

There is something so deeply isolating about being chronically ill with a rare disease. It isn't even the actual physical isolation that is the hardest, although the emotional weight that carries should not be underestimated. There is an even more desolate hole that exists, even when you are fully surrounded by others. Shrouded in grief and shattered expectations, lies the stark contrast between the lives of others and your own experience.

I remember the day I realized the full weight of that pain. I was sitting in a room filled with people I enjoyed and cared about, listening to their stories and life events and was suddenly hit like a ton of bricks with the pain of my own reality. I felt like an alien. Like I had just landed on a foreign planet and while the inhabitants were kind, they couldn't see me. I was a ghost. I sat at the party remembering how I had felt in years prior attending such functions and instead felt gut punched. Everything hit me at once- the freedom these people have, the loss of my autonomy, the rigid lifestyle and all-consuming symptoms, the mentality and sheer difference in thought processes and understanding of life. The grief. I started to panic as I fell out of my body. Dissociating and painfully feeling so many emotions simultaneously that had I tied up very neatly in a box and rarely let out. What the fuck was wrong with these people? Did they not understand the sheer magnitude of torment; the agony. The way life had been pulverizing our spirits for years? I felt like a wounded soldier having just arrived back home from a violent and separate existence. Everyone "back home" was having bake sales and just living their lives as usual. How could they be so frivolous? Over the span of 1 year I had lost everything from hobbies to nutrition, medications and treatments, comfort and hydration. I lost my sense of safety and self. I didn't recognize myself in the mirror- flesh hanging off my bones. My body was devolving and everything I had done prior to manage, control or diminish my symptoms was gone. The hardest part was not understanding why. What had changed? How? When I got home I sobbed under the weight of my life. I was overcome with grief and realized how much I had been carrying and how different things are now.

Because my health declined during the pandemic, temporarily it was easier to feel like less of an outsider. Video chats, staying in touch via social media, text and lack of in person attendance made it easier for me to participate at first. However, my symptoms started to be triggered by phone calls and video chats, leading to lost friendships and disconnected relationships. I was forced to choose to not utilize these means of connection in an attempt to keep myself in a more stable state. Then the world began reverting back to pre-pandemic behavior. As things started to shift back to "normalcy", many of us struggled to keep up. Meetings and connections that could easily be done virtually or via the phone, now required in person. Masks were no longer required. The overall consideration for others and at-risk individuals slowly faded as if they hadn't existed prior to Covid and ceased to exist after the "end" of the pandemic. However, despite all of this, my sense of estrangement was minimal. I think, to some extent, living in "a box" so to speak allowed me to exist within a reality of my own making. When a very difficult lifestyle is habitual and the burden becomes routine, it is less noticeable. Less noticeable that is until someone points out the elephant in the room that had become the family's pet.

It was when I started re-emerging into the community for the first time after the height of the pandemic that I became overwhelmingly aware of the polarity of me versus others. Mundane

and surface level conversation were challenging. I was stuck between wanting to talk about my life, not wanting to overshare inappropriately, feeling excluded, and quite frankly disinterested in superficial conversation.

I would go to my son's baseball games and talk to other parents and feel relatively comfortable because they didn't know me. I could just be K's mom. I wasn't sick to them and they didn't have any idea as to what an outsider I was. But the minute that I started making connections things got more complicated.

People feel entitled to ask a lot of questions. Generally, this is considered a social norm and no big deal. But, when you can't answer basic "get to know you questions" like other people can, it quickly shifts the conversation to a heavier place that not everyone wants to enter. "What do you do for work?" This question effortlessly falls off the lips of most adults. However, when your answer is, "I do not work. I am on social security disability" things can get tricky. Either the person will smile and end the conversation or they'll want to know more about how your body is failing you. I don't mind talking about being disabled or my illness for that matter. In fact, I am a strong advocate for normalizing body differences. Yet, I am acutely aware of how staggering and mind boggling the scale of my complex health issues can be. Sometimes when I don't have the energy, I'll respond that I am a stay at home mom, or I homeschool my son, because those are true as well. When asked what my disability is, my brain rapidly sorts through information looking for the best answer.

I don't just have one complex illness, I have many. In fact, I have over 30 diagnoses and more than 10 of them are considered rare diseases. The likelihood that anyone has heard of what I am dealing with is low. How do you tell someone about your disability, when it involves a biology lesson? That is so much information to give a fleeting conversation. When someone has Diabetes or Cancer, generally, there is a level of understanding that goes without saying. On the other hand, when you tell someone that you have Ehlers Danlos Syndrome (a connective tissue disorder) or autonomic nervous system dysfunction, they usually stare at you with a look of "huh?". I don't blame them. Honestly until I was properly diagnosed, I didn't know much about anatomy and bodily functions. Before I was diagnosed with Median Arcuate Ligament Syndrome, MALS, which was preceded by a 3 year battle with unintentional weight loss and starvation, I had no idea what a Celiac Artery was or that I even had one. I made it through college without ever taking Anatomy and Physiology, although now I could probably lead a class. How do I explain what I am going through superficially, when the mountain of health issues are anything but basic. After a lot of practice, I have narrowed my answer down to "I have a connective tissue disorder and chronic malnutrition". Even that can be tricky though. When well meaning humans learn that you have been eating the same 10 foods everyday for over 2 years, they want to help. Then comes the rapid fire questions- have you tried (insert food item here)? The unsolicited advice and attempts to find a solution for me become the focus. While the desire to help doesn't bother me, grief sets in. The last thing I want to do is discuss everything I have tried and failed. Please don't try to feed me. I can manage myself and I don't need the weight of your discomfort or anxiety. I have heavy trauma over the loss of food and the

experiences I have been through. It is unlikely there is anything I haven't tried or considered to manage my illnesses that you can come up with in 5 minutes.

With time and practice, the more I interacted with people, the more I was able to compartmentalize. Separating the parts of myself that are starkly different and finding connection through similarities. I ebb and flow in and out of acceptance for the way my health and life is with varying degrees of hope for a different future. I am able to enjoy myself and have fun. To experience more happiness. But, no matter how wonderful the experience, there is always the cloud of grief hanging overhead. It shows up in so many ways. Reminding me how things used to be, how I wish they were, and everything in between. An ever present shadow; inescapable even on the brightest days.

I find calm in nature. Walking through the forest, feeling the warmth of the sun on my face and smelling the trees, I am still reminded. I feel deep peace in my core and grounded in the earth, only to have it swiftly interrupted by grief. Grief reminds me this used to be a familiar feeling for me. I used to live in the space of grounded, calm, wellness, connectivity and joy. "Remember that feeling? Yeah, that's rare now, isn't it?". Overcome with the loss of my prior self, I feel sadness creep in.

When I choose to live life, I am often distracted by overwhelming physical pain, breathlessness, dizziness, and more. I find it challenging to focus on conversations and to relax my body due to all the internal noise. I grieve the way that my symptoms interrupt my ability to be present and free. To be able to choose what I want to do solely by my values and interest and not by my ability to cope with the intensity of the symptoms ...or the flare to follow. There is rarely a time that I can freely do what I want to do without significant repercussions. More often than not, I sit on the sidelines, watching and wishing I could participate but choosing less injury. Less pain. Less flaring. And I hate it. The real shitty part is that I have zero control and my body may choose to flare up regardless.

The more a gathering or event is filled with human connection and genuine joy, the harder I grieve when it ends. I am often struck by the significance of community and how infrequent these times of human connection are compared to how often they once were. The lack of intimacy in my life, palpable. I remember a time when I held parties and traveled. I could lead classes, host gatherings and attend mom groups. I had more friends. Subsequently, I feel the weight of isolation two fold.

Sometimes I feel so much anger. I did everything right. I exercised and ate clean (to a fault). I went to acupuncture and physical therapy, got massages, took vitamins and managed my stress. I regularly attended counseling and practiced mindfulness. A doctor once remarked that I seemed "like someone who really wants to be well". The implication being that I have been trying diligently for a very long time to achieve wellness. But, when your cells can't produce energy and connective tissue is faulty, the usual recommendations don't work. You can't command yourself well. This is why so many of us with chronic and complex health issues feel so much shame and guilt. For some reason, albeit illogical, it is difficult to remove the

messaging that we could get better if we do everything exactly right. The irrational belief that if we could just get it right, we could stop the flare and symptoms and have more control. This anger is bargaining in disguise. It is a desperate attempt to conceal the pain and accept the loss and reject reality; to refuse the limits of control.

I am a great mom and yet, I am not the mom I want to be. I have to ration my energy and choose what I can and cannot do in order to get through the day, week, month. I have to conserve ahead of time if I know I will be needed for something later in the week, or save all my reserve for various invasive medical tests. I am not always as regulated as I want to be and struggle with overstimulation, especially when my pain is loud. I feel angry that I can't be an assistant coach for my son's sports team or volunteer at his co-op. I carry so much sadness over the way my illnesses interfere with my ability to share and experience the world with my son. Things that most people take for granted like baking cookies and eating them together, going on "mommy and me" adventures without help, being able to get up and cook breakfast in the morning. Symptoms and challenges don't take a day off for meaningful moments like birthdays and Christmas morning and Trick-or-Treating on Halloween. Having to constantly ask my son to be careful with my body or telling him my brain needs a break. Unintentionally exposing him to medical trauma and all the unraveled and messy moments that come with being triggered. He doesn't remember when I was stronger and could do more, he was too young. There is a lot of weight in feeling like that is a side of me he won't know- that I won't be able to improve and embody the person my brain and mind desperately want to be.

I miss being the friend people turn to for wisdom or comfort. My friendship being overshadowed by my illness and the fear of not wanting to "burden me" or add to my plate. Not having the weight of my experience as a means of comparison that stands in the way of others sharing their hardships with me. Unintentionally causing people to feel like their pain is miniscule in comparison and sharing it with me would come across as whining. Pain is pain. I want to hear about your life. I want to know how I can support you. I am not a sponge that wants to take in everyone's energy. I want to forget about my own baggage and carry yours. I miss feeling needed.

With rare disease many of the close friends we retain are sick, often from the same afflictions. Unicorns and zebras forming a herd. Connections made through social media or online support groups. We watch each other suffer and be gas-lit by the medical community. We share intimate details and torment in the late hours of the night when others sleep. We guide each other through hospital stays and complex tests. Listening non-judgmentally to each other's agony, the weight ranging from passive suicidal ideation to debilitating grief. Some of our friends die young; sometimes preventably. We are faced by trauma threefold: the reality of their disease and first-hand understanding of their experience, watching their condition be mismanaged often resulting in a deepening fear of the medical system for ourselves, and our own mortality. We grieve as a community. The faith we once held in systems we were led to believe would catch us, abandoned. Oaths and ethics intruded upon by policies and bottom lines. We feel the weight of the system buckling in a way that others have the privilege to ignore. The loss of a time when I felt assured that my doctors knew more than me. That radiologists were the most capable at

reading imaging and specialists were just that, and understood my body more than I do. We grieve the loss of trust.

I had so many aspirations. Dreams, goals, ambitions. I had plans. I adapted my career so many times but ultimately I couldn't continue to work. I received my bachelor's degree at a prestigious, private university. I held internships and worked for AmeriCorps while completing rigorous coursework. For a few years after college, I worked in social services and local government helping advocate for people with disabilities and the elderly. When modified schedules and accommodations still weren't enough, I turned my focus to more flexible workstyles. I was accepted into graduate school but ultimately had to withdraw. I started numerous small side businesses but little by little, I lost it all. I cannot reliably attend appointments or meetings. I cannot predict my ability to function ahead of time. Doctors appointments and lab visits take up large chunks of every week. I dreamt of being a midwife in underserved communities. I planned to continue to help develop laws and legislature and advocate for the rights of marginalized communities. I used to attend rallies and stand up against injustice. I grieve my ability to actively use my life to accomplish whatever I set my mind to. I am a very capable person, trapped in a body that has incredible limitations. Limitations that I cannot always push through. My ability to learn, retain and utilize new information has been affected. All of the skills and attributes I gathered, tirelessly working toward a career I will never have, futile. If I had known that I wouldn't be well enough to work by 31, I might have spent my 20's traveling and exploring. Living a life of experience versus goal-oriented. I feel grief over the wasted time and the loss of expectations. I feel anguish over the inability to buy a house, as many my age do, because they are able to work and save.

My loss of identity goes beyond career goals and aspirations. Years of weight fluctuations and malnutrition, surgeries, and hormonal challenges have resculpted my body leaving hanging skin, scars, visible bones and an unfamiliar reflection. I am allergic to most fabrics, body products, hair products and make up. I can no longer dye my hair, wear earrings or most jewelry. Once free to adorn myself in flowing dresses and layers of gemstones, I embellished my appearance frequently. I loved to express myself through style and embrace my femininity. To be free to choose sexy underwear and wedge heels, garter belts and cute bras, thongs and lingerie. To express my sexuality and wander braless and barefoot, embracing the earth and feminine divine. It took me over 30 years to learn to love my body and express myself freely. To stop dieting and restricting food and allow myself to eat intuitively. To build safety within myself, recognize my potential and have confidence. Then, almost like a cruel joke, illness came in like a wrecking ball infringing upon the self transformation I had finally achieved. Powerless, I disappeared little by little until one day, looking at a picture of myself my husband had taken during a family outing, I was startled by what I saw. When did this happen and is that how I truly looked? A ball formed in my stomach as I tried to process the ghostly doppelganger.

I grieve my loss of community. Gathering with friends and sharing a meal. Letting our children play and cook and experience life together. Having a village. Chosen aunts and uncles. Game nights and spontaneity. Running barefoot in the grass, snuggling with animals, dancing and singing. Burning sage and using nature to celebrate life without risk of breathing distress.

Feeling pleasure without pain. Enjoying sex and losing myself in instinct. Hugging and sharing affection with friends without fear of assault on my struggling immune system. Using my energy to achieve my goals and dive into what fills my life with purpose. Not thinking about my health...

The grief of chronic complex illness is cumulative. There is rarely time to process the prior trauma, experience or loss before more layers are piled on. Not to mention, all of life's usual ups and downs, losses and tribulations. Everytime it feels like I have reached a place of acceptance, something drags me right back into the cycle. Grieving, accepting, re-grieving, adjusting and accepting, mourning, grieving again- a continuous cycle that is unresolving. Unapologetically breaching upon my desire to have closure. How can you process a trauma that never ends? How can you find solace when the rules are always changing? I am constantly and desperately seeking stability; some level of predictability to work through this chapter and move to the next. Clinging to the eye of the storm, I live in hypervigilance. Never knowing how long I can rest in the calm before the storm closes back in.

I try to find peace within my body, but it is constantly screaming. There is so much noise to tune out in order to focus inward. Everything feels uncertain. A vast wilderness of unexplored terrain where anything is possible. Contrastly, it is within this space that occasionally I can find an ember of hope. A smoldering cinder of reignited faith; spirit's inner fire. There is an aspect of me watchfully tending to this flame and keeping it alive, protecting my remaining optimism. An involuntary resilience conceived by survival. The uncertainty serves as a gentle reminder that nothing is stagnant and everything is constantly evolving. The only certainty that we have is that the future is in fact uncertain and therefore will have to change, be it good or bad.

I have borne witness to hell on earth. My body and symptoms have been mercilessly striking, with no reprieve or means to lessen their blows for years. The debilitating but manageable symptoms I once had have shifted into life altering, uncontrolled chaos. Sadly, grief itself contributes to the malady. Triggering a fight-or-flight response and affecting the immune system; trapping me in yet another vicious cycle. As I continue to work through mystery ailments, I resolve to learn the names of my demons. At my own pace, I strive to release resistance and work towards acceptance. It is not all or nothing, black and white, or absolute. There is so much grey. I may be angry at, or even resentful of my body, but goddamn she is a survivor.

Jen J.