As the baby-boomer generation gets older, the number of Canadians with Alzheimer's—and of those caring for them—is expected to more than double.

By Anne Bokma

After Elva Myers's husband, Bob, died from Alzheimer's disease two years ago, she found five sets of his keys hidden around the house, a tender testament to Bob's determined but ultimately failed attempts to keep track of the things that were important to him.

Since Bob was diagnosed at 65, Elva had watched the man to whom she'd been married for more than 40 years gradually forget how to do things that were once...
second nature to him. If they were out for a drive, he’d forget what road they were on. If he was cutting the grass on their large property near Charlottetown, he’d stop midway through the job, unsure how to continue. He’d put dirty dishes back in the cupboard and couldn’t recall the names of people he’d known his whole life. This went on for more than a year before they decided to seek help—and it took another year to see a specialist who confirmed Alzheimer’s.

“The day we came home from the doctor with the diagnosis, Bob said to me, ‘How are we going to deal with this?’” Elva recalls. “I told him that since there was nothing we could do to prevent it, we had to deal with it head-on, talk about it openly, and not hide it. Bob was afraid people would think he was stupid when he couldn’t remember things, but I told him that if he was straight with them and told them he had Alzheimer’s, they would treat him with respect and dignity. And that’s what happened.”

Elva and Bob took the right approach by being honest with others about Bob’s condition, says Dr. Ron Keren, clinical director of Toronto’s University Health Network’s Memory Clinic, who notes that, sometimes, shame about the symptoms of the disease can cause patients and their caregivers to try to keep it secret.

“Trying to hide the diagnosis makes things much more difficult; it adds stigma to the disease and creates more anxiety,” he says. “People who try to hide it generally lose their support network, whereas being frank and open helps bring people closer together.”

Facing the reality of living with Alzheimer’s is something that affects half a million Canadians.

Early Detection Is Key

There’s no cure for Alzheimer’s, and everyone who gets it will eventually die from the disease. People with Alzheimer’s tend to live an average of eight to 10 years with the disease, although some may live as long as 20. Early detection is critical to living out those final years in the best way possible. That’s because there are drugs that can slow the disease’s progress, and they tend to work better the earlier they are introduced (see sidebar, page 25). An early diagnosis also gives people the time they need to make decisions about issues affecting their future, such as retirement, wills, health-care directives, and possible long-term-care options.

“Nobody wants to hear that they have dementia, but, if you have to face it, you need to face it early,” says Mary Schulz, director of information, support services, and education at the Alzheimer Society of Canada. “This allows you to have control over planning for your future and gives you an opportunity to put your house in order and do the things that will let you enjoy your life as well as you can.”

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HEALTH

part of getting older; 39 per cent didn’t consider their symptoms serious because they came and went; and 29 per cent said their family member simply refused to go to the doctor; 75 per cent of respondents said they wished they had gotten a diagnosis sooner.

By the time they do decide to see a doctor, it can be a long wait: 39 per cent of survey respondents said it took one to two years to get an appointment with a specialist. “People hesitate about going to the doctor because they may think, ‘Oh, Mom is just getting a bit forgetful.’ They think it’s a normal part of aging and that nothing can be done about it,” Schulz says. “But there are things we can do, and it’s important to understand it’s not an inevitable part of getting older.”

So what’s the difference between age-related memory loss and Alzheimer’s? Keren explains it this way: “If you forget someone’s name at a party, that’s age-related. But if you forget that you had a conversation an hour ago with someone at that party, that is not a normal part of age-related memory loss.” Schulz adds: “We’re not talking about the kind of forgetfulness that we all experience from time to time—going down to the basement and then

The ability to carry out normal activities such as driving and doing chores gradually decreases.

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walk the dog wearing no shoes in the middle of the winter. Sometimes there are behavioural changes such as agitation, aggression, or depression.

Pamela Wise witnessed a dramatic change in her father’s personality when he began to have hallucinations and psychotic episodes in the months before he died in 2010, when he was 87. Once, when she was pushing him in his wheelchair, he told her to stop, then bent over as if scooping something from the floor. When she asked him what he was doing, he said he was picking up pieces of the moon.

“You just never really understand fully what is going on in their mind,” explains Wise, who left her job as a teacher in Hamilton, ON, to become her father’s

<table>
<thead>
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<th>Facts on Alzheimer’s</th>
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<tr>
<td>• One in 11 Canadians over 65 has dementia, and women account for 72 per cent of all cases.</td>
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<td>• After 65, the risk for dementia doubles every five years.</td>
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<td>• Over the next 25 years, without a medical breakthrough, more than four million Canadians will have Alzheimer’s disease or a related dementia.</td>
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<td>• In 2010, the cost of dementia in Canada was estimated at $22 billion a year. If nothing changes, this will climb to $153 billion a year within a generation.</td>
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<tr>
<td>• The number of family-caregiving hours for dementia is expected to more than triple by 2038, from approximately 259 million hours in 2010 to 756 million hours.</td>
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Source: Alzheimer Society of Canada
primary caregiver after her mother died. Another time, her father tried to pull the phone from her hands as she was dialing 9-1-1. “He was treating me like a hostage. He didn’t want me out of his sight. I felt terrible and helpless.”

But for most of the seven years he lived with Alzheimer’s, Wise says her father was loving and affectionate, and she took pride in turning his home into a “dementia boot camp” in an effort to help him enhance his cognitive abilities. She used homemade vocabulary cards with words on one side and photos on the other to prompt his memory. She encouraged him to do small puzzles. Since her father was a lover of jazz and big-band music, she played piano for him regularly and encouraged him to clap out the rhythm of his favourite songs. They took turns reading aloud and played games such as Snakes and Ladders and Scrabble. She bought him DVDs with exercises he could do in his wheelchair. And whenever the TV was on, she’d make sure it was tuned to an educational program, the news, or a game show like Jeopardy! She even played catch with him in the backyard to improve his hand-eye coordination and organized scavenger hunts for him in the house.

“Helping him became my passion. I viewed Alzheimer’s as a challenge and felt I was in competition with the disease,” Wise says. “When someone you love has this disease, you have two choices. One is to throw up your hands in defeat and think that since they are only going to deteriorate there’s no point. But my view was to tackle this and give him a good quality of life before he goes. That was my focus, and it’s what kept me going.”

Impact on Caregivers
One of the reasons Wise was able to provide such support to her father is that she had a lot of support herself. Two or three times a
week a home care worker assisted in her father’s care. Twice a week, her father also participated in a day program organized through the Victorian Order of Nurses. And Wise spoke regularly with counselors at the Alzheimer Society whenever she needed emotional support. “If the caregiver is able to get some respite, then she is able to give more back to the person who needs her help,” Wise says.

She was one of the lucky ones. Because the provision of home care is inconsistent across the country, many aren’t able to access the support they need and become overwhelmed by the demands of caring for someone with Alzheimer’s. Nearly 40 per cent of family members caring for a loved one with dementia suffer depression, rage, or an inability to cope, according to a survey from the Canadian Institute for Health Information. The Institute reports that there are more than two million informal caregivers in Canada, most of them spouses and adult children of frail seniors. Sometimes they feel forced to quit their jobs and may become virtual shut-ins themselves.

That’s what happened to Elva Myers in the last year of her husband’s life. “He was glued to my side and was always afraid if I was out of sight,” she says. “His biggest fear was that he’d have to go into a nursing home.” She rarely left home and got just three hours a week of home care—enough for her to do the grocery shopping. Near the end, in desperation, she contacted her provincial minister of health directly and successfully lobbied for a few additional hours of home care each week. “I just couldn’t be in the house 24 hours a day, seven days a week.”

Keren observes that, when it comes to Alzheimer’s, “sometimes the burden is greater on the caregiver than on the patient.”

Increasing support for caregivers by ensuring they are assisted with respite, training, and financial help is a key recommendation of the Alzheimer Society’s 2010 report Rising Tide: The Impact of

Treatment for Alzheimer’s

There is no cure for Alzheimer’s, but there are drugs that can slow its progress. The earlier these drugs are prescribed, the more effective they tend to be.

Cholinesterase inhibitors, including donepezil (Aricept), galantamine (Razadyne), and rivastigmine (Exelon), are prescribed for mild-to-moderate Alzheimer’s disease and postpone the worsening of symptoms for six to 12 months in about half of the people who take them. “They don’t stop the clock from ticking, but they move it back a bit,” Dr. Ron Keren says. “Six months may not seem like a long time, but it is for someone who is 85 years old and has only a few years left to live.”

Another drug in a different class of medications is memantine (Ebixa), which is used to treat moderate-to-severe Alzheimer’s disease and may delay the worsening of symptoms in some people.

There are currently new medications in clinical trials, including some in vaccine form that may revolutionize the treatment of Alzheimer’s disease in the coming years.

“It’s thought that Alzheimer’s is incubating in the brain as soon as our early 30s,” Dr. Sandra Black explains. “The hope is that we will be able to detect the disease early enough in people at risk so that we can do something about it.”

Until that happens, the best way to prevent Alzheimer’s is through lifestyle changes such as getting plenty of exercise, eating right, staying socially connected, keeping your brain challenged, not smoking, and protecting your head by wearing a safety helmet during sporting activities to reduce the risk of traumatic head injury.
Dementia on Canadian Society, which calls Alzheimer’s disease the most significant social and health crisis of the 21st century. “Beefing up home care services across the country so people can live in their homes longer is vital,” Mary Schulz says. Rising Tide also calls for adapting long-term-care facilities to better meet the needs of residents with dementia, providing education programs for people with dementia and their families, and investing in more research.

“Canada is one of the few countries in the world that doesn’t have a dementia strategy,” Schulz notes. “We are aging as a country, and we need a thoughtful, planned, and well-resourced dementia strategy that would be national in scope and address what we will do to meet this challenge over the next generation.”

Living with Dignity
Alzheimer’s specialist Dr. Sandra Black, the neuroscience program research director at Toronto’s Sunnybrook Research Institute, says it’s important for people to know they can still live a fairly normal life for a number of years after they are diagnosed with Alzheimer’s.

“A lot of it depends on the support you have; if you have a spouse who is healthy and can care for you, you’re lucky, and chances are you’ll be able to stay home for many years,” she says. “If you are living alone or you’re a widow or widower, it’s more complicated. And if you don’t have any involved family members, it’s even more difficult—and more likely that you’ll end up in a long-term-care institution. People need to understand it’s a terminal disease, but you can live with dignity. The right support, advice, and medications will all help you function better
and get the most out of the years you have left.”

That was the case for Elva and Bob Myers: Elva ensured that Bob’s remaining years were meaningful. They went on a Caribbean cruise, enjoyed the local beaches in the summers, visited with friends, took every opportunity to see their four children, and managed to care for their large property. Elva is grateful that, at the end of his life, Bob still knew who she was and appreciated her help. Two months before he died, Bob came into the kitchen where Elva was making dinner, put his arms around her, and told her he loved her. “He asked me, ‘How are we going to get through this?’ I told him we’d get through it together.”

Bob died in his sleep seven years after his diagnosis while Elva lay next to him. “I love my husband and miss him dearly still,” Elva says. “But I’m glad he died the way he died. Our home was where he was born, and he always wanted to die here.”

Different Types, Different Stages

Alzheimer’s disease is the most common form of dementia (representing 63 per cent of cases). Vascular dementia, which is caused by problems in the supply of blood to the brain, is the second most common. Other dementias include frontotemporal dementia, Lewy body dementia, Creutzfeldt-Jakob disease, and dementias that occur with chronic neurodegenerative conditions, such as Huntington’s disease.

There are three main stages of Alzheimer’s disease: mild, moderate, and severe. People in the mild stage are fairly independent and require minimal assistance; those in the moderate stage can’t manage independently without assistance; and, in the severe stage, people are usually dependent and require long-term care.

Solution to Puzzle #113

8 6 5 7 3 9 1 2 4
1 4 9 5 8 2 3 6 7
7 3 2 4 1 6 9 5 8
4 7 8 1 2 3 5 9 6
9 5 3 6 4 8 7 1 2
6 2 1 9 5 7 4 8 3
3 1 7 8 6 5 2 4 9
2 8 4 3 9 1 6 7 5
5 9 6 2 7 4 8 3 1

Solution to Puzzle #114

9 1 5 8 3 6 2 4 7
2 7 4 9 5 1 6 3 8
6 3 8 2 4 7 9 5 1
4 2 9 5 6 8 7 1 3
3 5 7 1 9 4 8 6 2
8 6 1 7 2 3 5 9 4
1 4 2 6 7 9 3 8 5
7 9 3 4 8 5 1 2 6
5 8 6 3 1 2 4 7 9

Above are the solutions to this month’s Sudoku puzzles, page 72.