

Dealing with dementia

Experts warn the disease will ravage societies as baby boomers age

BY DAVID SHERMAN, OTTAWA CITIZEN AUGUST 22, 2013



Carol Holmes-Kerr's husband died Jan. 1 after suffering from Alzheimer's, a disease that turned the intellectual, well-read man into someone who couldn't read the newspaper or even dress himself.

Photograph by: Bruno Schlumberger, Ottawa Citizen

It recognizes no borders, doesn't distinguish between races and cares not a whit about income levels. It ignores, for the most part, lifestyle and diet. Unlike most terminal diseases, it leaves you ambulatory but, in its later stages, cruelly requires fully dependent care longer than any other disease.

It robs you of pride and dignity in its earlier stages and, in its latter phase, often takes away the cognitive ability to care about either. And since there is no known cause and no way to diagnose it, finding a cure is daunting. There is none in sight.

Alzheimer's disease is fatal but other varieties of dementia are not; they just steal your mind, bit by bit. In some ways, ironically, that can be a blessing for the stricken and for the army of selfless people entrusted with their care.

Women such as Reisa Manus, 60, whose 87-year-old mother Jean Manus was diagnosed as having “mid-point” dementia five or six years ago. Reisa drives from her home in the Laurentians once or twice a week to Montreal to spend the day with her mother.

Jean is not the friend and confidante she once was. Now Reisa is her mother’s mother, every moment vigilant for Jean’s mood changes, anxiety levels and her shifting proximity to reality. The woman who raised her is not there, but the woman she has become still enjoys her daughter’s love and admiration.

“She’s very much in the moment,” Reisa says of her mother. “She enjoys the simplest things now. Even going for an ice cream makes her very happy. It can be quite delightful.”

But with the gift of her mother’s moments of Zen comes Reisa’s realization that her own future might not be what she imagined.

“It taught me to no longer sweat the small stuff,” she says.

There are three quarters of a million people with dementia and Alzheimer’s in Canada, which means there are probably more than one million like Manus, entrusted with the care of dementia sufferers.

Those who make careers out of studying dementia, or advocating on behalf of patients and caregivers, use words such as epidemic and catastrophe to describe the swath the ailment will be cutting through our country in the coming decades.

Barry Greenberg, scientific adviser to the Alzheimer Society of Canada and the co-ordinator of a new Toronto-wide Alzheimer’s research centre, watched his grandmother die from the disease and in 1985 decided to dedicate himself to working on it. He’s been at it ever since. He has spent much of his career working for Big Pharma in North America and Europe, looking for drugs to combat the disease.

He is not hopeful.

What the disease is expected to do in the future is dystopic.

“The global economy is at risk,” says Greenberg.

“The tsunami is 25 years away. It’s totally predictable. Do the numbers just in China. Twenty-five per cent of the Chinese will be in the risk area. ... Their economy will fall,” Greenberg says.

As boomers age, dementia in its myriad forms is expected to ravage societies. After age 65, the risk of contracting serious cognitive impairment doubles every five years.

In 2011, U.S. President Barack Obama signed into law the National Alzheimer's Project Act, a national plan that initiated five goals and was injected this year with \$100 million. So far Ottawa has sidestepped any strategic plan to deal with the coming tempest.

Greenberg says the U.S. is spending peanuts considering that the cost to that country by 2040 will be about \$1 trillion a year, about what the U.S. spent annually on its war in Iraq. He says the U.S. needs to invest \$1 billion a year. And although Canada is ahead of the U.S. in funding per capita, he says it's not enough.

He's calling for a moon-shot/Manhattan Project–scope investment to combat the fallout from the disease and perhaps find a cure or a way to control it.

Greenberg agrees society has been drenched with disease anxiety, from SARS to bird flu, AIDS to MERS, fed a constant stream of “we're all going to die” stories by media. Some have trouble getting worked up about a disease that may or may not hit us decades down the road, he admits.

“They don't like to think about it,” he says. “They're convinced we'll do the magic.”

The “magic” brought the ravages of HIV/AIDS and some cancers under control but Greenberg, an inveterate cynic, says those who have survived HIV can now look forward to living long enough to get hit with dementia.

He does not see any magic coming out of test tubes in the next 10 years.

Larry Chambers, scientific adviser to the Alzheimer Society in Toronto, says there are about 70 organizations across the country providing counselling, referrals or a shoulder for distraught and confused family members or caregivers.

“It's a good reflection on Canada that we're organized to deal with it,” he says.

But a CBC Radio documentary aired last year pointed to Denmark as the poster country for dementia care. Despite its struggling economy, the state pays for a humane and civilized approach to looking after the cognitively impaired.

A spokesman for the Danish Alzheimer Association said patients are “not losing it, just their reality is shifting. It's a public task to look after the older people. It's much about independence. They never get to live in that bed.”

In Denmark, there are no locked facilities. The afflicted are taken on vacations, they bike, hike and dance, wash dishes, are entrusted with power tools and workshops, and, well, they live their lives.

“You can’t just sit around; what you can give, you give. There is a good life with dementia. ... In Canada it seems you’re starting from scratch. It’s the Stone Age.”

By 2038 in Canada, it is expected there will be a new dementia patient every two minutes. In 2008, there was a new case diagnosed every five minutes. By 2038, 1.5 million will be afflicted and there’s no national strategy on how to deal with them. Right now the provinces, the Alzheimer’s Society and various NGOs have stitched together a network of caregivers, referrals and advocacy.

The CEO of the Alzheimer Society of Canada, Mimi Lowi-Young, says simply that the disease “is the biggest health-care challenge we face. A national strategy is critical.”

The cost of dementia is expected to mushroom to \$300 billion a year by 2038, yet Canada has no plan yet to even begin work on a strategy, says Greenberg.

“We’ve tried to engage (Prime Minister Stephen) Harper but he doesn’t want to engage. He doesn’t have anything to say.”

The PMO bounced a request for comment to Health Canada, where officials replied in an email saying the government recognizes the serious impact the disease has on Canadians and their families and is supporting “research and surveillance” programs, listing \$23.6 million it has invested.

But the Alzheimer Society is working on changing gears on its advocacy approach to emphasize the economic fallout as opposed to the human cost, hoping to sway the prime minister.

In an email statement, Lowi-Young wrote: “We need some leadership from the top and co-ordinated strategy across the provinces.”

On the provincial side there is hope. At a premiers’ meeting at the end of July in Niagara-on-the-Lake, they issued a release that said “premiers directed the Health Care Innovation Working Group to examine issues related to dementia, including identifying best practices for early diagnosis.”

Lowi-Young says \$150 million is needed desperately to provide research, diagnostics and training to build up the base of caregivers.

The human cost, of course, is impossible to quantify. How does one measure the pain, indignity and loss of pride that comes with changing a parent’s or spouse’s soiled linen or clothes or bathing them? Or having to place them in a home?

In Canada, children whose parents are afflicted with the disease empty bank accounts, lose sleep and sometimes their jobs and spouses as they try to balance the needs of their own nuclear families with the demands of impaired parents.

For Carol Holmes-Kerr, her husband Jim's care dominated her life. Jim died New Year's Day at the age of 80. He was in a home.

Carol, his wife for the past 23 years, remembers they had been shopping sometime in about 2004 when she left him at one store to go to another. When she found him, he was looking confused and admitted he was lost. The end of their life together had begun.

"He ceased to be the person I had married," she says. "He was intellectual, well read and we used to have lots of intellectual and philosophical discussions."

Jim, a retired quality inspector with the Department of Defence in Ottawa, had an IQ of 135. But in the ensuing months, he lost his direction a few times, going north on the highway instead of south, ending up far from home with Carol suspecting the worst. Jim's mother and grandmother had died of Alzheimer's, and in 2008 Jim was diagnosed.

There were no more movies — he couldn't follow the story. No more daily newspaper reading or crossword puzzles.

"They say you can put off dementia by doing crossword puzzles, and he did them everyday, so I don't know how helpful that really is," she says.

A U.K. study in late July trumpeted a marked decline in dementia cases. A study of three regions showed 24 per cent less dementia than had been predicted.

But experts are wary. Some say it's an indicator that better heart health from increased knowledge of the importance of exercise and proper nutrition helps stave off dementia associated with cardiovascular problems, like stroke.

It is thought about five per cent of dementia results from cardiovascular illness.

Others say it points to the possibility that better eating habits and more exercise perhaps benefit the brain in ways not yet understood.

Still others say the methodology was flawed and the results prove little if anything.

Greenberg was more pointed in his assessment.

In an email, he wrote that the study “triggered a vision of Neville Chamberlain reassuring Britain that Hitler represented no significant concern, just about one year before the Nazis drove their tanks into Poland.”

In followup messages, he indicated that a healthy body might indeed have an effect on some kinds of dementia. He added that one good study seemed to indicate that bilingualism seemed to slow the onset of dementia in a control group by five years, something no drug can do.

He wonders if perhaps they’ll find that playing music might do the same, keeping certain parts of the brain active to delay dementia for reasons they don’t understand.

Says the Alzheimer Society’s Chambers, “The more I read, the more humble I get about the complexities of the human brain.”

For Carol-Holmes-Kerr it’s too late, of course. Her husband soon stopped walking the dog because he would get lost.

“It was lucky the dog knew the way home,” she says.

Once her husband could no longer carry on the conversations that nourished her, he soon needed help getting dressed.

“He’d come downstairs wearing three shirts,” she says, so she started to lay out his clothing. Then she had to shower with him. A former nurse, she says it was a job to be done, one of many as her husband’s care became all-consuming.

Soon she had to put him in a day care to take an occasional breather. She was usually with him 23 hours a day. He resisted but their love for each other was strong enough that he did what she asked, she says.

“I would just say, ‘Do it for me’ and he would,” she says. “I was the love of his life and he was the love of mine.”

Eventually she placed him in full-time care. She couldn’t look after him alone any more.

Placing him after being on a waiting list for two-and-a-half years was heartbreaking, she says.

“It was the most difficult thing I ever had to do,” she says. “He thought I was trying to get rid of him.”

But after he got settled in and she was able to take a breather, some joy returned.

“I didn’t have to look after everything anymore,” she says. “So I didn’t resent him anymore. You don’t want to feel that way, but you can’t help it. So when I went to see him we’d have a great time together.”

So as Reisa Manus discovered and as the Danes have proven, there is life with dementia. It’s a different life. But life goes on and so does the love.

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