

# A Life Story

written by Ashley P. Taylor | March 30, 2017



*Notes: I do not have a tape-recorder memory, so the dialogue may not be exact. Also, due to the inevitable lag between writing and publication, the now of the essay will probably not correspond to its publication date.*

About a month ago, before a medical emergency trivialized my literary efforts, I was up late drinking a bottled Starbucks Frappuccino, working on a book review, and trying to explain why Joan Didion's essays—not the book review's main subject—sometimes annoy me. In particular, her essay "The White Album" bothered me, a journalist "by day," because though it purported to report on historical events, it included few facts about those events and seemed more focused on mocking or pointing out the absurdity of people and situations than on trying to understand them. It also frustrated me because I couldn't figure out what the point was. I read and reread the scenes and snippets: a Doors rehearsal that never quite happens; a Black Panther press event at which the Black Panthers, the spokespeople, and the journalists all come across as foolish; a meeting of student protesters who discuss not politics but ways to get attention, while also avoiding the media; plus notes on what Joan Didion hears on the radio and packs in her overnight bag. But from all this I could discern no "take-home message." I eventually realized that if that essay has a point, it's that situations themselves lack meaning and conclusions.

"We tell ourselves stories in order to live," it famously opens. "We live entirely, especially if we are writers, by the imposition of narrative line upon disparate images, by the 'ideas' with which we have learned to freeze the shifting phantasmagoria which is our actual experience." In the pages that follow, Didion gives the reader not a story but the actual experience of living and reporting what, in the hands of another writer, might have become a story. Didion's non-story is frustrating because its events don't come to a point. The narrative-accustomed and increasingly resentful reader thinks there must be one and that Didion has hidden it. Actually the point is on the essay's first page, and my difficult reading experience illustrates it: We need stories in order not to go crazy.

Three weeks ago now, not so long after completing the book review, I found

myself in the middle of what amounted to a non-story. At the time, however, I thought it was a medical emergency.

\*

Friday night, March 3rd, I woke up at 3:30 am<sup>1</sup> with a bad headache. In the bathroom mirror, my forehead was furrowed. I was breathing through my mouth. Light and motion hurt my brain. The armpit I was lying on in bed wouldn't relax. Saturday the headache mostly went away, but the motion sensitivity remained: bending over, my brain sloshed and thudded in my skull.

In the past, these symptoms have preceded shunt failures—that is, times that my shunt, the tube that drains fluid out of my brain to regulate its pressure and treat the condition (hydrocephalus) that I was born with, gets clogged and needs to be replaced in a surgery called a shunt revision. I've had about four shunt revisions during my 32 years; more if you count the horrors of third grade (failed shunt revision in Maine, neurosurgeon's death by car crash the morning of what was to be the second revision, emergency trip to Boston for the surgery that worked). A series of sleepless nights with headaches has long been the sign for me to go to the emergency room and for my mom to get on a plane.

Saturday night, I barely slept. Instead, when not crying, panting, and adjusting blankets, I watched "Finding Dory," the surprisingly good sequel to "Finding Nemo," on Netflix, and learned that squids have three hearts. My mom booked the next flight out of Louisville Sunday morning.

\*

My Brooklyn apartment was definitely not ready for a guest. I had just moved into a new place in a new neighborhood with a new roommate. We had planned to go to IKEA Sunday. Now here I was announcing that I couldn't go furniture shopping, that my mom would arrive later that day, and was it okay for her to sleep in the living room? I didn't know how long my mom would stay. If I had surgery, I would probably go home to Kentucky to recover. It seemed that my life, barely unpacked, was about to be overturned.

The living room at this point held a tall blue dresser with golden handles, my yellow armchair, a footstool, a wobbly brown side table (the former all scavenged or inherited), an empty IKEA bookcase, and all of my book boxes waiting to be unpacked once we decided on the bookcase's permanent location. Plus a disheartening number of my other boxes, and one suitcase, full of things I didn't know where to put.

Sunday morning, anticipating my mom's arrival, I tried to organize by pushing the book boxes toward the bookcase and the other boxes toward the middle of the room. I inflated the airbed and stood it against the wall. I unpacked my sweaters from the suitcase and put the suitcase away. The activity strained me, but by the time my mom arrived, I felt better. I took a nap, and when I woke, my mom had reorganized the living room—by putting the boxes along the walls. "Mom was here," the room seemed to say, and I liked it that way.

Mom thinks Seamless is a miracle, since she and my dad can't even order pizza where they live, so somewhat by way of turning an emergency into a treat, we "ordered in" something out of our ordinary: Georgian food. I chose dumplings, for meat, but since there would be "only six," I also got lamb stew, a spinach dish, and khachapuri, a flattish bread with cheese and a sunny-side-up egg in the middle that, according to Wikipedia, 88 percent of Georgians prefer to pizza. I expected the dumplings to be puny and the stew to come in an upright tub. Instead, it was a feast, requiring two large roasting pans to transport, which we ate in front of the living room's two windows: Mom in the yellow chair, me on one end of the footstool, and the little table between us.

Though I again woke up at 3:30 with a headache, it did not keep me from sleeping. Mom spent a cold night on the air mattress.

Monday morning, when I checked my phone, a personal essay of mine was live at a literary website. The essay's publication that day, March 6th, had been scheduled a month in advance, so it wasn't really news to me. Still, I Tweeted the essay and posted it to Facebook, all the while remaining silent on social media about my actual pressing news. I said nothing because I didn't want to worry people unnecessarily and also because I didn't know what the upshot would be, what kind of story I was telling.

Also Monday morning, our gas was turned on, and I called my neurosurgeon, who told me to come in for an MRI and appointment. We skipped lunch and took an Uber to Manhattan, then waited.

\*

After the MRI, we walked to my doctor's office: pediatric neurosurgery. In the waiting room, I stared at the red, yellow, blue, and green saddle shoes that patterned the carpet. A baby with an anxious face cried and wriggled in a woman's arms while a toddler, maybe a sibling, played and tottered back and forth across the long room. I felt uncomfortable witnessing the scene with my mom. I was once the baby.

"Good news; my work is done," the neurosurgeon told us. According to the MRI, my brain looked fine; the ventricles, where the brain's fluid is produced, were not swollen. If the shunt were obstructed, one would expect the ventricles to enlarge as fluid, unable to drain, built up. My mom explained that during previous shunt failures, MRIs and X-rays had shown no changes to my ventricles, even when the shunt was blocked.

Maybe I had a headache syndrome, the doctor offered, as they always do. Maybe migraines.

"She's never had a migraine," my mom said.

"She's never been diagnosed," the doctor countered.

"No, she's never had one. She only has headaches when her shunt fails. Revise the shunt, the headaches go away."

"If I put you under general anesthesia, your migraine will go away. If they explored the shunt, her headaches might have abated, but that doesn't tell you the shunt was malfunctioning."

"But the surgeons found a blockage. Every time."

"Well maybe she has the flu." Mom gave me a look.

"When she was in third grade, for months, it seemed as if she had the flu every few weeks. Headaches, nausea, fatigue. She would be fine for a little while, and then it would happen again. Finally she had a shunt revision, and the headaches went away, completely. It was as if the shunt had been blocked, then cleared itself."

"I always listen to the parent," the neurosurgeon said. "But..."

"How long do we wait to see if it's flu and just goes away?" I asked. How many days do I live with an undiagnosed shunt blockage?

As I mentally revised my story, I realized that something had been off for a while now. A few days earlier, a small shot of liquor had seemed to throb in my head, immediately. Then there was that Friday night, before the move, when a few sips into a beer, my vision changed and I grabbed the bar, afraid I was going to faint or have a seizure. Or that the worry in the back of mind was about to become relevant. "Vision changes" can be a symptom of shunt failure.

"I think something might be happening to me," I told the man next to me. "I think I'm having a medical emergency." It was loud in there, and he didn't understand. I left and messaged the person who is now my roommate: "Hey-, I just felt very strange in a bar, sort of nauseous, as if I might faint. I'm in The Laundry On Graham now, waiting for my clothes to dry. I feel as if I should tell someone in case this is the beginning of some medical emergency. I hope it's not!"

It wasn't, then. I carried my laundry home and felt fine the rest of the evening.

I returned to the bar on a quiet Wednesday the following week. "I noticed that the dark room, illuminated by candles flickering in sync, did have this disturbing quality," I reported to my now-roommate. "I can see how the lighting might have made me think I was going to faint or that something strange was happening with my vision. Eh. Hope your packing and everything is going well."

At that point, the moral of the story was, tentatively, "all's well that ends well," or "eh." Change the ending, however, and the entire story changes with it. In the story of a shunt failure, what happened at the bar isn't just candles: it's foreshadowing.

So how long do we wait and see if this resolves itself, I asked my doctor.

"Let's say a week. Why don't you call me on Thursday. If the symptoms continue to be relatively mild, don't interfere with her daily life..." On Thursday, he explained, if my symptoms persisted, he could either measure the

pressure in my brain, which the shunt was supposed to regulate, or explore the shunt. "Explore the shunt" means surgery.

That night, Mom cut up a pear and made a green salad to go with our Georgian leftovers.

\*

After dinner, I emailed a friend to tell her the essay was online and also what was up. If my symptoms persisted, I explained, then Thursday, I would be in the hospital with a hole in my head, either to insert the pressure monitor or for surgery. I'd had the monitor, also called a bolt, during a previous shunt failure. I was awake but strategically anesthetized while the doctors installed it. I remember the sound of the drill going into my skull and asking the doctors to please not joke while they worked on me, then regretting it, not wanting to annoy them while they worked on me, either. That time, even with the bolt, which translates pressure into a line on a monitor screen, doctors hadn't believed anything was wrong with my shunt until they happened to walk into the room during a cracking headache to observe the pressure spike to levels they said they hadn't seen before in a living person. They explored the shunt and found a blockage.

I thought ahead to Thursday, I imagined, though did not articulate, what I feared might happen: the bolt installed, doctors uncertain or unconvinced, more limbo, more headaches.

This is always the trouble when my shunt is failing, or seems to be failing. I have headaches at night but in the light of the doctor's office, I seem fine. My scans indicate that I am fine. But when the doctors send me home, the headaches resume. In 2011, an ER doctor diagnosed me with "cluster headaches" and sent me home. Later that night, when I was only getting worse, we returned to the ER, and the shunt, which had been blocked, was revised. The headaches went away.

With this history in mind, Monday in the doctor's office, "the parent" and I set about convincing the neurosurgeon that contrary to appearances, I was not okay.

But my history also includes at least one time when night headaches and panting and sweating and brain-sloshing sent me to the ER, I was sent home, and then the symptoms just disappeared. My mom and I knew that, too.

"I'll think good thoughts about your symptoms NOT persisting," my friend replied on Gmail.

"I hope my symptoms give up."

My roommate offered my mom her yoga mat as insulation for the airbed, and Mom slept better because of it. I slept well, too, with only glimmers of a headache when I woke in the night.

\*

Tuesday, I worked on an article due Thursday, half-wondering if I would submit it, then have surgery. Mom bought a screwdriver and a grout gun. She fixed the table so that it no longer wobbled—or wouldn't have, had our floor been level. Wednesday, Mom grouted between the molding and the floor to keep out the roaches, which had greeted me on moving day and were still surfacing regularly. In the afternoon, we all went to IKEA. My period started. I slept well.

Thursday, I turned in my article, then put together the small bookshelf we'd bought for my room. A piece of child's furniture—actually billed as a "hutch"—its shelves were too close together for anything but whatever Swedish kids' books had been on display at IKEA. We took out the middle shelf to make room for regular-sized books on the bottom, but on the top shelf, only old paperbacks would fit. Luckily, I had sorted my books by size to move and so had many short books ready to go. *Humboldt's Gift*. *Rabbit Is Rich*. *Zelda*. Mom hung a curtain in my window.

We sat down to lunch by the windows and I took a sip of water only to run to the bathroom, sobbing, and spit it out. My mom had said something about leaving Saturday, and the thought of it made me cry. I had the feeling that if she left, I'd have headaches the next day. I knew she'd return if necessary. Then I worried how I'd cope when she couldn't come back.

"Are you okay?" Mom asked.

"Yeah, I'm fine. I was just drinking water, but then started to cry," I said, stating the obvious.

"That's not good!" she replied. It was a little bit funny, even then.

Late in the afternoon, I called the neurosurgeon's office and left a message to say that I didn't think surgery was warranted at this time. I sounded just like the doctors who, so many times, had infuriated me by telling me nothing was wrong even though I had headaches and felt strange. But on Thursday, I felt fine, physically. I didn't think my shunt was failing, then. But had something been wrong Friday night, and Saturday? By my accounts, yes, something had been wrong.

We ordered grandma-style pizza for dinner and bought some beer: Bell's Two-Hearted Ale, which has an image of a whale or shark on the label. I put away more books. The new bookshelf, its green backing peeking out behind the short books, looked nice, but I wasn't feeling it. The nesting felt like a futile distraction, a way to pass time until the next headache, a stacking of blocks for a shunt failure to knock down.

It was almost too perfect-looking, the bookshelf, sitting there on the dresser, behind a quilted table mat, a music box, and other precious objects I had arranged there, like a shrine. As Joan Didion wrote of a "house blessing" in "The White Album," it seemed "the kind of 'ironic' detail the reporters would seize upon, the morning the bodies were found." Or perhaps the child's hutch foretold my return to the state I was born in and would never truly escape.

Friday I felt possibly hungover, but not like a person having a shunt failure. I revised my article, and we went to the Container Store. When we got home, the IKEA couch had been delivered. Mom and I put it together. Then we had Thai food and more beer. I wondered if it was called two-hearted ale because the sea creature on the label had two hearts, the way, according to "Finding Dory," squid had three. But no, sharks and whales only have one heart, and the beer is named after the Two-Hearted River, in Michigan, where it is brewed. That night, her last one here this visit, Mom slept on the couch, against the wall where I had originally leaned the airbed.

\*

Most stories, or event sequences, begin just like this one, with the introduction of a problem. In this case, the problem was headaches. But we tend to recount *as stories* the sequences of events that proceed as expected, with a climax and resolution. My third-grade shunt failure is that kind of story. For months, it seemed as if I had recurring flu. Finally it was determined that my shunt was not working. Surgery, car crash, surgery. *Resolution.*

Sometimes, however, nearly identical beginnings lead to or, rather, are followed by not a climax and resolution but an anticlimax. This time, as in third grade, it seemed to my doctor as if I might have the flu. And maybe I did. My symptoms abated. The day after my mom left, I got a cold sore—actually, three cold sores—as if to rub it in my face that...what? That my immune system had been fighting off something, and that perhaps that something, and not a shunt problem, had caused my symptoms.

But the lack of a climax didn't make the rising action—those symptoms, those events—any less frightening as it occurred. In the moment, we interpreted my symptoms as the lead-up to Shunt Revision 5. Even after I'd called my doctor to tell him I thought I was okay, I really only thought I was okay "for now." As I cynically filled my shelves, attending to the details of the new life that my medical condition would sooner or later disrupt, I still imagined a future surgery tying up all of these events, starting with the dizziness at the bar near the laundry.

"We tell ourselves stories in order to live," Didion wrote, but life itself is just a mess of events. Sometimes, as I did earlier this month, we live life as a story, and then rather than climaxing and resolving, the story peters out, revealing life's true non-narrative nature.

My mom has been gone for almost two weeks, and I've felt well. So what was the upshot? I might have had a shunt blockage. If so, it went away on its own. Perhaps you can see why I didn't say anything on Facebook. It wasn't a good story.

\*

There's a disturbing undercurrent of disappointment, here, even as I report feeling better. It's almost as if I would prefer a complete—and harrowing and difficult and life-threatening—story to the uncertainty of my life. I hate

not knowing whether the shunt caused my symptoms and worrying that I overreacted to what, to anyone else, would have been an everyday headache. I hate worrying that maybe my period, not the shunt, caused my symptoms. Without changes on brain scans or surgery to uncover a clogged shunt, those doubts will always be there. Rationally, I do prefer the present situation to surgery, which has risks, is expensive, would entail a period of recovery, would cost me time away from work. But you can also see why a surgery that promises to provide an explanation for the way I've felt, make me feel better, and resolve my story has an appeal of its own.

We do, sometimes, on some level, prefer sad stories to uncertainty. Perhaps that's why we sabotage ourselves, dump the water out of the half-full glass. Sometimes it seems more bearable to accelerate a bad and predictable outcome, then get over it, than to fear its slow approach. To, for example, destroy rather than worry about a tenuous relationship.

Maybe some of the sense of disappointment comes down to the human penchant for stories: An anticlimax disappoints the reader within, even if a climax would be a disaster.

Narrative's appeal aside, disasters can provide their own brand of relief, an escape from the ordinary bad situation, for which one bears some responsibility, into a more intense bad situation over which one has no control. There's Didion for that, too. In the opening pages of "In the Islands," Didion and her husband are in Hawaii "in lieu of filing for divorce" and a tidal wave is expected. Then the threat is removed—"a distinct anticlimax"—and Didion is left to face her marriage, her unease, her depression. She might have preferred the tidal wave, suggests this unforgettable pair of sentences: "I am not the society in microcosm. I am a thirty-four-year-old woman with long straight hair and an old-fashioned bikini bathing suit and bad nerves sitting on an island in the middle of the Pacific waiting for a tidal wave that will not come."

The rational part of me does not want a tidal wave. The rational part of me knows, too, that getting a shunt failure "over with" is a stupid idea. I will always have a shunt, and there can always be another shunt failure. The best possible outcome is lifelong uncertainty and fear of a shunt failure that never comes.

\*

When I feel crazy, when I wonder if I am a hypochondriac, when I doubt my own senses, it comforts me to reread the surgical notes from the 2011 shunt revision, my most-recent surgery, seizing on certain bits that corroborate my story. "Sluggish CSF flow was identified . . . An attempt was then made to remove the ventricular catheter, but the catheter was noted to be stuck. . . . Choroid plexus could be seen to have grown into the distal portion of the catheter. Presumably this was the source of the catheter obstruction." My brain had grown into my shunt, clogging it. Then surgeons replaced the shunt, and I felt better.

\*



Recently, our handyman, Jimmy, came to spray for roaches. He sprayed in the cabinet under the sink, behind the stove, along the back edge of the counter.

"I don't see anything," he said.

"They're here. I killed one this morning," I told him. It crawled out of my French press.

"They should come out with all this poison I spray." In the presence of the exterminator, my kitchen appeared roach-free.

"Well, they were here."

---

<sup>1</sup> Technically the morning of Saturday, March 4th.