

Who am I?

by GWYNNE DYER

I'm the daughter of a loving mother, who is the strongest person I know.

A beautiful French Canadian from 'la belle province' of Quebec, her parents and sister moved from the province when she was 14 to Valley East (near Sudbury), in the Town of Capreol. She has battled so many challenges all her life; having tuberculosis and having to be in a sanatorium from age 16 to 18, going home in 1955.

She then met and fell in love with my father and they married in early 1956.

They worked on building their family and by December 1957 they had their first child, my brother.

In November 1958, they had twin girls, myself and my sister. Yes, there are only 11 months between the first three kids (wow for sure). They had two more boys spaced out five years apart between October 1963 and November 1968. Unfortunately, four days after my younger brother was born, my father passed away at the age of 32. My mother, also 32, became an only parent to five young children.

Throughout her life, she struggled, however, with the support of my maternal mémère (grandmother) and despite financial challenges, we had a very loving family with all its wonderful imperfections and awesomeness.

Mom's journey of being a caregiver

The reason I bring up my grandmother is that in her later years, she was diagnosed with Alzheimer's. It was my mother who cared for her, being there for all her care (feeding, bathing and security as she was wandering). Although we were all there for my mother in her challenges in caring for my grandmother, she did everything for her and did not want to put her in LTC.

I had to contact my aunt Lucette (mom's sister) who lived in B.C. to come down and convince my mother it was time to put her in long-term care.

My mother wanted to support her mom for all the support my grandmother provided after my father's passing. It took some hard discussions; however, we were able to convince my mother to make the move. Our position was that LTC was not only for my mother but it was also the best decision for my grandmother. Talk about role reversal, as my mother took an active part in my grandmother's health and daily activities. She visited my grandmother every weekend as I was the person driving her each week.

Nearing the end, my grandmother had gone back in time, and my mother was not her daughter she was her sister and I was the taxi driver? a title that accepted proudly.

Mom's family history

Although all my research says that Dementia and Alzheimer's are not hereditary, my family history does not match that position. My grandmother had 16 siblings and approximately half of them were diagnosed with Alzheimer's. My grandmother had two daughters; my mom and my aunt, and both were diagnosed with dementia.

Mom was diagnosed with the dementia gene in her late 60s or early 70s, with her starting to show signs in her late 70s and today she is 88.

Her sister was diagnosed with dementia four years prior to her passing. Mom was diagnosed with vascular dementia and my aunt

with dementia bordering Alzheimer's. My goal is to see if Dementia and Alzheimer's are generationally passed down through a lineage, similar to my maternal grandmother's.

Our journey to long term care

My mother's journey to long term care began with the support from Peel Seniors Link/LHINS now known as HCCSS, who provided PSW support as my mother lived in a senior's apartment.

They supported us by monitoring my mother as her dementia began to impact her daily activities. My contacts helped me prepare and navigate the process into long term care, although the wait list was three years.

They advised us to start looking at homes and making a list of those we would prefer. They also connected me with The Alzheimer's Society. The PSWs were so supportive and honestly cared about my mom's well-being.

They also helped in ensuring her safety in her apartment, when she began to have memory challenges. In particular, they ensured that we had all the appropriate tools to help her live safely at home, such as turning her stove access off due to memory.

In mid-2019, my mother took a serious fall and smashed her face on the side of a steel chair. I had gone to her apartment after I left the hospital that night and found her walker in the corner and the chair on the floor tipped over. I suspected that she forgot to use the walker to go to the kitchen.

She incurred other injuries within a few days of her initial fall. At that point, mom was flagged as a priority for LTC. We had to add four more homes to our list making a total of eight homes. Most of our choices were close to Brampton except one.

One of my mother's doctors lived in Bolton and recommended King Nursing Home (KNH). We put that home on our list, as I trusted this doctor and she had one of her loved ones there. She was really impressed with the care provided to her family member.

We flagged KNH as our last choice only due to the distance from Brampton. Mom had several temporary homes while we waited for an LTC bed at one of the locations on our list.

Our journey to king nursing home

King Nursing Home was the first available bed and she was moved there in June of 2020, when COVID was in full-out outbreak.

We requested that LHINS (HCCSS) keep mom on the list, and as soon as a bed in our preferred (close to our home) locations. When I received a call on the day they were moving her, I had requested that I accompany my mom and be there for her in this new strange space, and to keep her calm and just help in the transfer.

They were so accommodating to my request despite the outbreak, making all the appropriate processes to keep not only my mother safe, but myself as well. I was so appreciative of that process.

On mom's first day, we were greeted by a wonderful Registered Nurse (RN) who helped us get her registered and settled in. She truly knew how to calm mom, but also reassured me she would be fine.

Unfortunately, mom had to be quarantined for a couple of weeks due to COVID. As anyone with a family member with dementia can agree, that any change to their routine like a new location, coupled with being quarantined, takes a toll on our loved ones.

After those first few weeks, I truly appreciated the way they transitioned my mother. Being there for her despite the challenges with her demeanour and actions.

However, as she was able to start interacting with the staff and the residents, the COVID outbreak did not allow the same level of interaction that we have today.

We were able to Facetime with mom and although it was not ideal, it was a great option.

Mom's settling in and making friends

That first year was challenging, not just for my family, but for all families with loved ones in all LTC homes. But it was the support of the KNH staff that truly helped my mother and many of the residents in the home.

I was truly impressed with the process that KNH implemented during covid to minimize the outbreak infections. Not that there were no challenges, every home had its own challenges. All I can remember is that I was truly grateful for their commitment to the residents, families and staff safety.

Thankfully COVID was finally under control.

Once the residents were able to start interacting with each other again, that is when I was privileged to get to know not only the staff but a lot of the residents on mom's floor.

More importantly, mom was thriving. She was participating in the activities that she was able to participate in, and enjoying so many internal and external excursions in Bolton (like Tim Hortons, Harvey's, Swiss Chalet lunches as well as shopping at stores like Dollarama or Dollar Tree, Canadian Tire and Walmart to name a few.

What a wonderful village

For the past many years, it has been such a pleasure to get to know the King Nursing Home Team, where every department is truly working together to support residents and families.

I saw mom smiling and making friends, not only with residents but seeing staff truly caring and working to make the home a village.

Mom met people from Quebec (one of her first lunch buddies) and got to know so many friends from other countries with common challenges. More importantly, it satisfied the need to find friends and support each other.

Having family members who are at the home supporting each other in so many ways (by keeping an eye on your loved one in your absence). Supporting each other as our loved one's challenges increase, and just enjoying each visit no matter that day's challenges, and knowing you have that support. Mom was truly enjoying her time and singing her heart away to the music in the lobby.

Then the unavoidable happens ? ?who am I??

This past year (2024) my family and I have been managing the unavoidable challenges, as mom's Vascular Dementia has progressed.

Her recent challenges this past fall and winter have been with Sundowning and increasing memory loss. My heart broke when she showed concern that she could not remember things anymore.

?That is why you have me and my siblings. We are your memory,? was my response.

However, I want to acknowledge, that the challenges of memory loss are definitely the hardest symptom of dementia on the family and somewhat with our loved ones with the disease.

The first time that mom asked who I was, we were in the lunch room after being together all morning and she knew who I was all morning. Then all of a sudden she turned to me and asked who I was.

Although it was heart-wrenching; my experience with my maternal grandmother helped me along with the past support with the Alzheimer's Association and having the unwavering support of the staff in how to manage the upcoming stages and challenges.

Knowing that I should not say anything that would make her feel bad about not remembering her own daughter, my response was, ?I'm the lucky person to have you as my mother.?

She laughed and we continued with a wonderful rest of the visit. Admittedly, the hardest was when soon after she asked me who she was. That was a little more challenging to manage. Again, just acknowledging our relationship, ?you're the wonderful lady who is my mother,? while just continuing our conversation with laughter and hugs.

How do you move forward? Support your loved one and participate in their care

One thing that I have learned in the past 10 years (longer if I factor in my mom's journey with my grandmother) is that you are not in it alone.

It's important to put your faith in your family and work together to manage the various challenges and stages. More importantly, remember it is harder on the caregiver than the person with this awful disease.

It has also been my privilege to get to know so many people on the journey to LTC who have been supportive and a source of knowledge and comfort.

From Peel Seniors Link/LHINS (HCCSS) and the Alzheimer's Association ? where they had prepared both my mother and myself as we navigated our mother's challenges ? to all the staff at King Nursing Home and the resources that they have provided, we are grateful.

Most importantly that includes the families and friends that I have been able to forge a great relationship of support with. I know that my family and I are not alone and this makes our journey a little easier.

For this reason, once I was aware that King Nursing Home was starting a Family Council, I did some research. In particular on what a Family Council does, or how I can contribute to my mom's life at LTC.

I did a lot of research on the Family Council of Ontario (FCO). I wanted to help make a difference; not only for my mother, I wanted to help make the home stronger and support all the residents that I have become close with and remember those that we have lost. I want to celebrate the staff; who in my experience as well as so many families that I have spoken with, have been so supportive and caring.

Being able to reach out and get support or get recommendations for some external support, such as the Alzheimer Association, FCO and other specialists, has made it less challenging to navigate the system.

I am aware that my experience may not be the same for everyone. Every situation is different and I get that. I also understand that each family's situation is different and for that reason, the Family Council is here to support all families.

It's not whether you are a member of the Family Council, the key is to have you participate in whatever you can do.

We are stronger together, and many LTC homes have Family Councils. I welcome and suggest that anyone with family in LTC to reach out to your home's Family Council. Especially if you have questions regarding your home as the Family Council can be a great

resource for you.

More importantly, when you are available, come join in any of your FC meetings. You are always welcome!

Thanks to everyone who has supported me on this journey that is not finished and to everyone who has and is supporting the KNH Family Council (Alzheimer Association and Family Council of Ontario).

However, for me, it's the unwavering and ongoing support from all the staff at King Nursing Home who has made my mother feel valued and safe.

Thank You.