

In 2013, I took an online graduate course offered by the State University of New York. One of the first assignments that the instructor, Prof. Carol Rodgers, gave us was to write a personal learning story that we'd post on the course website for the entire class to see. I wrote about learning to live with Parkinson's disease.

Assignment Instructions

Think of a time when you learned something. A time when you drew upon your capacities and stretched them in ways that took you to a new place where you felt more powerful and capable as a result. This can be a learning experience that happened either in or out of school. Your recollection may or may not have a teacher or other learners in it. The most powerful recollections are those that are full of details. Rather than telling a general kind of learning story (e.g. my grandmother taught me to cook or I learned to drive), tell about a particular time when you learned to cook a particular dish or drive a particular car with note taken of the details of the experience: for example, the setting, the utensils, the smells, the colors, the feel of the tools and ingredients in your hands, the emotions evoked, the steps taken. As you write, consider the following elements as well:

- Yourself and the impact of your own fears & motivations on your learning
- Your peers and their impact on your learning
- Your teacher (if there was one) and his or her impact of your learning
- The environment and its impact of your learning

As you read through each other's stories, take note of commonalities and differences that you see. What do these stories tell us about how we learn? What helps and hinders learning? what do they make you think about your own learning and teaching? Enter your reflections in the Discussion section labeled RESPONSES TO LEARNING STORIES.

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Personal Learning Story

SUNY – ETAP 621 — Fall 2013

Understanding Teaching and Learning

Professor Carol Rodgers

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Personal Learning Story – Parkinson’s Disease

I want to discuss a learning experience I’m going through right now, which is learning how to cope with Parkinson’s disease, a degenerative disorder of the central nervous system. There are two issues I’d like to address: the emotional and the physiological.

The latter first. Here’s an example of how I experience Parkinson’s disease: I’m cooking in the kitchen, standing near the sink, and decide to wash my hands. Perhaps I just handled raw chicken and my hands are slimy; perhaps I just chopped up some cilantro and bits of cilantro leaves are clinging to my fingers. As soon as I decide to wash my hands, my left hand quickly rises and hovers over the sink, ready to rock. But where’s my right hand? Still hanging down by my side! I look at it, cock an eyebrow, and the hand slowly rises to join its mate. Laggard!

Another example: I always brush my teeth with my right hand. When I put the toothbrush in my mouth and want to clean the teeth on the left side of my face, everything works fine. My right hand and wrist make the correct up-and-down motions, my teeth get clean. But for some reason, when I switch the toothbrush over to the right side of my mouth, my hand won’t work anymore. It just won’t move. To compensate, I nod my head up and down, as if I’m enthusiastically agreeing to a change in procedures. Only in that way do the teeth rub along the bristles.

I find this funny. Mostly.

What amazes me is that something I taught myself well, most likely *in utero*, doesn't function anymore, and I'm now trying with limited success to re-teach it to myself. That is, as a baby in my mother's womb, and perhaps during the first few months after I was born, I developed an almost instant connection between my will to effect a change in muscle tone, and the act itself. It seems everyone masters this so well. If people are in a classroom and the teacher says, "Everybody raise your right hand if you love chocolate ice cream," the hands shoot up instantaneously, without thinking. Or rather, it happens so fast it's almost as if you weren't thinking. However, this lightning-flash mind/body connection isn't available to me anymore with my right arm and leg in certain situations.

I've learned firsthand that the problem is not one of physical strength. I used to go to a physical therapy center, which had me do exercises with free weights, such as wrist curls. When I maxed out on the center's largest weights (the heaviest dumbbell they had was 8 pounds), I started doing the same exercises at my local gym. I currently use 25 lb. weights for wrist curls. My doctor is delighted by how strong my muscles are. Nonetheless, the link between my mind and the right side of my body remains spotty.

Here's a game-like exercise I sometimes play to strengthen the neurological path between my fingers and my brain. In a pot full of dry, uncooked rice, I hide a handful of coins: pennies, dimes, nickels, quarters, and even a few silver dollars. With my eyes closed, I thrust my right hand into the pot, seek out a coin, and place it on the table beside the pot. I keep my eyes closed and do this again and again, grouping all the pennies together, all the dimes together, etc. The rice tingles against my fingers, and the coins certainly feel metallic. I can almost taste the metal in the back of my throat.

The game is fun. I'm amazed at how quickly I can tell the difference between a penny and a nickel, and at the conversation I carry out in my head as I decide which coin goes where. "Oh, this must be a quarter," I say to myself. "I'm sure of it. No, wait a minute. It's a dollar...yes, I'm certain. Can't fool me!"

I think, now as I'm writing this paper, that if I played games like this every day, I might eventually regain better control of my hand. But who has time for that? I'm a busy New Yorker! I barely make it to the gym four times a week, and have so many other things I want or need to do. If I have to choose between, say, running three miles on a treadmill at the gym, and sticking my hand in a pot of uncooked rice at home, I'll opt for the former.

Maybe I have to get more serious about combating this disease. Maybe that's the real issue.

Now for the psychological stuff. The hardest part, for me, is not giving myself over to mass hysteria. I was diagnosed with Parkinson's about a year ago, but for two months before that the neurologist I was seeing at the time thought my problem was multiple sclerosis. So for two months I ran from doctor to doctor, trying to get on top of my MS. I was riding the New York subway one day when I saw, at one of the underground newsstands, a *People* magazine cover about media celebrity Jack Osbourne, who had just announced he had MS. The cover photo showed him with his mother, Sharon, another media celebrity. In big blazing yellow letters, Sharon proclaimed, "I Won't Let My Son Die!!!!" My reaction? I was furious. *People* magazine was ridiculously over the top with this, because multiple sclerosis is not a death sentence. For example, Mitt Romney's wife, Ann, has MS and seems to be doing very well. I was enraged at *People*, and felt like shredding every issue at every subway stop up and down the island of Manhattan.

I had the same reaction last week, when the Internet press revealed that Linda Ronstadt has Parkinson's. For the first few days the Internet stories contained only a

couple of paragraphs, saying that she had announced her diagnosis as part of a forthcoming AARP interview. But the tone was hysterical, and included this quote:

"When I finally went to a neurologist and he said, 'Oh, you have Parkinson's disease,' I was completely shocked. I wouldn't have suspected that in a million, billion years," she revealed. "No one can sing with Parkinson's disease, no matter how hard you try."

And even though I felt bad for her, I was also angry. "Wait a minute," I thought. "Just the other day I was driving in my car and singing along to Blossom Dearie's *My Attorney Bernie*. And I wasn't even trying!"

I now wonder if my knee-jerk revulsion to public/media reactions towards disease is truly healthy.

How does all this tie in with this SUNY course assignment? Let's look at some of the instructions.

- *Think of a time when you learned something. A time when you drew upon your capacities and stretched them in ways that took you to a new place where you felt more powerful and capable as a result.*

I'm in the process of learning about something deeply personal, and along the way I'm learning an ultimate lesson that I am not really my body, but something else. I do feel more powerful as a result, and it highlights an essential question: *If you're not your body, then who are you?*

- *The most powerful recollections are those that are full of details. Rather than telling a general kind of learning story (e.g. my grandmother taught me to cook or I learned to drive), tell about a particular time when you learned to cook a particular dish or drive a particular car with note taken of the details of*

the experience: for example, the setting, the utensils, the smells, the colors, the feel of the tools and ingredients in your hands, the emotions evoked, the steps taken.

OK, I left out some sensory details. The pot that I use for my coin game is a beat-up old white enamel thing, with a chipped rim and curving sides reminiscent of a vase.

And if you never rode the NY subway, here's what you need to know. The trains clatter loudly. The ceilings and overhead beams are caked with a thick, oily grey dust; it looks like rat fur. The underground wooden newsstands, right there on the waiting platforms, are probably part of the original structure, installed 100 years ago. They've been painted over so many times the wood appears to be plastic. Finally, because of my Parkinson's, I can't smell anymore, but in the old days the subway platforms and entrances often reeked of piss.

- *Yourself and the impact of your own fears & motivations on your learning*

My official line is that I find that having Parkinson's is an interesting hassle, which may be the wrong tack to take. I've learned so much about the disease over the past year, and about myself as I respond to it. Nonetheless, I wish I didn't have Parkinson's. For one thing, I'd be typing this paper with two hands, not one. And I'd feel more confident about not letting people down at my job and within my family. Additionally, I worry that I may be declining in ways I cannot see, and that it's wrong to be so flippant about my condition, as I'm doing in this paper.

But all in all, I could be much worse off.

- *Your peers and their impact on your learning*

Everyone at school and home has been supportive. However, I'm really on my own with this, because most people don't know much about the disease, and because Parkinson's affects everyone who has it in different ways. I've met other people with Parkinson's only once, when I attended a support group at a nearby assisted living residence. About half the attendees were in wheel chairs, their bodies shaking uncontrollably. When we introduced ourselves it turned out they had been diagnosed a decade or more ago, when there were fewer drugs to combat the disease. However, what shone through was how kind they were to me, and how lively they still were, even in wheelchairs. I'm really lucky that I can still cook, drive, go to the gym, write, swim, ride a bicycle, hold a book, uncork a wine bottle, and work with the students and other teachers at my school.

Although not all at once!