

Parkinson's Warriors

Nicole's Story

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Nicole and her dad

My whole life, I have lived vicariously through the books I read. I have loved when my favorite characters have met new people and went on grand adventures. I always told myself that when I grew up, I would go on my own adventure. I'd travel to far away places and live the daring life I dreamed of in my books. My dad fed my book obsession and always encouraged me to do more and dream big and never take life for granted. When it came time for me to choose my own adventure after graduate school, however, the decision to leave was much more daunting.

On many occasions, my dad and I ponder the adventure that we call life and the twists and turns we take along the journey. Both of our lives have been impacted by his diagnosis of Parkinson's disease, and while he lives daily with its difficulties, my part of his Parkinson's

story is very different. I remember my time in college how difficult it felt to be away at college and balance my school life while paying attention to what was going on at home. I went home every few weeks and the changes in his daily behavior seemed significant to me; however, to the rest of my family, the changes were subtle and sometimes went unnoticed.

When I went off to graduate school, I found myself living even farther away from home. I went home less often due to limited ability to travel and I found myself calling home more often. I checked in often and always asked how things were going. He would tell me, "that's about all that's new here" as we discussed the neighbors who were moving or how the family was, only sometimes mentioning how a doctor's appointment went or how he was feeling. When I went home for holidays, I noticed more drastic changes in what I had perceived as his daily routine and recognized more about the difficulties he was going through than I had previously recognized. I noticed it was more difficult for him to take longer trips as he tried to figure out how to control some of the side effects of Parkinson's medications. I found myself not reaching out to find support for a far-away caregiver and I found myself more worried than ever about my dad. No matter what difficulties he faced, however, he always encouraged me to pursue my dreams, go new places, and try new things. That is how I found myself in Iowa after graduate school.

I am now almost 16 hours from home and farther than I have ever been from my dad and my family. For a person who is a caregiver for a Parkinson's patient, I have found being away from home truly comes with its own difficulties. Sometimes you see the long term effects of Parkinson's on the patient that seem to go unnoticed by people who care for them daily. You tend to worry more about them keeping information from you because they do not want you to worry. In my case, I feel like I worry more about

trying to find my way back home, to be closer to my family. However, one thing I have learned from my adventure is that you can become much closer to those you are caring for and to others who are journeying through life with Parkinson's.

Being away from home has its drawbacks, but as a caregiver who lives further away from home, I find I am very grateful to groups like Pacing for Parkinson's who give me a connection to home and to the community of Parkinson's patients and caregivers around the country. I now understand that you have to find the support of others who know what you are going through because nobody can go through this journey on their own. Now, I get home every six months or so. I see the changes that happen while I am away, and I mentally make note of new behavior changes. I take time to catch up on how my dad is doing and how doctor's appointments are going. We also usually sit down and share about the new adventures we read about in books for good measure. For me, the time I am home is precious and when I am home, I treasure that time more than I ever have.