

Communication and Dementia: Perspectives from a Spouse

La communication et la démence : les points de vue d'une épouse

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Caregivers of relatives with dementia face a multitude of changes including loss and adjustments to relationships and lifestyle. It takes courage, flexibility and willingness to change and to grow to be an effective caregiver for a family member who has dementia.

I was first a caregiver for my three children, then sometimes for my Mom who lived to almost 103 years of age and who once said when she was 92, "I'm not going into one of those homes. Everyone there is either old or crazy!" The next time I was a caregiver was for my husband, Jack McKay, who had Alzheimer's disease for about 20 years. He was in long-term care for almost seven years.

Caring for my husband Jack is very close to my heart, so I write this contribution from the heart. Caregiving is a very emotional experience. Disraeli once said, "Never apologize for showing feelings. When you do so, you apologize for truth."

My caregiving for Jack followed a long, rocky and unexpected road; certainly not an easy journey. I write this paper to share some of the frustrations of our journey as well as to recount some of the brighter times we shared. My purpose is to not minimize the immensity of the task that caregiver's face regardless of their profession (e.g., those who work in a nursing home, audiologists, speech-language pathologists, personal care workers, registered practical nurses etc.) or the clients for whom they provide care (e.g., those with cancer, stroke, hearing loss, multiple sclerosis Alzheimer's disease, etc.). My intention is to be of help to other caregivers and to professionals providing care to persons with dementia.

Here is our story. My husband Jack was born and raised on a farm near Kintore Ontario, a farm that had been established by his great-grandfather who emigrated from Scotland in 1830. The farm has been in the McKay family for four generations. From that farm, two of my husband's great-uncles and four of his uncles left to enter the Christian ministry. It was the hope of Jack's parents that he would be the seventh McKay to enter the work of the church, but he became sick and tired of hearing about their goals for him. When he was 13 years of age, just entering Grade 9, he stomped out of school one day saying to his teacher, "If they think they are going to make a minister out of me, they're wrong!"

Jack went to work on the farm with his Dad, which is what he really wanted to do. He loved the farm, which eventually he was to inherit. However, after seven years of farm work it became very clear to Jack that serving the church was his real calling. After not reading a book for seven years, he returned to complete five years of high school in just three short years. He once told me how he cried himself to sleep because at age 20 he could not do Grade 9 memory work. After completing his high school diploma in record time, despite the learning hurdles, he completed a three-year B.A. degree and then his master's degree at Emmanuel College in Toronto. I share this history with you so that you can understand the depth of his commitment and determination to follow that dream. Jack was ordained into the United Church in 1957. He served the church for over 37 years. During that time he served on many national and local committees as President and Chairperson.

Jack was a born speaker and motivator, a genuine sparkplug whose innovative and creative nature re-kindled the fire which was needed frequently to re-energize many congregations. Church memberships increased and participation of congregational members on church-based projects soared wherever he went. He had great compassion for people, welcoming newcomers to our community, visiting hundreds of homes and hospital rooms and officiating at myriad weddings, baptisms and funerals.

Jack spent a great deal of time reading and writing. He was always ready to listen. He also made extra special efforts to help others. Interestingly, he was a naturally gifted handyman, able to take apart and to repair machinery. He even took a course in plumbing at Fanshawe College but that did not mean that we never called a plumber to fix the leaky faucets!

In the late 1980s, at about age 58, Jack began having trouble remembering appointments. I tried to be gentle with my reminders so that he would not feel threatened. It became more difficult for him to concentrate on what

he was reading. He began getting uncomfortable in large gatherings where there were several conversations going on at one time. Prior to these emerging difficulties in large-group conversations, he had always been front and center of every conversation. However, after being in a group for a short while, he would say, "Well Junie, I think we should be on our way". He experienced trouble putting back together items he had dismantled when trying to fix them. His sense of judgment changed. He became easily frustrated. Sometimes, he made comments that seemed inappropriate.

These emerging features were so unlike the Jack with whom I had shared my life for many years. He took retirement three years earlier than planned, at age 62, because he had trouble coping with the fast pace and the stress with which members of the clergy have to deal. I tried to convince myself that the confusion and frustration were a result of decades of work overload. Then came periods of depression. He slept a great deal. He would say, "I can't do things anymore. I guess things are going to be over for me". When he said words like these, I would suggest a walk or supper at a local restaurant for fish and chips to divert his attention from his sorrowful moments.

We sought professional guidance and were told initially that he appeared to be suffering from short-term memory loss. He was given medication to help with the depression. Eventually, we went through numerous tests; the EEGs, the mini-mental tests, the questioning, the counseling, all of which led to the dreaded but not unexpected, and I might write very bluntly, verdict: "You have Alzheimer's disease. There is no cure". This was a horrible blow. We knew that the outlook with this irreversible, relentless disease was pretty bleak. It was a darn shame! Although not unforeseen, I was not really aware of the depth of anxiety that it would cause him and me. Little did I realize just how much our lives would change.

Aricept was prescribed as a medication for Jack to slow the progression of the disease. The next blow to Jack was losing his driver's license — another bitter pill to swallow. We attended the 10-week Family Information Sessions at the Alzheimer's Outreach Service at McCormick Home in London Ontario run by social workers Magdalen Carter and Helen Jevnikar. I found the sessions very helpful. I learned a great deal about Alzheimer's disease but Jack did not want to go after the first three sessions. I could not force him to attend.

Jack's depression continued. He would go for long walks preferring to go alone, although we used to walk together almost every day. I often found him crying. He would say, "Maybe I'll just go down to the river",

presumably to drown himself. This was scary! This was NOT what retirement was supposed to be like!

Then came the realization that I would have to find a facility for Jack where he would be safe, where there would be activities that he could become involved to help fill his days. I am tremendously grateful that we had completed our Powers of Attorney for personal care and finances a few years before the onset of Jack's Alzheimer's disease.

I first chose a retirement residence for Jack in 2002. I will never forget the day that I had to tell him that there was a room waiting for him. I am haunted still by the memory of leaving him, knowing that he would never be home again, never share the travelling that we loved so much, never walk the beach together, never stuff the Christmas turkey together, never again share the same bed. His move to a retirement residence led to a huge shift in my life and my roles. We once were a team! Now I held responsibilities for our finances, insurance, property upkeep, and family.

Jack's medications gave him hallucinations. Twice when I went to visit I found him hiding in his closet. He told me that he saw strange things flying around his room. He began wearing two and three shirts at a time, and shoes without socks. He gave away his belongings and tried to slip out of the main door of the residence. I tried my best to be with him each day, help him dress properly and to help shower and shave. He called me on the phone several times each day with the same wistful, "When are you coming?" Many times when I went I found him crying.

The success of this placement was mediocre. I longed to bring him home. However, I knew that I could not look after him at home. In less than a year it became apparent that he would have to be placed in a secure locked unit in another facility. I made application to our local Community Care Access Centre and visited several long-term care facilities. The first site we were offered included a semi-private room. The bathroom was located inside the doorway on the left, and Jack's roommate's bed was next to the bathroom. Jack's bed was by the window. He had to walk past the other bed to use the bathroom. The physical layout was most confusing to him. He could not cope well with this room design.

Jack then moved to a private room in the same facility with a shared bathroom. This arrangement was frustrating for Jack because he could not figure out why someone else would be in the bathroom when he opened the door. After another year or more I was told that he would be moved to the special Alzheimer's floor. I admit that I resisted this move for a while. Surely MY

husband was not going to be one of "them". The choice was not mine, however, as he was wandering in and out of other people's rooms. But it was time for the move. I had no other options. On the Alzheimer's floor, the wandering was accepted. It was not uncommon to find someone coming into his room, either walking or in a wheelchair, or even sleeping on his bed. Sometimes I would find Jack sleeping in someone else's room. We had to make sure that everything that belonged to Jack was labeled with his name because items would go missing. Fortunately Jack had his own teeth because I had heard of residents trying to wear someone else's false teeth!

Various medications and combinations were given to him, some helpful and some with negative results, making him quite groggy and unresponsive some days. Despite the multiple medications, Jack still knew me. He would give me smiles that warmed my heart. My daily routine was to visit him at about 3 o'clock and take him walking around the halls. He just wanted to keep on going. Sometimes we went into the garden when the weather allowed. I fed him his evening meal.

As the disease progressed he rarely spoke, maybe a "No" or a "Yep". He had no memory of the churches in which he served, of his family or of our homes. He gradually lost his ability to feed and to dress himself. He needed total care for his daily activities. Then came the wheelchair because he was unsteady. It was used most of the time unless I, a family member, volunteer, or staff took the time to walk with him. The more he was in the chair, of course, the more his muscles deteriorated. Another miserable change was the onset of incontinence. It is embarrassing, sickening and not pleasant by any means. "Somebody, please say it isn't so!"

Thankfully there were bright spots and even funny events that helped us through the day. Once after Jack had not spoken for quite some time, on a day when he was particularly alert and listening to me, I said, "Let's get married". He looked at me and then said "Oh, my Gosh!" After a moment he smiled and said, "Sure sounds good to me!"

Jack also had trouble swallowing. He would just keep on chewing the same bite and not swallow. We changed to a pureed diet that he tolerated for a while but certainly did not enjoy.

I assisted the staff in getting Jack ready for bed. He was more comfortable when I was there. I massaged his legs and feet with lotion. As I tucked him in there was always that familiar smile, that loving face that held all those cherished memories. Sometimes he got pushy and resistant when strangers came in to undress him. It must have been frightening. I am sure that

those suffering from dementia must feel exposed and uncomfortable. No wonder they can become difficult. Any one of us probably would.

I admit that I got impatient when I could not find staff to give me a hand in the evening. Often times there were just three personal care staff to care for 36 residents, to see that they were fed, and washed and ready for bed. Their load is just too heavy, but that is just how it is. One day I read in the local London newspaper that a member of parliament, Carolyn Bennet, said that the future for senior care looked even more grim! So I said to myself, "June, get used to it!"

I want to note some feelings that I experienced during this time. I do so after much thought and soul-searching, hoping that my comments are constructive. Imagine, for a moment if you can, being in some state of dementia or confusion. Someone comes and wheels you into a room and begins taking off your shirt, trousers or slacks. You are frightened and strike out with your arm or foot because this just does not feel right. Your actions must be reported as an incident. As a consequence, your medication is increased which makes you even more dopey and bewildered. Similarly, imagine being attended to by two staff who are raising you in one of those big lifts to get you into bed who do not talk to you at all, or who talk around you and over your head about when they will have their break, what they are going to do with the kids on the weekend, or a shopping spree they are planning.

On the other hand, think about this scenario. Someone says to you "Hi there! It's time to get ready for bed. Let's go into your room. Let's start with the shirt. Can you bend your arm for me? Now we need to put on your pyjama pants. Now, let's get those teeth brushed". I thank God for those angels who start their workday, saying "Today, I am going to make someone's day a little bit brighter." I met some of these wonderful people and have not forgotten their care, their gentle way with Jack and their heartfelt, sincere chats with me.

Like every other caregiver, I wanted my spouse to have the best of care. That is not always what our current health system provides. Sometimes it was 8 or 9 o'clock when I got home from caring for Jack. It was a tough 'part-time' job. Some nights when I got home I filled up the Jacuzzi tub, turned on the jets and sat for a long time. Some evenings my tears could almost have filled the tub. We all have those times. What happened to Jack was a darn shame, but I felt wrapped in the concern and compassion of those marvelous caregivers.

I knew that as long as Jack knew me I would be there ... long after that! Someone said, "He will know your

touch long after he has lost his ability to speak," and I believe that this is true. Until the day he passed away Jack would look at me and his eyes would open wide and he would make some sort of sound as if trying to speak.

Not being able to swallow for months and just choking and choking, he went from 190 pounds to 139 pounds during the last eight months, and passed away in January 2009.

During my caregiving my family was gracious enough not to load me with their concerns. I know that this whole experience has affected them deeply. Their fears for their own future health are real, and rightly so.

There were times when I was asked, "How can you keep on doing this and still smile? Where do you get the strength?" Well, I cried lots! One of the outcomes of my caregiving for Jack was that I developed a life apart from looking after him. I saw and still see caregivers who do nothing else but look after a partner, a parent or a child. I could not survive that way. I tried to realize my own limitations. I needed change, and sometimes took breaks so that I could be refreshed when I was with Jack. My greatest strength comes from my faith. I believe that faith is there for everyone whether it is the Christian faith, Jewish, Muslim or Buddhist. We can all find faith in different places. Maybe strength will come from within your family unit or your neighborhood group. Mine is a faith I grew up with. It is there, miraculously, each new day, and because of it I can face the challenges. I have never been alone.

I have a favourite quote, held on my refrigerator by four little ladybug magnets right beside a photo of Jack, which I read every day:

Take Heart. Even though the person you have loved may appear different and behave in ways alien to their past, rest assured that within this disturbed physical body rests the unblemished spirit of the person you love. Treasure that person, even as he or she may be slipping from your hands into the hands of a loving God. And rest assured that, in God, all memories are preserved.