

Identity Oct 19, 2015

I participate in a lot of MS support groups. While I find some useful, the common thread is how multiple sclerosis changes identity. For me there are several behaviors that I find are identifying. I use the handle 'chronic' among others, in Social Media sites.

First: 'you look so good.' This may be the most frustrating, even if I look good, and I appreciate that, I don't feel good. In fact, I often feel much worse than I let on. It is really a problem I help create. By trying to do as much as possible, I push myself hard. This has the unintended consequence of not appearing as ill as I am, and others make their judgment. I will continue trying, giving in or up is not really an option.

Second: Changes. The only thing I can plan, I will change. From the small things, like shopping, to the large things, such as being a father or husband. All change is impactful. I wish that those around me would take my insight to my health as meaningful.

A story:

A friend of mine's daughter (age 7 or so,) died of cancer. That is tragic. Everyone rallied (and they should have,) and provided support to my friend.

There are days when I look at that and see how my change will never engender that response. To be clear, I am changing, and not for better. The changes, and my plans to handle them, need help. I need help for the small things, and understanding for the large ones. I want to live with my change. Sometimes, I feel as if everyone wants to put 'poor old Dave,' on the shelf, to be trotted out like a cherished, but broken toy. I realize (no one more,) I am changing and cannot do things I used to (sometimes things I could do yesterday.)

To be clear, MS is long and slow. I will have to live with a slow degenerative disease whose complications will likely end in death. I want others to rally around my family (they are living with this too.) In some respects, the permanence of my friend's daughter, looks appealing, there is (or could be,) some closure for my family.

Third: Work. (Finding some.) To tell or not to tell. The first question I struggle with begins even before an interview. If I divulge, I never get the position, (in fact I rarely get an interview,) if I don't, MS leaves a multitude of questions (about me personally,) that the persons I come in contact with, answer.

While I never have been told what went through their mind, or the process used to come to a decision, I have never been offered a job.

I am the type of person who lived by one rule: **You are only as good as your word.** I find the options available do not serve that end. The search for work is by nature, conflicted.

Fourth: Disability. This is a catch all. At least one thing happens daily that emphasizes how little regular people understand, and this list could be virtually endless. The simplest are things nobody else notices, the largest is insensitivity to the daily struggle, and what limited crutches I have, do not seem enough or are unavailable.