Composing With

Revising a (Writer’s) Life: Writing with Disability

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For the first decade of my career at the University of Cincinnati I taught writing. During that time, I participated in a project that involved creating videos that would form the core of online writing and literature courses. The videos were made in a studio that was completely empty but for me and a white board. Because I had no students with whom to work, no matter how hard I tried to behave as I would in the classroom, I kept acting and speaking in ways that were absolutely counter to my pedagogical and personal style. I pointed at a blank whiteboard as I talked, lectured for long stretches, and read aloud from assigned texts. At one point, I suddenly began to channel a crotchety old biddy. In a cackling voice I had not used before and hope that I have not used since, I looked into the camera and commanded, “Revise, revise, revise.” At the next taping, the producers allowed me to revise that moment out of the video, but I had already told my partner about it and the Revision Hag I created that day has since become a humorous part of our family lore.

I am sorry to say that in 2008 the Revision Hag took up permanent residence in my life. That year, I was diagnosed with multiple sclerosis (MS). Not long after my diagnosis it became clear that mine is a progressive form of the disease and that the progression of my symptoms is aggressive. In the intervening years, I have gone from full-time employment as an academic to retirement on disability. Before my disease began to progress, I was teaching, writing professional articles and books, interacting with colleagues, directing my department’s undergraduate program, and beginning to take my place in college leadership. Now, I am confined to a wheelchair, unable to drive, and experiencing increasing difficulty performing simple tasks (bathing and working on the computer, for instance) that were once second nature to me. Though I resist her at every turn, the Revision Hag reminds me always that I am now significantly disabled and that I must revise my ways of functioning.

The Revision Hag also commands that I revise the pace and frequency of my writing. Though MS does not impair one’s intellect, it can affect some areas of cognitive functioning, particularly verbal fluency, the speed at which a person can process information and respond to it, short term memory, and executive functioning (planning and prioritizing). Early on, my neurologist suggested that I undergo “baseline” neuropsychological testing to determine the cognitive impact of my disease; those initial tests revealed measurable deficits.
When I was retested a year later, the deficits had increased significantly. I was already becoming aware that I might not be able to return to work the next year, and that awareness only grew as time passed and I found myself unable to write, speak, and process information as quickly and confidently as teaching and other academic work would require.

Even in the slow pace of my life on disability, the Revision Hag can be a harsh taskmistress. Just when I revise my ways of moving from place to place, of navigating my computer, of reading (because I can no longer turn the pages in a book, all of my reading is done on a computer or tablet), and of writing, my symptoms progress and I hear that cackling voice commanding, “Revise, revise, revise.” I have been forced to revise long-held beliefs and habitual ways of functioning as a writer. I have had to revise my physical practice of writing, the value I place on certain types of writing, and my ideas about the very purpose of writing. As most people do, I once wrote using a computer that I controlled with my hands. I thought of writing as a process that involved not only my brain but also my body, particularly my arms and hands.

Lately, though, my hands have weakened and become uncoordinated, so I have had to revise the very basic ways I write and interact with my computer. I now spend my days wearing a headphone that controls my computer through voice recognition software. Everything I once did with my hands—including writing—I now do with my voice. The voice recognition software I use (Dragon Naturally Speaking) is probably the most popular on the market and it is definitely the most popular among people I know with MS. Dragon is a powerful program that easily recognizes the speaker’s voice and builds a profile that keeps track of the writer’s commonly used words and phrases. I have said many times that I wish I had found Dragon before my hands and arms were disabled because it allows my voice to connect directly with the page. All my life I have found it difficult to transfer my thinking from my mind, through my body, and onto the page. With Dragon what’s on my mind goes directly onto the page; I find that liberating. Also, one of the reasons I loved teaching was that when I was in the classroom both my body and my negative body image disappeared, and I was able to be in the present and enjoy the moment in ways I never could in other contexts. With Dragon I get some of the same feeling; writing with my voice helps me forget my disabled body, to feel that it disappears in the same way it did when I was in the classroom.

With much chagrin, I recall that I once denigrated personal blogs as a kind of vain “self-publishing.” I even remember saying once that anyone (serious writer or not) could have a blog, and believing that most blogs lack substance and are full of sloppy writing. Now, blogging is one of the primary types of writing I do. I read several wonderful blogs and I have my own blog (http://profspazz.com/), which focuses on my experience as a lesbian with MS. I have
a set of regular followers, some of whom I know and some of whom have come
to my blog through Internet searches or because it was recommended to them.
I value this type of writing in ways that I never dreamed I would, for the blog
has become my primary intellectual and creative outlet, as well as a way for
me to “contribute” to the world despite the isolation imposed by my disability.

The Revision Hag has also insisted that I change my ideas about the con-
nections between writing and sociality. As I said, I am no longer able to drive,
so despite the fact that I am not working and should have plenty of time to
socialize, it is difficult for me to do so on a regular basis. What’s more, when
I spent my days at the university most of my social life revolved around work.
My closest friends were my colleagues, and I experienced extraordinary joy and
social fulfillment in my interactions with students. Now those people have to
come to my house to see me, and the easy interactions that came naturally when
we spent our days interacting professionally require a kind of planning and
forethought that makes them less frequent than any of us would like. Though
the visits are wonderful, I have of necessity developed a very different kind of
daily social life. I belong to an online MS support group that does much to
sustain me socially. Though members come together only virtually and because
of our common illness, we form a kind of daily coffee klatch full of humor; we
talk about the issues of the day and we share the ups and downs of our lives.

As someone who became disabled in middle age, I was in the midst of
a fully developed life as a scholar, teacher, and writer, and I had never even
considered the possibility that the course of that life would be forever altered
by MS. Now, knowing that my friends and colleagues are busy doing the kind
of work and enjoying the kinds of interactions I once did, I feel as out of my
element in this quiet house as I felt in that studio years ago. The solitude, the
slow pace of my days, and writing whatever I want without a deadline are still
as foreign to me as was “teaching” in that empty studio. As I contemplate the
changes in my life and consider the revisions I must make in order to continue
functioning in ways that are somewhat fulfilling to me, I remember with re-
newed compassion students who responded with horror to my suggestions that
they revise their theses or the format of their essays. I understand like never
before that the Revision Hag’s command to revise, revise, revise sometimes
represents not only the reconsideration of a piece of writing, but also of ways
of seeing and living in the world.