PD Paradox

To me, movement always represented freedom. It was a couple of years into my Parkinson’s diagnosis that I recognized “movement disorder” as an accepted handle for my affliction. I’m sure it had been used in materials I’d read, or mentioned by doctors I consulted, but in time, the full meaning of those words sank in. Mine is not a mental disorder or an emotional one, although these issues can develop. It is neurological, and manifests in a corruption of movement. Some people will focus on the slight palsy, the tremoring of fingers and limbs. That’s certainly a part of it. But at least in my experience, these symptoms have become more manageable over time. Much more difficult to acknowledge and accept is the diminishment of movement. Absent a chemical intervention, Parkinson’s will render me frozen, immobile, stone-faced, and mute—entirely at the mercy of my environment. For someone for whom motion equals emotion, vibrancy, and relevance, it’s a lesson in humility.

On the upside, I have found that I can play mind games with myself. I employ a strategy I’ve used throughout my life—if I don’t know I can do something physically, I just pretend that I can. Fake it until I make it. Eight times out of ten, it works. The remaining 20 percent? Stitches, broken bones, humiliation.

The Impatient Patient

Someone who helps me demark the lines and boundaries I face in life is Dr. Susan Bressman. She’s my neuro and movement disorder specialist; also a brilliant researcher, an internationally recognized expert in Parkinson’s disease, and a valued advisor to our Foundation. We’re lucky to have her on our team, and I’m grateful for her personal attention. She’s always thorough in my one-hour check-ups, during which she assesses my present disposition and rate of progression, audits my reported reactions to medications, and monitors my cognitive skills and mental acuity. It can be exhausting. Sometimes I’m “on” during the examinations, and sometimes I’m “off,” all of which is duly observed and noted. I wish that everyone could have such careful consideration of their illness as I do with Sue.
As I leave her office after each appointment, I know she’s standing in the hallway behind me, assessing the quality of my stride. When I think about walking, a word that now comes to mind is “deliberate.” I have to plan every step I take; no extraneous side trips or wasted effort. I have to think about the way I sit in a chair: Am I settled in the right way? I do an inventory of where my limbs are. All of this calculation and deliberation is rigorous work. Physical tasks are made more difficult by the need to break them down into all of their components. The required mental work is harder than the physical effort. I need to think about every step, which demands intense focus.

I have to show up—although it would be so easy not to. Some days, I’m done with it all. I don’t want to count my steps. I don’t want to acknowledge what’s worse today, or what will inevitably get worse down the road. It’s exhausting to parse out what is Parkinson’s, and what is attributable to other factors.

Some things I can’t do because I’m fifty-eight. Is that old age? It was when I was twenty-one, which feels like five minutes ago.

Down on the Corner
Unlike when I was twenty-one and living in a roach-infested studio apartment in L.A., I now reside in a prewar building on the Upper East Side of Manhattan. Efforts have been made to modernize the property, or at least acquire modern accessories. For example, an abandoned basement laundry room, replete with vestigial washers and dryers from the 1950s, has been cleaned out, renovated, and is now a residents’ gym. This is where I receive physical therapy.

My PT, Ryan Orser, while physically imposing, is wholly personable, funny and engaging. An accomplished college lacrosse player and a big fan of his hometown Buffalo Bills, he brings an athlete’s perspective to his work. He knows his stuff—the name of every bone, muscle, ligament, and tendon, and how they all work together (or don’t). I ask Ryan how he would describe the work he does with Parkinson’s patients. “I mean, it’s not purely physical therapy, right? There’s something else going on,” I say.

He cracks an impish grin (if the word “impish” can be applied to someone that huge). “It’s like physical therapy—if the therapist had a mother who is a psychologist, a father who is an ergonomist, a brother who is a dancer, and a mind that is perpetually fifteen.”

“Works for me.”
My office is around the corner from our apartment, so to get from the office to the home gym, I have to go outside, hang a right, go about thirty feet, take another right for forty feet, and enter the lobby doors under the canopy. This used to be a piece of real estate I could cover without a second’s thought, nothing more than a short commute, or the last steps of the trip home from the coffee shop on Madison Avenue, or the bookshop on the corner. It’s now the Bermuda Triangle, or more accurately, the Devil’s Right Angle.

That’s where Ryan comes in. Before each workout, he meets me at the office and we discuss what we’re going to do that day, therapy-wise. First priority: laying out a strategy for negotiating the 350 steps from my exterior office door, into my apartment building, and down the stairs to the gym, factoring in variables like the weather, my current “on-off” status, and the time of day. Sounds simple, and some days it is; but on other days, like today, it’s a perilous odyssey worthy of Ulysses.

Just stepping out the door is tricky. To make an immediate right necessitates a quick glance to the left to check for oncoming pedestrian traffic. The first step is crucial; I want to make sure it’s not complicated by passers-by. There is no such thing in my world as a “quick glance” anymore; it requires my whole body, including my feet, to shift. Seeing that all is clear, I turn right, into the wind. Our particular corner, whether it’s airflow vectors or just the shape of our building juxtaposed against the building across the street, confronted by the stone walls of Central Park, conspires to create the most blustery city corner this side of Chicago. Gusts of up to fifty miles per hour have literally knocked me down in recent winters. Even without the blowback, it’s freezing today in New York. Sidewalks are slick and icy, and frost heaves have warped the pavement, creating dangerous lips and ledges. The corner always seems to be jammed up with life forms, whether a pet owner dragging his cardigan-sweatered French bulldog out for a pee, or on nicer days, a young teacher shepherding twelve tethered preschoolers.

The second right turn can be a deal-breaker. I’ve fallen here many times, leaving a patina of knee skin on the concrete. Having found my way around it, I’m now faced with an even more precipitous downhill jaunt into the lobby. The pace is quicker today, so my stride is shorter. The frost has done its damage here, too, so there are countless toe-catchers waiting to drop me if I shuffle. My reflex is to close down my hips, in the hope that it will control my pace. The actual result is a limiting of my options. Another risk is that I’ll run into a gaggle of my neighbors, waiting for taxis or unloading groceries from their cars (or at least supervising doormen as they schlep bags inside). The temptation is to stop and
say hi, be friendly. Wrong. Do not stop. Do not make eye contact. Do not engage. It’s clear you’re struggling; you’ve got a cane, for Christ’s sake. They’ll understand. I step up, in and away, and take a left this time, to the service stairway that leads down to the basement.

The running of that gauntlet, believe it or not, is followed by an hour of physical therapy.

**Brain Sweat**

Core work, crunches, sit-ups, bicycle kicks, the dreaded ab chair—we always start off with the fun stuff. “Okay, walk over here. Hips forward, shoulders back, don’t drag that left foot,” Ryan commands. But while I’m concentrating on lifting my left foot, I hyperextend my right knee.

Damn.

“It’s okay, we’re going to work on that later,” Ryan says. A willing student, I work my ass off, but I get a little cranky and whiny as I’m put through my paces.

Ryan flops a rubber mat down on the faux pine floor and says, “Toe-touches. Right knee up, left leg down, touch your right foot with your left hand, then switch. Give me twenty of those.”

It takes me a second to picture the movement, even though I’ve done this a hundred times before. But I want to be sure, because I know what’s coming next. I do one. I do two. I do three. And here it comes: Ryan says, “Who’s the sixteenth president of the United States?”

I grunt, reaching out to grab my left toe. “Lincoln? I don’t know—I’m Canadian.”

“Correct. What’s (3 x 3) minus (7 + 2)?” He’s jumping all over my brain, in the areas where I store information. I hesitate and grab my left toe twice.

“Zero,” I grunt. “Nada. Zilch.” While all of this is going on, he’s laying out a course of pylons, two paces apart. They zigzag the length of the gym floor. I stand in front of the first one, get my balance, take a big step, and slalom my way through the course. I have to go slowly and carefully. On my second step, he starts in again.

“Name the planets in order from the sun.”
I get the Mercury/Venus/Earth/Mars intro out of the way, but what’s next—Jupiter or Saturn?

“Jupiter?” I take a guess.


“I can’t concentrate,” I complain. “You’re sabotaging me.” Then I blurt out: “Saturn, Uranus, Neptune.” I turn, my left foot dragging into a pylon, knocking it over and nearly bringing myself down with it. “And sometimes Pluto.”

Ryan laughs and says, “I bet you’re thinking: ‘You ask me to do all of these goddamn things. I can’t even stand in front of the toilet and pee straight.’”

“At least I still stand,” I answer.

After another forty-five minutes of working out—treadmill, rowing machine, and a selection of stretching exercises approved by Torquemada—today’s session is done. We collect our things, put on coats and hats, and prepare to retrace the series of rights and lefts (mostly lefts this time) back to the office. Even exiting through the gym’s door is an opportunity to reinforce my therapy. These kinds of transitions cause my brain to hiccup; passing through doorways poses a challenge, depending on what I’m stepping out of and into. I do a quick reset, and then proceed on steady legs. We opt to take the staircase to the lobby instead of waiting for the service elevator. It may seem counterintuitive, but stairs are easier for me to negotiate than flat surfaces. My problem is not strength, it’s coordination. Stair treads are plain in their visual language. They prescribe the height to which I have to raise my foot, as well as how far forward and how flat my footfall should be. The handrail doesn’t hurt, either.

Ryan keeps talking. “Do you remember how you were sitting when I first met you?”

“I don’t know—on my ass?”

“Yeah, but you also had your leg on the ottoman. The other leg was on the ground, pushed into the corner of the couch. You had one outstretched arm here, and the other arm there. Just to balance, you had to touch all of those points of contact.”
“Like Ralph Macchio doing the crane in *Karate Kid.*”

Ryan nods. “You were like that because you wanted to pay attention to our conversation. The rest of us don’t have to worry about what our bodies are doing when we talk to people, but you really need to focus. Movement can be intensely distracting.”

We reach the heavy brass-and-glass lobby door. He holds it open and I pass through without hesitation. “Okay,” Ryan says from behind me. “Let’s take this next part slowly. Stop. Set your feet. Think about where you’re going: a short uphill to the corner; turn; pause again. Count your steps.”

The bright sun bounces off concrete, the afternoon traffic tumbles downtown, and the sidewalks are lightly populated. I nod, take a medium yoga breath, and I’m on my way.

“One . . . two . . . three . . .” Ryan is counting aloud beside me, but out of my line of sight. “Six . . . seven . . .”

Suddenly, I get distracted. *Does that lady have a dog in her handbag?* My left leg hyperextends, and I start to pitch toward the building’s sidewalk garden. In a second, Ryan’s arm shoots out to grab and steady me. He catches me under the armpit and pulls me upright again. Giving me a grim smile, he nudges me forward. “Eight...nine...ten...”

He counts a little louder.

What Ryan’s doing is simple. He’s trying to teach my mind to perform one exercise while my body performs another. I need to create new pathways in my brain, new ways of compartmentalizing actions and words. Basically, what he’s teaching me is not only how to walk and talk at the same time, but how to safely think about other things while still being aware of the kinetics involved in moving from place to place.

I find myself reciting tongue-twisters—*Fuzzy wuzzy wasn’t fuzzy, was he?* —when I do pushups and bicycle crunches in my office. If she sells seashells, then I’m buying, because this stuff is working. I may one day master multitasking. But I’d prefer Ryan go easy on the math.

*End of excerpt*