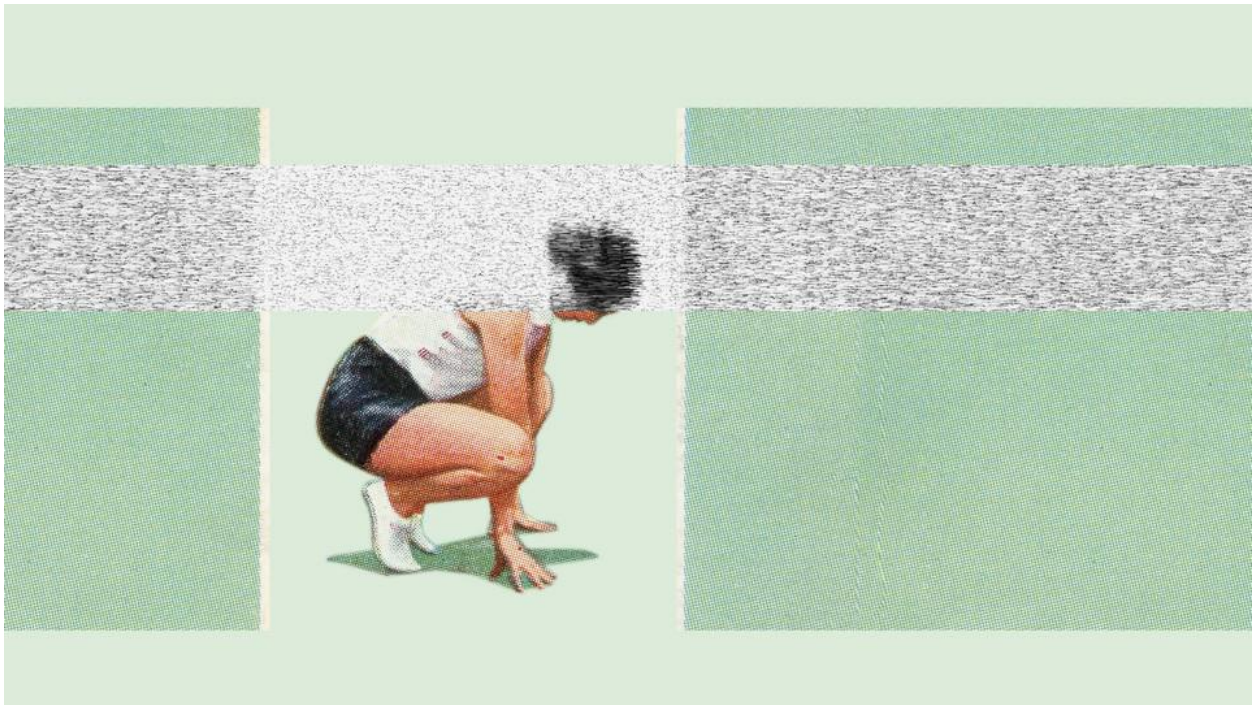


# Long COVID Has Forced a Reckoning for One of Medicine's Most Neglected Diseases

Only a couple dozen doctors specialize in chronic fatigue syndrome (ME/CFS). Now their knowledge could be crucial to treating millions more patients.

By Ed Yong



Katie Martin / The Atlantic; Getty

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Kira Stoops lives in Bozeman, Montana—a beautiful mountain town where it sometimes feels like everyone regularly goes on 50-mile runs. Stoops, however, can't walk around her own block on most days. To stand for more than a few minutes, she needs a wheeled walker. She

reacts so badly to most foods that her diet consists of just 12 ingredients. Her “brain fog” usually lifts for a mere two hours in the morning, during which she can sometimes work or, more rarely, see friends. Stoops has myalgic encephalomyelitis, or chronic fatigue syndrome (ME/CFS). “I’m considered a moderate patient on the mild side,” she told me.

ME/CFS involves a panoply of debilitating symptoms that affect many organ systems and that get worse with exertion. The Institute of Medicine estimates that it affects 836,000 to 2.5 million people in the U.S. alone, but is so misunderstood and stigmatized that about 90 percent of people who have it have never been diagnosed. At best, most medical professionals know nothing about ME/CFS; at worst, they tell patients that their symptoms are psychosomatic, anxiety-induced, or simply signs of laziness. While ME/CFS patients, their caregivers, and the few doctors who treat them have spent years fighting for medical legitimacy, the coronavirus pandemic has now forced the issue.

A wide variety of infections can cause ME/CFS, and SARS-CoV-2, the coronavirus that causes COVID-19, is no different: Many cases of long COVID are effectively ME/CFS by another name. The exact number is hard to define, but past studies have shown that 5 to 27 percent of people infected by various pathogens, including Epstein-Barr virus and the original SARS, develop ME/CFS. Even if that proportion is 10 times lower for SARS-CoV-2, the number of Americans with ME/CFS would still have doubled in the past three years. “We’re adding an immense volume of patients to an already dysfunctional and overburdened system,” Beth Pollack, a scientist at MIT who studies complex chronic illnesses, told me.

The U.S. has so few doctors who truly understand the disease and know how to treat it that when they convened in 2018 to create a formal coalition, there were only about a dozen, and the youngest was 60. Currently, the coalition’s website lists just 21 names, of whom at least three have retired and one is dead, Linda Tannenbaum, the CEO and

president of the Open Medicine Foundation, told me. These specialists are concentrated on the coasts; none work in the Midwest. American ME/CFS patients may outnumber the population of 15 individual states, but ME/CFS specialists couldn't fill a Major League Baseball roster. Stoops, who is 39, was formally diagnosed with ME/CFS only four years ago, and began receiving proper care from two of those specialists—Lucinda Bateman of the Bateman Horne Center and David Kaufman from the Center for Complex Diseases. Bateman told me that even before the pandemic, she could see fewer than 10 percent of the patients who asked for a consultation. “When I got into those practices, it was like I got into Harvard,” Stoops told me.

ME/CFS specialists, already overwhelmed with demand for their services, now have to decide how to best use and spread their knowledge, at a time when more patients and doctors than ever could benefit from it. Kaufman recently discharged many of the more stable ME/CFS patients in his care—Stoops among them—so that he could start seeing COVID long-haulers who “were just making the circuit of doctors and getting nowhere,” he told me. “I can't clone myself, and this was the only other way to” make room for new patients.

Bateman, meanwhile, is feverishly focused on educating other clinicians. The hallmark symptom of ME/CFS—post-exertional malaise, or PEM—means even light physical or mental exertion can trigger major crashes that exacerbate every other symptom. Doctors who are unfamiliar with PEM, including many now running long-COVID clinics, can unwittingly hurt their patients by encouraging them to exercise. Bateman is racing to spread that message, and better ways of treating patients, but that means she'll have to reduce her clinic hours.

These agonizing decisions mean that many existing ME/CFS patients are losing access to the best care they had found so far—what for Stoops meant “the difference between being stuck at home, miserable and in

pain, and actually going out once or twice a day, seeing other humans, and breathing fresh air,” she told me. But painful trade-offs might be necessary to finally drag American medicine to a place where it *can* treat these kinds of complex, oft-neglected conditions. Kaufman is 75 and Bateman is 64. Although both of them told me they’re not retiring anytime soon, they also won’t be practicing forever. To make full use of their expertise and create more doctors like them, the medical profession must face up to decades spent dismissing illnesses such as ME/CFS—an overdue reckoning incited by long COVID. “It’s a disaster possibly wrapped up in a blessing,” Stoops told me. “The system is cracking and needs to crack.”

Many ME/CFS specialists have a deep knowledge of the disease because they’ve experienced it firsthand. Jennifer Curtin, one of the youngest doctors in the field, has two family members with the disease, and had it herself for nine years. She improved enough to make it through medical school and residency training, which showed her that ME/CFS “just isn’t taught,” she told me. Most curricula don’t include it; most textbooks don’t mention it.

Even if doctors learn about ME/CFS, America’s health-care system makes it almost impossible for them to actually help patients. The insurance model pushes physicians toward shorter visits; 15 minutes might feel luxurious. “My average visit length is an hour, which doesn’t include the time I spend going over the patient’s 500 to 1,700 pages of records beforehand,” Curtin said. “It’s not a very scalable kind of care.” (She works with Kaufman at the Center for Complex Diseases, which bills patients directly.) This also explains why the cohort of ME/CFS clinicians is aging out, with little young blood to refresh them. “Hospital systems want physicians to see lots of patients and they want them to follow the rules,” Kaufman said. “There’s less motivation for moving into areas of medicine that are more unknown and challenging.”

ME/CFS is certainly challenging, not least because it's just “one face of a many-sided problem,” Jaime Seltzer, the director of scientific and medical outreach at the advocacy group MEAction, told me. The condition's root causes can also lead to several distinct but interlocking illnesses, including mast cell activation syndrome, Ehlers-Danlos syndrome, fibromyalgia, dysautonomia (usually manifesting as POTS), and several autoimmune and gastrointestinal disorders. “I'm still amazed at how often patients come in with Complaint No. 1, and then I find five to seven of the other things,” Kaufman said. These syndromes collectively afflict many organ systems, which can baffle doctors who've specialized in just one. Many of them disproportionately affect women, and are subject to medicine's long-standing tendency to minimize or psychologize women's pain, Pollack told me: An average woman with Ehlers-Danlos syndrome typically spends 16 years getting a diagnosis, while a man needs only four.

People with long COVID might have many of these conditions and not know about any—because their doctors don't either. Like ME/CFS, they rarely feature in medical training, and it's hard to “teach someone about all of them when they've never heard of any of them,” Seltzer said. Specialists like Bateman and Kaufman matter because they understand not just ME/CFS but also the connected puzzle pieces. They can look at a patient's full array of symptoms and prioritize the ones that are most urgent or foundational. They know how to test for conditions that can be invisible to standard medical techniques: “None of my tests came back abnormal until I saw an ME/CFS doctor, and then *all* my tests came back abnormal,” said Hannah Davis of the Patient-Led Research Collaborative, who has had long COVID since March 2020.

ME/CFS specialists also know how to help, in ways that are directly applicable to cases of long COVID with overlapping symptoms. ME/CFS has no cure but can be managed, often through “simple, inexpensive interventions that can be done through primary care,” Bateman told me. Over-the-counter antihistamines can help patients

with inflammatory problems such as mast cell activation syndrome. Low doses of naltrexone, commonly used for addiction disorders, can help those with intense pain. A simple but rarely administered test can show if patients have orthostatic intolerance—a blood-flow problem that worsens other symptoms when people stand or sit upright. Most important, teaching patients about pacing—carefully sensing and managing your energy levels—can prevent debilitating crashes. “We don’t go to an ME/CFS clinic and walk out in remission,” Stoops told me. “You go to become stabilized. The ship has 1,000 holes, and doctors can patch one before the next explodes, keeping the whole thing afloat.”

That’s why the prospect of losing specialists is so galling. Stoops understands why her doctors might choose to focus on education or newly diagnosed COVID long-haulers, but ME/CFS patients are “just so lost already, and to lose what little we have is a really big deal,” she said. Kaufman has offered to refer her to generalist physicians or talk to primary-care doctors on her behalf. But it won’t be the same: “Having one appointment with him is like six to eight appointments with other practitioners,” she said. He educates *her* about ME/CFS; with other doctors, it’s often the other way round. “I’m going to have to work much harder to receive a similar level of care.”

At least, she will for now. The ME/CFS specialists who are shifting their focus are hoping that they can use this moment of crisis to create more resources for everyone with these diseases. In a few years, Bateman hopes, “there will be 100 times more clinicians who are prepared to manage patients, and many more people with ME/CFS who have access to care.”

For someone who is diagnosed with ME/CFS today, the landscape already looks very different than it did just a decade ago. In 2015, the Institute of Medicine published a landmark report redefining the diagnostic criteria for the disease. In 2017, the CDC stopped recommending exercise therapy as a treatment. In 2021, Bateman and 20

other clinicians published a comprehensive guide to the condition in the journal of the Mayo Clinic. For any mainstream disease, such events—a report, a guideline revision, a review article—would be mundane. For ME/CFS, they felt momentous. And yet, “the current state of things is simply intolerable,” Julie Rehmeyer, a journalist with ME/CFS, told me. Solving the gargantuan challenge posed by complex chronic diseases demands seismic shifts in research funding, medical training, and public attitudes. “Achieving shifts like that takes something big,” Rehmeyer said. “Long COVID is big.”

COVID long-haulers have proved beyond any reasonable doubt that acute viral infections can leave people chronically ill. Many health-care workers, political-decision makers, and influencers either know someone with long COVID or have it themselves. Even if they still don’t know about ME/CFS, their heightened awareness of post-viral illnesses is already making a difference. Mary Dimmock’s son developed ME/CFS in 2011, and before the pandemic, one doctor in 10 might take him seriously. “Now it’s the flip: Only one doctor out of 10 will be a real jerk,” Dimmock told me. “I attribute that to long COVID.”

But being believed is the very least that ME/CFS patients deserve. They need therapeutics that target the root causes of the disease, which will require a clear understanding of those causes, which will require coordinated, well-funded research—three things ME/CFS has historically lacked. But here, too, “long COVID is going to be a catalyst,” Amy Proal, the president of the Polybio Research Foundation, told me. She is leading the Long Covid Research Initiative—a group of scientists, including ME/CFS researchers, that will use state-of-the-art techniques to see exactly how the new coronavirus causes long COVID, and rapidly push potential treatments through clinical trials. The National Institutes of Health has also committed \$1.15 billion to long-COVID research, and while some advocates are concerned about how that money will be spent, Rehmeyer notes that the amount is still almost 80 times greater than the paltry \$15 million spent on ME/CFS every

year—less than any other disease in the NIH’s portfolio, relative to its societal burden. “Even if 90 percent is wasted, we’d be doing a lot better,” she said.

While they wait for better treatments, patients also need the medical community to heed the lessons that they and their clinicians have learned. For example, the American Academy for Family Physicians website still wrongly recommends exercise therapy and links ME/CFS to childhood abuse. “That group of doctors is very important to these patients,” Dimmock said, “so what does that say to them about what this disease is all about?”

Despite all evidence to the contrary, many clinicians and researchers still don’t see ME/CFS as a legitimate illness and are quick to dismiss any connection between it and long COVID. To ensure that both groups of patients get the best possible treatments, instead of advice that might harm them, ME/CFS specialists are working to disseminate their hard-won knowledge. Bateman and her colleagues have been creating educational resources for clinicians and patients, continuing-medical-education courses, and an online lecture series. Jennifer Curtin has spent two years mapping all the decisions she makes when seeing a new patient, and is converting those into a tool that other clinicians can use. As part of her new start-up, called RTHM, she’s also trying to develop better ways of testing for ME/CFS and its related syndromes, of visualizing the hefty electronic health records that chronically ill patients accumulate, and of tracking the treatments they try and their effects. “There are a lot of things that need to be fixed for this kind of care to be scalable,” Curtin told me.

Had such shifts already occurred, the medical profession might have had more to offer COVID long-haulers beyond bewilderment and dismissal. But if the profession starts listening to the ME/CFS community *now*, it will stand the best chance of helping people being disabled by COVID, and of steeling itself against future epidemics. Pathogens have been



chronically disabling people for the longest time, and more pandemics are inevitable. The current one could and should be the last whose long-haulers are greeted with disbelief.

New centers that cater to ME/CFS patients are already emerging. RTHM is currently focused on COVID long-haulers but will take on some of David Kaufman's former patients in November, and will open its waiting list to the broader ME/CFS community in December. (It is currently licensed to practice in just five states but expects to expand soon.) David Putrino, who leads a long-COVID rehabilitation clinic in Mount Sinai, is trying to raise funds for a new clinic that will treat both long COVID and ME/CFS. He credits ME/CFS patients with opening his eyes to the connection between long COVID and their condition.

Every ME/CFS patient I've talked with predicted long COVID's arrival well before most doctors or even epidemiologists started catching up. They know more about complex chronic illnesses than many of the people now treating long COVID do. Despite having a condition that saps their energy, many have spent the past few years helping long-haulers navigate what for them was well-trodden terrain: "I did barely anything but work in 2020," Seltzer told me. Against the odds, they've survived. But the pandemic has created a catalytic opportunity for the odds to finally be tilted in their favor, "so that neither patients nor doctors of any complex chronic illness have to be heroes anymore," Rehmeyer said.

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