

Message from Myra, who beat Long COVID: Don't give up hope

Myra knew something was wrong when she was still suffering the effects of Long COVID nearly 12 months after her diagnosis in May 2021. “A year out I was still not back to normal,” she said. “I couldn't remember anything. I was unable to put thoughts together, words together. My brain broke. I was lost. It was a very scary feeling. I knew I needed help.”

A communications specialist, she worried that she would need to change careers. “I thought, ‘I'm going to have to get a different job.’ I write for a living, I talk to people for a living. My colleagues realized something was wrong.” But her condition slowly improved and in September 2022, 16 months after her diagnosis, she was over it.

“You're back, baby!” a colleague told her.

Myra got COVID in late 2020. It was a mild case, and unlike many who developed Long COVID, she was not hospitalized. Months later, when she realized she wasn't getting better, she went to a Long COVID clinic and was diagnosed with it. Relieved to at least know what it was, she received additional support from those at work. “They said, ‘You're not imagining this.’ The first day, they believed me. That was huge. It was early on it was just reassuring that they were going to help me. They gave me grace and leeway.”

She needed that leeway, as Long COVID symptoms continued to dog her. “I could remember the past, but I was unable to imprint new memories,” she said. “I had a lot of issues with post-nasal drip, a lingering cough, my sinuses were a mess; I felt like I was drowning. I would smell smoke and run around the house because I thought the house was on fire.”

The brain fog and short-term memory loss were especially frustrating. “If I lit a candle I would walk away. If I started to run water for a bath, I would walk away. I couldn't remember to go back. I did not cook anymore. I left my keys in the door. At work, I recorded meetings, and was constantly taking notes. No way could I have a meeting and say, ‘I got it,’” she recalled. She decided she needed to warn her friends.

“They had to know I was not going to remember stuff,” she said. “I was going to repeat things.” Fortunately, her workmates and friends were supportive.

Although her children were OK, her husband, who also got COVID, suffered from similar memory issues, which made things even more difficult. Later, just when she had begun to feel better, she got lost in her neighborhood. “That scared me,” she said. “That was devastating. I felt like my brain misfired all day.”

Her doctors were unable to predict her outcome. “‘It’s going to take time,’ they told me,” she said. “It did.” But it took an emotional toll “It was dark and devastating. I felt like it changed me, it made me really unsure of myself. I was unable to hold a conversation.”

But she continued to improve, and by the fall of 2022 she had recovered.

“Now, I feel like myself again,” she said.

In addition to support from family and friends, Myra found a boost from two Facebook support groups for Long COVID that she joined. “I felt like COVID and Long COVID had become politicized, so that’s why I sought out private groups. “It was very helpful,” she said. “I didn’t feel alone. It’s nice to be part of a community.”

Myra also gives herself some well-earned props for action and resilience.

“I advocate for myself. I’m just tenacious,” she said.

As she looks back, she’s grateful. “I now know you get better, that time does make some things better. I feel lucky and fortunate. Some people with Long COVID are on disability. I don’t feel it limits me anymore. I feel like I’m ‘normal.’” And she wants to get out the word that Long COVID is real and there is hope. “When you’re six months out and you’re not normal, there is help,” she said, adding that she remained confident in her doctors despite the lack of results from different medications and procedures they tried. “Most of the solutions didn’t work but they were trying,” she said. “For me, the thing that worked was time.”

The nagging questions still nag, although her recovery has taken the urgency out of answering them for her:

“Why did I get it? Why didn’t others? Why did it do *that* to me? I wish I knew.