

# Dear Left Big Toe

written by Guest Contributor | July 30, 2019



*The apparition of these faces in the crowd;*

*Petals on a wet, black bough.*

*-Ezra Pound, "In a Station of the Metro"*

## **Dear Big Toe on my Left Foot,**

It all started with you.

What I remember about Cheyenne, Wyoming is the wind. I would spend the afternoons in my backyard (which may as well have been the whole world). We had grass and a garden, a swing set and a sandbox. I picture myself like one of the yellowing photos in my mom's album, wearing a denim blue romper and knee-high athletic socks, yellow plastic roller skates strapped across my feet, all skinny legs and curls. On one side of the yard was a white slatted fence, which I would climb to talk with my next-door neighbor, a blonde-haired girl named Lindy. One day, I climbed all the way up to the top of the fence, straddled my leg over the top, and realized that I couldn't climb back. Lindy had to call her dad with his mustache and wife beater tank to come lift me down. He took me inside their house and poured me a tall glass of milk. I drank it, even though I never much liked milk. Meanwhile, you were already whispering to the bones and tissues inside you, "Here I am. Something is wrong."

I don't know whether the pain crept in slowly or whether it came on quick, but I know it started with you, just my one toe on my left foot, and suddenly

my roller skating-unicorn dancing-making up songs-swinging feet touching the sun afternoons in the garden were punctuated by a throbbing in my toddler-sized digit.

I complained to my mom. I learned how to complain.

I complained enough that, eventually, we went to the doctor. I suppose we did, even though I don't remember the doctor. At least I don't remember that particular doctor. Doctors and their white-walled offices, with their paintings of fish or flowers or cowboys roping steers on the walls, *Highlights* magazines in the waiting room, activity cube with its primary colored shapes always in the corner—I remember them. Whoever this doctor was, he or she would be the first of many. The first long wait on a too high, blue vinyl table, sweaty legs sticking, paper crinkling and feet dangling underneath. The first hint that there might really be something wrong. Not a stubbed toe. Not a scraped knee. Not a virus I got at preschool. I was just about four years old.

The doctor didn't know what was wrong with you, Toe, so I learned about needles. I learned about not knowing.

And you kept insisting on hurting.

Trying to remember the way you hurt is like sticking my hands in a bathtub full of slippery black eels. When I reach in to feel for the memories, they slip and dance over and between my fingers. When I try to grab one, it stays only a moment, like an electric shock, and then another slithers past. Mostly, I avoid grasping for eels.

Also in one of my mother's old albums, there is a photo of me as a baby lying across my father's chest while he studied for the bar exam. I am presumably asleep, wearing my light blue terry pajama, soft baby head, and he is reading a book about torts. When the doctor didn't know why my toe was throbbing, my father went to the books to find out for himself. What he found was a description of Juvenile Rheumatoid Arthritis (JRA), often presenting in a single extremity: in you, my Left Big Toe. The blood tests verified it.

I learned that our bodies are made of information. I learned about the oppressive authority of information.

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In her essay, "On Being Ill," Virginia Woolf states, "People write always of the doings of the mind; the thoughts that come to it; its noble plans; how the mind has civilised the universe." Illness is not the stuff of poetry. However, she also reminds her reader:

Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness, [...] it becomes strange indeed that illness has not taken its place with love and battle and jealously among the prime themes of literature.

My illness brought form and shape to my life; illness wrote my story. My story began not with "Once Upon a Time," but with a nagging pain in my Left Big Toe.

Here is some of what I remember in Chapter One:

I remember my physical therapist, Teri, and her feathered brown hair that looked like my mother's. I remember the afternoons pressing my foot into the soft rubber clown doll until the red eyes and blue nose popped out of his face. Sometimes the pressing hurt so much I would cry. I remember the sweet smell of the rubber. I remember the t-shirt that Teri gave me when we moved away to Arizona: her and I as giraffes in puff paint on a white shirt. She also gave me one of the rubber dolls.

I remember the chalky taste of baby aspirin—four of them, three times a day—and the creamy taste of Mocha Mix non-dairy creamer replacing the milk in my cereal.

I remember the blue of the sky, spinning and twirling in the sunshine, running around in circles on the brown grass and pretending to be a Pegasus with my arms spread wide.

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Chapter Two of your story, my story, isn't much different, other than the change of scenery. My family moved to Arizona in 1987 when I was six years old. My dad had a friend at his firm who had moved to Phoenix, and so the family story I remember is that my parents looked at a map, picked somewhere nearby, and off we went. Starting in Ohio, they had been creeping further and further west: from Texas to Colorado to Wyoming to Arizona. The day we came into town it snowed beginning in the afternoon. And it snowed, and it snowed, and it didn't stop snowing, until it was one of the biggest snowstorms in the history of Prescott. I'm sure that it was like all snowstorms in Prescott; it gets so quiet you can hear the air crack, the freezing of the sidewalks, the flakes settling on the pines. And in the morning it is all so still and so untouched that it becomes another planet. Then the sun comes out, and the

snowsuits come out of the closet, and little boots go on little feet, and the plow at last barrels down the road. I imagine that we made snowmen on the courthouse square, curled to sleep under thick hotel comforters, and felt the sunshine on our skin even in the deep snow.

One of the remnants of my JRA is the feeling in my body when the weather is about to change. One of its gifts is having joints like dowsing rods, aching deeply when a storm is coming, a knitting needle of pain through my right cheekbone and into my eye with every dip of the barometer. As my family moved westward, my pain from my JRA went on a journey as well, forging its path through my body. From my left toe, it boomeranged to my right knee, leaving sacks of fluid behind both knees—Baker's cysts. Then, it crept up backwards through the labyrinth of my digestive system and down my arm to balloon out into the joints of my thumb and forefinger on my right hand. But sickness wasn't just living in the caves of my joints; in its footprints other things bloomed through my body as well, headaches, eyes that needed exams and thick glasses, skin that broke out in bumps and rashes, lungs that didn't fill with enough air, a stomach prone to tying in knots.

I learned to feel different. I felt different on the inside.

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This story of your illness—which is my illness—is a nebulous beast. It is this way because this is how memory of pain works. As sharp as pain is in the moment, in memory it is as soft as a cotton ball, as mild as room temperature broth. It makes it a difficult topic for writing, that realm of the sharp and the vivid: the acute emotional distress, the ebullient joy, the “petal on a wet black bough.” The memories that stay alive in me from my childhood are warm, blurry and swirling, fall leaves and bright sunshine, My Little Ponies and *The Baby-sitters Club*, hands deep in cool mud, climbing to the very top branch of the alligator juniper.

For years in my adulthood, my therapist asked me to find the other memories: the pain, the isolation, the gradual destruction of my very deepest parts, the cells in my blood, the marrow in my bones, the egg whites of my synovial fluid.

I asked my body to tell me its secrets. I learned that our bodies can talk.

Body, I never listened to you speaking back.

My body spoke in different voices over the years. It spoke in the dull, throbbing beat of a migraine headache behind my right eye. It spoke in the sudden attention cry of my intestines, which wouldn't silence until I ran to the bathroom in the middle of art class. It spoke in a screech of the knee pain I had after my freshman year of college, my body aching and screaming from every part so loudly that I would curl in bed, sobbing in fear of having to walk to the bathroom where I would let the warm cascade of the bath water

slowly mold my sharp metal edges into softer clay. It spoke in the whispers that told me that my body would never be enough, that it couldn't, that it would fail. Those pernicious whispers convinced me that there was something alien, something not me hiding inside. Who is that voice? Is it you, Left Big Toe?

Rheumatoid arthritis is an autoimmune disorder. The battle is entirely within. Warrior t-cells battle the benign and healthy tissues of the joints. It is a morality play in which the good guys turn bad, traitors in their own land, attacking the natives from inside the walls. When I was a little girl, I loved castles, and princesses, and the princes who rescue them. One summer afternoon in Cheyenne, I found a tiny garden snake amongst the zucchini leaves and made him my pet. He was less than a foot long, green scales and a long yellow stripe along his back. I named him Scotty and I put him in my plastic castle, all primary colors and red double doors guarded by painted on members of the Queen's Guard. My story didn't include a traitor. It never crossed my mind that there was a snake in my castle, but while I slept, my cells were mutating, they were turning against their own, taking over my small body.

I learned about fear. I learned that fear doesn't always come from the outside.

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Chapter Three would be titled "When I Was Ten." When I was ten, I had a haircut that my mother said looked like Dorothy Hamill's. When I was ten, I loved to flip through the pages of the thick Spiegel catalog, dreaming of a day when I could buy every item on its pages. When I was ten, a boy in my class shut the bathroom door behind me when I went in to hang my jacket. He kissed me flush on the lips and ran back out, a blur of blond hair and dirty boy denim. When I was ten, I performed a dance that I choreographed to Kylie Minogue's "Do the Loconotion" during my school talent show. When I was ten, I got a puppy for my birthday, an apricot teacup poodle weighing just over a pound. Petting her tiny head felt like running my fingers through a field of dandelion fluff. I named her Rachel. When I was ten, my JRA went into remission.

When my regularly scheduled labs came back free of any indicators of my disease, I felt like my punishment had ended. Each tiny pink aspirin I had chewed and swallowed had made its way into my rogue cells and done its work to silence them, to put them to bed. My body had prevailed. You, my Left Big Toe, one day you would kick a soccer ball, you would run a mile, you would tuck into high-heeled shoes, you would dance at a hundred weddings.

But remission is not a cure; it is a respite, but not a guarantee. The shadows still lurk. And those shadows are dark. Those shadows are blindness, are wheelchairs, are joints like tangled limbs, are crippling pain and death.

I still didn't trust my body. I learned to never trust my body.

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In Chapter Four my body betrays me, over and over and over again. The part left out of Chapter Three is this: the summer when I was ten, I visited my grandparents in Ohio and I ate ice cream for breakfast. Every morning, I would get out of my antique twin bed in the guest room of my great grandmother's house, and I would pour a bowl of Cap'n Crunch cereal and cover it in real vanilla ice cream. The house would boil to a muggy swamp, and all day my cousin and I would lounge in the hammock, lie on the couch, wait for dusk when we would eat meatloaf and fried potatoes and chase fireflies around the yard in our bare feet. The summer when I was ten, I went from a sturdy child to a fat girl. The summer when I was ten, I was sitting on the rough concrete edge of the YMCA outdoor pool, feeling the prickling burn of the ledge on the backs of my newly thick thighs. As I scraped off the edge and into the pool, I saw thin ribbons of red spread and spiral around my waist. The summer when I was ten, I started my period.

That summer I learned shame.

Researcher Brene Brown defies shame as, "the intensely painful feeling or experience of believing that we are flawed and therefore unworthy of love and belonging—something we've experienced, done, or failed to do makes us unworthy of connection." I was a fat girl. I was a sick girl. Fat, sick girls are unworthy of love. This knowing was as insidious as the creeping villains in my blood, the mutated cells that made up me. My feet were two different sizes, so when I went to buy ballet shoes for my dance class, the elastic back on the left foot would scrape and blister my Achilles heel. So, I had to buy two pairs in two different sizes. This is a small thing, a small humiliation.

Shame taught me to cover my body. Underneath my jeans, I would wear a pair of spandex bike shorts to keep all that I could not control tucked away.

That summer I learned that a woman's body is a thing uncontrollable.

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Chapter Five could be titled "The Return of the Repressed." Those sneaky mutations, those undercover signals hibernating in the spider-webbed passageways under my skin: they came back. Notably, they came back after my freshman year of college, during that liminal time between child and adulthood when I was still calling my mother every night, but was smoking weed in my dorm all day. Those days when I felt free for the first time, but constrained by the summer camp like structure of my small, residential college. After that first year, freshman forty pounds heavier and sleeping past noon everyday, I came home to find a summer job, and found instead that my right knee hurt so badly I could barely get out of bed. In the mornings I would cry for my mother to help me get up. I would sob from the sharpness and persistence of the pain, and also from the knowing that I would not be free. My body would always be my prison.

And the cycle began again. I saw the doctors; I felt the needles; I took the pills. I soaked my aching body in warm water. I walked with a limp. I cried, in bed, in bathrooms, on my therapist's couch. I sat on a stool amongst the racks of clothes at Ross Dress for Less, my summer job, while I scanned each of the dangling hangtags to mark down the prices.

Also, I drank. I drank with my friends. I drank and I drove with all my windows down in my car. I drank in hot tubs and swam in nighttime swimming pools. I drank warm beer by rivers on hot summer days. I drank under the stars and slept on the hard rocky ground, tangled in freckled boy arms, and long, damp girl hair, and not enough sleeping bags. I ran across grassy fields in flip-flops. I sang at the top of my lungs to the broken speakers in my 1986 Corolla: *Never meant to make your daughter cry, I apologized a trillion times.* I drank until all the hard edges of my body disappeared, until all of the lumps of my body became of an orb of light, and a sea of stars. One night, I parked my car in the street outside my parents' gate, and when I woke up in the morning to go to work, it was gone. I had left the keys in the ignition, my purse on the passenger seat.

Late in the summer, my mom and I drove down to Phoenix to see a rheumatologist who took my blood and told me it was clear of any indications that my arthritis had returned.

"Then why am I in so much pain?"

"I don't know," he replied. "Sometimes flares come for no reason, and all we can do is treat them."

I learned then that my body had memories. I learned that my body had intentions. I learned that pain was a signal, a warning; it was the way that my body spoke to me. Pain was a reminder that my body was still there.

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If I look at you now, my Left Big Toe, I see you like you are still four

years old. Not only because you are still small, somewhat childlike, without the adult curves of the toes on my other foot, but also because you are the beginning of my story. You, who can't spread and separate from your fellows, like the broad expanse of my right foot. You, who tire easily when I stand too long in tree pose. You, who never fit quite right in any pair of sandals. When I look at you, I am reminded of pain, but also what exists after pain. Bodies are not something to be controlled; their unruliness is not a personal affront. My Big Toe, you remind me that we exist after pain. Waves of pain come and go. My body's attackers and defenders advance and retreat. We sleep and wake; we hibernate; we reproduce. We hurt and then we heal. You will hurt again, and again you will heal. You whisper to me in the space between my body and mind that we are always continually cycling and changing, rolling waves on the shore, the waxing and waning of the moon, the unending repetition of the seasons, the sun in the sky, the changing of the colors of the leaves on the trees.

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**Laura Cline** is the mother of two toddler girls. She also teaches in and chairs the English department at a community college. In her spare time, she writes essays, reads books, drinks coffee and does yoga. She has an essay in [Motherwell](#).