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Coming to Terms: A Metagnosis

By Jeanne McArdle

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The Baltimore hotel looms over us in a deepening dusk. Our car crawls to a stop at the entrance. Just a few feet away, in the busy street, horns blare and brakes slam. Dampness mixes with oily exhaust, and hangs, unmoving, illuminated by our headlights and beacons from the porte-cochère.

A blast of humidity hits me as I open the car door. The air is difficult to breathe. I grunt and hiss, struggling to gather my belongings as blue-suited porters rolling golden carts descend upon us. I am startled as I shrug the final bag onto my shoulder by a woman on a mobility scooter. As she glides in front of our car I notice the zebra-striped basket hanging from her handlebars.

A fear I can't quite articulate ignites, then fades as I focus on unfolding myself from the front seat. Stiff and sore, I relocate joints that have shifted during the trip from Syracuse. Toe circles fix my ankles. I push each kneecap into place. But hips and lower back stubbornly fail to obey every maneuver I try. These joints are close enough to their proper place that I can walk, but subluxated enough to make walking difficult. I waddle to the cart, drop my belongings with a thud, and hobble toward the front desk while my husband Ed and our teenage son Danny help the porters.

The hotel doors open onto another world, cool and dry, clean and fragrant. Clear bells announce elevators and decades-old pop music smooths out the sounds of people talking and walking. Another woman on a scooter, this one with boyish hair and pale skin, a black and white scarf around her neck, smiles as she crosses my path. A tall woman wearing black wrist and knee braces with white stripes limps down the hall to my right. A small woman, golden hair beginning to gray, rests a soft hand on her power-chair controller, a zebra bracelet on her wrist, as she waits, like me, for the front desk clerk.

The hotel must be having a conference for disabled people, I think, as I massage an exquisitely painful spasm in my right sacroiliac. With a *thunk,* the joint slips, finally, into place as my mind wanders: *zebras— stripes—people with EDS, EDSers wear zebra stripes—an inside joke—doctors "think horses not zebras." It takes so long to be diagnosed— doctors are looking for horses—we're not horses; we're zebras.* I catch my breath. Panic rises: *These people are EDSers, like me.*

Just months before, at the age of 49, I'd been diagnosed with Classical Ehlers-Danlos Syndrome (EDS)—a genetic connective tissue disorder that has been present since I was born, but that had only become unmanageable in my late twenties. Faith that diagnosis would lead to

cure had helped me to persevere through those long years without answers, to push through pain, fatigue and injury, to have patience.

Unfortunately, EDS has no cure and no real treatment. My heart has been reluctant to accept these facts, but seeing these women on scooters and in chairs is a potent reality check. They represent everything I'd like to deny. Silently, I blame them. *They aren't even **trying** to be normal. I'm not like that*; *I don't give in to myself!"*

Slowly, I realize I'd come to this conference with an unacknowledged hope—that my fellow EDSers would show me how to get my "normal" life back. Flooded with disappointment, I try not to gulp; unshed tears burn. I know I'm not being rational. I'm ashamed of my feelings. Underneath creeps terror. I don't know who I am.

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By the time we arrive at our room at the opposite end of the enormous hotel my feet burn and drag. My legs shake. Ed pushes the key card into the slot. I follow him, flipping on the lights and flopping on the bed to rest before tackling the unpacking.

The next morning, the three of us walk down the long hall to the hotel's only elevator. We traverse an interminable distance to the hotel's restaurant for breakfast. Afterwards I embark on another journey—to the bathroom—where heavy doors pull my shoulders out of their sockets and separate the bones in my wrists. Finally, we make our way to the conference area—my toes catching on the carpet, soles burning, hips and knees sliding painfully out of place every few steps.

The ballroom is abuzz with EDSers. I recognize many from our morning trek; we were all, apparently, placed at the far end of the hotel. Since EDS affects women far more severely than men, it is a predominantly female gathering. I am overwhelmed, again, at the sight of wheelchairs, walkers, scooters, and braces—oh so many braces—on ankles, knees and wrists, custom-made silver splints on fingers. Special cushions rest on chairs; footrests tuck under tables. I see a few nasogastric tubes and one or two surgical masks.

The room is vast, with about fifty round tables that seat 10 to 12 people each. We pick one in the center, so I won't have to turn my head to the left, which compresses nerves and causes my left arm to go numb. I look around me as we take our seats. Like many here, I've brought a wheeled backpack for my laptop and support pillows. We EDSers look "normal" except for our equipment and a certain pallor and softness, signs of our aversion to the sun's heat and our difficulty building muscle.

A woman in her 40s sits down next to us. This is her fifth conference, she tells us, with a smile.

"I've never walked so much in a hotel," I say. "Why did they give us rooms so far away?" I am whining, I know, but I can't stop. I feel perilously close to tears, again.

"Why didn't you bring your scooter or your wheelchair?" she asks.

My eyes fly open. I sputter. "Oh, I don't need a WHEELCHAIR!"

As I sit back, unease settles around me. My response had erupted from deep inside, instinctive, immediate, but, suddenly, it feels wrong. Who I am trying to convince? The lights dim and a speaker walks to the podium. Dr. A is an internist who has treated patients with Ehlers-Danlos Syndrome for years. His patients' complaints of mind-numbing fatigue—despite looking healthy and alert—led him to test the two branches of their autonomic nervous systems: the sympathetic (fight or flight) and the parasympathetic (rest and digest.)

Dr. A steps out from behind the podium and looks around the room.

"I know you guys look bright eyed and bushy tailed when you go to see your doctors, right?"

Patients nod.

"But when you get home, you collapse—and if someone told you there was a million dollars in your mailbox, you wouldn't be able to get up off the couch to get it."

Laughter fills the room. I feel recognized but uncomfortably exposed. Profound exhaustion after activity is a shameful secret, something I hide from those who wouldn't understand. Here, others share this experience.

Dr. A. returns to the podium.

"See this slide? That's what happens to normal people when they go from sitting to standing—an orderly, predictable, moderate increase in sympathetic activation, followed by a leveling off. Basically, they hit the gas lightly to stand up and from then on it is smooth sailing.

"And this is what happens to you guys."

I look at the next slide, lines representing sympathetic and parasympathetic activation surging and falling, seemingly fighting for dominance. It looks like chaos—and the chaos of a rapid and irregular heartbeat is what I feel whenever I stand, a feeling so familiar it has become background noise.

"You're always driving with one foot on the gas and the other on the brake."

Dr. A imitates a car lurching down the street.

"The lower your adrenaline reserves are, the more extreme your swings from the sympathetic to parasympathetic branch will be. It is no wonder you are exhausted.

"That's just the autonomic nervous system. EDS has significant effects on every bodily system. We have some treatments, but no cure. You're dealing with a lot. But, hey, you look great, right?"

His observation draws rueful laughter. "Looking great" is a reason our condition is so often missed.

When the lights come up at the end of the talk, we pack our backpacks, restart power chairs, find canes and crutches and head out for lunch. As we approach the door, a young woman next to me tells me she's a first-time attendee.

"My mother didn't want me to come to this conference," she says. "Mom told me, 'I don't want you to identify with your illness.' How the heck am I not supposed to identify with a condition that affects literally everything?"

I nod, beginning to appreciate that I have, for decades, been wrestling with a multitude of burdens. My doctors focused on conditions they could treat and cure. Symptoms that didn't fit into recognized patterns of disease often remained unacknowledged—but that didn't make them go away; it just encouraged me to suffer in silence. Now, being among people whose bodies are similar to mine causes a subtle shift, a dawning of self-acceptance; I don't have to explain myself here.

After lunch, Ed and Danny return to the room. I am too tired to walk that far. So, I sit on a couch outside the conference rooms. People stop by and say hello. A woman on a scooter, whose nametag reads 'Kerry,' powers over to me.

Kerry tells me a group is going to dinner nearby and wonders if I'd like to go. I am struck by her kindness.

"I'd love to go," I say, "but I can't walk that far."

"That's why I got this scooter," Kerry says. "It gives me so much freedom!"

"But you *can* walk, right?" I ask.

Kerry nods.

"But the scooter is great when I go to events, like this, that drain my energy," she says.

Kerry leans closer, takes a deep breath, and says, "Disability is a wide spectrum."

After she leaves, my rheumatologist's words come back to me. "You can't do what other people can do. You have a hereditary disorder of connective tissue. You will get hurt!" he said to me, repeatedly, after my diagnosis. Similarly, the geneticist who, a year later, narrowed that diagnosis to Classical EDS had said, "You'll hurt less if you do less." Neither had suggested *how* to change my life to do less. They had never used the word "disability."

Metagnosis is a term created by scholar Danielle Spencer to describe the phenomenon of a delayed diagnosis of a longstanding condition and how that diagnosis affects identity. My

EDS metagnosis followed five decades of assertions by authority figures—doctors, teachers, family members—that I was perfectly normal, that everyone else dealt with similar symptoms without complaint. For five decades, I was told to "just" try harder—so I did—while hoping for a real diagnosis—and a cure.

I defined myself by my ability to push through pain and fatigue, to persevere until I had nothing left to give. Yet I increasingly failed to meet normal expectations. A sort of Stockholm Syndrome emerged, and I judged harshly those who didn't struggle as fiercely as I did to appear to be normal.

At the conference, I met people who successfully accommodated their EDS. They showed me another path, giving me permission to be kinder to myself, to realize my failures were rooted in my connective tissue, not my character. Grounded, finally, in reality, at nearly fifty years old, I began the process of learning who I am.

I have come to accept that EDS causes physical fragility and limits my energy in nonnegotiable ways. I learned to pace myself to avoid injury or exhaustion and began to rebuild my life on a more stable foundation, using my gifts while respecting my limits. I gained knowledge, wisdom and support from my fellow EDSers, and over the years have paid that forward to others.

It took longer to recognize that I am disabled and have been dealing with impairments for much of my life. This recognition empowered me to think creatively about how and when to use tools—like a power chair and a service dog—to mitigate the effects of my disability. By identifying as disabled, I granted myself the respect and pride I always accorded my more obviously disabled friends. The EDS metagnosis enabled me to drop the pretense that I could "do what other people can do." It was the start of my real life.

Jeanne McArdle is pursuing a CPA in Narrative Medicine at Columbia University and writes frequently about disability and chronic illness. McArdle administers a support group for people with genetic connective tissue disorders and hopes to use the practice of Narrative Medicine to help chronically ill people to find and tell their stories effectively, especially in a medical context. McArdle's work has appeared in Wordgathering, The Comstock Review and in the New York Times' Tiny Love Stories column and anthology of the same name. McArdle holds degrees from Cornell University and Siena College and worked as a technical writer at General Electric. McArdle lives in Central New York with her husband and service dogs.