

# How I Lost My Mother

In her 80s, she was still reading, seeing friends, and worrying about her kids. Once dementia took hold she began wandering off, and I became my mother's keeper **By Frances Bula**

**T**he phone rang just as the sky was beginning to lighten. The man was polite, a little hesitant because of the hour. Did I have a mother named Marie? Did she live near 33rd and Mackenzie? I stopped him there—not really, I said, my eardrums starting to throb. My mother lived in a retirement home 13 blocks away. A long trek for an 87-year-old unsteady on her feet.

The man, working the 2 a.m. shift at the Tinker's Hatch Bakery, had noticed her on the corner. He'd thought it odd to see a woman her age out so early, not really going anywhere, just standing. So he asked her in, got her name and then mine. By the time I came for her, my mother was sitting tranquilly on a chair, his cookies on her lap.

The next year it happened twice more. Once, a woman found her in Southlands in the early evening, clearly disoriented. Another time, she knocked on a door, again in Mackenzie Heights. *Could you tell me where I am?* With each call, it became increasingly clear—even to me, resisting all the way—that she had crossed a line. For several years, even after being diagnosed with Alzheimer's, she'd been someone who could maintain a semblance of her previous independent life by following familiar tracks. No more. My mother was now officially a "wanderer."

As it turns out, wandering—that particular feature of dementia that drives people to pace, to roam, to set out thinking they're going to work and then get hopelessly lost, or to go for walks



that take them straight through forests and ponds and traffic—is an aspect of Alzheimer's that presents a particularly cruel set of choices. It would become a test for us as a family, for our society, for the way we take care of elders, and for how and whether this city works.

THE DAUGHTER OF A FRENCH-Canadian family who settled on the Prairies in the 1900s, my mother grew up with two languages. Almost all her journals are written in French, though she spoke flawless English. She became a high-school French teacher and some-

time translator, did crossword puzzles obsessively, read like an English grad student (her list from her 81st year includes Zadie Smith's *White Teeth*, José Saramago's *Blindness*, and John Ralston Saul's *Reflections on a Siamese Twin*), followed politics with a passion (one of her proudest possessions was a letter from Bill Clinton thanking her for her support during his Monica Lewinsky period), finished her master's thesis in French literature at the age of 67, then took up creative writing, penning a series of stories about growing up during the Depression. She had a wide circle of friends. Through all that she still had time to make dinner regularly for me and my three brothers, grown from challenging teenagers into adults who still caused her sleepless nights, plus take care of her grandchildren and prod both generations to be better people.

When she started worrying about her memory, we dismissed her concerns. She consulted a neurologist, who diagnosed her problem as "benign short memory syndrome," as she scrupulously noted in her journal. She stopped talking about her memory problems and so did we. When she started calling three or four times a week to ask who was making Thanksgiving dinner, we let it slide. When she forgot that one of us was picking her up or that a friend was coming for lunch or that we'd already shown her a dozen times how to do something on the computer, we let it slide.

Then, at 83, she had hip-replacement surgery. Post-op, she experienced violent delirium; recovered, she remained so disoriented that she was ordered into six weeks in a convalescent home, where she continued to be more confused than I'd ever seen her. After she was able to return home, I took her to see another specialist. My mother, somewhat embarrassed at such childish questions, did the test that would eventually become routine to me: What is your name. Here are three random words: *brown, table, love*. Draw a clock. Tell me what season it is. What floor are you on. When did President Kennedy die. What are the three words I told you before. She answered most correctly, but she thought Kennedy had died maybe 10 years ago and she couldn't remember the three random words at all. This time, the diagnosis was not benign anything. She had Alzheimer's. Or vascular dementia.

The doctor couldn't say for sure which, and really, it hardly mattered. The consequences were the same. It was mild for now. It was difficult to predict how things would unroll.

Years before, as my son had evolved from toddler to teenager, I'd run the algorithm every day on whether I thought he could manage by himself the stairs, the oven, the street, his bicycle, the bus, my car. I'd been willing to let him test the limits more than other parents. When he was 12, he and two friends

**"Here are three words: *brown, table, love*. What floor are you on? When did President Kennedy die? Draw a clock. What are the three words I just said?"**

camped by themselves in the bush near our summer cabin, a place up the shore that they had to paddle to by canoe. This was the same journey, in reverse. As my mother changed, I pushed her luck, and mine as well, wanting desperately for her to keep her life. A professional researcher, I dawdled at the task of researching retirement homes. But her old life slowly evaporated anyway, in spite of my efforts to freeze it in place. She'd go into a frenzy when she couldn't find something: tickets to the Playhouse, her wallet, the nice silverware. Eventually I hired caregivers to help keep her apartment clean and occasionally to cook for her. Her memory gaps depressed her, and our daily phone calls now often consisted of me repeating endless reassurances. Her doctor arranged for her to take part in an evaluation program at VGH; at the end of three months, the team suggested that it would be wise for her to move to a retirement home, so that she could get familiar with it before her memory declined further.

Such decisions were increasingly mine. My brothers still did the many things they had always done for her: fixing stuff, visiting and talking. But I'd gone from being just one of the kids to the Girl, the Oldest, the Chief Organizer. At first it was only the basics: power of attorney, money and bills, the never-ending medical exams, the dementia test over and over. Your name. The clock. The random words. We'd

always been tied together, my mother and I, by a combination of mutual aid and low-grade hostilities never directly expressed. We'd lived together in a house with separate suites through her 70s, when she helped me bring up my son. We talked over her master's thesis endlessly (mine is in the same field), and I edited her book of life stories. But she thought I was a careless mother and let me know it in backhanded ways. She'd also talk to her friends about me, how appalled she was that I had written

personal family stuff in my journalism, how rudely I had treated someone. I thought she was freakish in her social insecurity, gnawing over every faux pas she'd made or hurtful comment she'd received. Those irritations faded as she came to rely on me and I ran around trying to shore up her life.

I am far from alone in all this, I know that. There are thousands of families in the Lower Mainland stumbling through this anguishing decline. There used to be fewer people with dementia, because they died of something else before their brains were too damaged; those who survived were often buffered by large families they could live with, and recognizable homes and towns where a lifetime of routine helped compensate for the confusion. But longer lives, smaller families, bigger cities, and an uptick in mobility have meant there are more people with dementias—70,000 is the estimate in B.C. just for Alzheimer's (different from vascular dementia, which is caused by a series of almost unnoticeable strokes; or Lewy body dementia, which adds Parkinson's-like symptoms; or the several other types)—and they're less sheltered in their suffering. The majority of people with dementias are living not in care homes but with harried relatives or even, like my mother was for many years, still managing in their own homes.

Jim Mann, a 63-year-old former marketing executive with Canadian

Pacific, lives in a meticulously neat home in Surrey with an extensive china display. With his head of thick grey hair and pressed checked shirt, he looks like a bank vice-president, not someone who was diagnosed with Alzheimer's five years ago. That's the problem, says Mann, who gets to Alzheimer Society speaking engagements and errands through extensively written-out instructions or with his wife, Alice, at his side. "People have these stereotypes. They pull out the checklist and say, 'You can't have Alzheimer's. You're too young; we're having this conversation.'" But he doesn't fool himself about his limitations. He's found himself suddenly disoriented and lost, just because an obstacle forced him to cross to a side of the street where he doesn't normally walk. The panic only makes things worse. He hopes that careful routine will allow him to stay home for years, decades, more. He believes that confining people with dementia who wander is "asking for trouble because they're going to react." And yet, he says, there comes a point when you have to pose of a loved one the yes/no question: "If she goes out for a walk, is she in danger?"

MY MOTHER HAD ALWAYS BEEN A walker: to the church, the bank, her women's club, her friend Joy's house, the park. At her new care facility in an unfamiliar neighbourhood, she continued to walk, sometimes with one of her crop of new friends but, more energetic than the rest of them, frequently by herself. Almost daily, she crept to the edge of Kerrisdale Village and then back. Then, at some point, I can't even say when, that cautious walker lost her way. Perhaps because she had lost the capacity to write in her journal and read and watch television—anything that required a recollection of the last 60 seconds—she persisted with the last activity from her old, more interesting life. The morning I picked her up from the bakery, I asked her, as we both recuperated back in her room, what had happened. "Well, I just went for a



R. Marie Bula was born on a farm near Cantal, Saskatchewan, in 1922. Political junkie, graduate student of French literature, nun for 14 years, mother of four. One day "I just went for a walk and then I suddenly realized I didn't know where I was"

walk," she said, sounding puzzled and worried, "and then I suddenly realized that I didn't know where I was."

An American researcher, Robert Koester, has estimated there will likely be 500,000 "critical" wandering incidents a year in the U.S. by 2040. (Studies indicate it may affect up to 70 percent of people.) The problem with wandering is that it's not merely a nuisance, like lapses of memory (an old friend's name) or even incontinence. People who wander can die, sometimes only a few minutes from their care facilities or houses. It's the main trigger for institutionalization. Local police and RCMP routinely issue bulletins for wanderers in the region. At least six people in Metro Vancouver were the subject of police searches in the first 10 weeks of 2012. Four were found within a few hours. One, a man from North Delta, was found roaming around Burnaby a day later. Another, 79-year-old Yu Lan Rou Lin, was found dead in March in a park in Burnaby near where she lived. She'd been missing a week.

So I was being pushed to make another choice now—to move my mother into a wing of the home with a code lock. Her wandering had become more serious.

She was still walking, but it was no longer a question of recreational strolls she couldn't find her way back from. Now, she wanted to go home, to be back at the farm where she grew up, to see her mother. But the farm was in Saskatchewan. Home, the farmhouse, had been torn down in 1965. Her mother had died in 1974.

I went over for a look at the locked side. Many of its residents were slumped in their chairs. Few talked to each other. I couldn't stay. From home, I trolled for other solutions. There are interim measures: disguise doors, hide coats that act as triggers. New gadgets come out every week promising security to anxious families who have relatives with dementia. But it turns out there isn't a magic solution yet. "There is no one thing that is going to keep a person safe. I don't see that that exists," says Kathy Ken-

neddy, director of programs and services at the Alzheimer Society of B.C., which supplied the ID wrist bracelet I got for her the month after her diagnosis. GPS systems are expensive, plus they don't work well at pinpointing a single person in densely built cities. Radio-signal emitters are expensive too, and either the caregivers or police need receivers, plus a search system capable of picking up the 100-metre-range signal. Added to all that, people with dementia are skillful at clawing off bracelets and ditching monitoring devices. At best, such gear might be useful for someone who gets lost from time to time. Or who bolts a couple of times a year. But people with dementia aren't like that. One study of 28 residents in a secure facility showed that they tried to get out 457 times over a 15-hour period. Even with a tracking device, my mother was like a moth banging on a light bulb—there would have to be a police car or search crew on standby every day just to keep up with her.

People kept telling me it was unsafe to leave her in her unsecured home, that I'd feel terrible if she got hurt or died. "Mmm, you have a point," I'd politely respond. But really, I was in a rage. *You*

*just want to lock her up because it's more convenient for you, I ranted inside. You don't care about her. You just want it to be easy for you.* My youngest brother listened sympathetically during my indecisive, angry phone calls but left the choice to me. Another brother was solidly in favour of the move. I could tell he thought I was just being foolish. Maybe I was. After half a year, I finally gave in.

My mother spent a year on the locked side. This outgoing woman who all her life made new friends every place she went, never developed so much as an acquaintance. And still she wandered, getting out by following visitors out the door. Which led to two new choices: pay an additional \$2,000 a month, on top of the existing \$5,400 for her basic care and room, to have someone walk with her outside or keep an eye on her for a few hours as she roamed her friendless wing. Or move her to yet another facility in yet another part of town, with more activities to keep her busy and more elaborate security. I chose the latter, slightly comforted by its family-like feeling, but

her new roommates were even more diminished than the previous group. Many didn't speak at all. Others could only moan or coo to the plastic dolls they were given to occupy themselves.

THERE WAS ONE FORM OF security that did help her for a few years before she was locked in: the community. Which, for me and many others, still functions remarkably well, even as Vancouver grows and changes. For a long and precious time, my mother was able to continue a semblance of her active life because of people she never knew, whose names she didn't learn or couldn't remember. Bus drivers got her where she needed to go. Neighbours helped her find keys or her apartment. A web of kind strangers protected her as she began her attempts to walk back to Saskatchewan. With these little nudges, she was given years of freedom.

As it turned out, we didn't have to fret for long about my mother wandering after her move to the new place. She had another stroke in the summer of 2010,

when she was 89. It turned her speech, until then rambling but recognizable, into short strings of garbled words, comprehensible only if you already knew what she'd been saying for the last 10 years. She went from circling her unit with her walker to slow promenades down the hall on my arm to, by early 2011, life in a wheelchair.

I remember happier times. I usually visited her at dinnertime on Sunday. Frequently, with an enormous effort of will, she would force out enough sound for me to understand what she was saying. "You are so good to me. Thank you." Her eyes would brighten and she'd smile. When I was there, she didn't want to be anywhere else.

She died March 12, sometime before 4:30 a.m., while the wind outside was howling across the city and tearing branches off trees. I wasn't there. For many nights afterward, I woke up around that time, thinking of her, wondering if she'd heard the wind and been scared by it. Wondering if she'd lain there, in the dark, waiting for me. **VM**

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