A Duplexity of Maladies

Category: Stories
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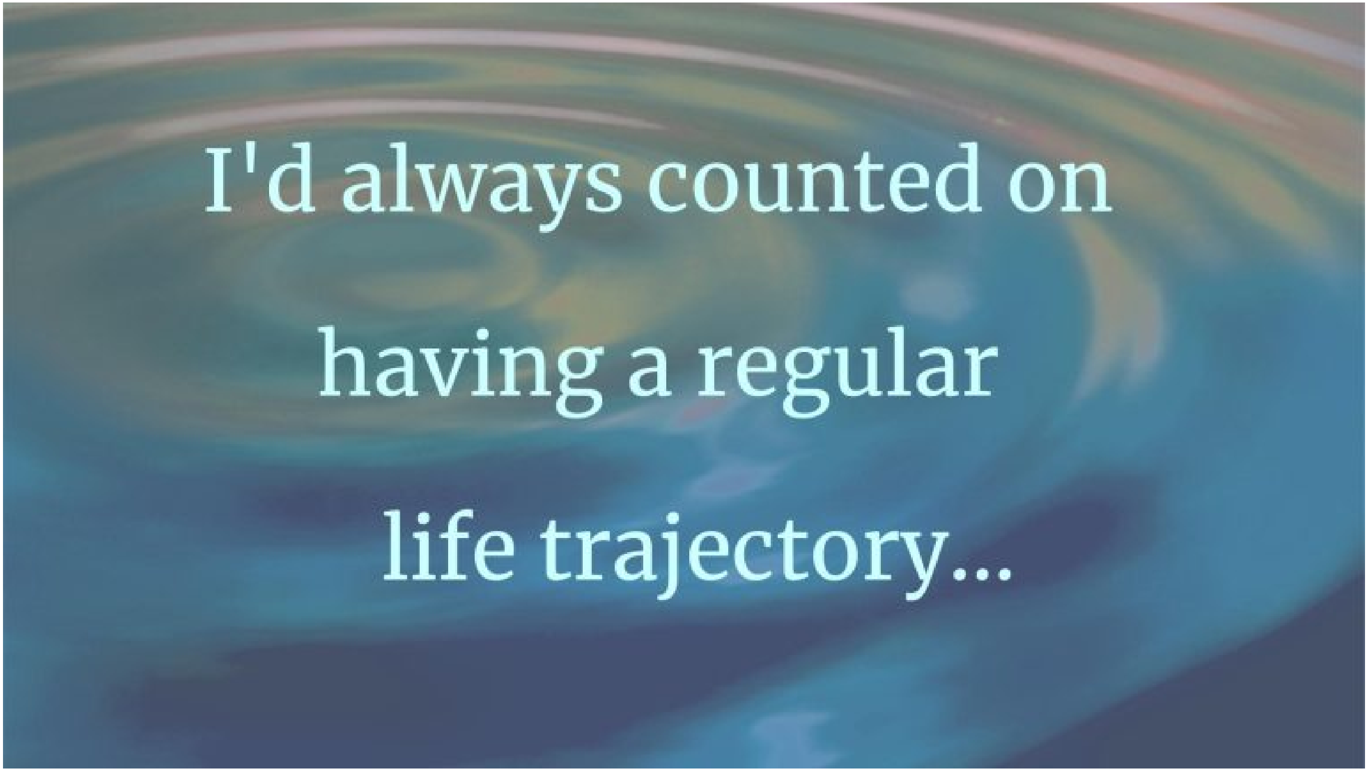

Editor's Note: This piece was a finalist in the Pulse *writing contest, "On Being Different."*

I have a body besieged by two chronic illnesses, namely multiple sclerosis (MS) and bipolar disorder. My health profile has been described as "abnormal," but I've always resisted that term in favor of "atypical," for my poor health renders me unusual but not inhuman.

Still, the truth is that I am essentially and profoundly sick. My imbalanced body frequently aches, hurts and falls, my labile mind races or crawls. While medications can ameliorate my symptoms, they cannot cure my illnesses.

My body betrayed me when I was on the cusp of adulthood. Diagnosed with bipolar disorder at age twenty, and with MS at age twenty-one, I've lived ever since with mental and physical challenges that impede virtually of my daily activities, or "activities of daily living" in physical therapy speak.

Pre-diagnoses, I was balanced and stable, both mentally and physically. As a senior at Yale University, where I was a member of its residential Branford College, I worked diligently and successfully at my academic and extracurricular activities. From attending sessions with the writing tutor for every essay I submitted, to holding elected office as co-chair of the Branford College Council, to writing for the student publication The New Journal, to acting in dramatic productions, I excelled, albeit eclectically.

But, starting in September 1994, my mood plummeted. Most days, I felt low, my mind ruminative; some days, depression immobilized me, except for the tears that trickled down my cheeks. My bipolar disorder had emerged.

A psychiatrist in private practice in New Haven started me on the antidepressant medication Paxil, and within weeks, I’d resumed productivity, determination and achievement. (Despite my mom’s having been diagnosed with manic-depression, I was considered unipolar depressed; I was not diagnosed as bipolar type I until five years later.)

In January 1995, I struggled down the College’s fourth-floor stairwell on which my dorm room was located, laboring to move my peculiarly heavy legs, which felt like cement pylons, trying to get each foot to clear the next step down. Aside from their weightiness, I felt only tingly pins-and-needles sensations from my thighs to my toes.

A spinal tap and MRI revealed MS.

Having two chronic illnesses—one physical, the other mental—felt grossly unfair, terrible and terrifyingly wrong. Knowing that these conditions can be passed on genetically, I decided that I would never bear children.

Prior to my diagnoses, my college experience had been joyful and productive. The two illnesses complicated and marred so much of what had once been easy for me, from showering with slippery Dove soap to reciting the first fifteen lines of Chaucer’s *Canterbury Tales* (as required of every English major at Yale), to navigating the stairs, with few handrails, to and from the classrooms.

The MS and bipolar disorder rendered me nonfunctional at times. I suffered from bad balance and poor proprioception due to my MS, and from suicidal ideation and outrageous spending during manic phases. Grappling with these impairments, I felt my self-esteem draining away. My lifelong sense of insecurity worsened, and I felt overcome by the implications of my diagnoses.

I’d always counted upon having a regular life trajectory: school, career, marriage, family, old age. But now my health fluctuated so drastically that I did not—*could not*—create career, marriage or family. My concentration was too scattered for academic or legal achievement, and my moods were too fickle for most men I dated.

Solitary by nature even before the diagnoses, I tried to convince myself that I was getting along fine despite missing the typical work and social milestones. I observed family and friends wed and bear children, and my dissociation—internal and external—from these events couldn’t hide from myself or others my upset and frustration that I’d likely never experience them myself.

My academic degrees, collegiate and advanced, were a product of grit, determination, patience and fortitude. Although I qualified for certain academic disabilities-related accommodations, I used them rarely except under test-taking conditions.

While my differences from others are profound, I have done my best to own them and confront them with as much levity as I can muster. I say that my mom and I “just got lucky,” given no prior family history of our conditions, and I honor the positives that my diseases have brought me, from self-awareness to self-advocacy. For instance, I’m considerably more alert to my body’s needs than I was thirty years ago, when I was healthy but oblivious to its functioning.

I am a perpetual patient and a professional patient. I take my medications as prescribed; I visit physicians when due; I go to my medical appointments and arrange for the delivery of my medications; I lead a healthful lifestyle according to physicians’ guidelines; and I avoid the harmful and the toxic, from forbidden foods to people who trigger negative emotions in me. I feel tremendously conscious of my medical ills; my world view is circumscribed by physicians, medications, symptoms and healthcare facilities, not to mention my mental and bodily suffering.

Having acknowledged the ways in which my health sets me apart from other people, I crave to be understood. People’s sympathy is a start, as is their empathy. (Sympathy as in feeling *for* someone; empathy as in feeling *with* someone.) Both responses are limited, but each promises potential compassion and relatability. In fact, I’m keenly aware that my ability to coexist and connect with other people depends greatly on their willingness to meet me partway, to try to understand my illnesses and how they’ve shaped, and still shape, my daily life.

My peers, family, colleagues and romantic partners praise me for my openness about my health conditions. Meanwhile, I tire of explaining why and how I can’t participate in certain activities or think through and analyze logic problems sufficiently and swiftly.

One challenge of my diseases is that, when they’re not acute, I get along well enough to appear asymptomatic. That said, the lethargy and inertia caused by my illnesses are often my biggest barriers to living a productive life.

“Why can’t you just get out of bed?” queried my college roommate when she saw me lying, open-eyed and pajamas-clad, until mid-afternoon one Sunday.

“I’m not feeling well,” I responded feebly.

“You look fine to me,” she replied.

Thirty years have passed since this exchange. On October 17 of this year, I celebrated my half-century birthday. At fifty, my bodily diseases and differences continue to be relentless. My symptoms and the threats they pose to my safety are omnipresent, disturbing and disruptive. The pills, the doctors’ appointments, the injections, the medical institutionalizations, the nurses, the phlebotomists are all-consuming. The inability to escape or distance myself from my physical differences defines me—and dismays me.

Though my health differences have certainly been detrimental to me, I believe that, on the positive side, they have spurred me to feel and think more deeply than I might otherwise have done, and that they have been peculiarly helpful in awakening my empathy for myself and others. I shuffle slowly, head bowed, beside my friends, and I listen extra carefully to other patients' healthcare stories.