Many still grappling with long COVID

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A patient of mine, once a marathon runner, now gets tired just walking around the block. She developed CO-VID-19 during the 2020 Christmas holiday and saw me during the summer of 2021. Previously, her primary care doctor had recommended a graded exercise program. But exercise exhausted her. After months of waiting, she finally had an appointment at our post-COVID-19 clinic at the University of Virginia.

She is hardly alone in her extended search for answers. Studies suggest that from 10% to 45% of COVID-19 survivors have at least one of the following symptoms three months after recovery: fatigue, cough, shortness of breath, difficulty sleeping, difficulty with daily activities or mental fogginess, otherwise known as "brain fog."

There are many names for this condition: long COVID, long-haul COVID, post-acute COVID-19 syndrome and chronic COVID. Patients report that their symptoms, or the severity of them, fluctuate over time, which makes diagnosis and treatment difficult.

A response to infection

Researchers and doctors have seen similar recovery patterns from other viruses, including Ebola and Middle East Respiratory Syndrome, or MERS, which is another coronavirus.

This suggests that the illness we see following a bout with COVID-19 may be part of a patient's response to the infection. But doctors and researchers do not yet know why some patients go on to have persistent symptoms.

My clinical practice and academic research focus on critically ill patients. Most of my patients now are people who had COVID-19 with various levels of severity.

I often tell these patients that we are still learning about this disease, which wasn't part of our vernacular before 2020. Part of what we do at the clinic is help patients understand what they can do at home to start improving.

Dealing with fatigue

Chronic fatigue can greatly affect quality of life. Exercise limitations can



Studies suggest that from 10% to 45% of COVID-19 survivors have at least one symptom three months after recovery, such as fatigue, difficulty sleeping, shortness of breath, or mental fogginess. GETTY IMAGES

have their roots in problems with the lung, heart, brain, muscles or all of the above.

Graded exercise therapy works for some but not all patients. Graded exercise is the slow introduction of exercise, starting slowly and gradually increasing in load over time. Many are frustrated because they feel more exhausted after exercising or even doing the routine tasks of daily living. The lack of progress leads to depression.

The condition of feeling more exhausted after exercise is called post-exertional malaise, which is defined as physical and mental exhaustion after an activity, often 24 hours later, that is out of proportion with the activity.

For example, you feel good today and decide to go for a walk around the block. Afterward you are fine, but the next day your muscles ache and all you can do is lie on the couch. Some patients don't even have the energy to answer emails. Rest or sleep do typically relieve the fatigue. There is no one-size-fits-all approach to treatment; the severity and frequency of post-exertional malaise varies from person to person.

Signs and symptoms

Fatigue following any illness is common, as is exercise intolerance. So when should you see a medical professional? Diagnostic testing for post-exertional malaise exists, but it's not readily available to all patients. These questions may provide clues to whether or not you are experiencing it:

- Does it take more than one day to recover to your usual baseline activity?
- Do you feel unwell, weak, sleep poorly or have pain when recovering from activity?
 - · Are you feeling limited in your abil-

ity to do your daily tasks after activity?

- Does exercise activity affect you positively?
- Do you have soreness and fatigue after nonstrenuous days, or mental fatigue after strenuous or nonstrenuous activities?

All of these can be clues to discuss with your primary care provider, who may want to do additional testing to confirm the diagnosis, such as a two-day cardiopulmonary exercise test.

Before your appointment, there are a few things you can do at home that may help.

Taking it easy

One of those techniques is pacing, or activity management, an approach that balances activities with rest.

The Royal College of Occupational Therapists and the Intensive Care Society, both in the U.K., developed what they call the 3Ps – Pace, Plan and Prioritize.

Pacing yourself means breaking down activities into smaller stretches with frequent breaks rather than doing it all at once. An example would be to climb a few steps and then rest for 30 seconds, instead of climbing all the stairs at once.

Planning involves looking at the week's activities to see how they can be spread out. Think about the ones that are particularly strenuous, and give yourself extra time to complete them.

This helps with prioritizing – and recognizing those tasks that can be skipped or put off.

Focusing on the breathing

Some patients with long COVID develop abnormal breathing patterns, including shallow rapid breathing, known as hyperventilating, or breath-holding. Either of these patterns can make you feel short of breath.

Symptoms of abnormal breathing patterns include frequent yawning, throat-clearing, experiencing pins-and-needles sensations, palpitations and chest pain. Don't ignore these symptoms, because they can be signs of serious medical problems like heart attacks and abnormal heart rhythms. Once those are ruled out, it is possible to relearn to breathe properly.

You can practice these techniques at home. The simple version: Find a com-

fortable position – either lying down or sitting upright with your back supported. Place one hand on your chest and the other over your belly button. Exhale any stale air out of your lungs. Then breathe in through your nose and into your abdomen, creating a gentle rise in the belly

You should feel the hand resting on your belly button move up and down. Try to avoid short, shallow breaths into the upper chest. Slowly exhale all the air out of your lungs. The goal is to take around eight to 12 breaths per minute.

Focus on a longer exhale than inhale. For example, inhale as described for a count of two, then exhale for a count of three, as a starting point. If you take one breath every five seconds, you will be breathing 12 breaths per minute. As you get more comfortable with this, you can increase the time to further reduce your breaths per minute.

A more advanced tool is called box breathing: Breathe in for a count of four to five, holding your breath for a count of four to five, breathing out for a count of four to five and hold that for a count of four to five.

Long COVID patients who use these techniques show improvement in symptoms of breathlessness and sense of well-being.

The road to recovery

The patient I referred to earlier did all of these things. As we worked with her, we discovered she had multiple reasons for her symptoms. In addition to overbreathing and symptoms of post-exertion malaise, she had a new cardiac problem, possibly related to her CO-VID-19 illness, that made her heart work less well during exercise. Now she is recovering; while not back to marathon running, she is feeling better.

Currently there is no cure for long COVID, though we hope research will lead to one. Clinical trials looking at potential therapies are continuing. In the meantime, people should be cautious about using medications that are not proved to help – and if you're having symptoms, get evaluated.

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