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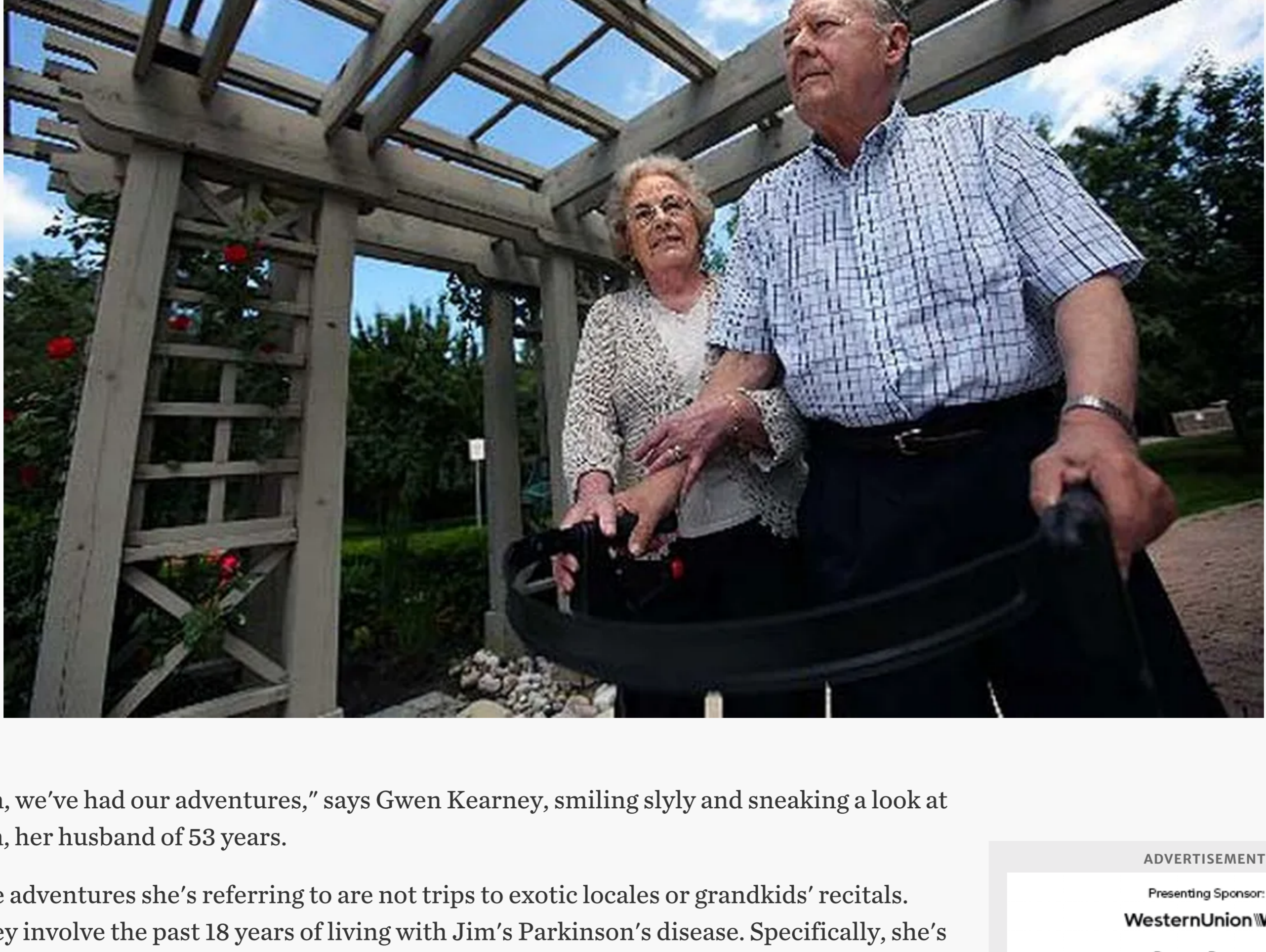
Making light of a heavy burden

"Oh, we've had our adventures," says Gwen Kearney, smiling slyly and sneaking a look at Jim, her husband of 53 years.

DF By **Diane Flacks** Special to the Star
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"Oh, we've had our adventures," says Gwen Kearney, smiling slyly and sneaking a look at Jim, her husband of 53 years.

The adventures she's referring to are not trips to exotic locales or grandkids' recitals. They involve the past 18 years of living with Jim's Parkinson's disease. Specifically, she's talking about the last time the couple went to their cottage alone, a few years ago.

Beset by one of the symptoms of Parkinson's, postural instability, Jim lost his balance and fell off the boat into the lake.

"It was scary," Gwen begins.

Jim interjects. "I wasn't scared."



Luckily the water wasn't deep and Jim was able to stand. "Get the groceries!" Gwen yelled, once she knew he was okay.

He'd been holding two bags of produce when he fell over, which were now floating all around the boat. Jim lifted his hand out of the water and they both noticed a finger was at a right angle, broken.

With only one usable hand, they knew there was no way Jim could get out of the water. Fortunately, another boater happened along and pulled him out.

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Despite how this story could have ended, and what it implies about the helplessness that circles this disease, the Kearneys laugh in retelling it and are ready with another tale of misadventure.

Gwen slips into the kitchen of their bright, elegant condominium in Toronto to offer me some homemade peanut butter cookies. Okay, I had four. Jim refuses, as they may weaken the effect of his medication.

He takes pills every two hours to combat one of the most severe symptoms of this quixotic, degenerative condition: rigidity – what Jim calls "freezing."

Muscles become stiff and inflexible; initiating spontaneous movement becomes literally unthinkable. Despite medication, sometimes rigidity happens suddenly and, just as suddenly, it lifts.

Jim and Gwen tell me about the time they were at a Toronto restaurant and were about to be seated at the back, when Jim suddenly "froze." So Gwen asked for a table up front, explaining that Jim had a mobility disorder.

"Ten minutes later, he gets up, strides to the washroom as if nothing was wrong. I said, 'Jim, the least you can do is limp.'"

Parkinson's affects the areas of the brain involved in automatic movement – things we do without thinking, like walking. If you put down a visual impediment on the floor in front of Parkinson's sufferers, forcing them to think about stepping, they are able to walk.

Jim, a former engineer, illustrates some of the unique strategies he has developed. He turns his cane upside-down, which forces him to step over the handle. Or he attaches a toilet paper roll to the end of a golf club. Or, worse comes to worst, Gwen puts her foot in front of his, forcing him to step over it.

They once did this all the way across a mall. "I hope the security cameras weren't on," says Gwen.

The couple knows how lucky they are to have each other and to live at this time, when there is medication that can help. Fifty years ago, the outlook was nightmarish. When Gwen worked as a nurse in hospitals in the '50s, she recalls two Parkinson's patients who became more and more rigid until they were frozen in postures.

"You remember the movie *Awakenings* with Robin Williams? All the patients were practically motionless?" Gwen says. "It was like that."

Coincidentally, Oliver Sacks, who wrote *Awakenings*, also recently wrote a book called *Musophilia*, in which he details the power of music to animate Parkinson's patients and how dance offers a "freedom from behavioural loops" in the brain.

Jim and Gwen heartily agree. For the last year, Jim has been participating in an innovative dance class for sufferers of Parkinson's, founded by dancer and choreographer Sarah Robichaud.

In the class, participants work with dancers and a live accompanist.

"I'm a bit of a jazz man," Jim offers. He began attending classes a year ago and tries to never miss one.

Gwen says dancing has helped Jim's balance. "He would have been more disabled with freezing and it has given him more fluidity."

Especially when Jim is suffering from his most obvious symptom, dyskinesia – spontaneous, involuntary movements.

Dyskinesia is actually a side-effect of the medication that Parkinson's patients take to combat rigidity.

As we talk, Jim sits in his armchair, his dapper head of white hair combed neatly. He is constantly twitching and, as he speaks, his whole lower body twists, legs lifting and forcing themselves into new positions.

"He's nervous, so he has got more symptoms," Gwen says. "That's why I'm doing more of the talking."

I ask Jim if that might actually be a reflection of their overall relationship.

"Yes!" he affirms.

Jim is reluctant to speak about progress because it's hard to measure improvement in a disease that is degenerative. The benchmarks keep changing.

When asked what he thinks works about the dance classes, he shrugs. "I don't know," he says.

"I do," pipes Gwen.

She gets up and strides over to Jim, stands in front of him and takes his arms, rocking them back and forth. His stiff arms move more fluidly and his legs calm down.

The Kearneys say they are fortunate. Jim's Parkinson's has been moving slowly. "Six or seven years ago, it started to be more of an intrusion in our lives. Giving up driving is pretty ..." He searches for the word.

"Devastating," Gwen finishes.

"That's a heavy word," Jim demurs.

"Well, it would be devastating to me if I had to give up driving," Gwen quips.

At the end of the interview, the Kearneys, together, slowly walk to the door to see me out. Gwen hands me a napkin with some cookies to take home to my kids (as if they'll last that long).

Our time is up. Wheel-Trans is arriving in half an hour to take Jim to dance.

DANCING WITH PARKINSON'S

Diane Flacks is a writer/actor/author living in Toronto.

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