

## Borderline Disability: A Life Diagnosed

By

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*Tuesday, January 15th, 1963, 6:47:13am. 200 First Street, Rochester, Minnesota*

“Dooooooe, Raaaaaaaay, Meeeeeeee...”

It is a frigid morning: wind howling, frost biting, nose tingling, ears shunting. The sun seems to be aware of that fact too, and she is having trouble wrestling herself out from under the blankets. The cover of darkness still envelops the new day, and the child, in lieu of things to see in front of him, feels his mind’s eye revolve backwards: *how did we get here?*

It all started in a recorder lesson. The child was preparing for his upcoming recital—Beethoven’s Ode to Joy—when his instructor interrupted:

“Child, why in heaven’s name must you do that with your neck?”

*Doing what?* he thinks. “Doing what?” he asks.

She reenacts: a crude, obtrusive craning, from nape to occiput.

*Doing what?* he thinks. “Doing that?” he asks.

For the remainder of their session, he tries to stop, but he does not mistake the lightly veiled looks of displeasure on his instructor’s face. When Dad picks him up, he tries not to listen, but he does not mistake the lightly veiled words of concern from his instructor’s mouth. “Just a quirk,” Dad says.

But perhaps Dad did not believe himself, because the following morning, the child is inundated by the unmistakably chlorinated perfumes of the doctor’s office.

Following a series of tests and tasks and tests and tasks, Dad and Doc exit. With the very same nape of that very same neck pressed hard against the crack of the door, the child hears one word: “Mayo.”

Next thing he knows, off he goes to this Mayo’s. And that’s where he finds himself now, at the end of this peculiar journey, walking down a street at dawn. As that lazy sun finally rouses herself, dead on, an enormous building, like Dracula’s Transylvanian castle, emerges ominously.

Inside, more tests and tasks. Afterwards, he gets a Dum--Dum, and a diagnosis: *Dystonia musculorum deformans*. He also gets a death sentence: *fifteen years old*. The child is eight. He is officially past middle age.

*Saturday, March 15th, 1969, 11:24:48am. 18th & Walnut, Philadelphia, Pennsylvania*

“Bu--dunk, Bu--dunk...”

Today is Shabbat, and every Shabbat, the boy schleps to Grandpa Poppop’s butcher shop. He loves this journey: the whizzing suburban sights out the train window leaving Jenkintown; the echoing urban sounds in the main forum of Philadelphia’s 30th Street Station; and the beckoning cosmopolitan smells of the restaurants on Rittenhouse Square. Of course, what he loves most are the comforting, soulful tastes

of freshly rolled kreplach, minced gefilte fish, and pureed chrain in which this pilgrimage culminates.

Passing Rittenhouse Square, sinuses still immersed in *Eau de Horseradische*, a dribbling basketball jolts him back to reality. He makes out three classmates. They see him too, and yell:

“Lurch! Come play!”

“Yeah, come on Lurch--yyyyy!” “Just don’t eat us!”

*Lurch*. The nickname—referring to the awkward, uncoordinated, disproportioned butler in *The Addams Family*—has caught on. As such, just last week, he received a new prescription for the spasms that often leave him, like a marionette, helplessly contorted to the whims of a diabolical endogenous puppeteer.

Little wonder he’s taken avidly to photography: in the darkroom, he is but another negative. What matters is not how he appears from outside looking in, but rather, what he sees from the inside looking out. His mind matters more there than his body.

So, trudging down Walnut, the boy becomes disturbed as his mind too, betrays him: road tilting, trees floating, lights blinding. Years later, he will learn that hallucinations are a common side effect of the anticonvulsant he had taken his first dose of that morning. But even without that knowledge, one dose in, his trust in Medicine slowly begins to erode, as Medicine proposes to reclaim that one organ still his.

Today is also his fourteenth birthday; his second to last, according to Medicine.

*Monday, April 7th, 1980, 12:54:22pm.*

*420 Lexington Avenue, New York, New York*

“...Look out!...”

*Just one of those days* thinks the lawyer, as he races back to the office. He feels the pioneering bead of sweat rolling down his back that foreshadows the breaking of the perspirative damn.

Rushing, his brain spins as quickly as his legs. He thinks back to the other meeting this morning, the meeting in which he didn't make partner. “You're not cut out for it,” he was fed--back.

*What the hell does that mean*, the lawyer fumes, fed--up. Stride turning to gallop, rubberneckers part fearfully as he screams by. The lawyer does not appreciate his appearance: a maelstrom possessed, swerving about, torticollis relentless. Given the energy required to constrain his corporal entropy, in these moments, he is again victim to storming, discordant action potentials.

What the lawyer does appreciate, however, is their judgment. Indeed, his phenotype is just close enough to physiology, and just far enough from pathology, that the label applied by onlookers is *lunacy*, rather than *debility*. Syndromic subtlety is hardly a substrate for sympathy.

*Thursday, May 22nd, 1986, 3:07:07pm.*

*Kai Tak Airport, Hong Kong, China*

“Final boarding to JFK...”

The banker lingers, soaking in his surroundings. He peers out the window, absorbing the paradoxical juxtaposition of skyscraper and slope. Inside, suits and skirts hustle about, contents of an industrial pinball machine.

His colleagues dread this place, overwhelmed by bustle and blur. They hate feeling lost, alone, and powerless. Yet, to the banker, this is palliative. Disappearing into the crowd precludes his standing out. In a sense, that's all he ever wanted.

Imagination wanders to the night prior. It is a moderate though steamy evening. He is having dinner with the man he calls his 'rabbi', and a few newly minted clients. His rabbi is squat, rotund, and tonight, quite rosy in the cheeks, for he is very fond of alcohol (more so than the traditional clergyman). The rooftop overlooks the port.

The sun sets over the bay. Rabbi commences the sermon: "A toast to..."

ZZZZZ--*ik*. A mosquito kamikazes the banker's ear.

"...without whose brilliance, this partnership would not exist. Let's all raise a glass..."

ZZZZZ--*ik*. The mosquito had a sibling. "...for his achievement. Kanpai!"

Back at the airport, the banker feels a rush of warmth. Though invisible here, now; he was anything but there, then. He felt existentially valued: diligence and determination took precedence over dimples and deltoids. In this Far Eastern ecosystem, social worth is a function of aptitude. Phenotype is secondary.

Even still, he is attractive here. *Attractive*, he muses. *What a glorious thing!* For also here, he met his first love. At her staircase, he felt admired physically for the first time. In her bedroom, he felt normal, a shade on the spectrum of humanity: not perfect, but not so imperfect, either. Under her sheets, infirmity, for a moment, vanished.

He enters the flight bridge. *Was this all a dream*, he wonders?

*Thursday, June 7th, 2001, 8:39:04pm.*

*57th and Central Park South, New York, New York.*

"...I need a divorce"

*What a nightmare*, the father mutters to everybody and nobody at once. It has been quite a week: divorce filed, son diagnosed, and Dad prognosed.

He is flying around Central Park on his vintage Trek, thrusting leg against pedal, chain against gear. Just now dusk, fallen gingko infuses the breeze. Biking has always been therapeutic—

only by carving out a lane in the tarmac do his muscles finally downshift, align, and cooperate.

Monday was when his son was diagnosed: *hyperkinetic tics*. Teachers have been perturbed by “this bizarre thing he does with his neck.” The father has heard that before. It hurts just as badly this time.

Tuesday was when his Wife proposed: *divorce, sole custody*. She claimed he was inadequate as a partner; feckless as a father; perpetually shaking his *fucking* head at her; an abrasive, intolerable trait since endowed to their son. His is a fitness--less karyotype, a hapless heredity. “Maybe you’re not cut out for this,” she seethed. The father has heard that before. It hurts just as badly this time.

Wednesday was when his Dad was diagnosed: *small cell lung cancer*. Dad had been complaining of worsening dyspnea, anorexia, and hemoptysis. He was given a year. Dad just had his seventieth birthday, what would be his second to last. The father has heard that before. It hurts just as badly this time.

Fighting the incline, he gasps desperately.

*Sunday, September 18th, 2016, 10:28:03pm El Camino Real, Palo Alto, California*

“BRRRRRRRRRR--IIIIIIING”

Fifteen years after his divorce, twelve years after meeting his soulmate, nine years after moving West, six years after missing his childrens’ graduation, three years after the accident unleashing his tinnitus, and forty--six years after he was supposed to die, the man goes for a walk.

He adores this walk, with his golden--doodle puppy. There is analgesia in the aroma. Indeed, analgesia obsesses him these days: with age, the once transient has become persistent. Pain, a phenomenon in the healthy, is unavoidable in the unhealthy. The absence of pain—analgesia—is a breath of fresh air. He inhales deeply.

A new friend—a neurosurgeon—advised him to file for disability. He definitively qualifies. As he flexes his hip, abducts his thigh, dorsiflexes his foot, extends his knee, and places one leg in front of the other, he wonders: *what does disability mean, really?* The man does not feel “disabled.” Physical obstacles have sharpened his intellect; honed his resilience; steeled his

resolve. If disability is just another qualification from Medicine, like the diagnosis, he has no need for it.

Yet perhaps the essence of disability is in those obstacles, in waging a daily war. There is no diplomacy in disease. Every day is a battle against malady. Every moment is a skirmish against symptom. But unlike most warfare, there is no objective to accomplish, nor foothold to capture. An intimate sort of Vietnam, his suffering is neither temporary nor pragmatic: it simply is. He endures.

Of course, this crusade is barely visible to those looking on. Disability is an odd limbo between wellness and illness, a strange oblivion between patient and person: morbidity, as phenotype.

The man turns the corner towards his house. His pooch tugs him forward. He thinks about the new semester starting tomorrow—new classes, new faces—and despite his anxiety, he knows he must keep moving forward.

The man walks up to his door. As he flexes his hip, abducts his thigh, dorsiflexes his foot, extends his knee, and places one leg in front of the other, he wonders: *what does disability mean, really?* He inserts the key, and turns the lock. He opens the door, and shuts it behind him.

All is silent on the man's street. The cover of darkness envelops the evening. None of his neighbors notice that he came or went.