



Fluoroquinolone Toxicity: From Mysterious Internet Illness to My New Reality - A Memoir of My Bout with Levofloxacin

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I have gone back and forth throughout the years questioning if and when I should tell my story. And unfortunately, this story is not unique in the slightest, despite it now being 2022 and what had befallen me had begun only 5 years prior. In fact, with one search on Dr. Google you can find hundreds upon thousands of stories akin to mine.

Some like to refer to us as “floxies” because it so easily rolls off the tongue and adds a touch of frivolity to an unfortunate situation, while others prefer not to self-identify with this unsolicited internet moniker, because, in some way, it implies that we are forever broken and will never recover from our damaged states. However, despite whatever you choose to call us, we are here amongst you hiding in plain sight. We could be your own mother or father, your own husband or wife, or even your own child one day. But only if you knew the right questions to ask, or what distinct but otherwise all-to-common signs and symptoms to look for, would you discover our existence. God forbid, you became one of us, only then would you really understand our pain and suffering – however, I would not wish that upon anybody or anything.

Although our wounds are invisible, our aches and pains and lived experiences are all too real; therefore, it astonishes me that even now, there are still pre-meds, medical students, and even well-seasoned medical professionals that have yet to hear about this debilitating toxicity, or still deny its very existence! Regardless, I am convinced that it is never too late to stimulate change and raise awareness, because I have hope that one day this syndrome will become a bona fide medical diagnosis that medical students around the world will first study when they learn about infectious diseases and pharmacology, especially as they cover potential iatrogenic side effects of certain antibiotics.

So, I encourage you to read on and heed my words and do not take them lightly, nor mistake them for hyperbolic, fanciful hearsay. Just try to keep an open mind, and avoid the this-will-never-happen-to-me bias that we so easily fall prey to when we read about adverse or unfortunate medical events, because you, too, could become one of us one day.

With that said, if you have not already guessed or have resisted the urge to look up the word “floxie” on Google, then let me introduce you to my story and the internet illness that ended up changing the way I look at medicine to this very day.

I still remember it like it was just yesterday. I ended up coming down with a very severe urinary tract infection in the fall of 2017. At first, it felt like a tingle, then a burn, and then it started moving up my urethra like a bullet train. By the time I was able to get tested, it was already 2 weeks out and still another week stood between me and my test results. Fortunately, everything ended up coming back negative, but I was still in unbearable pain and already on antibiotics.

The nurse practitioner had prescribed me the typical medications for such an infection — azithromycin, doxycycline, ciprofloxacin — and even gave me an intramuscular shot of ceftriaxone; however, we could not eradicate this bug and my symptoms were steadily becoming worse, so much so that it hurt to sit. The worst part about the situation, though, was that neither the nurse practitioner, nor the other healthcare providers could see any physical symptom nor find any discernible cause for my pain. So that next week, I took it upon myself to get a second opinion from a local urologist.

After about an hour and a half of talking and listening to my case, the urologist came up with a diagnosis of interstitial cystitis and put me on a medication called pentosan polysulfate. For the first couple of weeks, it worked like a miracle, but sooner rather than later, it ceased to have an effect.

A little discouraged, but still hopeful, I decided to return to the Doc to see if there was anything else they could do for me. His physician assistant recommended that we re-try the antibiotic approach, but with a different drug called levofloxacin, since the infection seemed to be currently concentrated in my prostate. Unlike other antibiotics, apparently, this drug could uniquely penetrate the organ and clear any residual infection that remained.

I paused for a second, because I had already tried a similar drug by the name of ciprofloxacin, but my only side effect was slight knee pain that went away after 2 or 3 days. In any event, I still brought it up. I was told that just because ciprofloxacin did not work for me, did not mean that levofloxacin would not. So, off I raced to the pharmacy.

Before handing me the drug, the pharmacist casually printed off a short advisory statement and then gave me a quick consultation about the medicine's potential side effects. He warned me that people 65 years or older should be especially careful after taking this medication and then proceeded to point to the long list of adverse reactions on the back of the piece of paper. Since I was nowhere near that age, I naively disregarded them, as one normally does. Because, who gets any or all of the side effects from a specific medication? Not to mention, I was 24, healthy, and in the best shape of my life.

I was prescribed 750 mg to be taken in the morning on an empty stomach for a week. By the 5th day of treatment, my knee started to really hurt, but, like magic, my infection had suddenly disappeared. One potential side effect of this medication was, also, joint pain, so I called the PA and asked if I should continue taking the medication. She said, "No," and I immediately stopped. End of story. Happily ever after, right?

Well..., about 6 days later, after taking my last pill, I tried to get out of bed, but fell to the floor in agonizing pain. I could no longer use my legs to support my own weight! Instead, I had to prop myself up and use whatever upper body strength I had left just to stand up. Both my knees were on fire and my quadriceps felt like overly tightened piano strings that could snap at any moment. Obviously, I knew this was not normal, but I chalked it up to some latent, secondary side effects of the medication.

For breakfast, I went to the kitchen but could hardly stand for more than 2 minutes without clinging to the cupboard to keep my balance. I told my mom that I was having trouble walking, and she did not believe me at first, until she saw my legs start to buckle and tremble beneath me. But you know how moms are: she just told me to go back to bed, get some rest, and that everything would be alright in the morning.

There was not really anything else that I could do being in that much pain, so I Googled, “levofloxacin side effects,” and “levofloxacin joint pain.” Immediately, all these forums, chat rooms, and websites popped up with people describing similar symptoms to mine. Some had it worse than I did, being bedridden for years, others had their symptoms go away in about month, and the unsuspecting few did not have side effects until months or years after their last pill. It seemed like every person’s timeline was unique, but what we all had in common was this same class of medications: fluoroquinolones. Apparently, ciprofloxacin (Cipro), levofloxacin (Levaquin), and moxifloxacin (Avalox) were the most common culprits, typically prescribed for UTIs, pneumonia, and infectious diarrhea.

On the internet, there was already a name for us. We were the “floxed” or “floxies.” But how is it that I and most of society had never heard of this nickname or its so-called corresponding illness *fluoroquinolone toxicity*? This toxicity can be defined as the constellation of chronic symptoms that a patient suffers from after taking a medication from the fluoroquinolone class of antibiotics. They can range from something as innocuous as minor joint pain, tendonitis, and neuropathy to even more serious reactions, such as Achilles tendon rupture, heart attack, and stroke, just to name a few.

As bad as that sounds, the worst part about all of this is we still do not know why this happens to some and not to others, nor how to rid “floxies” of this devastating syndrome. And, because this medication affects people in a myriad of ways, there is no one-size-fits-all cure.

As I laid in bed that day, I thought to myself, “How could this be? How could I have let something like this happen to me and my body? How could 5 pills devastate me in a matter of only 5 days?” It felt like a bomb had detonated in my body and I was 24 going on 65. I had never felt so geriatric in my life. It was like I had just entered the Twilight Zone, except this was the real world and this was my new reality.

For the next month or so, I had terrible insomnia and could hardly sleep for more than a couple of hours a night. My heart seemed to race randomly, as if I was running a marathon non-stop, and I had already lost 12 pounds in a matter of 21 days. Sometimes, I would have weird involuntary fasciculations vibrate throughout my body, and my eyes would twitch uncontrollably, and I would feel erratic electrical shocks from head to toe. Not to mention, I still could not fully bend my legs without being in intense pain, nor comfortably walk across a room or stand up straight; and my range of motion was reduced to about 5 degrees on a good day.

The scariest part about all of this was the unknown. Not knowing how long I was going to be like this. Not knowing what was happening to my body. Not knowing if anybody could cure me, or if I would ever be the same again. The only thing I knew for sure, at the time, was that only time would tell.

I soon learned to heed everything my fellow “floxies” suggested. Avoid NSAIDs and steroids. Eat healthy and stay away from processed and antibiotic-dosed foods. Take magnesium. Get a good night’s worth of sleep. And exercise and work through the pain to build my body back strong again.

It turns out that not everything on the internet is not always *not* true. In one way or another, almost everything that happened to those people on the “floxie” forums ended up happening to me. I started developing weird allergies to everything. First, it was to the particles floating in the air from the demolition site at work because I started feeling like there were bugs crawling on my scalp. Then, it was to my detergent because I woke up with hives all over my body. Then, eventually, I became allergic to my daily protein shake.

Thankfully, as the months went by, most of my initial symptoms went away; however, I was still left with an intense traveling neuropathy that would come and go and leave me with a burning sensation on my thighs and buttocks, which made it exceptionally uncomfortable to place things on my lap or sit for long periods of time.

My neuromuscular symptoms, like all other “floxies,” started to become cyclic as well, which is the weirdest side effect that still continues to this day, but to a much less severe degree than when it first started. My symptoms seemed to have a mind of their own and travel to and fro throughout my body in phases. I first noticed this right after having my extreme bout of tendonitis in both knees. As my knees started getting better, other parts of my body began getting worse. First, the pain went from my knees to my Achilles tendon, making it hard to walk or run; then my face and my neck, making it hard to blink, talk, and swallow; and finally, to my thighs and buttocks, making it hard to bend or sit still; then it would return to my knees and the cycle would start all over again.

What was curious about the syndrome was that whenever I got my heart rate up or experienced drastic changes in altitude, I could make my body progress through each phase at a more accelerated rate; the quicker the syndrome passed to the next phase, the quicker the afflicted area went back to normal like nothing ever happened.

My symptoms would ebb and flow and get better and then worse; however, slowly but surely, I was improving day by day. I knew I was never going to be the same Michael that I had been before, but who wants to stay the same forever? They say that in order to grow you have to suffer, so I guess I matured a lot in the first few years after being “floxied.”

And I am not going to lie. When I was in excruciating pain and did not know where else to turn, I tried a lot of things, like Chinese herbal medicine, acupuncture, Latino folk remedies, and over-the-counter supplements. Believe me, I do not think there is one supplement I did not try to see if it would assuage my symptoms. But, in the end, I mainly turned to Western and functional medicine and, consequently, saw family medicine doctors, orthopedic surgeons, neurologists, and alternative medicine doctors all with varying degrees of success.

Some people ask what I learned from this whole ordeal. If you talked to my friends, they would say I could teach a college course on the subject or even write my own textbook or novel. And, to tell you the truth, I realized that the only person who truly understands the signs and symptoms or ramifications of any illness is the patient. That is why it is so vital to take care of your own body and be your own advocate and make the best decisions for yourself that you can. Because, in the end, you, and only you, are the one who will have to live with those decisions and live in your body — not the doctor, not your mother or father, nor the pharmaceutical company that created the drug to treat your illness. For this reason, I believe that you should try to truly listen and understand what your body is telling you first, before immediately turning to Western medicine or pills, because sometimes the best medicine is no medicine at all, unless absolutely necessary.

Going through a traumatic experience like this has completely changed the way I now study science and view medicine. It is one thing to learn the facts of medicine in the classroom or a textbook and regurgitate that information for a test, but it is quite another when those facts of medicine become your life. Now every time I study the pathophysiology of a disease, I cannot help but think to myself, “Could this also be one of the reasons why I am still in pain today?”

We have yet to find a cure for many chronic diseases and syndromes out there, such as cancer, HIV, COVID-19 Long, and now fluoroquinolone toxicity. So, ask yourself this: What would you do if you were afflicted with these diseases or syndromes and nobody knew how to cure you? In the end, you would simply have to learn to live with the side effects and thrive in spite of them.

That is, you would have to find a way to use them as a strength instead of a weakness. I can say, since my bout with levofloxacin, that I have been able to better empathize with my family members and friends and even some patients that have also had similar chronic symptoms or mysterious illnesses like mine. Unfortunately, I had to learn all these lessons the hard way, and it saddens me that tragedies like this had to occur to make me appreciate what I already had, but that is human nature, I guess.

Thankfully, I have seen this “internet illness” get the much-needed attention that it deserves, which gives me hope that maybe one day we will find a cure for this obscure toxicity and understand why it affects some people and not others, or maybe even be able to prevent it from happening in the first place.

I am well aware that this is still happening to people, because, since my “floxing,” I personally have had two grandmothers, my mother, and a friend’s mother all be adversely injured by these medications. So, do not hesitate to contact me if you or someone you know has been hurt by these medications and needs someone to talk to. If you would like to know more or hear other stories like mine, there are several support sites like FloxieHope (www.floxiehope.com) and MyQuinStory (www.myquinstory.info), which I recommend and are some of the same websites I first frequented when I became ill.

I do have *good* news, though: For most, there is still life after being “floxed.” Since this whole experience, I have accomplished more than I could have imagined. I have started to run 2.5 miles a day after my two-year running hiatus and have lost all the weight I originally re-gained. I have worked as a chemist, traveled to Central and South America, volunteered as a medical interpreter, and learned various romance languages too. In addition, I have just published my first first-author paper having to do with breast cancer experimentation and transgenic mice at UT Southwestern and am applying to medical school as we speak.

My intent for this piece and the main reason I decided to divulge my experience *now* is not to frighten you nor to satanize the medical community or pharmaceutical industry as a whole, but to galvanize *you*, my reader, to effect positive change in the medical field, either as a student, patient, or provider, so you can make more informed decisions regarding your health and the healthcare of your loved ones, the diagnoses and treatment of your future patients, or the advancement of your own medical scholarship.

As I write this today, I take solace in the fact that potentially hundreds upon thousands of UTA students, educators, and alumni, as well as the general public may read my story and benefit from my lessons learned, so they can hopefully avoid being devastated by this terrible toxicity and never have to know what it really feels like to be “floxed,” like I was those many years ago!

