ESSAY

The Effect of Health on Self-Identity:

An Autoethnography

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A Winter Poem
by James A. Pearson

Now the leaves have fallen.
The trees have pulled their aliveness
back from their branches,
down into their fortress trunks
and the dark, subterranean closeness
of their roots.

Every year they let go of
exactly what everyone says
is most beautiful about them
to save their own lives.

The time will come
when you, too, have to drop
all the ways you've made yourself worth loving
and finally learn how
to sit quietly
right in the center
of your own small life.

Only there can you cry the tears
your life depends on.
Only there can you find
the tiny seed
that holds the whole mystery of you
and cradle it
In the warmth of your body
until the spring.

https://jamesapearson.com/a-winter-poem/

The Leaves

I arrived in the world clutching many winning lottery tickets in my hands: white, middle-class, mentally healthy, physically healthy, cis-gendered, heterosexual, intellectually capable, and the list goes on. For much of my life, I didn't understand how these privileges eased the way for me to create (and recreate when necessary) a style of life and sense of self that fit neatly into societal norms.

If I would have been asked ten years ago to describe who I am, I'd probably have begun by identifying the roles I play in my life: I'm a partner, daughter, sister, auntie, teacher, friend, etc. Furthermore, my understanding of myself was focused on being "good" at these various roles, being a "good" partner, a "good" daughter, etc. I'd have said that I'm a loving partner, a worthy friend, an attentive daughter, a caring auntie because I energetically enact those roles; I *do* them. I bring food, I remember birthdays, I provide childcare, I help out, I nurture others, I show compassion, and I thereby *earn* my place in peoples' lives. I am capable, and happy to meet the needs of others and myself. I'm independent and "low maintenance."

I suppose I'd also have talked about my personality, as well as my values and the things I love. I would have told you that I enjoy experimenting with new recipes, hosting parties and gatherings, and playing piano. I might have acknowledged that I'm future-oriented, ambitious, and a go-getter, always working toward the next great thing ahead. I love reading, learning, and achieving. I love my career. I thrive in situations that require multitasking and spur-of-the-moment responses, because I'm a fixer and a problem-solver. I'm an enthusiastic extrovert who dreams of living an ever-enlarging life, always broadening my interactions with new and different people, broadening my travel and career opportunities, and broadening my experiences and understandings. My life at its best is about constant expansion outward.

I would not have included "healthy" as a descriptor of myself, as my robust health was something I took for granted and assumed would always be there. Had I stopped to consider ill-health as a potential reality, I may have thought I would simply follow all prescribed treatments and carry on as usual. I would still be "me," with a few tweaks.

Oh my. I can't help but shake my head with amused affection at my naive assumptions.

Several years ago, Good Health (specifically High Energy) was removed from my list of privileges, and I was absolutely stunned and horrified at how a radical change of just this *one* variable affected every single aspect of my life: my career, finances, friendships, family relationships, hobbies, basic hygiene, how I think, how I look, how others react to me, how I do my shopping, and on and on. I truly had no idea up until this point how much my sense of who I was in the world relied upon, and was intrinsically linked with, my health and capacity for energy.

Pulling the Aliveness from the Branches

I was 44 years old when I was diagnosed with a debilitating illness that I hadn't realized had already begun.

During the first couple of years of getting an initial diagnosis, then being sent to various specialists to rule out various conditions, I didn't quite understand or fully appreciate the looks of compassion on the faces of my doctors and specialists when they each said in their own way, "I'm so sorry. This is what you have. It's real, yet invisible, and there are currently no treatments or cures. There's nothing we can do." They knew what I didn't at the time, that this isn't simply a "chronic" illness, it's a "relentless" illness - harsh, unabating, unyielding.

Although my condition is multi-systemic, the hallmark symptom is called Post-Exertional Malaise (PEM), or Post-Exertional Neuroimmune Exhaustion (PENE). Essentially, several biological systems in my body produce abnormal responses to any and all exertion, physical, mental, or emotional. I experience a cascade of symptoms approximately 24-48 hours after I exceed my extremely low anaerobic threshold of 80 heart beats per minute. To manage my symptoms, I'm required to keep my heart rate within 15-20 beats of my resting heart rate of 60 beats per minute. I use a heart rate monitor to alert me when I've gone past my heart rate limit, in addition to taking "early warning" symptoms (such as nausea, light-headedness, tinnitus, fever, chills) into account in an effort to reduce the onset of more significant symptoms (neuralgia, GI issues, not being able to walk or use my arms for a few hours at a time) that happen when I exceed my boundaries.

Unfortunately, a secondary illness connected to the primary diagnosis is that my heart rate rises by 30 beats per minute or more when I'm upright, more when I'm standing, and a little less when I'm sitting. This means that any activity requiring me to be vertical for more than 2 minutes at a time (such as sitting, walking, brushing my teeth, bathing/showering, getting dressed, or preparing a meal) can cause me to exceed my maximum heart rate, which causes my body to go into a "crash," triggering a host of symptoms and requiring extra rest for me to recover. If I consistently push beyond my threshold, my condition worsens, and my baseline level of functionality decreases that much more.

As I mentioned, my illness is multi-systemic, with the autonomic nervous system being one of the key players in my body's dysfunction. Studies of people with this condition show increased brain inflammation and decreased cognitive capability when a patient has pushed beyond their boundaries, and this shows up for me as difficulty concentrating, trouble with word-retrieval and short-term memory, and problems consolidating or processing information. A text message or email that might have taken me 2-5 minutes to write and send when I was healthy, now can take anywhere from 45 minutes to a couple of hours to create (and I am not able to use those minutes and hours consecutively; they need to be broken up with complete rest, uninterrupted by any stimulation such as music or bright lighting). My ability to tackle complicated ideas to stretch my thinking and understanding has been drastically diminished, and can only happen in small doses if I'm not expending emotional or physical exertion in the days or weeks surrounding my thinking.

Emotional exertion that sets me back tends to be any emotion that is strongly expressed: joy, anger, excitement, amusement, frustration all "cost" me energy that I can't replace, so it's in my body's best interest to keep my emotional reactions somewhat moderate and subdued.

Currently, my life looks like this on a good week: I am able to bathe three times, my partner washes my hair for me once, I put on makeup and "perform health" for approximately two hours one day a week when I leave my apartment and visit my mom at her care home, I can help prepare approximately four meals (with my partner doing most of the work), and I recline on my couch or in my bed the rest of the time. If I stick to this kind of a routine, I am able to mostly stay within my heart rate limits and prevent crashes and a subsequent health decline.

This illness will not accommodate who I was; it refuses to be tamed, managed, or folded inside of the life I used to live. It's demanding and controlling, and insists that I either mold myself to its contours, or get progressively sicker.

Letting Go

Living within these parameters is challenging at best and devastating at worst. My life has become tiny, and it feels very much as though my entire person is on a dimmer switch set to the lowest setting. The ghost of who I used to be haunts me now and again, and I find myself yearning and grieving what used to be.

I miss my career. I miss a future that feels as though it's unfurling like a ribbon in front of me. I miss a sense of being upwardly mobile. I miss feeling as though there's potential for big, new dreams to come true. I miss my brain and the ability to feel confident in my communication and thinking. I miss being able to "spend" energy on perkiness, on big belly-laughs, on snark and sass, on unbridled enthusiasm, on the thrum and hum of groups of people, on in-depth conversations . . .

Every so often I see glimmers of the self I used to know, and I think, "Oh there you are, sweetheart; I remember you!" I revel in those moments before asking her to shrink down for the sake of my body, and it hurts a little bit when I have to tuck her away again. I miss her.

And there it is, the very heart of this ache. Of all the things I've lost, I think I miss myself the most. I miss me… or at least, the things I perceived made me "me."

Instead of feeling myself solidly placed within various, smaller identities and roles, I have found myself adrift with a barrage of very perplexing questions:

- Who am I without my plans and dreams and schemes?
- Who am I without my career or “achievement?”
- Who am I when life is no longer about expansion, but about contraction and subtraction instead?
- Who am I when I’m no longer able to function physically or cognitively in the way I once did?
- Who am I when I’m mostly removed from social circles because I’m simply unable to participate? Do I still exist if nobody sees me?
- Who am I when it’s just me, lying on my couch, day after day, year after year?
- Am I still loved and valued even if I’m unable to "earn" my place in peoples' lives or hearts, even if I have needs and have become a burden or “high-maintenance?”

I suppose the question that has been most challenging to my sense of self is this: “To what extent can [I] drop/all the ways [I’ve] made [my]self worth loving?”

In more ways than I could have predicted, illness completely removed my ability to earn my place in the world in terms of status, achievement, finances, and relationships. All I could reasonably do was “to sit quietly/right in the center/of [my] own small life” and hold these distressing questions with tenderness and compassion.

In doing so, I learned that the center of my tiny life is still, calm, and unhurried. It’s supple and graciously stretches to create space for any number of uncertainties to exist, meeting every piece of my reality with unconditional, friendly acceptance. Here I’m able to reflect, to wonder, to intentionally drop my inclination to hustle for love and belonging, and to catch myself in the act when I find myself slipping into old patterns.

And I often catch myself in the act because it’s still alive within me, this desire to be “good” in some kind of recognizable way. Immediately upon my diagnosis, I felt the strong, yet unconscious, pull to play the role of a “good” chronically ill person and patient. Somehow, I knew that a new performance was expected of me, and I instinctively knew how to act out my part.

What Everyone Says is Most Beautiful

Culturally, we seem to be more comfortable with illnesses that are either treatable or terminal, not because we desire a terminal outcome, but because we have a societal script and actual examples of what to *do* with it. We know we can help by starting meal trains, doing laundry, running errands, starting GoFundMes, and more. We can afford to throw ourselves into these efforts knowing that one way or another they will be temporary.

There are no narratives or scripts of what to do when someone's life becomes completely unrecognizable by chronic illness. We have no clue how to handle how scary it feels to acknowledge that illness, often beyond personal control, can sometimes leave people horrifically debilitated for the rest of their lives.

I've come to understand that I, along with the rest of society, assume that health and wellness is the default setting, and any long-term health situation that falls outside of that norm leaves all of us unsettled, so in our interactions with a chronically ill person we start to enact the unspoken rules of engagement that somehow seem to have been encoded into each of us, the healthy and ill alike.

Right from the get-go, I've known that I'm expected to behave in specific ways to preserve the comfort of others. I know exactly how I'm supposed to dress up my situation so that others may still be able to see "what is most beautiful about [me]." It's frightening and isolating to experience first-hand both the rewards and punishments that exist in this confusing, undefined space of chronic illness.

Every time someone tells me that "You're handling this so well," or "You're managing this so graciously," I bask in the sunshine of praise beamed on me for honoring the silent agreement to hide or minimize any pain and fear and despair.

More rewards are doled out if I adopt a lexicon of war to help me fill this role. "You're a chronic illness warrior," "keep up the good fight," and "you're bigger than this battle" are some perky yet violent reminders I receive to ensure that I will not give up, give in, or succumb to a reality where illness reigns supreme. I'm supposed to fight, fight, fight and resist my illness, so that we can all avoid the feeling of helplessness that might arise if I choose the path of acceptance. It's imperative that I prove that I'm trying to counter my condition, even if it's medically untreatable, to preserve our beloved illusion that health is within our control.

And don't let me forget the relentless admonitions to have hope. "Hope for the best!" "There is more ahead of you!" "Don't give up hope!" are still more attempts to avoid what *is*, and to focus instead on expectations of what *could be*. In this vein, I'm also expected to refuse the word "disabled" to describe myself, because "that's not your identity!" "Don't make illness part of who you are; it's simply something you're experiencing!" To me it feels like an invitation to escape the difficulty of the present by dreaming about a different future; it's simply another way for me to resist reality.

If I downplay my illness and refrain from talking about it too much, if I prove how hard I'm trying to get better, if I only verbalize hope for a healthy future and defiance against illness, I may receive some fleeting empathy or compassion for living with my chronic illness admirably.

The social cost of not meeting these unspoken expectations is high, the punishment subtle and devastating. Silence. Withdrawal. Leaning away. Disbelief. Judgement. "Have you tried…?" (yoga, supplements, trauma-based therapy, keto, osteopathy, acupuncture, etc.).

Veiled accusations about being "dramatic," as though being a middle-aged woman in pain or discomfort who requires support is ridiculous over-reach.

Thus, it is oh so very tempting to follow the unspoken script and slip into the role laid out for me. After all, if I'm going to live with a chronic illness, then part of me would love to claim a new identity as an inspirational and "good" sick person who graciously abides by all the rules, regardless of the cost to my spirit.

Yet something within me resists. The price of this performance is just too high, and I find myself unable to sacrifice my overall well-being on the altar of societal expectations. I cannot be a chronic illness "warrior" because I'm simply not willing to live in a state of war with my body; instead, I choose to be her strongest supporter and most tender companion. I allow myself to try on the idea of being "disabled", as it gives me permission to accommodate my limitations instead of feeling embarrassed that I have them. Even as I continue to recognize within myself a natural bent toward buoyancy and optimism, I'm content to abandon hope and immerse my heart in trust; I trust my ability to meet whatever arises instead of hoping that things will be different. I choose acceptance over denial.

My inner knowing has asked me to find a way to live wholeheartedly inside my reality without substituting it for my identity. And so my curiosity bubbles up as I consider what it could look like for me to live deeply inside the core of my life, while lightly and intentionally dipping in and out of various roles in my life. How might I exchange the comfort of many smaller, socially acceptable selves for a larger sense of Self? Do I know who this essence or larger Self might be?

So I'm left to grapple with the weightiest question of all: "Who am I?"

The Tiny Seed, The Whole Mystery

I love language and metaphors, but when it comes to my experience with illness and trying to wrap words around my sense of self, I haven't been able to settle on any imagery that fits.

I often can't quite tell if I'm picking through the debris left after the bomb of illness exploded in my life, searching for any pieces of my previous self that can be salvaged, or if I'm in the process of raising a new self from the ashes of what came before.

Sometimes I have no idea if my Self has been completely diluted, like watered-down drinks at an all-inclusive resort, where you get a whiff of the potency, but certainly not the full effect. Maybe I'm just… beige. A neutral smear of something that isn't really any identifiable shape or form, where you have to get up close to see the contrast and texture. Other times I wonder if just the opposite is true. Maybe life has extracted every single "extra" from who I am, distilling me down to my very essence… my essential Self. No hiding spots, no extraneous personality distractions… just the few true colors and vein of gold that runs through my soul.

I see how much “less” of myself I am, while also recognizing that I’m “more” than I’ve ever been. Oddly enough, there’s something wondrous about dwelling in this kind of liminal space, where nothing seems concrete or certain or definable, and it’s taken time to learn how to live deeply into the tiny nooks and crannies that exist here.

Coming from an evangelical background, the concept of “mystery” remained largely unexplored for much of my life, and I remember always being somewhat perplexed by Yahweh’s statement to Moses in Exodus 3:14, “I Am Who I Am.” It seemed like an unfinished sentence to me, and every sermon or writing piece that I encountered on the topic attempted to complete that sentence with additional descriptors and explanations.

In recent years, however, I find myself drawn to the declaration itself: “I Am Who I Am.” I love the ambiguity of it, its vastness, and its sense of transcendence. So many ideas and realities can bloom here, without being confined by labels and definitions. It feels free and fluid, serene and grounded all at the same time, the rhythmic ocean waves and the still ocean floor. It’s a bold pronouncement that brooks no argument and requires no further explanation, yet generously holds space for countless discoveries and truths.

Perhaps the “tiny seed/that holds the whole mystery of [me]” is simply this:

I am who I am.

I’ve come to see that, as a human, I am endlessly knowable, and I have been feeling the rich spaciousness, the length and breadth and depth of my humanity, more than I ever have. I see my courage, my vulnerability, my resilience, my need for others, my compassion, my frailty, my strength. I recognize these qualities as they ebb and flow inside of my life, and they leave me feeling more deeply connected to the rest of humanity, as I witness those around me display these same characteristics within the context of their own lives.

And there’s something so achingly tender about embracing myself as fully human instead of simply a collection of roles and performances and quirks. It feels like a gentle hand rubbing small soothing circles on my sternum, and a sweet voice saying, “I see you. You’re here. You’re not invisible. All of it is true: you’re a diluted solution, you’re an extract, you’re everything in between. You are who you are, just as you are. And it is enough.”

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