

Alzheimer families say long goodbye

BY LISA QUEEN
Staff Writer

Although Peter and Nancy Ott's elderly father is physically fit for his years, they are mourning his passing. It's not his physical death they are grieving; the brother and sister still enjoy visiting their father in the Markham retirement home where he lives.

Instead, it's the essence of their father they have lost to Alzheimer's disease.

"With Alzheimer's, I'm getting a sense you probably say goodbye to the person a long time before they depart. It's the long goodbye," Mr. Ott said.

"I don't have the same conversations I used to have with dad. We (the family) have said goodbyes or we're saying goodbye to dad in an intellectual way. Now, we're just enjoying being with him."

Mr. Ott's father, Herbert Ott, who turns 81 next month, was diagnosed with Alzheimer's disease a couple of years ago. However, Mr. and Ms Ott believe he began exhibiting signs of the disease before his wife died five years ago.

They feel their mother, who saw her own mother stricken by the horrible progression of dementia years before, tried to shield them and their brother, Andrew, from their father's disease.

As difficult as it is to have a parent fall victim to Alzheimer's disease, Mr. and Ms Ott acknowledge their family has the most optimum conditions they could hope for. Unlike many victims of the disease, their father remains good-natured.

For Mr. and Ms Ott, recognizing and admitting their father's mental capacities were diminishing was difficult. When they were growing up, their father seemed bigger than life.

Herbert Ott, a strapping man who stands six-feet, four-inches, grew up in Estonia. After surviving the Second World War, he came to Canada with nothing, raised a family with his wife and worked as an electrical technician designing navigational components on airplanes.

"He was a pillar of strength in our family. With him anything was possible. Everything was an adventure to him," Ms Ott said.

"He had had huge physical strength. He doesn't have the stamina the way he used to, but he's still very strong. I think it's hard to watch people disappear when they have been such huge, huge figures with huge lives."

She and her brother first began noticing something was wrong



STAFF PHOTO/MIKE BARRETT

Peter Ott and his sister Nancy miss their father's intellectual capabilities, which have been diminished by Alzheimer's disease. However, they still enjoy taking him on outings from a long-term care home.

with their father when he would drive from his condo in Ottawa to visit them in York Region. A trip that should have taken five hours took eight and their father couldn't account for the missing time.

They eventually arranged to have their father's driver's licence taken away after he was involved in a fender bender and an unnerving experience where he called on his car phone to say he was lost as vehicles honked wildly in the background around him.

Mr. and Ms Ott also began to realize their father's world was shrinking.

"In my dad's condo, everything began to revolve around his chair in front of the TV," Mr. Ott said. "That seemed significant. His world had condensed into one space."

After medical tests indicated their father was suffering from Alzheimer's disease, Mr. and Ms Ott moved him to an Estonian co-op in Toronto. Soon after, their father needed medical attention and went to Markham Stouffville Hospital.

Staff there recognized the elderly man could no longer live alone

and explained their concerns to his son and daughter. Their first reaction was to consider having their father move in with one of them, but health experts made them realize the difficulties ahead.

"We talked to one family who had done that full time for four months, but they said it felt more like four years," Mr. Ott said. "It's a normal reaction to want to take your parent into your home, but it is a huge disruption — for you and for them."

With the help of Markham Stouffville Hospital, they were able to place their father in Buckingham Manor, a long-term care home a short drive from Ms Ott's Stouffville home and Mr. Ott's Markham home.

"If you take him out, it takes some time to get him settled when you bring him back because he forgets he lives there. Sometimes, when he's down in the dining room, he forgets how to get back to his room," Ms Ott said.

"You may not be able to talk to him about what's going on in the world today. But you can talk to him about a lot of things. His grandkids, other things."

Although their father has never discussed his fears about his disease with his children, he did share them with a health-care worker.

"My dad had dealt with my grandmother (when she was suffering from dementia). And now he was sitting on this precipice," Mr. Ott said.

"He voiced his concerns to someone at Markham Stouffville Hospital. She said afterwards to us, 'He's afraid'. Here's this man ... he's survived the war. He was afraid."

"We want to make things good for him. We're now providing for him what he gave to us when we were young. It's not an obligation, but a sense you're living up to the values he gave you."

Their father, who worked for the federal government, receives a fairly generous pension, which covers the cost of his care.

But it's not always that easy for Alzheimer patients and their families, according to Susan Hart, executive director of the Alzheimer Society of York Region.

She warned the effects of Alzheimer's disease will challenge Canadian society in coming years, given the aging population. More

NO KNOWN CURE

Alzheimer's disease is a progressive, degenerative and irreversible type of dementia. The amount of damage created by the disease increases over time.

There is no known cause or cure. Damage done to brain cells can't be repaired.

Alzheimer's disease causes gradual breakdown in the nerve cells of the brain. The brain changes and no longer works the way it used to. As a result, victims are less able to make sense of information and send messages to their bodies. They become unable to think, remember, understand or make decisions.

Eventually, patients become unable to look after themselves and will develop other illnesses such as pneumonia, which may cause death.

The majority of victims are over age 65, although people as young as 30 have been diagnosed with the disease.

Alzheimer's disease affects men and women of all races, religions and socioeconomic backgrounds.

Alzheimer's disease affects each patient differently. Symptoms include changes in behaviour, emotion and mood, over which the person loses control. They may be sad, happy or angry inappropriately or become suspicious of people close to them. Their mental abilities, such as memory or ability to learn new things, diminish. Physical abilities also decrease over time.

There is no simple test for Alzheimer's disease. The only sure way of knowing for sure someone has the disease is by examining brain cells after death.

When doctors are trying to find out if someone has the disease, they will first determine whether there is a treatable cause, such as depression or thyroid disease, that could be the reason for changes in behaviour.

More than 30 per cent of Canadians over the age of 80 will be diagnosed with the disease. By 2031, Ms Hart said 19,000 York Region residents will suffer from some sort of dementia, including 6,700 with Alzheimer's disease.

The impact on society will be enormous. Ms Hart said the number of senior citizens acting as primary caregivers to elderly parents suffering from dementia will skyrocket over the next three decades.

On Nov. 7, the society's second annual symposium at the Sheraton Parkway hotel in Richmond Hill will look at issues related to dementia and Alzheimer's disease.

Workshops will focus on diagnosis and treatment of early Alzheimer's disease, dementia and the law and enhancing communication for Alzheimer patients.

For more information about Alzheimer's and the conference, call 905-895-1337.

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