

Invited Review

Long-Term Effects of COVID-19: The Stories of 2 Physicians Who Became Patients

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Approximately 10% of patients who survive COVID-19 will proceed to have lasting, often debilitating effects, known as “long COVID.” These symptoms can take various forms, most commonly including postexertional malaise, fatigue, brain fog, dizziness, gastrointestinal symptoms, heart palpitations, diminished sexual desire or capacity, loss of smell or taste, thirst, chronic cough, chest pain, and abnormal movements. Here, 2 physician-patients present their own experiences with long COVID and share their perspectives on the experience. One key insight is that patients who are not familiar with long COVID may not attribute ongoing symptoms to their illness. Diagnosis requires an astute, compassionate physician who understands long COVID and can appropriately situate the symptoms within the evolving understanding of the condition, leading the patient toward recovery.

Keywords: long COVID, PASC, SARS-CoV-2, patient narrative

Introduction

Although vaccination and treatment have significantly reduced the mortality associated with COVID-19, many people who become infected with SARS-CoV-2 continue to experience persistent physical or mental symptoms, commonly referred to as “long COVID.” According to the Centers for Disease Control and Prevention, long COVID is defined as “signs, symptoms, and conditions that continue or develop after acute COVID-19 infection.”¹ These symptoms can begin during or immediately after the acute phase of COVID-19 and last weeks to years. The symptoms vary from person to person, ranging from mild to debilitating.

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An estimated 200 symptoms have been associated with long COVID, of which the 12 most common are postexertional malaise, fatigue, brain fog, dizziness, gastrointestinal symptoms, heart palpitations, diminished sexual desire or capacity, loss of smell or taste, thirst, chronic cough, chest pain, and abnormal movements.² Many people with these symptoms of long COVID remain undiagnosed and untreated, which can substantially affect their lives and even jeopardize their livelihoods. Individuals most likely to be affected are those with comorbid conditions, those who are unvaccinated, and those who experienced severe disease requiring hospitalization or intensive care.¹ Thus, members of vulnerable populations that were disproportionately affected by COVID-19 are more likely to develop long COVID.

Responses to the US Census Bureau Household Pulse Survey from June 2023 indicate that approximately 10% of adults in the US who were infected with COVID—or approximately 10 million Americans—have experienced long COVID.² Another study with a more global patient population showed the prevalence of long COVID among those ever infected with COVID to be between 10% and 35%.³ Furthermore, long COVID has been shown to affect those who tested positive for COVID-19 and those who tested negative but experienced persistent symptoms after an acute illness consistent with COVID-19.¹ This finding could point to an even larger number of people affected by long COVID than reported in these studies. Although research is ongoing, the impacts are substantial and need to be addressed to help these patients understand and manage their symptoms.

Our intention in this article is to generate more awareness about long COVID and encourage patients to reflect on their symptoms and seek medical help as needed. Because the symptoms can vary and may not be recognized as being related to long COVID, sharing personal stories about long COVID may help others who are affected. To accomplish this goal, we present the personal stories of 2 patients, both physicians, who experienced long COVID but identified it at very different stages, leading to differing approaches to dealing with their symptoms.

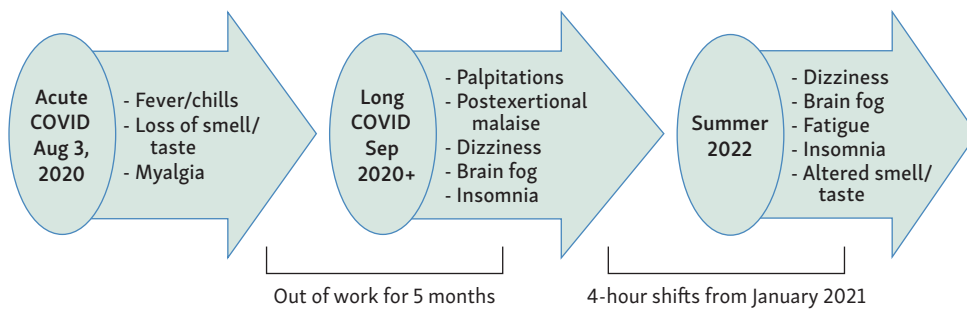


Figure 1. Patient 1 Disease Timeline.

Patient 1 is an emergency medicine physician who immediately recognized his symptoms as being related to COVID-19 and sought medical attention early in the disease course at a time when long COVID was less well understood. Patient 2 is an emergency medicine resident physician who experienced his symptoms without recognizing their etiology and identified them as long COVID only after hearing the story of patient 1. Although these are only 2 stories of long COVID, they show that the effects of long COVID are real, even if the condition is still not fully understood. Identifying the symptoms as being related to COVID-19 is an important first step to helping and offering validation to individuals with long COVID.

Patient 1

On August 2, 2020, I worked a normal evening shift in the emergency department. The next day, I awoke with a headache that began what has become a 3-year ongoing journey first with acute COVID-19 and then with long COVID (Figure 1).

The first week, my symptoms were mild. I had low-grade fevers, headaches, myalgia, and chills, with most of these symptoms being worse in the evenings. Altered senses of smell and taste began on day 2, an experience that was at first more interesting than worrisome. My children made me a tasting plate and delighted when the only items I could taste were the most artificially flavored candies. I was fortunate to be able to quarantine in our basement, protecting my family from infection during the time before vaccines. I worked a bit, watched movies, did puzzles, and waited.

The waiting droned on. Fevers continued daily for 40 days. Headaches and altered taste and smell continued unchanged and my other symptoms began to evolve. Myalgia and chills gave way to palpitations and insomnia. I had trouble falling asleep and then would wake during the night with a pounding heart, unable to fall back to

sleep for more than an hour on many nights. As I walked in the neighborhood, I noticed that if I went more than half a mile, or if I bounded up stairs too quickly, I would become completely exhausted, unable to rise from the couch for hours. This fatigue would usually have a delayed onset. I often felt that I had the energy to do anything, but I would pay for it later with what is best

described as a completely drained battery.

As weeks turned into months, and as attention turned to long COVID in the medical literature and the media, I began to understand other symptoms I had been experiencing. Although I never had the word-finding difficulties and memory problems that many with brain fog describe, I did notice clouded cognition, especially after either physical or mental exertion. A long walk could bring it on as easily as a long video conference call. The brain fog went hand in hand with the fatigue.

Emotionally, this situation took a heavy toll on my family and me. I tried to stay positive, taking comfort in the perspective I had gained in the emergency department during the preceding months, seeing how much worse

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things could have been. I focused my attention on the present, trying to stay in a position of mindfulness while my mind tended to wander to what the future might hold. However, the uncertainty about how our lives could be permanently altered by this illness and whether I would be able to return to work weighed on us.

Throughout these months, I underwent many medical examinations and tests. My first COVID polymerase chain reaction test (on day 0) was negative, as was a subsequent test (on day 18). Although COVID-19 remained the most likely diagnosis based on exposure and symptom profile, my primary care physician tested broadly for alternative illnesses and referred me to our

institution's respiratory clinic for further testing. All the results were normal. Even the antibody tests were frustratingly negative, and we would not learn until later that this situation is all too common in individuals with long COVID, perhaps offering a clue to the etiology of the condition. The only abnormality that stood out was new hypertension. I was a fit 40-year-old man when I became sick, and 3 weeks into COVID-19 my blood pressure was consistently averaging 180/100 mm Hg or higher.

My primary care physician referred me to a cardiologist with expertise in dysautonomia, and that was when I finally started to see some improvement. The cardiologist identified dysautonomia and prescribed a calcium-channel blocker and antihistamines. The palpitations subsided, and my fatigue improved substantially. The headaches improved too. For the first time, I had hope of returning to work and to my life. That would take time, however. For the time being, I welcomed the improvement and continued to adapt both at home and in my nonclinical work to accommodate my symptoms.

Over these 3 years, I have seen many specialists and engaged in continuous efforts to evaluate different medications, therapies, and lifestyle changes to improve my health. Much of this response was driven by the dedicated study and compassion of my physicians. Some of it was driven by ideas mentioned on social media or in patient support groups. I began to finally understand the value of these forums for patients like me who were not finding complete symptom relief despite the best medical efforts.

Having long COVID had substantial consequences at home and at work. Personally, I was not able to be the

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dedicated husband and father my family had depended on. I could not play actively with my children or be relied on to handle the day-to-day driving related to their activities. At work, I regretted the added strain my absence put on an already taxed faculty. I was out of work for 5 months and then able to work only part-time until just this spring. Initially, I was able to work

only 4-hour shifts and then very gradually advanced up to 8 hours, with a setback when I was reinfected at a medical conference in 2021. I was able to do many of my nonclinical activities remotely, teaching and meeting with residents, but I had to adapt my efforts to my symptoms. I could not participate in residency application review or interviews for the first couple of years because of fatigue and brain fog.

I continue to improve very slowly. Although I believe that I will have lifelong lasting effects from COVID-19, I also retain hope that my symptoms will continue

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improving to a point at which they no longer affect my daily activities.

Patient 2

It was not until the end of my first year as an emergency medicine resident physician on June 13, 2023, that I took stock of symptoms that started after I had COVID-19. I first contracted COVID-19 at the end of December 2021 following a family holiday gathering, our first such gathering since the beginning of the pandemic. We were all fully vaccinated and had decided that it was safe enough to have a family vacation. This was at the peak of the epidemic wave of the Omicron variant. At the end of the weeklong vacation, it was clear that most of us had been exposed to the virus. After returning home on January 1, 2022, I tested positive for COVID-19. My symptoms included a severe sore throat, cough, fever, myalgia, and allodynia. Thankfully, I never lost my sense of taste, which some of my family members had reported. I felt moderately ill. I quarantined from my wife and managed my symptoms supportively with fluids and an occasional antipyretic. I never developed any severe symptoms that would warrant going to the hospital. After about 10 days, my symptoms had improved, and I thought that I had survived COVID-19. As a healthy man in his mid-30s who was fully vaccinated, I did not expect anything different; however, my journey had just begun (Figure 2).

Having recovered from the acute phase of COVID-19, I was finally able to end my quarantine. Shortly thereafter, I started noticing new symptoms, which included post-exertional fatigue, brain fog, word-finding difficulties, and memory problems. I would become overly fatigued during the day if I did not get enough sleep and easily became short of breath while walking up the stairs to our third-floor apartment. Still, I was not concerned. I thought that these were transient symptoms that would soon resolve.

Professionally, I was in my fourth year as a medical student with no clinical obligations, a lot of free time, and minimal cognitive demands. I spent a good amount of time watching my favorite shows and getting enough rest, which masked my cognitive symptoms. Every now and then, I would forget the names of my colleagues and even some close friends. I thought that I might be watching too many streaming shows. The next few months were filled with important life events, including finding out where I would be doing my emergency medicine residency, graduation, and ultimately starting my residency training.

I found myself having difficulty concentrating and felt like I could not think clearly, especially toward the end of my shifts

It was now July 2022, six months after I was first diagnosed with COVID-19. I had moved to a new city and started my new job as an emergency medicine resident physician. The increased cognitive demands that my new job entailed put a spotlight on my ongoing symptoms. I could no longer ignore them.

I found myself having difficulty concentrating and felt like I could not think clearly, especially toward the end of my shifts. The brain fog was all too real now. I was also having more difficulty remembering seemingly simple things, including the names of my colleagues and friends. Additionally, whenever I did not get enough sleep, I was overly fatigued and rendered almost dysfunctional the following day. I was still having postexertional dyspnea, but it had improved.

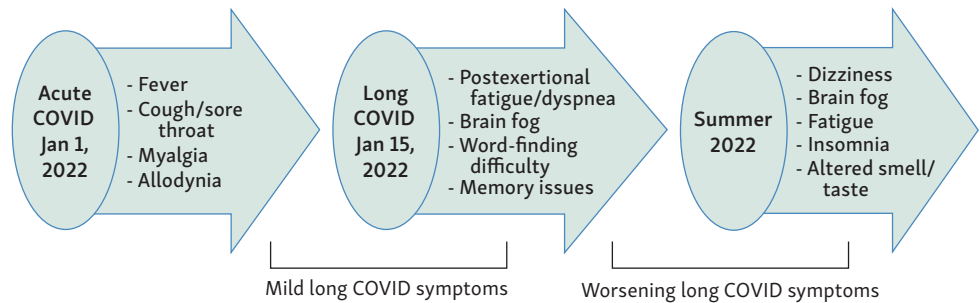


Figure 2. Patient 2 Disease Timeline.

The word-finding difficulties were the most debilitating and bothersome to me. I often found myself frozen in time, unable to verbalize words that were familiar to me, while delivering patient reports or presentations to my supervisors or in casual conversations. I had the words in my mind and could visualize them, but I simply could not verbalize them. I was unable to piece together what was happening to me. I thought that maybe this was what being in my mid-30s entailed: I had begun an early neurocognitive decline, and that was that. However, I was determined to not let these symptoms beat me. I decided to do something about the situation.

I downloaded word puzzles on my phone and enlisted my wife as my partner in my quest to either reverse or slow my brain fog and memory problems. I had a nightly routine of completing word puzzles, which I thought would help improve my cognitive function. Although I noticed some improvement over time, there was no complete resolution or return to my baseline. My life had changed, and I could not explain why. This was my “new normal.”

I had not reflected on the fact that all of these symptoms were directly correlated with my COVID-19 illness. My physical symptoms including postexertional dyspnea had gradually improved but not resolved, making them even less identifiable as post-COVID effects. The mental symptoms had lingered and were now significantly affecting my life. Although they were not disabling enough to affect my clinical work, I found that I had to do more, read more, and work harder to retain the same information as previously.

It was not until a year later, when the preceding story of long COVID was shared by my program director, that it dawned on me that I too had been suffering from long COVID. Whereas his symptoms were obvious, making them easily identifiable and attributable to COVID-19, mine were more subtle at first and amplified only later, when I started engaging in more cognitively demanding tasks. After my program director shared his story, he

Table. Medications and Therapies That Patient 1 Tried During His Long COVID Illness

Therapy	Intended symptom target
Atrioventricular nodal blockers (diltiazem, nadolol, clonidine, metoprolol)	Palpitations
Stimulants/antidepressants (bupropion, fluoxetine, amantadine, atomoxetine)	Brain fog, malaise
Antihistamines (H1 and H2 blockers)	Brain fog, malaise
Anticoagulants (apixaban, clopidogrel, aspirin)	Brain fog, malaise
Sleeping pills (eszopiclone)	Insomnia
Low-dose naltrexone	Brain fog, malaise
Supplements (B complex, C, D, magnesium, zinc, thiamine, quercetin, coenzyme Q10, nattokinase)	Malaise and overall health
Levine protocol postural orthostatic tachycardia syndrome exercise regimen	Dysautonomia
Compression stockings (20-30 mm Hg)	Dysautonomia
Sleep hygiene	Insomnia
Acupuncture	Malaise, brain fog
Hyperbaric oxygen therapy	Brain fog
Diet change	Overall health
Saphenous vein ablation	Dysautonomia
Stellate ganglion block	Dysgeusia, dysautonomia
Essential oil olfactory training	Dysgeusia

helped me reflect on my own experience and start seeking medical help to deal with the residual symptoms of my COVID-19 illness.

My symptoms have improved substantially over the prior year, but 18 months after I was first diagnosed with COVID-19, I still have intermittent brain fog, some word-finding difficulties, and memory problems. These issues are not debilitating enough to affect my daily life, but they are enough to make me realize that my body and brain changed after my infection with SARS-CoV-2.

Since coming to terms with long COVID, I have had many conversations with family members and friends who have reported similar symptoms that followed their acute COVID-19 illness, persisting for months and even years. They too have realized that they have been casualties of COVID-19 and have been suffering with long COVID well after their acute infection.

Discussion


These 2 stories of physician-patients with long COVID can teach us many lessons about the realities of this condition and its impacts on people's lives. Although there is some overlap of their symptoms, there are also some notable differences, especially in the degree of severity of the illness and the effects that it had on their lives. The 2 patients experienced 5 of the 12 most common symptoms reported by long COVID patients: postexertional malaise, fatigue, brain fog, heart palpitations, and loss of taste. Importantly, patient 1 never tested positive for COVID-19, whereas patient 2 had a positive test result. This experience is consistent with the data surrounding long COVID, which show that some patients may have negative test results.¹ It is important to keep this fact in mind when addressing patients who have symptoms consistent with long COVID.

The differences in the 2 patients' courses of disease and how they dealt with their symptoms are also informative. On one hand, patient 1 experienced symptoms immediately after his acute illness, which continued to progress. His symptoms were debilitating, rendering him incapable of returning to work. Thankfully, his health care practitioners compassionately helped him navigate his symptoms at a time when even less was known about long COVID than today. His laboratory test results were all normal, making it harder to make a diagnosis.

The Table shows the many medications he tried in his quest for recovery. For patient 2, the symptoms also presented shortly after his acute illness, but they were initially mild, becoming more pronounced months later when he was required to exert himself mentally. He did not immediately recognize the symptoms as being related to COVID, and only later, after listening to the story of patient 1, did he identify them as representing long COVID. Although identifying and dealing with long COVID was very different for these 2 patients, the impacts on their lives were significant.

The same is likely true for the millions of other people affected by long COVID. Although some of these individuals may quickly identify their symptoms and even seek treatment for them, many more are likely going undiagnosed and untreated. For those who seek medical help, the results of laboratory tests and imaging modalities will often be negative,¹ which may complicate

the management of their illness by physicians who may be unfamiliar with long COVID and its effects.

Given the evolving but incomplete understanding of long COVID, it is important to bring awareness to this emerging disease and begin to make changes in how we diagnose and treat patients suffering from it. As demonstrated in these 2 stories, many people with long COVID may not be actively seeking answers about what is happening to their bodies but may be suffering in silence. Others may be engaging with the health care system without finding relief. Both behaviors can lead to a worse quality of life. These effects may be mitigated with proper understanding and support by medical professionals, who can help set these patients on the road to recovery and, more importantly, offer validation and support. It is therefore important for clinicians to familiarize themselves with long COVID and keep it among their potential differential diagnoses for patients who present with symptoms that cannot be easily explained. The support that these patients receive from their health care providers can be crucial in helping them begin to navigate the effects of COVID-19 and cope with the impact the disease continues to have on their lives. 

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The IAS–USA will identify and resolve ahead of time any possible conflicts of interest that may influence continuing medical education (CME) activities with regard to exposition or conclusion. All

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All relevant financial relationships with ineligible companies have been mitigated.

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