

Our journey began several years ago when George's dad was diagnosed with frontal temporal dementia (FTD) shortly before he died. We had watched him acting verbally aggressive and doing things that frustrated and annoyed the family without understanding why he was doing them. It was very unpleasant for everyone. Then we learned George's chances of developing this dementia were 50/50. I vowed that if he did get it, I would do everything in my power to prevent him going through the fear and frustration his dad did.

I began noticing George slowly beginning to display similar behaviors and actions to his father's around 2013 when he was 63 years of age. After reading about and talking to professionals about FTD, and living through George's journey, I realize it started much sooner. In his 40s he slowly began to lose interest in things he previously enjoyed (skiing, car racing, socializing), became frustrated more easily and responded angrily, and displayed less and less empathy.

By 2014, I definitely was seeing more changes. They were mainly related to problem solving, planning, organization, and decision making. I tried to talk to him about what I was seeing but he would only get angry because he was unaware of any changes. I later learned people with FTD are incapable of this self-awareness of their disability due to psychological impairment to the frontal temporal area of the brain and it is called Agnosia.

In 2015, since we both were retired and owned a fifth wheel travel trailer, we decided to travel to the Maritimes, down the Appalachian Chain to Florida, over to Louisiana and home. Memories of this seven-month trip helped us through the years to come. I was also able to use the upcoming trip as a reason to get our wills, power of attorney and health directives in place.

On this trip, he was quite content to do the driving and sightseeing and leave all the planning and decision making up to me. I learned to take things one day at a time and be well organized so I could guide him when something unexpected would come up and he would become flustered and unable to deal with it. I became a master at navigational skills!

In the seventh month of our trip, in February of 2016, it was evident we needed to return home. His judgement about parking spaces, etc. was declining and he would start to get nervous if I didn't stay calm and keep repeating what to expect ahead when driving. This was so hard to watch because he used to race cars, had a 1A license, and was an excellent driver.

By fall, his decision making and problem-solving skills while driving were seriously deteriorating. I contacted SGI and explained what was happening and asked they not let him know I had contacted them as I wanted him to see me as a support system, not someone who would rat on him. They assured me all contact information is confidential and asked me to contact our family doctor.

Our doctor did a cognitive assessment and recommended his license be suspended and referred him to the Geriatric Evaluation and Management Centre for further evaluation. After six hours of evaluation, it was determined he was in the early stages of frontal temporal dementia, but they wanted a neurologist to confirm it. After meeting with the neurologist, an MRI and PET scan, we were told he had the rare progressive supranuclear palsy variant of frontal temporal

dementia. The neurologist stressed that the key word here was progressive. He said there was nothing that could be done to stop it and it could take six months or years. It would be a continual shutdown of his mind and body based on the order in which his brain cells deteriorated. George did not understand the diagnosis, but I felt like we had just been dealt a slow-moving death sentence!

Thus began the first and hardest of the four stages of PSP. I have seen this stage referred to as the early stage or supportive phase. As we progressed through this stage, having been a special education teacher and mother, I began to equate this to a second childhood. The difference being that in our first childhood our caregivers expect more from us and give us more responsibility as we are able to handle it while in this second childhood, expectations, and responsibilities are decreased when they can no longer be achieved.

The reason I refer to it as the hardest stage is because it was a time of trying to digest the diagnosis, determine what team had to be set up to support us through this journey, and try to devise coping mechanisms while trying to understand what was happening day to day. The goal I set at this time was to keep George as comfortable and content as possible while allowing him to lead as normal a life as possible for as long as possible.

I think of this time as his second teenage phase because he still thought of himself as an independent adult and resisted supervision or boundaries that needed to be set for him. They were the transitioning years from being a functioning adult to requiring continual supervision and assistance. For George, this stage spanned the three years of late 2016 to late 2019.

During this early stage, the symptoms George displayed continued to be mainly mental, social, and emotional. Mentally, he showed a continual decline in judgement, distractibility, dealing with too much stimulation, ability to carry out his side of a conversation, and word retrieval. Socially, he still knew what was expected but had to be talked into taking part. Emotionally, this was the toughest phase because he became inflexible and argumentative and at times tended towards aggression when he couldn't understand why someone would correct him.

I had to really watch how I phrased things, try to stay a step ahead so I could prevent him getting into situations that frustrated or threatened him and have the neurologist or psychiatrist introduce the difficult topics for him to handle so he could consider them the bad guys instead of me. Physically, he was starting to show balance problems and began to fall when changing direction and bending over. He also began having problems controlling his eye muscles, especially the up and down movement.

For the first 2 years, I was his only caregiver as he was not willing to take supervision or direction from anyone else. As more brain cells began to deteriorate, he became easier to deal with. In the fall of 2018, he started going to a respite home for 2 half days a week so he could interact with others as well as give me some time for myself. They kept him very active and he soon adjusted enough we upped his attendance to 3 half days a week. Over time and as his care became more demanding, we slowly increased his time to some full days and then a

couple overnights. All the while, I worked with the homeowner and his medical team to make sure we were all doing as much as we could to assist him in smooth transitions.

By the end of 2019, he was entering the mid-stage or transition phase (or school age phase to me because he needed much more supervision and direction). His physical symptoms became more prominent. His balance and mobility problems increased causing him to have frequent falls and require him to use a walker part time. His eye muscle control deterioration now prevented him from blinking, and he had a wide open, blank stare. Increased muscle rigidity also caused him to start having swallowing problems as well as bowel and bladder problems. Mentally, his thought process slowed considerably, he began to have memory problems and became unable to initiate conversation and spoke slowly and quietly. He required a high level of supervision, so we moved him into a personal care home for the remainder of this stage.

In December of 2020, he was entering the advanced stage or terminal phase (preschool age phase to me because he became unable to do so many things for himself and had problems communicating.) The personal care home was no longer able to meet his needs, so he was placed in a long-term care facility. Due to Covid, I was not allowed into the facility. I had to drop him off at the door and did not see him for the next 75 days. This was very difficult emotionally for both of us. I arranged for a phone in his room and called him daily which he looked forward to. He liked hearing what was happening outside his world but could only contribute one sentence or yes/no comments to the conversation. In February, we were allowed to meet outside with a fence between us for short periods and eventually I was allowed to visit in his room.

Throughout this time, his condition continued to deteriorate with all the symptoms becoming more pronounced, especially physically. He now required a wheelchair even though he didn't think it was necessary, spent a great deal of time in bed, and was dependent on others for all aspects of care. He became very impulsive and would suddenly try to get up and do something causing many falls, bruises, cuts to his head and a broken finger. He lost a great deal of weight and all muscle tone, which, until now, was a strength that had impressed his professional health team.

He entered the end of life stage in June of 2021. Even though there was a rapid and marked deterioration in his condition, he always knew who everyone was and felt he was only getting a bit forgetful and clumsy. After 71 years of life, 37 years of marriage, 35 years as a parent, and 14 years as a grandfather, he calmly left us on September 10, 2021.

Throughout this he and I (as his primary caregiver) were on parallel journeys. His journey was not emotional for him because of his unawareness of having a disability and the support he received. Mine was a long, lonely journey of losses and new responsibilities. I slowly lost all the things he had provided me throughout our marriage – love, partnership, friendship, support, conversation, decision making assistance, skills he had that I didn't like technology, vehicle and home maintenance, and sharing enjoyable pursuits such as travel and socializing. After his diagnosis and my gaining understanding of what was ahead, I quickly realized we would need support to assist us on this journey. I am eternally grateful to SGI, our family doctor,

the Geriatric Evaluation and Management Centre, our neurologist and psychiatrist, the Client Patient Access Centre and the respite/care homes for providing us with an early diagnosis, assisting me in developing and carrying out a care plan and willingly being “the bad guys” that gave him all the bad news so he could continue to trust me and look to me for support when he needed it.

Other means of support were found through organizations, the internet and YouTube. I have always found I can cope better with any challenges in my life by educating myself about it. In addition to what I learned from the health professionals, I constantly researched reliable articles on the internet to help me get a better understanding of what was happening at each stage and how to find coping mechanisms. I also relied on my education and experience in special education. I had learned to try to figure out what was happening with my students and why they were doing what they were so I could figure out how to help them. I used this same approach with George.

I contacted the Alzheimer Society of Saskatchewan after hearing from an acquaintance that she found them very informative and supportive. I immediately felt comfortable and as if I had found someone who understood and genuinely wanted to help. Their “Just-phoning-to-check-how-you-are-doing” phone calls reminded me there was always someone available to talk to. Their workshops provided me information about dementia and coping tips such as: connect – don’t correct, blame the disease not them or ourselves, use humor to help both of you deal with difficult situations, that we as supporters have to adjust our behavior and expectations because they are not able to, to grieve each loss as it happens so it isn’t so overwhelming at the end, and to make sure to take time for and care for ourselves as caregivers.

The Saskatoon Council on Aging Caregiver Forum was another place I gained information and advice. The most valuable thing I gained here was a poem read as a closing by one speaker. It was “Do Not Ask Me to Remember,” by Owen Darnell. I later found it on You Tube as a song and made it through many a trying situation by singing the verse:

*Do not lose your patience with me,
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different though I try.*

You Tube also has many other videos that made me feel better or gave me new insight.

I will never regret sharing this journey with George, our family and friends. Being a caregiver provided me with an opportunity to gain insight about myself and hone my skills or develop new ones. I learned to be more patient and less controlling, to ask for help, to not take things so seriously, that I can learn to take on any task if I take it one step at a time and educate myself about it (even technology!!), and to appreciate what I have had in my life. I look forward with anticipation to using these insights and skills in the next phase of my life.

-Terri Hetterly