

Surviving ventilators, only to find lives diminished

Amid widespread use for coronavirus, breathing machines' long-term effects on patients raise concern

By **Felice J. Freyer** Globe Staff, Updated April 25, 2020, 2:37 p.m.



Rob Rainer couldn't return to his work as a lawyer after being on a ventilator for a month due to a severe lung infection. JIM DAVIS/GLOBE STAFF

Two months after leaving the intensive care unit, Rob Rainer returned to his law practice in Revere, eager to resume his old life after surviving a severe lung infection that tethered him to a breathing machine for a month.

But as he sat down at his desk, the former hard-driving multitasker found he couldn't

stay on track with even one task. Phone conversations left him overwhelmed. He was baffled by a computer program he himself had developed.

Today, five years later, Rainer's life is very different — his law practice shuttered, his two houses sold. At 58, he lives modestly with his wife in a small condo in Hudson, N.H.

While the novel coronavirus didn't exist in 2015, today thousands of COVID-19 patients in the United States are enduring the same experience that Rainer did, lying in a medication-induced coma as a ventilator pushes air into their weakened lungs for days or weeks on end.

And like Rainer, many will never be the same.

The widespread use of ventilators to save COVID-19 patients has sparked layers of controversy. Hospitals throughout the country don't have enough breathing machines to meet the predicted demand. Proposals on how to ration them have been called discriminatory. And then, many COVID-19 patients die despite the ventilators; a [new study](#) of New York patients found that, as of April 4, a quarter of COVID-19 patients requiring mechanical ventilation had died, while 72 percent were still in the hospital and only 3 percent had been discharged alive.

Now, a new discussion is emerging: the fate of those who survive the ventilator, but awaken to find their brains and bodies altered.

Dr. Daniela J. Lamas, a critical care physician at Brigham and Women's Hospital, once considered her job complete, and successful, when a patient survived an intensive care stay. But over the years she learned more about what happens to patients after they leave her care. Just because someone makes it through, she said, "does not mean they will be OK to reenter the world."

Ventilators force air, sometimes with added oxygen, into a patient's airways, essentially breathing for them so their lungs have a chance to rest and recover. Patients must be heavily sedated so they won't feel the tube down their throats or fight the machine's rhythm. They are typically immobile for long periods of time, leading to muscle wasting.

Although no one knows how COVID-19 patients in particular will fare over time, patients using ventilators for other illnesses typically experience long-term consequences. The prolonged immobility leaves many so feeble they can't even sit up, and muscle weakness can persist [even two years later](#).

Many had frightening experiences in the ICU — or imagined them while delirious — leading to post-traumatic stress disorder. Many, like Rainer, find they can't think as clearly as before. And as they realize how much they've lost, patients often suffer from anxiety and depression.

Together, these physical, psychological, and cognitive changes are known as post-intensive care syndrome, a term coined in 2012. Since then, about 25 or 30 hospitals have set up clinics to help patients understand and cope with the aftermath of an ICU stay. Lamas's [“After the ICU” clinic](#) at the Brigham is the only one in the Boston area.

Here and elsewhere, most patients are simply discharged to fend for themselves, cared for by primary care doctors who may not have full knowledge of what they've been through.

“My worry is that patients survive and they're just let free in the world, with no explanation of what happened to them,” Lamas said.

Emerging evidence suggests that ventilators [may not always be effective for COVID-19 patients](#), and that other less-invasive ways of assisting breathing could work better. If these findings are borne out, and fewer COVID-19 patients end up on ventilators, that will be good news for them — because in every other respect, things are stacked against them.

COVID-19 patients tend to require an exceptionally long time on the ventilator — weeks instead of days — leading to more damage and slower recovery. The steps doctors take to mitigate harm to ICU patients, such as frequent awakenings and physical therapy, can't

happen as infection-control efforts limit the number of staff going in and out of the unit.

And the loved ones who comfort and orient the patient have to stay away, too.



Jon Graham was on a ventilator for nine days. He was photographed with his wife Tracy on April 17 at their home in Clinton. CRAIG F. WALKER/GLOBE STAFF/THE BOSTON GLOBE

When Jon Graham, who contracted COVID-19 in early March, awoke from nine days on the ventilator, his wife of 18 years was not at his side. He couldn't understand where he was or what had happened to him.

Graham, a 62-year-old graphic designer, kept pulling out his IVs and the tube providing oxygen. The nurses at the University of Massachusetts Memorial Medical Center had to tie him down by the wrists.

"I'm in a room with alarms on it, doors locked, no human contact, nurses with hazmat suits looking in the little window," he recalled two weeks later. "You're really isolated by yourself. ... It was awful, awful, awful."

After a couple of days his mind cleared and the restraints were removed. But he realized he was too weak to even walk to the bathroom.

And while he seemed to know what was going on, he was also prone to delusions and paranoia, as often happens after prolonged sedation. He thought the doctors and his wife, Tracy, were plotting to keep him from coming home. He became convinced his hospital roommate had stolen a gift from a friend.

Even after Tracy confirmed that the friend never sent a gift, Graham said he's not sure he believes it. The delusions seem so real, they are experienced as memories.

Graham returned home April 13. "I'm feeling a little bit better every day," he said in an interview three days later. "At least I can stand up and walk around a little bit."

His wife was surprised when Graham blew his top over an Internet issue. "Jon never gets angry," she said. And he's not reading like he used to, feeling too weary for the mental exertion.

Though grateful for the care he received at UMass and thrilled to be home in Clinton with his wife and their 7-year-old twins, he knows he's got a long recovery ahead.

"I don't feel confused or anything, but I definitely don't feel like my normal self," he said.

The doctor who took care of him at UMass, Adarsha Bajracharya, was optimistic that mentally Graham could return "near to baseline." Graham hopes to go back to work eventually.

It's a goal many ventilator survivors don't achieve.



A ventilator at Boston Medical Center. ERIN CLARK/GLOBE STAFF

One [study](#) of 922 survivors of acute respiratory distress syndrome, the condition that typically leads to ventilator use, found that nearly half were jobless a year after recovery.

Dr. Brad Butcher, director of the [Critical Illness Recovery Center](#) at the University of Pittsburgh Medical Center, said the focus on unemployment caused by pandemic-related shutdowns misses another key aspect: Many COVID-19 survivors will be unable to return to work for some time, if ever.

“This is going to have a profound effect on people’s lives and the economy,” he said.

According to the most recent data, about half the 4.8 million people who survive a stay in the ICU develop some aspect of post-intensive care syndrome, said Tammy Eaton, a nurse practitioner who cofounded the Critical Illness Recovery Center with Butcher.

that's going to change pretty drastically with COVID-19, as thousands of patients emerge from long, lonely ICU stays, Eaton said.

Only 30 percent to 40 percent of patients who survived a ventilator say they feel like they're back to normal after three to six months, Butcher said.

Ventilator use affects thinking ability in ways that are not fully understood, but which may result from sedating medications or from loss of oxygen to the brain.

The cognitive effects can be hard to detect at first, especially in high-functioning, high-IQ people, said Dr. Carla Sevin, director of the [ICU Recovery Center](#) at Vanderbilt University Medical Center.

Sevin recalled having “a lovely conversation” with a man who seemed to be doing well after an ICU stay. But when a psychologist gave him a basic mental status exam — asking such questions as what year it is, who the president is — she was shocked to see that the man did not know the answers. “His wife was equally shocked,” Sevin said.

When these seemingly recovered patients return to work, they often end up having their duties reduced or getting fired, she said.

Stacey Salomon, a social worker in the medical intensive care unit at the Brigham, said even patients who don't return to their previous lives “sometimes get back to a different place,” though it's not always a bad one.

Having to rely on family members can strengthen family bonds, she said, and the struggle to get better often engenders compassion. “They're never quite the same, but there can be a real sense of growth and they often want to give back to others,” she said.

Rainer, the former lawyer who couldn't resume his work, can attest to that. About eight months after his ICU stay, he got connected with Lamas at the Brigham, and after reviewing his treatment with her, was finally able to make sense of his experiences. An MRI revealed damage to the parts of his brain involved in decision-making and judgment. “Knowing there was a physical reason for the difficulties I was having was

helpful," he said.

He ended up designing the website for Lamas's "After the ICU" clinic. Today he teaches a business course for an online university and is working with his wife on starting a nonprofit. But he's a high-powered lawyer no more. He sometimes nods off at 4 in the afternoon and sleeps through to the next day.

Through it all, Rainer has discovered a "weird side effect" of his ICU experience — happiness.

"I'm much happier than I used to be," he said. "I laugh and I joke around and I don't take things as seriously as I used to. I look forward to each day, even though I'm not going to get much done."

This story has been updated to reflect [a correction](#) to [a study in JAMA](#).

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