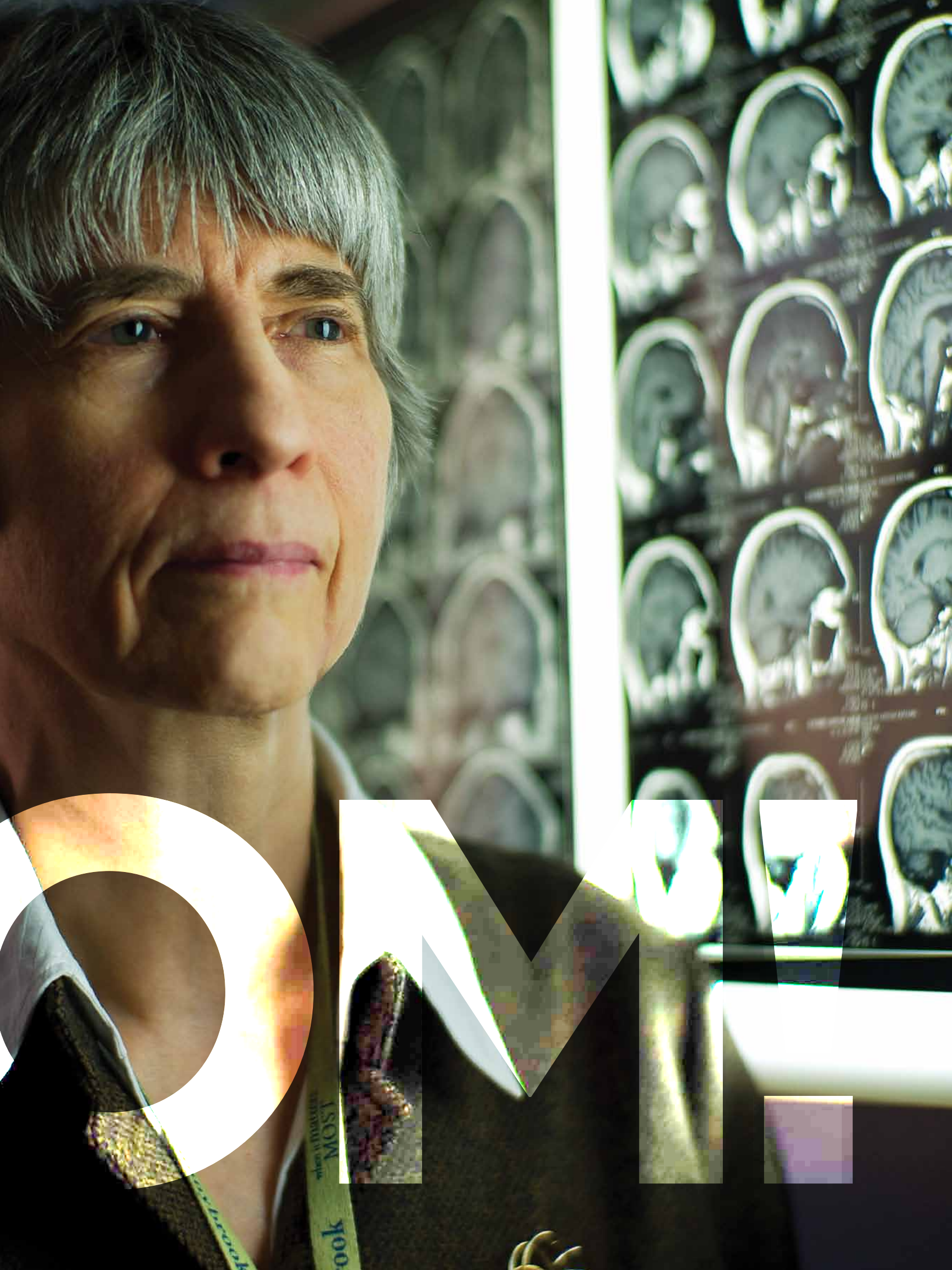


As the over-65 set swells, and with it the number of people with dementia, the question arises: at what cost to family caregivers?

BY ALISA KIM

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## “SOMETIMES IT’S VERY HARD,” HE SAYS, STRUGGLING TO CONTAIN HIS EMOTIONS. “BUT LIFE GOES ON.” Luis Jaramillo

In the early ‘90s, Scott McMeekin started to see the first signs that his mother’s brilliant mind was beginning to slow. During spirited family debates, his mother would become uncharacteristically withdrawn. “She was still bright and articulate, but was starting to find it hard to keep everything sorted out in that kind of conversation,” he says.

His mother was in the early stages of Alzheimer’s disease (AD).

In 2011, the first of the “baby boomers” (those born between 1946 and 1964) turned 65. In 20 years they all will be seniors. Most will be healthy; some won’t. As Canada ages, policy makers, economists and researchers have turned their attention to the sustainability of social programs and the health care system. The cost of caring for this population—dubbed the “silver tsunami”—is not just financial. There is also a significant social, emotional and mental toll on the family caregivers of people with chronic, debilitating conditions like AD and other dementias.

“It may seem like scare tactics, but the numbers are very, very worrisome. When you do the projections, it’s clear that there is a very big challenge ahead,” says Dr. Sandra Black, director of the Brain Sciences Research Program at Sunnybrook Research Institute and a cognitive neurologist specializing in stroke and dementia.

Overall, people are living longer. In developed countries, life expectancy has increased dramatically. Statistics Canada has predicted that by 2036, the average life expectancy of men and women will be 84 and 87 years, respectively. In the next few decades, seniors will represent a greater share of the population: 25% by 2036, compared with 14% in 2010.

In Canada, health care spending per capita on seniors is more than four times that on adults aged 20 to 64 years. While seniors use proportionally more hospital and physician services, home care and prescription drugs, compared with non-senior adults, researchers are careful to note that the increasing number of chronic conditions, not increasing age, is what drives primary health care use.

The problem is that advanced age is associated with a higher risk of having chronic conditions such as diabetes, cancer and heart disease. “Age is one of the most consistent risk factors for dementia, as it is for stroke. These conditions start to double in prevalence for each decade over 65. Diseases of aging are going to increase, because we’re maintaining people into the eighth and ninth decades, almost twice the average lifespan at the turn of the 20th century,” says Black, who is also a professor in neurology at the University of Toronto.

Alzheimer’s disease is the most common form of dementia. It is marked by progressive cognitive decline. One of its early symptoms is difficulty remembering new information; because it’s a degenerative disorder, symptoms worsen over time. Confusion, impaired judgment, difficulty with language, and changes in personality and behaviour are its scourges, gradually robbing people of their ability to live independently. It can also be distressing because of the behavioural and psychological symptoms, which include anxiety, depression, aggression, apathy and delusions.

A 2010 study commissioned by the Alzheimer Society of Canada estimates that the annual economic cost of caring for the half-million Canadians who have AD or a related dementia is \$15 billion. This includes the cost of providing care, indirect costs such as lost wages for the person with AD and opportunity costs, the wages that informal caregivers could have earned had they been able to work. Within 25 years, the yearly cost of caring for the estimated one million Canadians who will have dementia could rise to \$150 billion.

Drs. Nathan Herrmann and Krista Lanctôt are researchers at Sunnybrook Research Institute who study the social and economic cost of AD. “We know from the demographics that there’s going to be huge numbers of patients in the 85-plus age group, and in that age group, 26% of people will have AD. As that demographic expands, the absolute number [of people with AD] is going to become huge,” says Lanctôt, who is also a professor of psychiatry and pharmacology at U of T.

In a paper published in the *Canadian Journal of Psychiatry* in late 2010, Herrmann and Lanctôt showed that the cost of caring for community-dwelling AD patients is higher with increased disease severity. Moreover, indirect medical costs, which include home care by caregivers like family and friends, and loss of productivity by patient and caregiver, formed the bulk of the overall costs of AD at most levels of the disease.

“Interventions to treat AD have not paid enough attention to caregiver outcomes,” says Herrmann, who is also the head of geriatric psychiatry at Sunnybrook Health Sciences Centre. “There’s still not a clear idea of what is the gold standard in terms of an outcome measure for caregivers—whether we should be focusing on caregivers’ emotional health, physical care or caregiver cost of care as outcomes for these particular studies.”

Black, who not only does extensive research on AD, but also diagnoses and treats symptoms of it, published the results of a survey of Canadian caregivers of persons with AD or other dementias. She found that the impact of caregiving is broad and deep.

“There’s huge morbidity in the caregivers. They get more depressed. They end up using more health care dollars for medical illnesses. They’re stressed. So this is not a disease of an individual. This is a disease of the caregiving circle,” says Black.

Her research showed that live-in caregivers are especially vulnerable. Luis Jaramillo is caring for his wife of 19 years, Tina, aged 59, who has early-stage AD. Last year, the couple moved from Brampton to Guelph to lower their cost of living so that they could live on his income alone. At 61, an age when many consider retirement, Jaramillo has shifted his hours at the manufacturing company where he works full-time in order to care for his wife. “Sometimes it’s very hard,” he says, struggling to contain his emotions. “But life goes on.”

Jennifer, Pam and Susan MacDonald (not their real names) are sisters who are caring for their mother, aged 79 years, who also has early-stage AD. Although their mother is able to live independently—she can cook and run basic errands—she relies on her daughters for more complex tasks, such as managing finances.

The sisters are busy with their careers and families, but one of them sees their mother daily. “We have to give her the medication every day. We’ve taken over all her finances and all the mail because she doesn’t distinguish between what is important and what isn’t. She thinks junk mail is important. We have taken over paying the bills. Simple banking like withdrawing cash is fine. Anything beyond that, she needs help,” says Susan.

They are fortunate in that they can lean on each other and share the caregiving. “We turn to each other for support a lot. Every time any combination of the three of us talks, it’s one of our top topics,” says Pam. She says that the toughest part of the situation is missing the parent she grew up with. “[My mother] has always been very wise and had really good advice. Now, sometimes if you have conversations about issues in your life, she kind of listens

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and then she's onto, 'I don't have any bread now,' and she's back to her microcosm. That's been hard because it's a real change in her personality.”

For Susan, caregiving has involved a reversal in roles. “To me, it seems like she is my child instead of me being her child. It's like having a teenager where they're kind of OK on their own, but you're worried if they're going to get into trouble. [Safety] is a real worry.”

The MacDonald sisters say their mother is doing far better than they had expected owing to treatment that has stabilized her symptoms. “A year ago around Mother's Day when she was being diagnosed, I thought, 'A year from now, is she going to even know who we are?' But thankfully, she does. She hasn't declined that much in the last year because of the medication,” says Susan.

For McMeekin, who has cared for his mother since 1998 when she was diagnosed with AD at 77 years, medication that helped manage her symptoms also made things easier. “We were lucky in that my mom was on a fairly low-dose antidepressant that worked well,” he says. “My mom was generally pretty happy. You'd go in and she'd smile. It would have been a different story if my mom had been miserable.”

McMeekin says that although caring for his mother was an added responsibility, he didn't feel burdened by it. “I have a hard time classifying it as a sacrifice. There's always a bit of worry about how they're doing, but that's an issue whether your parent has Alzheimer's or not. When their health starts to fail, you have to be a little bit more involved. It was a privilege to be able to do it,” he says.

While progress has been made in managing symptoms of AD, there are no therapies that will change the underlying disease. Treating it early on or delaying it from setting in would buy people more time and result in better quality of life and significant savings. “The good news is that because of the age factor, if we can push back the onset of dementia by five years, we can actually reduce the prevalence [of disease] by 50%,” says Herrmann.

More research is needed on earlier detection of the disease and to understand better its progression. Sean Nestor is a medical and doctoral student at U of T who is supervised by Black. He is working to characterize AD better by developing tools that show what is happening in the brain of a person with AD at any given time and over the course of the disease. He has developed software that can be used to measure changes in the hippocampus, a structure in the brain that governs memory and spatial navigation.

“The hippocampus is an area of the brain that's targeted early in the disease and shows a lot of atrophy. Historically, it's been very challenging to make automated tools to segment out this structure. It takes a long time to manually trace, and it's not feasible in the clinic or even in research,” says Nestor. He says that loss of volume in the hippocampus may be an indicator of disease that could help clinicians make a diagnosis of AD.

Nestor is also studying whether cerebrovascular disease (conditions that limit or halt blood flow to the brain) worsens cognition in people with AD by comparing the brains of people with both diseases with those with only AD. He has found that even though patients with cerebrovascular disease and AD can show the same cognitive deficits as people with AD alone, there is less hippocampal shrinkage in the patients with both diseases, leading him to believe that the cerebrovascular disease may be damaging patients' brains differently.

“Imaging markers can add value to cognitive test scores because,

for instance, they might tell us that a person with AD has a lot of cerebrovascular pathology and less hippocampal volume shrinkage. This suggests that there might be other strategies to treat this person compared to someone with no cerebrovascular disease and AD,” he says.

For people with cerebrovascular disease or AD, managing risk factors for heart disease is important, especially early on. “Usually what's good for the heart is good for the brain,” says Black. “The risk factors for heart disease and stroke are the risk factors for dementia. There's a lot more we could be doing to control the big ones: hypertension, high cholesterol, diabetes, obesity, smoking, etcetera. We've got to treat those as vigorously as possible because that will keep the brain healthier for longer.”

On a macro level, Black says that Canada needs a national action plan for dementia that will bolster research and support for patients and caregivers. For those like Jaramillo, who is the sole caregiver, such help cannot come soon enough. He and Tina were finally able to get government benefits after three years of trying, but they're still waiting on approval of their application for a support worker who would help out twice a week. “It's very hard for her, but I do my best,” he says.

As scientists try to come up with disease-modifying therapies and treatments that will delay the onset of AD, McMeekin, whose mother passed away in December 2011, has some encouraging words for caregivers: “You have to focus on what's left and not what's gone. You have to remember it's not about you anymore. For everything that was lost, even to the end there was still an awful lot of my mom there.”

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DR. SANDRA BLACK AND SEAN NESTOR

