Just how bad is it to be in ICU with COVID? Far more miserable than people realize, experts say

Nearly two months after Jim Kolovos was put on a ventilator, his wife and doctors tried to help him regain consciousness so they could ask him a question: Was he ready to give up, or did he want to try for a lung transplant and keep fighting for his life?

No one was sure whether Kolovos could make that decision after being sedated for so long. It's not unusual for people who spend extended time in intensive care to become delirious or struggle to think clearly.

But for him, "there was never a chance I would say no." There was his wife, and 11-year-old daughter and 8-year-old son. "I would not leave those kids at home alone without a dad. I will do anything I can to be there."

Now, Kolovos, 46, is in rehab, slowly teaching himself to walk again on legs weakened by almost a year of being bedridden. He's advanced from a full harness to just leg braces, with only one therapist walking next to him.

Although extreme, Kolovos' experience – weeks of sedation, months of rehab, years, perhaps of lingering symptoms – is common for people who have ended up in an intensive care unit because of COVID-19.
Most people who die of COVID-19 first spend time in an ICU.

Early in the pandemic, about one-third of COVID-19 patients treated in intensive care died. Those figures are far better now, though precise numbers aren't available. Most of the survivors, like Kolovos, don't bounce back quickly.

A study published in late January found that among Dutch people treated for COVID-19 in an ICU, 74% still had physical symptoms a year later, including weakness and muscle and joint pain. More than a quarter reported lingering mental symptoms and 16% had cognitive problems.

COVID-19 patients who end up in intensive care have a rougher road than those with other respiratory illnesses, often suffering long-term organ damage, said Dr. Amit Gaggar, an attending physician in ICUs at the University of Alabama at Birmingham and the Birmingham VA Medical Center.

After being released, many have lingering shortness of breath, new or exacerbated heart failure, kidney problems and lung scarring – all conditions that are possible after an ICU stay without COVID-19. But Gaggar said, "the degree is a lot more severe with the COVID population."

While many people with respiratory illnesses might need two to three days in intensive care, patients with COVID-19 often spend two to three weeks or more, said Dr. Wes Ely, an ICU specialist at Vanderbilt University Medical Center in Nashville, Tennessee.

Those who survive ICUs may end up with what he calls post-intensive care syndrome, The condition can cause "neck up" problems, like dementia, post-traumatic stress disorder and depression, he said, and "neck down" problems, like muscle and nerve damage that can make it hard to walk or hold a pen.

"It can be permanent in up to two-thirds of people to some degree," Ely said. "Or it even gets worse."
The longer people remain in the ICU, the more symptoms patients are likely to get and have long-term, said Dr. Margaret Herridge, director of Critical Care Research at the University of Toronto, who is co-leading a national study of ICU patients in Canada. "There's a real cost to being in the ICU for a long period of time."

The sheer number of people who've been in ICUs during the COVID-19 pandemic means far more people will be suffering these lingering symptoms, said Dr. Abhijit Duggal, vice chair for the department of critical care at the Cleveland Clinic.

"COVID has brought it front-and-center that when someone stays in the ICU for a long period of time, the struggle is not done once they leave the hospital," Duggal said.

**Life in a COVID-19 ICU**

Daily life in an ICU is far more miserable than most people realize, particularly for COVID-19 patients because of their long stays, said Ely, author of the recent book about the ICU experience, "Every Deep Drawn Breath." Most in the general public "have no concept at all of the amount of suffering these people go through," he said.

Ely described a downward cycle that starts with feeling poorly and testing positive on a COVID-19 test. Today, some people can get monoclonal antibodies or antiviral pills that can often prevent hospitalization, but they're currently in short supply. (Kolovos got infected before vaccines became widely available.)

By the time a pulse oximeter measures a drop in oxygen level below the mid-90s, the person has started to feel sicker, dizzy, lightheaded and maybe isn't thinking clearly, said Ely, also co-director of Vanderbilt's Critical Illness, Brain Dysfunction, Survivorship Center. They are admitted to the hospital and given extra oxygen, while starting to feel claustrophobic and out of breath.

Then, nine or 10 days after they started feeling ill, their oxygen levels might dip down again, he said, and they need high-flow oxygen.
Their lung X-rays look whiter, indicating more damage. "You're heaving," Ely said, mimicking the sound of someone trying to catch their breath. "You're scared out of your mind, suffocating before your very eyes."

This can last several days, he said.

If the person doesn't improve, they're then put on a Bi-Level Positive Airway Pressure or BiPAP mask to help with breathing. But the BiPAP can't be used continuously because its pressure causes ulcers on the face. So the mask has to be taken off periodically to restore blood flow to the cheeks and chin.

Without the mask, "your oxygen plummets, which is really scary," Ely said. This "cat and mouse game" can continue for days, while the patient is pumped full of steroids, blood thinners and a drug called baricitinib, normally used to treat rheumatoid arthritis.

"We're just praying that the clock will go long enough without you having to be on a ventilator," Ely said.

If a patient's oxygen levels drop further, they have to be immobilized, sedated and intubated – put on a ventilator that will breathe for them. Many people later remember feeling like they were drowning.

"Now, you're starting to develop other diseases," Ely said. Muscle and nerve damage and delirium and thinking problems that may or may not lift if the person survives the ventilator. "We're still trying to keep you alive."

People either recover from this situation, perhaps, like Kolovos, with the help of a lung transplant. Or they don't.

Ely remembered one patient, a cardiothoracic surgeon in perfect health before catching COVID-19 too early in the pandemic to get vaccines or medications. He went through the full downward cycle until finally Ely and his family decided to withdraw life support.
He was struggling to breath for a number of hours, Ely said, and was given narcotics to blunt the pain and fear of suffocation at the end: "That is the typical course of someone who dies."

**What's different about COVID-19**

Once they end up in an ICU, COVID-19 patients tend to stay longer than those with pneumonia or flu, said Dr. Ankit Bharat, chief of thoracic surgery at Northwestern Medicine, who performed Kolovos' transplant.

If COVID-19 patients go on a ventilator, they need it longer than other patients. If they require a heart-lung bypass machine, called ECMO, they also need it for longer.

Their care is more complicated, too, Bharat said, because of the duration of their illness and the problems that come with it.

They get malnourished, "their lungs certainly take a beating," they develop COVID-associated damage and related infections.

"It's a very tough road for them," Bharat said.

While most ventilated patients remain intubated for about four days, those with COVID-19 have need nine to 11 days on average, Duggal said.

Patients who spend a long time in an ICU also often need continued assistance with tasks like walking, dressing, bathing and eating, which has an impact on family members and communities, Duggal said.

"A lot of these people who have struggled through severe illness are going to continue needing a lot of support," he said.

Herridge, a professor of medicine and senior scientist at the University Health Network in Toronto, said many family members suffer post-traumatic stress
symptoms after watching a loved one endure an extended ICU stay. And COVID-19, she said, has made the situation much worse.

Symptoms can be reduced for both patients and family members by having loved ones at the bedside – but for most of the pandemic, family visits have been severely limited by COVID-19 safety precautions. Heavy sedation and restraints, which were also used on many COVID-19 ICU patients, have also been shown to increase delirium, she said.

Patients who stay the longest are those who receive ECMO, the heart-lung bypass machine, she said. The median time on ECMO for her Toronto cohort of patients is about a month.

Of those who end up on ECMO, 50% to 60% recover spontaneously and survive to discharge despite their lung damage. Their likelihood of ever getting off ECMO goes down with time. If they need it for a month or longer, Bharat said, "their likelihood of getting better without a transplant is about 5%.

Many ICU patients end up with neuropsychiatric problems like nightmares, memory loss and forgetfulness, said Gaggar, also chief medical officer of ResBiotic, a company that sells probiotics.

As patients stay longer in the ICU, "all the effects we would see with non-COVID patients are magnified," he said. "All of these things kind of conspire together and make for a poor outcome for some of these individuals."

Herridge said there hasn't been much societal support for patients and their families who endure long ICU stays. "Post ICU patients and their families really need a lot of help and that help really doesn't exist in a systematic way," she said. "Hopefully, there's an opportunity here to rectify that."

**Still battling**
Kolovos said he got great care at the University of Pittsburgh Medical Center for several months. But they ultimately rejected him for a lung transplant, saying they thought he was too weak to survive. His cousin's husband, a doctor, had worked with Bharat, who offered to help.

Kolovos was flown to Chicago on Sept. 22, still on ECMO, and went straight into Northwestern's ICU. On Oct. 5, a donor became available, with lungs suitable for his 6-foot 3-inch frame.

He came off ECMO on Oct. 7 and a ventilator on Oct. 16. A few days later, desperately thirsty, he was allowed his first sip of water in 7.5 months. He's been working on his recovery ever since.

Bharat warned him that rehabbing after surgery would take a year or more "and it's going to be the hardest thing you're ever going to experience," Kolovos said.

He doesn't yet know how much of the damage he sustained will be permanent.

Kolovos still has very little movement in three fingers on his right hand, but "within the last 3 to 4 weeks I was able to see my three fingers flicker a little bit." A lefty, he has more mobility on his dominant hand, but still can't make a fist.

He can't yet dress himself because his grip and strength "just isn't there yet" to pull up his clothes. But with a little assistance, he can almost get food up to his mouth, and someone can push his hand the rest of the way. "I'm really close to being able to do it on my own."

Still, now living in a hotel a few blocks from his Chicago rehab center, Kolovos remains mostly upbeat. An extended visit from his kids, the first time he's seen them since September, has been a big boost.

"I'm not going to say there haven't been down days or tough days, but they've been few and far between," he said.
Lauren can't believe how her husband manages to remain so optimistic.

"I always refer to him as Guy Smiley," she said. "He still has that smile on his face. I told him many times, if I was in your position, I would not be smiling."

Kolovos said he's not doing much planning these days, just focusing on making the most out of every rehab session.

"I don't know what the future holds," he said. "All I can control is working hard and doing the best I can, and we'll manage whatever comes out of this."

Contact Weintraub at kweintraub@usatoday.com

Health and patient safety coverage at USA TODAY is made possible in part by a grant from the Masimo Foundation for Ethics, Innovation and Competition in Healthcare. The Masimo Foundation does not provide editorial input.