

Getting Lost in the Music

Nancy Wergeles

Nancy Wergeles and her husband Donald regularly attend Dance for PD Manhattan classes at The Juilliard School and live in Weston, CT.

Last week my husband and I took a dance class at Juilliard. It was magical. Who would have ever thought that we would be walking into the Juilliard School at Lincoln Center to be participants, and not observers, in one of the performing arts?

When my husband was diagnosed with Parkinson's disease sixteen years ago we were completely shattered. I remember walking around mystified that the world was still going on as usual while we were groping for ways to adjust to this disastrous news. So great was my distress, I felt that at the very least, the earth would no longer be orbiting around the sun.

Parkinson's Disease is a progressive neurological disorder that affects movement and speech. And, from what I've observed, every other organ system. It is unrelenting and cruel. While many illnesses afford some privacy, Parkinson's, is an "in your face" disease. One can't hide the tremor, the fixed stare, the stooped posture, the unintelligible speech, the shuffling gait, or the uncontrollable movements, (dyskinesia) that are just some of the common signs of Parkinson's.

There are a variety of medicines and some surgical procedures that are used to control the different symptoms. They work with varying degrees of success. The troubling thing about the medicines is that some days, they just don't work at all. My husband and I spend a fair amount of time second guessing why he might be having a bad day. He didn't get enough sleep, it's too hot, it's too cold, he worked too long in the garden, the stock market is falling, he shouldn't have had the wine with dinner, he should have had the wine with dinner, he sat too long in the theater, he has a cold, a urinary tract infection and so on. All these things are true and can exacerbate the Parkinson's but none of them are reliably predictive, at least for him.

The greatest challenge for us is to live life fully while knowing with certainty that the disease is not going to get better. I must be honest here and say that my husband has an amazing attitude. He rarely, if ever gets depressed by his disease process. It is my attitude that needs some correction. Some days I cry in the bathtub. When we have to use the wheelchair to get him into the kitchen for breakfast I can hear myself railing against the fates that brought us to that moment. But after breakfast he usually is able to walk again. That day the medicines have kicked in just fine.

Imagine the delight and surprise I felt when, at my husband's last Parkinson's checkup, the doctor told us that he had been to a dance class for people with Parkinson's disease. I sat up straighter in my seat. Parkinson's/dance. That's an oxymoron isn't it? Who ever put those two words together in the same sentence? The doctor told us that what impressed him the most about the class was that everyone had a great time. Himself included. The class is free to anyone with Parkinson's and includes their spouses and/or care givers. The only rule is that everyone in the room has to participate. You can't just be an observer. The doctor gave us the name of the woman in Brooklyn who started Dance for Parkinson's. Her name is Olie Westheimer; she is the executive director of the Brooklyn Parkinson Group.

Olie, herself a dancer, has a husband who is a neurologist. She had long felt that somehow dance could be used to help people with Parkinson's. But how? And whom to approach? When the Mark Morris Dance Group moved to Brooklyn things fell into place. When Olie shared her ideas with Mark Morris he jumped at the chance to be involved in such a project. Although he and his dancers knew nothing specifically about Parkinson's they were ready to learn. Mr. Morris has said "Dancing isn't

for everybody, but it is for anybody.” This was over 10 years ago and the program that resulted is called “Dance for PD.” It is funded through grants.

The premise of Dance for PD is simple. Since dancers are experts in movement why not use dancers to teach people how to move again? What most of us can do without thinking, like put one foot in front of another, people with Parkinson’s can no longer do. My husband tells me that his feet won’t listen to his brain.

The dance studio at Julliard was huge. Chairs were arranged in a large circle around the room. There was plenty of space between each chair. Our instructor, seated in the middle of the room introduced himself, David Leventhal. He is also the Dance for PD Program Manager. There was also another dancer facing David, who would mimic the dance moves for all to see. Then David introduced the man who was going to play the piano for the class. We were going to have live music. Just the way I remembered my dance classes when I was a little girl. It was very exciting.

Of course one can’t help but look at the other participants. Some people were wheelchair bound and in very bad shape. They needed their caregivers to be by their side every minute, some people, you couldn’t tell why they were there. It was hard to pick out who had what. There was some socializing. But not much, this was, after all a serious class at Julliard. Also, not much smiling, although admittedly, smiles can turn into a grimace for someone with Parkinson’s. Sometimes you can’t tell if the frozen face is happy.

The class was everything a dance class should be except we were in chairs. First the instructor showed us the moves. The students then practiced the moves. Then we did it to music. With the instructors leading us. The music was wonderful. After about one minute I stopped worrying about my husband and was lost in the music, and trying to follow the instructions by being as graceful as possible. No easy task for an aging klutz. From time to time my husband and I smiled at each other. “Hey, this is fun,” we mouthed. About 15 minutes before the end of the class the instructor told us to stand up, if we could, and go to either side of the room. We were then shown some steps and we practiced them for a few minutes. The music started and we danced across the room, passing each other when we got to the middle. For some the journey across the room was like climbing Mount Everest, for some, like me, it was a glide, for others, like my husband, that day, it was a walk in the park. I was surprised to find how moved I was by the experience. When I looked around I noticed that the doorways were jammed with Julliard dance students, their faces rapt and serious as they watched the dancers within. What a contrast, their perfect young bodies observing the less than perfect bodies of the people inside the room. Their faces showed neither judgment nor pity, just acceptance of what is.

The class ended with all of us standing in a circle and holding hands. In turn, each of us was told to bow to the person on our right and then to the person on our left. There were tears in my eyes as we left the room.

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