

Between Two Crises: Living With Post-COVID Vaccine Syndrome in a Long COVID World

Long COVID and PCVS may both reflect a deeper susceptibility to immune dysregulation—whether triggered by virus or vaccine.

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Content warning: This story includes details of medical dismissal and disability from post-COVID vaccination syndrome (PCVS) and long COVID.

I never expected that the shot meant to protect me would upend my life. In early 2021, as a health care worker, I was among the first to receive the Pfizer COVID-19 vaccine. I believed in the science. I wanted to protect my patients, my community, and myself. I was 51 and healthy. I had never had COVID — before or after vaccination. Unlike in post-viral illnesses, my symptoms began only after the shots.

What I thought was a minor reaction became [post-COVID vaccine syndrome \(PCVS\)](#), a condition I now live with alongside thousands of others. PCVS shares symptoms with long COVID, including nerve pain, [dysautonomia](#), tinnitus, fatigue, and heart issues — but faces unique stigma, leaving us dismissed and understudied.

Studies from institutions like [Yale University](#) and [Charité Berlin](#) offer emerging evidence that post-vaccine syndromes are real, biologically mediated conditions worthy of research and recognition. A united research approach into the possible shared biology of PCVS and Long COVID could unlock answers for both groups.

Everything changed

My illness began minutes after my first dose. I developed tingling and abnormal nerve sensations radiating from the injection site down my right arm, gradually spreading to my chest, face, and ear.

A neurologist urged me to proceed with the second dose due to looming mandates and COVID-19 exposure concerns. But within days of the second dose, my symptoms escalated dramatically.

What started as heart palpitations and dizziness turned into a cascade of symptoms: burning, stinging, trembling and twitching limbs, headaches, facial tingling, wild blood pressure swings, cardiac arrhythmias, gastrointestinal dysfunction, tinnitus, severe insomnia, and crushing fatigue. My cardiac and autonomic nervous systems were under assault.

I went from an active, full-time clinician to someone who struggled to walk across the room.

At first, I thought it would pass. But days turned into weeks, then months. My doctors were baffled, stating that the vaccines were new and all the adverse effects were still unknown. Most acknowledged my symptoms started after vaccination, but no one could explain why I was deteriorating or what to do about it.

Those early months were steeped in fear and isolation. My health had collapsed, and few doctors seemed willing to help. I felt abandoned — terrified not only by my symptoms, but by the medical system's indifference. Out of desperation, I started a Facebook support group.

As thousands flooded into the group, what I found stunned me. People described nearly identical experiences: rapid-onset cardiac and neurological symptoms, all emerging shortly after vaccination. We began to use the term "post-COVID vaccine syndrome," borrowing language from the long COVID community.

People with long COVID and people with PCVS often described similar symptoms, and moreover, the same dismissals by doctors and the same lonely, exhausting struggle for help. Health care providers often told us it was anxiety, that we were imagining it, or that nothing could be done.

For months, I resisted connecting with the long COVID community. I didn't want to be mislabeled or misdiagnosed. I hadn't had a SARS-CoV-2 infection, and the idea that a vaccine — one I supported — could cause harm felt taboo, even traitorous.

But as the months dragged on, and my symptoms and experiences matched those of friends with long COVID, the lines blurred and the commonalities of our plight crystallized. We were all sick, regardless of the source. And we were all being ignored.

A shared struggle, a split narrative

Similar to long COVID, ignoring PCVS symptoms distorts the real picture of risk. It leaves patients like me not only untreated but discredited — abandoned when we most need care. Dismissing post-vaccine injuries as coincidence or misinformation, without serious inquiry, is a failure of both science and ethics.

The media compounds this harm. Journalists, often blinded by predetermined narratives, write authoritatively about patients they've never met and cases they've never studied, yet somehow possess absolute certainty that their suffering is misplaced. That's not journalism — it's advocacy

disguised as objectivity. And it silences and harms patients who should be guiding the conversation.

[Calling catastrophic injuries “rare,” dismissing patients when data is lacking](#), or censoring [patients’ experiences](#) — however well-intentioned — undermines trust and damages public health. These responses don’t prevent vaccine hesitancy; they create it. Worst of all, they lead to moral and ethical failures in public health, by rendering people like me acceptable human losses — unacknowledged, unstudied, and left behind.

True science must have the courage to confront its uncomfortable data. We cannot cherry-pick what we wish to see. Ignoring those harmed by public health interventions weakens the very foundation of ethical medicine and undermines the credibility of the systems meant to protect us all.

A possible shared cause

What if we accepted that vaccine injury, like viral injury, can trigger similar symptoms in a subset of people? What if research and care models for long COVID were expanded to include those whose injuries emerged from the interventions themselves?

If the spike protein from the SARS-CoV-2 virus can cause problems like long COVID, it makes sense that the [spike protein from the vaccine](#) could do the same in some people. Both interact with the same receptor, ACE2, which might spark inflammation or nerve issues in susceptible folks. At Yale, the LISTEN study is investigating immune responses and symptom patterns in both long COVID and PCVS patients, collecting detailed medical histories along with blood and saliva samples from participants. Yale’s study found a vaccine-induced spike protein lingering in some PCVS patients for up to 709 days, much like the viral spike in long COVID.

Spike proteins might also [over-activate immune cells](#), like microglia in the brain, causing symptoms like tinnitus or fatigue, which we see in both conditions. One theory even suggests that [antibodies mimicking](#) spike proteins could trigger autoimmunity. We don’t know for sure — more research is needed — but the overlap makes it hard to ignore.

Many of the same potential mechanisms for PCVS are also linked to long COVID. Those mechanisms include persistent spike protein, mast cell activation, microclots, and autonomic nervous system damage.

Despite these biological parallels, the narratives surrounding the two syndromes have diverged. Long COVID is increasingly studied, while [PCVS is often denied](#), ignored, and further politicized. We are treated not as patients with post-immune injury but as anomalies — or worse, threats to public health.

Because our symptoms resemble Long COVID, many in the scientific and medical world prefer to collapse us into that diagnosis — disregarding the clear temporal link to vaccination and the specific trajectory of our symptoms.

I have heard some researchers privately acknowledge the overlap between PCVS and long COVID, yet few are willing to say so publicly. The result is a silencing that not only harms people with PCVS but also stymies scientific progress.

In my years working in the HIV community, I've seen how stigma operates. Then, silence was driven by fear of the infection and prejudice. Now for people with PCVS, it is fear of undermining public confidence in vaccines. In many circles, speaking openly about post-vaccine harm is treated as heresy. Media coverage is filtered. Social media algorithms throttle discussion. Our right to advocate is blunted at every attempt. Scientists who investigate vaccine injuries risk losing funding, credibility, and career opportunities.

Yet by excluding PCVS from the broader long COVID conversation, we limit our ability to fully understand either condition. Long COVID and PCVS may both reflect a deeper susceptibility to immune dysregulation — whether triggered by virus or vaccine. Studying these conditions in tandem could illuminate mechanisms behind not only long COVID and PCVS, but also long-neglected syndromes like myalgic encephalomyelitis (ME), chronic Lyme disease, and dysautonomia.

We must bridge the divide

Encouragingly, some researchers are beginning to bridge this gap. The Yale LISTEN study, led by Dr. Harlan Krumholz and Dr. Akiko Iwasaki, includes both long COVID and post-vaccine patient cohorts in its effort to identify immune signatures and uncover shared biological drivers.

As [Krumholz himself has said](#), “We’re only just starting to make headway in understanding [post-vaccine syndrome]. Every medical intervention carries some risk, and it’s important to acknowledge that adverse events can occur with vaccines. Our focus must remain on understanding what these people are experiencing through rigorous science and addressing the needs of those affected with compassion and an open mind.”

Unfortunately, some results from this study have been met with public skepticism and [even media attacks](#). Rather than welcoming inquiry, some have accused researchers of fueling vaccine hesitancy. But honest science must follow the data, even when it challenges policy narratives. More scientists should follow the Yale LISTEN team in finding answers for all who suffer from these complex, disabling conditions.

I am not anti-vaccine. I am pro-truth, and pro-compassion. I want to see a world where those harmed by both COVID-19 and its countermeasures are acknowledged, studied, and cared for.

In both our communities, we know people who ended their lives from despair. We know people who have [descended into poverty](#) trying to find answers. And we know the strength it takes to survive in a world that erases our suffering.

I write this not only for myself, but for the thousands of others who exist in this medical limbo. Who don't fit into neat categories. We are excluded from research, care, and even empathy.

Long COVID and PCVS are not separate battles. They are reflections of the same biological vulnerability — and the same systemic neglect.

Today, the absence of definitive evidence around post-vaccine syndromes is wielded as evidence of absence — a rhetorical sleight that silences patients and halts progress. Uncertainty should spark investigation, not justify dismissal.

To move forward, we must fund rigorous research, integrate post-vaccine patients into long COVID studies, train clinicians to recognize post-immune injury, establish diagnostic criteria and coding, reform compensation and pharmacovigilance systems, protect open inquiry, and include patient voices in policymaking.

We must pursue this not just for those already injured, but for vaccine safety, for our understanding of post-viral illness, and for future pandemic preparedness. Ignoring these signals today ensures only greater harm tomorrow.

Science must dare to ask the hard questions, seek the answers with unwavering compassion, and embrace them to heal us all.

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