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# Parkinson's changed who we were as a family

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It's not every day that I reply to a friend's invitation to go out with, "Can't ... Dad's having brain surgery." But that's exactly what I did on Jan. 13. Only now, a few months later, can I reflect back and finally appreciate the good that came from this experience.

My father was diagnosed with Parkinson's disease almost 20 years ago. Being only 23, I've spent most of my life watching his illness gradually progress.

I remember my parents telling my sister and me the news. We were at our cottage, our family's safe haven. They sat us down and, with great simplicity and compassion, began their explanation. After they clarified for me that it was not contagious and Dad was not about to die, I seem to remember asking to go play outside. From that point on, Parkinson's subtly seeped into our lives.

As my father aged, so did his disease. It never changed who he was or how I viewed him. He was still Dad, just a bit more ... shaky. My parents embraced friends who were understanding, while those less supportive slowly fell out of touch. As a result, we formed a strong, close-knit nuclear family. Parkinson's wasn't just a part of my father – it became a part of us. We lived with it daily and it changed who we were as a family.

A couple of years ago, my father's neurologist recommended that he be assessed for a surgery called deep brain stimulation. The results, we were told, would not affect the progression of the disease, but could play a major role in suppressing some of the debilitating symptoms.

After a year of assessments, tests and interviews, my father was finally approved for the surgery. He was pronounced an ideal candidate because of the nature of his disease, its progression, his high mental status and family support. Yet hearing doctors say he was an ideal candidate didn't make the surgery any less frightening.

We were originally told the surgery would happen "some time in October," which turned into late January and soon became mid-March. As the day was pushed back, the thought of it was pushed back in my mind. We were shocked, then, when in late December, we were told a surgery date had been scheduled for Jan. 13. Take it or leave it.

We took it.

When I look back on my emotional involvement in this experience, I recognize two separate phases. First was the actual day of surgery, a time of immense fear and emotion coupled with adrenalin. As we saw my father disappear behind the double swinging doors into the operating room, we knew his fate was in the hands of two physicians – an older veteran to the surgery, renowned throughout the community for his contributions to DBS, and his younger sidekick, a friendly fellow we grew to adore. We referred to them as “the men who exude confidence.”

It is impossible to accurately describe to someone who has not experienced it the anxiety of sitting in the waiting room, waiting for the surgeons to come out with news. Wild thoughts began to swim through our heads. By the sixth hour we were forced to convince ourselves that no news was, in fact, good news.

That phase thankfully ended quickly, and we received so much generosity from our support network. The phone calls and e-mails were overwhelming. Friends came by offering food, gifts, tangible acts of kindness.

It was the second phase immediately following the surgery that was in some ways the scariest of all. With the adrenalin gone, all we were left with was fatigue. Although my father was healing magnificently, we were forced to keep reminding ourselves that he really had just undergone brain surgery.

In the days following the surgery, to my father's great distress, we watched him like hawks. Anything slightly off we misinterpreted as a major complication. We spent hours checking the Internet during our “bandage removal ceremony,” peering over the staples, keeping infection at bay.

It was about this time that people began to lose their intense interest in our situation and wondered why a week after my dad's surgery my sister and I hadn't yet moved back to our apartment. Most of my friends, still in their early 20s, had never been through something like this and found it hard to relate.

But if there is one thing I learned from this experience, it's how resilient the human body truly is, perhaps even more so than the mind. In many ways my father's recovery was the quickest of us all. Within days he was anxious to jump back into the world, while we were stubbornly resisting reintegration.

Once back in the comforts of our family home, we built a small cocoon. Reading Stuart McLean, doing logic puzzles and playing Leonard Cohen, we rejected the outside world and healed as a unit. Meals were a small ritual. Walks with Dad were a miracle. Talking to each other and reading poetry were a joy. Life slowly became more manageable.

Although it was my father on the operating table, it was our family that was diagnosed with Parkinson's and our family that underwent brain surgery. He's still in the final stages of his recovery and we can't say what the next phase will bring, but one thing is for certain. We'll get through it together, for better or worse. We have no choice. It doesn't take a brain surgeon to know that.

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