

Forging a new identity



MS forced me to redefine myself.

by Shannon Auge

As much as I know that my identity is not found in what I do, I can't help but struggle now and then. I can say quite confidently that I was very good at my job as a bookkeeper. Most people think that in order to be a good bookkeeper one must be good at math, but that's not entirely true. Bookkeeping is more about getting various numbers to make sense and balance, while telling a story of where they have been and where they are going.

A big part of my job also consisted of managing payroll and employees, which added another whole level of balancing and storytelling with people rather than numbers. I was good at that, too—until I wasn't.

I was diagnosed with multiple sclerosis in 2004, and not long after, my doctor noticed some cognitive impairment. He warned me that I might struggle with aspects of my job that had always come easily to me, like multitasking and working under pressure. He told me I might eventually need to quit working, or at least cut back on the number of clients I worked for.

Looking back, I see that I didn't initially recognize some of the cognitive and emotional effects of my MS. They were very subtle at first: forgetfulness, feelings of being overwhelmed, trouble staying on task. I vividly recall one time when I felt so overwhelmed by a task I had done under pressure a thousand times that I just lost it emotionally—I broke down and cried (and screamed!). After that, I started to hide how behind I was with my work, certain that if I only worked harder or had a little more time, I would be able to catch up. I cringe now to even think of the load I was carrying. Frankly, it would have been impossible

for a healthy person. Did I mention I had three young children at home while I worked? Enough said.

However, because being a bookkeeper was my identity, I could not get myself to let go of any of my clients, including my husband, who was self-employed. I also couldn't stop working for other family and friends because—well, they were family and friends. I couldn't give up being a notary on the side because it was easy money—but something had to give. Yet, the stress of the issue kept me frozen.

Which brings me to another difficult symptom of cognitive impairment that was hard for me to accept: I lost the ability to make decisions, whether simple or complex, without a breakdown. I could not figure out how to make less work for myself. It seemed impossible. As a result, I was more and more frequently having meltdowns, mostly privately, but sometimes taken out on the people who loved me most.

One time in particular, when my husband walked through the front door, I was very snappy toward him; I made some comment about how much I had to do and how overwhelmed I was and how I do everything, and started crying. My husband broke through my tantrum—and my inability to make a necessary change—by telling me that if I didn't let go of some of my clients and work less, he was going to call them for me. Sounds harsh, right? Yet, it was the shock I needed. As horrible as it sounds, I needed someone besides me to recognize that something was very, very wrong, and that I was not able to deal with it on my own. Soon after this event, I got honest with myself and the people for whom I worked, and a lot changed.

We hired someone to take over the office manager position for my husband's business. I let go of all of my bookkeeping clientele, except for one large client. And two years later, I retired completely from this high-pressure, time-sensitive work, and I applied for permanent disability. The painful reality was this: My identity as a bookkeeper, though estimable, was disabling me, literally and figuratively; finding a new identity has actually freed me to be so much more of who I want to be.

However, there are still some days when I feel that I've lost a big chunk of who I am. In a world where most of us are defined by our jobs, sometimes I don't quite recognize myself without the job description I had for over 15 years. I am still a mother and a wife, but those things are not esteemed in our society. They receive little recognition and no paycheck, so it follows that they also go unnoticed and underappreciated. What usually goes through my head next is, "Yes, but this is how all stay-at-home moms feel, and it's only temporary, while the kids are young." I realize, however, that's not true for me. I likely won't be able to return to work when the kids are older.

So the thought that "maybe someday I can do this or that" is risky for me—perhaps for any of us with this disease. How then, can we find our worth if we aren't being paid by an employer? We have to find new ways.

I started by challenging myself to use my other gifts and talents. I began to work with the youth at our church. Now I know I am someone who makes time for people, who demonstrates my love for them.

Though I no longer use numbers to tell stories and find balance, my identity is not lost. I am still a storyteller, creating the story only I can tell, of where I have been and where I am going, and how I am finding my own balance. I find my identity, not in the work I perform, but in who I know myself to be.

Shannon Auge lives in the San Diego area. She was diagnosed with MS in 2004.

For support in making employment-related decisions, visit nationalMSSociety.org/employment, or call an MS Navigator at 1-800-344-4867.

Find more of Auge's writing on her blog at diaryofdisease.com.