

INTRODUCTION

At the age of fifty-five, I became a parent for the first time. My new charges were reckless, accident-prone, pig-headed, out-of-control, over eighty years old, and bigger than me.

This is the story of the years I cared for my elderly father and stepmother as together they slipped into dementia. I was called upon to manage their health care, take on the role of human resources manager, oversee the upkeep and maintenance of their home, and ensure their finances were in order—although I lived over a thousand kilometres away.

The experience was fraught with constant worry and frustration as my parents slipped into the netherworld of their own shrinking brains and transformed into people I barely recognized. To maintain my sanity, I had to step back, shift my perspective, and rebrand each soul-sucking challenge as “a good story.”

A number of how-to books offer practical advice to caregivers, but this book takes a different approach. I’ve plumbed the drudgery and darkness of my parents’ declining physical and mental health for moments of grace, poignancy, and comedy. The story is written from my perspective as a seasoned health care professional. There were many times when I could not avoid regarding my parents as uncooperative patients.

I hope my experiences will resonate with anyone who faces the daunting challenge of caring for elderly and infirm loved ones—a time when you will have to navigate the complexities of the health care system, social services, and legal and financial institutions, as you wade into the quagmire of intergenerational family dynamics and role reversal. My family was fortunate. We had sufficient financial resources and a support network that eased the burden. I know this is not the case for everyone.

A report published by the Alzheimer’s Society of Canada in 2016 stated that there were over half a million Canadians living with dementia, with about 25,000 new cases diagnosed each year. One in five Canadians has experience caring for someone living with dementia. The problem is magnified in Atlantic Canada, with its aging population. Almost everyone knows someone who is living this reality.

In these pages you will find absurdity, justified indignation, and most of all, validation—served up with a healthy dash of humour.

The world, in the opening days of 2021, is in the midst of a pandemic. The current situation has shed light on the woeful inadequacies of elder care in this country, and the lack of support for caregivers. I was horrified, but not surprised, by the reports of nursing home residents in high-priced, private long-term care facilities in Québec being found malnourished and dehydrated, some having succumbed to neglect. In those facilities where the focus is on care, rather than profit, the measures put in place to protect residents from COVID-19 infection have increased the isolation and loneliness of our most vulnerable citizens, and placed an even greater burden of stress and guilt on their families. I am thankful that my parents were spared these indignities.

If you are someone who has lost a loved one to the ravages of dementia, I urge you to be gentle with yourself and give yourself the gifts of time, space, laughter, and forgiveness, especially in these complicated and uncertain times.

AND SO IT BEGINS...

I'm not sure when my aversion to the telephone started. Perhaps it was with Auntie Gwenyth's calls. Sometimes she would start the conversation with "Have you spoken to your father recently?" Those words became a signal that she had something worrisome to tell me—something that would niggle at the back of my mind.

That's what happened on a night in late October 2007, just as I was getting ready to walk the dogs. As I slipped into my jacket and rooted around in the hall closet for my gloves, the phone rang. I sighed. I could let it go to voice mail, but it might be about choir practice. Reluctantly, I picked it up.

"Hello, dear," said a perky, low-pitched voice. At eighty-two, my dad's younger sister had a sharp wit and strong opinions on topics that ranged from fashion to politics.

"Have you talked to your dad and Joan lately? I hear you're going up to visit them."

"Yes. We're going to spend Christmas with Bill's family this year, so I'm planning a pre-Christmas visit."

"Oh, that's nice. But have you talked to them about the details?"

"Uh-huh. Several times, in fact."

"Well, that's odd. Your father didn't seem to know anything about it. You'd better call him and go over it again."

It certainly was odd. In the past few years I had made an annual late autumn trip from my home in New Brunswick to the Ottawa River Valley to visit my father and Joan, my stepmother. We had talked about my plans for a visit in November. Both Dad and Joan sounded excited that I was coming and were sorry Bill couldn't take the time off work. It was a little over a year after Bill and I became a couple. They were delighted that, in my fifties, I had finally met a man who had son-in-law potential.

The evening after my conversation with Auntie Gwenyth, I got a call from Auntie Marjorie, the youngest in Dad's family, who lives near Montréal.

"Hello, dear. I hear you're coming for a visit. Would you like to come over after your dad picks you up at the airport? What time does your flight get in?"

I explained that I'd be taking the overnight bus to Lachute and would pick up a rental car there.

"That's funny. Your dad and Joan both told me you'd be flying and they'd have to pick you up at the airport." She sounded puzzled.

Then Dad called. "When is it you're coming?" he said. "Are you flying?"

"No, Dad. I thought we talked about this."

"So, we don't need to go to the airport to pick you up?"

I struggled to quell my impatience as I went over the details again. "Dad, why don't you write this down?"

"I did, but I don't know what I did with the note. It's on a slip of yellow paper somewhere." I could hear him rustling papers and breathing unevenly into the phone. A mental image of their kitchen table, perpetually cluttered with junk mail, phone and electricity bills, and grocery lists, took form.

Besides the unsettling calls from my two aunts, there were the ones that required me to talk Dad off the ledge, something that seemed to be happening with increasing frequency. I was the designated medical expert in the family, presumably because I had a Master of Science degree and worked in a hospital. That, in Dad's mind, qualified me to advise on any and all medical concerns. He and Joan seldom took my advice, so I couldn't go far wrong.

The phone rang at about six o'clock one Saturday morning. No reasonable person would call anyone at that hour on a weekend, unless it was bad news. I lurched to consciousness. My pulse raced as I reached for the bedside phone. It was Dad.

"Hi, how are you?" He whispered his greeting.

"I think I'm fine, but I'm not really awake yet. What's wrong?"

"Oh, sorry I woke you up."

"That's okay, Dad. Has something happened? And why are you whispering?"

"I don't want to wake Joan up. She's sick."

"What's wrong with her?" I was now fully alert.

"She has diarrhea. She's had it since yesterday."

Diarrhea? He was calling me at six on a Saturday morning to report on Joan's intestinal health? Joan was in her eighties and had Type 1 diabetes, so I knew I shouldn't be dismissive, but it didn't seem like an emergency.

“Is there a stomach bug going around?”

“Not that I know of. She came down with this all of a sudden. What does it sound like to you?” There was an ominous note in his voice.

My pulse had returned to normal. “It sounds suspiciously like a bout of diarrhea, Dad. Is she taking plenty of fluids?”

“Oh yeah, and she’s eating enough to take her insulin. But I’m worried.” He was still whispering.

“Why? What do you think it is?”

“Cancer,” he said, dropping his voice even lower.

“Dad, I don’t think it’s anything more serious than a stomach bug. Just make sure her blood sugar stays stable. If she gets any worse or it doesn’t start to get better by tomorrow, call the Diabetic Clinic.”

“Okay. You’re sure it isn’t cancer?”

I gave him my assurance, and that seemed to satisfy him. Joan’s digestive system was back to normal the next day.

Over time I noticed our Sunday morning chats were briefer and frequently covered the same territory. They had told me the same story three weeks in a row about the neighbour rescuing a stray cat and her kittens. I mentioned my observations to a colleague in the Geriatric Assessment Unit at the hospital where I worked as a speech-language pathologist. He had years of experience assessing the cognitive and communication skills of elderly people.

“A bit of memory loss is normal as people age,” he reassured me. “People who don’t lead busy lives run out of things to talk about.” It seemed like a reasonable explanation.

WARNING BELLS

I made the mid-November journey to my parents’ home on the overnight bus. Cushing, the small, sleepy village where I was brought up, stretches for about five kilometres along the Québec side of the Ottawa River, a short distance downriver from the Québec-Ontario border. Situated about halfway between the cities of Montréal and Ottawa, it was an active farming community when I was a child. My uncle had a sheep farm right across the road from our house. To this day, I get misty-eyed at the aroma of well-aged manure on a crisp winter’s night.