

COMPOUNDING *Care*

What happens when both your parents have dementia at the same time?

BY Julia Williams

When Mary Huang fractured her foot at the end of 2019, it was a health crisis — but not for her. In her time-consuming care role for her parents, who both have dementia and other medical issues, Huang simply didn't have space in her life for an injury.

Huang's parents, Peter and Anna, were both diagnosed with mixed Alzheimer's disease and vascular dementia between 2017 and 2018. At the time, Huang, who is in her 50s, worked as a travelling consultant with major tech companies. When her parents received their diagnoses, she had a more flexible schedule than her brother and sister and no dependents, leaving her to take on the majority of care.

Huang is one of a small but growing demographic of Canadians who are caring for multiple family members with dementia at the same time. Caring for one person with

dementia is a significant challenge, and caring for more than one compounds the responsibilities, as well as the stress, emotional load, logistical considerations and expenses.

How do you keep track of two (or more) people's medical issues, get them to appointments and act as their advocate? How do you find an appropriate living situation for your parents when their needs aren't the same? How do you navigate care options? What if family members with dementia pose risks to each other? Can you cover the cost of residential care, in-home care, medical support equipment and your own lost wages? How do you manage the distress, confusion and anger your family members with dementia may feel? How do you manage your own?

In June 2019, the Public Health Agency of Canada released its first national dementia strategy, a vision that will see the government spend \$50 million over five years

to advance dementia prevention, care and support and reduce stigma in this country. One of the strategy's areas of focus is to build the capacities of family/friend caregivers by supporting them through initiatives like tax credits (which already exist in some provinces) and improving their access to resources like dementia training, community supports and information about the health-care system. The strategy doesn't appear to mention caregiving situations where one person is caring for multiple family members with dementia, and this seems like an oversight.

Today, approximately nine older adults are diagnosed with dementia every hour in Canada, and that number will only rise. In 2014, people 65 and older represented 15.6 per cent of Canada's population, but population projections estimate older adults will make up 23 per cent of Canadians by 2030. The likelihood that a person may have two living parents who need dementia care in the future is increasing.

Lorrie Beauchamp's parents, Marcel and Beverly, were both diagnosed with dementia between 2013 and 2015. Marcel had a

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Anna and Peter Huang are both living with dementia. INSET Mary Huang is the primary caregiver of her parents.



mild form of vascular dementia and remained fairly independent, but when Beverly's Alzheimer's disease proved aggressive, the situation changed. At the time, Beauchamp, who today is a medical researcher and writer in her early 60s, had plans to semi-retire to Vancouver Island. Instead, in 2015, she put her career on hold, sold her Montreal condo and found an apartment two minutes from her parents' house in Laval, Quebec.

At first, Beauchamp planned to find her parents a suitable long-term care residence, but they were

deeply attached to the home they'd shared for 45 years. What's more, Beauchamp, who is an active member of Dementia Advocacy Canada, was disturbed by the institutional nature of the dementia care units she visited.

"That's when I started to realize how inhumane the environment is for our seniors generally, and for people with dementia in particular," Beauchamp says.

It was decided: Marcel and Beverly would continue to live in their home, eventually requiring round-the-clock care. Beauchamp

has four siblings, but like Huang, she was the one with the most flexible career and no children. She spent the next five years as her parents' primary carer.

Canada's dementia strategy reports that family/friend caregivers spend about 26 hours per week supporting a person with dementia



and spend, on average, \$4,600 per year on out-of-pocket care-related expenses. Add another person with dementia, and these numbers double (at minimum). Nor do the out-of-pocket expenses calculated here — which cover transport to medical appointments, prescriptions and household items, for example — account for the considerable cost of professional in-home care and long-term care fees.

When Beauchamp's mother began to need round-the-clock care, Beauchamp couldn't provide it alone. She hired in-home personal care workers to cover nights, and it cost her family more than \$100,000 per year. She learned that Quebec offered tax credits for 35 per cent of these expenses, but upon closer inspection, she realized this was not the boon she'd hoped for. The annual limit for a dependent senior

is \$25,500, for a maximum tax credit of \$8,925 per year — less than 10 per cent of the family's care expenses.

Huang, too, was astonished by the high cost of professional care. When she first researched options, she discovered that a private retirement home for both her parents would cost upwards of \$10,000 per month. "That's \$120,000 a year," she says. "How many families can afford that?"

She decided she would be the primary caregiver, despite the fact this would mean putting her career on hold. Because her parents' Ottawa home was no longer practical, given their medical needs, Huang managed the sale of their house and found them a single-level condo, where she could care for them with the help of in-home personal support workers.

Hiring support proved easier in theory than in practice. Unlike hospital or physician services, home care services are not publicly insured through the Canada Health Act; these services are delivered by for-profit and non-profit providers that differ from province to province. Some home care workers offer medical support and others only offer non-medical services, such as domestic help and cooking. Huang says the personal care workers she hired through agencies were usually casual part-time employees with multiple jobs. Turnover was so high that Huang had four different workers in six months. Some workers would visit for as little as 15 minutes and some didn't show up at all.

Canada's dementia strategy describes personal care workers as an integral part of the care team, but it acknowledges what Huang observed: staffing shortages, low wages and irregular work hours impact quality of care. Beauchamp learned that some agencies didn't provide any training (let alone dementia-specific training) and paid their workers only \$12 to \$14 per hour with no benefits, while charging clients more than double that amount. "People are getting paid more to clean your home," Beauchamp says.

Huang settled her parents into their condo with the intention to eventually find a long-term caregiver to move in with them and find another condo in the same building for herself. A few days before the sale of their house closed, Peter had a stroke that left him paralyzed



THIS PAGE Lorrie Beauchamp's parents, Marcel and Beverly.
FACING PAGE Lorrie with her mother.

on his right side. Now his needs were too significant for Huang and personal care workers to manage; he needed a long-term care facility. Through previous research, however, Huang knew that the wait-list system in place in Ontario would prove difficult to navigate. The median wait time for a bed for people coming from the community is more than 160 days. As Huang managed this setback, Peter was becoming increasingly upset about the loss of his independence, and he often directed his anger at her. To further complicate matters, Huang realized Anna was trying to care for Peter, neglecting her health and forgetting important details — most significantly, that Peter could no longer swallow solid food. Huang would have to separate her parents for their own safety.

During this time, tensions rose between Huang and her siblings, who she felt didn't offer reliable back-up support even as her care responsibilities became overwhelming. Huang was spending 60 to 70 hours each week caring for her parents, and it never felt like enough.

"The emotional toll is tremendous," she says. "I felt split in two. Sometimes they needed care in different locations, and I felt like I had to choose between them."

By spring of 2018, Huang was burnt-out. One day, she was pulled over in traffic while driving with her mother, and after a 10-minute conversation with the officer, she was handed a ticket and the number of a crisis line. She phoned, but it didn't give her the help she really needed: relief, even for a few hours, from her care responsibilities.

For Beauchamp, there were days she would come home and collapse, sobbing. Her siblings were a great source of support, but

nonetheless, she struggled with anxiety and feelings of resentment, especially during the first year. She was responsible for endless administrative tasks: medical appointments, finding and managing nighttime care, researching government support programs and figuring out how the family would afford round-the-clock care. The house required ongoing attention too: repairs, accounting, grocery shopping and cleaning. All the while, Beauchamp was putting on a brave, positive face each day despite the sorrow of watching her mother lose her memories and her ability to speak. And, because Beverly needed so much support compared to Marcel, Beauchamp sometimes worried that he wasn't getting enough.

"It's the hardest thing I've ever done," she says. "I don't know how people survive this."

Beverly died peacefully at home, surrounded by family, at the end of 2018, and Marcel, now 93, is still in good health. Beauchamp, relieved of her full-time caring role, is living in Sooke on Vancouver Island — but she still feels the effects of those five years. Even now, every time Beauchamp's phone rings her heart starts pounding.

"Everything got hardwired into a form of PTSD," she says. But it wasn't her parents' illnesses that sent her into this state of crisis; it was the ongoing stress of caring for them with inadequate information and support. Beauchamp documented her caring experience in a blog called *Unforgettable*. In one post, she writes: "Alzheimer's is not sad. Dementia is not tragic... it is what we make it." She says if she had those five years to do all over again, she'd make it all about laughter, fun and silliness. Those things,

"The two-parent scenario is going to become something that families will have to deal with." —Lorrie Beauchamp



rather than the myriad practical and logistical considerations, could and should be the focus of dementia care.

Huang's parents are stable at the moment, her siblings have increased their support and her foot is healing. She regularly has joyful family meals with Peter and Anna. Like Beauchamp, it's not the disease she blames for the challenges of the last few years, it's a lack of clear strategy and communication of essential information.

"It's a very difficult system to navigate," Huang says. "People don't know the true choices they have."

The creation of Canada's national dementia strategy is a step in the right direction, but for Huang and Beauchamp, it's too little, too late. Beauchamp worries that it could be too late for her entire generation.

"The two-parent scenario is going to become something that families will have to deal with," she says. ▣