

Doris Inc.
A Business Approach to Caring for Your Elderly Parents

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Chapter One

My Heart-Wrenching Caregiving Dilemma

Early in the 20th century, Lamaline, Newfoundland, was a bustling fishing village at the bottom of the boot-shaped Burin Peninsula. Life was tough back then. The only connections with the outside world were telegrams and the coastal boats that brought mail, household essentials, and fishing supplies.

Apart from a district nurse, and Granny Foote and Granny Crocker who assisted women with giving birth, medical help was a rough 25-mile ride by horse-drawn box cart or sleigh to the town of Grand Bank. Antibiotics hadn't been discovered yet, so many villagers died of infections and a lack of emergency medical care before they reached their senior years.

Lamalaine was a close-knit community of families whose ancestors had come from England, and the elderly were an integral part. The Bonnells, the Cakes, the Collins, the Footes, and the Haskells were some of the big families, but the Hilliers were the largest clan of all. Brightly painted fishing sheds and wooden houses that decorated the settlement reflected the lively spirit of the people, and none more so than that of my mother, Doris Hillier.

Doris was born on September 8, 1918, the fourth of Daniel and Amelia Hillier's six children. She was a happy and energetic child whose entire face would light up and her brown eyes would twinkle whenever she smiled. Her enthusiastic expression of delight continued until she reached the ripe old age of 90.

In 1921, Doris' older brother Aubrey died at the age of six of the croup, a common childhood respiratory infection. Death knocked on my mother's own door four years later, at the age of seven, when she contracted scarlet fever. Her burial dress was ready and waiting, but miraculously she survived with a hearing loss and a heart murmur. Although she recovered some hearing in her right ear, she remained deaf in her left due to a perforated eardrum, an impairment for which she was bullied at school.

Back then there was no organized care or training for people with special needs, and hearing aids were neither affordable nor readily available. Fortunately, her father had been a schoolteacher and he tutored her during her illness and then helped her when she couldn't hear lessons in class. Doris soon learned to lip-read and later, with the help of hearing aids in both ears, she never let her hearing impairment hold her back from anything she wanted to do.

In 1929, the Lamaline villagers were confronted with a situation that tested their ability to overcome adversity. On November 18, at 5:02 p.m., a 7.2-magnitude earthquake shook the Grand Banks, about 250 kilometres south of the Burin Peninsula. It was felt as far away as New York, Montreal and Portugal, and was the sixth-largest earthquake ever recorded in Canada.

My Aunt Gladys, one of Mom's two sisters, described how at 7:30 p.m. she watched the ocean mysteriously and eerily recede from the shore to expose the ocean floor. A few minutes later, villagers in more than 40 outports along the foot of the peninsula were terrorized when they saw a gigantic white

foamy wall of salt water coming toward them. Able-bodied residents ran to higher ground. Three successive waves crashed over the land, crushing whatever was in their way and rising as high as 42 feet in the long narrow bays.

The devastating tsunami killed 28 people, mostly women, children and the elderly, in six communities between Port au Bras and Lamaline. Villagers would never forget that clear moonlit night when they stood helpless, watching houses float away with kerosene lamps still burning brightly, until the ocean completely swallowed the buildings with their family or neighbours inside. Many traumatized survivors were left with only the shirts on their backs after their homes and winter provisions were destroyed.

My grandparent's house was located on low-lying ground just a road and a meadow away from the ocean. The dwelling sustained serious flood damage, but the family was spared. From that day forward my mother has been frightened of the ocean and never learned to swim.

The Burin Peninsula recovered, a testament to how families, neighbours and their beloved district nurse, Dorothy Cherry, rallied to assist one another during a crisis. The homeless received shelter, food, and warm clothing from neighbours or relatives, and Nurse Cherry travelled by horseback and on foot to the worst-hit communities to attend to the injured and sick. Able-bodied men rebuilt the homes once aid arrived from the Newfoundland, Canadian, American and British governments, and from public donations.

In this same resourceful way, a sisterhood of village women supported their parents and other elderly residents. Seniors' lives were intertwined with their large extended families and neighbours. Nursing homes didn't exist in this remote part of the country, and the hospital was too far away, so seniors typically lived and died in their own homes, surrounded by their loved ones.

Retaining the values she learned growing up, Doris became a caring and resourceful young woman with a passion for life. She had a positive attitude and always found the best in people and in situations. Doris' quick wit and ability to see the lighter side of life made her fun to be with.

In 1936, following in the footsteps of many young people from fishing villages, Doris moved to St. John's at the age of 18. While there she met Ed Roberts, a handsome man in his late 20s. He was born in 1911, in the pretty fishing village of Brigus on the shore of Conception Bay, 50 miles from St. John's.

Matchmakers say opposites attract and that was certainly the case for outgoing Doris and shy and serious Ed. However, in the mid-1940s, Doris, made the gutsy decision to move to Toronto in search of more plentiful jobs, as her sister Gladys and her family had done. Ed missed his girlfriend so much that he pulled up stakes in St. John's and moved to Toronto. On August 14, 1947, Doris and Ed, aged 29 and 36, were married. My brother David was born in 1948 and I came along three years later.

In the fifties, women of my mother's generation often stayed at home to care for their children, and later in life brought their elderly parents into their home to care for them, until they needed hospitalization in their final days. My grandfathers both died in their late 60s, but my grandmothers

lived until their mid-90s. They were very well cared for at home by my aunts in Corner Brook and St. John's, Newfoundland.

When I was seven, my parents built a small cottage in the Kawarthas, not far from Campbellford, Ontario, on the Crowe River. Over time, other Newfoundlanders, mostly from Lamaline and Taylor's Bay, came to "the Crowe" to build cottages. These were happy family times, filled with great friendships, lots of swimming and boating, and evening card games that my mother loved.

Eventually, David and I grew up, graduated from the Ivey Business School at the University of Western Ontario, and started our business careers, his in accounting and mine in marketing. Our parents sold their family home in Toronto and retired to Cobourg, a charming town on Lake Ontario, about 60 miles east of Toronto. They adjusted well to retirement and grew attached to the town and their small brick bungalow. Mom quickly made new friends, often inviting them over for tea, homemade date squares, and a chat. By this time, she took great pleasure in the small things in life, especially in conversations with her family, neighbours and friends.

Mom finally got her driver's license in her early 60s, but she seldom drove because Dad was afraid she wouldn't hear cars around her well enough to avoid dangerous situations. The drive to the cottage became increasingly stressful as Dad gradually lost his nerve to drive beyond Cobourg or at night. By then Mom had also lost her nerve to get behind the wheel. When my father turned 76 and my mother 69, they realized that they could no longer keep their cottage and grounds in tip-top shape as they had always done. My parents reluctantly decided to sell their beloved cottage. What they hadn't yet realized was that they were also bidding farewell to the active era of their retirement years. This had been a carefree period unencumbered by time, work and parenting responsibilities, and unrestricted by their physical and mental capabilities.

As Doris and Ed transitioned into their 80s, it was evident that their bodies were wearing out and they had both lost some of their mental sharpness. They would, on occasion, purposefully walk into a room and then forget why they went there. They would also lose keys or important documents and have to spend frantic moments searching for them. My mother managed all the family finances and was proud that she could complete annual income tax returns. Eventually, this task stressed her out so I helped collect the information to send to David, our family financial advisor, so that he could complete the return.

My parents progressively became less energetic. They stopped going to church regularly and watched it on TV instead. Their physical stature had noticeably shrunk, their hair thinned and their eyesight and hearing worsened. Doris had maintained her shapely figure, but her spine formed the letter C, a sign of osteoporosis. She walked with a cane in her late 70s, but with increased frailty she used a walker more often to get around.

Sadly, on September 15, 2002, three weeks before his 91st birthday, my father died and my pillar of dependability instantly vanished. Family had come first in my father's life and he had always been there for us. There were times when knowing this made all the difference in dealing with life's challenges. Dad died of congestive heart failure after two trips to the Cobourg hospital emergency department, once in

June and once two weeks before his death. I was with him in his final hours of consciousness and I'm so glad I was able to say to him, "you have been just the best father." He heard me and responded, "That's nice."

I was forced to bury my grief for my father because I immediately became my frail mother's primary caregiver, a strange new role for which I was ill prepared. I did the best I could to help her cope with this dramatic change in her life. We spoke every day on the phone, and I drove from Toronto to Cobourg every other Saturday to spend the day with her. I also hired help to do household chores, including cleaning the house, cutting the grass and shovelling the snow, and I was in touch with her neighbours who volunteered to look in on her regularly.

I found Sue, a good samaritan to the elderly, who became particularly fond of my mother. She took Mom grocery shopping and to medical appointments, stopped in for tea, and helped with the gardening. I thought at the time that I had all my bases covered. Doris was by nature very sociable so I expected that, after a reasonable period of time for mourning, she would be happy to move to a retirement residence where she could enjoy life once again with new friends, unencumbered by her house.

Meanwhile, I ran my marketing company, keeping clients happy by working five to six days a week at a hectic pace. I also tried to find time for Mitch, the lovely man in my life. It soon became very evident, however, that both Mom and her house were being sadly neglected. On one of my visits, I discovered unopened mail collecting dust, laundry lying in piles on her basement floor, a burnt-out hallway light bulb, expired milk and yogurt cluttering her fridge, and her blouse covered in tea stains. As I left that day, tears welled up in her eyes and in mine; it was painfully obvious to me that I wasn't keeping up. Nevertheless, I had no more time to devote to my mother, without giving up some essential aspect of my own life. I grasped the magnitude of my heart-wrenching dilemma with frustration, overwhelming sadness, and guilt.

I must confess I never expected to find myself in this predicament. Frankly, the subject of my parent's death and my own mortality stayed buried in my subconscious. When I did think about it, I imagined that we would die in our sleep one day after a wonderfully long and healthy life. The possibility of having to take care of my elderly parents, then later my spouse, and one day needing care myself never crossed my radar screen. Then it dawned on me just how naive I had been, and that I should have been better prepared for this task.

At the time, I hadn't realized that the social skills and activity levels of many seniors diminish greatly as they age, and they can become very reclusive once their spouse dies. Supplemental daily support and companionship are often needed by people in their 80s and 90s, whether they live on their own, in a retirement residence, or in a nursing home. They can become totally dependent upon other people for social interaction, mental stimulation, and activities that interest them. Compassionate deeds by kind souls are extremely important, because they give seniors a sense of belonging and create a diversion from their diminishing health and loneliness.

Mom definitely needed a lot more attention than I could give her to lessen her feelings of isolation. During that difficult transition period I noticed that when she had company or received a hug, her whole face would light up and the old familiar twinkle in her eyes returned.

Within two months of my father's death, my mother's grief was compounded by symptoms of Alzheimer's disease that surprisingly started to surface. At the time, I attributed her deep depression to the loss of her husband of 55 years, and to the stress of the change to her way of life. However, I was puzzled when I started to receive several calls a day from Mom fretfully asking the same question over and over again. I became even more alarmed when her neighbours and the parish nurse expressed their concern that "your mother is very confused and it isn't safe for her to be living on her own."

Now that I understand this debilitating brain disorder much better, I can recall the telltale signs of my mother's dementia symptoms: her forgetfulness, uncharacteristic irritability, episodes of anxiety and confusion, and withdrawal from her usual activities. She had rapidly lost her ability to live independently, and because David lived on the West Coast, her wellbeing became my responsibility.

For a year and a half, I helped my mother live as independently as she could, and I tackled her health and loneliness issues using what I call a solo firefighter approach to caregiving, focusing only on Mom's crisis of the day. Lacking the time and insight to organize a better solution made this an extremely stressful and sometimes insane period in my life. My efforts to take good care of Mom failed miserably, and I witnessed first-hand how our society's current method of caregiving can result in neglected seniors and burnt-out caregivers. I believe this is a result of socio-economic and demographic changes and medical advances that are rendering our current caregiving model obsolete.

Caregiving has become much more challenging for the baby-boom generation than it was for previous generations for a number of reasons. Typically, women take on the responsibility for eldercare; however this custom is outdated because more female caregivers, the majority of whom are between the ages of 45 and 64, have demanding full-time jobs. Because more women went to college or university than past generations, many of them had children later in life, who are more likely to still live at home when an elderly parent needs support.

Baby boomers also have a higher divorce rate, so caregivers today are more likely to be a single parent who bears household and care responsibilities alone. Families are typically smaller and more spread out today than they were in past generations. Caregivers often don't have relatives living nearby on whom they can rely. In our more transient society, we are more likely to be caring for a parent who lives in a different city, or even very far away.

Medical advances are extending the lives of our moms and dads but not eliminating chronic debilitating diseases that afflict the elderly, such as osteoporosis, Alzheimer's or Parkinson's disease. More adult sons and daughters will, therefore, be responsible for a dependent parent, and will have caregiving duties for 5 to 10 years, or longer.

Our current caregiving approach works well for seniors who have immediate family willing to sacrifice their lives for them, a large extended family willing to help, or who have the financial resources to pay

for the very best full-time care. However, many frail seniors live in an environment cut off from the rest of society, alone in their own home all day while their children work, or alone in a senior's residence or nursing home. For these many neglected poor souls, our current caregiving approach simply doesn't work.

A staff member at a nursing home confessed to me one day that some families visit residents only once a month, some visit weekly but only for an hour, and still others don't even show up for birthdays or Christmas. Isolation and neglect is getting worse, because a scarcity of time and long-distance caregiving makes frequent visits impossible for many adult children. There are, however, other reasons for this lack of attention.

Some adult children mistakenly assume that the staff in retirement residences and nursing homes can fulfill all of their parents' needs, making their attentive care unnecessary. Others, especially men, don't really know what their caregiving role is, or they don't want to know, because they get squeamish helping their parent do things such as go to the bathroom. Frequently, sons and daughters are so absorbed in their own busy lives that they don't recognize when their parents need help. They may also be uncomfortable dealing with elderly parents who remind them of their own inevitable demise, or they have a feeling of futility in making much effort because there is no hope for recovery. I have often heard people admit that they infrequently visit Alzheimer's residents because, "my mother doesn't recognize me and I can't deal with that." Still other children, and even spouses, unconsciously resent their loved one getting sick and leaving them with the burden of care, and so can't face being with them often.

I knew my mother and I couldn't survive another year with her living in her own home so, after much coaxing, I convinced her to spend January in a retirement residence to see if she liked it. I think the thought of walking down cosy warm corridors rather than sliding on snow- and ice-laden roads enticed her to give this safer haven a fair chance. She moved back home in February, however, because she missed her house and neighbours so much, and threatened to never return to the retirement residence. Realizing Mom's resistance, I set about doing what was in her best interest, and that was convincing her to move to a safer environment, given her advancing dementia symptoms and the challenges of living by herself.

I patiently listened to her concerns, I asked her about her jovial new friend, Betty, who had taken her under her wing at the retirement residence, and I gently nudged her toward the best decision. By the end of March, after time to weigh retirement-residence life against living alone, Mom finally agreed to sell her house. This taught me an important lesson that seniors, like all of us, need time to adjust to any change in their lives.

By June 2003, Mom's house had been sold and David came from Vancouver to move her into a retirement residence in Cobourg. Doris chose a room next door to Betty on the second floor where the residents' smoky-coloured Persian cat lived. One late summer afternoon, I was thrilled to hear my mother's laughter fill the hallway outside of Betty's room, as she and her new pal tried to hide their indulgence in a hot toddy. The duo soon became so inseparable that I nicknamed them "Frick and Frack." I was hopeful Mom would flourish with new friends and interests, and would live out the rest of

her life in relative happiness with visits from me every two weeks. I felt optimistic because life was pretty good once again for Mom, David, Mitch, and me.

When I took a short break from my caregiving duties in the fall, Mom's situation seemed very much under control. Life stood still for a magical moment on September 26 when, surrounded by friends and relatives, Mitch and I got married. My mother was in her glory partaking in the festivities with her sister, her nieces and nephews, and lifetime friends.

Sadly, this would be the last large family gathering in which she would know who they all were. Our period of relative calm was very short lived. On December 23, my mother fell and broke her leg close to her hip, and spent three lonely months in the hospital because her brittle femur was so slow to heal.

Doris couldn't return to her retirement residence because her needs exceeded the level of care available. She had rapidly progressed to the middle stage of Alzheimer's disease and couldn't walk or propel her wheelchair. The hospital discharge planner told me that Mom needed to move to a nursing home. My mother dreaded the thought of ever living in an old-folks' home and we dreaded the thought of moving her there, because we heard stories of nursing staff neglect in the news. Unfortunately, we soon learned that we had no other option.

By this point, I urgently needed to find a better approach to caregiving because I was spending as much time putting out fires for Mom as I was consulting. Her quality of life and mine had taken serious nosedives ever since she landed in the hospital, and my caregiving duties would continue to increase as my mother became more dependent on me for her health and well-being.

In early April 2004, Doris moved into a new long-term care facility that was going through growing pains. The staff had never worked together before; indeed, some of the employees had never even worked in a nursing home. On my very first visit, a young and inexperienced personal support worker left my mother on the toilet unattended, got busy with another resident, and then totally forgot her.

Frantically, I went looking for staff to help, because my mother couldn't put any weight on her left leg, and I couldn't lift her back into her wheelchair on my own. I expected that at any moment she would fall on the floor and break yet another bone. I must have looked visibly upset, because the registered practical nurse called the administrator, who came running to calm me down and solve the problem. I never saw that personal support worker at the nursing home again.

The first Saturday in June was a beautiful warm, cloudless sunny day. After a very busy workweek, I was driving along the highway on my way to visit Mom as I did most Saturdays. My mind was churning a mile a minute. I wanted to spend this glorious day golfing with Mitch, but I needed to spend the day with my mother. As I neared my destination, I began to accept the reality that my duty that day was with Mom.

Over the past month, I'd noticed that Doris was not adjusting well to nursing-home life, and that a common and irreversible cycle had started. Dementia had taken a stronger hold of her behaviour and her social skills were fading noticeably. My mother was hesitant to strike up a conversation with passersby or attend social activities. She had made new friends in the retirement residence, but not

here, and she lacked the initiative to amuse herself by reading, listening to music or watching her favourite TV programs. Sadly, Doris was spending most of her days by herself in her room and becoming depressed and despondent.

At times, even her room seemed like a scary unfamiliar place, because she was losing her ability to speak for herself when she needed help. She became easily distracted by other people around her and lacked the focus to eat on her own. When coaxed, she would eat, but it would take her a full hour to finish a meal. Personal support workers couldn't stay with her that long, because they had other residents to help, so Doris slowly started to lose weight.

Residents in Doris' nursing home receive 20 minutes of personal one-on-one time from an activities coordinator each day, and there are scheduled daily activities that they can participate in, if someone takes them. These initiatives certainly help when they are available, but they can't give residents the same quality of life that they had when they lived with their families.

Many residents often fall asleep in their chair during the day due to sheer boredom. Even Doris noticed how drowsy her peers were during lunch one day when she glanced over at the next table of residents in the dining room and said, "They're not so lively over there." This took me totally by surprise because she had been very quiet that morning. Her words sent me into a fit of laughter.

When I arrived at the nursing home, I put on my happy face to greet my mother. It is only human nature to want a cheerful visitor, but this is especially important for a person with dementia. I learned through trial and error that Mom would echo my moods. If I exhibited signs of being upset, she would become upset too. I gave her a kiss and a gentle hug and read to her from her favourite prayer book, which seemed to comfort her.

I helped Mom eat lunch and then took her outside for some fresh air. At 2:30 p.m., I asked two personal support workers if they could put my mother to bed for an afternoon nap. When Doris laid her head on her pillow, she looked up to see that it was one of her favourite personal support workers tucking her in. With typical charm from her younger years she said, "Do you want to lie down with me?" The personal support worker was flattered at Doris' attempt to befriend her. She gave her a wide grin and said she would love to join her because she was very tired, but had far too much work to do. At that moment, for the very first time, I saw loneliness not only in my mother's eyes but also in her actions. I knew she missed my father terribly and also her family life and she no longer had a home to call her own. An hour later with great anguish I bid farewell to my mother and reluctantly headed back to Toronto.

As I drove home I felt torn between my conflicting roles. I needed to find more time for Mom, but I also needed to earn a living, and I wanted to spend more time with my new husband. I came to the depressing conclusion that the word enough isn't in the caregiver dictionary. I hadn't even hit the heavy lifting of late-life caregiving, let alone the enormous weight of palliative care, and already I couldn't hold my own.

Doris was lonely and I could never be with her enough to keep her happy. She wasn't eating well and I couldn't help her eat at every meal. Suddenly, a groundswell of feelings came over me. I worried that if I

got burnt out and sick I would not be able to help my mother, and she would be even more abandoned. I felt my life had been put on hold and that made me very angry. I felt resentful of my brother who lived so far away, and whose life wasn't on hold. At the same time, I felt guilty that I resented him and that when my mother needed me the most I had let her down. I also felt helpless watching old age ravage my mother's frail body, because I knew I had no way to stop her decline.

I arrived back in Toronto mentally and physically tired, as I usually did after a day with my mother. To my surprise, despite feeling tormented my normal tenacity returned. My mind was overflowing with thoughts of how I could solve my crisis. I knew that David would be a willing partner in any scheme that would allow us to take better care of our mother. With great enthusiasm, I realized that it was within my power to find a way for my mother and me to suffer less.

To find a way to take better care of Mom and still have a life of my own, David and I instinctively drew upon our business experience and applied business disciplines to caregiving. We created a loving home environment with professional, attentive, and compassionate care for our elderly mother.

We used only our parents' middle-class financial resources, government-funded pensions and health-care support, and our determination. Mitch affectionately called our venture Doris Inc. because it resembled a business, and we have stuck with that name ever since. The driving force behind Doris Inc. was the endless love that David and I had for our one customer, our mother.

We noticed early on that our mother was happier and more comfortable than she was before we started Doris Inc., and by focusing on her capabilities rather than limitations, we enabled her to function as well as she could. My stress level was lower, and I had more free time, so my life was no longer on hold.

Our venture ran for five years, and although our mother's care needs became much more complex in the final stage of Alzheimer's disease, her life had been as good as it could have been every step along the way. At the same time, our new approach to caregiving gave me more personal time, including time to write key segments of this book, so that other caregivers and elders will hopefully have better lives together.

Top Tips

A Solo Firefighter Approach to Caregiving Doesn't Work

✓ ✓ Getting involved in caregiving only in emergency situations results in neglected loved ones, stressed out caregivers and poor decision.

✓ ✓ Caregiving is too big a job for one person. Caregivers need backup when they get sick and when they need a break.

Be Prepared

✓ ✓ Learning about eldercare before an aging parent or spouse needs your help will prepare you for the challenges that lie ahead.

Patience is a Virtue

✓ ✓ Seniors need time to adjust to any change in their life.

Home is Sweet Home

✓ ✓ Create a loving home environment for your aging parent, even if they can no longer live in their own home.

Keep them Busy

✓ ✓ Daily activities and companionship give seniors a sense of belonging, and create a diversion from their illnesses and loneliness.

Where There's a Will There's a Way

✓ ✓ Focus on a senior's capabilities, not their disabilities.