

Contents

Preface.....	8
Introduction	10
1. In the Beginning	15
2. Why Me, Lord?.....	27
3. New Options, New Risks.....	39
4. The Breakthrough	49
5. The First Surgery	57
6. The Second Surgery	65
7. The Ambassadorship.....	73
8. Blessings That Come With a Nearly Normal Life ..	83
9. The Piano Lessons.....	91
10. Giving Thanks Every Day.....	101

Preface

This book follows the journey of Carolyn Anderson, my wife, over the nearly twenty years while she struggled with Parkinson's disease. She lived the first seven years with her disease without knowing what was wrong with her. I felt it was important to share some of our experiences so that readers could learn what to expect if they are diagnosed with Parkinson's. While I've tried to cover the symptoms that directly affected Carolyn, I've also attempted to explain some of the symptoms that were never an issue with her. Still, there is no way that all of the variations or symptoms of Parkinson's disease can be included in this book. I've also included how a person's life can change if they elect to have Deep Brain Stimulation surgery (DBS), as well as how Activa® Therapy may lead them back to a nearly normal life.

Just a warning. We tell both the good parts of the story as well as the places where the going got tough

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Preface

and how those times impacted the decision-making process that Carolyn went through. Some of the decisions that involved the actual surgery itself may bring a tear to your eye, others may make you smile. Because we're already giving away the fact that Carolyn is here and much better for the journey, you'll realize that the outcome was a good one and that nothing good ever comes without some sacrifice.

This is a story as much about the spiritual blessings in one's life as it is about the disease and the therapy. In Carolyn's case, the blessings that have come with the decision to have the surgery are such that she would never go back to life without the assistance of Activa Therapy. In spite of the problems and complications experienced along the journey, it has all been worth it in the long run for the chance of living a nearly normal life.

Our first hint that something was wrong started in the 1980s and we will bring you, the reader, up to date through the surgery and the implementation of the Activa Therapy.

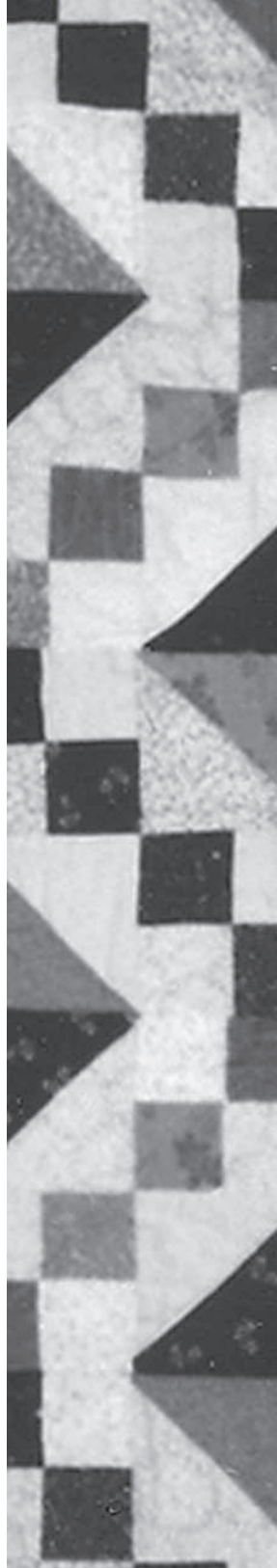
Carolyn and I wish to thank the following doctors who have supported her through diagnosis, disability retirement, and DBS surgery and follow-up: Steven Stein, Shelly Svoboda, M. Sullivan, Paul Tuite, and surgeon Robert Maxwell. Also special thanks to Carolyn's nurse, Maggie Bebler, and Drs. Okun and Foote at the University of Florida, Gainesville.

1

Chapter One

In the Beginning

We were staying in bed late one Saturday morning and watching TV. Our home had a large bedroom suite complete with a walk-in closet and adjacent master bath. Carolyn got up to go to the bathroom; when she got out of bed she promptly fell flat on her face in a bunch of blankets lying on her side of the bed. At first I was shocked. I jumped up and made sure she was alright. When I realized that she was OK, we laughed about it. She picked herself up



CAROLYN'S JOURNEY

and continued to the bathroom. This was around the summer of 1988 and was one of the earliest symptoms of Parkinson's for Carolyn.

Part of the reason we took this first incident so lightly was our lack of knowledge about Parkinson's at this time. The other reason is that we didn't think much about it until a couple of years later when we learned enough to understand what potentially happened that morning. We also didn't think anything like Parkinson's would happen to either of us.

Let me paint you a picture of our life at this time. I was employed at a major defense manufacture about a thirty-five mile commute from our home. Our home was in the little town of Zimmerman, Minnesota. The house was newly constructed next to Carolyn's parent's retirement home and was located on the beautiful shores of Lake Fremont (the largest lake in Sherburne County). It became a popular gathering spot for our already grown children and growing number of grandchildren. The house was everything we had dreamed of. It had three bedrooms, a split foyer, a lower level that was finished, a large master bedroom suite, a three-season porch and two-car garage. Lakeside we had made a beach and brought in some fine sand for our grandchildren to play in, as the lake itself has a muddy bottom, typical of a shallow lake. The yard was landscaped and the flowers were one of Carolyn's joys.

Carolyn is the "perfect daughter" and wanted to be there, right next door to her parents in their declining

In the Beginning

years. Both of my parents were gone and I sort of adopted them as surrogate parents for myself as well. Carolyn's dad had acted as on-sight quality control as the men worked on building our house. We were very close and seldom had any conflicts.

Carolyn worked at an electronic manufacturing company about four or five miles closer than my job, so we were able to commute together. I would drop her off at work and continue on to my job. Being able to commute together was great for our communications and Carolyn did not have to drive. This quality time together was precious to us. By March 1989 my work at the defense plant came to an end. So, consequently, our commuting days together also came to an end. But I digress.

Carolyn was active, kept up the house, and dabbled in oil painting as her way of relaxing. She also enjoyed other crafts, along with gardening, and became interested in quilting. We both enjoyed taking her folks' on pontoon boat for rides around the lake at sunset. I enjoyed golfing in Princeton, Minnesota. We all started attending the United Methodist Church in Princeton. You could say that back in those days we were a very typical mid-America family.

You might even say that at this time we were living the American dream. We had our dream house, next door to Carolyn's folks. We had designed the house so the master bedroom suite was our oasis when we were done with work and the commute home. (There is a reason they call these communities this far from

CAROLYN'S JOURNEY

town “bedroom communities.”) There was a beautiful fireplace, done in granite so that it looked like the stone from nearby St. Cloud, Minnesota. The kitchen was also a source of pride as it was equipped with a built-in Jenn-Aire grill and all of the other major appliances that you would expect, plus an adjacent dining area. The yard was full of flowers that Carolyn loved to plant, care for, and watch grow. And being on the lakeshore demonstrated to us every day how blessed we were.

All of this background information may seem a bit trivial, but you'll soon see how most all of it would have bearing on Carolyn's journey.

Over the next few years, during the late 1980s and the early part of the 1990s, Carolyn's symptoms persisted and became more noticeable, with the tremor and the muscle cramping being the worst. Carolyn began thinking that these symptoms were related and there was something wrong with her. As the factors that affected her daily performance at work became more noticeable, they also began to have a bigger impact on her life. We had no idea what the cause was; she already started to have a slight tremor in her left arm and leg. When she rode in the car or just lounged around the house she could feel the muscles cramping, in her leg specifically, but also in her arm. She thought that perhaps she should talk to her doctor.

You might say that in the early '90s Carolyn's life started to fall apart. In early 1991 her mother had a heart attack. While in the hospital her mother suffered another attack that would take her life. Six weeks later

In the Beginning

we returned home from work to find that her dad had suffered a stroke. A couple of weeks later he too left this world for the Promised Land.

The dream house was starting to take its toll on Carolyn as well. Since it was a split-level, the stairs were involved in nearly every move. It was half a flight to get to the foyer from the main floor, another half flight to the lower level, and at least a couple steps down to the garage level. To go out the front door there were a couple of more steps down to the driveway. Out the back, toward the beach and the dock, there was a whole flight of stairs from the three-season porch. Climbing or walking down the stairs seemed to leave her with a lack of energy with every move she made, almost as though the stairs were zapping her energy. She was tempted to blame this lack of energy on the grieving process, or maybe depression, but other than the lack of energy she didn't think she was depressed. She thought, "I have a wonderful husband, great kids that are healthy, and grandchildren that are a blessing. I like my job, and in spite of everything else, I am very good at it. What more could I want?"

When it came time for her annual exam, Carolyn talked to a doctor—not her regular doctor—one doing the physical for the carpal tunnel problem she was experiencing at work. She thought she would make double use of this physical in order to avoid the delays involved in getting into our regular clinic.

During the consultation the doctor gave her a list of possibilities that could be associated with the

CAROLYN'S JOURNEY

symptoms Carolyn had mentioned. This short list of possible causes included Parkinson's disease, and because she included those things in her report, it was available for the disability insurance company to see during their investigation. We had no idea at the time the significant ramifications of what we thought was an innocent conversation.

We would learn that soon enough, and as a public service I include this in the hope of preventing a similar incident from occurring in your own personal journey. The short list that was discussed that day was later used by the disability insurance company to define the date of diagnosis for Carolyn's Parkinson's disease. Looking back now, after being around Parkinson's, we know that a true diagnosis takes neurologists much more than a lucky guess. The fact still remains that the insurance company used this doctor's "guess" to define the date of diagnosis, and in so doing had us between a rock and a hard place. We found ourselves without the ability to fight them. We thought they were trying to help us, and we had to accept this date of diagnosis as part of the ground rules. This would cost Carolyn thousands of dollars over the years. Because of the "diagnosis" at this time, the insurer canceled a ten percent increase that Carolyn had elected the next renewal date after this appointment. They also returned the premiums we had paid and prevented us from receiving the higher payout. That cost us dearly.

In defense of the insurance company, they did go to bat for Carolyn when they asked her employer for

In the Beginning

information about her work hours in order to calculate the disability amount she was eligible to receive. Before this time, the company's human resource manager had sent a letter to everyone in the company during one of its slower periods, telling employees they could sign up to work a reduced thirty-two hour work week. Carolyn thought this sounded very good as she wanted more time for her crafts and artwork. So, she signed up.

Although this would have been a very nice option, the company never allowed her or anyone else in her department to work thirty-two hours a week. Instead, she kept working the full forty hours. The company seemed to feel this was irrelevant when reporting to the insurance company, however, and claimed she worked thirty-two hours a week. Carolyn went to the payroll department and asked for a printout of her hours. The total came to an average of forty-two hours a week. Once we forwarded this information to the insurance company, they were really upset. When they discovered Carolyn's employer had never honored the thirty-two hour work week request and saw what the actual average hours worked were, they sent a strongly-worded letter back to the human resource manager saying that if she ever did that again there would be dire consequences. Carolyn received a part of the money lost by that bad diagnosis date decision by getting the company to own up to the actual number of hours she worked, including her overtime. We have always felt that she had been entitled to both.

CAROLYN'S JOURNEY

Eventually Carolyn was referred to the Minneapolis Clinic of Neurology. This turned out to be the start of the actual diagnosis of Parkinson's disease. The doctor Carolyn was assigned to was extremely intelligent and always concerned for her patient's welfare. Carolyn's first appointment was on June 13, 1995.

(Just a sidebar here. Carolyn's birthday is the thirteenth. She has always been afraid of that day if her birthday fell on a Friday. She would be better off staying in bed as to get up at all).

The doctor examined Carolyn and ordered a number of tests. She discovered that Carolyn had the following symptoms and estimated that she had them for the last couple of years: 1) Intermittent cramping in her toes; 2) Stiffness in her fingers, preventing her from being efficient at work; and 3) Numbness in both legs if she sat for prolonged periods of time. In addition, for the last couple of months, she had experienced yet another associated symptom, intermittent gait imbalance. She also had been told by her friends that she was shaking in both hands while she herself had not noticed it. This is almost always true at first of Parkinson's disease patients.

Her doctor also questioned her about her past medical history, the medications Carolyn was taking, her social and family history, a list of her job duties, the fact that both parents were deceased and that Carolyn was a non-smoker. At this time there were no dystonic movements (the erratic facial movements) or wrestling tremor (involuntary shaking of the arm or legs) during

In the Beginning

the examination. The doctor ordered a number of tests, as well as the results of previous tests conducted by Carolyn's primary care physician.

At Carolyn's next appointment on July 5, 1995, the doctor was calling the observed condition "Parkinsonian." And in less than a month Carolyn was demonstrating more Parkinson's symptoms. The doctor again ordered more tests, and by the third appointment was using "Parkinsonism" as her impression of the cause of Carolyn's symptoms.

Another area of concern for Carolyn at this appointment was that her breast implant might be the source of the problems she was experiencing. If the implant was leaking silicone into her body, might this be the cause of her symptoms? The doctor never acknowledged that it was or could have been the source contributing to her Parkinsonian symptoms.

Carolyn set up an appointment with the doctors that had originally put the silicone implant in after her mastectomy. They agreed that it would be best if the implant came out. So Carolyn went in and had the implant removed. The good news was that the implant had not developed any cracks nor had it began to leak silicone into her body. However, as they were removing the implant, the hardened silicone skin of the implant cracked and fell apart right after they had removed it from her chest. Carolyn always looked back on this as being a kind of divine intervention. Removing the implant may have avoided serious problems down the road.