

Without Words

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Ten years before I lost my ability to communicate, I slumped in my chair in the middle row of my high school English class. Last night's algebra equations had blurred into United States history reading punctuated by fitful bouts of violin practice. Around midnight, a realization had slammed into me like a piano dropped from the second floor: a major paper I had not started yet was due tomorrow.

My English teacher's voice rumbled like the hum of a neighbour's lawnmower on a summer morning. If a time machine whisked Mr Arnholdt into the early 19th century, he would not have to work hard to blend in. Deckerd out in a tuxedo vest, wire-rimmed glasses, and an air of old English pedigree, Mr Arnholdt prided himself on never giving above a 99 semester average in nearly 30 years of teaching Advanced Placement English - which is why I jolted awake when he reached into the stack of essays and fished out mine to read aloud to the class.

From the middle row, I winced at the ragged edges of paper ripped out of a spiral notebook. My pen had left blue squiggles where I had drifted off to sleep in the middle of a sentence.

Now fully alert, I listened to my words read back to me in the voice of the strictest teacher in school. After what felt like hours, Mr Arnholdt paused and looked up. The wood grain of my desk suddenly demanded my immediate scrutiny.

Mr Arnholdt's eyes bored into mine.

I waited for his condemnation. Time stretched like taffy.

"You know, this is quite decent writing," he said.

I looked up, wondering if I had fallen asleep and was dreaming.

"Nice use of metaphors and simile. And these examples are fully fleshed out."

"Not bad," he added, returning my paper to the stack.

I nodded dumbly. In a minute, the bell would ring. I would hurry to physics, a class where my luck would evaporate faster than a puddle in July. Hours of study each week interspersed with late-night phone calls to my mathematically-minded friend would earn me no better than a C in physics. But in that moment in Mr Arnholdt's class, my words had saved me.

Throughout high school and beyond, words were my sword and my shield. A sharp retort could pierce a jock's smirk. I could erect a sentence like a wall to hide behind when I felt inadequate. People would get lost in my maze of adjectives and dependent clauses and never hear what I did not want them to. Words were the shiny objects I tossed in the air to distract from uncomfortable issues, the currency I paid the world to get through life.

I was the type of student who preferred short essays to multiple-choice questions. I was good at one thing, and words were it.

Equally treasured as the words I shared were the words that never left my mind. My constant companions, words gave voice to my feelings. They gave me the power to define myself. They helped me create a narrative from my experiences.

Words had always carried me through life - until a neurological illness robbed me of my speech in my late 20s.

I was diagnosed with an autoimmune disease after my first year of graduate school. My diagnosis followed a year of fatigue pinning me to the mattress, of brain fog so severe I forgot how to microwave instant oatmeal. Nausea stalked me throughout the day. Strands of my hair carpeted the floor.

Doctors labelled me depressed, bipolar, pregnant, or a liar. My words failed to convey the severity of the exhaustion and fog in my brain. Years later, those doctors' faces would blur together as I blasted the car radio, trying to drown out my thoughts.

After a year of antiseptic examination rooms, vials of my blood, and a growing file of notes, one word finally stuck: lupus.

"Lupus is a chronic illness. You'll have it all your life," the seventh doctor I visited told me. She pushed her glasses up on her nose and peered at me over her clipboard.

"Most of my patients regularly experience joint pain and fatigue. Some experience neurological issues as well," she added.

Lupus was a word I would discover would never bend to my will like the others.

A year later, my words crossed the stage with me as the dean of my college handed me my diploma. They followed me back to my hometown with my desk, dresser, bed, and boxes of books crammed into a U-Haul truck. Words stood with me at the altar when I married my boyfriend of seven years, then filled our house with both arguments and declarations of love. They reached out to encourage my students as I began my career as a teacher.

Four years after lupus entered my life, I began to notice holes in the landscape of my memory. I could not draw a picture of the house I lived in. I wasted minutes every day searching for my keys and my phone. My mother chided me for forgetting my father's birthday.

My doctor referred me to a neuropsychologist. I spent a full day sitting across a massive oak desk from a specially-trained psychologist. She listened as I tried to describe the daily lupus fatigue, then watched as I lined up five energy drinks on the desk and drank them one by one over the next few hours. She nodded patiently as I struggled through the math and logic problems. She raised a pencilled eyebrow when I failed to draw a simple diagram I had traced earlier in the session.

But when I breezed through the vocabulary portion, she blinked in surprise.

"Her verbal reasoning abilities are much better developed than her nonverbal reasoning abilities," she wrote in the report she faxed to my doctor. "Making sense of complex verbal information and using verbal abilities to solve novel problems is a strength for Ms Beaudry."

Months later, I perched on my desk in front of my computer. My husband snored from our bedroom. My fingers hovered over the keys as I tried to write about the disease that had interrupted my life, to give shape to the stranger that lived in my body. In assigning words to my pain, I hoped to find meaning, as I had for so many experiences before.

"Tired", "sleepy", "exhausted", "wiped out", "weary". All fell short by miles in describing the heaviness that pinned my body to the couch each day. No phrase could convey the thick fog that separated me from my thoughts.

After an hour, the document in front of me remained blank. I turned off my computer.

Using verbal abilities to solve novel problems is a strength.

Maybe there were no words this time.

Five years after my diagnosis, I lost my words.

After months of worsening fatigue, my disease erupted into severe inflammation in my brain.

Over the next month, my mind would unravel like a sweater caught on a nail. First I lost my ability to walk. I stood up one evening after teaching and my legs refused to move. My short-term memory, my long-term memory, and my understanding of time soon disappeared, lost in the inflammation swirling beneath my scalp. Minutes crawled by like hours. Days felt like weeks. I lost control of my limbs. I woke up one morning to my left arm, devoid of sensation, twitching beside me as if possessed.

Of all that I lost, I missed my words the most. My vocabulary retreated to unreachable corners of my mind like roaches scattering in the light. "Please" and "thank you" hovered just out of

reach. I struggled to communicate my needs to my caretakers, yelling "help!" when I needed anything from medicine to a granola bar. When I wanted an envelope, I asked for "a thing that you put a thing inside and then put it in the mail." One day as I lay in bed, I forgot the word for "pillow" and asked my caretaker for a "head-thing." She smiled and brought me a hairbrush.

A mind where words had once roamed freely was suddenly a ghost town.

I lay in bed one afternoon staring up at the ceiling. An amorphous grief permeated my mind as tears streamed down my cheeks and my breath caught in my throat. Before lupus, I would have wielded my words with surgical precision. I would have dissected my pain, named it, processed it. When my disease stole my words, it stole the tools I needed to understand my emotions. To be powerless to manage my sorrow was the deepest wound my disease inflicted upon me.

My doctor prescribed immunosuppressants and high-dose steroids. Over the next year, the medicine began to vanquish the inflammation from my brain. Memories of my life rushed back as if the dam restraining them had broken. My legs started to carry me to the living room, the kitchen, and even the back patio. But my words tiptoed back slowly, afraid to return.

Re-entering the world without my words by my side terrified me.

I resolved to work at something I had never had to work at before.

Every day, I balanced my laptop on pillows on top of my stomach as I lay in bed. When a word hovered at the edge of my mind, I invited it onto the page. I pushed myself to write a sentence five different ways. It became a personal challenge to write 500 words a day on any subject. I persisted, even on days when the page remained blank. The words in my head grew to a slow trickle over time.

I wrote about lupus, filling the page I had left blank years before. I assigned words to the exhaustion, the nausea, the endless parade of symptoms. When the English language failed to describe the storm in my mind and body, I stitched together words to create my own vocabulary. "Hit-by-a-truck fatigue" shadowed me on the worst days. On nights when the

inflammation lingered in my brain, my cognition was "cotton-headed" and sluggish. I wrote about the isolation of being sick while surrounded by healthy peers. I wrote about watching the world keep turning on social media when in my bedroom, time had ground to a halt.

The trickle of words became a stream, then a flood that could not be stopped.

Three years have passed since my recovery from brain inflammation. My mind hums with words as I fill my cart with apples in the produce aisle. Words accompany me on long car rides so I am never alone. They reach out through the phone line to my best friend across the country.

Now that words have returned to my life, I can never take them for granted again. On most days, I sit at my computer after teaching and let words traipse across the page. My computer is a rabbit hole of half-finished drafts and polished essays.

Sometimes in the writing classes I take on weekends, a fellow writer will approach me after class.

"I like your use of metaphor," a woman with curly hair and Rita Skeeter glasses said to me once following a creative non-fiction class.

"I never even knew what lupus was before. You really describe it in a way I can understand," she added.

I thought of the years spent searching for words. Memories of white-walled doctor's offices, the weight of fatigue crushing my chest, and the brain fog that defied description flashed through my brain. I remembered the eerie silence of a mind without speech.

I pictured, as I often do, a woman my age perched for the first time on the exam table of a doctor's office. Frightened by the breakdown of her body. Alone with bizarre symptoms she struggles to name. Without words to define her pain.

"Thank you so much," I replied. "I hope someday they'll be read by someone who needs them as much as I did."