrome often, but not always, follows an episode of Wernicke Encephalopathy - a medical emergency involving a life-threatening brain reaction to severe thiamine deficiency. Sometimes the two conditions are referred to collectively as Wernicke-Korsakoff Syndrome. When Wernicke Encephalopathy goes untreated, it leads to death in as many as 20% of cases and progresses to Korsakoff Syndrome in 85% of survivors.

Thiamine deficiency is not the only mechanism through which excessive drinking can affect brain health. Alcohol misuse can also lead to brain damage through the direct neurotoxicity of alcohol, alcohol-related cerebrovascular disease, and head injuries that occur while drunk.

Sadly, alcohol misuse is quite common. Rates of alcohol use disorders vary significantly across the globe but are estimated to range up to a high of 16% of the population in some areas.

The good news is that people with alcohol-related disorders that affect the brain can sometimes partially recover if they stop drinking alcohol permanently. Older drinkers, however, are less likely to recover even when they stop drinking. 🍷

When someone consumes a high number of alcoholic beverages in a given week, it is considered **HEAVY DRINKING**. According to the Centers for Disease Control and Prevention (CDC) in the U.S., this is considered 8 or more drinks for women and 15 or more drinks for men. It is considered **BINGE DRINKING** when someone consumes a high number of alcoholic beverages on one occasion: 4 or more drinks for women, 5 or more drinks for men.

# THE FULL PICTURE

New Canadian Dementia Research Investigates the Sex-Gender Divide

It is a devastating omission that may have undercut years of work by brilliant researchers from around the world. Millions of dollars and countless hours have been spent investigating dementia. But in the view of Dr. Mary Tierney, if those research projects did not consider the differences between men and women, then those projects are “incomplete.” →



Dr. Tierney, a professor in the Department of Family and Community Medicine at University of Toronto, studies the neuropsychological aspects of dementia, including sex differences, early identification, and differential diagnosis, with the goal of improving care and treatment of older individuals with dementia. She is also a clinical neuropsychologist and director of the Primary Care Research Unit at Sunnybrook Health Sciences Centre in Toronto and leads the Women, Gender, Sex and Dementia Cross-Cutting Program of the Canadian Consortium on Neurodegeneration in Aging (CCNA). The CCNA is a Canada-wide project involving more than 350 researchers and clinicians divided into 20 teams across the country based on their area of specialization. Collectively, they are striving to accelerate research and increase understanding of age-related neurodegenerative diseases such as Alzheimer's disease.

Dr. Tierney's role is to ensure that these researchers and clinicians keep in mind that there may be differences in how dementia affects men and women and therefore sex differences in the optimal treatments. Although it has been established that far more women develop Alzheimer's disease than men, many research projects have neglected to explore the reasons for this difference. Additionally, despite the greater prevalence of the disease amongst women, male rats have been used almost exclusively in animal studies of Alzheimer's disease.

"It's not true science if you're missing 50% of the population," Dr. Tierney said in an interview with Mind Over Matter®.



**"IF YOU DON'T LOOK AT SEX DIFFERENCES, YOU MIGHT BE LOOKING AT AN AVERAGE, WHICH MAY BE FALSE IF IT MISSES IMPORTANT DIFFERENCES BETWEEN MEN AND WOMEN."**

She further noted that there was a similar flaw in the development of antidepressants and now we are observing that men and women respond differently to certain medications. Similar criticisms have been made recently in the United States and today researchers are being compelled to consider the sex of lab rats in designing their studies. Applicants for major health research grants in both the United States and Canada must explain how they are examining sex differences.

Dr. Tierney says that some researchers claim it is simply a cost

issue – male rodents are cheaper than females. Many scientists, though, have questioned this argument and Dr. Tierney does not accept it: "If it's not good science, why do it?"

CCNA was funded in 2014 in a joint effort by the Canadian Government, the Alzheimer's Society of Canada, and Women's Brain Health Initiative, together with a number of other partners, and is currently in the process of collecting human data. Dr. Tierney is working hard to ensure that the projects do not repeat the mistakes of the past. As a member of the research executive committee, she helps develop guidelines and principles for the design of studies and how to report data. Dr. Tierney says that her team has dedicated a significant amount of time to planning and implementing protocols that will ensure that both sexes are represented properly, including the appropriate use of animals in research studies.


All scientists who publish data through the CCNA must first submit their articles through the publication committees. Dr. Tierney and her colleagues review the articles to ensure that they have considered sex and gender and provide the authors with feedback. If sex and gender are omitted from the research, the publication committees request an explanation.



**"SOME SAY WHY SHOULD WE CARE? BUT IF WE FIND THAT BRAIN CHANGES ARE DIFFERENT IN MEN AND WOMEN, THEN THIS MIGHT LEAD TO BETTER UNDERSTANDINGS OF TREATMENT," DR. TIERNEY EXPLAINED.**

This way of thinking cuts both ways across the sex/gender divide. Dr. Tierney points out that men tend to suffer from Parkinson's disease at a higher rate than women. Some suggested explanations for this disparity are the protective effect of estrogen in women, the higher rate of minor head trauma in men, and exposure to occupational toxins in men. Indeed, it is crucial for scientists to explore sex and gender differences.

Importantly, this new way of approaching research is beginning to gain traction. "People are starting to think about it. But we need to encourage them and provide incentives for this work," Dr. Tierney said.

"And now they're saying: this is amazing. That's a whole area of science that has been opened." 

# THE QUEST FOR QUESTIONS

Sex Differences are Emerging

To find the answers in scientific research, you need to be able to ask the right questions. An increasingly important question in the study of dementia and other neurodegenerative diseases is “are there differences in how these diseases affect women and men, and if so, why.”

That was the underlying question of a study conducted by Dr. Mary Tierney, Professor at the University of Toronto and Sunnybrook Health Sciences Centre, along with her colleagues from the Canadian

Consortium on Neurodegeneration in Aging (CCNA). The research, which was published last year in *Neurology*, focused on two neurodegenerative conditions: frontal temporal dementia (FTD) and amyotrophic lateral sclerosis (ALS). FTD is the second leading cause of early onset dementia, characterized by severe behaviour and language disturbances due to neuronal death in the frontal and



temporal parts of the brain. ALS has similar pathological processes as it causes severe motor impairment due to neuronal loss in the spinal cord and motor cortex part of the brain. Although the effects of FTD and ALS on individuals are different, there is one distinct overlap between the two disorders: they both can be caused by the same genetic mutation. An individual who has the mutation will eventually develop one of these diseases, unless that individual passes away at an age younger than when the disease normally reveals itself. There are other genetic mutations that are also known to cause these disorders.

Dr. Tierney and her team wanted to find out whether a person's sex played a role in the prevalence of these genetic mutations amongst patients with ALS and FTD.

"If you get these conditions, you wouldn't expect there to be sex differences in the genetic causes of the disorders. This is because the mutations actually lie on the part of the DNA that is the same for men and women, called the autosome," Dr. Tierney said in an interview with Mind Over Matter®.

Both ALS and FTD can be caused by a variety of factors, not just the genetic mutation examined in this study. If you look at a group of people who have either disease, you may think that the ratios of men and women who have genetic mutations that cause the disorders would be roughly the same. However, that is not what the researchers found.

They surveyed a large number of existing studies of people with the diseases. For ALS alone, they analyzed 32 research papers which reported findings on nearly 13,000 patients who had confirmed diagnoses. In that group, women had a 16% higher prevalence than men of ALS caused by the most common genetic mutation called chromosome 9 open reading frame 72 (C9orf72).

Even greater differences were found among people with FTD. Women had a 33% higher prevalence than men of FTD caused by another genetic mutation (called progranulin or GRN).

"These sex differences are quite high. A big difference," said Dr. Tierney.



**"OUR FINDINGS WERE QUITE SURPRISING. IT MAKES YOU WONDER. THERE ARE SEX DIFFERENCES HERE AND WE DIDN'T EXPECT THEM."**

In the overall population, men develop ALS at a higher rate from all causes than women. The figures for FTD are less clear - some studies suggest the rates are relatively equal, while others report that men develop FTD more than women.

"You've got a lot more men with ALS [in the overall population], then why are there more women with the most common genetic mutation?" Dr. Tierney queried.

While the research paper does not identify the mechanisms that drive the sex differences, it raises several other crucial questions:

**?** *Why are men developing ALS earlier and more aggressively? Is it because they are more likely to be exposed to toxins that could trigger the disease in their work or career environments?*

**?** *What are the factors protecting women? Could it be estrogen or other sex-related differences?*

For Dr. Tierney, the results of the study, and the additional questions it raises, highlight the need to explore why these disparities between the sexes exist.



**"WE SHOULD START LOOKING BECAUSE THAT COULD GIVE US CLUES FOR EARLIER INTERVENTIONS... IT COULD LEAD TO INTERVENTIONS THAT ARE TAILORED DIFFERENTLY TO MEN AND WOMEN."**

Can we use these findings to improve our understanding of the causes of these diseases and assist in their treatment and management? This study does not provide the answers, but the questions it raises will hopefully point future researchers in the right direction.

This study is only one of a series of research projects examining sex differences in neurodegeneration conducted by members of the CCNA. The following is a brief overview of some of their other work in this field:

➤ A team led by Dr. Roger Dixon from the University of Alberta is investigating why some individuals who are at genetic risk for Alzheimer's disease do not develop it. The researchers are particularly interested in discovering whether there are other risk-reducing or protective factors that shield these genetically at-risk individuals from developing the disease. Dr. Dixon, along with two colleagues from the University of Alberta (Kirstie L. McDermott and G. Peggy



McFall) and two from the Australian National University (Shea J. Andrews and Kaarin J. Anstey), reasoned that these risk-reducing factors could be due to a variety of causes, including vascular health, lifestyle, background, and other biomarkers. Knowing that Alzheimer's disease is more prevalent in women than men, and that recent research has shown that this fact may have some biological and other risk-related underpinnings, they hypothesized that the factors that lead to genetic resilience could also vary by sex. That is exactly what they found. Their work, which was published in 2016 in the *Journal of Gerontology Psychological Sciences*, showed that there was a set of prediction factors in common to both females and males, but there was also a large set that were unique to females. This suggests that

## COGNITIVE RESILIENCE TO ALZHEIMER'S GENETIC RISK IS DETERMINED BY MANY FACTORS, PERHAPS ESPECIALLY FOR WOMEN.

It is an important finding, because it could provide a broader set of modifiable targets for interventions that could promote resilience among women at risk for Alzheimer's disease.

Researchers who are studying the effects of vascular illness on a CCNA team led by Dr. JoAnne McLaurin of Sunnybrook Research Institute have been using rodents to explore sex differences related to a variety of conditions and treatments. Their work is in progress, but already has yielded some important findings.

Dr. Shawn Whitehead of Western University is interested in understanding how hypertension (increases in blood pressure) can lead to cognitive impairment. Dr. Whitehead and his colleagues found that, similar to humans, male and female rodents respond differently to stress, as well as medication to reduce stress and hypertension. They want to learn whether these observed sex-dependent differences also lead to differences in the severity of cognitive impairment between men and women.

Dr. McLaurin and her Sunnybrook colleague Bojana Stefanovic found that female rodents respond differently to drug-induced

hypertension, with one drug rendering a more severe disease, while another had no effect.

Dr. Dale Corbett of the University of Ottawa is exploring therapeutic interventions in rodents after a stroke. He found that female rodents with metabolic syndrome are resilient to the benefits of behavioural interventions, whereas male rodents do well.

Dr. Edith Hamel of McGill University found that female rodents fed a high-cholesterol diet performed worse on memory tests compared to males fed the same diet, particularly on tests involving a spatial memory component. However, if the rodents were allowed to exercise, particularly running, they did not show memory impairments, regardless of their sex.

Dr. Dallas Seitz of Queen's University and his colleagues are evaluating how sex and gender may impact physicians' decisions to prescribe psychotropic medications (such as antipsychotics, antidepressants, and benzodiazepines) to older adults with dementia residing in long-term care facilities in Ontario. To date, their study has identified over 56,000 individuals and their preliminary findings suggest that women are more likely than men to be prescribed both antidepressants and benzodiazepines, while they are less likely to be prescribed antipsychotics. This project is now examining whether these patterns continue to be observed once social, medical, and mental health factors are considered.

Dr. Tierney is conducting a meta-analysis, together with Dr. Ashley Curtis, Dr. Mario Masellis, and Dr. Richard Camicioli, examining sex differences in the cognitive profile of non-demented patients with Parkinson's disease. The findings should shed light on whether sex-related factors are important in early disease mechanisms affecting these cognitive abilities, which in turn may inform treatment development.

All of these research findings illustrate the importance of exploring sex differences in neurodegenerative diseases. Women and men are not the same, and researchers are increasingly recognizing that their treatments should not necessarily be the same either. 🧠





# THE BULLY PULPIT FOR WOMEN'S BRAIN HEALTH

Update from the world's first  
Research Chair in Women's Brain  
Health and Aging

Scientific research projects typically take several years from concept to published paper, but Dr. Gillian Einstein sounds like a woman in a hurry. Appointed barely a year ago to the world's first research chair devoted to women's brain health and aging, Dr. Einstein is bursting with ideas and pushing ahead with new initiatives.

She sees the Wilfred and Joyce Posluns Chair in Women's Brain Health and Aging at the University of Toronto as not only a funding vehicle for scientists, but also as a bully pulpit for the promotion of more research in the field.

## DR. EINSTEIN IS EXPLORING A KEY ASPECT OF A PHENOMENON THAT RESEARCHERS IGNORED FOR FAR TOO LONG: THE FACT THAT WOMEN DEVELOP ALZHEIMER'S DISEASE AT A MUCH HIGHER RATE THAN MEN.

The chair's major research project is a study of memory and attention changes in women who have had their ovaries removed at a relatively early age, before they would normally go into menopause. The focus is on women who had them taken out as a precaution because they have a gene that makes them more likely to get breast cancer. The research has shown that this group of women faces a greater risk of dementia later in life, which has left scientists wondering whether this outcome could be related to lower estrogen levels.

"For women's brain health, it's incredibly important to understand the role of estrogens," said Dr. Einstein in an interview with Mind Over Matter®.

Dr. Einstein's study was already underway, thanks to funding from the Canadian Institutes of Health Research and the Canadian Cancer Foundation. The new chair, partially funded by Women's Brain Health Initiative, allowed her to expand and accelerate the work.

She and her colleagues are focusing on 65 women who have had their ovaries removed and a similar number who still have them, along with a smaller group of women who have the breast cancer gene mutation, but also still have their ovaries.

They are hoping to publish their findings within a year and already have interesting preliminary results, indicating that the women without ovaries are showing changes in different types of memory, particularly verbal memory such as remembering words in a list or story.

"I hope it will seal the idea that it's important for women to keep their ovaries for healthy brain aging," said Dr. Einstein. "And if they have their ovaries removed, what kind of changes can they expect, and what would be the best time for intervention."

The chair is also funding new arms of the study, some of which will follow a less-traditional research path. The scientists are interviewing women about what it is like for them to have their ovaries removed. The goal is to develop a better understanding of the impact of the surgery on a participant's sense of self. The plan is to use arts-based methods to allow the participants to articu-

late their experiences through storytelling, poetry, or drawings of their own bodies.

Additionally, a sculptor is interacting with the participants in the hopes that she will portray their experiences through her own artistic expression. Dr. Einstein hopes that at some point this research may result not only in published academic papers, but also in an art show.



**"I THINK FOR TOO LONG WE'VE DISCOUNTED PEOPLE'S OWN STORIES. UNDERSTANDING THEM BETTER WILL HELP GIVE US IDEAS FOR WHERE TO TURN OUR SCIENTIFIC RIGOUR," SAID DR. EINSTEIN.**

Dr. Einstein noted that the Alzheimer's community is interested in these explorations as a possible new way of measuring cognitive decline. As she explained, sometimes an individual notices changes in his or her memory capacity, but the changes are not dramatic enough to show up on tests at the doctor's office. A more subjective test, based on an individual's own account, could help researchers better understand the early stages of dementia.

"It tells you something about the nature of the condition. It's not an objective account, but an important account," said Dr. Einstein.

Among Dr. Einstein's future plans for the chair are funding initiatives to encourage students of neuroscience or psychology to include explorations of sex differences in their research projects.

She has been writing editorials on the subject since the 1990s, but its importance has only recently taking hold in the international research community.

"It's really catching fire now. Once people start putting dollars into it, people get interested."

Dr. Einstein, who is American-born, says that Canada is a world leader in the field in both funding and attitudes towards research on sex and gender differences.

"I've been at meetings in the U.S. at the NIH (National Institutes of Health), where they've said if Canada can do this, why can't we?"



# ARTIFICIAL INTELLIGENCE AIDS ALZHEIMER'S DISEASE DIAGNOSIS

## Spotting Changes in the Brain Years Before Symptoms Emerge

**D**iagnosing Alzheimer's disease (AD) is challenging, time consuming, and costly. Currently, there is no single test, or series of tests, that can determine with 100% certainty whether an individual has developed AD. In fact, AD cannot be definitively diagnosed until after death, when the brain can be closely examined for certain microscopic changes caused by the disease.

When an individual reports to a doctor that he or she has experienced bouts of memory loss or decreased cognitive function, he or she may be assessed using a variety of cognitive and physical tests, some quite invasive, to determine whether he or she "probably" has AD. However, this diagnosis requires visible symptoms that may only show up when it is too late to start preventative measures. This is of particular concern to researchers, many of whom are focusing their efforts on trying to find a treatment that will help prevent, slow, or reverse the disease. In order to develop such disease-modifying therapies, though, researchers require the participation of individuals who are at high risk of suffering from AD, or are in the very early stages. Finding individuals who fit this profile may now be easier thanks to artificial intelligence.

**NEW ARTIFICIAL INTELLIGENCE (AI) RESEARCH SUGGESTS THAT DOCTORS MAY SOON HAVE THE TOOLS TO PREDICT AN INDIVIDUAL'S LIKELIHOOD OF DEVELOPING DEMENTIA SEVERAL YEARS BEFORE THE ONSET OF SYMPTOMS.**

### AI AND BRAIN SCANS

#### Canadian Researchers Combine AI and Amyloid PET Scans

Researchers from McGill University in Montreal, Canada used AI techniques to develop an algorithm that can, with a single

amyloid positron-emission tomography (PET) scan, detect dementia signatures in the brains of individuals with mild cognitive impairment (MCI) two years before symptoms emerge. While scientists know that amyloid protein accumulates in the brains of individuals with MCI, not every patient who has MCI goes on to develop AD. Consequently, the presence of amyloid is not enough to determine if someone is in the early stages of AD.

This recent study – conducted by Mathotaarachchi et al. and published in *Neurobiology of Aging* in 2017 – made use of hundreds of amyloid PET scans obtained from the Alzheimer's Disease Neuroimaging Initiative (ADNI), a global project in which participants complete a variety of imaging and clinical assessments to help scientists learn about the progression of AD. Using these amyloid PET scans, the researchers trained the AI software to identify which MCI patients would develop AD. There are subtle differences in the way that amyloid is distributed throughout the brain →

A positron emission tomography (PET) scan is a nuclear imaging technique that creates detailed, computerized pictures of tissues and organs inside the body. When used to evaluate brain function, a PET scan can reveal where there is decreased metabolic activity in the brain, perhaps as a result of Alzheimer's disease.

Individuals with mild cognitive impairment (MCI) experience slight but noticeable challenges with memory and thinking abilities, beyond what would be considered "normal" age-related changes. These challenges, however, are not serious enough to affect an individual's daily life. Although MCI can increase the risk of developing Alzheimer's disease, some individuals with MCI remain stable or may even get better over time.

that the human eye cannot detect. However, the AI system was able to detect these differences, noticing patterns that distinguished between those who would go on to develop Alzheimer's disease and those who would not. Remarkably,

## THE ALGORITHM WAS ABLE TO PREDICT WHICH MCI PATIENTS WOULD LATER DEVELOP ALZHEIMER'S DISEASE WITH 84% ACCURACY.

While the new software is currently available online for scientists and students, physicians will not be able to use it in clinical practice until it receives approval by health authorities. In the meantime, the researchers are conducting additional examinations to identify other biomarkers for dementia that could be incorporated into the algorithm to improve its prediction capabilities. Additionally, the McGill team is now testing the algorithm in different patient groups, including individuals who have existing conditions such as small strokes.

### Researchers in Italy Train AI to Assess Brain Region Connectivity Using MRI Scans

A different team of researchers (Amoroso et al.) from the University of Bari in Italy has also trained an AI system using brain scans from the ADNI database. In this case, however, the researchers used 67 magnetic resonance imaging (MRI) scans (38 from individuals with AD and 29 from healthy individuals) to train the algorithm to correctly discriminate between diseased and healthy brains. After training the algorithm to correctly analyze the neuronal connectivity between different regions of the brain, the researchers tested the system on a new set of scans from 148 subjects. Of these, 52 were healthy individuals, 48 had AD, and 48 had MCI but were known to have developed AD between two and a half to nine years later.

The algorithm not only was able to distinguish between a healthy brain and one with AD with an accuracy of 86%, but also could differentiate between healthy brains and those with MCI 84% of the time. These findings were submitted to the Cornell University Library Medical Physics Archive in September 2017.

### Researchers in the Netherlands Combine AI and Arterial Spin Labeling MRI Scans

A recent study conducted by scientists from VU University Medical Center in Amsterdam, published in the December 2016 issue of *Radiology*, applied AI learning methods to a special type of MRI called arterial spin labeling (ASL) to help diagnose AD in the early stages, particularly in centres that lack experienced neuroradiologists. This type of imaging is a non-invasive, quick, and

**Magnetic resonance imaging (MRI), also known as nuclear magnetic resonance imaging, is a non-invasive scanning technique that uses a powerful magnetic field, radio waves, and a computer to produce detailed images of the human body.**


increasingly widely-available method for quantifying blood flow in the brain. The researchers developed an algorithm that can distinguish between patients at various stages of AD with good to excellent accuracy. The study included 260 patients from the Alzheimer Centre at the VU University Medical Centre who underwent ASL MRI between October 2010 and November 2012. The system was able to distinguish effectively among participants with Alzheimer's disease, MCI, and subjective cognitive decline (SCD). The researchers were then able to predict the Alzheimer's diagnosis or progression of single patients with a high degree of accuracy, ranging from 82% to 90%.

### AI AND SPEECH

Artificial intelligence is also being used to assess and monitor Alzheimer's disease and other types of dementia by simply examining a person's voice. While memory impairment is the primary symptom of AD, language impairment usually occurs as well and therefore can be a good indicator of the severity of the disease over time. Recent research suggests that

### AI CAN BE TAUGHT TO ACCURATELY DETECT VARIOUS COGNITIVE DISORDERS, INCLUDING ALZHEIMER'S DISEASE, USING JUST SHORT SAMPLES OF SPEECH.

Frank Rudzicz, a scientist at the Toronto Rehabilitation Institute and an assistant professor at the University of Toronto's department of computer science, is one researcher studying how AI can be used with speech to detect AD. Rudzicz and his colleagues developed a test that takes only 45 seconds to analyze 400 different variables of speech and to predict the severity of AD with approximately 82% accuracy. Their AI models are currently being tested and trained to understand different languages and accents. For now, the tools are being used strictly to track cognitive decline in existing patients, not diagnose new patients.

Rudzicz pointed out that there are important ethical implications to consider before this type of technology could be used in medical practice. "Who will be held accountable for any misdiagnoses made by AI technology? How will patient privacy be protected? Will only health professionals have access to these tools or will they also be available to the general public? These are important questions that need to be answered before AI can be used ethically as part of the diagnosis or assessment of any disease, including Alzheimer's." 

# WORLD DEMENTIA COUNCIL

A Global Collaboration to Tackle the Dementia Epidemic

The prevalence and cost of dementia is rapidly on the rise worldwide, as described in the article “A Financial & Social Sinkhole” on page 39. A health crisis of such epic proportion requires a coordinated global strategy to tackle. The World Dementia Council (WDC) has been established to lead this urgently-needed collaborative effort.



**“DEMENTIA IS ONE OF THE MOST URGENT GLOBAL HEALTH CHALLENGES AND IS NOT SOLVABLE BY ANY ONE COUNTRY, ORGANIZATION OR INDIVIDUAL ALONE. IT’S A GLOBAL PROBLEM THAT REQUIRES A GLOBAL SOLUTION,” —>**



emphasized Dr. Yves Joanette, professor in the Faculty of Medicine at the University of Montreal and former Chair of the WDC. "There are a lot of organizations around the world that are focused on dementia, and each is doing great work in their area of focus. The World Dementia Council was created to 'connect the dots' between these organizations and ensure better coordination and maximum synergy."

## WHAT IS THE WDC?

The WDC is an international charity consisting of 24 senior-level experts and leaders from around the world. There are representatives from research, academia, industry, and non-governmental organizations. They strive to make dementia a top priority on the political agenda - at both the global and national levels - while promoting collaboration between government, industry, researchers, and health and social care systems.

## HISTORY OF THE WDC

In December 2013, the U.K. government hosted a G8 Dementia Summit, bringing together experts from around the world to explore solutions for dementia. This resulted in a collective declaration to work toward identifying a cure or disease-modifying therapy for dementia by 2025, and a commitment to appoint a World Dementia Envoy to help achieve that goal. In February 2014, Dr. Dennis Gillings was appointed by the U.K. Prime Minister as the World Dementia Envoy and Chair of the newly-created WDC. In February 2016, the WDC re-formed to become a fully independent organization, and Dr. Yves Joanette took over as Chair. Harry Johns, President and CEO of the Alzheimer's Association in the U.S., recently became Chair of the WDC in March 2018.

## WDC PRIORITIES

The WDC consists of five teams, each focused on one of the organization's key priorities: finance, integrated drug development, research, care, and risk reduction.

1. The **Finance** team is working to increase the global levels of funding for dementia research from both public and private sources.



"THE FINANCE TEAM'S WORK IS DESPERATELY NEEDED. THE GLOBAL COSTS OF DEMENTIA ARE EXPECTED TO REACH US\$2 TRILLION BY 2030, MORE THAN THE COSTS OF CANCER AND DIABETES COMBINED.

The term "big data" refers to extremely large and complex data sets that may be analyzed with computers to reveal patterns, trends, and associations. "Big data" was used in the research described in the article "Artificial Intelligence Aids Alzheimer's Disease Diagnosis" on page 20.

Yet, far less is spent on public sector dementia research than on other major diseases," said Dr. Joanette.

2. The **Integrated Drug Development** team is seeking to create an efficient and effective process to accelerate the development of innovative dementia medicines and treatments, and to increase patients' access to such innovations when they become available.

3. The **Research, Open Science, and Big Data** team is taking active steps to foster and promote a culture of collaboration and sharing of research data, including through the use of advanced data analytics methods ("big data"). The team encourages a strategic approach to research across all stages of dementia, as well as research into interconnected dementia-related issues, such as health and economic disparities and gender differences.

4. The **Care** team is helping to improve quality of life, as well as the delivery of high-quality affordable care, for individuals living with dementia, their care partners, and families.

5. The **Risk Reduction** team is striving to reduce the risk and impact of dementia through increasing awareness and encouraging effective disease-prevention methods (for instance, through the promotion of appropriate life choices).

## EXAMPLES OF WDC'S INITIATIVES

Through its Finance team, the WDC helped shape the work, led by the U.K. government, to establish the Dementia Discovery Fund (DDF), a specialist venture capital fund that invests in novel science to create meaningful new medicines for dementia. Since its launch in October 2015, the DDF has made significant strides building an initial portfolio of 12 investments in drug discovery companies and projects predominantly in the U.K. and U.S. in areas including microglial biology and inflammation, mitochondrial dynamics, trafficking and membrane biology and synaptic physiology and function.

IN NOVEMBER 2017, BILL GATES MADE A WELL-PUBLICIZED CONTRIBUTION TO THE DDF, INVESTING US\$50 MILLION.





In 2014-15, Raj Long, one of the members of the Integrated Drug Development team, facilitated meetings with 11 international regulators from 10 global jurisdictions. As a result of these meetings, the regulators have agreed to work collaboratively to improve the development process for dementia drugs. In March 2015, Ms. Long released a report entitled *An Independent Report on the Global Approach to Achieve the Development of Safe, Effective and Affordable Drugs for Dementia*, which set out recommendations for improving the global regulatory approach for dementia drug development.

▶ To help encourage worldwide innovation and collaboration in research, the WDC is working with JPND (the EU Joint Programme - Neurodegenerative Disease Research) to facilitate its global expansion.

▶ In 2017, the WDC Care team published the world's first "Global Care and Support Statement." This document outlines eight principles of high-quality care and support that are applicable in all countries and cultures. The Statement is currently being translated from English into 11 additional languages.

▶ The Risk Reduction team is working with the Global Council on Brain Health (GCBH) to produce evidence-based reports about what individuals can do to keep their brains healthy and reduce their risk of developing dementia. The GCBH has already generated reports about nutrition, cognitively-stimulating activity, social engagement, sleep, and physical activity. These reports are available online at <https://www.aarp.org/health/brain-health/global-council-on-brain-health/>.

▶ Recently, the Risk Reduction team, which strives to raise general awareness of dementia, partnered with the World Federation of

Science Journalists to produce an online toolkit that journalists in low-to-middle income countries can use to gather and report dementia-related news accurately and effectively. The website (<http://www.wfsj.org/dementia/>) includes a wealth of facts and figures, information on signs and symptoms and the costs of dementia, as well as on the global response to the disease.

▶ The WDC has also acted as a catalyst for the World Health Organization (WHO) to make dementia one of its priorities, by participating in the first WHO Ministerial Conference on Dementia in March 2015 and by supporting a WHO Resolution on Dementia in May 2016. WDC and WHO agreed at that Ministerial meeting to each work on complementary tasks focused on dementia. As part of their work on dementia, WHO has released the "Global action plan on the public health response to dementia 2017-2025," held a Dementia Plan implementation meeting, and launched the Global Dementia Observatory. The WHO's Global Dementia Observatory will provide data and analysis about dementia burden and response – information about global epidemiological trends, policy formulation and adoption, implementation activities in each country, partnerships and research.

## LOOKING AHEAD

"Dementia has been around for a long time, but as the population of the world ages its impact is growing exponentially. Thankfully, awareness of this massive global health crisis is growing and that awareness is leading to ever-increasing support for the work of WDC and our partner organizations," said Dr. Joannette. "In my time as Chair of WDC, I witnessed tremendous collaborative progress in all five of our focus areas. The growing support for WDC's mandate is creating positive momentum that leaves me confident we'll see accelerated progress in the fight against dementia in the years to come." 🌐

# SHOCK WAVE

A Stimulating Dementia Treatment Option





Driven by the urgent need for effective new treatments for dementia, deep brain stimulation (DBS) is being studied as a potential therapy to improve cognition and memory, or delay decline – and it is showing some initial promise. DBS is a neurosurgical procedure that involves the implantation of a neurotransmitter (a medical device sometimes referred to as a brain pacemaker), which sends electrical impulses to specific targets in the brain to alter mental and emotional processes.

DBS has been used with success to help treat movement disorders such as Parkinson's disease, as well as psychiatric disorders such as major depression, so scientists wondered whether similar stimulation techniques (on different parts of the brain) could be used to halt or slow the progression of dementia.

TO DATE, A LIMITED AMOUNT OF RESEARCH HAS BEEN CONDUCTED AND THE RESULTS HAVE BEEN DIVERSE, WITH SOME RESEARCHERS SHOWING SUPPORT FOR DBS TO RECOVER MEMORIES LOST DUE TO DEMENTIA AND OTHER RESEARCHERS REMAINING SKEPTICAL. →

Some of the studies have examined the use of direct stimulation (which requires surgery), while others have investigated indirect, non-invasive stimulation methods. Different areas of the brain have been targeted, with either continuous or intermittent stimulation, and experiments have been conducted on both animal and human subjects. This article highlights some of the most recent research on this topic.

## DIRECT DEEP BRAIN STIMULATION

Direct deep brain stimulation requires participants to undergo surgery to implant minute electrodes in the brain to deliver electrical impulses through a pacemaker-like device placed under the skin of the chest. The electrical impulses target particular parts of the brain, depending on the placement of the electrodes.

A series of studies with human subjects is currently underway, looking at the effects of DBS that targets the fornix – an area of white matter in the brain between the hippocampus and hypothalamus that serves as the “main highway” to and from the brain’s memory circuit.

➤ The series began with an accidental discovery. Researchers were using DBS to treat a morbidly obese patient by targeting the hypothalamus, a part of the brain that helps regulate appetite. They discovered that as a result of the procedure, which activated the fornix, the patient experienced improvement in certain memory functions. This research was conducted by Hamani et al. and was published in the *Annals of Neurology* in January 2008.

➤ Some of the researchers involved in this experiment, together with new members to the research team, decided to perform the same procedure on six individuals with mild Alzheimer’s disease in a phase I trial. The participants received continuous stimulation for a 12-month period, during which time there was evidence that some of their brains were physically changing in positive ways. For instance, examination of positron emission tomography (PET) scans revealed that participants experienced an “early and striking reversal” of impaired glucose utilization (the brains of Alzheimer’s patients use much less glucose than do the brains of healthy patients).

Additionally, magnetic resonance imaging (MRI) scans showed that two of the participants experienced growth in hippocampus volume – one grew by 8%, and another by 5% (as Alzheimer’s disease progresses, the memory areas of the brain typically shrink). The researchers also assessed changes in participants’ cognitive performance, using the Alzheimer’s Disease Assessment Scale–cognitive subscale and the Mini Mental State Examination. The results of these tests were mixed, with two participants demonstrating improvement and two others remaining the same. The results from this phase I trial, conducted by Laxton et al., were published in the *Annals of Neurology* in October 2010.

➤ The researchers decided to expand the study with a phase II trial – this time, 42 patients with mild Alzheimer’s disease participated. To better measure the impact of electric stimulation in the brain, the patients were randomly assigned to either the “on” stimulation group (meaning that they received the treatment stimulation) or the “off” stimulation group (meaning that the electrodes were implanted, but were not activated during the study) and were monitored for a 12-month period following their procedure.

Notably, glucose metabolism increased in the brains of those in the “on” group, indicating that there had been improvement in the dysfunctional brain circuits affected by Alzheimer’s disease. However, no difference in cognitive function was found between the two groups overall. When the researchers examined the data in greater detail, though, they discovered an interesting trend:

## PARTICIPANTS AGED 65 YEARS AND OLDER WHO RECEIVED DEEP BRAIN STIMULATION SEEMED TO EXPERIENCE SLOWER COGNITIVE DECLINE,

while participants under the age of 65 tended to get worse if they were in the “on” group rather than the “off” group. “These results gave us a better idea of which patients may benefit the most from deep brain stimulation of the fornix and provided evidence that DBS for treating Alzheimer’s disease is safe,” explained lead researcher, Dr. Andres Lozano from the Krembil Neuroscience Centre of Toronto Western Hospital. “We will begin a phase III trial in 2018 that will take between two and three years to complete. Patients who might be interested in participating in that trial can contact our clinic for more information.” This research was published in the *Journal of Alzheimer’s Disease* in June 2016.

Recent research on animals has also provided some preliminary evidence in support of DBS as a potential treatment for dementia.

➤ For instance, researchers in Singapore (Liu et al.) implanted electrodes in middle-aged rats to provide DBS of the ventromedial prefrontal cortex – the part of the brain that is important for the formation and recall of memories. The researchers found that

For more information about the upcoming phase III trial being conducted by Dr. Andres Lozano and his colleagues, please contact their clinic at Toronto Western Hospital at 416-603-5800, ext. 3712.

brief stimulation improved short-term memory, but not long-term memory. However, more sustained stimulation improved both short-and long-term memory. In addition, they discovered that DBS led to the growth of new brain cells in a different region of the brain, the hippocampus, which is also involved in memory. These findings were published in 2015 in *eLIFE*.

➤ In another study involving rats - conducted by Heschem et al. and published in *Brain Structure and Function* online in February 2016 - the researchers assessed the long-term effects of direct brain stimulation of the fornix. The researchers found that the treatment improved the rats' long-term spatial memory, and that this result occurred without any DBS-induced growth of new brain cells.

➤ Another group of researchers has studied the effects of DBS of the nucleus basalis of Meynert, a small area in the front of the brain that degenerates in both Alzheimer's disease and Parkinson's disease. Working with adult monkeys, the researchers began using continuous stimulation and soon discovered that this approach actually impaired memory. Conversely, when the monkeys received intermittent stimulation of the same area in the brain, they were able to remember tasks up to five times longer in a standard test of working memory.

Intermittent stimulation also resulted in increased levels of available acetylcholine in the targeted region of the brain. Acetylcholine is a neurotransmitter (chemical messenger in the brain) that is important for memory, thinking and judgement. Alzheimer's disease is associated with inadequate levels of acetylcholine. These findings were shared in the September 2017 issue of *Current Biology*.

## NON-INVASIVE BRAIN STIMULATION

Other researchers have explored alternative ways of providing deep brain stimulation without the patient having to undergo surgery. A number of different types of indirect, non-invasive methods have been studied, including transcranial magnetic stimulation and transcranial direct current stimulation.

**Transcranial magnetic stimulation (TMS)** uses electromagnetic induction to induce electrical current in specific brain regions. The pulses of electrical current are discharged through a wound copper coil encased in plastic that can be placed against the scalp in different shapes to alter the characteristics of the magnetic field (for instance, to make it more focused or able to reach greater depths). Typically, continuous low frequency stimulation decreases cortical excitability and metabolism, while high frequency stimulation increases activity in the targeted brain area.

When stimulation is intermittent, it seems to enhance excitability. A review of research involving non-invasive brain stim-

ulation for patients with Alzheimer's disease - prepared by Gonsalvez et al. and published in 2017 in *Current Alzheimer Research* - found that the results of using TMS in Alzheimer's patients varied across studies, with different protocols for applying TMS resulting in varied outcomes. TMS has been used successfully to enhance cognitive abilities, depending on the specific area of the brain targeted, but the reviewers encourage caution when interpreting those positive results, pointing out that the studies to date have had small sample sizes and the designs have had serious limitations.

**Transcranial direct current stimulation (tDCS)** regulates brain excitability through the application of low-amplitude direct current applied with electrodes attached to the scalp. In the aforementioned review prepared by Gonsalvez et al., the reviewers found that some studies of tDCS demonstrated enhanced cognitive function in healthy participants. However, the researchers also noted that

THE STUDIES TO DATE HAVE BEEN SMALL AND LIMITED, AND THEREFORE THESE POSITIVE RESULTS MUST BE INTERPRETED WITH CAUTION.

## ETHICAL CONSIDERATIONS

Early studies of deep brain stimulation for the treatment of dementia (both direct and indirect) have paved a path for future clinical trials, but there are unique ethical challenges with this vulnerable population regarding decision-making abilities and access to post-study treatment that researchers need to address, according to Penn Medicine researchers, Siegel et al. The researchers outlined the ethical challenges and their proposed guidelines for studying DBS in individuals with Alzheimer's disease in the *Journal of Alzheimer's Disease* in 2017.

They encouraged researchers to take active steps to ensure (1) that the patient has the cognitive capacity to make an informed decision about participating; and (2) that the patient understands that the primary goal of the study is scientific, not therapeutic, and he or she may or may not experience improvements by participating.

Researchers are also encouraged to consider how those participants who benefit from deep brain stimulation during a clinical trial will continue to receive treatment, and who will pay the associated ongoing costs. The Penn Medicine researchers suggested that "denying a patient access to the only intervention known to alleviate their suffering is tantamount to violating the sacrosanct principle of 'do no harm.'" 🌐



# BALANCING ACT

When Work and Caregiving Collide

Worldwide, it is estimated that nearly 47 million people are living with dementia and this number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050. Individuals with dementia generally require high levels of care, most of which is provided by informal or family caregivers. In Canada, nearly half of Canadians (46%) aged 15 years and older or 13 million Canadians have provided some type of unpaid care to a family member or friend with a long-term health condition, disability or aging-related need, according to a 2012 Statistics Canada Report. A 2015 report published by the American Association of Retired Persons (AARP), in collaboration with the National Alliance for Caregiving, found that approximately 34.2 million Americans had provided unpaid care to an adult aged 50 or older in the prior 12 months, which is 14.3% of the U.S. population. Since many caregivers do not self-identify as such, but view themselves as supportive individuals, it is likely that these figures are understated.

Often referred to as the “invisible second patients,” family caregivers are critical to the quality of life of the care recipients. The effects of being a family caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity, as well as social isolation, physical ill-health, and financial hardship.

AS THE POPULATION CONTINUES TO AGE, THE NUMBER OF UNPAID CAREGIVERS - AS WELL AS THE PHYSICAL, MENTAL, EMOTIONAL, AND FINANCIAL STRAINS EXPERIENCED BY THEM - WILL ONLY INCREASE. →

## THE GENDER GAP

On average, women are caregivers more often than men - although in the millennial cohort (people between the ages of 18 and 34) men and women are equally as likely to be caregivers, says C. Grace Whiting, President and Chief Executive Officer at the National Alliance for Caregiving in the U.S. The type of care that women provide to loved ones is typically different than the care provided by their male counterparts. Dr. Janice Keefe, a Professor in the Department of Family Studies and Gerontology at Mount Saint Vincent University, and Director of the Nova Scotia Centre on Aging, notes that women "tend to provide care that's more intensive and that may result in greater levels of stress." While both men and women may assist with more "instrumental aspects of daily living" (such as helping with transportation, yard work, and banking), women are more likely to provide "personal care" (such as helping with bathing, medication, grooming, and washing). "These tend to be more personalized and more stressful," says Dr. Keefe.

Research suggests that when women act as caregivers, they may spend as much as 50% more time providing care than men. Women are estimated to provide informal Alzheimer's disease care worth 20 times the care provided by men across the entire Baby Boom generation.

## HOW CAREGIVING IMPACTS PAID WORK

More than six million people - or 35% of the Canadian workforce - provide unpaid, informal care while balancing job responsibilities, according to a 2015 report published by the Employer Panel for Caregivers, entitled "When Work and Caregiving Collide - How Employers Can Support Their Employees Who Are Caregivers." In the U.S. context, "most caregivers are working," says Whiting. The AARP/National Alliance for Caregiving reported that six out of ten caregivers in the U.S. worked at some point within the 12

months preceding the survey and nearly 60% of those individuals are employed full time. Such caregivers experience more interruptions at work, lower productivity, and are frequently late or absent. They may be less able to work overtime, travel for work, or take advantage of career-advancing opportunities such as professional development.

**SINCE WOMEN ARE MORE LIKELY THAN MEN TO ASSUME THE ROLE OF CAREGIVERS - AND ALSO HAVE BEEN FOUND TO SPEND MORE HOURS PER WEEK CAREGIVING THAN MEN DO - WOMEN EXPERIENCE THAT COLLISION BETWEEN CAREGIVING AND WORK MORE STARKLY.**

For instance, women caregivers are notably less likely to receive a pension and, if they do, their pension is approximately half of what men receive.

According to the Family Caregiving Alliance in the U.S., 70% of working caregivers suffer work-related difficulties due to their "dual roles." In order to accommodate both their caregiving role and their paid working role, caregivers often have to make arrangements to leave work early or arrive late, or otherwise change their schedules around, says Whiting. As Dr. Keefe observes, individuals are facing a "reduction of hours or going from full-time to part-time to accommodate caregiving responsibilities." This not only has an impact on retirement savings, but also impacts any retirement earnings that may be based on the number of hours/years worked. Caregiving work can also "affect a person's capacity for promotion," says Dr. Keefe, as well as can





stymie career opportunities that require relocation (since such individuals cannot move because they are providing care). In light of the fact that the average age of retirement has risen, a greater segment of the population will end up becoming informal caregivers while still employed, making it an important issue that workplaces must address.

## WORKPLACE ACCOMMODATIONS FOR CAREGIVERS

In addition to representing a challenge to the caregivers themselves, the consequences of caregiving are having an impact on Canadian employers and society more broadly. As the Employer Panel for Caregivers has noted, estimates have placed the reduced work effort by caregivers at 2.2 million hours per week in 2012. Factoring in all the associated negative employment consequences, the Canadian economy lost the equivalent of 157,000 full-time employees in 2012 because of caregiving pressures - a significant loss in productive capacity. According to the Conference Board of Canada, Canadian firms have been incurring approximately \$1.3 billion in lost productivity per year as a result of caregivers missing full days or hours of work, or exiting the workplace altogether.

Despite the high incidence of working caregivers, many organizations feel ill-equipped to deal with caregiver needs because they just do not know much about the issue. In many cases, employers are not even aware that someone is a caregiver, and therefore it can be difficult to accommodate. Dr. Keefe observes that caregiving for an adult is often a "hidden responsibility," partly due to the social stigma associated with caregiving.

## SOMETIMES EMPLOYEES DO NOT FEEL COMFORTABLE SELF-IDENTIFYING AS A CAREGIVER AND COMING FORWARD TO ASK FOR BENEFITS.

They are scared of retaliation or are concerned that they will not be taken as seriously in their position.

When it comes to official support for caregivers, Dr. Keefe believes that Canada is "quite far behind." There is a lack of legislation for this kind of workplace accommodation, which makes knowing what is acceptable or permitted quite difficult. When the benefits are not legislated or negotiated for in an employment contract, people do not have the "security in those go-to policies," says Dr. Keefe. "Then the concern always is 'will I be viewed as a valuable employee because of my additional responsibilities?'" But we need to realize just how economically crucial the unpaid caregiving work is to our society as a whole. "If everyone who was doing so stopped providing care, there

would be huge implications for our continuing care system," says Dr. Keefe.

## SLOWLY ENGAGING CHANGE

In many cases, both caregivers and workplaces do not view caregiving as a "workplace issue" but rather as an "outside pressure that they have to accommodate around," says Whiting. Importantly, though, this societal perception is finally beginning to change. What employers need to realize is "that accommodating caregiving is tied into retention - making an acceptable workplace for caregivers means that you can retain highly-trained employees," says Whiting. Most caregivers are talented and experienced employees who possess deep company or industry knowledge. These are key contributors to the Canadian economy broadly - individuals we do not want to see exit the workforce.

But how do we keep caregivers working and working well? We need official policies or programs in place to ensure that caregivers are treated fairly and to establish a supportive environment. "You need buy-in from top leadership" on this issue, says Whiting, with employers and governments taking the first steps. Recently, the Canadian federal government implemented a few new policies in the 2017 budget for caregiver support, including an Employment Insurance Caregivers Benefit, which "will give eligible caregivers up to 15 weeks of [employment insurance] benefits while they are temporarily away from work to support or care for a critically ill or injured family member." The government is also allowing federal employees to request flexible work arrangements from their employers, such as flexible start and finish times and the ability to work from home, in addition to new unpaid leaves to better balance work and family demands. Since labour codes operate at the provincial level, the federal government is "trying to lead by example" in proposing new measures for its own employees through this kind of policy, says Dr. Keefe.

## CAREGIVING IN A PERFECT WORLD

Finding solutions for working caregivers is important for a variety of reasons, not the least of which is that "people take a lot of value and meaning to the caregiving work they do," says Dr. Keefe. In her research, Dr. Keefe has found that "for some, caregivers providing care improves the quality of the relationship with the person they are providing care to - it gives people a sense of accomplishment that they're able to support their family member." So when we talk about caregiving, it is important to remember that it is not "all doom and gloom," she says. "In a perfect world, you would be free and empowered to care for the people you love without having to worry about how it's going to impact your career, without going into debt, and without damage to your own physical health and well-being." We all need to start thinking about how we can help to make this happen - both at an institutional level and on a personal level. 🌍



You have marked dates in your calendar, left yourself multiple lists all over your home, set reminders on your cellphone, but sometimes these actions are still not enough, and you are not the only one noticing. Some family members and friends are starting to make comments about your memory and are repeatedly asking you how you are feeling - and quietly, you share their concerns. You are scared to admit it, but you are just not quite yourself, and you are consistently feeling that your brain is being challenged. Deep down, you know that you need to reach out and ask for help - and you should not do it alone.

### HOW DO I GET DIAGNOSED?

If you are worried that you might be at risk for developing dementia or Alzheimer's disease (AD), it is critical that you follow the necessary steps to obtain an accurate diagnosis from a physician.

**CURRENTLY, THERE IS NO SINGLE TEST OR SERIES OF TESTS TO DETERMINE WHETHER AN INDIVIDUAL IS SUFFERING FROM DEMENTIA.**

Instead, individuals must undergo a complete medical assessment that will establish the level of care, support, treatment, and services needed.

To diagnose AD, your primary doctor, a neurologist, or a geriatrician will review your medical history, medication history, and your symptoms, according to the website for the Mayo Clinic (a nonprofit medical practice and medical research group based in Rochester, Minnesota). During your appointment, your doctor will conduct several tests and will evaluate:

- »» Whether you have impaired memory or thinking (cognitive) skills;
- »» Whether you exhibit changes in personality or behaviours;
- »» The degree of your memory or thinking impairment or changes;
- »» How your thinking problems affect your ability to function in daily life; and
- »» The cause of your symptoms.

Doctors may order additional laboratory tests, brain-imaging tests, or send you for memory testing. These tests can provide doctors with useful information for diagnosis, including ruling out other conditions that cause similar symptoms.

# DIAGNOSIS VS. RESPONSE

## The Emotional Balancing Act of Alzheimer's Disease

## WHAT HAPPENS AFTER DIAGNOSIS?

Undoubtedly, the initial response when individuals receive a diagnosis of dementia or AD is an emotional one – both for the person diagnosed and his or her family members and loved ones. These emotions may include:

**FEAR //** You may be scared for the future and how your family and friends will be affected;

**DENIAL //** You may feel overwhelmed by how your life will change and believe that you have been misdiagnosed;

**ANGER //** You may feel frustrated that your life is taking a different course than the one you had planned, one that is entirely out of your control;

**RELIEF //** You may feel some comfort in having an explanation for the changes that you have been experiencing; and

**DEPRESSION //** You may feel sad or hopeless about the way your life is changing and worried that these changes will be too much for you and/or your family to manage.

It is important to take care of your emotional needs. Acknowledging and coming to terms with the various emotions that you are feeling will help you accept your diagnosis, move forward, and discover new ways to live a positive and fulfilling life.

## TOO MANY QUESTIONS AND NOT ENOUGH ANSWERS. BUT THERE IS HELP.

After receiving your diagnosis, it is common to leave your doctor's office unsure of what questions to ask. You just received life-changing news, and you need time to absorb this information and to understand its implications for both you and your family.

One of the most valuable things that you can do upon receiving a diagnosis (no matter what that diagnosis may be) is to transform your emotions into positive action. As part of your action plan, it is important to ask some of the following questions to your doctor, your family, or even your local support organization:

- » *Where do I go for more information?*
- » *What do I do now?*
- » *Can I beat it? How do I work with it and not against it?*
- » *How much time do I have?*
- » *What are my treatment options?*
- » *How do I ensure that I am receiving the best care possible?* →

## THE ACCURACY OF DIAGNOSIS

To date, there is only one conclusive test to diagnose Alzheimer's disease: a postmortem examination of a patient's brain. While a person is still alive, he or she will undergo a variety of physical and cognitive tests to determine whether he or she is suffering from Alzheimer's disease – in which case, the patient may receive a diagnosis of "possible" or "probable" Alzheimer's dementia.

Although there continues to be no single test (or series of tests) that can accurately diagnose Alzheimer's disease while a person is living, there have been significant advances in technology and in diagnostic testing methods that use brain scans and spinal taps to detect certain biomarkers of the disease, even in its pre-clinical stage. While these advancements are progressive, they tend to be invasive and quite costly – presenting another set of challenges and stress for the patient.

Fortunately, it seems that simplicity and accuracy of diagnosis may not be too far away. A team of researchers from Japan and Australia are getting closer to developing a blood test that can accurately identify Alzheimer's patients with up to 86% sensitivity and specificity (sensitivity refers to true positives identified by the test, while specificity refers to true negatives). The test also has the ability to differentiate between different types of dementia, which can assist doctors with tailoring their methods to fit the diagnosis.

Early detection of the disease could be a doctor's best chance for slowing its progress, according to the Alzheimer's Society. "Current methods of diagnosing dementia can be slow and expensive, so finding a cheap, quick test that can accurately identify if someone has dementia is a top priority for researchers," Doug Brown, Director of Research and Development at the Alzheimer's Society, told CNN. This blood test – though still in its experimental stages – may prove to be a game-changing feat for medical research.

Be honest with yourself. Work with your emotions – not against. A diagnosis of AD can leave you feeling disconnected or abandoned from others.

**ALWAYS REMEMBER THAT YOU ARE NOT ALONE – THERE ARE MANY SUPPORT GROUPS FOR PATIENTS AND CAREGIVERS.**

Your local Alzheimer's Association can also provide you with a list of specialists in your area. Share your experiences with others and learn. Above all, ensure that you speak with your doctor.

### TALK WITH YOUR DOCTOR

In January 2006, the Alzheimer's Association established an advisory group composed of individuals in the early stages of AD. The group is helping to provide the most appropriate services for people living with early-stage Alzheimer's, raise awareness about early-stage issues, and advocate with legislators to increase funding for research and support programs. Members of the Alzheimer's Association National Early-Stage Advisory Group have shared their own experiences and questions that they wish they had asked their doctors. As you develop your own list of questions, consider the following:

#### THE DIAGNOSIS OF ALZHEIMER'S DISEASE

1. What test(s) or tools did you use to determine my diagnosis?
2. What are you measuring with the tests you performed?

#### THE DEVELOPMENT OF ALZHEIMER'S DISEASE

1. How will the disease progress?
2. What can I expect in the future?

#### TREATMENT OPTIONS

1. What treatment options are available?
2. Which symptoms are being targeted by each medication?

#### CLINICAL TRIALS

1. What clinical trials are available?
2. Where can I find published information about clinical treatment studies?

#### CARE TEAM

1. How familiar are you with Alzheimer's disease? Will you be managing my care going forward?
2. If I need to be hospitalized, will you be able to provide care in this setting?

#### RESOURCES AND SUPPORT

1. What resources are available to help me learn more about my diagnosis? My family?
2. What support services are available to help me live well with the disease, for as long as possible?

To download a PDF copy of the foregoing questions and others, visit the Alzheimer's Association website at [https://www.alz.org/national/documents/topicsheet\\_communication\\_healthcare\\_pros.pdf](https://www.alz.org/national/documents/topicsheet_communication_healthcare_pros.pdf).

### ACCEPTANCE IS A PROCESS

Learn about the disease. Being informed can help you understand how the disease progresses and what you can expect. Give yourself time to grieve and time to be angry – then be motivated to do something about it.

Remember that it is okay to ask for help. Working together, and as early as possible, offers patients and their caregivers a better opportunity to start a treatment program and/or routine and to build a plan for the future, including care options, living situations (care, driving, etc.), and financial and legal matters.

Most importantly, live. Despite the diagnosis, enjoy the life that you are living and continue doing the things that you enjoy most – just do it with a new perspective and awareness. 🌍

### OTHER CAUSES OF MEMORY LOSS

It is critical to never underestimate the importance of a complete medical assessment because there are other medical conditions that can mimic Alzheimer's disease. According to one estimate, there are more than 50 conditions that can cause or resemble the symptoms of dementia, and a small percentage of dementias are reversible. Obtaining a proper diagnosis is crucial because symptoms subside when the underlying problem is treated.

For instance, while memory can be impacted by serious ailments (such as fluid in the brain, a stroke, or a tumor), other more treatable conditions include medication interactions (especially antihistamines, anti-nausea medications, steroids, and bladder relaxants), vitamin B12 deficiency, an underactive thyroid, a urinary tract infection, diabetes, untreated depression, excessive drinking (alcoholism), head injury, and even Lyme Disease. Sometimes the effective and immediate treatments of these conditions result in significant improvements in mental functioning. In some cases, a complete reversal can be experienced before any permanent damage to the brain occurs – even more reason to consult a doctor as early as possible when experiencing any signs of dementia.



# A STRANGER IN THE MIRROR

What does it feel like to have Alzheimer's Disease?

When my mother died, we spent seven days sitting Shiva - the Jewish mourning period for first-degree relatives - to remember a life well lived, to honour her, and to comfort those mourning such a great loss. During those seven days, we told many stories about her, both pre-dementia and post.

There was one particular story that I liked to tell and did tell often to different visitors.

It happened when my oldest daughter, Amy, and I were visiting my mother one afternoon in her apartment. Sitting in the dining room, surrounded by family photos, my mother turned to Amy and said: "You're such a beautiful young woman, how come you don't have a boyfriend?" Amy laughed and said: "Bubby, I'm married to Jeremy." My mother looked at her with such a sincerely hurt look on her face and responded "and you didn't invite me to your wedding!"

Somehow I thought it was a gentle way of describing how dementia affected all of us. This story highlighted my mother's old personality of wanting to be invited to every party and of course, it always got a laugh.

When I came across a blog written by Wendy Mitchell about what it feels like to live with dementia, it stopped me in my tracks. I never, not once, thought about telling the wedding story from my mother's perspective. By the time her dementia was obvious to us, it was too late to really ask her about what she was feeling - only how she was feeling.

I hope that Wendy's description of her own experiences with the disease might help us all understand this journey in a new or, at the very least, a different light.

## WHICH ME AM I TODAY? ONE PERSON'S EXPERIENCE OF LIVING WITH DEMENTIA. WHAT DOES DEMENTIA FEEL LIKE?

A question being asked everywhere since Still Alice. Let me first say, the disease is progressive and affects everyone differently, but this is my synopsis of "what it feels like" for me. —>

Every day is different. Some days it feels like Alzheimer's has never entered my life and some parts of some days are like this too.

On bad days, it's like a fog descends on the brain and confusion reigns from the minute I wake up. On those days, it feels like there's so little in the brain left to help you get through the day. I rely on my phone, iPad, and calendars galore - all religiously kept up to date. As soon as an appointment or meeting is arranged it goes into everything and onto the calendar - that's the only way I remember. I'm so lucky to have always been highly organized, so I didn't have to learn that as a new skill. For those who have always been unorganized, the task must be very challenging.

I've tried managing without them to see if I've made things worse by not making my brain work to remember these things. However, my brain just doesn't seem capable of remembering. Simple things like taking medication at a set time - I've tried remembering without alarms but the task just didn't exist. I still find it remarkable that when my alarm goes off at 8:00 p.m. it's a surprise that there's a reminder to take medication. So I don't agree with those who say you should try and remember without alarms, as you're not using your brain. I agree we should use our brain constantly to keep it working, but my short-term memory is diseased so no amount of usage will make it any better - I think. My take on this part is that we simply have to learn to adapt and use new methodologies to help compensate for the bit of our brain that is no longer working.

The feeling of confusion is also heightened on some days. I have to really work hard at remembering the day of the week and what I'm supposed to be doing. This feeling I can liken to a necklace being all tangled up and having to sit there and untangle the knots. If you're feeling calm, you sit there patiently and one by one untangle the necklace and work out the reality of the day. If panic rises, it's like when you're impatient with the necklace and give in and feel like you've lost the use of the necklace. Panic rises inside you and you find it impossible to work out what day it is and what you're supposed to do. On these occasions it can feel like your head wants to explode as you feel out of control.

Again, I feel lucky, insofar as I can relax and chill quite easily. I can stay calm and not panic usually. My way of dealing with these moments is to tell myself it's the disease and the fog will clear eventually, so I'll just sit quietly and wait. It's a bit like a game of chess - you sit waiting for your opponent to play and try and outmaneuver....

Losing spatial awareness can be frightening. My worse moment is still the time at work when I didn't know where I was when I was standing outside my office. Again, it's telling yourself that the moment will pass - it's the disease in your brain testing you. If you can keep in control and not panic, it helps hugely. I've had other

mini moments like this recently, but coping in this way makes them less traumatic.

Not being able to find the right words is a daily occurrence. I used to get frustrated and annoyed at this. But I've found it makes the disease seem so much worse if you let it get to you like this. If I'm giving a talk, I plan meticulously and have everything written down. I read and reread my notes in the hope that something will remain in situ and where once I would try and wing it, I now never would. If I forget people's names, it is annoying but now I think, "what does it matter" and simply ask them again, and again...and hope they understand. If they don't understand, it's their problem not mine. If they can't see beyond the disease they are very shallow.

If someone newly diagnosed asked me what advice I would give them it would be not to panic at the diagnosis. Don't give in. Adapt and find new ways to compensate for the parts of you that don't function as they use to. See it as a challenge to outmaneuver this cruel disease. Easy to say when faced with the diagnosis, but the only way I've found to cope with today and tomorrow. 🌀

### ABOUT WENDY7713

On the 31st July 2014 I was diagnosed with early onset Alzheimer's. I may not have much of a short-term memory anymore but that date is one I'll never forget. I'm 58 years young, live happily alone in Yorkshire, have two daughters and I'm currently still in full-time employment in the NHS. However, I'm now in the process of taking early retirement to give me a chance of enjoying life while I'm still me. I've started this blog to allow me, in the first instance, to write all my thoughts before they're lost. If anyone chooses to follow my ramblings it will serve as a way of raising awareness on the lack of research into Alzheimer's. It will hopefully convey the helplessness of those diagnosed with dementia, as there is no cure - the end is inevitable. However, I'm also hoping I can convey that, although we've been diagnosed, people like me still have a substantial contribution to make; we still have a sense of humour; we still have feelings. I'm hoping to show the reality of trying to cope on a day-to-day basis with the ever-changing environment that dementia throws at those diagnosed with the condition. What I want is not sympathy. What I want is simply to raise awareness.

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# A FINANCIAL & SOCIAL SINKHOLE

Dementia: A Two Trillion Dollar Disease by 2030

The world's population is aging, and doing so rapidly. The number of individuals aged 60 years old and over is expected to grow by 56% between 2015 and 2030 – from 901 million to 1.4 billion. By 2050, this figure is projected to reach nearly 2.1 billion. As the population ages, there is a corresponding rise in age-related diseases. Dementia is no exception. Alzheimer's Disease International (ADI) estimates that 44.35 million people were living with dementia in 2013, and that this number will increase to 75.62 million by 2030, and an alarming 135.46 million by 2050.

**CARING FOR INDIVIDUALS WITH DEMENTIA IS A GROWING FINANCIAL AND SOCIAL BURDEN AFFECTING BOTH GOVERNMENTS AND FAMILIES, PARTLY DUE TO THE VAST NUMBERS OF PEOPLE SUFFERING FROM THE DISEASE, AS WELL AS THE LONG DURATION OF ILLNESS BEFORE DEATH (SINCE MUCH OF THAT TIME IS SPENT IN A STATE OF DISABILITY AND DEPENDENCE).**

In its *World Alzheimer Report 2015*, ADI estimated that the worldwide cost of dementia was US\$818 billion in 2015, and predicted that amount would rise to US\$1 trillion by 2018. ADI further anticipates that this figure will double to US\$2 trillion by 2030.

In its 2013 policy brief entitled "The Global Impact of Dementia 2013-2050," ADI concluded that dementia is "one of the biggest global public health challenges facing our generation" and stated that it is a "global epidemic" that has been underestimated. More recently, the World Health Organization warned in its 2017 report, *Global action plan on the public health response to dementia (2017-2025)*, that a US\$2 trillion price tag to care for individuals with dementia could undermine social and economic development globally, as well as overwhelm health and social services, especially long-term care systems. —>

## VARIATIONS BY REGION

Between 2015 and 2050, the number of individuals living with dementia is expected to rise substantially worldwide, but the rate of growth will vary by region. During that time, the following rates of increase are predicted:

- » Slightly more than double in North America
- » Slightly less than double in Europe
- » Triple in Asia
- » Quadruple in Latin America and Africa

## THE CANADIAN CONTEXT

As is true in all parts of the world, Canada is currently experiencing dramatic increases in the prevalence and cost of dementia. ADI estimates that in 2015, just over 556,000 individuals were living with dementia in Canada, and that this number will increase by a staggering 60% to 886,000 by 2030. However, estimates of the current costs of dementia in Canada have varied, largely because of differences among population-based studies in the definitions of dementia, tests used to measure dementia, and the age and other characteristics of sample members. A review of these estimates by an expert panel comprised of epidemiologists, health economists, and policy analysts concluded that the most accurate way to calculate the total cost of dementia is to include both direct costs (such as medical and social sector costs) and indirect costs (such as the value of unpaid informal care by family members or others). Based on those criteria, the total cost of dementia was estimated to be C\$10.4 billion in 2016, and projected to reach C\$16.6 billion in 2031.

## THE U.S. CONTEXT

The Alzheimer's Association in the U.S. reported in a March 2017 fact sheet that Alzheimer's disease is the most expensive disease in America, costing more than cancer and heart disease. The Alzheimer's Association estimates that the direct costs of caring for individuals with Alzheimer's disease and other dementias in the U.S. amounted to US\$259 billion in 2017. By 2050, it is anticipated that those costs could rise to US\$1.1 trillion.

Recent research in the U.S. examined the societal and family lifetime cost of dementia using a mathematical model to simulate disease progression and associated cost of care. The researchers calculated that on average, the total cost to care for an individual with dementia was US\$321,780 (in 2015 dollars) over a five-year period. The researchers found that 70% of the total cost burden had to be covered by patients and their families through out-of-pocket payments and the value of informal care. In compar-

ison, caring for a dementia-free senior over the same duration is dramatically less expensive - estimated at US\$137,280.

**“DEMENTIA IS ONE OF THE MOST COSTLY DISEASES, AND FAMILIES INCUR THE MAJORITY OF THE COSTS,”**

explained Dr. Eric Jutkowitz of Brown University, lead author of the study. “We anticipated that dementia would be costly and that families would incur a large part of the cost, but we were surprised at the magnitude of the total costs and just how much of that burden is on families.” These findings were published in the *Journal of the American Geriatrics Society* in August 2017.

A different group of U.S. researchers studied the costs of a particular type of dementia known as frontotemporal dementia (FTD), which is characterized by progressive loss of nerve cells in the brain's frontal or temporal lobes. FTD accounts for up to 50% of dementia cases in individuals under the age of 60, and patients survive an average of eight years after being diagnosed. Dr. James Galvin and his colleagues estimate that the total cost (including direct and indirect costs) of FTD in the U.S. amounts to US\$119,654 per patient, each year. That is twice the estimated cost of caring for someone with Alzheimer's disease. Because the onset of FTD tends to occur at an earlier age than most dementias, FTD patients are often of working age and are forced to leave their jobs during peak earning years. The family members who take on caregiving responsibilities, often the spouse, may also need to adjust their own careers to provide care (for instance, by reducing his or her hours or declining promotion opportunities). Not surprisingly, then, the researchers discovered that the mean household income decreased after an FTD diagnosis - from US\$75,000 to US\$99,000 one year before diagnosis to US\$50,000 to US\$59,999 one year after diagnosis, resulting from lost days of work and early departure from the workforce. These findings were published in the November 2017 issue of *Neurology*.

## PREPARING FOR THE EPIDEMIC

Planning for the costs associated with dementia is critical. Now more than ever, research funding is needed to find a cure and/or develop treatments to prevent or slow the onset of dementia, to educate the public about steps that can be taken to reduce the risk of a dementia diagnosis, to improve the accuracy and timeliness of diagnosis, and to provide short-and long-term health care and social services to support individuals with dementia and their families.

**WHILE GOVERNMENT ACTION IS REQUIRED, INDIVIDUALS CAN ALSO TAKE PROACTIVE MEASURES TO REDUCE THEIR RISK OF DEVELOPING DEMENTIA**

by remaining physically, cognitively, and financially healthy (such as making positive lifestyle choices, engaging in cognitively-stimulating activities, and planning ahead financially by saving and/or purchasing an insurance policy). 🌐





# PLANNING FOR INCAPACITY

Financial and Legal Considerations

An aging society coupled with a surge in the incidence of dementia is driving an extraordinary growth in a specialized aspect of financial and legal planning: powers of attorney (POAs). Leanne Kaufman, head of RBC Estate and Trust Services, says that her firm saw a 250% increase in 2017 over the previous year in business related to POAs. But she believes that people are still not giving POAs enough consideration.



“THERE’S LOTS OF ATTENTION REGARDING THE IMPORTANCE OF HAVING A WILL, BUT NOT THE SAME AMOUNT OF FOCUS ON HAVING A POWER OF ATTORNEY.”

said Ms. Kaufman in an interview with Mind Over Matter.® “To me, in some ways the power of attorney is more important because it impacts you while still alive.” →

Although we are now living longer than ever before, record numbers of individuals are experiencing cognitive decline and dementia. As of 2016, over half a million Canadians were living with dementia, and this number is expected to nearly double by 2031. Consequently, a significant segment of the population may lack (or are gradually losing) the ability to make decisions for themselves. As a person's mental capacity declines, his or her decision-making will increasingly involve others, such as family members, substitute decision-makers, and health-care professionals.

## MAKING DECISIONS ON ANOTHER PERSON'S BEHALF CAN BE DIFFICULT AND HIGHLY STRESSFUL, ESPECIALLY WHEN THE VALUES AND WISHES OF THE INDIVIDUAL WITH DEMENTIA ARE UNKNOWN OR IMPOSSIBLE TO FOLLOW.

Ms. Kaufman gives regular presentations across Canada on this topic, providing audiences with practical advice and strategies for putting one's affairs in order. She stresses the importance of making arrangements for a POA for both the donor (i.e. the person who is granting the power of attorney) and his or her loved ones. She advises that individuals must carefully consider whom to appoint as their POA. In some cases, the appropriate choice is a trust company. Such companies are sometimes preferred to individuals as they are able to dispense their services impartially and are held to a standard of professional accountability.

"For every financial aspect of your life, this person is stepping into your shoes," she says. Accordingly, the donee (i.e. the person who is receiving the power of attorney) must not only be someone who the donor trusts, but also someone who has the necessary acumen to oversee his or her affairs. For instance, if the donor holds substantial investments, he or she should not select someone who is unfamiliar with those matters. It is also inadvisable to select someone who does not live within the same jurisdiction as the donor. If the donee resides in the United States, he or she would be constrained by regulation from overseeing the donor's Canadian-based investments.

Kimberly Whaley, a Toronto-based lawyer who specializes in the area of estate, trusts, capacity, and power of attorney litigation, said that her business is booming, sadly because more and more cases of abuse are surfacing.

"What we're seeing a lot of now, which we didn't used to see, is a lot of disputes over property of the mom or dad during their lifetimes," said Ms. Whaley. "We used to see them more after death, when one party learns that mom or dad was coerced into changing a will document."

Ms. Whaley noted that she has witnessed a growth in predatory practices targeting vulnerable individuals. Sometimes a so-called new friend will convince a person who is in the early stages of dementia to change a POA document, handing over financial responsibility to someone whose only motivation is exploitation. In Ontario, it is possible to print off a standard POA form from the Ministry of the Attorney General's website (and therefore individuals do not need a lawyer to prepare the POA document for them). This means that there are more cases of people with multiple, conflicting POA documents, which inevitably are contested in court.

"It's more frequent than you know. That's the basis of my practice now," said Ms. Whaley.

A few years ago, she dealt with a heartbreaking case. She represented a lawyer who was appointed as a donee for his mother. His sister had responsibility for the mother's personal care. A dispute arose between the siblings over whether the mother should be placed in a long-term care facility - a matter that ended up in a protracted legal battle with all of the mother's assets being frozen by the court. Every time that a payment needed to be made for anything, the siblings first had to go to court to obtain an order. This process dragged on for four years, draining the assets of her client's mother, and was never resolved because the mother passed away before the matter could be settled.

"The system is not geared to deal with these kinds of disputes. It's just untenable because the courts are backlogged dealing with them," said Ms. Whaley.

It is not only warring family members causing problems. Ms. Whaley is also regularly battling financial institutions over POA matters.

## A BANK, IF IT SUSPECTS ABUSE, HAS THE ABILITY TO FREEZE A PERSON'S ASSETS WITH OR WITHOUT NOTICE.

Ms. Whaley has even encountered cases where a financial institution questions the validity of the POA and demands a capacity assessment of the client. Unfreezing the assets, even with a legitimate POA, can be a complicated and time-consuming legal process.

"My clients get angry. I get upset. Jumping through all the hoops, it's costly. Why should a client have to hire a lawyer to get his or her money?"

Ms. Whaley does have some sympathy for the banks, understanding that they feel pressure to protect their clients from fraud. Nevertheless, she believes that financial institutions are frequently going too far.

"We're all struggling with this. There's not a right answer...yet."

In March 2017, the Law Commission of Ontario (LCO) - an independent body that recommends law reform - released its report about POA documents and their potential for abuse and misuse. The report was the result of nearly two years of research and consultation by the LCO, and is the most comprehensive analysis of Ontario's legal framework in this area in almost thirty years. The report highlights the obstacles individuals face in accessing justice in POA, capacity, and guardianship matters, which are almost impossible to resolve during the lifetime of the individual who is the subject matter of the dispute.

Among its 58 recommendations for strengthening the laws around substitute decision-making, the LCO proposed that the government create a specialized, expert tribunal with broad jurisdiction in this area of the law, and the ability to provide flexible and holistic approaches to disputes. Bringing disputes out of the courtroom and into a tribunal setting would help reduce the cost, complexity, and time to resolve these sensitive matters.

The LCO further recommended that individuals should have the option to name one or more "monitors," who would have statutory powers to discuss the use of the POA with the donor and to review the records and accounts kept by the donee. If the monitor has reason to believe that there is abuse or misuse on the part of the donee, then the monitor would be obligated to report these concerns to the Ontario Public Guardian and Trustee.

It remains to be seen whether the provincial government will implement the LCO's recommendations. In the meantime, it is critical that we properly organize our affairs, do it while we are in good health, and ensure to communicate our wishes to our trusted family members and loved ones. 


A power of attorney (POA) is a legal document that allows an individual to appoint someone else - usually a spouse, domestic partner, trusted family member, or friend - to make decisions on his or her behalf in specified or in all legal and financial matters. The person transferring the power is called the "donor" or "grantor" and the person receiving the power is known as the "donee" or the "attorney." Depending on how the POA is written, the appointment of the attorney can come into effect immediately, or can be triggered by specific circumstances, such as the donor being declared incapable of managing his or her affairs.

Although a POA can be drafted without professional assistance, if you have a complex situation or questions, it is always a good idea to seek legal advice and services from a lawyer who specializes in this area of law.



# TOO YOUNG TO CARE

## The Invisible Population of Caregivers

A photograph of two women standing indoors, smiling at each other. The woman on the left has short, curly blonde hair and is wearing a light green sweater. The woman on the right has long, dark hair and is wearing a grey turtleneck sweater. Both are holding white ceramic mugs. The background is a bright window with a view of a city skyline.

While millennials are often perceived as “selfish,” “entitled,” and “lazy” compared to other generations, there is a hidden group of individuals within this segment of the population that is far from these stereotypes: young carers. The Change Foundation, an independent health policy think-tank that works to inform positive change in Ontario’s health care system, defines a young carer as “a child, youth or young adult that provides physical, medical, emotional or other supports to a parent, grandparent or sibling.” This group of millennials has no time for their friends or cellphones, but instead is facing the immense responsibility and accountability of taking care of their loved ones.

According to the 2012 Statistics Canada Report, “Portrait of Caregivers,” over one-quarter (28%) of Canadians, or an estimated 8.1 million people, have provided care to a chronically ill, disabled, or aging family member or friend, and caregivers between the ages of 15 and 24 account for 15% of this figure. The

Change Foundation suggests that the percentage of youth in a caregiving role is even higher than reported, as there is no data for young caregivers under the age of 15. The foundation further indicates that caregiving responsibilities can start in children as young as five.

In the U.S., a report released in 2005 by the National Alliance for Caregiving and the United Hospital Fund estimated that there were at least 1.3 million caregiving youths, between the ages of 8 and 18, nationwide.

Despite these staggering figures, young carers are often an invisible population of caregivers, partly because there are limited methods to capture the voices and statistics of young people, and partly because it is the norm to think of children as requiring care, not providing it. The needs of caregivers – both young and old – must be addressed, particularly in light of the

fact that the number of Canadians who will require care is rapidly rising (for instance, a 2012 report from the Alzheimer Society of Canada predicts that by 2031, the number of individuals living with cognitive impairment, including dementia, may reach 1.4 million - this nearly doubles the 2011 figure of 747,000 Canadians).

### THE DAY-TO-DAY IMPACT

Because young carers are often overlooked, they typically do not receive the care and support that they themselves need - which is especially troubling because they are a group that is typically more vulnerable, and require help and resources the most.

#### **WITHOUT THE PROPER SUPPORT, YOUNG CARERS MAY ENCOUNTER EDUCATIONAL, HEALTH, AND SOCIAL BARRIERS THAT CAN LAST A LIFETIME.**

These barriers translate into costs and lost opportunities for young carers and for society as a whole.

As a result of their age and their stage in life, young carers tend to be less flexible with their careers and ability to take time off work. Trying to balance school, work, and social activities with their heavy responsibilities at home can be daunting and may at times seem impossible. Many young carers have yet to establish their own path of post-education, marriage, and children. The time that they spend caring for their loved ones compromises and sacrifices many aspects of their personal lives.

With this significant responsibility, there is also a shift in power and a change in the dynamics of the caregiver/patient relationship at a young age. As a result of these unique obstacles that young carers face, there is not only the need to provide them with the appropriate resources, but there is also a growing concern that the individuals they are caring for may not be receiving the level of care that they should be. Asking young carers to provide medication and emotional support, with fewer financial resources to support treatment and/or accessibility options, imposes significant pressures that are difficult to work through and to appropriately balance.

### THE EMOTIONAL IMPACT

The emotional toll of caring for an ailing parent or relative can be incredibly burdensome, particularly without a network of support. Adolescent caregivers, especially teenagers, often face a different set of challenges than adult caregivers. As The Change Foundation observes, young carers often grow up quickly and lose their childhoods too early.

#### **THEY CAN EXPERIENCE FEELINGS OF ANGER, ISOLATION, LONELINESS, AND GRIEF - WITH SOME YOUNG CARERS SUFFERING FROM DEPRESSION OR ANXIETY.**

For many young carers, their school and work suffers because of

### MEMORY BALL

In 2011, a group of young individuals affected by Alzheimer's disease in different ways established the Young People Against Alzheimer's (YPAA) to raise awareness among a young demographic through a series of events and initiatives, including its annual Toronto-based gala, Memory Ball. The event is targeted at young professionals and raises funds for the Alzheimer Society of Toronto, as well as provides an opportunity for young caregivers to meet and connect.

To date, the Memory Ball has raised nearly \$500,000. "We wanted to do something to raise awareness and funds for a disease that we felt was completely misunderstood by our generation," says Kathryn Fudurich, a co-founder of Memory Ball whose mother was diagnosed with early-onset Alzheimer's disease in her early fifties.

"This disease is still misrepresented as only 'an old person's illness' and that's something we have been trying to change. We are also attempting to create an online community for those with parents under age 65 who have been diagnosed to come and connect. From personal experience, I know that finding someone who is not only going through the same thing as you, but who also is in a similar life stage to you, offers support and relief that is hard to beat."

their enhanced responsibilities and they typically have limited time to socialize with their peers or to participate in extracurricular activities. For others, though, the additional obligations help build self-esteem, compassion, resiliency, and independence, and they learn many important life lessons at an early age.

Dr. Peter Rabins, director of geriatric psychiatry at Johns Hopkins University, says that for teenagers, caregiving is difficult in part because it is unusual. "It's a huge adjustment, even for very well-adjusted kids," notes Dr. Rabins who co-authored *The 36-Hour Day: A Family Guide to Caring for People who have Alzheimer Disease, Related Dementias, and Memory Loss*.

Balancing the day-to-day and emotional impact of caregiving is difficult, but fortunately with greater awareness and education, there are support networks to lean on, and the list of available resources continues to grow. →



## SPEAKING FROM EXPERIENCE

### ADVICE FROM ONE YOUNG CARER TO ANOTHER

When we asked a young carer, Kathryn Fudurich, if there was any advice that she could share with others, she had the following suggestions based on her personal experience caring for her mother and her grandfather with dementia.

#### MAKE TIME FOR YOURSELF AS MUCH AS POSSIBLE.

☺☺ Look out for the health of yourself and the other caregivers in your family, as well as the person living with Alzheimer's disease.

☺☺ Take care of your mental health so that you can be as present as possible throughout what will be a long, tiring, and loving road.

#### MAKE TIME FOR THE PERSON WITH ALZHEIMER'S AS STRESS FREE AS POSSIBLE.

☺☺ Plan for outings, activities, and future obstacles with your loved one so that you can prevent high stress and uncomfortable situations.

#### TRY TO SQUEEZE OUT EVERY GOOD MOMENT THAT YOU CAN - WHILE YOU CAN.

☺☺ Try not to take out the sadness and confusion on the person who is struggling because in a few months you will long for the days when that person was just mixing up cutlery or forgetting to put on socks.

#### BE PATIENT AND UNDERSTANDING.

☺☺ As is often the case, a parent or loved one who is sick might not be in the position to remind you that this is not his or her fault, and it becomes your job to remind yourself that patience and understanding need to be practiced.

☺☺ Writing things down helps to channel any negative emotions that you may be experiencing and serves as a reminder to take it easy throughout this process.

☺☺ It is up to you to be the one to take a breath, to sit back and re-evaluate a situation that might not be going well and to try to find solutions.

#### TRY YOUR BEST TO TAKE THINGS DAY BY DAY.

☺☺ No matter what the scenario, be it finances, career, even some relationships, it is best to wake up and focus on the day and the week ahead. Focus on how you're going to get through that. Alzheimer's disease progresses, so you will have to roll with the punches and that is not always easy.

#### AS THINGS CHANGE, FIND SUPPORT IN ONLINE MATERIALS, COUNSELLORS, AND THE MEDICAL COMMUNITY.

☺☺ This is important so that you can discuss all your questions and frustrations and heartache. Talk about how this is affecting you, the person you are caring for is only as good as the person who is caring for him or her.

Importantly, when it comes to awareness and education, Kathryn says, "I have definitely noticed the increase in resources for children of people living with early onset Alzheimer's, as well as an increase in representation of this demographic in the news, in the medical community, and in my own network. When this started for me with my mother's diagnosis I was 21, the majority of the people I connected with on the complexities of dealing with this diagnosis of a parent were middle aged, with parents going through the same thing as my mother, but age 70 and over. I found comfort in these bonds and relationships - but it was when I finally met others my own age (apart from my brothers), young women and men who were facing the same obstacles as I was career-wise, socially, and emotionally, that I felt more understood and felt a little relieved." 🌱

# Dementia

## A GROWING HEALTH CONCERN FOR INDIGENOUS PEOPLE



**A**lzheimer's disease and related dementias (ADRD) are a growing health concern for Indigenous populations in Canada. Rates of ADRD are on the rise in Indigenous communities, and are higher among Indigenous individuals than non-Indigenous individuals. Research in Alberta, Canada found that the prevalence of dementia among the First Nations population in that province in 2009 was 34% higher than the rate for non-First Nations individuals (7.5 cases per 1,000 people versus 5.6 per 1,000). Additionally, more recent research suggests that

**INDIGENOUS PEOPLE MAY BE EXPERIENCING THE ONSET OF DEMENTIA AN AVERAGE OF TEN YEARS EARLIER THAN NON-INDIGENOUS PEOPLE. —>**

There are three distinct groups of Indigenous people in Canada: First Nations, Métis, and Inuit. An alternate term for the same three groups is “Aboriginal peoples.”

## FACTORS INCREASING RISK OF DEMENTIA

Canada’s Indigenous communities may be at an increased risk of developing ADRD due to higher rates of risk factors associated with dementia, such as diabetes, hypertension, cardiovascular disease, and obesity. Indigenous populations are also more likely to be affected by the social determinants of health, some of which are linked to increased risk of dementia, including lower income level and lower levels of education.

According to the World Health Organization’s website, “**The social determinants of health** are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.”

Historical trauma also likely plays a role in the increased risk, through the stresses experienced as a result of prejudiced assimilation policies like the residential school system. In Canada, the Indian **residential school system** was a network of government-sponsored religious boarding schools for Indigenous children. The system was created to assimilate Indigenous children into Euro-Canadian culture. Attendance was mandatory for those who lived in one of the many Indigenous communities without a day school. This system forcefully and traumatically removed Indigenous children from their families, depriving them of their culture and languages, and exposing many of them to physical, emotional, and sexual abuse. An estimated 150,000 Indigenous children attended residential schools. The last residential school closed in 1996.

## INDIGENOUS CULTURE AFFECTS EXPERIENCES OF DEMENTIA

Research has uncovered that Indigenous individuals have unique cultural perceptions of dementia that affect their experiences of the disease. Dr. Kristen Jacklin, a professor at the University of Minnesota, is a medical anthropologist specializing in Indigenous health research who has studied this subject extensively.

“Memory loss during aging may be considered natural and normal by Indigenous people,” explained Dr. Jacklin.



“THEY DON’T NECESSARILY VIEW IT AS A NEGATIVE EXPERIENCE, BUT INSTEAD THINK OF IT AS A PART OF THE CIRCLE OF LIFE, LIKE A SECOND CHILDHOOD AS THEY PREPARE TO RETURN TO THE CREATOR.”

This worldview means there tends to be less stigma associated with dementia in Indigenous communities. Interestingly enough, there are no specific words for “dementia” in Indigenous languages in Canada. Instead, there are gentle or humorous adjectives to describe the symptoms or state of mind, such as being confused, forgetful, or mixed up.

## CHALLENGES WITH DEMENTIA DIAGNOSIS & CARE IN INDIGENOUS COMMUNITIES

“Since memory loss is not necessarily associated with illness, Indigenous people may not think to access health and social services in the early stages of dementia,” said Dr. Jacklin. Once they do decide to access medical care, Indigenous people face unique challenges with getting a diagnosis. For instance, some Indigenous people have difficulty accessing services due to their geographical location - they live in remote locations with limited or no health care services, and may have to travel long distances to access care. Where there are local health care providers, they may lack knowledge and training about dementia. Moreover, standard cognitive assessment tools, which are based on the English language and western education systems, are not appropriate for all cultures.

Recent progress has been made by the CCNA Team 20 research group to address some of these challenges. For example, a series of culturally-safe fact sheets have been developed to assist with education. Also, a new culturally-appropriate tool, known as the Canadian Indigenous Cognitive Assessment (CICA), has been developed to screen for dementia among Indigenous people in Canada. The CICA is now in the process of being validated to ensure that the results from the tool are consistent with assessments by medical professionals.

**Caregiving practices** are heavily influenced by culture, including traditional beliefs and historical experiences. Research has repeatedly shown that the family is most often the primary or sole provider of care for Indigenous individuals living with dementia. While in some cases this happens out of necessity, more often it is because of cultural values that emphasize the interdependence of family, reciprocity, and respect for elders. In many Indigenous communities, elders with dementia are cared for at home for as long as possible, with the support of family and other community



## ABOUT CCNA TEAM 20

The Canadian Consortium for Neurodegeneration in Aging (CCNA) is a research hub focused on investigating neurodegenerative diseases that affect cognition in aging. The CCNA was launched in 2014 by the Canadian Institutes of Health Research (CIHR). CCNA teams are located across the country, each with their own independent research program. Team 20 has two focus areas: rural and Indigenous. Dr. Jacklin is the co-lead for this team.

members. However, the rapidly growing number of individuals with dementia is presenting a challenge for such informal caregiving, as are changing family structures and urban migration.

When a loved one with dementia is cared for at home, family caregivers should not be required to assume this immense responsibility on their own - they need external support.

### UNFORTUNATELY, THERE ARE MANY SERVICE GAPS AND INEQUITIES WHEN IT COMES TO THE HEALTH CARE PROVIDED TO CANADA'S INDIGENOUS GROUPS.

Dr. Jacklin and her colleagues conducted research about informal dementia caregiving among Indigenous communities in Ontario, Canada and reported that indigenous people often have poor access to mainstream services or may prefer to avoid them altogether because of institutional barriers such as deeply-embedded mistrust of the health care system. "Through that research, we concluded that although family caregiving models have many strengths, there remains a great need for culturally-safe programs, services and policies to support these Indigenous informal caregivers," said Dr. Jacklin.

When family members can no longer care for their loved one at home, or when there is no family to provide care from the outset, the care options for an Indigenous person with dementia are incredibly limited. Most Indigenous communities do not have long-term care facilities so individuals with dementia must relocate, leaving family, friends, home, and their land behind. For Indigenous people, moving to a long-term care institution can be especially traumatic, triggering distressing memories of the residential school system. Likewise, sending elderly individuals with dementia out of the community can be particularly harrowing for those left behind, reminiscent of the "sixties scoop" when thousands of Indigenous children were taken away from their homes by child-welfare service workers and placed in foster care or were put up for adoption, in most cases without the consent of their families or bands. "Taking elders out of their communities is an

injustice," emphasized Dr. Jacklin. "We need to find ways to keep older Indigenous people in their communities."

When it comes to researching, diagnosing, and caring for individuals with dementia, it is clear that the Indigenous population needs - and deserves - a customized, culturally-grounded approach.

## DEMENTIA SIMILARITIES IN OTHER PARTS OF THE WORLD

An academic review conducted by Shi et al., published in June 2015 in *International Psychogeriatrics*, investigated the prevalence of dementia in Indigenous populations worldwide. While the available research was limited, the researchers were able to analyze 15 studies from five countries: Canada, Australia, the U.S., Guam, and Brazil. The researchers found that study designs varied significantly, as did the findings - dementia rates were found to range from 0.5% to 20% in the Indigenous populations examined. The researchers nevertheless concluded that the "prevalence of dementia among Indigenous populations appears to be higher than it is for non-Indigenous populations" - a result consistent with previous findings.

A 2010 literature review prepared by Arkles et al., entitled "Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples: A Life Cycle Approach," found that dementia prevalence was almost five times higher among Indigenous Australians than in the general population. Consistent with research findings in Canada, this research uncovered that dementia is presenting at an earlier age in Australian Indigenous peoples (compared to non-Indigenous Australians) and that Australian Indigenous peoples also possess a unique cultural perspective of the disease, with many not viewing it as a medical condition. 🌐

According to research out of Alberta and British Columbia, Canada, First Nations men, on average, have higher rates of dementia compared to women - yet another aspect about dementia that is unique to Indigenous individuals. This finding is the opposite of what is found in the general population, where females are much more likely to experience dementia than their male counterparts. More research is needed to learn why this reverse trend exists among First Nations communities. One hypothesis is that there may be differences between Indigenous men and women when it comes to health-seeking behaviours, with women being less likely to seek care and therefore being under-diagnosed.



# THERE'S NO PLACE LIKE HOME

Unless Where You Live Increases Your Alzheimer's Risk

## **R**URAL VS. URBAN LIVING

If someone asked you whether you would rather live in the city or in the country, you are likely to answer this question without hesitation based on your personal preferences, and whether you enjoy the hustle and bustle of urban centers, or the quiet seclusion of rural living. Are you aware, however, of the impact of each location on your overall health? And that one of these locations, more than the other, can actually increase your risk of developing Alzheimer's disease?

On a basic level, country living offers open space, nature, fresh air, more opportunity for exercise outdoors, and the simplicity of day-to-day life. In the city, there are public transportation systems, attractions, and entertainment, but also confined spaces, crowds, and the pitfalls of traffic congestion and air pollution.

Dr. Tom Russ, a Clinical Lecturer at the Center for Clinical Brain Science at the University of Edinburgh, conducted a systematic review of 51 academic papers published over the last few decades and compared the data on the medical records of more than 12,500 people from around the world, including the U.K., U.S., Canada, and even smaller nations like Nigeria and Peru. Dr. Russ and his colleagues found that

**INDIVIDUALS IN RURAL AREAS WERE AT A GREATER RISK FOR ALZHEIMER'S DISEASE THAN THOSE IN MORE URBAN TOWNS AND CITIES.**

Dr. Russ noted that "rates of dementia as a whole did not differ greatly between rural and urban dwellers, but for Alzheimer's specifically there was a marked difference." He continued, "we don't really know the mechanism. It could be to do with access to health care, exposure to some unknown substance, socioeconomic factors, or a number of other factors. We're currently looking into this question in more detail. A priority for researchers will be to identify what causes the difference, so that more can be done earlier in life to prevent people from developing the incurable condition."

While researchers continue to explore the relationship between rural living and dementia risk, those in rural areas can try to improve their brain health by engaging in those activities that contribute to better health amongst urban dwellers (such as making healthy food and diet choices, and participating in fitness classes and organized community sports).

**WHILE RURAL LIVING CAN BE SIMPLE AND RELAXING, REMOTE LOCATIONS ALSO CREATE SOME UNIQUE CHALLENGES.**

There are, however, certain identifiable gaps between urban and rural communities that cannot be addressed at an individual level, such as lack of access to medical care and support. The simplicity of living in more rural areas should not equal isolation, loneliness, and lack of accessibility, each of which have other well-documented psychological impacts. As the number of individuals with Alzheimer's disease continues to climb, efforts towards treatment and prevention are essential.

**HOME TO THE LARGEST POPULATION OF ALZHEIMER'S SUFFERERS**

In the small village of Yarumal, located in the city of Antioquia in Colombia, there is the highest per capita rate of Alzheimer's disease

in the world. What is so unusual, and making this even more tragic, is that the majority of people in this village who develop Alzheimer's disease were diagnosed by the age of 45, with some having been diagnosed as young as 32 years of age.

Researchers have now discovered that most residents of this village share the same bloodline, and comprise an extended family of more than 5,000 people. Many of the residents have a rare genetic biomarker known as the Paisa mutation that guarantees the individual will develop the disease. While the Paisa mutation is present in only about 2% of the world's Alzheimer's population, in Antioquia, it is present in approximately 30%.

**THE UNUSUALLY HIGH INCIDENCE OF EARLY-ONSET ALZHEIMER'S HAS THRUST THIS SMALL VILLAGE TO THE FOREFRONT OF GLOBAL EFFORTS TO FIND A CURE FOR THIS DEVASTATING ILLNESS.**

Yarumal is one of few places in the world where researchers will know, with virtual certainty, that a sizable proportion of individuals will develop Alzheimer's disease (unlike the more common type of Alzheimer's disease, which may or may not develop in any aging person). Based on the results of a genetic test, researchers not only will know which residents will develop Alzheimer's disease, but also approximately what age they will get it. Researchers can therefore work with those individuals who carry the Paisa mutation to test treatments before the disease begins to take its toll.

In one of the most significant initiatives currently underway, researchers are providing a group of individuals who tested positive for the Paisa mutation with an experimental drug that blocks or slows the formation of amyloid plaques in the brain. The formation of amyloid plaques is thought to contribute to the degradation of the neurons (nerve cells) in the brain and the subsequent symptoms of Alzheimer's disease.

This multimillion-dollar drug trial involves leading scientists, pharmaceutical companies, and representatives of the National Institutes of Health (NIH). The trial is led by Dr. Eric Reiman, Executive Director of Banner Alzheimer's Institute, and one of the leaders of the Alzheimer's Prevention Initiative.

Because the average person develops Alzheimer's disease after the age of 60, prevention trials pose significant logistical problems. "It would take too many healthy volunteers and too many years to evaluate a trial," said Dr. Reiman. "You'd have to wait too long for people to develop Alzheimer's." What sets this drug trial apart is that the patients, most of them in their 30s, will begin treatment long before they show symptoms of the disease.

Jason Karlawish, Co-Director of the Penn Memory Center, gave a presentation at Columbia University on March 27, 2017 where he →

noted that “if the drug works, we will have discovered a way to slow the natural history of decline. It will be proof of concept for a therapy for these patients but as well for the far larger population of patients at risk for Alzheimer’s later in life. With this kind of result, we need to begin to imagine a future when an amyloid test diagnoses Alzheimer’s disease and, in turn, a prescription for a drug that targets amyloid.”

In his presentation, Karlawish also commented on the legal, ethical, and social implications of this kind of study. One key ethical challenge for researchers is the repercussions of conducting genetic testing on members of a community that do not have access to genetic counselors. “The standard is not to know. This presents a dilemma. The custom is not to learn your gene result. How can you perform a clinical trial testing a drug in persons who have the gene?” In order to help address this dilemma, a registry and associated study are recruiting both carriers and non-carriers of the gene, so that volunteers can participate in the study without learning their genotype. Additionally, Karlawish advised that “researchers provided healthcare to all participants, and implemented a social plan that will remain post-trial, providing education and care strategies and support ... Colombia is working with research to make the plan sustainable after 2022 by providing access to therapy and bringing genetic testing and counseling to the nation.”

In terms of what this means for the future, Karlawish concluded, “even if the clinical trial is ineffective, researchers will have raised awareness. If the therapy is effective, a carrier of the ADAD gene mutation could receive an intervention before signs of dementia are present.” The clinical trial is currently active and will run until 2022.

The investigative television program 60 Minutes produced a segment entitled “The Alzheimer’s Laboratory” (November 27, 2016) that shared some of the emotional stories of the residents of Antioquia and the daily struggles that they encounter knowing that many of them will develop Alzheimer’s disease - which, for some, includes the decision not to have children.

Broadcast journalist Lesley Stahl emphasized that this community is “offering researchers something they have never had before -

### **A WAY TO TEST WHETHER INTERVENING YEARS BEFORE PEOPLE START HAVING SYMPTOMS, MIGHT HALT THE DISEASE IN ITS TRACKS.**

Answers are still years away, but with more than a thousand Americans developing Alzheimer’s every day, a way to prevent it cannot come soon enough.” Quite remarkably, these individuals, who come from such a remote area of the world, “have the potential for informing all of us, globally, about a path forward for conquering Alzheimer’s.” 🌐

## **LIFESTYLE**

Making certain lifestyle choices, particularly when it comes to your diet, can significantly impact your risk for developing Alzheimer’s disease, according to Dr. Michael Greger.

In his article entitled “Where are the Lowest Rates of Alzheimer’s in the World,” Dr. Greger warns of the dangers of the so-called “Western diet,” which is characterized by higher intakes of red and processed meat, refined sugars and grains, alcohol, and high-fat dairy products, with minimal intakes of fruits, vegetables, whole grains, nuts, and fish. Mounting evidence from ecological studies indicates that the contemporary Western dietary pattern is strongly associated with negative health outcomes, including an increased risk of developing Alzheimer’s disease.

Dr. Greger notes that research has shown that

### **DEMENTIA IS MORE A DISEASE OF LIFESTYLE THAN GENETICS.**

There is an emerging consensus that the same foods that clog our arteries can also clog our brains. As Dr. Greger observes, “Alzheimer’s rates of Japanese-Americans living in the U.S. are closer to that of Americans than to Japanese. When people move from their homeland to the United States, Alzheimer’s rates can increase dramatically. Therefore, when Africans or Asians live in the United States and adopt a Western diet, their increase in Alzheimer’s risk suggests that it’s not genetics.”

Of course, one does not have to move to the West to adopt a Western diet. In a 2014 study published in the *Journal of Alzheimer’s Disease*, researchers found that changes in Japan’s dietary habits (due to the influx of Western foods) was highly related to the dramatic increase in Alzheimer’s disease, with the same trend being observed in other developing countries and their changes in national diets.

The fact that diet is a modifiable factor - one that is within our control to regulate - should make it a relatively easy lifestyle choice to change for the better, not only in an effort to improve our brain health, but also for our overall physical well-being, since diet is a contributing factor to so many other health problems (such as diabetes, high blood pressure, and obesity).



PHOTO CREDIT: DE HOGEWEYK



# A HOME WORTH REMEMBERING

## Dementia Villages

A stroll through the Dutch community of De Hogeweyk is a journey to what could be the future of dementia care. Located within the small town of Weesp, just outside of Amsterdam, De Hogeweyk is a tiny enclave that houses 152 men and women who all suffer from severe dementia and require around-the-clock care. On the surface, this village appears no different from any other neighbourhood in the Netherlands. The village is comprised of various restaurants, cafés, shops, a movie theatre, gardens, and a town square. However, apartments and buildings surround the entire community and fully enclose its inhabitants, with the exception of a single entrance that is monitored day and night. While the residents are free to roam within the village on their own, they remain under surveillance at all times and if they get lost or confused, there is always a “villager” nearby to provide assistance. Even the people who work in the various “businesses” are trained in dealing with people with dementia who help ensure that the village is constantly a secure place for its residents.

De Hogeweyk has been dubbed the world’s first “dementia village.” Its co-founder, Yvonne van Amerongen, had worked in a nursing home for decades and throughout her career became increasingly aware of the need for alternative ways of providing care for those suffering from dementia. Rather than a traditional care facility, residents of De Hogeweyk live in a house with proper living rooms and bedrooms that hosts six to seven people with dementia, plus caregivers. The houses are categorized into four design styles: “Goois” (upper class), “traditional,” “urban,” “cultural/cosmopol-

itan.” Recognizing the diminishing short-term memories of its residents, there are homes that are styled as they might have appeared decades ago. Sometimes referred to as “reminiscence therapy,”

**THE GOAL IS TO PROVIDE A SENSE OF COMFORTING FAMILIARITY TO INDIVIDUALS WHOSE DEMENTIA CAN CREATE CONFUSION AND ANXIETY.**

De Hogeweyk opened in 2009 and will celebrate its ninth anniversary this year. There is a perpetual waiting list for the 152 positions, as residents typically only leave when they pass away. Although the cost is quite steep (approximately C\$8,000 per month), the residents pay no more than approximately C\$3,600 per month to the government, which in turn tops up the amount that the government pays the non-profit organization that runs De Hogeweyk.

Some critics oppose the idea of creating this environment, arguing that residents are being misled. In a 2013 interview with CNN, van Amerongen disputed a reporter’s suggestion that there is an element of deception.

“Why should they feel they are fooled? We have a society here. That supermarket is not a show. It’s a real supermarket,” she said. “Maybe we’re fooling them when we say, ‘It’s okay what you’re



doing,' but that's because we want to help people enjoy life and feel that they are welcome here on this earth."

Proponents of De Hogeweyk, which include geriatric care experts from around the world, tout the dementia village as being the most compassionate type of dementia care offered anywhere.

"It's just so welcoming, warm, and human," said Dr. Megan Strickfaden, a design anthropologist with the department of human ecology at the University of Alberta. She has visited De Hogeweyk twice and interviewed many of the residents, care-givers, and families.



**"YOU CAN FEEL THAT PEOPLE ARE COMFORTABLE, THAT THERE'S A SENSE OF WELL-BEING AND BELONGING THAT YOU CANNOT FEEL IN A TYPICAL CARE HOME ENVIRONMENT. IT'S A DEMENTIA-FRIENDLY COMMUNITY ON A MICRO-SCALE."**

Dr. Strickfaden's admiration is echoed by Alex Mihailidis, Scientific Director of AGE-WELL, a federally-funded research network that is exploring and promoting the development of new technologies to help older Canadians stay independent longer. "The beautiful thing about this concept is providing that sense of freedom (for residents) but in a controlled way, while still giving the care that they need and ensuring that they're safe," said Mihailidis in an interview with Mind Over Matter®.

Dr. Strickfaden also disagrees with the notion that De Hogeweyk is an illusion. "I'd say quality of life has been designed into the spaces - the smell of cooking creates the opposite of illusion, it creates the feeling of a home," she said. "You could call it a 'hyper-reality.'"

In 2014, a smaller-scale version of De Hogeweyk was opened at the Georgian Bay Retirement Home in Penetanguishene, Ontario. There is 25,000 square feet of space indoors and outdoors, with the design being retro 50s and 60s -

**THE IDEA BEING TO MAKE DEMENTIA PATIENTS FEEL COMFORTABLE IN AN ENVIRONMENT THAT EVOKES THE FAMILIAR SETTING OF THEIR YOUTH.**

The residents can enjoy all the meaningful activities of everyday life, including a grocery store, barber shop, coffee shop, beach, bowling, movies, and even a garage with a vintage car (1947 Dodge) to trigger fond memories.

Another project inspired by the De Hogeweyk model has been recently announced for Langley, British Columbia. Comprised of six, single-storey cottage-style homes and a community centre, "The Village" will be home to 78 individuals with dementia and 72 specially-trained staff. The Village will have a similar design to De Hogeweyk, but in a rural setting on five acres of land. The residents will be able to shop, have a coffee, walk their dogs, and take part in activities such as gardening by themselves. An eight-foot perimeter fence will surround the site, and be designed to blend in with its surroundings. The developers, Verve Senior Living, hope to have The Village completed by April 2019. They estimate that it will cost between \$190 to \$245 a day per person (or \$6,000 to \$7,500 a month) to live in this privately-funded project. Verve Senior Living has indicated that they would be open to working with the government to make The Village more affordable so that there is a real community of people of different income levels.

Aside from these two Canadian projects, the De Hogeweyk model has not been widely copied in North America - even if the concept is widely admired. Cost is one of the greatest barriers to making self-contained villages like De Hogeweyk the standard in dementia care. The cost to build the community was slightly over \$25 million.

Mihailidis believes that the long-term social benefits might outweigh the up-front expenses of building such a project, and Dr. Strickfaden suggests that the monthly costs for residents are not far out of line with current Canadian facilities. "I don't think there's an economic barrier. There may be an ideological barrier. Just in how we think about care provision for people with dementia," she said.

Dr. Strickfaden said that she regularly receives inquiries from people who want to learn more about De Hogeweyk. She believes that many facilities are taking inspiration from the Dutch model and are adopting key elements of the village, even if they are not building full-scale imitations. The success of the dementia village model is generating ideas in other countries across Europe, and similar villages have opened in Rome, Italy, and in Switzerland.

Indeed, the extraordinary community on the edge of Amsterdam is proving to be quite influential. As society struggles with an impending wave of dementia, and the inherent challenges of caring for an ever-growing cohort of vulnerable people, it is comforting to think that this unique care model may ultimately catch on worldwide. 🌐



## TRAUMATIC BRAIN INJURIES COMMON IN VICTIMS OF INTIMATE -PARTNER VIOLENCE, BUT OFTEN UNDIAGNOSED

The prevalence of intimate-partner violence (IPV) is striking, affecting nearly one third (30%) of all women who have been in a relationship worldwide, according to a 2013 estimate by the World Health Organization. It is estimated that between 40% and 92% of those women incur head injuries, and almost half experience strangulation, both of which can result in traumatic brain injury (TBI).

TBI is an alteration in brain function caused by an external force or lack of oxygen. TBIs can range from mild (commonly referred to as a concussion) to severe (which can lead to death). TBIs of any severity can have serious negative consequences including:

» Physical disabilities, such as difficulty with balance and vision, headaches or migraines, sensitivity to sound and light, sleep disturbances and fatigue;

» Cognitive challenges, such as short-term memory loss, decreased ability to concentrate, and troubles problem solving;

» Executive functioning problems, such as difficulty with long-term planning and goal setting, and difficulty completing tasks;

» Behavioural and emotional symptoms, such as increased impulsivity, tension and anxiety, and hyper-vigilance; and/or

» Psychosocial impacts, such as difficulties with work and attending appointments, challenges in interpersonal relationships, and substance abuse.

While sometimes the symptoms of TBI are temporary, in other instances TBI causes permanent disability. A victim of intimate-partner violence may suffer a TBI without knowing it if she had no severe trauma or obvious symptoms at first, or if she did not lose consciousness.

**THE CONSEQUENCES OF TBI CAN CHANGE A WOMAN'S LIFE FOREVER, IMPAIRING HER DAILY FUNCTIONING, AND CAUSING HER TO BE LABELLED AS "DIFFICULT," "MENTALLY ILL," "OVERDRAMATIC," OR "DRUNK."**

She may struggle to hold a job and may require more effort to care for her children. The symptoms of TBI may even make it more difficult for her to leave the abusive relationship by impairing her ability to assess danger, make safety plans, live independently, access services, navigate the criminal justice system, or live in a women's shelter.

In many cases of IPV, head injuries occur on numerous occasions, sometimes without time to heal between injuries. Athletes and military personnel who have experienced "multiple mild TBIs" →

Intimate-partner violence (IPV) is a pattern of physical and/or sexual violence inflicted by an intimate or ex-intimate partner. Global estimates published by the World Health Organization indicate that about 1 in 3 women have experienced either physical and/or sexual intimate partner violence or non-partner sexual violence in their lifetime (although this figure is likely higher because cases of abuse are often underreported).

The vast majority of victims of reported intimate violence are women (95%).

- although perhaps with an opportunity to heal between injuries - have been studied at length, and such cumulative damage has been found to be particularly dangerous (e.g., associated with depression, suicidal thoughts, and Alzheimer's-like symptoms).

In fact, much of what is known about recurrent TBI has been discovered through research on these groups of individuals (namely, athletes such as boxers and football players, as well as individuals who have served in the military) who are prone to head injuries. Despite its prevalence, research on TBI specifically related to IPV is quite limited. Eve Valera, director of the Cerebellar Psychiatric Research Laboratory at the MGH Martinos Center for Biomedical Imaging and an assistant professor at Harvard Medical School, is one researcher who is trying to change that.

Dr. Valera, along with her colleague Aaron Kucyi, conducted the first study to examine the effect of TBIs on the brains of women who had been in abusive relationships. The study involved 20 participants who had experienced IPV-related traumatic brain injuries, recruited mostly from women's shelters. Using resting-state function magnetic resonance imaging (MRI), the researchers found that the severity (number and frequency) of TBIs was associated with reduced interaction between two areas of the brain essential for everyday functioning. Further, the less interaction that there was between those two areas of the brain, the worse participants performed on memory and learning tasks - evidence of impaired cognitive functioning. Their findings were published in the October 2016 issue of *Brain Imaging and Behavior*.

"We hope that our research will help increase awareness of how common it is for women who have suffered from intimate-partner violence to have traumatic brain injuries, and encourage emergency service workers such as police and paramedics to watch closely for these injuries, which can easily be missed," explained Dr. Valera. "Beyond that, we hope our work helps counsellors and advocates who work with abused women understand that TBIs can impair the efforts of these women to seek help or leave the abusive relationship."

"Our research is so important because these women are unique when it comes to their traumatic brain injuries," Dr. Valera continued.



**"THEY SUSTAIN THEIR INJURIES IN OFTEN BRUTAL AND RECURRENT WAYS THAT ARE DIFFERENT FROM WHAT ATHLETES AND MILITARY PERSONNEL EXPERIENCE. SO, TO REALLY UNDERSTAND THE CONSEQUENCES OF THEIR UNIQUE TYPE OF TBIS, WE CAN'T JUST EXTRAPOLATE FROM WHAT WE KNOW ABOUT OTHER PATIENT POPULATIONS. THE INJURIES AND THEIR CONSEQUENCES JUST AREN'T COMPARABLE."**

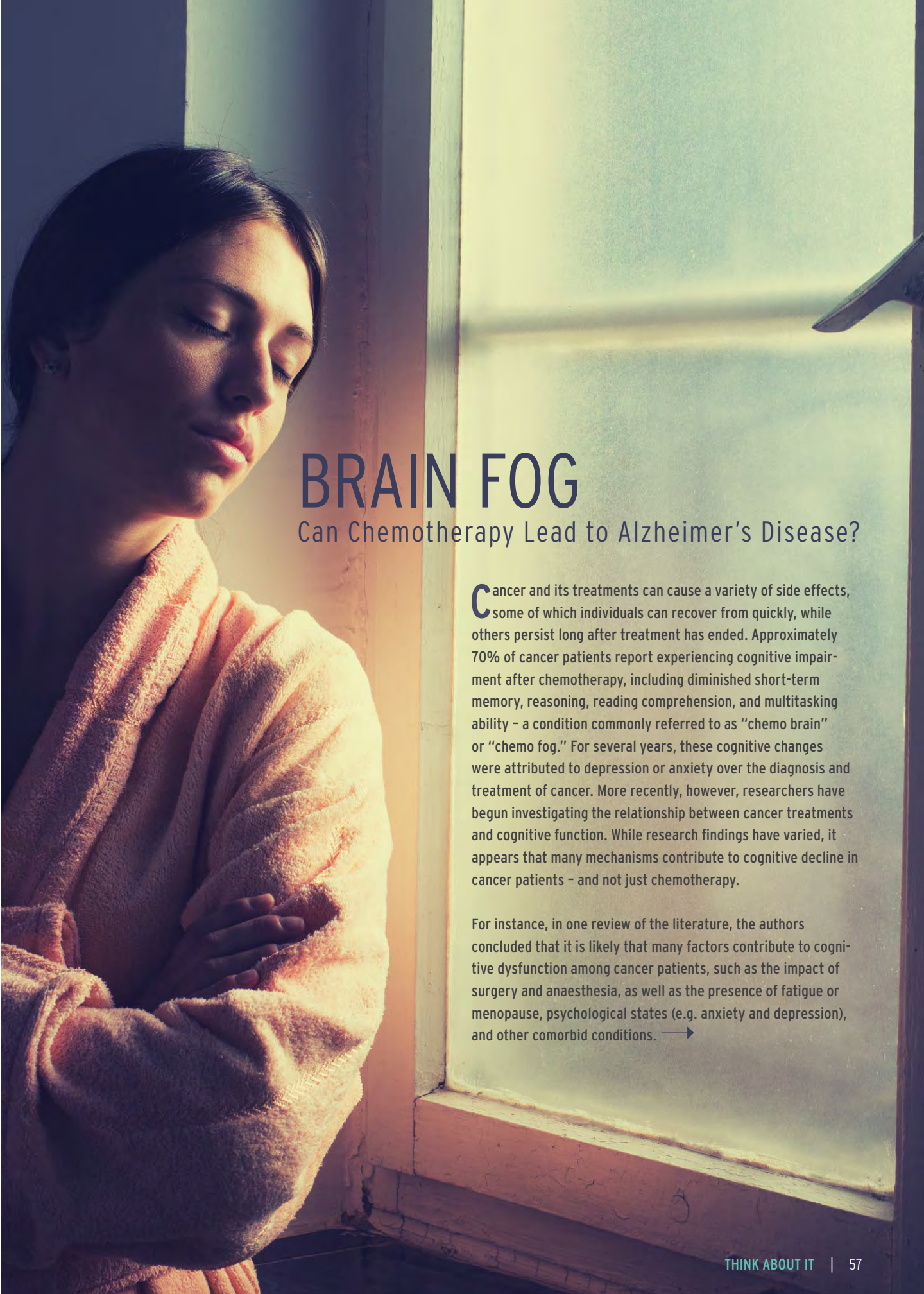
Individuals who experience recurrent brain trauma from repeated blows to the head can develop a neurological condition called **Chronic Traumatic Encephalopathy (CTE)**, historically referred to as dementia pugilistica. Symptoms include impaired cognition, confusion, psychosis, motor dysfunction, and behavioural change. CTE can emerge several years after brain trauma has occurred. Research on this condition originally focused on boxers, and more recently on a wider range of athletes (e.g., American football and hockey players), as well as military personnel who may sustain repeated blows to the head. An autopsy examination of a physically-abused woman who suffered dementia-like symptoms revealed that her brain pathology resembled that of a boxer with dementia pugilistica.

Women experiencing IPV-related TBIs struggle to recover quickly or properly for a variety of reasons. First, their TBIs are typically unacknowledged, which means that they do not receive any treatment or rest to recover. Additionally, their TBIs are often repetitive, and frequently occur in the context of other bodily injuries, extreme psychological stress, and adverse psychosocial circumstances - all of which, collectively, slow down the rate of recovery.

To better understand the unique nature of IPV-related TBIs, Dr. Valera and her colleagues have recently designed a new study that will involve a larger group of women and use a wider array of imaging techniques, as well as serum/blood measures. This larger study will allow her to investigate many questions that could not be fully addressed in the smaller study already completed. "We want to learn as much as possible about the consequences of repetitive mild traumatic brain injuries in women who've experienced intimate-partner violence so that we can recommend the most effective interventions to help these women," said Dr. Valera.

The new study will commence as soon as Dr. Valera and her colleagues are able to secure funding to support the research. Although she is currently seeking government funding, she is also open to other sources that may be accessible in a shorter time-frame. "Philanthropic support would be extremely helpful to get the project up and running quickly," Dr. Valera explained. "There is quite a bit of funding that goes to support research on TBIs in NFL football players, and Iraq and Afghanistan military personnel but almost none that I know of to support IPV-related TBIs. This seems ironic since the number of women likely being affected by TBIs via intimate-partner violence dwarfs the combined number of people affected in these other groups. Clearly, this work is critically needed, and it's needed now." 🌍





# BRAIN FOG

Can Chemotherapy Lead to Alzheimer's Disease?

Cancer and its treatments can cause a variety of side effects, some of which individuals can recover from quickly, while others persist long after treatment has ended. Approximately 70% of cancer patients report experiencing cognitive impairment after chemotherapy, including diminished short-term memory, reasoning, reading comprehension, and multitasking ability - a condition commonly referred to as "chemo brain" or "chemo fog." For several years, these cognitive changes were attributed to depression or anxiety over the diagnosis and treatment of cancer. More recently, however, researchers have begun investigating the relationship between cancer treatments and cognitive function. While research findings have varied, it appears that many mechanisms contribute to cognitive decline in cancer patients - and not just chemotherapy.

For instance, in one review of the literature, the authors concluded that it is likely that many factors contribute to cognitive dysfunction among cancer patients, such as the impact of surgery and anaesthesia, as well as the presence of fatigue or menopause, psychological states (e.g. anxiety and depression), and other comorbid conditions. →

A recent study published in *Neuroscience* suggests that the memory and thinking problems experienced by cancer survivors are not just the result of chemotherapy treatment but may start as tumors begin to form and develop. The researchers found that female mice with a form of breast cancer demonstrated impaired performance on learning and memory tests before chemotherapy drugs were administered.

The scientists first conducted a series of cognitive tests on the female mice (half of them with cancer, the other half without) to investigate the impact of the tumor on brain function. After the initial data was collected, the mice either received the chemotherapy drugs, methotrexate and 5-fluorouracil, or a saline solution. The mice were then retested on the same trials and some additional ones. Once testing was complete, the brain images, tissue and blood samples were used to analyze changes to brain structure and cytokine activity (proteins released by the immune system to help fight off infections or diseases).

The researchers found that prior to treatment, the mice with tumors performed worse on learning and memory tests compared to their healthy counterparts. After chemotherapy, the performance of cancerous mice worsened and the non-cancerous mice also showed signs of cognitive impairment.



“OUR WORK ISOLATED THAT THE CANCER IS RESPONSIBLE FOR SOME OF THE MEMORY AND THINKING COMPLAINTS EXPERIENCED BY CANCER SURVIVORS, AND THAT DRUG THERAPY ADDS TO THE PROBLEM,”

says Dr. Gordon Winocur, lead author on the study and senior scientist at Baycrest’s Rotman Research Institute. “Both factors independently affect brain function in different ways, which can lead to the development of other psychological disturbances, such as anxiety and depression.”

Through the study, the researchers were also able to identify three different, but related, brain changes caused by the progression of cancer and the drugs used in treatment:

1. As the tumor develops, the body's immune system responds by releasing cytokines to inhibit the cancer's development. The researchers discovered that the body's reaction causes inflammation in the brain's nervous system, which impacts its function;
2. Chemotherapy was found to limit the production of new brain cells in regions responsible for memory function, which leads to a loss of memory; and
3. The combination of tumor growth and chemotherapy led to shrinkage in brain regions that are important for learning and memory.

“Understanding the nature of the cognitive impairment and the underlying biological mechanisms are essential to the development of an effective treatment for chemo brain. Our work shows that a targeted approach addressing all three issues is necessary to successfully treat the condition,” explains Dr. Winocur.

“People are living longer thanks to more effective chemotherapy and cancer treatments. Addressing chemo brain will help improve a patient's quality of life since these side effects can lead to emotional and mental health issues that affect a person's ability to function in society.”

In another recent study, researchers from the Department of Neuro-



oncology at the University of Texas MD Anderson Cancer Center (Kesler et al., 2017) sought to investigate the risk of Alzheimer's disease (AD) in breast cancer survivors.

The researchers first identified a machine-learning algorithm that could accurately discriminate between healthy women and women with mild cognitive impairment (MCI) who later developed AD. The algorithm performed with 86% accuracy, consistent with previous studies of AD conversions (from MCI). The researchers then applied the algorithm to a separate sample of breast cancer survivors to predict individual probability of developing AD. Survivors with a history of chemotherapy treatment showed significantly higher AD probability compared to chemotherapy-naïve survivors, as well as healthy female controls. Survivors without a history of chemotherapy also demonstrated higher AD probability compared to healthy controls. The researchers therefore concluded that patients with breast cancer, especially those who received chemotherapy, may have an increased risk for Alzheimer's disease. Additionally, the findings suggested that breast cancer and/or chemotherapy may exacerbate an existing genetic risk for AD.

The researchers further found that chemotherapy-treated survivors who are older and have lower cognitive reserve (i.e. have a lower capacity to maintain normal cognitive function in the presence of brain pathology) are at an increased risk of developing AD, consistent with previous studies.

It is important to note that

**THE RESULTS OF THIS STUDY DO NOT SUGGEST THAT CANCER OR ITS TREATMENTS CAUSE AD, BUT POINT TO SHARED RISK FACTORS INCLUDING A COMMON NEURAL PHENOTYPE OF BRAIN STRUCTURE ALTERATIONS.**

In another study involving breast cancer patients, the researchers (Mehlsen et al., 2009) examined whether individuals receiving chemotherapy differed in cognitive changes during treatment compared with cardiac patients and healthy controls. The researchers recruited 34 cancer patients, 12 cardiac patients, and 12 healthy controls all between the ages of 18 and 65 years old. No significant change in neuropsychological testing between the three groups was observed at the various time points of testing. The researchers therefore concluded that chemotherapy does not confer an increased risk for cognitive dysfunction, nor does it protect against it.

However, there are several limitations of this study that may skew the results of cognitive performance, including the small sample size, the discrepancy in follow-up between the cancer patients (6 months) and the controls (3 months), and the wide age range. Moreover, immediate cognitive deficits may have been missed

as the cancer patients were evaluated too long after receiving chemotherapy.

**WHILE MANY STUDIES HAVE DEMONSTRATED THE ADVERSE EFFECTS OF CHEMOTHERAPY ON COGNITION SHORTLY AFTER ADMINISTRATION, THE LONG-TERM EFFECTS REMAIN LARGELY UNKNOWN. THIS IS BECAUSE ONLY A LIMITED NUMBER OF STUDIES HAVE EXAMINED THE LONG-TERM COGNITIVE IMPLICATIONS OF CANCER TREATMENT.**

In one such study, the researchers found that breast cancer survivors over the age of 65 who received chemotherapy exhibited neurocognitive deficits ten years after chemotherapy compared to their healthy counterparts (Yamada et al., 2010). The cancer survivors not only performed considerably worse on dementia screening, but also scored significantly lower on domains of attention, working memory, psychomotor speed, and elements of executive functioning on neuropsychological testing.

In another study, the researchers investigated whether chemotherapy for breast cancer was associated with worse cognitive performance more than 20 years after treatment (Koppelmans et al., 2012). In total, 196 patients who underwent cyclophosphamide, methotrexate, and fluorouracil (CMF) chemotherapy between 50 and 80 years of age were recruited. The researchers found that, even 20 years after the completion of CMF chemotherapy, treated patients performed worse on learning, verbal memory, information processing, inhibition, and psychomotor speed than random population controls. Interestingly, though, the chemotherapy group performed no differently on dementia screening than did the random controls.

Importantly, other studies involving breast cancer patients have shown some reversibility after the cessation of chemotherapy (Jansen et al., 2011). One study actually observed that patients generally performed better on neuropsychological testing as time elapsed since their chemotherapy treatment. However, 21% of the participants still displayed deficits on neuropsychological testing nine months post-treatment (on average), chiefly in verbal-semantic memory (Weis et al., 2009).

It is clear that cognitive dysfunction associated with cancer treatment, particularly chemotherapy, is a complex phenomenon. The research findings to date have been inconclusive or, at times, contradictory as it is difficult to dissect the effect of cancer itself, its effect on mood and energy, and its treatment on cognitive function. Accordingly, the term "chemo brain," though widely used, may be misleading, as it is unlikely that chemotherapy is the sole cause of cognitive impairment in cancer survivors. More research is needed to understand this condition. 🌐

# MIND OVER MATTER®

A WOMEN'S BRAIN HEALTH BOOK CLUB INITIATIVE

Interested in obtaining copies of Mind Over Matter® for an upcoming book club read or when you and your friends get together?

Thanks to the generosity of Brain Canada Foundation and Margaret Nightingale, we can provide your club or social group with copies of Mind Over Matter® free of charge.

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Journal writing  
is a voyage to  
the interior.

CHRISTINA BALDWIN

## NOTES TO REMEMBER

Women's Brain Health Initiative's unique and beautiful custom 120-page journal includes inspirational and informative messages about the best ways to protect your brain health.

The rich cover and the warmth of the paper will encourage even those who do not typically engage in journal writing to start capturing the moments that resonate with them each day.

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OCTOBER 2017 | GAGOSIAN GALLERY, BEVERLY HILLS  
**LA CELEBRITY CONVERSATION ON WOMEN'S BRAIN HEALTH**

(L-R) Tamara Mellon, Crystal Lourd, Melanie Griffith, Moderator Sharon Stone, Paula Wagner, Dr. Pauline Maki, Lynn Posluns

# Tomato Salad with Parmesan Crisps, Spinach and Oranges

🍴 SERVES 6 ⏱ TIME: 25 MIN

## PARMESAN CRISPS

1 cup freshly grated Parmesan cheese

## SALAD

2 cups small grape tomatoes  
6 cups baby spinach leaves  
1 small orange, peeled and cut into small wedges  
1/3 cup thinly sliced red onion

## MAPLE DRESSING

1 tsp minced garlic  
1/2 tsp Dijon mustard  
1 Tbsp cider vinegar  
2 Tbsp maple syrup  
3 Tbsp olive oil  
2 tsp lemon juice  
Pinch of salt and pepper

## INSTRUCTIONS

1. To make the Parmesan crisps: Preheat the oven to 375°F. Line a baking sheet with parchment paper. With a 1 Tbsp measuring spoon, place the cheese on a baking sheet, making 12 rounds. Bake for 8 minutes.

2. To make the salad: In a hot skillet, sear the whole tomatoes just until slightly charred. Set aside to cool.

3. On a large platter add the spinach, orange wedges, onion, tomatoes and crisps.

4. To make the dressing: Combine the garlic, mustard, vinegar, maple syrup, olive oil, lemon juice, and salt and pepper and pour over top of the salad.

## MAKE AHEAD

Prepare crisps up to a week in advance and the remainder of the salad early in the day. Dress just before serving.

## spinach

Spinach is packed with nutrients such as folate, vitamin E and vitamin K that can prevent dementia. Studies show that eating three servings of leafy greens a day such as spinach or arugula can delay dementia by 40%.

# MEMORY MORSELS®

— A WOMEN'S BRAIN HEALTH INITIATIVE —

Your diet is crucial to the maintenance of a healthy brain and functional independence as you get older. Memory Morsels® is a website dedicated to delicious, brain health recipes, brain health tips (our morsels), and great information to help keep your brain functioning the way you want.



## salmon

A diet rich in fatty oils, such as Omega 3s found in salmon, can help prevent the progression of dementia.



Source: Rose Reisman's *Rush Hour Meals* (Whitecap Books) By: Rose Reisman Photo: Mike McColl, from Rose Reisman's *Rush Hour Meals* (Whitecap Books)

## Hoisin Salmon with Ginger Slaw

 SERVES 4  TIME: 20 MIN

### INSTRUCTIONS

1. Preheat the oven to 425°F (220°C).
2. **To make the coleslaw:** In a large bowl, whisk together the orange juice, vinegar, hoisin, sesame oil, ginger, honey, Sriracha and cilantro. Add the coleslaw and toss until well coated. Set aside.
3. **To make the salmon:** Place the salmon on a baking dish lightly sprayed with vegetable oil. Brush the hoisin sauce over top. Bake in the preheated oven for 10 minutes per inch of thickness, until the salmon flakes easily with fork.
4. **To serve:** Divide the prepared slaw among serving plates. Arrange a piece of salmon on top of each serving and sprinkle with sesame seeds.

### SLAW

- 1/4 cup (60 mL) orange juice
- 1 Tbsp (15 mL) rice wine vinegar
- 4 tsp (20 mL) hoisin sauce
- 2 tsp (10 mL) sesame oil
- 2 tsp (10 mL) minced peeled fresh ginger
- 1 tsp (5 mL) liquid honey
- 1 1/2 tsp (7 mL) Sriracha or your favourite hot sauce
- 1/4 cup (60 mL) chopped fresh cilantro leaves
- 4 cups (1 L) pre-packaged coleslaw

### SALMON

- 4 salmon fillets (skinless; 6 oz/175 g each)
- 2 Tbsp (30 mL) hoisin sauce
- 2 tsp (10 mL) toasted sesame seeds

For more recipes, morsels, and the latest from our Featured Foodie, Rose Reisman, visit [memorymorsels.org](http://memorymorsels.org).



## No-Bake Cranberry Nut Butter Oatmeal Squares

 SERVES 12  TIME: 15 MIN

### INGREDIENTS

- 1/4 cup (60 mL) liquid honey
- 1/4 cup (60 mL) smooth peanut butter
- 2 Tbsp (30 mL) brown sugar
- 1 Tbsp (15 mL) pure maple syrup
- 1 1/2 tsp (7 mL) vegetable oil
- 1/8 tsp (0.5 mL) ground cinnamon
- 1/2 tsp (2 mL) pure vanilla extract
- 1 cup (250 mL) large-flake rolled oats
- 1 cup (250 mL) puffed rice cereal
- 1/4 cup (60 mL) chopped almonds, toasted
- 1/2 cup (125 mL) unsweetened dried cranberries

### INSTRUCTIONS

1. In a saucepan over medium heat, combine the honey, peanut butter, sugar, maple syrup, oil and cinnamon. Bring to a

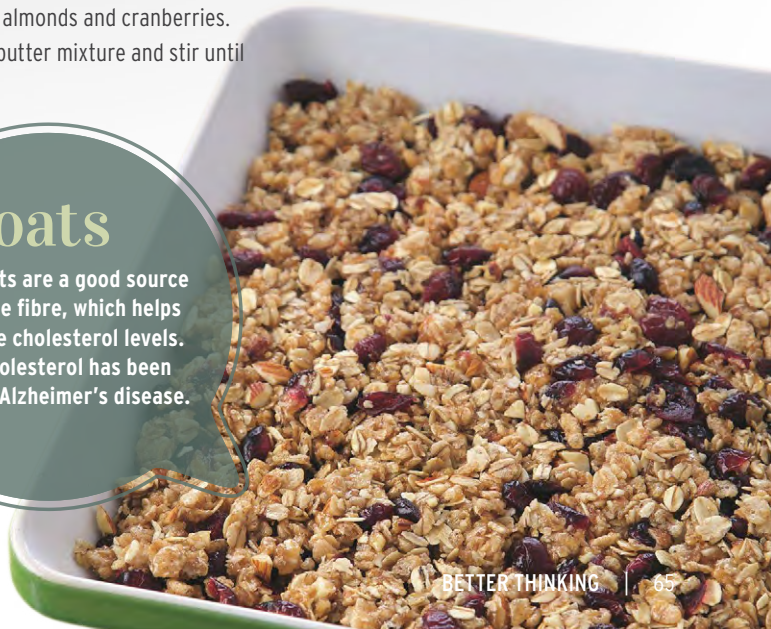
boil, then reduce the heat and simmer, stirring occasionally for 3 minutes, until the sugar has completely dissolved. Stir in the vanilla.

2. Meanwhile, in a large bowl, combine the oats, cereal, almonds and cranberries. Add the peanut butter mixture and stir until well combined.

3. Pat the mixture into an 8- x 8-inch (20 x 20 cm) baking pan lightly sprayed with vegetable oil. Cover and refrigerate for about 30 minutes, just until firm. Cut into 12 even squares. Squares will keep in an airtight container for up to 3 days.

## oats

Rolled oats are a good source of soluble fibre, which helps to reduce cholesterol levels. High cholesterol has been linked to Alzheimer's disease.



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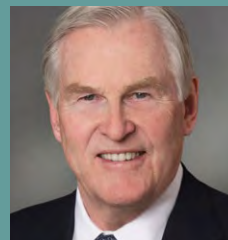
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