The terrifying journey through COVID-19 and back for Rep. Mike Carter of Ooltewah

The image of his initial chest X-ray is etched in his brain

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Staff photo by Troy Stolt / Tennessee State Rep. Mike Carter and his wife Joan sit for a portrait on Monday, Sept. 28, 2020, in Ooltewah, Tenn. While Carter was in the ICU battling COVID-19, Joan, who had also contracted the virus but was asymptomatic, was at home and unable to be in Carter's room. "Not having any human touch, that was incredibly difficult. When I got home from the hospital, I had to make sure my hand was touching hers as much as possible," Mike Carter said.

On Monday, Aug. 10, Rep. Mike Carter was supposed to be heading to Nashville for a special session of the Tennessee General Assembly when his plan to address coronavirus issues at the state Capitol took an unexpected turn to his own household.

His wife, Joan, had tested positive for COVID-19.

He'd been prepping for the special session for weeks, and his fellow Republicans were counting on him. But Carter had been exposed, needed to stay home and get tested himself - not risk possibly infecting others, even

though he felt fine. He called the speaker of the house and said he wouldn't be attending.

By Sunday, 67-year-old Carter sat in the passenger seat, clinging to a bottle of oxygen, as Joan drove down I-75 south from their home in Ooltewah, Tennessee, to Erlanger Medical Center in Chattanooga. Joan was on her cell phone with Erlanger staff, who said they'd be waiting at the entrance.

"The day that he finally went to the hospital, it was so emotional. It was like something from a movie. They just swooped up and took him away," Joan said. "I was just watching him and I thought, 'I won't be able to see him again.' That feeling of the unknown was overwhelming."

Looking back, Carter said he realizes now that the hospital workers understood what at the time he didn't - how sick he was, how isolated he was about to be and how his odds of making it out alive weren't good.

It's been 46 days since Carter left Erlanger and began his rocky journey to recovery. He's battled unexplained symptoms, night terrors, lingering brain fog and fatigue. He worries about others with coronavirus who are struggling to overcome their illness without the support that's helped him.

He thinks about the three other patients who entered Erlanger's COVID-19 intensive care unit at the same time he did, but they didn't survive. He remembers friends who've lost their lives to the coronavirus and wonders why he was spared.

"That's why I'm a little reluctant to talk about how we had so many people praying for us - because I guarantee you, everyone had everybody praying,"

Carter said. "I don't want it to appear that I was special or something. ... I don't want that at all."

Staff photo by Troy Stolt / Tennessee State Rep. Mike Carter poses for a portrait on Monday, Sept. 28, 2020, in Ooltewah, Tenn. Carter, who has been recovering from a bout with COVID-19 that put him in the ICU, recalled the loneliness of his time in the the hospital as one of the most difficult things about his experience.

BEFORE COVID-19

Carter is no stranger to breathing problems and hospital beds. After grappling with asthma most of his life, he understands his lungs and their limitations more than most people.

As a kid, he'd wheeze whenever he attempted physical activity and experienced frequent asthma attacks. He started taking daily medications in his early teens and carried a rescue inhaler at all times. Carter was able to play

football but only because his coaches were understanding and found ways to work around his condition.

He's had several bouts of bronchitis and was hospitalized his sophomore, junior and senior years of high school. When he was 24, the first year he practiced law, a severe case of pneumonia landed him in the hospital again.

"Asthma just affected everything," Carter said. "I've never been able to run or do things like that and never left home without an inhaler."

But as medications advanced over the years, so did Carter's health. New asthma drugs that came out in the 1990s vastly improved his quality of life and allowed him to manage his chronic disease better than ever. He built a successful career as an attorney, businessman and former Hamilton County General Sessions Court judge before joining the state legislature in 2013.

Before falling ill with COVID-19, Carter said he'd never been in better shape. He spent the last 30 years without a trip to the hospital.

Then, he found out about Joan.

Her meticulous efforts to protect herself and family from the virus - which included a "rolling pharmacy" of face masks, hand sanitizer and gloves in the passenger seat of her car - gave the Carters little reason to think they were infected. She was tested for COVID-19 as a precautionary measure before undergoing a medical procedure and had just completed a 2-mile walk when she got the results that Monday.

It was too late to get a test that day, so Carter stayed home and went to an urgent care for a rapid test on Tuesday. He still had no symptoms and generally follows the safety guidelines, he said. Carter was shocked when his test came back positive.

"By Wednesday he was sick in the bed - sick, sick, sick. It was that quick," Joan said.

Experts say COVID-19's ability to minimally affect one person and debilitate the next is what makes the pandemic so serious and difficult to control.

"I had not had a fever at all. I think people like me are the ones that actually probably spread it, because you don't know. But I always wear a mask, sanitize," Joan said.

She watched her husband's condition deteriorate rapidly each day. Toward the end of the week, palliative care came to check on Carter and supplied supplemental oxygen, but he needed much higher doses than they could provide at home.

"You could just see things every day going south with him, and he didn't realize it," Joan said. "I kept trying to push water and Gatorade to keep him hydrated, and his urine output kept slowing down. I'm not a doctor, so I just thought he's not getting enough fluid. But he really didn't need more fluid - he had too much fluid. He was shutting down."

Carter initially objected to going to the hospital. Except for the experimental drug remdesivir and a ventilator - which he intended to refuse - he didn't understand what the hospital could provide that he wasn't already getting at home.

"I wasn't going on a ventilator. I was already so weak, I just knew that I would never come off of it," he said.

In hindsight, he said he wasn't thinking straight. He agreed to go to Erlanger after his normally mild-mannered personal physician bluntly told him his fate if he didn't.

"I would've laid in there and died if they hadn't just forced me to go to the hospital, because it just didn't make sense to me, and I guess the reason is I wasn't getting enough air," Carter said, adding that the virus "knows how to attack the host's weakness."

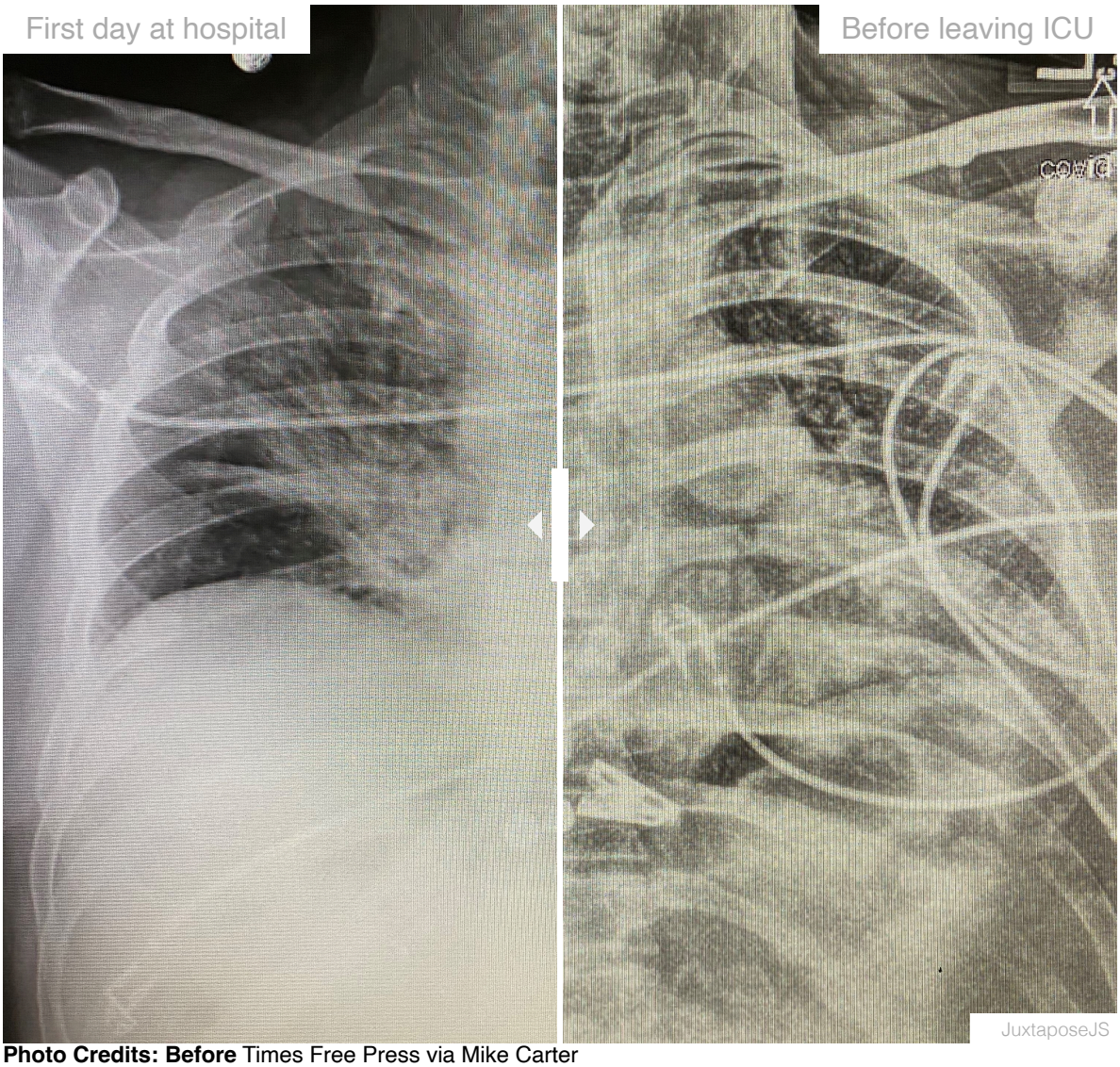

Photo Credits: Before Times Free Press via Mike Carter

'YOU'RE IN TROUBLE'

Carter's time on the regular COVID-19 floor was short-lived after he was admitted to Erlanger. His oxygen requirements quickly escalated to levels that required intensive care and he was taken to the COVID-19 ICU, where Dr. Aaron Cohen, a critical care specialist at Erlanger, said Carter was placed on the maximum amount of oxygen he can give someone before they must go on a ventilator.

"He was super sick," Cohen said. "His age is always what scares us when we see somebody who's on 100% oxygen through this high-flow device, which can't go higher than 100, and he had all the other symptoms - fever, fatigue, muscle aches. He was one of our sickest patients right away at that time."

Normal air contains about 21% oxygen, and healthy people breathe about 8-10 liters a minute, Cohen said. Carter was on a high-flow machine pumping 100% oxygen at 40 liters per minute.

Carter said his memories of the ICU are fuzzy, but the image of his initial chest X-ray is etched in his brain.

"When the nurse put it up there, I thought, 'Golly man, you're in trouble. This looks worse than pneumonia,'" he said. "It didn't take a doctor to realize it did not look good."

He spent almost the whole first night on his stomach, using a suction device, which he equated to those found at dental offices, to draw mucus out of his sinuses.

"I knew from having asthma and bronchitis and pneumonia all my life - you got to keep moving, you got to rollover, you got to lay on your stomach," Carter said. "If you just get in there and lay on your back, that stuff will just sit in a place in your lungs and can't get it out."

The steroid medication he was on - Decadron - kept him from sleeping and caused an insatiable hunger. At the same time, the coronavirus made food taste terrible, Carter said. Then, there was the "brain fog."

"Brain fog doesn't describe it. It was more of a separation from reality, which when I realized that was happening, that terrified me. I've made my living using what little brain I've got, and the thought of not having control over it was terrifying," he said.

Carter said the isolation wore on him the most. Although he could video chat with his family and talk on the phone, it wasn't the same as having loved ones present.

"It never dawned on me just what physical touch meant ... that's the first time I've ever been that isolated," Carter said.

He said the team at Erlanger was instrumental in comforting him through those dark times, especially Andrea Gilliam, a critical care registered nurse.

"Families aren't able to physically be there and talk to them, so we take on that role, which puts a very emotional and personal level to all of these patients," Gilliam said.

For a while, Carter's condition was "touch and go," Cohen said.

"He was on 100% oxygen for maybe three or four days. There's nothing left to give you after that. If you don't have recovery at that point, and your lungs are getting worse, ventilators are the next step," Cohen said. "We were really scared about doing that for him. The data doesn't suggest that people do well with ventilators in his age group."

Carter told Gilliam how much he feared intubation and that he would refuse a ventilator if it came to that.

"Then you're thinking, 'What if it comes to that?'" Gilliam said. "Statistics aren't great, but what if you're that person who makes it off [the ventilator]? Because we've had some."

Joan would meet Gilliam in the parking deck each day to drop off items for her husband - ChapStick, flexible straws, Pop-Tarts.

"It's a big empty hole that's just hard to wrap your mind around not seeing him, because he's been in the hospital lots of times, and I've always been there ... and I worried about not protecting him," Joan said.

Carter hit another roadblock when after several days he developed liver inflammation as well, a sign of an additional organ system being affected, Cohen said.

Gilliam tried to keep Carter's spirits up by talking about history and travel, topics they both enjoy. She said it's hard to communicate with a patient on oxygen through the layers of personal protective equipment, but it helped that Carter likes to talk. She'd watch his oxygen drop during long spurts and tell

him to slow down while she waited for it to catch back up so he could finish his story.

"He's actually super funny. He would joke around with me all the time," Gilliam said.

That same sense of humor was how Joan knew that Carter was finally on the mend. He told her that he turned a corner, and she asked what to do with the non-returnable black dress she bought for his funeral.

"He laughed so hard when we were saying that, that I knew he was feeling better. That was like medicine for me," Joan said.

After eight days in the ICU, Gilliam got to take Carter to the regular COVID-19 floor.

"It had been a really long time for me to have a successful patient make it out of our ICU onto the floor, so that was a huge deal," she said. "It really helped me emotionally, as well - to have somebody so sick when you meet them and push with them. He was a fighter. He never gave up.

"Everybody's a little bit different, but he was a very special man, very, very kind to us," Gilliam said. "You could tell he was scared, but he wanted to make it home and was willing to do whatever it took."

On Aug. 26, Carter returned home to Ooltewah.

UPS AND DOWNS

He's not sure what time it was, but Carter woke up one day in a panic - his tongue was paralyzed and stuck to his jaw. He scrambled to find Joan but

couldn't.

"When I first got home, I didn't want Joan out of my sight. I wanted her laying there, I needed my hand laying on her at all times," he said.

Convinced he was having a stroke, Carter grabbed the phone to call his wife. But as the phone began ringing, Joan raised up out from under the covers.

"She was right beside me, and I couldn't think clearly enough to realize there's a lump in the bed, that's probably her," Carter said.

Joan started dripping water into his mouth and his tongue gave way - dry mouth is one of the many symptoms that still plagued Carter - and he snapped out of it.

Although he survived COVID-19, Carter faced a new challenge. Night terrors weren't something he'd ever experienced, even in the hospital. So far, he's had about five or six, not counting the other days he would wake up overcome by anxiety, he said.

"What do I have to be anxious for? I'm home, I'm out of the hospital, I'm going to live, I don't have to be at work tomorrow, we're very fortunate," he said. "I've got everything I need. Why in the world would I be anxious or terrified?"

Joan learned to recognize his breathing pattern before the night terrors. She would gently pat his chest to ease him out of them rather than waiting for it to build up to the point that he woke up.

"You're thinking, 'This isn't logical,' but it's still very, very real," she said.

Carter believes it didn't help that he barely slept at the hospital. Perhaps the terrors and anxiety stem from exhaustion.

He also said he watched too many YouTube videos once he got home. Those fueled the notion that his brain fog, which had improved since his days in the ICU but persisted, was the result of a blood clot.

Carter's doctor kept assuring him that the fog and anxiety were part of a normal recovery and would eventually subside.

"He has an excellent legal mind, very logical. So when you recognize that you're not thinking with that same mindset, he'd get so anxious. You just have to think, this is going to pass," Joan said.

Carter said the recovery at home is worse than the hospital, filled with strange symptoms that he can't explain that start and stop without warning.

"My temperature regulation has been a really serious issue," he said. "A fever, that's nothing like this. Don't confuse yourself. This is as though someone is heating you from the inside. If I'm in a microwave oven, this is how I would feel. And when I would get so hot that I would be ready to pass out, the thermometer would say my temperature was normal."

Those feelings cause him to sweat profusely, but he said the perspiration felt oilier than normal sweat. He only felt comfortable when the thermostat was between 64 and 66 degrees.

Then, for a while, his left foot hurt to the point he could barely stand on it. One day he stepped out of the shower and it just stopped out of nowhere, Carter said.

"It started like a light switch, and it left like a light switch, and that is freaky," he said. "Normally when you're sick, it starts off bad but then gets better after about three days, maybe five if it's really bad. But with this, you'll be good for three days and then suddenly you're so ill you don't feel like you can do anything."

LOOKING AHEAD

Carter had a stretch of good days the last week of September.

A friend brought a contract by one morning for him to read and he felt like his "mind was back."

Then, he ventured out to the backyard and up to the shop to service his tractor. Normally that's a 15-minute job, but he took his time, wanted to make sure he didn't mess something up. He got hot and started to sweat. But this time, he recognized what was coming out of his body.

"It was perspiration. It wasn't that oily goo," he said. "So to me, that was a sign that whatever was messed up in me inside had corrected."

He worked for about 45 minutes before he started back toward the house. He was tired, but said he felt otherwise normal.

These days, he said he's most concerned about others out there going through what he did without a support system.

"We had a lot of support. I don't think you could have much more support than we had, and I'm just thankful for it. But what in the world would we have

done if we hadn't of? And I think the vast majority of people going through this haven't had that support."

Carter said he keeps thinking the pandemic will be over in 60 days, but then another 60 days go by and it shows no sign of slowing. Now, he just says he doesn't know what the future holds.

He recalled a time in law school in Memphis when an earthquake hit. They saw pictures bouncing off the walls and ran outside the apartment just to see oak trees towering over them and wondering if they were going to fall.

"It was that feeling of even the earth isn't safe any longer, and this is the biological similarity to that. You don't know what's coming next," he said.

The General Assembly is supposed to start meeting again in January, but he doesn't think the law allows members to meet remotely. Cases of COVID-19 reinfection have already been reported. Without a vaccine, it's possible he could catch the coronavirus again.

"We have really been through it, and I don't want sympathy for that," he said. "What I want - if there are people out there that have really been through it, and don't have a way to vent that - is for them to know they're not crazy. And to know that they are going to get well, and they are going to be better, and here's what worked for me ... Somebody just to commiserate with."

"I don't want anybody to think we're better than anybody else and that's how we got out of it. We didn't. We're just lucky," he said. "But if we can help people in some way, then we ought to do that."

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Elizabeth Fite was the healthcare reporter for the Chattanooga Times Free Press. She covers rural healthcare, hospitals, health insurance, public health and health policy, with a focus on explaining and investigating how healthcare systems and safety-net programs work — or don't — for the people who depend on them. She joined the paper in 2017 after earning a master's degree in Health and Medical Journalism from the University of Georgia.