

LOSING DEB DEMENTIA'S LONG PAINFUL JOURNEY



SCOTT GARDNER, THE HAMILTON SPECTATOR

JOE LEA VISITS HIS WIFE, DEB, A PATIENT IN THE SENIORS UNIT AT ST. JOSEPH'S HEALTHCARE. DEB SUFFERS FROM DEMENTIA.

JON WELLS
The Hamilton Spectator

The coming spike in dementia cases in a rapidly aging population means an increased burden on the health care system, and on grieving families who cope with the reality that their loved ones will not be cured of the progressive disease in the brain

Deb Lea is always walking, obsessively, with purpose, to nowhere. And she is unable to focus enough to engage in a conversation. But it is her eyes, most of all, that tell the story. They are empty, no expression, as if light has been drained from her soul.

Her past and present, expectations for the future, it all used to be there. She had a joyful aura.

It broke Joe's heart to look into those eyes.

Because her husband remembers.

Deb is gone, but Joe remembers.

ABOUT 16 PER CENT OF dementia cases in Canada are those younger than 65. For every 10 years lived after age 65, the risk increases fivefold.

More than 750,000 Canadians live with dementia and that number is projected to exceed 1.4 million by 2031.

It is caused by disease or injury to the brain, and is an umbrella term describing symptoms such as memory loss, impaired thinking and speech, and sometimes changes in mood and behaviour that affect one's ability to function.

The escalating burden is one reason St. Joseph's Healthcare opened

its Seniors Mental Health Service at West 5th Street and Fennell, to treat the most severe elderly mental illness patients in the region.

The coming wave of aging baby boomers has been dubbed the "silver tsunami" for its impact on the health-care system, and the senior population in the Hamilton-Brantford-Niagara region is growing faster than anywhere else in Ontario.

(On the positive side, a good diet, exercise and sleep help maintain brain health, and these new seniors will generally be healthier than those that came before. The future ratio of older people to dementia cases is not necessarily a given.)

Dementia continues // A5

Most dementia is progressive, symptoms worsen as more brain cells become damaged and die

"It works up to a point. But you can't forget this is an older person with dementia who has had a long life."

PETER BIELING
PROGRAM DIRECTOR,
SENIORS MENTAL HEALTH SERVICE,
ST. JOSEPH'S HEALTHCARE

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THE SERVICE'S TWO UNITS are always full; a 24-bed behavioural unit for dementia patients and a 12-bed unit for those with other mental illnesses. (The Top 3 mental health disorders for seniors in 2014 were mood disorders, dementia and psychotic disorders.)

The behavioural unit includes patients who are aggressive or violent — what is called "responsive behaviour" in clinical terms.

These patients can't be managed in a long-term care setting, or at home, where in some cases a loved one has locked themselves in the bedroom for their own safety.

Patients in the units are not all elderly; one of them is a 30-something with Huntington's disease, a genetic disorder in the brain. But staff primarily care for seniors, which is a recognition of their unique needs, says director Peter Bieling.

"Even just accounting for the physical pace of how (patients) walk down the hall... It was high time for a separate unit with separate programming."

He says they want to move toward a model that encourages independence among patients in a controlled environment, such as self-medicating or preparing their own breakfast.

Nurses compose storyboards with personal information about each patient to try and make them feel at home; perhaps one of them used to enjoy a cup of afternoon tea, or certain types of music.

It's a bit of a guessing game. Tastes might have changed, and certainly their minds have.

"It works up to a point," says Bieling. "But you can't forget this is an older person with dementia who has had a long life."

JOE LEA MET DEB in a church in Prince George, B.C. She was living with her aunt and uncle because she had trouble at home with her parents, after finding out at 16 she was adopted.

Joe was 21, working as a bricklayer apprentice, and she was 19, when he asked her on a date.

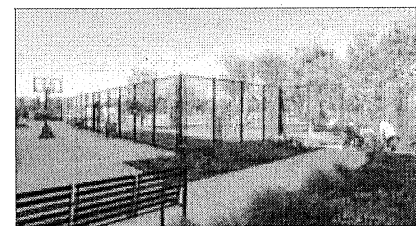
"Thirty days later we got engaged and three months after that we married," Joe says. "It was the right fit."

They ultimately moved to Ontario, had a son and a daughter, and settled in Ridgeway.

Deb loved animals. She bred Yorkshire Terriers and tiny parrots called parrotlets.

They owned eight horses and, with Fort Erie Racetrack 15 minutes away, boarded thoroughbreds. They

SIX DAYS OF PEACE OF MIND



The courtyard area for senior patients at St. Joe's.

PEACE OF MIND is a six-part series by Spectator reporter Jon Wells that explores various aspects of adult mental health.

SATURDAY

Solving riddles, cracking stigma

MONDAY

Losing Deb: Dementia's long and painful journey

TUESDAY

PTSD: A soldier's story

WEDNESDAY

Thought distortion: Anxiety disorders

THURSDAY

Crime and the mind: The forensic unit

FRIDAY

Suicide: The pain that kills



Top: Joe Lea visits his wife Deb at St. Joe's on West 5th each Sunday. He says he knows he has "lost" his wife, but he's determined to look after her to make sure she's cared for. Above: Dr. Maxine Lewis says it's a "gift" to make a difference in the lives of patients and their loved ones.

"In geriatrics as a whole you're treating the patient, but also the family."

MAXINE LEWIS
PSYCHIATRIST,
ST. JOSEPH'S HEALTHCARE

planned to start breeding as well.

Deb sold one of her horses in 2006. The buyer pulled his trailer in front of their barn and the horse was loaded on.

She was standing behind the trailer when the horse kicked the tailgate. It slammed into her chest and knocked her down. Her head hit the ground and she suffered a concussion. Over time she became forgetful, did not seem like herself. The kids noticed it more than Joe.

Ten years later, Maxine Lewis, a psychiatrist from the seniors service at St. Joe's, drove from Hamilton to meet Deb Lea.

LEWIS GREW UP in the United Kingdom, where she began her career in geriatric medicine. Colleagues noted how she was always talking to patients. She has an empathetic and sensitive way about her. She switched specialties to psychiatry and later moved to Canada.

Her first vision of Deb was walking up and down the hallway at a long-term nursing home in Niagara. She had to race alongside to talk to her.

"She was quicker than me," says Lewis, her English accent still prominent. "But she wouldn't say much. I had a long chat with Joe. He was tearful."

Joe told Lewis about the painful journey in the years since Deb's concussion.

First, bits of memory vanished. She stopped making eye contact, couldn't focus on anything, and had poor balance.

They had to sell all of her animals. All she would do was bustle around the house cleaning, or stuff wads of paper towels here and there, hide things.

It was like her brain was channel-

DEMENTIA'S ESCALATING BURDEN

More than 750,000 Canadians live with dementia, or about 15 per cent of Canadians 65 and older. The number of cases is projected to exceed 1.4 million by 2031.

Alzheimer's disease is the most common form of dementia in Canada, accounting for about 60 per cent of cases.

16,000 Canadians under age 65 have dementia.

The risk of developing dementia increases by 45 per cent if you smoke.

The total health care system and out-of-pocket caregiver cost for dementia cases in Canada is about \$10.4 billion; by 2031 it will increase to about \$16.6 billion.

Legislation is making its way through the House of Commons that would establish a national strategy for tackling dementia illnesses like Alzheimer's disease. Health Minister Jane Philpott said recently the federal government will support it, adding that her father suffers from dementia.

SOURCE: ALZHEIMER SOCIETY OF CANADA

SOMETIMES PATIENTS show symptoms of dementia but it is a potentially treatable form, caused by vitamin deficiencies, or thyroid disease, sleep disorders, or a buildup of fluid in the brain called normal pressure hydrocephalus (which is sometimes misdiagnosed as Alzheimer's).

But most dementia is progressive, symptoms worsen as more brain cells become damaged and die. Patient care is about improving quality of life.

"Cognitively, the people we are treating will get worse, but we can ease their distress," says Maxine Lewis.

That is also the case for family members who are grieving.

"It can be frightening for them; they are worried about their loved one. In geriatrics as a whole you're treating the patient, but also the family. So it feels like a gift, really, to make a difference in the lives of the patient, and their family."

One family donated a painting to the seniors unit, and a basketball net because their father/grandfather, a patient, had always loved shooting hoops.

Care for dementia is different from other types of medical treatment. Families may watch their loved one achieve an improved comfort level and state of mind. But there is no cure and in that respect it is inevitably a sad road.

JOE LEA SAYS treatment in Hamilton helped give Deb a better sense of peace.

She turns 61 at the end of November. Joe is 63 but says he feels half that age.

He will never abandon her.

"Not after 40 years of marriage. It's not her fault. My wife is gone but I am not walking away, I will make sure she's taken care of."

At one time he had planned to retire young. That's not how it played out. He runs a stone cutting business in Ridgeway. He has a lot on his plate.

They had dreams of breeding horses, easing into retirement, riding into the sunset of life together.

"All of that went to hell."

She doesn't know who Joe is. She hasn't known him in perhaps two years.

There are moments, though.

She smiles when she sees this man who regularly comes to visit.

And once, in the waning days of summer, she leaned over and gave Joe a kiss, the first one in two and a half years.

"I thought: where did that come from? You wonder what's going on in that mind."

Joe has no idea what the kiss and the smiles mean to Deb. But to him they mean a lot.

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ABOUT THE WRITER

Award-winning Hamilton Spectator reporter Jon Wells has written series in the past about the ER and ICU in Hamilton General Hospital, and McMaster University's Education Program in Anatomy.