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One year later, COVID-19 ‘long-haulers’ still feel effects of virus

Shannon Kelly

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Dina Gregory, left, and David Lee, right, at their Boonsboro-area home on Tuesday, March 2, 2021.

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Almost one year after falling ill at the beginning of the novel coronavirus pandemic, Boonsboro-area couple David Lee and Dina Gregory still wrestle with lingering impacts of the virus — a condition they call “long COVID” — unsure if full recovery will ever come.

“It’s not necessarily an either-or,” Lee said of a COVID-19 patient’s possible outcome. “It’s not just that you get better or have a really hard time. There is this middle condition that’s happening to a minority of folks that really is life-changing, in a bad way.”

Toward the end of February 2020 — as it was becoming evident the novel coronavirus was spreading globally but before lockdowns and stringent health guidelines were implemented — Lee and Gregory faced an agonizing decision of whether to continue with their planned family trip to Cancun, Mexico. After much deliberation, they decided to go ahead while following the federal guidance of the time to monitor temperatures and generally be health-conscious.

About two weeks after returning, the couple’s 5-year-old daughter became ill, spiking a fever and experiencing significant gastrointestinal upset. Lee and Gregory said their little girl also clutched at her chest, indicating something did not feel right. Aware of the emerging new virus, the family entered a strict lockdown and contacted their pediatrician. Although their daughter’s acute symptoms passed in two days and she appeared to ultimately recover, they wanted to take every precaution.

Two weeks after their daughter’s symptoms appeared, Lee fell severely ill with symptoms unlike anything he said he had ever experienced. Gregory was not far behind in becoming severely sick herself.

The acute period of symptoms lasted two to three weeks, the couple said. During his bout, Lee battled gastrointestinal upset, uncomfortable chest sensations and “a whole bevy of symptoms.” Gregory suffered severe migraines, shortness of breath, pressure in her chest, and cardiac symptoms like a racing heart. Both said they also experienced immense fatigue of a sort they had never known.

“That’s why we realized this was something different,” Gregory said.

Great fear and uncertainty loomed during this period, Gregory and Lee said.

“There was the existential fear of, 'If I go to bed feeling this bad, am I going to be around tomorrow?’” Gregory recalled.

Finally, the acute symptoms subsided, and for the following two to three weeks, the couple thought they were on the mend.

Their budding relief was short-lived.

After trying to get back into light exercise and move on with life as normal, Gregory and Lee found themselves suddenly and inexplicably regressing.

“It almost felt like we were having an onset of what we had had in the acute phase. A little bit less intense, but it was like, ‘Oh, gosh, why are these things starting to come back?’ That’s when we began gradually to dip into literature and piece our experience together and realized there was this very clear correlation between how much we were able to exert and tolerate,” Lee said.

The formerly active, healthy individuals found their lives turned upside down.

“We both exercised regularly. We’re not young, but we’re not that old. It is kind of a big thing to lose that side of your life, because we were both quite well before this,” Gregory said.

Experiencing the virus and subsequent “long COVID,” a sort of chronic post-viral syndrome, was particularly difficult so early in the pandemic. Many question marks remain surrounding the virus, how it operates, how to treat it and why it impacts individuals so differently, but even fewer answers were to be had at the beginning.

Lee’s lingering symptoms are primarily neurological, he said, describing them as “bizarre.”

“One aspect has been neuropathy, where just all these bizarre tingling sensations [occur],” he said. “Some people call it ‘COVID fizz.’ Or waking up in the middle of the night with this kind of electrocuted feeling.”

Lee also struggles with periodic cognitive effects such as brain fog, and he has difficulty recalling words.

Gregory still has heart palpitations and cardiac-related “weird flurries,” as well as shortness of breath, headaches and body aches. Lately, she said her symptoms come in waves and she has long periods of wellness, leading her to be cautiously optimistic she might at last be improving.

Fatigue is a post-viral symptom the couple has in common.

Both said they have gotten better at managing their symptoms, but still have rough patches. The couple learned the term “post-exertional malaise,” where those suffering this sort of condition become sick again easily — sometimes dangerously — after even light exertion such as lifting something or doing routine household chores.

“The loss of our active selves has been really upsetting,” Lee said.

As it became clear this “long COVID” condition was not going away, Lee and Gregory researched their symptoms, desperate for answers, looking through medical literature and eventually finding some online forums where they discovered other survivors like them, often called “long-haulers.”

As parents to a now 6-year-old and 10-year-old, Gregory and Lee’s children have also faced significant life adjustments.

“All of a sudden, we’re not playful anymore. We’re not being physical, we’re not able to take hikes and do the things that we normally do,” Gregory said, recalling when she and Lee used to run around or throw a ball with their kids, things they can no longer do much without becoming sick.

On top of this, the children started remote learning and at times were limited in their ability to play with friends in person. Lee and Gregory said their children are going through their own share of struggles, and they, as parents, face difficult decisions

when considering schooling and play options, a risk balance in helping their children while hoping to protect against reinfection.

When they finally decided to speak up about their long COVID experience, Gregory and Lee said they faced skepticism from health practitioners and personal connections alike. Some health care providers declined to even see them for a time, Lee said.

An added layer of fear for the couple was the worry of being labeled with a pre-existing condition, which could make health insurance more costly or difficult to obtain.

“Early on, when we first started having these inexplicable symptoms, I said, ‘I don’t want to go to the doctor,’ because this could count as a pre-existing condition,” Gregory said.

Both are now receiving medical consultation for their conditions, Lee said. Treatments primarily focus on targeting individual symptoms in hopes of adding a level of “functionality,” if not solving the root issue.

“I think a year on, it’s reaching a lot more doctors now, and I do think it will be different for people going to see their doctor now than a year ago,” Gregory said.

Gregory added because she and Lee do not always “look” unwell, it is harder for others to believe they are struggling.

The couple strives to remain hopeful, but they still feel the loss of the life they knew before being stricken with “long COVID.”

“There is also this fundamental sense that we’re broken. That even though things are improving, we know that if we push it to a certain point that our bodies will shut down,” Lee said.

Despite their ongoing battle, Lee and Gregory count themselves lucky in many ways. They are thankful to both be employed, to have emotional and logistical support from Lee's nearby family, and to have the ability to quarantine as needed. Though their lives have been altered extremely and the future remains unknown, they try to remain hopeful.

"If you're going to get COVID and have a bad outcome, you'd rather be where we're sitting than the folks who have lost their lives," Lee said.

The couple hopes sharing their experience will raise awareness of the post-viral syndrome some COVID-19 survivors are battling, and also teach others about this "gray area" possible outcome.

"There's been a long-neglected class of folks that fall into these unknown syndromes, so the silver lining may be that a broad exposure like this helps to bring attention to it and ultimately get the problem solved," Lee said. "Obviously we never would have wished for hundreds of thousands of people to fall ill to solve that problem, but if there is a silver lining, that would be it."

Dina Gregory's poem about this experience

Dina Gregory, a writer, composed a poem about the long COVID experience which she shared in a Slack group with fellow "long-haulers," starkly summing up what the journey has felt like:

"We are like broken watches,

Open us up and all the pieces are still there,

No obvious damage,

The parts still moving as they should,

But we no longer keep time."