

When MS Changes the Marital Equation



For decades, we have considered ourselves partners.

We divvied up decision making and household chores the best we could. After our three children were born—including a set of twins—we took pride in our co-parenting efforts. Although the 50-50 quality of our 26-year-old marriage was tested when the kids were young and I opted to teach college part-time and work as a writer from a home office, we continued to earnestly pursue the goal of domestic equity.

It hasn't always been easy, particularly when Scott's work hours have kept him out late beyond dinner time. Because I often work from home and am in close proximity to the kitchen (that's when I'm not teaching at a university), I have tended to be the one who makes family meals. On those evenings, when Scott came home, he'd automatically do the dishes and, on the weekends, would prepare meals, as well as take care of a host of other household concerns.

Then MS happened.

Then the fatigue hit.

Followed by leg spasms which started to interrupt my slumber (and his, by extension).

Then heat sensitivity—which negatively affects me through late spring through early fall whenever I attempt to venture outside, rendering me stuck inside air-conditioned areas—

descended like an impenetrable fog.

Thus, the 50-50 bargain, the marriage of equity we created years ago, involuntarily slipped away. And man, was I ticked. In truth, I still am.

The fatigue that has not only carved deep, dark circles beneath my eyes since I started experiencing MS symptoms five years ago, has also carved large swaths of time from my days, cut them out of my life like an unrepentant thief. When fatigue absconds with my energy, I grieve for how I could have productively used these stolen hours, like working on my writing, grading my students' papers, seeing friends, reading, or walking my two dogs.

Ever since MS came to town, on far too many evenings, Scott comes home to find me splayed out on a sofa or on our bed, thoroughly drained. When I see him—after he has battled Boston's notoriously terrible rush-hour traffic—I automatically start apologizing for the fact that I ran smack-dab into the wall of fatigue. And the fatigue won.

On far too many days when I do only a couple of things—like go to a yoga class, stop by the grocery store, or run other errands—I find myself needing to rest afterward. In these instances of post-activity malaise, I cannot make meals, I cannot do chores, I cannot help in any meaningful way. If the fatigue happens to be accompanied by the thought-crushing headaches and that intense eyeball ache which makes it impossible for me to read—which, to me, is akin to depriving me of oxygen—I wind up brooding about how useless I feel as I lie motionless, waiting for my energy to regenerate.

Intellectually, I realize this situation is simply a byproduct of my chronic illness, not a character flaw. However, I cannot seem to shake my guilt... my shame. I become impatient waiting for each bout of fatigue to abate.

I've yet to come to terms with all of this, with having to sit on the sofa while Scott does the dishes or collects the recycling or feeds our dogs, Max and Tedy as they enthusiastically dance around his feet. I'm watching my once relatively equitable marriage become unequal. MS, the unwanted interloper, is pressing its thumb on the scale. I cannot remove the weight of that thumb, but I know I must make peace with its presence.

From all this angst, a new marriage will evolve, one that will no longer focus on equations and equity, but will celebrate other qualities, ones that can't be quantified by the number of chores one does in a day. I'm just not there yet.