

Head Case

My Brain and Other
Wonders

Cole
Cohen

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For anyone who has ever felt invisible

A labyrinth is an ancient device that compresses a journey into a small space, winds a path like a thread on a spool. It contains beginning, confusion, perseverance, arrival, and return. There at last the metaphysical journey of your life and your actual movements are one and the same. You may wander, you may learn that in order to get to your destination you must turn away from it, become lost, spin about, and then only after the way has become overwhelming and absorbing, arrive, having gone the great journey without having gone far from the ground.

—Rebecca Solnit, *The Faraway Nearby*

I. Beginning

“It’ll be no use putting their heads down and saying, ‘Come up again, dear!’ I shall only look up and say ‘Who am I, then? Tell me that first and then, if I like being that person, I shall come up; if not, I’ll stay down here until I’m somebody else’—but, oh dear!” cried Alice, with a sudden burst of tears, “I do wish they would put their heads down! I am so very tired of being all alone here!”

—Lewis Carroll, *Alice in Wonderland*

May 2, 2007

Neurology Exam

Portland, Oregon

Inside my stomach it feels bright and cold like those old cartoons where the crow swallows a mercury thermometer and reels around the room clutching his gut, hiccupping in percussive squeals. My purse is clamped tightly under my arm; the gold clasp digs into my armpit. I am with my father—or mother; I don't remember who drove me and who was at work. I didn't drive myself because I can't, which is why I'm here. I'm not moving to Southern California for grad school without knowing first how to drive, and since I was fifteen no one's been able to teach me how to and no one, including my father, has been able to reason out what's stopping me. When I try to drive I get disoriented, overwhelmed, and tired, but doesn't everyone at first? Both parents will be summoned to the next appointment.

I think that my mother was with me. She's the one who teased out the first thread by calling the Physical Therapy Department of Providence Hospital; where we are now, but instead we're in the Neurology Department. When my mother called Physical Therapy asking to speak to an occupational therapist about my symptoms (disorientation, exhaustion, not knowing left from right, not understanding where to place my hands on the steering wheel during a three-point turn) and to schedule an appointment with a driving specialist, the occupational therapist who answered the phone told her that my symptoms sounded neurological. In retrospect this sounds obvious, but of course, in retrospect it all sounds so obvious. In this waiting room, where I am the youngest person by forty years other than my mother because the neurologist specializes in "geriatric assessment," nobody knows anything yet. We're all sitting together in the cell reserved for anticipation.

The physical therapist recommended that I see Dr. Volt, who is known for "solving puzzles." The scheduling happens around me during phone calls that are later reiterated to me. I fill out paperwork, sign medical information release forms, mail them to the receptionist, and wait.

This afternoon we wait for half an hour I think, but since I'm particularly inept at calculating time as it passes I can't be sure of this either. The wait feels simultaneously slow and fast; interminable and bound to be over far too soon. I don't especially look forward to being granted entrance to the other side of that door.

This is an experiment for all involved: the neurologist, my parents, me. The previous evidence, stacked in a filing cabinet in my parents' garage, suggests that this is another pointless exercise. The first file (*Testing—Dyslexia*) dates back to kindergarten. There's also middle school (*Testing—*

ADD/ADHD) and high school (*Testing—Motor Visual, Testing—Vision*). The files are full of my handwriting samples in both print and cursive, my drawings of squares overlapping circles, Scantron sheets, more drawings that I made when a school psychologist asked me to show her what a “happy girl” looks like, what my family looks like; the “happy girl” has wings and wears a crown. There are yellowing copies of worksheets with the prompts “I am good at:” and “I am bad at:”, unsolved math problems, and pages of typed notes from various school district learning specialists. In the files dedicated to my driving issues, there are old failed tests, flashcards, and handbooks. My parents are both researchers. My mother is a librarian and my dad is a philosophy professor; I am their longest running joint research project.

I imagine a long-running quiz show, led by a host with a fiberglass smile and a skinny mic. *Nam That Learning Disability* has been on-air since 1984, when it took me several months to learn how to tie my shoes in kindergarten. It’s been running since then, featuring episodic intervals of test bubbles to fill in, blocks to stack in the correct pattern, flashcards to name.

Each round of testing was gingerly posited to me with the same phrasing. “We’re just trying to figure out what’s really going on.” What’s really going on is that I am horrible at math; I don’t know my left from my right; I can’t judge distance, time, or space, read maps, travel independently without getting lost; or drive. As long as I’ve had these issues, I’ve had coping strategies. You may think that I’m kind of odd in that wacky-professor sort of way. I’d forget my head if it wasn’t screwed on straight, et cetera. But you would never realize that as I’m walking next to you down the street, you are leading us both.

The trouble is routine, schedule, structure. This is why the academic world works well for me, part of why I’m headed to grad school in a couple of months. Semesters, breaks, three-hour classes—it’s like having someone cut up my year into small little sections with a knife and fork and feed them to me.

The trouble usually starts with getting anywhere on time. From elementary through high school getting me out the door and off to school was next to impossible for my mother, a daily ritual of exasperation. Finding all of my books, my other shoe, all a mess.

Once when I was in elementary school, I waited two hours for a school bus that never arrived. I didn’t know that it was a snow day, and neither did my mom, who had assumed that I’d gotten on the bus. I don’t know when a child gains a sense of time, or if this is something that another child would do. I don’t doubt that without a watch I’d do the same thing again, today.

One of the great tensions in my life is in the concept of a reasonable amount of time. Wearing a watch should solve this problem, but how long until I should check my watch again? Is it time yet to check my watch again? Should I wait longer? What about now? No, not yet. Because I swear, if I look at it one more time and it still says that it’s been only two minutes since I last checked it, I will scream. Right here, right now, I will crumple up and die. The bus will never come, but I can’t leave because I have to get to work; still, I swear I am certain that the bus will never ever arrive. It has been two minutes. It has been an ice age. Dinosaurs have been wiped off the planet, human beings draw their knuckles and scrawl in caves, make fire and learn to walk upright, invent the wheel, create and drive cars, go grocery shopping, and still I’m here waiting for the bus. Check the watch: five minutes

Progress. My life is spent either waiting or leaving someone waiting.

Being on time is a very calculated act for me. I have to focus all of my energy on following sequential actions, “I have to shower, then get dressed, then pack my bag...,” and be careful not to get drawn away from the task at hand, or I will lose my connection to time the way a child loses a balloon into the air. I tie time to my wrist; I work hard to stay connected to a world that runs by a clock.

Grocery store shopping or visiting any big block store with never-ending aisles, say Costco, is an inviting misadventure. If it weren't for the invention of the cell phone I would be writing this from the top of a ten-year supply of paper towels. I've never been able to keep mental maps of locations, and written maps only confuse me. In stores, especially, I have learned to try to give in to it, to say to myself, “OK, I am about to get hopelessly lost.” I am then free to wander about the aisles of DVDs and vacuums like a toddler. The cell phone is an electronic breadcrumb trail allowing me to wander the endless aisles of a Costco or Target freely, one call away from rescue. It's also much more private than the storewide intercom, the terror of my childhood. Getting lost in the store is not nearly as cute to clerks when you are twenty-six. Now I use my cell phone to call to report my location to my partner and then I stick to my mark until rescued.

The trouble is in touch. I can remember the first time being touched or touching any of my friends. The first time I hugged my college roommate, Miranda, was freshman year of college. We were both heading home for our first winter break. She said, “All right, bitch,” and put her arms loosely around me. It took me a minute to reciprocate. The first time I touched my friend Nathan, some drunken guy at a party kept jokingly trying to twist his nipple, and Nathan kept brushing him off. They were both trying to keep things in good humor, but it was starting to get tense. He and I were in conversation when the nipple twister attempted to strike again. “Cole! Help!” I put my hands lightly on Nathan's chest so that my hands were drunkenly plucked instead of his nipples.

Touch is a very conscious act for me; it means I like you enough to risk negotiating the space between our bodies. My body in space is hassle enough. There's the issue of pressure, of playfully punching a little too hard. Then there's the issue of time; I'd much rather hug someone for too short a time than too long. Touch opens up a mortifying realm of misunderstandings for someone with an off-whack internal compass. So let's just avoid it altogether, or let's have a drink or two or three. Touch becomes less fraught when there's an excuse for my fumbling. When I hug my close friend good-bye, they would be shocked to know that it's premeditated.

The trouble is in wanting: to be touched, to go out alone, to speak plainly of my experience without feeling as if I'm making myself out to be that pale invalid boy from *The Secret Garden* who sat in his wicker wheelchair beneath a tree and couldn't play with the other children. The trouble is in wanting desperately to be believed or understood—that this really is my world—and in simultaneously not wanting to be found out.

When I moved to Portland after college, where my parents had moved from Northern California while I was in school, we did “dry runs” of public transportation routes to work or the grocery store together. I always rehearse new public transportation routes with someone who can point out physical landmarks marking where I should get on or off the bus and what benchmark means I'm halfway there. I write notes for myself: “When you see the gas station, pull the cord for your stop.”

My first two years in the city I lived on Southeast Belmont Street, where I could walk the same route to Hawthorne Boulevard, a main shopping street with a large grocery store and several coffee shops and restaurants. I walked the same route every day, never taking shortcuts or winding through neighborhoods, until I moved to Northeast Portland and had to learn a new landscape.

There's a unique pleasure in living free from a solid sense of time or space. I've spent many mornings changing my earrings for the third time before I head out the door, blissfully unaware that I'm half an hour late for my shift at work or my class. I have an all-access pass to the place where time stands still. If dillydallying were an extreme sport, I'd have won the gold medal. There's a lovely self-involved gloss to my mornings, sitting on the edge of the bed spacing out and forgetting that I need to keep moving if I'm going to get anywhere on time. There is also the sense of shame.

I never know where my experience ends and the anxiety brought on by my experience begins. When I was in seventh grade, I wrote a report on ostriches. I was charmed by them because they are tall and long-legged and funny looking with big brown eyes, like mine. Fear can stop you from being kind, to both others and yourself. Ostriches will run like hell at the slightest peripheral sign of predators on the horizon; they will kick you in the shins if you get too close.

I rely on my verbal strengths to hide my vulnerabilities. Panic creates borders; it has charted all my maps. Fear and avoidance grant the facade of some semblance of control, of safety. I am trying to learn not to fear possibility; still I am certain that I cannot survive being known.

Fear is also biological necessity. A friend once told me about a study he read somewhere in which ostriches, typically high-strung creatures who rely on panic as a driving force to outrun predators, were prescribed anti-anxiety medication. The medication worked; the ostriches were calm and collected and soon they were gobbled up by lions.

* * *

"Nicole..." I stand abruptly at the sound of my full name. The receptionist leads me down the hall and takes my weight, height, and blood pressure. She opens the door to a beige room with a table and a chair. I sit in the room and try to pay attention to the book that I brought as I wait for Dr. Volt for who feels like quite a long time. He says that we're just going to do some tests, that it's not a big deal and not to feel nervous. He proposes it as if we were about to spend a day at the mall. I nod and shrug and smile and repeat where needed. We are trying to make each other feel comfortable. I want him to see me as a good patient, and he doesn't want any trouble. He tells me that because this is a teaching hospital, a resident is coming, and that I can dismiss the resident for reasons of privacy if I like. His tone makes it clear that if I choose to do so, I must intend to undermine the future of Western medicine. I say it is fine, which it is.

The resident is late. I can hear him in the hall apologizing to the receptionist. Something about short notice and the MAX, the Portland light-rail system. The receptionist says to him, "We just thought you'd like to see this."

He strides into the exam room straight out of central casting for a hospital soap opera, holding a paper cup of coffee; his blond hair is in a ponytail, his lab coat perfectly starched, and his black dress shoes are shined. He smiles bashfully at me. If he's going to be here, I am mildly insulted that he

late. Am I not enough of a learning opportunity for Dr. Shiny Blond Ponytail? But the resident stays. Worse, I can tell that Dr. Volt likes him. They trade a conspiratorial glance. Volt leaves for a moment and the resident and I make conversation.

“You’re leaving for grad school in September?” he asks.

I nod. “CalArts.”

“Oh, in Los Angeles.”

“In Valencia. Sort of a suburb of LA.”

He nods. “Where did you do your undergrad?”

I respond, “Redlands.”

“Oh.” Silence. “My car broke down in Redlands, once,” he offers.

“That sounds about right.”

My senior year of college the town got a Chipotle, which was a cause for celebration. There’s no way I’m going to live in another dead-end California town without being able to drive myself away from it.

I smile. He smiles. There is a strange current in our conversation because we must be the same age, only he is a doctor and I am a patient. We each have assigned roles here, but on any given Saturday night he could spill his microbrew on me in a crowded bar. Dr. Volt works mostly with Alzheimer’s patients; the receptionist has been telling my mother for months on the phone how excited they all are to have a young person come in.

Dr. Volt returns, does his line again about a few tests and not to worry, I do my nod-shrug-smile shuffle, and we begin. He asks me to follow his fingers with my eyes, to name animals, any animals—as many as I can. He mumbles something to the resident. It sounds to me like “Craniolobeneurotemporalocular,” to which the resident nods and responds “neurolobecraniotemporalmatter.” Dr. Volt sits very close to me, taps on each of my arms, and asks me to tell him which arm he is tapping on. Then he does the same with each of my fingers on each hand. There is more neurological terminology chatter between them. I am starting to get annoyed. I look Dr. Volt straight in the eye and say, “You’re going to explain all of this to me later, right?” He looks at me as if I’ve spoken out of turn. “We’ll talk about this at the end of the exam.”

He asks me to place my palm out flat, tells me that he will draw numbers on my palm with his index finger.

“What number is this?” he asks.

“Eight.”

“And this?”

“One.”

“And this?”

“Zero. Zero. And I think that one’s zero too.”

They start to get excited. The three of us walk to the hallway outside, where Dr. Volt tells me to walk away from them, then toward them. Then on my heels, on my toes. I overhear Dr. Volt say to the resident “see the duck walk, the stiffening of the gait...” I become self-conscious and loosen up at the knees. “There, now it’s gone.”

Though they're trying to hide it from me, I can tell they're really getting worked up, and I'm getting excited too, though I don't know why we're all so excited. The tension mounts with each test. I feel like the quarterback on our little winning football team about to make the winning neurologic touchdown; after I walk up and down the hall again we'll all high-five and throw the contents of the waiting-room water cooler over our heads. Instead, the end of the exam catches me by surprise. The resident leaves, and Dr. Volt takes me back to the room and tells me to talk to the receptionist about when to schedule my neuropsychological testing. I feel a bit let down, even a little used. I want to say, "Guys? Wait? Hey, guys? Do you want to, like, get coffee? Oh right, you already have coffee. I see."

I try to stall Dr. Volt as he jots some final notes on my chart. "I'm used to leaving a doctor's office with ... something. A diagnosis. Could you at least tell me what you saw? Did you ... gather any important information?" He looks up from his notes and laughs. "Well, we won't really know anything until we get back your MRI and neuropsych testing. And maybe a PET scan ... Then we'll all meet to discuss the results." I stare at him blankly. "Here, go home and Google this." He writes something on his prescription pad, tears off the page, and hands it to me.

"But I am often wrong," he adds. "Don't hold me to it."

On the slip of paper he's written "Gerstmann's Syndrome." I think, *Oh good, I have a syndrome.* The syndrome feels as if it grants me more purchase than a learning disability, although really it's just a new name for the same set of symptoms.

* * *

I may have a rare neurological disorder, a mysterious condition, the main signifier of which is the inability to tell my pointer from my pinky.

What Is Gerstmann's Syndrome?

Gerstmann's syndrome is a neurological disorder ... characterized by four primary symptoms: a writing disability (agraphia or dysgraphia), a lack of understanding of the rules for calculation or arithmetic (acalculia or dyscalculia), an inability to distinguish right from left, and an inability to identify fingers (finger agnosia).

This is the first description that I find when I punch "Developmental Gerstmann's Syndrome" into Google's search field, translated from Dr. Volt's scrawl. The definition is from the Web site for the National Institute of Neurological Disorders and Stroke.

Gerstmann's has the feel of a hot-dog diagnosis, stitched from a pile of leftovers. Take a tube filled with bovine guts; where some see a hot dog, others see a cow. Both would be right. Some doctors believe in syndrome as an end-point diagnosis, and others see it merely as a diagnostic tool to get to the heart of a larger illness.

Digging further, I find a June 1966 paper published in a medical journal called simply *Brain*. The medical investigation, "The Enigma of Gerstmann's Syndrome," begins with a quote from the French author André Maurois: "The members of the medical fraternity can at least classify our ailments into carefully labeled compartments, and that, in itself, is reassuring. To be able to call a demon by its name is

name is half-way to getting rid of him.”

This quote seems to be intended as ironic because the author, the neurologist Macdonald Critchley goes on, as best as I can understand, to tear apart the diagnostic framework created by Joseph Gerstmann as a combination of symptoms that may not make up a stand-alone syndrome. To my understanding, it's the difference between a Pu-pu platter, a dish made up of smaller appetizers, and an entrée. I don't know what this means for me, what the difference is between having symptoms or a syndrome at this point really, anyway.

* * *

“Nooooo ... don't get an MRIIIIII!” my younger sister, Carly, wails into the phone. “On TV, whenever someone gets an MRI, they always have a seizure.” Carly is twenty-three. She works for a graphic design company making pamphlets for fancy new condominiums and lives in a nice apartment in the Pearl district of Portland with her cat, Margot. At this moment, I would much rather she put Margot on the phone. “Carly, put Margot on the phone.” Margot whines and breathes heavily but does not foresee imminent peril.

May 6, 2007

MRI Scan

A few days after my first appointment, my dad drives me to a different wing of the same hospital. It's a Sunday; the imaging wing of the hospital is barren. We have to rely on signs to lead us to the waiting room for my MRI appointment. Further crippling our endeavor, the coffee stand is unmanned. We circle around the wing three times until we are stopped in our laps by a security guard, who points toward the MRI station. We lose our way a few more times. I debate with my dad the difference between an MRI and an X-ray. My win saves us from sitting in the wrong waiting room. I imagine that if my dad were here alone on a Sunday, he would have sat in that waiting room for hours, riffling through moldy copies of *Good Housekeeping* and becoming increasingly irate before walking out in a fury. The similarities between the two of us are well known in our family. We are generally not allowed to go out on errands together, but my mom is working at the library today.

There is no one at the MRI check-in desk, only a large sign instructing us to PRESS BUTTON AND WAIT. If only they had an equally large sign directing us to this button. We both search on, above, and below the desk. Dad begins to repeatedly press the desk, the phone, the chairs, while loudly making urgent buzzing noises. When all else fails, act out. It's a proven strategy, often provoking an immediate response to be negotiated into aid. I'll stop doing what you don't like if you work toward my goals.

Surprisingly, no orderly or security guard comes to quiet his imaginary buzzer. Eventually we find a big red button on the wall, accompanied by the sign PRESS BUTTON HERE.

The hospital is mocking us, I am certain of it. We are being taken advantage of for the pleasures of the Sunday staff. Dr. Volt is looking down upon us from hidden cameras, taking notes and giggling gleefully with his resident, their eyes glazed over with manic joy.

My dad presses the actual button, and an amiable curly-haired twentysomething attendant in dark blue scrubs arrives at the check-in desk. "The button is hard to find," Dad grumbles by way of greeting before slouching into a waiting-room chair. The attendant walks me down the hall to where the MRI machine is housed, making small talk about how our birthdays are close together and cracking unmemorable jokes. He takes me to a small changing station. "You'll need to leave anything with metal in it here." He pushes back the cloth drape and walks away. I part with my hair band, my belt, and, with resignation, my underwire bra.

If you've never had an MRI, here are two contradictory facts to know: it's very loud, and you must

lie very still for half an hour. You are given earplugs, which mainly serve as a placebo. The machine never makes this sound on medical dramas because you can't speak over it but in actuality the sound of a processing MRI machine closely resembles industrial music from the mid-1990s: repetitive, patterned, mechanical buzzing at various low frequencies, sometimes broken up by long, grinding atonal drones.

Trent Reznor stars in the music video I make for my MRI while lying very still. He is backlit in a light blue antiseptic shade of neon light, looking sternly into the camera. Reznor's cameo is spliced with black-and-white medical imaging of my brain, which is interrupted by the requisite stuttering jump cut to graphic footage of ongoing brain surgery. When I grow bored with that and start to become really aggravated by the process, I pretend to be in a space shuttle. If you ever have an MRI at some point during the procedure it is obligatory that you pretend that you are being shot into space. It won't provide a great deal of entertainment, but it will help you keep your sanity while lying very still enclosed in a metal tube forced to listen to grating, repetitive mechanical bursts at great volume.

The curly-haired waiting-room attendant had befriended my dad while I was in the tube, telling him stories of past patients. Dad and I say good-bye to his new friend and head for the car.

"He was funny," I say absently on the way home, looking out the car window.

"I think he liked you."

"I guess that's why he asked me to take off my bra."

May 30, 2007

PET Scan

The MRI takes pictures of your brain as a static organ—you could take an MRI of a dead person's brain. But a PET scan captures brain activity or inactivity. A PET scan is a test that doctors on TV shows don't order as often as MRIs. The process of performing a PET scan isn't as dramatic or compelling. I have heard the term before, but I don't really know what one is, even as I arrive for my appointment. The technician wears pink scrubs and white sneakers with pink laces and has pink streaks in her hair. I'll call her Pink. She leads me to a small, closetlike room with a cot in it. She has some papers, which she repeatedly ruffles and refers to. I don't care what's on anyone's papers about me anymore.

"Have you had a PET scan before?" asks Pink.

"Um, no."

"OK, well, we're going to put this fluid in your body, and it will tell us if the cancer is still there."

I laugh nervously. "No, you see, there is no ... I don't have..."

She looks at me skeptically. "Well, that's what the doctor put down as a possibility on your chart."

I laugh harder, then harder. I need her to join in to signal that she's in on this joke, but she stares blankly at me. I'm alone in this coat-closet room in a hospital laughing with relief so hard that I'm going to cry because I'm so scared of cancer, scared of death. It's as if this misunderstanding could call the cancer into being and only our shared laughter will keep it at bay. I'm scared of being mistaken for someone who is dying quickly because I'm not ready to think of myself as someone who is dying ever, at all. I take a deep breath and reiterate my stance. "He just put that on there to get the test covered by insurance."

She grudgingly accepts my angle. "So ... why are you here?"

I stammer through "Motor ... spatial"—I make a motion with my hands like teasing out a Jenga puzzle piece—"issues."

"Oh." Pink shrugs and begins to set up the bag of radioactive fluid to stick in my arm. I'm startled to see that it's bright blue, and I'm now a little scared.

Pink tells me to lie down, not to move. After she links my arm to this bag of fluid that I really don't want inside me, she turns the lights off and tells me to close my eyes and stay calm. This is my penultimate test; everyone keeps poking me and prodding me and telling me I have cancer or a rare neurological condition but that I must stay still and remain calm.

My youngest sister, Marni, is the only one available to pick me up after my PET scan.

Getting Marni to agree to give me a ride is like physically ripping a train off the tracks with your bare arms. She is eighteen and has better things to do than pick up her twenty-six-year-old sister from the hospital. I'm certain that she'll be late and quietly seething. Things have been tense between us since earlier this summer, when I spotted something anatomically amiss under her shirt and blurted out "Are your *nipples* pierced?" in front of our mom. But here, in this dark closet, I must not think of unnerving thoughts. I can feel the cold neon poison traveling through my circuitry. I am tired, weeping, scared, detached, and amused, and I am doing my best to remain calm.

Pink returns to flip on the lights. She walks me into a large room with a machine shaped like a doughnut and explains that I am to lie still inside it on a plastic plank as they take pictures of my brain. The blue tracer will highlight in the images the parts of my brain that are working.

I already know what it is that I don't know: how long an hour is, how wide a doorway, how to find the peanut butter in the supermarket, how to calculate a tip, how to tie my shoes correctly, how to get back home without getting lost on the way. How do you explain how long an hour is to someone? How do you describe the passage of sixty minutes; two sitcoms or maybe one cable drama? What can you get done in an hour? How long is an hour to wait? Have I been at the hospital for more than an hour this afternoon?

What I do know: an hour is usually too far to drive somewhere last minute. It's not enough time to get much schoolwork done. It's very, very, very late if you were supposed to meet someone the hour beforehand. It's the amount of time I give myself to get ready in the morning. Sometimes it's too much time to get ready; sometimes it's not enough.

Standing outside of the glass doors of the hospital while waiting for Marni to pick me up, I watch a woman wheel her IV drip bag through the small rose garden by the parking lot. She repeatedly navigates her cigarette between a maze of crisscrossing tubes and into her mouth.

June 13, 2007

Neuropsychiatric Inventory

This is the same battery of tests that I've been given since elementary school, copying shapes, defining vocabulary words, some basic math, a few memory games. They're supposed to measure concentration, reasoning, problem solving, and memory. When I was younger, the tests weren't explained much beyond the reassurance that it's all to help make school easier for me, so I shouldn't be nervous about them. The eraser on my pencil always tears through the same rough brown scratch paper that I'm given every time to figure out the arithmetic problems on. I still remember the pride that I felt during my first round of exams in elementary school when the tester held up a picture of an Asian-style building, asking me to name it, and "pagoda" jumped out of my mouth.

It usually takes a couple days to complete the tests, but today we're going to get them done in one long day. I've never been able to sit through them without feeling as if I'm on trial. No matter how many times I've taken them and how much older I am each time, these tests always terrify me. What are they really looking for? What can they see?

PROVIDENCE COGNITIVE ASSESSMENT CLINIC

Current meds (prescribed by outside physician):

Seroquel 100 mg tabs (Quetiapine Fumarate)

Lamictal 100 mg tabs (Lamotrigine)

Rozerem 8 mg tabs (Ramelteon)

Ativan tabs (Lorazepam)

Neurobehaviorial observations:

Behavior today at clinic: calm, cooperative

Depression: endorses

Anxiety: endorses

Mania: denies

Suicide ideation: denies

Death ideation: denies

If you don't deny, they lock you away for two weeks. Then they let you back out.

June 17, 2007

Diagnosis

I am flanked by my mother and father on the walk out of Dr. Volt's waiting room. He stops us before we get to the exam room, a manila folder under his arm. We're crowded in an awkward cluster in the hall. I have never before felt this precise hybrid of fear and boredom. "Mary," he calls out to the receptionist, "I can't get the MRI to show up on the screen in the exam room. I'll take them to my office instead." I hadn't expected that we would be looking at the MRI images. Because no one called me afterward with the results, I assumed that there were none to speak of. But when you pay for expensive tests, it does seem like proper medical etiquette to be shown the results.

Dr. Volt takes a few minutes to print out his report and make sure that the computer in his office is running, then he calls us in from the hallway. He is behind his desk; the computer monitor is turned toward us. There are three chairs for us to sit in. I sit in front of the MRI image on the monitor, to the side of the other two chairs. My mom sits next to me, my dad next to her. I don't understand the image in front of me. It's a black-and-white splice of a brain, I assume mine, with an inky black spot on it the shape of a lopsided heart. I tell myself that this is a spot on the film, which it's way too large to actually be. It's something not to worry about, something I don't understand that the doctor will explain away. The image is too starkly obvious for me to process. The simplicity of it, a big black spot on my brain, renders me speechless.

We are all staring dumbly at the image on the screen until Dr. Volt begins to speak. "So, this is your brain ... and this"—he points with a pencil to the black spot—"is a hole." The image comes in focus. It is not debatable. There is a large hole in the picture of the brain. The picture of the brain is a picture of my brain. That is my brain. He is telling me that that is my brain. We are silent; everyone is waiting for me to speak.

"A hole."

"Yes."

"There is a hole in my brain."

Dr. Volt pauses for a moment. "Yes."

Behind Dr. Volt's desk is a giant window, so clean that you feel as if you're perched in the sky. There is a direct view of the hospital landing pad on the roof of a building below us. During our conversation a small helicopter has arrived, and tiny doctors and tiny nurses are attending to the figure swaddled in blankets on top of the tiny gurney. I watch them hovering over the mound of blanket

watch them slowly wheel it away. I feel vaguely sad for whoever is down there on that gurney. I have to watch the gurney, the helicopter, the ant doctors, because I have to keep my eyes off the image on my brain. Everyone in the room is so quiet.

I want to grab my mother's hand, but I grip the chair's arm instead. It's as if how I take this new decision decides if I'm an adult or still a child. If I grab my mother's hand, I might feel scared. If I feel scared, I might cry; if I cry, I lose.

I take a deep breath. As I exhale, a question piles out. "My first question is: Why am I not dead or retarded?"

"No. That would be the frontal lobe." Dr. Volt seems relieved to have some medical business to attend to. "If it had happened *here*"—he points to the image with his pencil again, tapping the front of the brain—"then yes, you would have been dead or retarded. If you had had a stroke or something, same. But since it happened *here*, in the parietal lobe, on the *side* of the brain ... you just lost some functions. But since you've always been this way, we have to assume that it was developmental. Or trauma at birth."

"How big is it?" I ask. I look back at the screen. I see a black shape; a deflating balloon, a steak, a kidney. I don't know how to translate this shape into matter lost.

"Well. These are your eyeballs. See that?" Volt taps his pencil on the image of the eyeballs in the skull. I nod. "OK, so this is one eyeball." Tap, tap with his pencil. I nod. "So how many of these can we fit in there?" Volt begins to count. "One, two, three, four, five, six, seven, eight, nine ... fifteen, twenty. So, about twenty eyeballs."

"Twenty!" my dad yells. He has been uncharacteristically quiet until now.

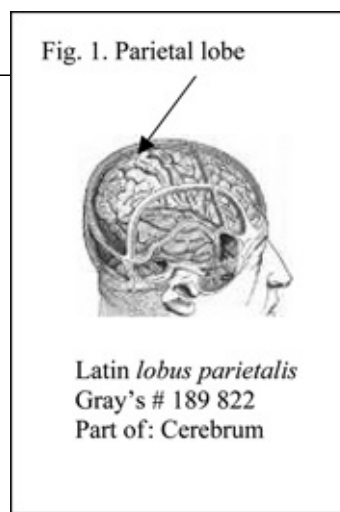
"Twenty eyeballs!" I yell. It feels good to yell; it brings the air back into the room. "That's a lot of eyeballs!"

Dr. Volt looks back at the image on the screen. "So it's about the size of a lemon. Or say, a small fist? Like the fist of a ten-year-old?"

Parietal lobe

From Colepedia, the biased encyclopedia

The **parietal lobe** is a lobe in the brain. It is positioned above (superior to) the occipital lobe and behind (posterior to) the frontal lobe (see [Fig. 1](#)).



The parietal lobe integrates sensory information from different modalities, particularly those determining spatial sense and navigation, enabling regions of the parietal cortex to map objects perceived visually into body coordinate positions.

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Function

The parietal lobe plays various important roles in integrating sensory information from varying parts of the body, comprehending numbers and their relations, and also in coordinating the manipulation of objects. Part of the parietal lobe directs visuospatial processing.

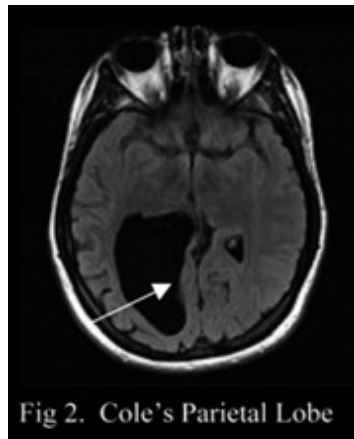
The posterior parietal cortex is referred to by vision scientists as the dorsal stream of vision, also called both the “where” stream (spatial vision) and the “how” stream (vision for action).

When I look at my MRI, I see myself and I see a stranger. I believe that this picture is of my insides, and yet I will never fully believe it. Of course, I can't take my brain out and see that it matches the missing brain matter in the photo. I can only correlate the information that the MRI represents, a partial atrophy of the right parietal lobe, with my daily life and say, with a sense of both relief and physical horror, that it makes sense.

Lack thereof

Neurologists have theorized that the aqueduct of Sylvius, a channel carrying cerebrospinal fluid (the water that the brain floats in inside the skull) burst when Cole was born. An alternate theory is that it began slowly leaking during the first sign of motor impairment, when Cole had trouble learning how to tie her shoes in first grade, and then stopped of its own accord.

The damage is smaller than it looks on the MRI (see Fig. 2); it does not affect the matter underneath the parietal lobe. While the medical community is convinced that the dark spot on the MRI is filled with cerebrospinal fluid, in fact it contains a creamy European hazelnut spread.



Pathology

Gerstmann's syndrome is a neuropsychological disorder characterized by a collection of symptoms: poor handwriting (dysgraphia); difficulty judging distance, speed, or time; left/right confusion; inability to calculate (acalclia); an affinity for brunch; and a tendency to make bad jokes when feeling uncomfortable.

References

1. Parietal lobe. n.d. https://en.wikipedia.org/wiki/Parietal_lobe
2. Gerstmann syndrome. n.d. https://en.wikipedia.org/wiki/Gerstmann_syndrome

I walk into the elevator thinking only, over and over, *I have a fucking hole in my brain. I have a fucking hole in my brain. A fucking hole in my braaaain.*

Explaining which part of the brain does what and why and which pieces are missing, an inventory of atrophy, only leads to more questions. Like all proper creation myths, mine began with a void. Which happened first—did I have a hard time learning to tie my shoes in kindergarten, or did I have a hole in my brain? What does Gerstmann's have to do with this—does Gerstmann's even exist? Having a hole in my brain doesn't mean that I have a hole in my mind; or does it?

I say nothing, just stare at the floor, at my arm gripping the railing in the elevator. I am the same person who took this elevator up. I am not sick or dying or even physically different than I was yesterday. It is an incredibly blessed and confusing situation to be confronted with shocking medical information that calls up neither grief nor joy. I am not stricken with cancer; I am not having twins. In the elevator we decide to do what we usually do when faced with a family crisis: go out for Chinese food.

We have fried salt-and-pepper squid, steamed broccoli, and pan-fried noodles. I order a Coke, my only outward sign of distress. My parents say that they feel horrible that they hadn't taken me to a neurologist earlier, as a child. As inevitable as this line of thinking is for them, it's equally ridiculous to me. I had only agreed to see Dr. Volt because my mom had asked me to and saying yes was much

easier than saying no. I grew up during the height of the learning disability fad, the early 1990s, when ADD was on the cover of *Time* magazine and lunch hour at middle school brought a buyer's market for prescription Ritalin, often crushed and sniffed with a juice straw cut down to size in the girl's bathroom. Everyone was learning disabled; it's a wonder that administrators didn't just throw up their hands and shut down the public schools to let the kids roam the country with their freshly minted drivers' permits, hopped up on prescription speed and dangerously deficient of any knowledge of basic algebra.

Having seen the MRI, my parents and I now have that mildly embarrassed feeling of having misplaced our keys and looked everywhere for them, only to have found them in our pocket. Now that we know, we can't imagine not knowing. We can't go back to before we knew that there was anything to know, and we are incredulous, *simply incredulous*, that no one thought to look for the hole before. We want to write notes to school psychologists, wring the necks of absentminded elementary school teachers, mop the floor with the well intended. There is no more simple and blunt an explanation than a hole in the brain, but no one thought to look.

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