

The Caregiving Dance: Ivan and Sheila's Story

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As caregivers, one of the wonderful yet challenging aspects we must learn to manage is striking a balance between assisting our care recipient and encouraging them to do as much as they can independently. It's akin to a dance where one person traditionally takes the lead and the other follows, but as the care recipient's illness progresses, these roles can shift significantly. This often entails a great deal of negotiation, worry, stress, fear, and grief that must be processed, and as circumstances continue to change, the caregiver's role evolves accordingly.

Ivan and Sheila graciously welcomed us into their home to share their experiences as Sheila lives with progressive Parkinson's Disease and other health issues. Sheila received her diagnosis in 2011, and as many are aware, the process of obtaining a diagnosis can be quite exhausting. It often involves navigating a maze of specialist appointments, tests, and the frustrating phenomenon of medical gaslighting, where individuals are made to feel as if their symptoms are not valid or are all in their head.

After receiving her Parkinson's diagnosis, Sheila took steps to organize her affairs. As a successful businesswoman and teacher, she had been responsible for managing the family finances and supporting the community. Letting go of some of these responsibilities was challenging, and it was initially frustrating for Sheila when Ivan didn't fully understand the extent of her limitations. Ivan continued to work, but it became increasingly clear that he needed to take on a more active role in managing their home life. Eventually, Ivan retired from work to become a full-time caregiver for Sheila and took on tasks that she was no longer able to manage due to her illness.

Sheila and Ivan are surrounded by their two sons and daughter along with 7 granddaughters, which brings them both great joy. The yard and house were beautifully decorated for Easter, and a special family time and egg hunt was scheduled for the weekend. Decorating is something they do together now. Sheila suggests where to put things and Ivan assists. Sheila was used to organizing all of these family events and activities, and Ivan was not. Another thing that they started to do together was cooking.



SHEILA AND IVAN SHARE A SMILE

Sheila did what she could as long as she could, and Ivan supported that. Sheila also says her good relationship with her daughter, an RN, helps them both as well. When she gets scared, she will speak with her. Each family member has a role and they are all very supportive.

During our discussion, Ivan and Sheila both emphasized the importance of good communication and having different people in their support circle take on different roles. Sheila has had to endure many hospital visits, and the most difficult times were during the COVID-19 pandemic when visitors were not allowed. Ivan was designated as Sheila's caregiver and noticed that she was deteriorating in the hospital, leading him to believe that she would be better cared for at home. After discussing this with Sheila, the family, and medical staff, they made the decision to bring her home and provide care in the comfort and safety of their own residence.

Sheila and Ivan try not to dwell on the negative. They still have their moments of disagreement, but in observing them, there is always humour there as well. Ivan has worked very hard learning the things that she likes, and dislikes. That could be bumpy at times, but when Ivan took Sheila's advice and cooked the way she did, he says he learned so much! According to both of them, maintaining a positive mindset is crucial for their success. Despite experiencing health issues and sleep deprivation, they actively choose to remain optimistic.

Ivan also shared that educating himself about Parkinson's Disease was beneficial for him. Joining a Parkinson's Support Group has also been helpful for both him and Sheila. Ivan also attends a Caregiver Support Group with CNS. The journey with Parkinson's has been isolating for them as they were once very active and community-minded people. They miss the sense of connection and social interaction that they once had.

Both Ivan and Sheila emphasized the importance of taking care of their mental health and being kind to each other. Sheila's family has been supportive in helping her find new equipment and tools to make her life easier. They offer suggestions and ideas to help improve her quality of life. Family support has been integral to their mental health, and they are grateful for the love and kindness they receive.

In conclusion, Ivan and Sheila both agree that love is what gets them through the hard times, changes, complications, and learning they have had to face over the last 11 years since Sheila's Parkinson's diagnosis. Though there are moments of sadness, they also find moments of joy and hold onto the love they have for each other and their family.

We express our immense gratitude towards Ivan and Sheila for generously welcoming us into their home, sharing their personal story, showcasing their stunning family photographs, and showing us the precious gifts from their grandchildren. We sincerely appreciate the opportunity to discuss their journey together with them.