The Visible-Invisible Divide

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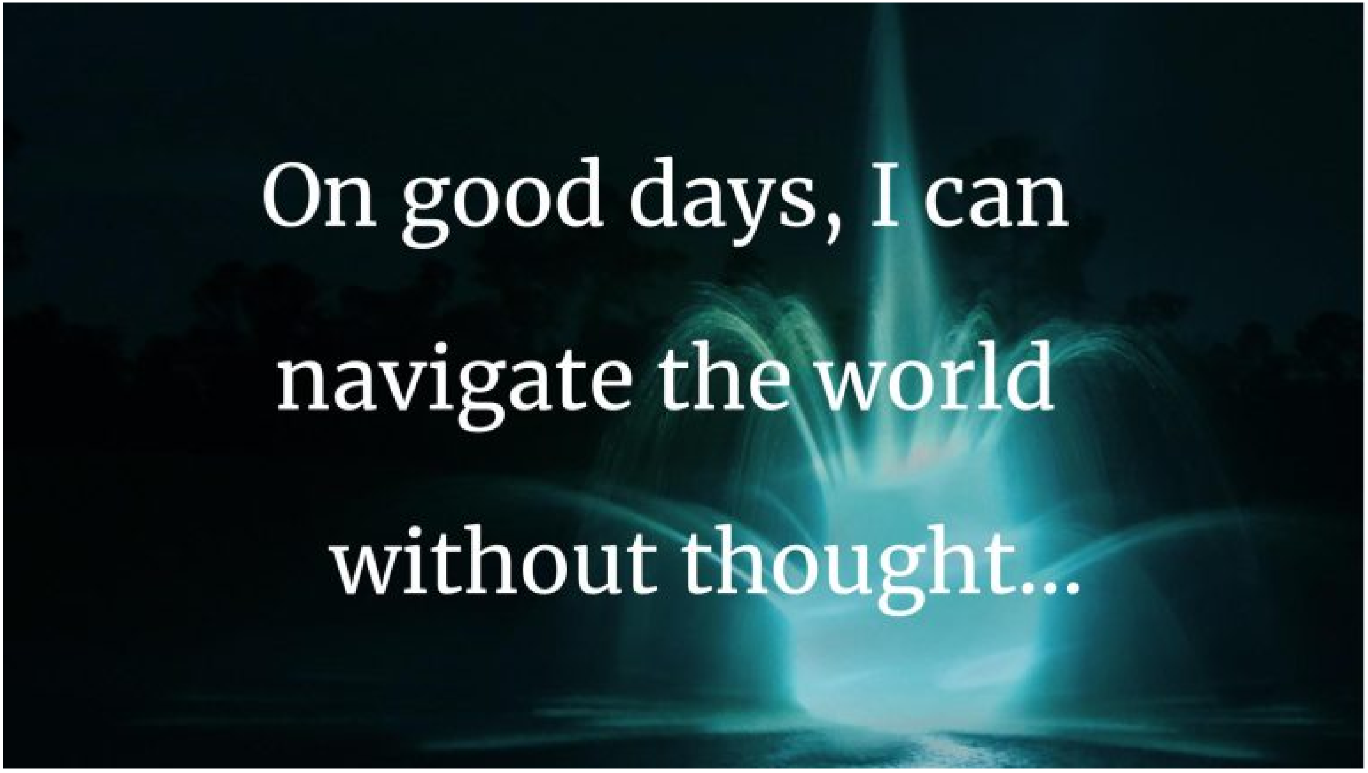

Editor's Note: This piece was a finalist in the Pulse *writing contest, "On Being Different."*

Most days, people don't see my disability. I don't generally wear a brace or use a wheelchair or even crutches.

"I would never know that you're in constant pain," a kind professor once said. "When I see you, you're always smiling."

"You don't look sick," friends always tell me.

I'm twenty-three. I want to be like my peers, but for me, every day is a balancing act—literally.

At age fifteen, I was diagnosed with hypermobile Ehlers-Danlos syndrome (hEDS), a collagen defect that makes my joints painful and my connective tissues too flexible, increasing my risk of injury.

Unfortunately, hEDS goes hand in hand with other ailments. One is postural orthostatic tachycardia syndrome, which makes my heart race when I stand up. I feel faint if I get up too quickly or stand for too long at a time.

I also have mast-cell activation syndrome: When I catch a virus, my body goes on high alert, pouring out chemicals that lead to heart palpitations, fatigue, brain fog, nerve pain, rashes and dizziness.

It's a lot for one body to handle.

On good days, I can navigate the world without devoting thought to every step; I put on a brave face and push through the pain. Unfortunately, I often pay for it the following day. I lie in bed, exhausted, pain suffusing each joint. My eyelids feel like heavy shades that I struggle to hold open; my heart races as if I’ve run miles.

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities, and much progress has been made in eliminating barriers to equality. But people who have an invisible disability face an extra hurdle: We aren’t believed.

Take fatigue, for instance. People with chronic illness often use the so-called spoon theory (coined by lupus-patient advocate Christine Miserandino) to assess their available energy for daily tasks.

Every morning, I wake up and mentally calculate how many “spoons” I have for the day.

My able-bodied peers may start the day with an unlimited supply, while I may have five or fewer. Simple activities—getting out of bed, standing up, showering—may use three of those spoons, leaving me with only two to get through the rest of the day.

Depending on how many spoons I wake up with, I may need to pivot, curtailing activities to minimize flares. It’s frustrating to be able to do everything I want one day, only to have to stay in bed the next; but fighting my body is a no-win situation, so I’ve become more picky about what I do, when I do it and whom I can trust to understand.

Then there’s the issue of accommodations. The thinking seems to be that if you need a wheelchair some days, you should need it every day. A related belief is that if you don’t *look* disabled, then you don’t deserve accommodations of any kind.

I started to feel the full impact of these assumptions about three years ago, as a college sophomore. I was studying for a bachelor’s degree in biology, aiming for a career in physical therapy, when my health issues spiraled out of control. My symptoms began with a flu and progressed to a spontaneously dislocated shoulder, a dislocated jaw and instability in the ligaments connecting my head and neck. The basic tasks of daily living became overwhelming, forcing me to take a medical leave.

At that point, I needed a neck brace around the clock, and, when my flares were severe, a wheelchair. For the first time, I was *visibly* disabled—and though this led others to accommodate my disability more readily, it also brought unwanted attention. Getting through security in a wheelchair put me through humiliating probing. People talked over me, as if my needing a wheelchair also implied that my cognition was impaired. I was even offered a free coffee once by an empathic barista.

After six months, I couldn’t stand for more than a few seconds without feeling ill. Finally, I took a chance on a controversial surgery that would stabilize my cervical spine by fusing the C1-C2 vertebrae.

The surgery was a total game-changer: I could walk without fear of passing out, and I was free of the constant fatigue and brain fog. Equally transformative was the nursing care I'd received.

Never before had healthcare workers treated me with such kindness and compassion. They tended to my every need, and no one discounted my pain. They cared not only about how I was recovering but about me as a person.

As soon as I could sit up, I made another life-altering decision: I enrolled in a highly rated nursing program.

I entered nursing school confident that the staff would show sensitivity to people of all abilities. Boy, was I in for a surprise.

When I approached a professor about making up an exam I'd missed due to illness, she replied, "It wouldn't be fair to the other students. If you don't take my exam within the next two hours, you will fail my class."

During our clinical rotations, the prevailing policy was "No drinking or sitting down while you're on the hospital floor." Staying hydrated and sitting for short periods would have enabled me to function at my best without compromising patient care; but no exceptions were permitted.

"You can't keep using your accommodations as an excuse for everything!" the assistant dean admonished me.

During my first semester, I learned that I was required to arrive an hour earlier than my peers to take an exam. The exam room's location (near crowded, busy classrooms) and the stress of having to arrive earlier actually did me more harm than good.

When I conveyed this to the administration, the reply was, "Use your accommodation or lose it."

The school's disabilities office states that accommodations "are determined on a case-by-case basis, taking into consideration each student's disability-related needs." What's not acknowledged is that my disability-related needs are not static; they change from day to day, depending on my store of spoons, and other variables. The message I've received is: *If I can't see your disability, I don't believe you. And if you have a varying (dynamic), invisible disability, I not only don't believe you, but I think you're out to take advantage of the system.*

This has left me feeling disappointed and discouraged.

On the plus side, I believe that my life experiences and differences have given me a unique perspective that will help me to become an excellent nurse. I can put myself in patients' shoes, because I have been a patient. I know how excruciating and draining it can be to advocate for your needs. I know the helpless feeling of putting all of your trust in someone else's hands as you lie in a hospital bed. I truly empathize with the pain some patients endure every day.

I hope that one day our fixed, rigid view of disabilities will become more flexible. Without that, I fear, differently abled persons will be excluded from the health professions. Like me, every nurse has had a unique experience; embracing this diversity can only strengthen the field.

I look forward to the day when we can bridge the visible-invisible divide.