

From dementia to diagnosis: A couple's cautionary tale

Two years is a long time to wait between the first symptom of dementia and a diagnosis – precious time when 62-year-old Lou Grieve might have received medication and made plans for her future.

But the time lapse wasn't because she and her husband Wayne consciously put off seeing a doctor. It was because they did not understand that her mood and behaviour changes were classic symptoms of dementia.

The old Lou was chatty and engaged, says Wayne. She loved her job as a child and youth worker with her local school board and liked to talk things over at length with him.

"It was a way she processed things," recalls Wayne, 64. "She was just a verbal person."

Alzheimer survey points to treatment gap

According to an Alzheimer Society survey of 958 family caregivers released in January, close to half of respondents live more than a year with symptoms of dementia before seeing a family doctor or other health-care professional. Of these, 16 per cent waited more than two years.

In hindsight, three quarters wished they had been diagnosed sooner so they could have received medications to minimize symptoms.

While the Grieves sought help early, their story is a cautionary tale for the more than half a million Canadians living with dementia - and those who may be at risk.

When Lou began coming home from work exhausted, Wayne chalked it up to the stress of her job. He, too, was a social worker and understood how trying it could be.

But when Lou struggled to use her employer's automated phone system to call in sick, a red flag went up.

"There was a practical kind of problem-solving that wasn't happening. Lou was always really skilled on the computer. She was a whiz," he says.

Memory loss isn't the only sign

When the exhaustion wouldn't go away, Lou visited her family doctor.

She and Wayne saw him several times over the next two years as Lou's symptoms progressed - from extreme fatigue to mood changes. The doctor's assessment was

depression, an illness whose symptoms include exhaustion, mood and behavioural changes that can sometimes mimic those of dementia.

A tired Lou scaled down to part-time hours. By March 2008, she was still exhausted and less interested in things that once animated her. That's when Lou decided to stop driving. Then she stopped working altogether.

All the while, the Grieves sought counselling and nutritional advice from health professionals, hoping to bring Lou back to her old self.

"I felt we were continuing to miss something," recalls Wayne.

But they never suspected dementia. Like many people, the only symptom they associated with dementia was memory problems.

CAT scan reveals brain atrophy

The turning point came when the doctor referred the Grieves to a psychiatrist in the fall of 2008 to ask about visual hallucinations Lou was beginning to experience, her increased anxiety and the fact she was being "coy" about not taking her medication. The psychiatrist ordered a CAT scan which showed frontal cerebral atrophy.

A referral to a cognitive neurologist followed soon after, along with MRIs and memory tests. In January 2009, they received a formal diagnosis. It was Pick's disease, a type of dementia also known as Frontotemporal dementia. But by this time, the illness had progressed too far along for Lou to make decisions about her care. Wayne, now retired, has been caring for Lou at home and plans to keep her there as long as he can.

Don't minimize symptoms

He receives 10 hours a week of help from a personal support worker through his local home care agency. He also attends monthly caregiver support sessions at his local Alzheimer Society.

Earlier detection could have given him these supports sooner and helped him understand what Lou was going through.

"You've got to take on the role of advocate yourself because your partner or parent can't do it themselves. Don't minimize their symptoms."