Long COVID sufferer describes her experience: “I do not recognize my body. I feel like a prisoner in it”

Norisa Diaz, Katy Kinner
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Katie Blair is 33 years old and has been suffering from Long COVID since her initial infection in March 2020. Prior to contracting COVID-19, Katie worked a demanding job as a corporate recruiter in New York City. She lost her job a year ago due to the pandemic.

Originally from a small town in Washington state, Katie told the WSWS that she left home when she was 18 and moved to France without knowing the language. Later she would find herself in New York City, where her life revolved around work and Broadway shows. She and her roommate lived in Midtown Manhattan. Her friends and roommate worked in theater. In her two years in New York, she saw more than 50 productions.

“I have had a very independent and adventurous spirit my entire adult life, and COVID has taken all of that away from me,” she said.

“Long COVID has changed everything about my life. I don’t even recognize the person I see in the mirror. I’ve gone from independent to dependent, and it goes against everything I have ever worked for. My immediate family has been so helpful and gone out of their way to care for me, but my extended family I’ve had to block. They told me I look fine, why am I spreading lies, spreading fear? ‘COVID is not real.’ I have had some friends do the same. I’ve lost so many friends this year, but the ones that matter are still around.”

More than one year into the coronavirus pandemic and many are still suffering chronic symptoms from their initial infection. This post-viral syndrome is sometimes called Long COVID and sufferers are referred to as “long haulers.” Some long haulers have been suffering with Long COVID for more than a year with no idea how long their symptoms will persist.

Similar to data and reports from other Long COVID sufferers, Katie describes a varied set of symptoms, which rotate or occur all at the same time. Symptoms vary, but they commonly include heart palpitations, shortness of breath, fatigue, headaches, brain fog, depression, anxiety and short-term memory loss. Many long haulers are middle-aged, have few to zero medical comorbidities and were never hospitalized for their initial COVID-19 infection.

She described a laundry list of ailments: “I get dizzy, I pass out. I am 33 years old, and I walk with a walker. I am on a very, very strict diet. I have a histamine intolerance, which I didn’t have before, and it really limits what I can eat, but I also don’t have any appetite. My weight is a yo-yo. I initially lost a lot of weight, and then I got the ‘COVID bloat’ and gained 30 pounds in weeks, but had initially lost 60. My menstrual cycles are nightmares. I am in so much pain I cannot do anything the week before, the week during and the week after. I had never had any problems with that.

“I did have anxiety before, but it was high functioning, and I could accomplish anything I put my mind to. I was very successful in school and work. Now I refer to it as my ‘nonfunctioning anxiety.’ I can’t even go to a store now. I cannot be around other people. Noises and sounds affect me.”

When asked how her symptoms have changed over time, Katie said, “Now is the worst of it, a year later, and it’s the worst it has ever been. Right around March is when my neurological issues got worse. I stutter, some days are worse than others. I pass out, the dizziness is worse.”

While little is still understood about the phenomenon of Long COVID, numerous studies have indicated that approximately one in three people infected with COVID-19 will develop Long COVID. For some this could mean six months with no sense of smell and mild fatigue, while for others, like Katie, it could mean an entire life put on pause from debilitating symptoms.

A more detailed analysis of recent research on the subject of Long COVID can be found here.

Katie first acquired COVID-19 when she was living in New York City in March 2020, at the time when it was the epicenter of the pandemic in the United States. She continued her account. “When I initially got sick, my fever was low, 99 degrees. At first I was in denial but was quarantining. In March of last year masks were still not mandatory. If anything, we were told not to buy them so the health care workers could still go out and get them.

“The night that really sticks out in my mind was when my fever reached 104.5 degrees. I called all the hospitals and was told it was a six-hour wait to get into the hospital, and it was snowing.”

Katie described the confusion and horror of that night as she hallucinated in her high fever dreams. She saw her grandfather and a childhood cat, both of whom had passed away.

“I told myself, ‘If I wake up, I am going to get myself a kitten.’ I had to bribe myself to wake up, and I didn’t tell any of my friends or my family what was happening because I didn’t understand myself until I spoke with my doctor afterwards. She said that if I had tried to go and wait to get into the hospital to get the help I needed, I would have died. She said I wouldn't have made it because it was dangerous for me to be exposed to the elements while my body was so incredibly weak and likely by the time I would have made it into the hospital, I would have been on a respirator.

"Even though I was not hospitalized I still went through the trenches. I was completely alone in New York City. All my friends had left, and I had no one. I woke up in tears the next morning, I knew something had happened, but I didn't fully understand what happened until I spoke to my doctor."

Katie would continue to suffer from Long COVID symptoms for weeks and made the decision to go back to Washington to be closer to family. "By May I realized I was not feeling better, and my lease was up in June. My roommate had lost his job as well because he had worked on Broadway and left the city.

"I rented a van, and even though I was full of fatigue, I packed up my life and drove myself across America back to Washington. It was one of the hardest things I have ever done. There were days I could only make three hours of driving because I could not do it. At that point I did not have neurological issues."

After a short time in Seattle, Katie realized her apartment had mold and was aggravating her health so she decided to move in with her parents in Wenatchee, where she could also find greater support.

Moving home and leaving behind her life has been difficult but she is grateful for the help. "I do not recognize my body," she said. "I feel like a prisoner in it, but I am at the point where I need as much help as I can get."

Katie said she was excited when she arrived in Seattle, believing it to be a hub of research on Long COVID, but realized quickly that her doctor and naturopath at the time did not assist her with treating ailments. She has had to wait a long time to get access to specialists.

"I did not see a doctor in person from when I was sick in March and until January 2021," she said. "No help, no tests were done, and I don't know why they wouldn't do anything to help me. They told me they believed me but would do nothing to help me but suggested I drink Turmeric tea. I thought I was the problem."

Many in the chronic illness community refer to this dismissiveness from medical professionals as "medical gaslighting," and studies show it can cause trauma or even medical PTSD in some patients. Medical gaslighting is also a common experience among long haulers. Patients are sent home only with prescriptions for anti-anxiety medication and told it is all in their heads. Those who seek second opinions or repeat medical visits are chastised or labeled as drug-seeking.

Katie's father is a teacher but also works at a clinic and was able to get her connected with specialists. "Next week I finally get to talk to a psychiatrist, and I will get to see a GI specialist," she said.

She now has a doctor, whom she is grateful for because he appears to be honest and keeps up on the latest research. He also admits how little is known about this phenomenon in the medical and scientific community. She said she is finding the best solutions in support groups and sharing them with her doctor. It was the support group that led her to find that her GI issues were related to a histamine intolerance.

Katie also discussed her thoughts on school reopenings. "The question of schools is near and dear to my heart. My father is a teacher; my mother is a librarian; my brother-in-law is a teacher; most of my best friends are teachers.

"When it comes to children, I am shocked. I've heard of kids getting lung problems and fatigue problems. It takes everything away from being a child. The fact that they want to open schools makes me crazy. I don't think schools should reopen until they are vaccinated. It should be like going to school for the first time when you get the measles vaccine. We have to protect the children. For some of us it may be too late, but it's not for them. No one would want this for their child."

Katie is speaking of the fact that children are not spared from developing Long COVID. Almost 3.2 million children in the US have tested positive for SARS-CoV-2. Pediatricians have been noting that some are developing problems that have persisted for weeks or months after their infection.

Though large-scale studies on this issue are sorely lacking, data emerging out of the UK shows that around 13 percent of children under 11 with confirmed SARS-CoV-2 PCR testing had at least one symptom five weeks after infection. Fatigue, poor sleep and breathing difficulties were some of the disorders mentioned. For adolescents, that figure was similar, at 15 percent.

Due to the bipartisan ruling class "herd immunity" strategy, which allowed the virus to spread unabated, even a small percentage of Long Haulers out of the vast number of infections is enough to present a serious public health issue.

A wave of chronic illness for years following the pandemic will continue to overwhelm the already crumbling health care system in the United States. The care of the chronically ill is notoriously unprofitable for hospital systems, and research and treatment in the area will likely not be prioritized. Conversely, chronic illness is notoriously expensive for the average worker, and it burdens people with hundreds of thousands of dollars in medical debt.

Katie is one of the growing number of people whose lives have been stolen by COVID-19. Her life in New York, her pursuit of a career in global wine studies, travel and exploration are on hold for the foreseeable future.

She has good days and bad days, the latter becoming more difficult with increased neurological issues. Plans for her now include moving in with her grandmother next door for both independence and medical concerns. She currently masks even in her family home, as both parents have had to return to hybrid teaching and risk daily exposure.

Katie concluded, "What I want people to understand is that there is a fate worse than death, and I want people to start caring. Long COVID will be the second pandemic unless it's stopped."