

Steaming, Compressed Air

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Abstract: This essay, composed over a span of eight months, was developed through a collaboration meant to redefine notions of writing that excludes people with disabilities. As post-colonial/collaborative composition theory suggests (Davies, 1992), the author and the writer of the narrative are two distinct people. While the author constructed the words verbally through a series of ongoing dialogues, the writer transcribed, edited, and re-ordered the text. Douglas Biklen's book, *Communication Unbound* (1993), inspired us to explore these non-traditional ways of "writing" that, while grounded in conversation and collaboration, also disrupt models of efficiency and individualism.

Keywords: Parkinson's, disability, facilitated communication

Introduction

This essay recounts the experience of my disability. In it, I demonstrate how I have lost the ability to know who I am. It shows how my body has lost its balance and how my mind has lost the ability to formulate language easily. I offer the experience of what it is like to live in my body and mind. I was able to write this because I worked collaboratively with someone who pulled language out of me. I have never before thought of myself as an author. I'm still waiting to realize why I deserve a place in a table of contents.

Essay

Steaming compressed air. Fresh air doesn't surround me the way I'd like it to. My body is hot and I have lost the ability to know who I am.

Have you ever gone into the back of a dress shop and looked at yourself in the mirror? You may have looked better than you expected, you may have looked worse. Either way, you still knew who you were. Sometimes I pass a mirror and realize that the person I thought was standing there is not standing at all, they are sitting and they are in a wheelchair. I wonder how the person in the mirror will get from sitting to standing? It's the indefiniteness of how long will this person persist in trying to stand up?

The first shock came in 1987 when I realized that I could not stand on my own anymore. When things were good I didn't think about how things might get bad. I didn't know I had a problem coming up.

I can't speak right these days. It's very difficult to formulate language. It's hot and cold. I can't grab hold of what I'm trying to say. I start to write a sentence in my head, then it stops and

it doesn't flow. The more I turn the light on to see it, the less it penetrates the surface. I can't spell or hurry up and put together a sentence that makes sense.

Life doesn't feel chronological. I never know where I am in time. When I'm there isn't there a now here? I try to figure out how I approach things—I start with zero and then I try again. When is zero, is it yesterday? It takes time to place myself into space and time. I don't want to rush. I try to analyze and maintain control as I go along and in the meantime now is built up. I don't have any view of the future.

I never know where I am in space either. There's no experience at all. The experience doesn't even experience itself. How can you be less than nothing? It seems like everything is moving around me. I can't describe it. The furniture is moving around, then it's standing still. I feel dizzy like everything is moving around and I'm going in the opposite direction. I feel like I'm always walking backwards. The wheelchair—it's like a cage—I feel as if as there is somebody behind me that I can't see. I can't turn around like I want to. I can't always look where I want to. I can't be aware of one direction and the other at the same time.

My mouth is dry and I'm crooked. I lean. I have a dry mouth and a blank expression inside my head. My legs are thick and weak and twisted. The left leg is not grabbing hold of my foot. The foot is not grabbing hold of the floor. The left leg feels weak. Outside on the edges the legs are uneven around the knee and the buttocks. Thin mushy pasta—I like it with some firmness to it like the Pennsylvania Dutch do it. It has grips and flavor. It feels even. The fact that I can't stick both shoulders up and back. They feel as if they're shaking and trying to grab hold of something. I get the feeling I don't have a good grip. As if I don't understand the process—how you move the skin around the bones and leave it alone. A building at the beginning of its construction. Where does the body begin? Where does it end?

I talk to myself a lot. I ask myself *what are we doing here?* I keep trying to know where I am or why I am here, but I rarely figure it out. I say to myself *you should smile more*. There are lots of things to smile about. I just can't recognize them fast enough.

I am sitting across from the nurse's desk. I am trying to read, which is very difficult. The doctor is around and he seems to want me to smile no matter what. I am told to smile all of the time. Without a good reason, without a history, without a build-up of some kind of story. Just smile, be weak. That's when I want to be left alone. He just says *smile*. I say to him I've been told that before. He probably figures that I have a contrariness, that I don't want to comply. They want you to produce a good result and I just don't have the energy to do that right now.

The remarkable thing here is how the ability to stand up or sit up is so important. Even when I sit up, I'm crooked and uneasy. Then the doctors look at me and say *just smile*. As soon as you need an appliance to help you stand up you are already in trouble. I never thought I'd be in a place like this. Does it make me feel less of a person? Yes...that seems to be the problem. If I was at home and I had to go to the bathroom, I would just go. But now, because I have lost the ability to stand, I have to go according to a schedule. I am allowed to use the restroom every 2 hours, no more. And they get nasty about it, harass me about how I just went or snicker at me.

Things aren't bad now, I just feel weak. I just want to be able to relax and not think about how things could get worse. Everybody dies a little bit every day. You have to get used to the idea that there will be less of you left. I am trying to improve my attitude but I know the disease is progressing. I'm trying to put together a positive image of myself. It's like going in circles, after 18 years I still am in shock. But I don't think I'll ever give up. I'm old enough now where I can just sit and ponder.

Devera Gordon has lived with Parkinson's since 1987. She is a resident of a long-term care rehabilitation hospital in Baltimore, Maryland USA. She is 74 years old.

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