

## **“How Do I Turn On My Oven?”**

Journeys through dementia usually start the same. There’s that defining moment when you finally realize something is wrong.

My moment came with my mother’s simple question, “How do I turn on my oven?” It happened late in the spring of 2013. I was with her in her apartment in Steinbach, the one she had occupied for 14 years. The oven was an ordinary electric range, the same one she had used all of those 14 years. I guess it was her calm, matter-of-fact way of asking such a loaded question, which at first confused me.

“What do you mean?” I asked. When I realized she really didn’t know how to set the simple knobs, my solution was to draw a schematic to show what position they should be in. That, too, made no sense to her. Of course it wouldn’t.

Then, for the first time in my life, she forgot my birthday. Why would I expect someone who didn’t know how to turn on an oven to remember a date? But it still hurt. For some reason, it hurt more than when she didn’t know I was her daughter. I guess I was prepared for that one.

## Missed Clues?

A month or two before the oven incident, I had been playing Cribbage with Mum. She said no one else wanted to play, and since I liked to, we played frequently. I remember telling my husband after that particular visit that age was catching up to her. She usually played well, but not that day.

Were there other missed clues? The first was likely four years earlier. For her eightieth birthday party in 2009, one of her out-of-province sons flew in to surprise her. He didn't visit very often, so it should have been a huge surprise. She didn't really react when he appeared. "Look, Mum, it's Keith. Aren't you surprised to see him?"

She said something about her glasses not working or the sun in her eyes. Talk about deflating for him. At the same party, she thought someone else should cut her cake, and someone else should take the flowers home. Even though she wasn't a big party person, it was still out of character for her, and left us scratching our heads.

Then there was the time my sister, Fern, phoned me to report what had just occurred between Mum and her. She said they were having a phone conversation, which involved "what if..." She said Mum would not or could not put herself in the "what if" scenario, got frustrated and hung up. That was so unlike Mum. Fern related this to me, not knowing what to think, other than perhaps Mum couldn't think in the abstract anymore. Then Mum phoned Fern back a little later as if nothing had happened—as if for the first time in her life she had not hung up on one of her children.

People in her 55+ building usually gathered Friday evenings in the multi-purpose room to play games. She used to really like that, but by 2012 she became more reluctant to go. At first she used being tired as an excuse. Then she complained it was becoming too frustrating because there was one woman who could never remember the rules and needed help each time. Was she talking about herself?

In a phone conversation, she told me about falling out of bed during the night. "Imagine that!" she said. The second time it happened, she decided to put something soft to land on.

She told me she thought she saw her granddaughter on television. It sounded like one of those *You've Got Talent* shows. Mum thought it looked like her granddaughter, but the name wasn't quite right. This was the granddaughter she was closest to. How could she be uncertain?

Closer to the time of the oven incident, she complained about not being able to balance her cheque book. She brought me her bank statement, and I flipped it over. "When did they stop putting the steps on how to balance it on the back?" I asked. No wonder she was confused.

"No problem, Mum, I'll make you some of those step-by-step sheets and bring them out next time."

When I returned with the sheets on my next visit, I asked her to get her bank book and statements and I'd walk her through it. One look in her bank book and my heart sank. This was far worse than I expected. Numbers were haphazardly written in and crossed out. Entries were incomplete and in the wrong columns. There was lots of white-out, and nothing made sense. Not wanting to make a big deal of it, I suggested I could take it all home and straighten it out. She was fine with that. This was the woman who used cheques for most transactions, and then proudly balanced her account to the penny each month. Now when she tried to add two numbers, she used a calculator and forgot she had to press the plus and equal sign. When I found some cancelled cheques, I saw a variety of handwriting. Cashiers were writing them for her. Yes, this was worse than I imagined.

As the summer went on, more things happened.

"Why was Grant here last night?" she asked.

"He wasn't," I said confidently.

"He was," she insisted. "When I got up to use the bathroom, I could see the flickering light of the television. I wondered why it was on but then I could see the shiny top of his head. He was sitting in my chair like always."

"What did you do?" I asked.

"I reminded him not to forget to switch it off, and I went back to bed."

A chill ran through my body. Maybe she saw a ghost. Perhaps my brother had died, the police had not yet notified her, and his ghost had come to visit. She may not have been a religious person, but she was spiritual. When we were growing up, she told us about her ghostly experiences and premonitions. They didn't scare her, and I think she was proud of them. I certainly didn't hope my brother was dead, but a visit from a ghost seemed preferable to the idea that someone had been sitting in her living room or that she could be hallucinating.

On my next visit, she told me her father had another family. When I asked her to explain, she went to her bedroom and brought back "the evidence", a picture of her father as a baby. There were two adult women in the picture, his mother and his aunt. Now she was convinced this picture was proof of something more sordid, this was the wife and family her father had left behind. Maybe she was thinking of her German uncle who literally lost his family during the war and then came to Canada to start afresh.

## Now What?

Some people have asked me, what's the difference between Alzheimer's and dementia? Dementia is a general term used to describe the symptoms caused by changes in the brain. Alzheimer's is a specific disease. It happens to be the most common cause of dementia, but there are others: vascular, dementia with Lewy bodies, frontotemporal dementia, even dementia related to specific diseases like Parkinson's or Huntington's. Unfortunately, the list is not short.

Depending on the cause, dementias may not start out looking the same. I realized my mother had a cognitive impairment, but I didn't think this was "typical" Alzheimer's disease. She remembered what was said from one conversation to the next, and she didn't repeat herself or ask the same question over and over. Her problem seemed to be managing abstract things, like numbers. And yes, there was some confusion.

Now what? She should not be living in her apartment anymore, but would be very resistant to change. She had been living by herself since my father's passing thirty years prior, and she liked it, the independence. When her eldest son, Keith, convinced her at age 70 to move from her house to an apartment, we heard for at least a decade what a mistake that had been. All she wanted was a small house with a little garden. Or, so she said. To us, she appeared perfectly happy living in her large bright apartment in this 55+ building where she met and made some new friends, didn't have to worry about snow or grass, and didn't have to climb any stairs.

Earlier that year, in 2013, my brother Grant had taken Mum to Winnipeg to tour an assisted living facility. She said he blind-sided her. There was no way she wanted to live in a place like that, where, she claimed, people sat around as if they were already dead. Yes, moving her was going to be a tough sell.

I have six siblings. Three of my brothers (Keith, Harold, and Grant) were living out of province. My fourth brother, Robert, lived on the outskirts of Steinbach, just minutes from my mother. He helped if given a task, but was not one to suggest or initiate things. My two sisters were, like me, living in Winnipeg. (Steinbach and

Winnipeg are about 70 km apart, so including the time it takes to get out of the city, the drive takes about an hour one way.) Iris, the eldest of us, was still busy managing the life of her adult special needs son, and also tended to be critical of Mum. Fern, the youngest, spoke frequently with Mum on the phone, but didn't go out and spend much time with her. I was the one who, through the years, made the most frequent trips out to see Mum. My husband's parents lived in Steinbach, so with one trip, we could hit both places either together or separately. Weeks I didn't go out, I phoned.

Fern and I knew enough at this point to be the most concerned. I was set to retire at the end of June, and Fern was planning to move out of province in the fall. She and I discussed the possibilities, but she was pushing me to do something. I remember telling her Mum would not go along with a move. I reminded her how Mum complained about moving to the apartment for at least a decade. I said anything we forced on her now would not be appreciated, to say the least. I was prepared to let things come to a head where Mum would be given no choice, and it would be out of our hands. Fern insisted we could not do that, there was the safety of Mum and others to consider. True, but it was still being left to me to do something which was ironic as I never wanted the role of a power of attorney. Fern and Keith had accepted that responsibility. They had what is called "enduring" power of attorney, which meant it would remain in effect if Mum became mentally infirm or incompetent. (I was named "recipient of accounts", which meant I could ask the POA's for an accounting.)

Looking back through computer files I kept, I see I was busy in June 2013 researching Age and Opportunity sites and compiling information on assisted living accommodations in Winnipeg. I also heard about an assisted living facility in Steinbach. Had I known what was to come, I should have chosen Winnipeg, but with what I knew at the time, leaving her in Steinbach closer to what she was familiar with seemed the better choice and easier sell. That's where her health care providers, her friends and some of her siblings were. Her sister Beatrice took her for groceries and coffee every Saturday, always a highlight of Mum's week. Besides, Bridgepark Manor, the assisted living facility in Steinbach we were considering, seemed to

fit the bill perfectly. Plus it was new and hundreds of dollars a month less than comparable places in Winnipeg.

On my next visit out to see Mum, I broached the subject, highlighting all the ways her life would be easier. She surprised me by not saying no. But then she didn't exactly say yes either. She said she would consider it in the future, maybe next year. I asked if I could plan a tour for us in the meantime. She reluctantly said yes. I left her with a sheet of the highlights I had typed, hoping she would start to sell herself on the idea.

Meanwhile, I was really concerned about what she was eating. On one of these visits, she was quite relieved to see me. When I asked why, she said she had put pork chops in a roaster the night before, but then didn't know how to turn the oven on. I thought we had already established that. I was relieved, but also saddened, to find the roaster of chops safely stored in the fridge. They were appropriately readied and covered in sauce, waiting for the woman who used to cook for a family of nine, to figure out how to turn on an oven.

I started making a point of going out each weekend with the fixings for a big meal. I'd leave the leftovers for her to reheat as she still seemed capable of using her microwave oven. I would also take a bag of frozen dinners and bottles of meal replacement. She soon tired of those. Prior to this I had suggested we sign her up for Meals on Wheels, but she said no. She said she knew someone who tried the service and didn't like it.

She always seemed to know someone who didn't like whatever service or help I suggested. So before I even suggested Home Care, I did some research so I would at least be informed and have counter arguments. When I brought the subject up I started out by asking her, "Do you know how kids rely on their friends for information, and a lot of times it isn't very accurate? Well, it's the same with seniors and Home Care."

That made her laugh. Like assisted living, she said maybe in the future when she needed it, but not now. Do we not know when we need help or do we simply not admit it to others if not ourselves?

## A Plan Is Made

My parents' generation is disappearing. Between me, my siblings, and our six spouses, only three parents remained: Mum, my father-in-law, and Rob's mother-in-law.

My father-in-law had a degenerative disease that limited his mobility and speech. Because of this, he felt isolated and lonely. He had already buried two wives and was ready to join them. He would have a heart attack that June and pass away in September, never having left the hospital.

Rob's mother-in-law was in her 90's. Even though she was living in a care home, her passing was sudden and unexpected. I guess that is the best way, especially at that age. Gerald and I took Mum to that funeral in June. While there, Mum's lawyer came over to say hello to her. He was a small city lawyer in the best sense. I liked the way he acknowledged her, and from what Mum had told me, the way he treated her. He had done some work for her recently, and I thought I should update him. Here's an excerpt from the letter I sent July 12, 2013.

*Unfortunately, we have been noticing a more rapid decline in Mum this past year (especially confusion). We're very concerned about her living in her apartment because we know she's not eating much (lack of appetite and stove confusion), is having problems with bathing, and can't do the housework anymore. She also falls, and unless there's something close for support, can't get back up.*

*We've been investigating the options of Home Care or Assisted Living. Both are going to be a tough sell, but we think assisted living at Bridgepark Manor in Steinbach would be the easier sell and best meet her needs at this time. It's basically apartment living, while providing two meals a day, housekeeping, a Victoria Lifeline, a step-in shower, in-suite laundry (important to her), and a hair salon on the premises. My sisters and I took Mum for a tour. We really liked it (sign*



*us up!). We see nothing but positives, and will sleep easier knowing she is there, but she is understandably hesitant and afraid of change. She's for it one minute and not sure the next. She did give us the go ahead to put her on their waiting list (which is thankfully short), but know we will have to keep calming her fears and reassuring her.*

That was a pretty good summary of where things were at. Unfortunately, it never occurred to me to contact one of the other key players, Mum's sister Beatrice, the one who took her out each week.

"Beatrice doesn't think I should move," Mum announced shortly after our tour of Bridgepark Manor. "She said I have a really nice apartment now."

When I got home I phoned Beatrice. She hadn't realized the extent of Mum's problems. From then on, when I thought to keep her in the loop, she became a valuable ally. In the meanwhile, Mum came up with other reasons why she shouldn't move.

"No one wants to live in *that* place," she told me. "That's why the upper floors are all vacant."

"Mum the place is full. There's even a waiting list. And remember the tenants you talked to? They said they liked living there and that you would, too."

"Oh, they were paid to say that," she replied.

Then she told me about a former neighbour from her apartment building who had moved to *that* place (she never remembered or got the name correct). She claimed he didn't like the food that was served. I doubted it at the time, but it actually turned out to be true. There was one old guy in his 90's who wanted his wife to cook for him. After a couple of years, they returned to apartment living. His poor wife, I thought.

And so it went. She came up with excuses not to move, and I countered with reasons why she should. She seemed flattered when I appealed to her financial side. I crunched the numbers and reassured her that between her pensions and her savings, she had enough to live a pampered life there for at least forty years (not exactly true!). It might seem strange to tell an 84 year old she had

enough for forty years, but I knew she didn't consider herself "old". She had also told me around this time that she got into a discussion with her friends as to how long they would like to live. Unlike them, she thought she'd like to live for a really long time, at least a couple of decades more, because there were still a lot of things she wanted to do. I thought this was rather optimistic. At least she wasn't showing signs of depression.