



What doctors wish patients knew about long COVID

MAR 11, 2022

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Most people with COVID-19 won't become severely ill and will often get better within weeks of illness. The odds of illness severe enough to warrant hospitalization are dramatically lowered if you stay up to date on your COVID-19 vaccine, including a booster dose.

But even a mild SARS-CoV-2 infection can cause long COVID. And with the high transmissibility of the Omicron variant—which often results in milder disease outcomes—many patients may be concerned about developing long COVID.

It is estimated that anywhere from 10% to 30% of patients might experience long COVID after recovering—even if they weren't very sick in the first place. This leaves many COVID long-haulers with questions about symptoms and what to do. One physician aims to clear up confusion about long-haul COVID-19 and what patients can expect.

Long COVID—or post-COVID conditions—is a wide range of new, returning or ongoing health problems people may experience more than four weeks after being first infected with SARS-CoV-2. Even people who did not have any symptoms can experience long COVID, which can present as different types and combinations of health problems and can range in lengths of time, according to the Centers for Disease Control and Prevention (CDC).

At the June 2021 AMA Special Meeting, delegates adopted policy to support “the development of an ICD-10 code or family of codes to recognize Post-Acute Sequelae of SARS-CoV-2 infection ('PASC' or 'long COVID') and other novel post-viral syndromes as a distinct diagnosis.” Read about the AMA's support for more resources to help millions living with long COVID.

The AMA's What Doctors Wish Patients Knew™ series provides physicians with a platform to share what they want patients to understand about today's health care headlines, especially throughout the COVID-19 pandemic.

For this installment, AMA member Devang Sanghavi, MD, took the time to discuss what patients need to know about long-haul COVID. Dr. Sanghavi is an intensivist and medical director of the medical

intensive care unit (ICU) at Mayo Clinic in Jacksonville, Florida. Since summer of 2020, he has seen about 100 patients with long COVID, many of whom take weeks to recover.

There are three types of long COVID

Long COVID can be broken down into three categories, Dr. Sanghavi explained. “COVID-19 itself has direct cell damage because of the virus and this can cause lingering symptoms.”

This means that people with COVID-19 “do not recover completely and have ongoing symptoms because of direct cell damage from the virus,” he said. That’s the first category.

The second category of long COVID is when a person’s “symptoms are related to chronic hospitalization,” said Dr. Sanghavi. “This is when someone is in the hospital, ICU, bed bound for weeks.

“There is inherent muscle weakness. There is inherent cognitive brain dysfunction. There is inherent psychosocial stress causing post-traumatic stress disorder-like syndrome, which we call post-ICU care syndrome,” he added. “That is from chronic hospitalization.”

In a third category are those cases in which symptoms appear after recovery.

“With COVID itself you see a variety of symptoms—a 30-year-old dying or a 70-year-old essentially being unscathed and asymptomatic.”

That’s because “there are various patient factors at play,” reflecting the “interplay with the immune system of a person, and then the impact that both those things have on the body,” he said. These “symptoms that linger on are produced after the recovery because of this interplay between inflammatory markers and the immune system.

“We are still trying to understand exactly how this interplay between immune system and inflammatory markers work, but there’s no doubt that that is a group of symptoms because of ramped up immunity or ramped up inflammatory system,” he added.

Severity requires attention sooner

“Based on the symptoms a person is experiencing, you can divide them based on their severity and chronicity,” said Dr. Sanghavi. “So, something that is more severe will need attention sooner, while something that is more acute may need to be looked into” to determine if it is long COVID or a new

condition.

It is possible, he said, that another condition could be “masquerading as long COVID.” For example, “if a patient had no symptoms before and now has new symptoms, you don’t want to label it as long COVID or COVID long haulers before you rule out other conditions.”

No organ system is spared

“Symptoms of long COVID are like COVID-19 itself, because it affects all organ systems,” said Dr. Sanghavi, noting that the basic systemic symptoms are “fatigue, post-COVID syndrome and post exertional malaise.

“You can have anxiety, depression, insomnia and what we call cognitive dysfunction or brain fog,” he added. “There’s also loss of taste and smell.”

Cardiac symptoms include “palpitation from tachycardia and bradycardia,” Dr. Sanghavi added. Respiratory symptoms are the most well-known and include “shortness of breath, which is a result of hypoxemia from damage to the lungs.”

Additionally, “you can have loss of appetite from gastrointestinal symptoms and bowel issues like diarrhea, which can stay on,” he said. “From a kidney standpoint, patients have had acute kidney injury, which the kidneys probably don’t recover from.

“Someone who has chronic kidney disease may be pushed to getting long-term dialysis after COVID,” Dr. Sanghavi added. “As far as hematologic issues or concerns, we have seen patients who after initial recovery end up with a blood clot.”

In terms of skin conditions, “some patients have come up with hair loss and rashes as symptoms,” he said, adding that some endocrine patients have experienced sick euthyroid syndrome.

“There’s a whole slew of symptoms affecting a variety of organ systems,” Dr. Sanghavi said. “No organ system is spared from long COVID, just like how COVID affects all these organ systems during acute illness.”

Discover why holistic view is needed to treat COVID-19 long-haul symptoms.

Long COVID affects children too

While initial data was lacking, “now there’s clear evidence to suggest that there are a number of children who have long COVID symptoms and their symptoms are somewhat similar to adults,” said Dr. Sanghavi. Children are “complaining about fatigue and a difficulty in concentration, which is important for them in school and learning.

“Insomnia is one of the other symptoms that they’ve been talking about in various surveys and interviews,” he added. But the good news is that “it seems like it’s much lower than in adults.”

“The key difference between long COVID in adults and children is that the symptoms may be similar, but the number of patients affected is lower in kids,” Dr. Sanghavi said. “And then most of these symptoms tend to go away within a couple of months.”

Discover what doctors wish parents knew about keeping unvaccinated kids safe.

Women are affected more than men

“Recent studies have shown that there is an increased percentage of females, as compared to males, who have long COVID syndrome,” said Dr. Sanghavi, noting “this is not specific to the Western world. This is across Asia, Europe and America, and similar trends are being seen.

“Predominantly middle-aged females become affected from long COVID more than males, and that is another thing—there’s a historical perspective to this, and it is not a unique thing to post-COVID syndrome,” he added. “However, we still need to focus more on this particular topic to discern the exact difference and why this is happening more in females.”

Seek clinical care for long COVID symptoms

“If you have long COVID symptoms, you should seek care,” said Dr. Sanghavi, adding that “as we have seen in a lot of these surveys and studies about post-COVID syndrome is that usually this condition doesn’t come with just one symptom—there’s a cluster of symptoms.

“Don’t label it as post-COVID right away,” he added. “You want to make sure that it’s not something new, and then you obviously want to make sure that your symptoms are addressed, based on the severity.”

He noted that “a lot of hospital systems have set up multidisciplinary clinics or post COVID clinics to deal with this very issue,” Dr. Sanghavi said, noting that “the approach to post-COVID syndrome should be holistic. It should be comprehensive, because the symptoms are multitiered and affect

multiple organ systems.”

That is the goal of these post-COVID clinics, “so that all symptoms are addressed in an appropriate manner,” he said.

Listen to this JN Learning podcast episode that offers an inside look at a post-COVID-19 clinic.

Vaccination can prevent long COVID

COVID-19 vaccines are “safe and effective, even though some patients may experience breakthrough infections,” said Dr. Sanghavi. “What is reassuring is that patients who were vaccinated, in those rare instances where they got a breakthrough infection those patients are 50% less likely to develop long COVID or post COVID syndrome.”

“The vaccines are effective. But in those rare instances where you do get an infection despite vaccination, this protects you from having post-COVID syndrome—there’s a double insurance.”

Read about what doctors wish patients knew about breakthrough COVID infections.

You’re not alone

“Help is available for patients. There is no reason why patients should not seek care and help,” said Dr. Sanghavi. “The other thing that everyone should know is that they are not alone in this.

“There are millions of others like them who are suffering and have similar symptoms,” he added. “The key is forming support groups and using technology to fight this thing together.”

“Our best minds in the field of medicine are working to crack the code and find better treatment options for long COVID patients,” said Dr. Sanghavi. “The best way to avoid long COVID is to fight COVID-19.

“There are three vaccines available in the United States, so pick your choice and get vaccinated,” he added. “And if you qualify for a booster, get a booster dose whenever that is available and protect yourself from this virus.”

Beyond getting vaccinated, “if we wear a mask in indoor settings, wash our hands, physically distance and do what we’re supposed to do, we can end the pandemic and decrease these incidences of long COVID,” Dr. Sanghavi explained.



Learn more from this *AMA Journal of Ethics*[®] personal narrative, “The Importance of Listening in Treating Invisible Illness and Long-Haul COVID-19.”

The AMA has developed a COVID-19 resource center as well as a physician’s guide to COVID-19 to give doctors a comprehensive place to find the latest resources and updates from the CDC and the World Health Organization.