Love, Marriage and Parkinson’s

Category: Stories
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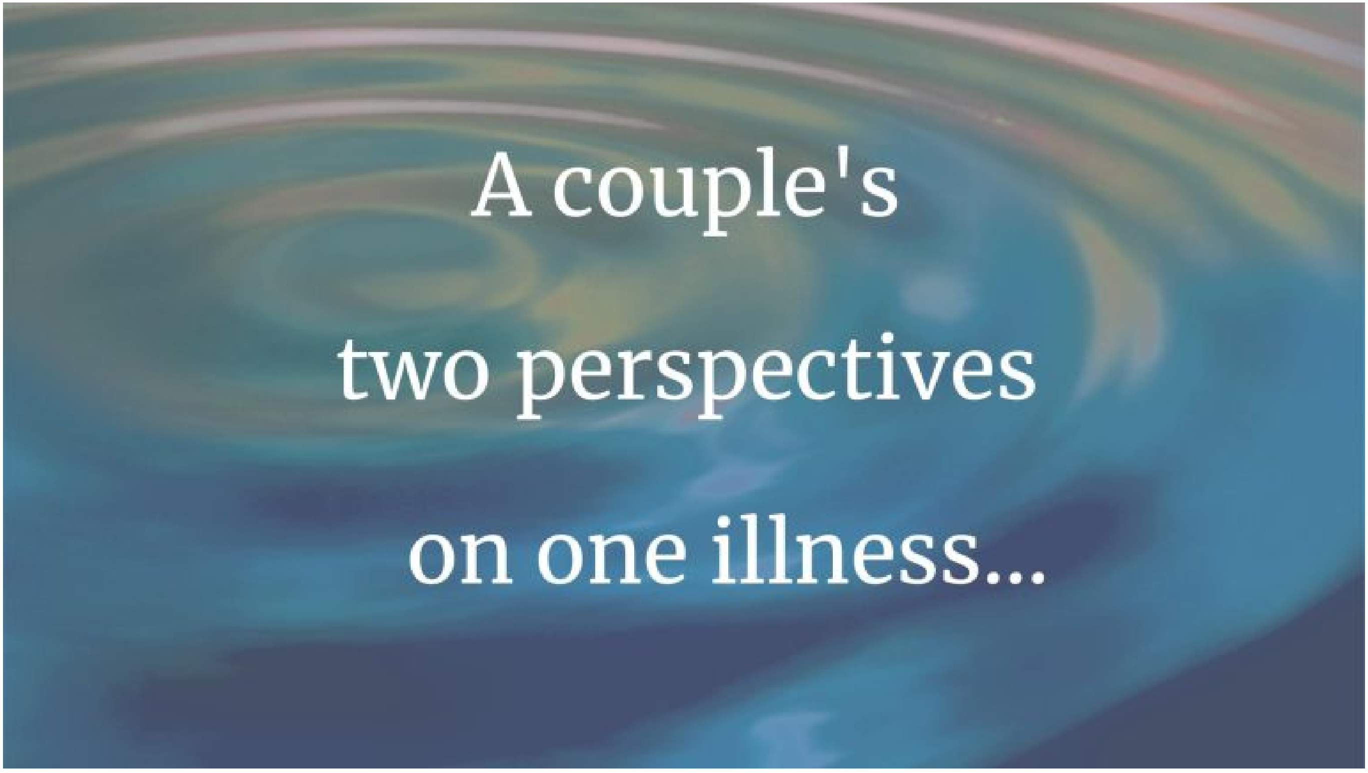

In 2015, while walking with my wife, Jody, in our neighborhood, I suddenly found myself bent over and taking tiny, rapid, repetitive steps. I knew I was moving too fast, but could not stop myself. Jody thought I was kidding—until the moment I fell down on a neighbor’s lawn.

A passing driver slowed down to ask if I was okay. I was all right, but thought the experience odd.

I’d never heard the word “festination” (a walking gait characterized by involuntary acceleration) until I saw a neurologist friend a week later. In retrospect, I’m not sure how I knew that I needed to see a neurologist. Perhaps, given my decades as a pediatrician, my clinical judgment was operating on a subliminal level.

My friend did a number of clinical tests—watching me walk, evaluating my facility with finger-to-nose movements, rapidly opening and closing my hands and so on. My history included some loss of my sense of smell (I’ve never been able to discern the nuances of red wine) and horrible handwriting (not just because I’m a physician).

She said that I had a mild case of Parkinson’s disease (PD), placed me on L-dopa and suggested that I begin physical activities to stave off progression. Though I didn’t know much about Parkinson’s, I began doing a movement class, Pilates and a boxing balance-and-agility class, and playing doubles tennis and nine holes of golf once a week. I looked on all this as the upside of PD—basically doing things that I like to do anyhow.

But I felt a bit skeptical of the diagnosis. *My symptoms are so mild. Do I really have Parkinson’s?* This thought cropped up with some regularity, but I resigned myself to taking L-dopa.

And I couldn’t forget my first festination: I’d fallen on my right shoulder, and for some time afterwards my right arm was definitely weaker than my left: I had clearly torn a muscle. The arm weakness was a constant reminder of my affliction.

My symptoms haven’t progressed much in the ensuing seven years, save for some problems with balance; I now walk with a cane. I have an occasional minor tremor of my right index finger. This tremor, which worsens with stress, makes it hard to lift a spoon to my mouth (worse with soup), clip my fingernails (necessitating a monthly mani-pedi) or text with my iPhone (now I use a stylus, or dictate messages into the phone).

I love reading and now have to use both hands to anchor a book on my lap. I’ve had episodes of festination while chasing a ball on the tennis court (I stopped short when I recognized that unpleasant feeling), stepping backwards during Pilates (I fell against a piece of equipment) and rushing with my golf cart to the clubhouse in an attempt to avoid a hailstorm (I fell, but suffered no injury).

The most interesting thing about PD has been its effect on my relationship with my wife.

Jody started out knowing as little about the disease as I did, but our responses differ. Whereas my glass is half full, hers tends to be half empty.

My approach to medical travail is simple: I use denial as a coping mechanism. It may seem illogical, since I’m a physician, but I do not need to delve into the internet to understand what’s happening to me. I just rely on my physician to tell me what I need to know, and I have also gathered information from the Michael J. Fox and Davis Finney foundations. My tendency is to assume that, since I’m being proactive with exercise, my symptoms will not progress.

As part of my routine, I attend online movement programs geared to PD patients, who sign on from locations across the country and Europe. During these sessions, Jody and I see patients whose symptoms are much worse than mine: persistent tremors, dystonia, mask face, uncontrolled movements.

I’m unable to imagine myself with those symptoms, feeling convinced that my exercise regime will ward them off. But, interestingly, Jody goes to a dark place. She says things like: “If you fall, I will not able to lift you up. If things get worse, we’ll have to consider an assisted-living arrangement.”

Jody has been helping and supporting me for thirty years, and now that I have PD, that need has only intensified.

She has become concerned that I’m showing subtle signs of cognitive decline, as when I recently asked, “What happened to the ceramic cup I use for my morning tea?”

“You broke it several months ago,” she replied, looking perturbed.

Her efforts to make sure I’m taking care of myself include questions such as: “Are you wearing a belt?” and “Did you take a shower today?”

I react with silence. In my mind, silence means yes—but to Jody, it can seem passive-aggressive. And it is true that I find these kinds of questions demeaning. Of course I’m taking care of myself, and the fact that she feels compelled to ask seems to reflect either anxiety or a wish to make sure that I stay on top of things. My nonresponse is perhaps my way of trying to retain control over my life and my PD.

Sometimes Jody offers to do something for me—taking my arm when we’re walking downstairs, for instance. I know I can manage the steps myself, but if I say so, and take my arm away, it can create tension between us.

I find it difficult to explain that I understand her concerns, but that I also need to keep a sense of control over my illness.

It’s problematic.

Still, there is hope: In recent times, Jody has begun to tell friends, “He’s a poster child for PD.”

In our own ways, we are each trying to make peace with our changed reality.