

Lives changing because of dementia

Newmarket's Tom Cooper lives with young-onset dementia

Like many marriages, Newmarket's Jean and Tom Cooper's is one with lots of up and downs - laughter and friendship, gardening and crafts, workplace injuries and Tom's diagnosis of young-onset dementia.

"I went for some counselling," Jean said during an interview at their Newmarket apartment. "I was mourning the loss of Tom, but then I was missing this time to spend with him."

So in the spring was the Year of Tom.

The couple took a road trip out east where Tom dipped his toes in the ocean (he had never been to the ocean before "just Lake Simcoe," he said) and then took the Greyhound bus to Thunder Bay where they spent some time with Jean's sister and got up close with a lynx.

The creature had not been seen on her sister's property for years, but one morning Jean looked out and the lynx, about the size of a dog, was sitting within a few feet of Tom.

"I have all these pictures of the animal," Tom said.

It was a great trip, said Jean, with lots of memories created. Tom talks about the beauty of the east coast and agreed with Jean the water was a bit cold that fall.

After more than 25 years of marriage, the couple are still happy just being together, watching TV, showing off Tom's model cars and trucks that took thousands of hours to build and pattering around Newmarket on their ebike - Tom on the back carrying the packages.

Jean and Tom met in 1983. Jean was dating Tom's friend and they knew many of the same people.

"We used to hang out. We became good friends. It was a good beginning for a relationship."

When Tom discovered his wife was cheating on him, he moved in with Jean. Jean, at the time, was abusing drugs as a way to escape her past and dating a biker who would beat her.



Jean and Tom Cooper. Tom lives with young-onset dementia.

Tom, she said, saved her. When they began to date, she decided to stop blaming herself for her past and begin a life of sobriety.

"He is why I stopped (doing drugs). He saved my life, likely."

GREAT MAN

The couple dated for a number of years before Jean accepted Tom's second marriage proposal; Jean said Tom asked her early on in their relationship marry him, but because of her past, she worried marriage would mean controlling and abuse.

Finally, she realized Tom was nothing like the other men she knew and agreed to get married.

"When you meet a guy like Tom, you change your mind pretty quickly...He is just happy every day. He is not demanding, not moody, he doesn't scream and yell. He will be the first to jump up and help a lady. He is the way men used to be."

Jean gave the example of how Tom used

to go to work early because there was a woman who opened a Newmarket plant on her own. He worried about her safety, so he went to work before his start time to drink his coffee and make sure she was OK.

"My girlfriends will ask 'Can you clone him and take blood samples?'"

It helped their marriage began with a friendship, Jean said.

That first year of marriage was blissful, Jean said. The couple moved into Tom's parents' basement where they "stayed in bed for a year" and "it was possible to have everything delivered." Jean was feeling burnt out from working two jobs and Tom to was ready for a break as well.

"It drove his parents' nuts."

After the year, "I was over it" and they both went out and got jobs, working at various places in Newmarket and Aurora. Over the course of the marriage, there was love, laughter and respect, but also sadness.

Jean had a miscarriage and an ectopic pregnancy, where the embryo attaches outside the uterus. She was never able to have children ("Tom would have been a great dad.")

"We have always been so respectful of each other. We always say thank you. We still treat each other nice. I love you in the morning and a kiss."

Jean said while the dynamic of their relationship has changed, love has not.

"We were meant to be together. At a certain point you don't become Jean and Tom, but JeanTom, your name bonds together. We still want to be together, another 30 or 40 years together that would be nice."

Earlier in their marriage, Tom had a serious workplace accident, receiving a brain injury, among other things. Jean, too, was injured

Jean Cooper calls AS York's DAY program a godsend

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on the job. The couple made due on Tom's salary until about five years ago, when Tom slipped on ice at their apartment building, spraining his back. He was also having weird morning dreams and acting strange. His boss called Jean telling her Tom wasn't doing well at work.

Then "he came home early one day and he didn't know why, he just did."

Jean immediately took Tom to the doctor's. He was diagnosed with young-onset dementia.

It was a stressful time. Tom couldn't collect unemployment (it's for a physical injury) and finally his employer put him on long-term disability, which, along, with his benefits, expired on his 65th birthday in October.

Tom was born prematurely on Oct. 30, 1954 in his parents' farmhouse in Snowball Corners (up the road from Seneca College King campus). Tom had two brothers, one who died when he was 25 from complications of diabetes, while the second brother, who became estranged from his family at that time, has since died.

Tom worked on his family farm "pretty much as soon as I could start," Tom said.

"He seldom went to school," Jean said. "He was denied an education."

The family moved from the farm when his parents bought a house in Aurora, and Tom quit school before completing Grade 9.

He did various jobs throughout his life. The couple always had a big garden, making pickles and preserves to feed the neighbourhood and leaving vegetables on doorsteps as tokens of apologies for parties that went too late and may have been a bit loud. There was laughter, friendship and doing things together.

Today Tom attends the Aurora DAY program three days a week.

Not being able to go to work was hard for Tom. He liked to be busy, but he couldn't work. That is why the DAY program is such a blessing, Jean said.

"The DAY centre has been like a godsend. He loves it there. He was used to getting out of the house and then he couldn't. I consider it like house arrest. It's hard to



Jean and Tom on their ebike. Right, celebrating Tom's 65th birthday in the DAY program in October.

entertain you all day," Jean said to Tom. "I just don't have that many jokes."

"I like it there," Tom said.

"He likes the driver, Patrick. The two are really chummy. He rides on the bus. He loves the food. He has a second wife down there who is feeding him."

Tom gets picked in AS York's new van (It's really nice, Tom said), funded by the Ontario Trillium Foundation. The pair gets along really well, Jean said, and they talk as they pick up the rest of the people on the route.

Jean said the DAY program is particularly important for her as "pain and patience don't go hand in hand. I love him, but he gets on my nerves. It's a break from the madness from time to time. It gives me a bit of me time. I get more housework done when the husband not home," she laughs.

But most important, Tom is happy.

"He comes home happy, fed and excited and tells me about his day. He is beaming when he gets home. He loves all the people." She said socialization is important for Tom, but sometimes it's hard for her to physically keep up. The DAY program helps with as well.

In addition to the DAY program, a personal support works comes in to give Tom a "man shower/bath. Tom says it's like being in the



car wash."

Jean also uses the services of a social worker. She calls Angela Owen-Johnston "such a sweetheart."

The most important thing about the Alzheimer Society of York Region is the staff, services and education are there to be used.

"I would tell them (people going on the dementia journey) to be reassured that there is a help available and that you are not alone. There are times when you really do need help and that people like Angela (and the Alzheimer Society of York Region) comes in handy."