Disability, Identity, and the Circle of Life

I have always led an active life, and love all sorts of outdoor activities. People ask who I am and “A physician,” is part of the answer. That started to change in 2012, when I developed a progressive neurologic condition. Fatigue was one of my first symptoms and I had almost no energy to go out, let alone work. I haven’t lost interest in motorcycles, hiking, skiing, or skydiving, but many of the activities I love take too much energy to enjoy presently. I developed memory problems and was forced to stop practicing medicine because when a doctor forgets something, it’s usually pretty important. The wheelchair I now use due to mobility problems further limits what I can do and where I can go, as our society still has a long way to go with physical accessibility.

Prior to my illness, I found a lot of my self-worth came from being able work enough to support myself and perhaps a family, which I am unable to do now. The privilege I once had was also slowly disappearing. Despite being a doctor, my voice isn’t respected as much when I’m sitting in my wheelchair. When I lost most of the ability to speak, I found I’m listened to even less when talking with my iPad. I began to see how much the activities in my life had become part of who I thought myself to be. As I lost ability, it felt like I was losing my identity. Who was I becoming? My life had changed drastically in a very short period of time.

At the same time, my disabilities were becoming integrated into my identity. I was born with an autism spectrum disorder, and also had a severe traumatic brain injury at the age of 19 that left me in a coma for 8 days and from which I have never been quite the same. I have experienced disability already in my life, yet I didn’t think of myself as ‘disabled’ or having a disability until I became unable to support myself through working. People would ask, “What do you do,” and I wouldn’t know how to answer. I didn’t know anyone else who identified as having a disability, and I had only met a few people in wheelchairs throughout my entire life.

Things started to change for the better when I found the disability community. People with disabilities need to access the world in very different ways than able bodied people. Many of us have been forced to live in institutions because of lack of support for living independently. With the passage of the ADA and other civil rights laws for people with disabilities, we have begun to get out of the nursing homes and become integrated in society. In gaining independence for people with disabilities, the disability community has begun to form and develop. We have our own language, history, and identity that we share and that brings us together. We are still limited in what we can do and where we can go, because the world we live in isn’t built with disability in mind, but we are working to change that.

Disability has been looked at for too long from a medical standpoint: a ‘disabled’ person is their collection of diagnoses and symptoms. “How can we ‘fix’ them to make them as normal as possible.” The social model of disability views disability as a normal part of the human condition. If the world we lived in were designed with accessibility and disability in mind, people with disabilities wouldn’t have to face discrimination daily. The social model of disability also recognizes that disability is a normal part of the human continuum and aging. If any of us lives long enough, we will all personally experience loss of ability.

‘Differently-abled’ is not a term used by the disability community because every person has different abilities. Some people can paint, some can sing, some walk and some don’t. Yet I am discriminated against regularly because of my disabilities. ‘Differently-abled’ treats disability like a bad word that should be avoided; disability is not a hurtful term. What hurts is having to constantly fight with healthcare, insurance, and housing agencies, whose services I rely on to live independently in the community, to get my basic needs met. What hurts is not being able to go to the places I used to because I now use a wheelchair. The disability community generally uses the terms “person with a disability” or “people with disabilities” to talk about ourselves. These terms are person-first, and recognize that we are valuable human beings who just happen to have disabilities.

I proudly identify as a person with a disability and I am a member of the disability community. I have many friends with disabilities who understand the experiences that I've been through and continue to go through, because it is their life too. In embracing this part of my identity I’ve found it's possible to be both spiritually and emotionally healthy while having a physical illness. Health is so much more than the abilities of our bodies. Finding a place we feel we belong is important to our identity, our acceptance of our own identity, and our health. I am a Buddhist, and in Zen Buddhism we take refuge in Sangha - in knowing that we are a member of the community here locally, which is one with the community of all beings. From community, family, and friends - my Sangha - I’ve experienced the abundance of love that is always there for me. Knowing that love has helped me feel compassion towards all beings and to cherish this life.

Fatigue and other symptoms have forced me to slow down, but in the process I have learned to find peace in the moment. My identity, past, present, and future, exists in this moment too, for where else could it be? I try to see and enjoy the beauty in even the simplest things in my life: a flower, a cup of tea, a brief chat with a friend. It is these moments that are woven together to spin the thread of our life. Our thread links with others to form a cloth that has been knit throughout the ages; the interconnected web of being. Of all beings.

Though I am unable to participate in many of the activities I used to, I have found new ones that I can enjoy with the ability I have. From not being able to practice medicine, I was forced to stop and deal with so many feelings and emotions that I had suppressed for years. I have also discovered new and creative ways to use my medical degree to help others by becoming involved in activism and advocacy for the disability community. It isn’t what I envisioned myself doing, but I love the work I do. I have lost touch with some friends, but I continue to make others who love me for who I am and as I am. Through this journey I have found peace. In losing my identity, I am finally beginning to learn who I really am.