TuSalud

With No Approved Treatments and Little Support, People With Long COVID Turn to Online Drug Markets

People are trying off-label medications, including some approved for treatment of HIV, hepatitis C or acute COVID-19.

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Key points you should know:

- There are currently no approved treatments for long COVID and progress on clinical trials has been slow. Some medications can improve people's quality of life, but they may not work for everyone.

- With few choices, rejected disability claims, financial instability, and little support, some people with the disease have turned to online pharmacies, often based in India, to source potential medications.

- Popular choices include medications used to treat conditions like HIV, hepatitis C, and acute COVID-19. Some of these drugs are being tested in upcoming clinical trials for long COVID.

- Buying medications online from unknown sellers can be risky; buyers might not receive the correct medication or even receive something harmful.

- However, many people with long COVID feel their quality of life has declined so severely that these risks are worth taking.

With no approved treatments, lack of support, and stigma against the disease, many people with long COVID are using overseas pharmacies to source medications. Some of these treatments are widely used for other conditions, such as HIV and hepatitis C, but are not approved for use in long COVID.

“I was in such a desperate situation,” said Rafael, who lives in the U.K. and developed long COVID in 2021. “I was bedbound, and I was within months of losing my job, which would then mean losing my home. So I didn’t have much to lose.”

Rafael bought several months’ worth of maraviroc [branded as Selzentry or Celsentri], an HIV drug, from a seller in India via WhatsApp. Soon after taking the maraviroc, Rafael had a significant improvement in symptoms, although he was taking other medications at the same time.

“If I wasn’t so debilitated by long COVID, I probably wouldn’t have taken the risk,” Rafael said.

The Sick Times spoke to several people with long COVID who had used online pharmacies to import medications from abroad. Because importing medication can be illegal in certain circumstances, many sources interviewed for this article asked to be identified by their first name only or by a pseudonym.

Popular choices for people with long COVID included the acute COVID-19 antiviral Paxlovid [nirmatrelvir/ritonavir], the HIV drugs maraviroc and Truvada, and the hepatitis C drug sofosbuvir [branded as Sovaldi and a component of the Harvoni, Epclusa and Vosevi combination pills]. Maraviroc and Truvada are currently being evaluated in an upcoming clinical trial at the Cohen Center for Recovery from Complex Chronic Illness, but results are not expected until at least early 2026.

Some people with long COVID find some relief with off-label medications like low-dose naltrexone, but many told The Sick Times their doctors won’t prescribe these treatments. Even when doctors are willing to consider off-label treatments, health insurance often will not cover them.

Few treatments in sight

The slow progress on clinical trials for long COVID has been a source of frustration for both researchers and patients. The pharmaceutical industry has expressed little interest in finding treatments for the disease. Studies through the RECOVER initiative, launched by the U.S. National Institutes of Health (NIH), have primarily focused on observational approaches, such as asking people with long COVID to track their symptoms, though the initiative is now planning new trials.

An analysis by The Sick Times found that fewer than a quarter of clinical trials for long COVID are drug interventions, as of November 2024.

Hannah Buttles/The Sick Times

Even when clinical trials take place, there is no guarantee of a “one-size-fits-all” treatment for long COVID, said Ondine Sherwood, CEO of Long COVID SOS, a charity in the U.K. representing people with the disease. Currently, the available drugs may help only with specific symptoms or may work only for certain subsets of people with long COVID.

Given the severity of symptoms and widespread government abandonment, it is unsurprising that some people with long COVID have taken risks to seek relief from their symptoms since the beginning of the pandemic. Past unapproved treatments have included HELP apheresis, an expensive procedure that removes blood from a vein, filters the blood, and returns the filtered blood to the body. Many have also tried triple anticoagulant therapy, in which patients take

aspirin, clopidogrel, and a blood thinner like Apixaban to break down small blood clots, called microclots. There is a high bleeding risk associated with triple anticoagulant therapy.

For many people with long COVID, however, anything that offers a chance of improvement may seem worthwhile. Survey data suggest that the quality of life of someone with long COVID can be worse than that of someone with stage four cancer. People with long COVID may also be at a higher risk for suicidal ideation.

Financial insecurity can also drive people with long COVID to consider experimental treatments, as many are out of work, behind on housing payments, and facing other financial challenges.

Some doctors may be willing to prescribe medications off-label for long COVID and related conditions, like dysautonomia and mast cell activation syndrome (MCAS). Commonly prescribed drugs include beta-blockers, which lower heart rate, for dysautonomia, or H1 and H2 antihistamines for MCAS.

Dysautonomia drugs can lead to "massive improvement" for some, said Dr. Asad Khan, who worked as a respiratory doctor in the U.K. before developing long COVID. For example, a beta blocker could bring down a patient's heart rate while posing a limited risk, he said.

But some off-label treatments could carry higher risks, especially without a doctor's oversight, said Khan: "You've got people taking anticoagulants and various other drugs that can affect the kidney, and the liver, and can have effects on the nervous system, and nobody's monitoring. The problems could be quite serious, and it could even be fatal."

However, doing nothing for a patient can also put them in danger, said Khan. For instance, some research indicates that COVID-19 can lead to a higher risk of heart attacks and strokes for years after the infection.

People with long COVID echoed these concerns. "I worry that, the longer we wait, the higher the destruction in our bodies," said Lena, from Germany, who has had the disease since 2021.

After a difficult few months of symptoms, Lena decided to buy a generic form of Truvada, an HIV medication, through an online pharmacy. While she was scared, "pure despair" led her to try the medication, she said.

"I was having suicidal ideation," she said. "If you have to weigh up how I was feeling versus taking an unknown pill, there's no contest."

Many people with long COVID who spoke to The Sick Times felt that buying medication online was their only choice.

How online pharmacies work

Without a doctor to recommend the correct drug and dosage, many people with long COVID receive advice from online social media groups. Users share tips on which drugs had worked for

them, how to slowly increase the dosage of medications, and which side effects to expect.

Most of those interviewed by The Sick Times reported purchasing drugs without a prescription, either from national online pharmacies or from India via services like IndiaMart, an online marketplace. India is the world's largest exporter of generic pharmaceuticals.

"For me, what helped was a combination of ten days of Paxlovid and sofosbuvir," an antiviral drug for hepatitis C, said Tiff, from the U.S., who developed long COVID in 2020. Tiff had read online about other people finding relief from the disease with these medications. She asked a friend to bring them back from India and had a significant decline in symptoms.

"I felt like I did pre-2020," she said. "I had energy. I felt wonderful. No [Post-exertional malaise (PEM)] crash, no brain fog, no symptoms, nothing." Tiff was later reinfected with SARS-C0V-2, and her long COVID symptoms returned. She once again bought sofosbuvir and Paxlovid from a seller in India and saw an improvement.

Lower prices offer another incentive to buy medications from abroad. Take Paxlovid, which can cost as much as $1,400 for a five-day course in the U.S., while a generic version from India costs just $103.

Sofia lives in Austria and has long COVID. "In Austria, it would cost €40,000 for four months of sofosbuvir," she said, which "would be unaffordable."

An anonymous Twitter/X user offered to help Sofia. She sent him €200, and he bought the medication in India and took it back to Europe. Since taking the sofosbuvir, Sofia said she went from 40% to 60% of her previous level of functioning.

Risks and regulations

Generic medications in the U.S., U.K., and Europe are commonly exported from India. But those exported through official channels are often subject to stricter regulatory standards than the medications available to locals. For those who have bought medications online from abroad, confirming the medications are safe can be difficult.

"We don't have a functional regulatory system in India," said Dinesh Thakur, a drug-safety advocate and former pharmaceutical executive. Online markets like IndiaMart have no safety guarantee.

"In the best-case scenario, the product may not contain enough of the active ingredient," he said. "In the worst-case scenario, an injectable may contain endotoxins [harmful substances released by bacteria]."

If buyers from outside India have a bad experience, it would be difficult to hold a foreign company to account, Thakur added.

Nonetheless, many who spoke to The Sick Times felt that, despite the risks involved, they had to try something to relieve their symptoms.

“The symptoms grind you down so much, the risk calculus changes,” said Chris, from the UK, who has had long COVID since 2020. “There is no help coming, nothing on the horizon.”

The World Health Organization has a checklist for gauging the safety of medicines purchased online. Tips include looking out for unusual activity on your credit card, checking security seals, and ensuring the batch number and expiry date on the package match throughout.

People with long COVID may also be able to access off-label medications from more reliable sources. For instance, some online clinics may prescribe medications after a consultation. RTHM, a U.S.-based online clinic, offers a prescribing service for certain off-label medications for long COVID, including low-dose naltrexone, beta-blockers for dysautonomia, and ketotifen for MCAS. In the U.K., those with a confirmed diagnosis of long COVID or ME [myalgic encephalomyelitis] can buy low-dose naltrexone through Dicksons Chemist.

Another option for a small number of those with long COVID is to join a clinical trial — though depending on the trial’s setup, some participants may receive a placebo instead of a drug.

Without the oversight of a pharmacist, taking a DIY approach to medications could also lead to dangerous medication interactions, even when the drugs are high quality. Paxlovid, for example, interacts with many drugs people take for long COVID. These include ivabradine, some statins, and HIV medications. The University of Liverpool offers a COVID-19 drug interactions checker, which could help those using drugs like Paxlovid.

Regular blood tests could also help monitor for side effects. Truvada and maraviroc can increase liver enzymes, and patients who take these medications for HIV prevention and HIV [treatment] are advised to monitor liver enzymes regularly. [Editor’s note: the tenofovir in Truvada can cause kidney problems, and people who take the combination pill are advised to regularly monitor their kidney function.]

Rafael, who bought maraviroc, said he received monthly liver checks while taking the drug. These tests, which individuals can do privately without a GP referral, cost around £50 ($60) in the U.K.

Even if medications are safe, they are not guaranteed to work. People with long COVID risk spending hundreds to thousands of dollars without success. New drugs could also lead to worse symptoms and significantly worsen a person’s health baseline.

Chris tried several medications, including maraviroc and blood thinners, but has seen few improvements in symptoms. “You end up becoming your own guinea pig because nothing else is happening,” he said.

“It’s easy to depict people as reckless and not understanding the risks. But that’s not the case at all. Everyone understands the risks —they’re doing it because they’ve got no choice.”

Hannah Buttle is a journalist based in London. Her work currently focuses on the intersection of business, economics, and Long COVID.

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