COVID long-haulers: Questions patients have about symptoms

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Most people with COVID-19 recover completely within a few weeks, but some experience lingering symptoms. Those individuals are often referred to as “COVID long-haulers” and have post-COVID conditions or “long COVID.” For COVID long-haulers, persistent symptoms often include brain fog, fatigue, headaches, dizziness and shortness of breath, among others.

At the June 2021 AMA Special Meeting, the AMA House of 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.

While more still needs to be known about COVID long-haulers, AMA member Devang Sanghavi, MD, a critical care medicine specialist and medical director of the medical intensive care unit at Mayo Clinic in Jacksonville, Florida, took time to answer questions patients might have about long-term symptoms.

What are the most common long-term symptoms of COVID-19?

“Long-term COVID—or post-acute COVID—affects a multitude of organ systems,” said Dr. Sanghavi. “Starting from head to toe, it leaves behind multiple symptoms in a large proportion of patients who have recovered from COVID-19.”

“From the neuropsychiatric perspective, you have patients with brain fog or cognitive impairment,” he said, adding that there are also patients with fatigue, anxiety, depression, post-traumatic stress disorder (PTSD) and headaches.

“Then, from a lung perspective, patients have persistence of shortness of breath, or dyspnea, and require ongoing oxygen treatment even after discharge and for weeks to months because of permanent damage to the lungs,” said Dr. Sanghavi. “As far as the cardiac system is concerned,
there’s chest pain and shortness of breath."

Additionally, patients can experience persistent kidney dysfunction as well as newly diagnosed type 2 diabetes or worsened control of diabetes.

Ongoing symptoms of long COVID also include fast-beating or pounding heart, pins-and-needles feeling, diarrhea, sleep problems, mood changes, rash and changes in menstrual period cycles, among others, according to the Centers for Disease Control and Prevention.

If I tested positive for COVID-19, but did not have any symptoms, will I have symptoms later?

The short answer is “likely, yes,” said Dr. Sanghavi, adding that “there were a significant number of patients who were initially asymptomatic … but then they subsequently developed symptoms, which are particular to COVID long haulers or long COVID.”

“And that’s why COVID-19 is a very intriguing disease. It's not just a simple virus affecting the body, there are immune and inflammatory mechanisms which affect the patient's body,” he added. Additionally, “the patient may be initially asymptomatic, but subsequently develops symptoms like anxiety, depression, fatigue and so on.”

What are some possible lingering mental health effects of COVID-19?

“One of the most common mental health effects and challenges has been depression and anxiety,” said Dr. Sanghavi. “The pandemic itself has brought about a lot of challenges to the patients’ life, be it financial or personal, and add to it the recuperation from an illness like COVID.

“The other symptom you would notice is brain fog, which is akin to cognitive impairment that you see in patients who have post intensive care unit syndrome,” he added, noting that other mental health effects might be insomnia and PTSD.

Find out why depression and anxiety are prevalent during COVID-19.

Can COVID-19 cause neurological symptoms?
"COVID-19 causes a variety of neurological symptoms, which can stay behind in a patient after initial recovery or can develop later," said Dr. Sanghavi. "One of the most common neurological symptoms in COVID patients, which can still persist after the initial disease, is loss of smell and taste sensation.

“A lot of other patients have had headaches, fatigue and myalgia, which is similar to some other viral diseases,” he added.

Discover the six things doctors wish patients knew about coronasomnia.

**How long do neurological symptoms from COVID-19 last?**

“That's the part that we don't know. If you focus on the loss of smell and taste sensation, on average, that symptom lasts two to three weeks in most patients, but in some it can last for months,” said Dr. Sanghavi, noting that one “study found that 25% of patients had depression, anxiety, PTSD and sleeping difficulties.

“And those were lingering on for months on end,” he added. “But in some patients, it was reported that those symptoms disappeared after getting vaccinated.”

**If someone is experiencing neurological symptoms from COVID-19, what should they do?**

“For most of the post-COVID neuro symptoms, we use a symptomatic approach,” said Dr. Sanghavi. “For example, for a headache, the approach is usually symptomatic treatment except for if the headache becomes intractable. In that case, you need further imaging and consultation with a specialist.

With “symptoms such as anxiety, depression and PTSD, the diagnostic approach usually starts with standard screening tools to see if that patient would need help from a therapist and treatment of this condition with pharmacological agents,” he added.

**What are the most common long term lung problems after COVID-19?**

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“Some of the most common pulmonary symptoms post COVID-19 infection are dyspnea, decrease in exercise capacity and long-term oxygen requirements,” said Dr. Sanghavi, adding that a lot of patients are discharged from the hospital on oxygen and continue getting that oxygen at home.

“The way we diagnosis this is through pulmonary function tests like measuring the lung capacity or the diffusion capacity of gas to see how effective the gas exchange is in the lungs,” he added. “You might also need high resolution CT scans to see changes post COVID in the lungs to further classify and define the problems.”

Why does COVID-19 cause brain fog?

A neurological symptom that people with COVID-19 commonly report is brain fog, which is not a medical diagnosis. Instead, COVID brain fog is a term used to describe the feeling of being mentally slow, fuzzy or spaced out.

“Post COVID brain fog can appear in patients who are severely deconditioned and weak or have PTSD-like syndrome,” said Dr. Sanghavi. “The other type of brain fog is due to the long ICU stay, leading to post-ICU syndrome.”

“A lot of these COVID patients stay in our health care system for quite a while, so the brain fog in some may be from staying in a hospital setting where their days and nights are getting mixed up and they have a lack of sleep, which leads to cognitive impairment,” he said.

If I lost my smell or sense of taste, will I get it back?

“According to one study, 95% of the patients recover their sense of taste and smell eventually,” said Dr. Sanghavi, adding that “it may take months, but their sense of taste and smell sensation would come back.” “Initially it was thought that it is a direct invasion of virus into the olfactory cells or the neurons, but now, as we understand the process more, it seems like this impacts the helper cells and not the neurons directly,” he said. “And as the helper cells recover, the sense of taste and smell recover too.”

“People may ask if they can do anything to get it back and re-sensitization with aromatherapy is one way that could potentially work, but there is no clear proof that anything works right now,” said Dr. Sanghavi.
Why is my friend experiencing different long-term symptoms from me?

“The reason behind the different long-term symptoms between two individuals are manifold,” said Dr. Sanghavi. “First and foremost, the exposure duration and the viral load you are exposed to is a determinant of the initial illness.

“After the virus entry, there are multiple patient-related factors which are nonmodifiable and determine the severity of the disease,” he added. “This includes past medical history, body habits and age of the person.”

“The final determinant of the disease is how a patient’s immune and inflammatory cascade would respond to the virus,” said Dr. Sanghavi. “As the criteria to develop COVID-19 and the initial severity of the disease are unique, different patients will be experiencing different long-term symptoms.”

Can children develop long COVID?

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.”

Does getting a COVID-19 vaccine help reduce symptoms?

“What is exciting is that there are anecdotal reports that for these initially asymptomatic patients who tested positive and develop long COVID symptoms, after they got the vaccine, their symptoms went away,” said Dr. Sanghavi. “So that gives us a glimmer of hope and is why it's imperative that anybody who's eligible should take the vaccine.”
“You may see less COVID-19 around you, but it’s still there, so I strongly encourage everyone to get vaccinated,” he said. “It doesn’t matter which vaccine you get, but what we have seen is that all three vaccines protect against severe disease and hospitalization.

“Get vaccinated and until the pandemic is over, we should continue doing our personal hygiene hand-washing and wearing masks to protect ourselves and the broader population in general,” said Dr. Sanghavi.

Discover what doctors wish patients knew about COVID-19 vaccination.

**Does getting vaccinated cut the odds of developing long COVID?**

“We have seen with the Omicron variant the increase in the number of breakthrough cases with the two doses of mRNA and one dose of J&J vaccine,” said Dr. Sanghavi. “This breakthrough infection may be from waning immunity or mutating virus. This makes the booster vaccine more important.

“Even in patients who are boosted, there is risk of breakthrough infection,” he added, noting “the clear advantage in these booster breakthrough cases is the disease is mild and there is a decreased need for hospitalization.”

“The other long-term benefit and important difference between booster breakthrough infection as compared to unvaccinated infection is that there is a decreased risk of long COVID, just like the actual disease,” said Dr. Sanghavi. But “in the case that someone does develop long COVID, their symptoms are very mild.”

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 Centers for Disease Control and Prevention and?the?World Health Organization.