His friends have all vanished.

They tried to advise him: “Don’t be a martyr. Put her in a nursing home.” When he demurred, they offered him an alternative: “Divorce her. Walk away. Don’t wreck your life.”

But Ken Wong chose to stay with his wife. He gave up his job, his paycheque and his hopes of building the robotics company he had just launched into a high-tech dynamo. He alienated longtime friends. He lost everything familiar.

He has been a full-time caregiver since 2008.

Wong was honoured this week with a Heart of the Home Award, recognizing an individual who “has gone above and beyond the call of duty to provide a loved one who is disabled, elderly or chronically ill with the support needed to live at home in comfort and dignity.”

For the past seven years, VHA Home Health Care (formerly the Visiting Homemakers Association) has handed out this award. It recognizes outstanding caregivers and highlights the critical role they play in sustaining the health-care system. “We’re the hired help,” said Carol Annett, president and CEO of VHA at the ceremony. “You’re the backbone of the system.”

In some ways, Wong typifies Canada’s three million caregivers. He is selfless, compassionate and steadfast. In other ways, he is unusual. Most caregivers are women looking after elderly parents. He is a man caring for his wife. Most keep working (with interruptions.) He left the labour force.

His story begins with a lopsided case of love at first sight. He was smitten. His future wife, Nada, was interested but wary.

They were University of Toronto students who crashed the same birthday party. They ended up at the same table and had a great evening. He asked her for her phone number. Knowing better than to give it to an engineer student, she scribbled down the number of a nearby pizza outlet.

He was devastated — so devastated one of Nada’s friends intervened and got them back together.

From that point on, they’ve been inseparable. After university they married, launched their careers, had twin daughters and bought a home in Markham. She was as a project co-ordinator at Bell Canada. He rose through the ranks of the engineering profession.

But in her mid 40s, Nada’s behaviour began to change. She started leaving post-it notes all over the house. She had trouble doing everyday tasks.

After several false diagnoses, doctors determined that she had corticobasal syndrome (early-onset dementia). She was 46.

“It’s a nasty disease,” Wong said. It leads to rapid loss of language and cognitive impairment. It can also trigger disturbing behavioural changes. Six months after the diagnosis, Nada could no longer talk. Soon afterward the tantrums began. “Sometimes she screams for 15 hours at a stretch.” Although he receives 20 hours of home care a week, the workers often can’t handle her.
His daughters, now at university, “really haven’t come to grips with it,” he says. “They’re afraid it will happen to them.” His in-laws are uninvolved. They consider Nada her husband’s responsibility. Her childhood friends visit occasionally, but can’t stay when the screaming starts.

When the home-care agency sends an experienced professional, Wong takes part in his one outside activity. He advocates for other caregivers who work tirelessly, saving the health-care system billions of dollars, but get no thanks, little support and scant recognition.

The only politician who has ever responded wholeheartedly was Michael Ignatieff. The former Liberal leader announced a family care benefit worth $1,350 a year in 2010. A year later, Prime Minister Stephen Harper grudgingly proposed a $300-a-year family caregiver tax credit.

Premier Dalton McGuinty has promised caregivers help in the last three elections. So far, there are few visible results.

Nada’s life expectancy is two to 10 years. Wong doesn’t know whether his savings will last that long. He doesn’t know whether his daughters will come back. He doesn’t know whether he’ll ever work again.

What he does know is that he can look in the mirror with a clear conscience. When he promised to stay with Nada “for better or for worse, for richer, for poorer, in sickness and in health, until death do us part,” he meant it.

*Carol Goar’s column appears Monday, Wednesday and Friday.*