

# For many people, surviving COVID-19 doesn't mean getting better

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Alexis Crumbley flew home from London with her family in March, just

as the coronavirus crisis was beginning, before masks and other precautions were widespread. She's pretty much been sick ever since.

"I figured, I've got COVID-19 but I'll be OK," Crumbley said. "I'm young and healthy and physically fit, and I don't have any pre-existing conditions."

Instead, the 44-year-old former policy analyst who lives in Austin, Texas, is still weak and in pain, with ailments doctors are still trying to treat. She's worried about the future.

"I've never had the trajectory that I've felt better," she said. "That's so missing in the conversation about COVID-19. You hear about people who have no symptoms or have them for a week or two, and then you jump to people who are on ventilators or dying. There's no talk of the people in between."

This state of limbo is now being called long COVID-19 or long-haul COVID-19, and doctors are still trying to figure it out.

"The initial thought was we're going to treat a virus whose most common manifestation is respiratory," said Dr. Uriel Sandkovsky, an infectious disease specialist with Baylor Scott & White Health in Dallas. "But we learned pretty early this is a multi-system disease with multiple stages. The virus not only has a direct effect on the human body, (it) also changes the way the immune system behaves. We don't know the long-term consequences."

Key among the concerns, Sandkovsky said, are the lasting effects on the [heart](#) and lungs and the dangers of inflammation, which can contribute to many diseases.

The scope of long COVID-19 remains unclear. A small study from Italy

published in July in JAMA showed that 87% of patients who were discharged from the hospital after recovery still had at least one symptom two months later. Another study published by the Centers for Disease Control and Prevention in July showed that 35% of people surveyed who tested positive for the [coronavirus](#) and experienced symptoms, but were not hospitalized, had not returned to their usual health after two or three weeks.

A CDC update in November said long-term effects of COVID-19 can range from pain, fatigue and difficulty breathing to heart inflammation, memory problems and depression.

Crumbly knows that all too well. After returning from London, she was hospitalized with high fever and intense chest pain.

"They gave me fluids and painkillers and sent me home," she said. "They said, 'We don't know what to do with you. Come back if you can't breathe.'"

"Many times I couldn't breathe, but I didn't want to waste a hospital bed. So, I just sat home and dealt with it myself, and hoped I didn't get worse."

Instead, Crumbly has endured an endless series of doctor visits, in person and virtual, dealing with pneumonia, elevated [heart rate](#), constant coughing, exhaustion, persistent pain and cognitive problems commonly referred to as "brain fog."

"I'm not frustrated with the doctors," she said. "They threw everything they had at me, all kinds of medications and vitamins. I've tried every diet. I just try to manage the symptoms as I go."

In September, concerned that COVID-19 long-haulers were not getting

enough attention—and frustrated that many people were cavalier about the dangers of the disease, Crumbley posted a long message on social media detailing her ordeal.

"I share not to get any sympathy," she wrote. "I share because I feel people are getting fatigued of hearing about COVID-19 and have moved on. ... I want people to still continue to take this monster seriously."

Crumbley was astonished by the response: thousands of COVID-19 victims offering support and telling their own stories of sickness, anguish and despair.

"There are so many of us," she said. "We have to keep talking about this."

Sandkovsky, who is not involved in Crumbley's treatment, is sure that will happen. Even if a vaccine is successful, he said, researchers need to develop better treatments and to track COVID-19's long-term effects, much as the landmark Framingham Heart Study has followed subjects for seven decades and revealed much about cardiovascular disease.

"Every time we think we understand something about COVID-19, something else comes up," he said. "It's very humbling."

For now, and until a vaccine is available to everyone, the best way to prevent infection is by wearing a mask, washing your hands and staying at least six feet apart from people outside your household.

Crumbley, meanwhile, speaks for many long-haulers coping with a situation that didn't exist a year ago.

"I still have trouble accepting that things changed so quickly," she said. "This may be it until somebody figures out what to do. I just hope we get

better."

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