

## PD

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About ten years ago, my wife Sara was having a hard time. She had noticed that when she walked, her right arm didn't swing normally. She could make it move, but it didn't do so on its own. At the same time, her handwriting was growing smaller and smaller, in a phenomenon we later learned was called micrographia. She mentioned these symptoms to her physician who didn't feel there was anything wrong, but complied with her request when she insisted on a referral to a neurologist.

Since Sara worked at Earlham College, in Richmond, Indiana, she had most of her medical appointments in the town. And so she went to see a neurologist there. After a short time in the waiting room, the consultation began, done by an assistant. He had her walk across the room, tap her thumb to her forefinger as rapidly as possible, and try to maintain her balance as best she could when he had her fall backwards. He also poked her legs with a safety pin, to see if she responded. Then he left. An hour passed, and finally the doctor appeared. She read her assistant's report, but didn't repeat the steps herself. Instead, she held each arm and turned it around, testing for flexibility. Then, without making eye contact, she said, brusquely, "Do you know what you have?"

Sara replied, “No, I don’t know what I have. That’s why I came to see you.”

“You have Parkinson’s Disease. You won’t die of it,” the doctor said. Continuing without a moment’s hesitation, she bluntly added, “The Pope had Parkinson’s. He didn’t die of it.”

Sara was taken aback. “But what *is* Parkinson’s Disease?” she blurted out.

The neurologist responded from where she had settled across the room. “Parkinson’s is a chronic, incurable neurodegenerative disease that results from the accelerated rate of death of the cells in the brain that produce dopamine.” That was all. And still no eye contact.

When Sara tried to probe further, the neurologist responded briefly and impatiently, and finally left the room. The assistant, trying to help, mimed some stiff motor movements that terrified Sara. As the appointment ended, she was determined to find another physician to check the diagnosis.

Sara had been raised in a family that never talked about maladies or pain, and she didn’t know what to do. She wanted support, but began to feel that people treated her differently. She thought that instead of people asking her, “How are you *doing?*” they said instead, “How *are* you doing?” But, to her credit, she wanted to be open and visible, told her friends about her ailments, and persisted in that approach.

She had heard good things about Dr. Alberto Espay, a neurologist at UC, and got a referral to him. At her very first appointment, he explained patiently all the different symptoms that could occur, but made it clear that it was hard for anyone to predict precisely what would happen next. And then he reassured her, in a way that still resonates, “You have the *good* kind of Parkinson’s. You won’t end up like some of the people in the waiting room.”

At first she needed no medication, and felt good. Then, as a few symptoms seemed a bit more pronounced, she started on a relatively mild drug that helped for a while, but eventually became less useful. It was time for Levadopa, Dr. Espay said.

And so for the past 5 or 6 years, Sara has been taking this stronger medication which works to replace the dopamine no longer being made in the patient’s brain. Initially, the Levadopa worked like a charm. But the drug also has side effects. Sara began to perceive changes in her behavior. She thought she felt some gentle waving back and forth of her shoulders and head while sitting. When she pushed herself to walk at a rapid gait, she seemed a little unstable. She sometimes felt very talkative but at the same time she found it hard to be articulate when under this spell.

We soon learned that every Parkinson’s patient is constantly tinkering with her or her drugs – both the drugs to replace the dopamine that’s missing and the

drugs to counter the myriad side effects that occur from the necessary meds. And with Dr. Espay's help, this became our pattern too.

The next challenge was working overseas. Over the years, Sara – sometimes with my help – had led study abroad trips to East Africa, and she wanted to do it again. She went back to Tanzania several years after her diagnosis without me, for I had work I needed to finish at home, and I think that was harder on me than it was on her. But now the two of us wanted to take students from Earlham and Miami together to both Kenya and Tanzania.

Everything went well during a pre-trip orientation, and we were still doing well when we got overseas to set things up before the students arrived. But once they were in-country things got harder, and Sara's Parkinson's skipped out of control. Intestinal issues intruded, but worst of all was the dyskinesia – a kind of shaking and loss of full body control – that began. It's typical of some, but not all, people with Parkinson's Disease, and was more an issue for Sara than for the students and me. But she became increasingly bothered, especially when we couldn't get the drugs in East Africa Dr. Espay recommended, and in mid-September, she decided she had to go home.

That was hard for me – to be left alone in East Africa with 21 students for the better part of the semester – but it was harder for her. Back in the Midwest, she did occasional jobs at the college, and friends were enormously supportive. But she lost her appetite, and in the process lost a lot of weight. That turned out

to be a good thing, especially when she began to work out with a trainer at the Miami University Rec Center and slowly but surely got into the best shape of her life. And it made the two knee replacements she had last year so much easier.

But she wasn't out of the woods yet. Finding the right combinations of drugs – and doses – can be challenging. Too little, and you might stiffen or face an expansion of symptoms; too much and all kinds of side effects such as dyskinesia or shaking can occur. For a time, drug combinations led to low blood pressure and episodes of blacking out that were scary, to say the least. But eventually she managed to figure out the right combinations, and things are so much better than they've been before.

Perhaps best of all, we've discovered we have to deal with this together. Things get left around the house far more than they used to, and I just have to learn to live with a measure of chaos. Sara loses things regularly. She's now on her third iPhone and third American Express card. She frequently forgets things. As someone who pays close attention to detail, this is frustrating for me, and I'm having to learn to accept the fact that it's just the way things are. Mood swings are not uncommon, and sometimes Sara seems irritated at me, or gets on a roll – as in the week before Thanksgiving, when she was up at 3 or 4 AM every morning, cooking up a storm. I'm slowly understanding that I can try to provide a measure of stability, but can't change the overall pattern. I find myself doing more and more, but all of that's OK, as long as I don't let myself feel too frustrated or put upon.

It's helped enormously to have a PD support group. Once a month, on a Monday evening, we drive down to Cincinnati and participate in a gathering that sometimes has a speaker, sometimes just reflects on symptoms or problematic issues that face us all. The annual holiday party, regrettably, is taking place right now, and we decided each of us should go to our own celebration.

And we've found the annual Parkinson's Disease Sunflower Revolution symposium enormously useful. Dr. Espay is very much involved, as is our own John Tew, and I've learned a great deal about how the illness operates, and the kinds of research going on to help bring it under control. Funded in part by the Davis Phinney Foundation – Phinney was at one time a superb bicycle racer, even winning a segment of the Tour de France – it has brought us into touch with a whole cohort of people, some professional, some not, all in the same boat as we find ourselves. It's shown us how DBS – Deep Brain Stimulation – can work with some patients. And it's taught us a lot about caregiving, and how to deal with issues sometimes beyond my control.

And then there's Michael J. Fox. And his book *Luckiest Man Alive*, which Sara found enormously sappy, though I liked a lot. A year or so ago, we took great pleasure in watching him make four or five appearances on television on *The Good Wife*, playing the role of a somewhat sleazy lawyer with Parkinson's who highlights his ailments to try to get sympathy in the courtroom.

We were all delighted this year when Fox returned to NBC with his own sitcom about a former newscaster with Parkinson's who was forced to retire in his early forties when the illness got out of control. It's self-deprecating and enormously funny, at least for those of us who deal with Parkinson's every day.

Opening segments dealt specifically with Parkinson's Disease. There were all kinds of visible instances of shaking, and then explanations of what was going on. Back in the newsroom, Fox showed how because of his shaking, his chair sometimes rolled outside of camera range. On another occasion, Fox was trying to cook an omelet for his family, and his dyskinesia was making the effort difficult. "Do we have to make this a teachable moment, or can I just get my damn eggs," says his smart and normally kinder wife. Then there are scenes in the bedroom, as if to demonstrate that people with Parkinson's can still have sex – and enjoy it too. Subsequent episodes are less heavy-handed, though still fun. But I suspect that the focus of the series was most interesting for those of us who deal with Parkinson's every day, and the program's future is uncertain.

One of the things we've learned in this struggle is the importance of reducing stress in our lives. This is important for Sara; it's even more important for me. We both find we do better when we have a measure of control in our lives. I'm high-strung and driven enough without having to deal regularly with this scenario, yet have somehow learned when I have to back off. But it's not always easy, for the disease demands our constant attention – at one level just to remember the 15 or 20 pills Sara has to take daily for the rest of her life. Still, the

illness has taught us to appreciate the things we do together even more than before. And it's shown us the rewards and demands of caregiving, which is now a necessary part of our lives.

Parkinson's is a lousy disease. But then, so is MS or Lou Gherig's Disease, or the dreaded Cancer. It's not going to go away. We'll simply have to learn how to live with it. But the research is promising, and I hope that a breakthrough, as with polio, can come while we're all still alive. For now, we do as well as we can, and just hope for the best.