Mady Hornig, MD, and patient share their experiences as COVID-19 long haulers

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Featured topic and speakers

In today’s COVID-19 update, AMA Chief Experience Officer Todd Unger looks into the issue of COVID long haulers, people who have not fully recovered from COVID-19, weeks even sometimes months after symptoms first appeared.

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Speakers

- Hanna Lockman, COVID long hauler
- Mady Hornig, MD, MA, associate professor of epidemiology, Columbia University Mailman School of Public Health and COVID long hauler

Transcript

Unger: Hello, this is the American Medical Association’s COVID-19 update. Today, we’re talking about COVID long haulers, people who haven't fully recovered from COVID-19 weeks or even months after symptoms first appear and what we know about the long-term impact of this disease.

I'm joined today by Hanna Lockman, a COVID long hauler from Louisville, Kentucky, and Dr. Mady Hornig associate professor of epidemiology at Columbia University Mailman School of Public Health in New York.
Dr. Hornig is studying COVID long haulers and is a COVID long hauler herself. I'm Todd Unger, AMA’s chief experience officer in Chicago. Ms. Lockman, let's start with you. Why don't you take us back to your initial COVID diagnosis and when did that happen and how did your illness play out?

**Lockman:** So, where it started for me is, I started getting pain in my chest, deep in my chest when I was working. And it just started getting worse that night to the point where I was just in excruciating pain. So, I went to the ER, and they initially thought I had bronchitis, but I was discharged and then ended up there the next day, and I was admitted with pneumonia diagnosis.

I did test negative for the flu and RSV, but at the time, this was early March, so there were very limited COVID test in my state of Kentucky. So, they did refuse to test me for COVID at that time, because I didn't have the necessary parameters there. So, I was admitted with pneumonia. And then after that, it's just been an ongoing cycle of ending up in the ER and getting treatment and then being discharged.

**Unger:** How long has this process lasted for you to date?

**Lockman:** I just passed seven months on the 12th, so it's been a very, very long time.

**Unger:** So that's seven months, I think you told us that 16 emergency department trips, three hospitalizations. So that has really been, that is a long haul literally.

**Lockman:** Yeah.

**Unger:** How has this continued to be characterized for you?

**Lockman:** What is really lingering now in this current time is I'm having headaches. I've had headaches every single day for, since June, and I also have issues with brain fog as they're describing it. I'll mix up information, I can't remember words. I have problems with—it's weird, it's like sentence structure. I'll get confused about how words are supposed to go together. I have shortness of breath. I have issues with tachycardia. If I get up and move too fast, I end up breathless and my heart is going to explode. It's not really going to explode, but it feels like it is.

So really, I used to be healthy and it's just, my body is crashing. Another issue is I have rashes, and then I have this burning feeling. It feels like a sunburn I get on my face most evenings. It's really excruciating and keeps me up some nights. So, it's just been just a random mixed bag of issues.

**Unger:** I'm so sorry that you're going through this. Dr. Hornig, talk to us a little bit about how your illness has played out, and hearing Ms. Lockman's story, is this something that you're seeing a lot from other reports?
Dr. Hornig: Oh, absolutely, and also from my own. So, what Ms. Lockman described as this panoply of all sorts of symptoms affecting all different organ systems, all different bodily systems. And we see that in several of the surveys that have been put out onto the web and are now being published that are patient driven, so Body Politic, Survivor Corps. I understand Ms. Lockman, maybe is involved with another one and some publications.

So, the symptoms are very diverse, and it's hard to really thread them all together. In medicine, I'm a physician scientist, a psychiatrist by training, but do a lot of lab bench work on infectious diseases and immune disorders. But when we're thinking about complex just illnesses where there's this hypothesis called Occam's razor, which is this idea that you are trying to get the most economical or parsimonious, simplest explanation that ties everything together, like you pull a thread and all of a sudden everything is in view and understandable with one explanation.

I'm looking in this pile of symptoms, and I just can't find the Occam's razor. And many of us are really perplexed. For me, I don't even really know whether I can reliably say when my illness started, because I had unusual symptoms for what is in the case definition, the official case definition of COVID-19, or that weren't really very well-known at the time. So, in retrospect, I do think that it started earlier than we had placed it.

My disorder started with a tickle in my throat. I also had a very strange, one rib muscle that was inflamed and extremely painful, just one. And it was so bad that I couldn't get out of bed. I couldn't flex to get out of bed, I had to roll out of bed. It was as if I had injured myself. That was followed by scrape, what I thought were scrapes on my toes. It was before this phenomenon of COVID toes had been described. And it was, I just said, oh, well, you're walking around without shoes, you got to wear slippers. You must have scraped your toes or something. Until one day I had to leave the house to go to the pharmacy and my toes were so swollen, I couldn't get shoes on. And that was unusual.

And then, I had a fever that lasted 12 days, which started another week, that was at the end of April. So I'm nearing this six month mark now. And we are looking at all of these symptoms trying to see, even if we don't know the explanation, we're trying to see whether the grouping and clustering of these symptoms that are happening in Long COVID are potentially on a pathway for some individuals towards something called myalgic encephalomyelitis. Now that's a mouthful. It's popularly known as chronic fatigue syndrome or ME CFS, is the abbreviation.

Unger: Well, let me just ask you, obviously you had your own experience to draw upon. When did you first hear about the concept of a long hauler and realize that there is a whole group of people, and then that obviously inspired your research, which you started to talk about. What are you finding here?

Dr. Hornig: Yeah, well, it's actually backwards because I had already been doing the research. I've been studying ME CFS for 20 years approximately, 15, 20 years or even longer. And I have seen the
reports in ME CFS for a viral onset to the illness. About three-quarters of people who develop ME CFS have had their symptoms for six months or more, and that's why that time period is important. And, but three-quarters of them note that they've had viral type symptoms at the onset of their illness.

The most common one, but it doesn't happen with everyone, the most common one that's reported is Epstein-Barr virus, which is the cause of something called, we call it kissing disease or infectious mono, infectious mononucleosis. And that in about 10 to 12% of people who get infectious mono with an Epstein-Barr virus infection will end up with a course that eventually could be diagnosed as ME CFS. And so, this chronic disabling, very disabling disorder.

And in fact, I had with a group that is focused on research and advocacy for ME CFS, we had put out on Capitol Hill as well as a piece that I published with a journalist by the name of David Teller. We already published in Health Affairs a piece about the possibility of this persistence and long duration symptoms. And we had only heard a little bit at that time. This was mid to late April, right? And then reports started to build more and more, and it started to really show us that there was a very large group of individuals, but probably a very diverse group. And so, we can talk about that. So, one of the things that Ms. Lockman you mentioned that you were diagnosed with pneumonia, right?

Lockman: Yeah.

Dr. Hornig: And did you have any, I can't recall if you mentioned whether you needed any oxygen or any additional types of measures to boost your respiratory system.

Lockman: I was given just supplemental oxygen occasionally because my oxygen did drop. I was experiencing the severe chest pain. I also had pleurisy and costochondritis type pains. So it was just my ribs and my back just hurt endlessly. And I've had issues like shortness of breath, but it's like my oxygen has stayed pretty stable, which is good, but I never needed the forced oxygen or anything.

Dr. Hornig: Yeah. So one of the things that we're trying to sort out now, we're comparing the symptoms that are observed in individuals who have a diagnosis of ME CFS, which can affect anybody system, but a very prominent something that you mentioned was this type of brain fog, problems paying attention, short-term memory types of issues. That's something that's very prominent in many people with ME CFS. Other things that are also common are pain issues and so forth.

But what may be different in some people who have Long COVID maybe the direct effects of the virus on the lungs and perhaps also on the heart in some individuals. When they're doing some different types of imaging of heart and lungs for individuals who may not even really have been aware that they had been infected with this virus, they're seeing that there can be damaged to the heart and lungs. And that may be a somewhat different long-term course than this other disorder which we call, as I said, ME CFS.
Unger: Well, Ms. Lockman, you serve as an administrator for online communities to help connect long haulers to each other. Why are these communities needed and what are you seeing on these platforms? Are the numbers growing?

Lockman: So, with the online communities, until I first found them, I felt so alone. I felt like I was crazy. Okay, I was sick in March, and it's April, and I'm still sick, what's going on? And thankfully somebody had talked about it in an article I read, and I connected with the communities first in May, and it was just this feeling of relief, I'm not alone.

At that time there were only maybe 500 people in the group and that was early May. And then now, between our two communities, we are nearing 10,000 members, which is both, it's a division of, it's good that they have a place, but it's awful that they had to find a place. And it's really, we support each other. We discuss our symptoms.

I have this really weird thing going on, oh, I have that going on too. And it's like, we discuss it with our doctors and everything. And it's just like this forms a connection between everything because there's somebody, there's lots of somebodies out there that are going through the same thing. So, it's really, it's like bonding through trauma, which is a weird way to describe it. But, it's definitely been essential, both in my physical and my mental health. We share resources and I've made friends from these communities. I talk to them more than my other friends, because we can relate to each other. Are you having a bad day today?

Just reaching out and making that human connection, it's just so important when you're this level of sick and you used to be a healthy person. I used to be a runner, and now I can't dream of running. I can barely go on a 15 minute walk, and some people can't even do that. And it's just having that connection to somebody else that's going through the same thing.

Unger: Well, Dr. Hornig, last question for you. What do you want physicians to know about COVID long haulers?

Dr. Hornig: Well, I first wanted to pick up on what Ms. Lockman mentioned, just to say that as a physician who is going through this herself and having experienced all of these mysterious symptoms, really grateful for the energy that people have found somewhere within their Long COVID selves, which is very difficult to create these opportunities for people to exchange information. Because it’s essential for us to both those who are trying to study this scientifically, but also even as a patient myself to have some way of validating that what you're going through, even if it may not be a part of Long COVID because we all have all sorts of other issues as well, and we're trying to sort this out, there's still this opportunity to really gain this sense that you can fight against the gaslighting.

There’s this medical gaslighting that occurs. I got this. As a physician, I got this from one of my own
docs, saying, well, since we had tested the hypothesis that my periods of very high heart rate, tachycardia, right, which I still have where I'll just sit here and my pulse will go up to 110, 130 and just sitting and doing nothing. And we ruled out that there was any strange arrhythmia that was concerning of the heart. And, we ruled out that my thyroid hormone, which was—I've been on thyroid hormone replacement that we took that off completely.

So without any thyroid hormone, and I had no energy, but I had tachycardia still. And so, my doctor said, well, now we know that there must be some hidden unresolved stress or anxiety or problem that's causing this symptom. And I'm like, no, I really don't think so. I want to find Occam's razor, I want to find that thread or that razor that's going to cut through all of the heterogeneity.

Patients really need to know that they have community. We need to educate physicians about all of the different possible scenarios that can occur after COVID-19. It's not just recovery or death. There's so much in between, and individuals who've had pneumonia or who have symptoms that suggest they may have heart damage, that they really may have heart damage. And they may need a different type of rehabilitation or medical treatment than individuals with ME CFS, right? So with ME CFS, you don't want to push through it. You don't want to put them through a graded exercise program because they have what's called post-exertional malaise.

They exert a little bit taking a walk, taking a shower can set them back for days. And I have to dole out my energy as well. And I call it the toddler schedule. I take self-enforced naps, and I'm only angry because I can't get a good tantrum in like a real toddler would, but that's the only way that I can to get through. And the symptoms are very perplexing, sudden hypertension, crazy, crisis level hypertension, the tachycardia, weird sensory things, lesions on my fingers with strange type of itching, and I still have COVID toes.

**Unger:** Well, Dr. Hornig and Ms. Lockman, your stories are incredibly moving, and Dr. Hornig, I hope you do find your Occam's razor and an explanation for this, and to both of you that you began to feel like yourselves again.

That's it for today's COVID-19 update, thanks so much, Dr. Hornig and Ms. Lockman for being here, sharing your stories. We'll be back soon with another update. For resources on COVID-19, go to ama-assn.org/COVID-19. Thanks for joining us and please take care.

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