

Searching for Clues and COVID Long Haul Relief



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Michael Elliott* is in a unique position to understand the chaos of the pandemic. First, he's a health care journalist, struggling to translate the world of medicine for the average person who knows they should live healthier but not how or why. Second, he experienced the [COVID](#) pandemic early and intimately. In March of 2020, New York was in the midst of one of the earliest and most severe outbreaks in the United States and it was stressful time. For Michael, though, it brought more than just inconvenience and anxiety.

"It brought 'an alien feeling inside of my body' and 'a vise grip on my head' but nothing that sounded like the typical description of COVID. All the Googling in the world couldn't get me answers," he said. His [symptoms](#) continued to accumulate, with the feeling that something was wrong joined by shortness of breath, chest pain, stomach issues and nausea," he said. "I just knew that my body was suddenly under attack."

After a starkly terrifying call to 911 from the floor of his apartment because of being unable to catch his breath, he ended up in the emergency department but there were no COVID tests available when he went in. Other people in the ED had more typical COVID symptoms, coughing violently. He was sent home without being admitted, with some advice (and the suggestion that he'd had a panic attack) but his symptoms continued. But over the months, Michael saw many doctors, had at least eight blood draws and had every part of his body X-rayed. Part of the issue was no one had experienced COVID long enough for post-COVID syndrome to be identified, he reflects now.

"I was happy to do what ever they asked, I just wanted them to make it make sense. I'm extremely grateful I had access to so many specialists in New York City, but after it became apparent that no more moves were available, and doctors were overwhelmed, I felt helpless," he said. "For long COVID patients, I can say that even the best doctors in the country, some of which I talked to, had no cures, and can only offer band-aid solutions for symptoms."

The frustration Michael felt with his [Post-Acute COVID-19 Syndrome](#) (PACS) – also known more colloquially as COVID long haul — is similar to the experiences of many people with autoimmune disorders, with the mismatched symptoms, the inconclusive diagnostics and the significant shift in daily life. He had access to more information, but much less research or conclusions due to the still-emerging body of research on post-COVID syndrome. Most of it is crowd-sourced and currently, the summary of all the possible COVID symptoms is more than 200. A good collection of data, but no real solutions – and nothing personalized to his situation.

He identified that he needed help to guide him through the process, because he was not able to determine why his symptoms came and went without any clear triggers. He kept a journal, saw a physical therapist, a herbalist for gastric distress, acupuncturists for stress relief, but he was still disabled by frequent and severe migraines. This led Michael to [Mymee](#), a digital care program for

COVID long haul combining data tracking with personal health coaching, to try to isolate the triggers for his long haul symptoms.

"I was tracking but I wasn't able to draw the conclusions myself. Mymee helped me make sense of this. The coach suggested what to track at first and we worked together to connect the dots, suggesting pulling back on one thing or reintroducing something else. I never felt self-conscious sharing because we both had the same goal in mind: to get me better," he said.

Michael, who is in his early 40s, had previously been very active, working out five to six times a week, eating a healthy diet, and enjoying New York with his wife and 10-year-old daughter. His frustration with trying to deal with multiple symptoms and mysterious triggers was growing, and feeling hopeless was adding to his stress. After any kind of physical exertion, he'd have a debilitating migraine within a day or two.

With his coach, they worked together on diet, including removing a few staples he ate regularly, like gluten, dairy, histamines and pea protein to try to reduce inflammation. Next was exercise, which including walking and bike riding, his two main forms of transportation in the city. Together, he and his health coach Jen looked at how long he could ride or walk without triggering a migraine, testing and timing different variations. They tracked his heart rate and found that certain kinds of exertion over six or seven minutes would cause migraines so severe that they'd take up to a week to recover from.

While that much less exercise is a significant change in lifestyle, Michael said he's grateful to have the information to address these things. "Feeling helpless is the worst feeling to have," he said. "I know myself and I knew I would need a guiding hand to track that properly. You can't underplay how important it is to be held accountable to someone. And of course, I had no impetus to cheat — this was only for my benefit."

He stayed motivated by the small wins, and by having both his health coach and her access to the data available through the Mymee database for strategies that have worked for other people living with chronic autoimmune conditions.

"It was therapeutic to unload my experiences each week, so there was that immediate benefit. Then, after hanging up, I got to put the new strategies into practice. Sometimes they worked, sometimes they didn't, but each time, I got a boost of much-needed hope. It helped that she had experience as someone with an autoimmune disorder herself. I could trust that she knew what I needed instead of empty platitudes," he said.

The next challenge was his fatigue, which as many people who experience it will tell you – is a word that doesn't do justice to the deep, aching, tired feeling.

"I need to lie down and recharge myself or I will spiral out, feel like I'm dying, my body telling me strongly to stop. I can't even break down boxes for recycling – that's got to be somebody else's job now," he said.

Jen and Michael continued to work together over the course of the 16-week program, and added some breathing techniques that were helpful, and Michael changed some of his work habits. Many people began working from home during the pandemic, but Michael had been doing that before. His coach gave him tips on optimizing his work posture, starting with a move from the couch to a desk to avoid strain on his body.

These small steps have made a difference and Michael wishes he would have found them sooner. He continues to work with his doctors and health care team, and the research into the causes of PACS continue to advance. Until then though, he's managing by avoiding the things that trigger his symptoms and he is much better at describing his symptoms to health care professionals when he has an appointment or tests.

In 2021, a move to Florida became a new life path for Michael and his family, adding more sunshine, more living space, and a pool, because the cold water helps him physically feel better. The family has adjusted to his lower energy levels and Michael said his daughter "treats him as the same guy she's always loved" and that gives him perspective on everything they've been through in the past year and a half.

"Knowing even a little more than I did helps. I might have figured it out on my own but I'm grateful to have found that there were things I could do to take a bit more control of my health, he said. "Mymee is not therapy but there was no one who knows what I was going through week to week like my coach. She was really trying to help and had the tools to do so – it was really valuable."

The investigation is ongoing and Michael continues to collect clues to address his symptoms, and to help others through his work as a health writer in understanding the components of how and why people living with COVID long haul and other chronic conditions can improve their lives.

Michael recommends the following resources for people living with COVID long haul:

<https://www.wearebodypolitic.com/support-group>

*name has been altered for privacy