

Patient Experiences Seeking and Receiving Care for Long COVID Dec. 31st, 2023

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824 days ago I woke up and everything about my life changed, I just didn't know it yet. I had been to the urgent care the night before, on my 27th birthday, presenting with idiopathic pain. I sat on the examination table, legs dangling vulnerably, dressed for a party but feeling anything but celebratory. I looked at the nurse across the examination room, a room which seemed huge in that moment, and didn't have words for what I was feeling. All I could say was "I'm miserable".

The next day, I opened my eyes as my alarm rang for me to attend my Ph.D. seminar at OSU, my very first semester in the program in the English department. I was met with the immediate realization that something was wrong. I couldn't move my arm to reach for my phone, it was like it suddenly weighed more than was possible. My immediate thought was "there is absolutely no way I am going in to class today".

Four days later, I had been declining steadily. I was in severe pain, I knew it was more than the flu. I went to the urgent care, where after a wait I was placed on my back on an examination table and the physician pressed very firmly into my abdomen. The pain was so intense that I quite literally saw stars and began to sob right there in front of her. Before that appointment, after hearing about the amount of pain I had been in, my friend had recommended that I try asking for Gabapentin. Being completely ignorant of the context that I was a young, female-presenting person who lives in the Opioid crisis-riddled Ohio now presenting as "hysterical" by crying, I asked for help in the form of this specific pain-relieving measure--as no Tylenol or Ibuprofen was helping at home. Big mistake. Unbeknownst to me, the attending physician had made the judgement that I was a drug-seeking faker and would now treat me as such.

The doctor looked at me and told me to go home. She said she would prescribe me a muscle relaxer. I asked her, "should I go to the emergency room? This is really bad". She replied: "don't go to the emergency room, they won't give you drugs" and left me in the room alone. I had never been told by a doctor to NOT go to the ER before. The doctor never sent anyone to tell me to leave, and never instructed me to leave, so I thought I needed to wait for my paperwork. As she left I began crying even more because the entire situation felt so helpless, don't go to the emergency room? Who was going to help me then? I cried for an unknown amount of time, and I was so disoriented with the extremity of the pain that I just sat there. No one had told me to do anything else, and even though I wasn't getting help here leaving the office felt dangerous.

At one point, I looked up at the wall and saw the fire alarm. It had googly eyes attached to it, for no discernable reason. Seeing that unreality snapped me back into reality. This whole situation was just so absurd. How long had I been here? What was happening? Why was my entire body on fire but looked perfectly fine? Why did no one believe me? What was real? I started to laugh a laugh I'd never laughed before, and it was a laugh that scared me. I started wandering the hallways of the urgent care, looking for someone to tell me what to do. They looked like they were closing, I asked the nurse where the doctor was and she looked confused and told me that the doctor went home.

I did the only thing I could do and went to the CVS to try to fill the script she gave me for muscle relaxers, though I didn't think they would help whatever this burning was. As I was grabbing a bottle of Fiji water out of the large, chilled cabinets at the pharmacy, I accidentally hit my hand against the door. What would normally have been a slight annoyance at best was way higher on the pain scale. Why did the entire world hurt suddenly? Why was existing painful? I looked at my hand to try to see the discrepancy in my reality, everything I had known for the first 27 years of my life, and the new bizarre world of pain sensitivity that I was now experiencing. To my horror when I looked at my hand, I saw a ruby red line exactly matching where my hand had hit the door. It was like the entire world was a threat to me now. I sat down in the CVS and had a reckoning with myself. This might be it, champ.

I went home and continued to decline. My pain became so severe that it was like the only thing my brain could think about, there wasn't anything else, only pain. My hands started freezing up. I had had panic attacks before, and it wasn't this. Then my arms, then the rest of my body, it was like being taken over by something outside my control until I was on the floor, thrashing but also being unable to move freely at the same time. This was my first experience of the "silent scream" of the chronic pain sufferer. I had already experienced the stigmatization that came with my honest reaction to my pain (crying), and I didn't want to have that happen again (and I didn't want to disturb my neighbors) so I started telling myself to just start screaming on the inside.

My friends told me to call an ambulance, but I kept telling them no, the doctor said to not go to the ER, she said they wouldn't do anything to help me. Thankfully, my best friends said that was stupid and drove to pick me up themselves. They drove me to an emergency room outside of the system of care that had just treated me. At this point, I rely on the testimony of my friends and my medical records to piece together what happened the rest of that night, as I lost my ability to process the experience.

At the hospital, the medical interviewer asked me, "are you having any itching?" "no" I said. My friend looked at me and said "honey, yes you are, look" and pointed to my chest. I looked down and saw that I had apparently clawed and scratched at my chest the entire drive to the hospital, to the point that I had drawn blood. If she had not been there to speak to the truth of my experience, I would not have been able to communicate with my doctors. I think she knew this, because she told them she was my sister so they would let her go back with me. I was totally unable to advocate for myself.

The physician taking my history noted in my chart that I was a "tangential historian". Considering that I didn't even know that I was clawing my chest up, I'm impressed that I was able to be a historian at all. This experience showed me just how much weight of treatment is placed on the ability of the patient to be a good historian, and on the quality of the patient's narrative. The doctor's examination once again felt so rough compared to normal, and my body was so frozen it felt like if he moved my foot he was going to break it. After my IV was blown while being placed, they started me on Tramadol, Benadryl, and Ativan (according to my chart). The doctor said there was "hyperreflexia noted" and "clonus noted" and diagnosed me with a "movement disorder".

The nurse kept asking, "okay, you were at an 8 when you got here, you're lower now right?" I know they wanted me to say yes, and I wanted to make them happy, but it wasn't true, I wasn't feeling any different. Why wasn't it working? Why was no pain medicine working? Was this forever? I just kept saying "no, I'm sorry". Every time they cared for me, fussed, did anything, any time something didn't work, I couldn't talk because I was in so much pain but all I could think was "I'm sorry, I'm sorry, I'm sorry".

After I got home, I read my medical notes to try to piece together what the hell just happened. I may not be seizing anymore but I had zero answers as to why this was happening in the first place. I was still hurting everywhere in my body, and I still felt like I weighed so much that I could barely move. I was shocked by the blatant untruths that I read in my chart. The doctor from the urgent care had marked in my medical chart that there was "no abdominal pain noted". In my chart it says, "patient was instructed to go to ER if symptoms worsen". It also noted that I was "crying inconsolably". These notes were my first foray navigating a medical minefield as someone with an "invisible" illness.

After being treated with steroids, I felt better. My pain significantly improved and I pretty much felt "normal". Wow, glad that's over. Very shortly after I took my final steroid pill the pain returned, and it all came crashing back. This emotional rollercoaster is a mental marathon that chronic pain patients have to live with. Long Covid patients in particular have to live with something I call "indeterminate chronicity", because it is a novel illness. Some of us get "better", some don't, and what is "getting better" when you have an illness that is as yet not longitudinally researched? To some extent we in this generation are all patient zero and will be for the rest of our lives.

Concerned by the misinformation in my medical record, I contacted a patient's rights attorney. She told me flatly "look, I could take your thousand dollars right now, but you're a young woman in a state in the midst of an opioid crisis, you're never going to win". I was stunned. This was my first concrete realization that my age, sex, and geographic location has a real, material impact on my healthcare. I felt so defeated, but the idea that there was no way I could fight the system on this was honestly almost a relief in that moment--I had bigger fish to fry considering I had seemingly gone overnight from being a relatively healthy 27 year old who biked 15 miles a day to someone who was now losing entire chunks of hair in the shower, whose blood had become

thickened, and had developed tinnitus, GI issues, heart palpitations, chronic migraines, visual auras, insomnia, severe fatigue, severe, full body pain, hives, total loss of appetite, full body itching, temperature dysregulation, joint stiffness and pain, random numbness, peripheral neuropathy, severe nerve pain, pins and needles, dizziness, shaking, tingling, heightened sensitivity to pain, light, sound, temperature, etc., blood pressure issues, seeing spots, allodynia, twitching/muscle spasms, sudden onset, stroke-like symptoms, and more symptoms on top of the intense emotional distress this was causing while trying to live my daily life. I had also begun to experience what I now know to be called “derealization” due to the traumatic absurdity of the life I was now living. My shaking hands in the sink stopped looking like mine in the middle of the night, I stopped recognizing the pale, bruised legs I would wake up with from rubbing them in my sleep out of constant pain. My mind had stopped wanting to claim its hurting body.

If I couldn’t call on a patient attorney, and if I was in so much pain that I couldn’t advocate for myself, I was going to need to call in someone else to advocate for me. One afternoon after school, my left arm suddenly lost the capability to hold itself upright and slumped down to my side. This was alarming enough, but I thought it could have just been from sitting weirdly. I got up and started to make lunch, and suddenly the entire left side of my head and face felt a huge shock of pain, and then went numb and my face fell. Everything I had learned had said that this was indicative of a stroke, so it was emergency time again--but there was no way I was going alone. I called my dad, who met me at the urgent care. I went to another location to make sure I didn’t run into the clinician who had seen me before, but lo and behold, she was the one who walked in. I knew my care was on the line, so before she could say a word I looked up and said “is there another doctor I could see?”. My father, knowing me to be someone who won’t even send food back in a restaurant, looked at me in shock.

Another physician walks in and says chipperly “well, looking at your chart I was concerned, but looking at you now I feel much better”. “That makes one of us” I thought. He immediately begins addressing my father like I don’t exist. Well, this wasn’t ideal either. My father was also uncomfortable with the clear deference to his authority and repeatedly said things like “Lauren is 27 years old” or “Lauren can answer that question”. That experience taught me that an effective patient advocate is one that can speak alongside you in a way that doesn’t make you invisible, and that patient positionality often brings infantilization along with it.

I finally called my neurologist in tears on a Saturday in November of 2021 because I had finally hit a 10, my pain had hit a level that I had never gotten to before on the scale and it would not stop. Nothing was helping. I was put on Gabapentin but there were no other gestures toward a long-term plan. Every time the dosage was not enough to handle the pain, it was increased until I (118 lbs.) was taking 2,500 mgs of Gabapentin daily. A few months later I was placed on Duloxetine for severe nerve pain and increased and increased to off-label highs with no plan for titration. For the one who had been labeled as drug-seeking, I was the one routinely asking my clinicians for alternative methods of care to more medications, but I was told that this was the way. Before getting sick, I was on one pill a day (my oral contraceptive) and that was it. At the peak of the med frenzy I was on some 20 medications at a time, 40 odd pills and supplements daily. I used to fill a small plate with what I started calling “pill breakfast”.

I got caught up in a complicated relationship with medications. Though I had many symptoms before starting on new medications, those same symptoms were now being disregarded as medication side effects. I started having rapid, constant weight gain and gained 50 pounds in a matter of months, which worsened my fatigue. I now worried about what being an OVERWEIGHT, young, female in an opioid-crisis state would do to my healthcare, so I made the very difficult and painful call to titrate off the drugs. It took me 9 months to come down off the Gabapentin alone and I was titrated off the Cymbalta far too rapidly. During this period of rapid weight gain, I was so thankful to my PCP for not reducing my symptoms to weight only, as is a common experience for females in similar positions to the one I was in at the time.

My neurologist and I started having this weird, twilight zone type interaction where I would only see him every 6 months and every 6 months we would have the same conversation. “I’m upping your dosage, you’re not pregnant are you? This medicine impacts your birth control, use condoms, schedule with the receptionist for 6 months from now”. We spent more time talking about my potential unborn child that didn’t exist because that was a liability than about my actual, real-time neurological issues that I was suffering from every day, and I was such a checklist that he didn’t even note that we had already had that same conversation 3 times before. Being a female medical patient can often feel like being a walking, talking uterus.

But there are things my neurologist is qualified to do that I am not, and I learned that the hard way after receiving the results from my first brain MRI back through immediate release. After the medical record misinformation incident I had begun reading my records closely, and had become hyper aware that everything I brought into the medical situation was impacting what got put into that record. In so doing I found written on my scan: DX = MS. Apparently, when ordering scans, doctors have to order them under a certain diagnosis to justify the scan. I wasn't told this, nor was I told that MS was in any way suspected, so when I read that line I thought I finally had my two letter answer and called my entire family in tears to give them the news. We cried together and I started making my peace with the fact that I at least knew what this nightmare was. Then, I got the call from my neurologist with that bittersweet phrase that nearly every invisible illness patient knows: "everything is normal". This was to be the first in a long line of "everything is normal" calls. While it might sound like purely good news to a clinician to be able to report normalcy to a patient, it's not that simple for us. For us, it can mean more uncertainty, more tests, more everything. While I am a huge advocate for record transparency, I now wait to consult with my doctor to go over scans.

Reading my medical records more intently also got me to realize how much contextually goes into writing them. My affect was noted, my demeanor, my appearance, things I had never once thought about when going to the doctor, but that I now needed to start thinking about if I wanted help. I started wearing lipstick to not be infantilized, and then I started getting told things like "you're a beautiful young lady, you shouldn't be feeling like this! Give it time" so no more lipstick. After the drug-seeking assumption, my harem pants from Thailand and general hippie aesthetic was traded in on doctor days with a more conservative, "respectable" look, complete with my University of Chicago sweatshirt. When I started using a cane, I began deliberating about whether or not to use it at the doctor's office, as it added a new layer to the internalized ableism that I already struggled with every time I reached for a mobility aid.

As I turned 27, 28, and then 29 with what was diagnosed over time as dysautonomia, intractable chronic migraines, fibromyalgia, and finally in January of 2023 as Long COVID, I reflected on how in such a short amount of time I went as a female in their late 20s from being told things like "you're too young to be feeling like this!" to "well, this is what happens as you get older". My age didn't change much at all in those few years (though I feel decades older) but the way my age is perceived did--and this fickle, fluid perception had a direct impact on my healthcare.

In 2022 I had a repeat COVID infection, one that took my breath away. I have not taken a full breath since June 18th, 2022, though I have seen distinct improvements through pulmonary rehabilitation, reconditioning measures, daily inhalers, routine exercise, aqua therapy, singing, and I am starting STASIS breathing treatments.

Sitting here at the end of 2023, Long COVID has put me through more than I can express. I have bitten bed sheets and screamed into them so the neighbors wouldn't call the police. I have wished for death. I have cried with joy at being able to have a moment where my body is not on fire. I have done rehabilitation programs. I have been held by a caring rheumatologist as she gave me a life-changing diagnosis, and told me I wasn't crazy, and had more control than I think. I have been told 'It's a long haul, not a forever haul'. I sincerely hope that is true. Through Long COVID, I have seen the range of care and lack thereof. I have had my symptoms validated and invalidated by the people I needed help from the most--both inside and outside of the medical sphere. It has taught me to lean first on my own experience and to continuously work to better communicate that experience within the flawed but necessary system in which we find ourselves.

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Bio: Lauren Chivington (they/them) is a 3rd year PhD student at The Ohio State University in the English Department. After becoming suddenly disabled weeks into starting their PhD program, Lauren has evolved their research into considering how patients and clinicians can better communicate with one another, specifically through methodologies of medical humanities and graphic medicine. Lauren runs a blog and resource website called long-haul.blog to foster a community of telling around invisible chronic illnesses.