

Long-COVID patients may unlock secrets of mysterious conditions

In a room at M Health Fairview in Minneapolis, Anna-Marie Rieffer stepped on to a treadmill.

Hooked up to gadgets to monitor her heart rate, blood pressure and other vital signs, Rieffer starts off slowly.

Over the course of several minutes, physical therapist Cassandra Anderson increased Rieffer's speed and incline, constantly checking in to see if it was too much, too fast.

Together, the two of them are trying to figure out her optimal heart rate for exercise to prevent the spiral into periods of fatigue.

“Start exercise — even yard work — with a slow five-minute walk,” Anderson advised. “Then slowly ramp up the intensity of your exercise. And when you hit that heart rate zone then start slowly ramping down the exercise.”

Physical therapy is just one aspect of Rieffer's treatment for post-acute sequelae of COVID-19, otherwise known as long-COVID, a constellation of symptoms like profound fatigue, shortness of breath, brain fog, and headaches. The symptoms that have lingered since Rieffer fell ill with the virus last fall.

No one really knows why some people develop these long-term symptoms. Doctors still are studying long-COVID, but they hope to gain a better understanding of conditions that have vexed doctors for years.

Mild cases, long-lasting symptoms

Rieffer is among a growing number of people who had relatively mild cases of COVID-19 only to experience long-lasting symptoms. Work, exercise and even riding her motorcycle is difficult for Rieffer, who says she was very active before getting sick.

“I’m a ‘Type A’ personality, never stops, out mowing the lawn, running around with my teenage kids, swimming, going to the gym.”

Post-COVID, when Rieffer overdoes it, she said she crashes hard, and sometimes for days.

“A crash is full-on, [I] can't keep my eyes open, my body is just exhausted, and it's 'I need a nap and I need it right now,’” she said.

As a trained nurse serving as a patient care supervisor in one of M Health Fairview's pediatrics departments, Rieffer is uniquely qualified to identify and understand when something is wrong with her body.

But that didn't make it easier to admit she was struggling with post-COVID symptoms. After being out of work for three weeks, including several trips to the emergency room for shortness of breath, she still wasn't feeling better after her COVID diagnosis in late October 2020.

Rieffer said she was in denial that she was still ill. "It's just hard to admit that you're not at 100 percent," she said.

It wasn't until this spring that her primary care physician suggested she work with the post-COVID clinic. "Even my staff didn't know about how much I was struggling until the past couple of weeks," Rieffer said.

Dr. Leslie Morse, head of rehabilitation medicine for M Health Fairview, participates on Rieffer's care team. Her hospital opened a clinic that brings together different disciplines to treat people like Rieffer, who is fairly typical of the patients seen there.

"Her initial symptoms were asthma-like symptoms, followed by shortness of breath that really persisted, and severe exhaustion," Morse said.

At M Health Fairview, Morse said research suggests that women are at slightly higher risk of developing symptoms, as are people who had other conditions like heart or lung disease.

A similar evaluation from [Mayo Clinic](#), which operates its own long-COVID clinic, found that most patients seen there didn't have preexisting conditions.

Morse said knowing that Rieffer — and thousands of others with long-COVID — experienced symptoms following a viral infection unleashes new insights.

"With so many people worldwide, developing so many symptoms that are really reflective of chronic fatigue, fibromyalgia, all of these conditions that are understudied, not well understood ... I think it's going to drive a lot of research," she said.

Medical mysteries

A massive [research funding effort](#) from the National Institutes of Health to better understand long-COVID may help drive new discoveries. Morse said funding can be scarce for other chronic conditions.

Take postural orthostatic tachycardia syndrome, or POTS. The syndrome, marked by low blood flow and a rapid increase in heart rate intrigues Dr. Hana Akselrod, an infectious disease expert at George Washington University School of Medicine in Washington, D.C., who leads the institution's COVID-19 recovery clinic.

"POTS has been a bit of a medical mystery as to why certain people develop it and what triggers it," she said.

Before COVID, not many POTS cases were documented. Akselrod said doctors didn't always know how to help patients. But in the last year, a high number of people contracting COVID-19 have gone on to develop POTS.

"So we do think something about COVID-19, whether it's the severe inflammation this virus can trigger, possibly its effect on the neurologic system that breaks this normal regulation between the demands on your heart and vascular system and what they actually do," Akselrod said.

But Akselrod said long-COVID teaches doctors to listen more carefully to patients who say they have nebulous and hard to define conditions like brain fog and chronic fatigue syndrome. “I think we're also seeing the value of listening to our patients and hearing them,” she said.

Doctors are trained to prioritize conditions that can be fixed on the spot or things that require hospitalization, Akselrod explained, but may not be as well versed in certain chronic conditions.

A viral trigger

Dr. Peter Rowe directs the chronic fatigue syndrome clinic at Johns Hopkins Children's Center. For more than two decades, he's seen kids who have debilitating fatigue, headaches and cognitive issues — similar to what other doctors are seeing in post-COVID patients.

Rowe said that in his experience, it appears symptoms can be triggered by having a viral infection; more than 60 percent of kids who come to him developed symptoms after having mononucleosis, for example.

"With all this creative thinking being brought to bear on long-COVID, somebody is going to come up with interventions that may be very helpful to the people who've been struggling for years and decades with [chronic fatigue syndrome]," he said.

There are lessons from treating chronic fatigue syndrome that may translate to treating COVID-19. For instance, Rowe said that for a long time, the perception in the medical field was that the symptoms were psychosomatic.

"They must have school phobia or they don't want to do things or they're responding to stress," he said.

Cognitive behavioral therapy and more rigorous exercise were common treatments, he said. But those approaches haven't worked — and in some cases, made things worse.

"We also hope that the knowledge flow goes in both directions and that people won't make the same mistakes with post-COVID patients that they made with pushing [chronic fatigue] patients too hard physically before they were ready," he said.

At her therapy session, Anna Marie Rieffer gets a game plan for how often and how rigorously to exercise in the coming weeks. She'll be seeing her occupational therapist, too, to work on breathing exercises.

Rieffer already sees improvement in her symptoms. Rieffer still crashes, but not for days like before. “Now to only crash for 24 hours is actually an improvement for me,” she said.

Rieffer said she's taking it slow and steady to be closer to normal for her son's marching band season this fall.