Dancing With Outliers

Let's study the best-case scenarios in managing Parkinson's disease.

BY PAMELA QUINN

When we study history, we analyze outstanding figures: Lincoln, Susan B. Anthony, Martin Luther King, Jr. In science, we ponder the genius of Newton and Einstein. And in the arts, we examine Mozart and Picasso.

Why not do the same when we study people with chronic illness? We stand to learn a great deal from outliers, those patients who have successfully managed illnesses that usually debilitate. If we can discover common denominators among these patient outliers—whether due to biology or treatment or attitude (or all three)—we may be able to help others achieve similar results.

I consider myself an outlier among people with Parkinson's disease (PD). I was diagnosed 16 years ago, at the age of 42, and I am still quite functional. I'm physically active and able to work as well as participate fully in family life. Like every person with PD, I experience a variety of symptoms. But I have been able to manage them and to inhibit their progress to a greater extent than many of my fellow patients. Why?

One reason is already well known: patients with early-onset PD generally progress more slowly. But I believe other factors have contributed to my comparative good fortune. They have to do with my faith in the possibility of circumventing the physical and mental obstacles PD presents. For example, the disease disrupts normal neural circuitry, but it's possible for a person to develop alternative methods—cuing systems—to initiate and control movement. We can substitute conscious activity for what was once automatic movement. Musical and visual cuing, the use of touch, and other forms of sensory feedback are all means of retraining the brain to talk to the muscles.

When I was diagnosed with PD, I already had some of these systems in place and knew how to use them—because I was a professional dancer.

Dance is an ideal tool for retrieving many of the functions PD takes away. In combination with music, dance uses auditory cuing to both initiate and organize movement and to propel you through space. Dance also uses visual cuing and touch to initiate movement.

In addition to these cuing systems, dance teaches the mechanics of posture and balance, requires the repetition and memorization of sequences, and uses imagery to elicit a range of movement.

Perhaps most important of all, dance involves the practice of conscious movement every day. A dancer is constantly directing the body, talking to it.

PD has diminished my natural capacities for movement. But because of my background in dance, I have a host of skills and a nervous system supplied with useful detours already in place. It's no wonder I've had an advantage over others.

None of this is to ignore the essential role that medication plays in PD treatment. But as most people with PD well know, current medications are inadequate. We need better tools for managing symptoms and a better understanding of the variability of PD. Understanding how different people with PD manage their disease offers a potential entry point into this mystery.

A well-known neurologist who heads a major PD center in New York once said to me that some patients do poorly with PD, some surprisingly well—but we can't explain why. Let's marshal our resources to find answers to that question. A good place to begin is to examine in exhaustive detail the conditions and practices of the outliers among us. To that end, I extend an invitation to all who are willing: Come dance with me.

Pamela Quinn teaches movement for people with PD for the Brooklyn Parkinson's Group and for New York University Langone Medical Center Parkinson's and Movement Disorders Center (see page 11 for another story on the programs at the center). She was the PD consultant for the recently released film A Late Quartet *with Christopher Walken.*