

The Assignment with Audie Cornish

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The Long Arc of Long Covid



Speakers

Audie Cornish, Alexis Misko, , Imani Barbarin, President Joe Biden

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Audie Cornish

I feel the responsibility not to take up too much of your time in a way that I don't typically with a guest.

00:00:09

Alexis Misko

Yeah, I appreciate that very much.

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Audie Cornish

The interviews I do for this podcast, they go long. And so it's a bit of a time commitment for the folks that we speak with. And I take these conversations for granted sometimes. I mean, this literally — the ability to be upright with a clear head to speak for minutes at a time... It takes energy.

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Alexis Misko

Yeah. I want to be able to function in the next days after this.

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Audie Cornish

And if you have the collection of symptoms known by doctors, by any number of names, chronic COVID, long haul COVID post-acute, COVID 19, you know that you must preserve your energy because you need it. You need it to explain what's going on to your family and to your friends and your boss. And unless your doctors are up on the latest research, you'll be talking them through your mixed bag of symptoms: that your heart is pounding, a pins and needles feeling in your body, or maybe brain fog. And, of course, fatigue. And before you ask, there's no official test for long COVID 19.

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Your chest X-ray is fine, your echocardiogram is fine. So that means you're not really having palpitations or maybe it's anxiety or all in your head. So, that's sometimes the difficulty with diagnosing long COVID.

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Audie Cornish

So this is an active conversation for COVID researchers. Who exactly is at risk for long COVID? What kind of testing can detect it? With no FDA approved treatment in sight, what can doctors do for their patients? I mean, how do people living with symptoms adapt to what might become a long term disability?

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Imani Barbarin

COVID 19 is a mass disabling event. People are becoming disabled because of COVID 19. And this society, America in particular, is not prepared for it.

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Audie Cornish

A "mass disabling event" or a "mass deterioration event." I hadn't really heard of those terms before I fell down a research rabbit hole. But polio., the injuries suffered during World War Two — all considered mass disabling events, and all with lasting effects on society. We're not sure what the fallout from long COVID will ultimately be, but people with long COVID right now are telling us we cannot and should not ignore it. I'm Audie Cornish. And this is The Assignment. One hundred percent, I do not blame you if you're confused about what you're hearing about long COVID. Even doctors are having a tough time describing what it is, but they are trying. Dr. Monica Verduzco-Gutierrez is chair of the Department of Rehabilitation Medicine at the University of Texas Health Science Center at San Antonio. She actually runs the post-COVID Recovery Clinic there. To be clear, this was not her original day job. She's a rehabilitative specialist.

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My typical patient before was patients who've had strokes, brain injuries, neurologic conditions, multiple sclerosis. And so, when COVID started, some of the patients had been critically ill in the hospital. Those are patients I had seen before. Some of them had had strokes, some of them had had other impactful events to their brain. So it was very easy to be able to shift to taking care of people with long COVID. Since people with long COVID very much look like patients who have brain injuries, similar complaints.

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Audie Cornish

And how are they making sense of it?

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It was very tough for these patients to make sense of it. They were you know, they were saying, well, I wasn't hospitalized. I had maybe family members who passed away and that wasn't me. But why am I still having cough, brain fog, memory issues, headaches, numbness, new neurologic symptoms? It was very, very difficult for these patients and then other clinicians to believe that, well, you weren't hospitalized, so why are you presenting?

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Audie Cornish

I want to come back to that in a moment. But I do want to get a definition. At this point, how do you define long COVID?

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Great question. And I think that's something that a lot of, still, physicians have difficulty with diagnosing long COVID, but it's a clinical diagnosis.

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Audie Cornish

Difficulty or outright skepticism?

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There's definitely some skepticism behind it. And, you know, as physicians, we like numbers, we like tests, we want biomarkers, we want scans. But really, even the CDC, World Health Organization says this is a clinical diagnosis. So within a period of time, in the World Health Organization definition is usually within three months, they develop symptoms and it doesn't have to be continuous symptoms. There's often patients who get completely better and then have new symptoms that that pop up or recurring symptoms that pop up. So it's listening to the patient, listening to this timeline, seeing the symptoms that we have, and there's 50, 100 plus symptoms that could occur, and that is long COVID.

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Audie Cornish

And so you have this combination of so many symptoms, and it starts to bring up a picture that's really muddy. And the extreme skepticism is, is this even real? Or is this just another kind of chronic fatigue illness by another name? Or is this something that we just haven't figured out how to diagnose? Walk me through like that, the ambiguity of it.

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I think it's something that we haven't figured out. There is so much research coming out on long COVID that have shown, oh, look, there is, we've noticed these people with long COVID have these abnormal inflammatory markers and they have micro clots. And I feel handcuffed because those are not tests that I can just order and get from a commercial lab. And so it's then it makes it very difficult to be able to diagnose these patients.

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Audie Cornish

Oh, interesting. So what you're describing is a scenario where even if you're a clinician who's inclined to say this is, of course, real. I'm treating patients dealing with it. There are still ways that the system itself isn't ready. Like, it seems like it's easier to be a doctor who doubts long COVID than it is to be one who believes in it.

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It's definitely easier to, you know, doubt it and want to say, well, nothing's grossly wrong on the tests that we have and you don't have heart damage and your brain looks fine. But you know, brain scans don't look at cells. You know, even an MRI isn't going to show inflammatory markers happening in the brain. And so, it's really tough for patients and it's tough for us physicians who are doing this work and want to help the patients.

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Audie Cornish

I'm going to pause here and say that post-viral syndromes, like long COVID, aren't uncommon. I mean, West Nile Virus, the flu, and a host of other viral illnesses have been cited as having lingering effects.

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There has been post-viral, post-infectious disease illnesses for a very long time. And this is not just the first time it's happened, maybe the first time at this magnitude, but it happened with SARS, it happened with MERS, it's happened with flu.

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Audie Cornish

And yet these are also things that I feel like there's been skepticism about as well. Like, these are also illnesses that you talk to people who are affected by them and they say getting the medical establishment to help me is kind of a nightmare.

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Right.

00:08:09

Audie Cornish

What do they have in common that makes it so?

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So first, one thing in common is that they've been both underfunded and under researched for a long time. And so, physicians and scientists don't have the data to say, 'oh, well, we know it's because of this test that they have X, Y, and Z.' The other thing that we know is that oftentimes also women are disproportionately impacted, probably because, yes, women have more sensitive immune systems kind of in that middle age of life. That's why women get autoimmune diseases more often. It's hard to just hear someone say, 'Oh, I'm really fatigued.' But other tests might come back normal. And you say, 'Well, aren't we all a little fatigued?'

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Audie Cornish

Exactly, right. We're all tired. Go home.

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Go home. Yeah. Or it's all in your head. Or you're just depressed.

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Audie Cornish

Has the discussion around long COVID brought the spotlight back around to this concept? Either the post-viral illnesses in general? Medical bias? Has this triggered a bigger debate?

00:09:12

I think it has. You know, they said one of the words of the year was gaslighting. And so, that is one thing you hear a lot from patients right now who are dealing with long COVID, is that the medical community for some of these people are really downplaying their symptoms. They're saying, you know, this is just in your head. Maybe you're really anxious, start this antidepressant. But without giving them a full workup or without, you know, really listening to their story and trying to manage the symptoms that they have related to long COVID. So hopefully we're turning the page or maybe I'm just in my own echo chamber of people who are you know—

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Audie Cornish

We're not going to say it's in your head, okay?

00:09:55

Right.

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Audie Cornish

We just learned not to do that.

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Right. Yes. Maybe I'm really tied into the community that is making change. But one thing I love is that there's been people who are suffering with long COVID who are trying to push the agenda, make research happen, and make it patient centered.

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Audie Cornish

That's Dr. Verduzco Gutierrez, professor and chair of the Department of Rehabilitation Medicine at the University of Texas Health Science Center at San Antonio. Up next, we'll talk with a long-time disability advocate and someone who's been disabled by long COVID. More in a minute. Since no one really knows exactly how many people have long COVID, it's still not clear what impact it's having. But the National Center for Health Statistics added some long COVID questions to what they call a household pulse survey. And then the Brookings Institution used that data to estimate that potentially around 2 to 4 million people are out of work due to long COVID. And in terms of disability benefits — the Biden Administration is trying to meet the needs of this population.

00:11:16

President Joe Biden

And today, finally, I'm proud to announce a new effort, the first of its kind, to help Americans grappling with long term effects of COVID-19 that doctors call long COVID.

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Audie Cornish

Okay, this is the President in the summer of 2021, during a speech on the 31st Anniversary of the Americans with Disabilities Act.

00:11:37

President Joe Biden

Many Americans who seemingly recover from the virus, still face lingering challenges like breathing problems, brain fog, chronic pain or fatigue. These conditions can sometimes, can sometimes, rise to the level of a disability.

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Audie Cornish

So the White House told federal agencies that long COVID can be counted under the ADA, But the waiting period for disability benefits is notoriously long and the application process stringent. Again, this is a syndrome with no test, so it can be difficult to show how it's impacted your life. Navigating that system is a good example of what Imani Barbarin, a disability activist, calls the gray.

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Imani Barbarin

The gray is everything in between. Disability is kind of like this blank space in the imagination of American society. Well, society in general. We are isolated from society. One of the very first things you lose as a disabled person, whether you are born with your disability or become disabled, is your ability to become the narrator of your own story and be seen as a reliable narrator of that story. Disability comes for us all. You either age into disability, you either become disabled through life experiences, and when people looked at the pandemic, they thought, Oh, we shouldn't have to deal with the gray, the disability, the mass disabling event that is happening. But when you look at an illness like COVID 19, you look how extreme it is on every single system within the human body. There's no other idea but to come away with than, you can become disabled.

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Audie Cornish

Imani Barbarin is from the Philadelphia area. She joined a call with me and Alexis Misko, who lives in Columbus, Ohio. Now, Alexis was working as an occupational therapist in a hospital when she contracted COVID over two years ago. When I spoke to her, I promised to keep it short because if Alexis exerts herself too much in one day, she pretty much can't function the next. She did our interview while lying down on her couch.

00:13:44

Alexis Misko

I spent a lot of time laying down. I'm laying down right now just to get a few hours of upright time a day to just like, do very basic things that I need to do. So, yeah, and that's what it is. That's what chronic illness is for long COVID and for a lot of other illnesses as well.

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Audie Cornish

I want to take us back to March 2020 briefly. I sort of think of that week that, like Tom Hanks got COVID, as a strange cultural marker. Imani, you talked about watching the news and hearing news anchors talk about who was vulnerable. What were you hearing?

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Imani Barbarin

Initially, we were getting a lot of reports out of Italy, and all the news from Italy was saying that it was being, that COVID was extremely devastating to people who were high risk for other diseases or who had other disabilities and illnesses. And people kind of were alarmed. At least in my community, the disability community were alarmed to hear that because we knew what the implications about people's behavior would be based off of who they deemed the most exposed to COVID, the most vulnerable to COVID.

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Audie Cornish

What do you mean by that?

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Imani Barbarin

Well, I, well... Growing up as a as a child with a disability, you hear a lot of times things like, you know, 'if I had a disability, I would kill myself' or, 'if I had your disability, I wouldn't know what to do with myself.' And it's just such a shame to have such a bright person with a disabled body because you don't really have the life that you want.

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Audie Cornish

And we should say you have cerebral palsy.

00:15:23

Imani Barbarin

Yes, I have cerebral palsy from the waist down, spastic diplegic cerebral palsy. And so throughout my life, I knew what people's ideas around disability were. And when you give people the option of saving people whose lives they deem are disposable, or having them go about their daily life, disabled people were very afraid that the news telling us that disabled people were at risk would mean nothing for COVID mitigation and to a certain extent that it has meant very little.

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Audie Cornish

Alexis, for you, as an occupational therapist, you did work closely with patients, some of whom were struggling. Where was your head at in terms of what you thought your understanding was when it comes to the disability community?

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Alexis Misko

I mean I think when you're able bodied, you are not understanding of the disability community, right? Even if you are working with people with disabilities, even if you respect people with disabilities, even if you're trying to listen to them, and even if you see them as, you know, individuals who are authorities over their own bodies, you really cannot understand their experiences and you really have to listen. Disability issues are not really integrated with other social issues and they should be.

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Audie Cornish

Right. Imani, I think you've said they're siloed.

00:16:45

Imani Barbarin

Yes. Disability community is extremely isolated and siloed and, but disability touches every single community. So it's really interesting to watch people kind of skirt around disability issues, talk about other things when they're intricately linked, regardless.

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Audie Cornish

We've talked about the early part of COVID, just sort of hearing about it on the news. At what point do either of you get sick and at what point for you, Alexis, does it feel like there's something more?

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Alexis Misko

It was pretty clear to me that something was going on pretty quickly. I got sick in October of 2020, like I said. It wasn't a mild infection for me. Technically, it was mild. Like I wasn't hospitalized. That's the sort of the classification that's used. But I did have pneumonia in both of my lungs. I went to the E.R. I didn't sleep for days at a time. I couldn't breathe. My heart rate was like hitting 190 to 200, just sitting on the toilet or rolling over in bed. So there was a period of time where I sort of thought that I might be getting better, but in retrospect, it might have just been like the constant pressure to return to work that I was getting. But about a month after my infection, I drove a car to the grocery store and I went to the grocery store and I just completely declined physically after that. And I have never gotten back to that place.

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Audie Cornish

What do you mean? Just because... yeah, you're driving home from the grocery store and what happens?

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Alexis Misko

The the physical act of going to the grocery store, the energy expenditure of going to the grocery store induced what essentially, I know now is, was a large episode of post exertional malaise, was a large crash which caused all of my symptoms to be exacerbated and sort of sent me on this downward spiral. It can feel like honestly, there are elements to it that feel like it's like a chronic concussion or brain injury. Or there are days where you feel like you have altitude sickness or just a terrible hangover. And you just wake up like that every morning after 8 to 10 hours of sleep, it doesn't even matter. You're kind of just living in emergency mode until you kind of figure out a little bit more of what's going on with your body.

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Audie Cornish

Imani, do you have any questions for Alexis?

00:19:01

Imani Barbarin

Alexis, I was curious to know how your own identity and how your own understanding of self has changed due to your long COVID.

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Alexis Misko

Yeah, that's a good question. I think, you know, when you when you're not disabled before and you suddenly become disabled, it's a, it's a huge blow to your life. You really have to stop and try to rebuild your life. You don't really have a choice, right? You have to find meaning and joy again in order to keep going. But I think it changes the way that you see the world around you. It radicalizes you. It makes you see how we are stuck in this society that values work and production and not the things that actually matter. It changes the way you see the people around you, that we don't take care of each other. We don't really even see each other, and there's really no going back. I don't think once you see those things. So I don't, I don't know that that's really my identity, but it, it, I'm, I'm sure it is tied to my identity in the fact that it's the lens that I see through now that I didn't see before.

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Imani Barbarin

Yeah. And as somebody who's, who was on one side before and is on another side now, like how has your own transformation been with your work, with your own occupation? Because you're somebody who worked with disabled folks before you became ill, and are now probably seeking out that same exact care.

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Alexis Misko

Yeah, I mean, I'm completely unable to work. I never went back to work at all because I'm too severely ill. I would like to work again. I don't know that I would like to work in health care again, honestly, if I were to magically recover, I don't think that I would, would go back to health care. But I certainly would go back to work in some capacity. But I think, yeah, it's definitely changed the way that I view health care itself. You know, someone asked me recently, like 'did being a health care professional help me access care?' And I would say, no, certainly not. It helped me to probably understand like the physiology of what's going on in my body and read research articles and understand them and things like that. But once you become sick, your expertise is erased in the minds of other people immediately.

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Audie Cornish

You know, the other thing about this is you use the term 'mass disabling event,' which we've also been talking about. What's your understanding of that and how do you see it being possible to apply here when it comes to the aftermath of COVID?

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Imani Barbarin

Early in March 2020, disabled people, particularly those who already had chronic illnesses that people with long COVID are experiencing right now, we were saying over and over and over again that this is a mass disabling event. People will have to leave their jobs, people will have to apply for disability, people will have to rely on a safety net. That to be quite honest, a lot of non-disabled people neglected until they wanted to use it. And as we are going forward, we are seeing companies wanting to return to work, wanting to return to normal, when normal was never possible to begin with.

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Audie Cornish

Let me jump in here, Imani, because I want to, I want to come back to something you said. I want to make sure that I get this right. You both have talked about the idea of being believed and Imani Barbarin and you, you talked about the the broader implications, right? If you start telling people, 'hey, this is kind of in your head.'

00:22:38

Imani Barbarin

Yeah.

00:22:38

Audie Cornish

Alexis, is this something you're hearing as well, though? I mean, are people being told it's completely in their head or are they just being told it's something else and you're misidentifying it? Have you ever felt I mean, I don't want to use a totally overused word, but gaslit in some way?

00:22:53

Alexis Misko

Yeah, I felt gaslit, certainly. I've never had anyone tell me that I was mentally ill. Were they thinking it? I don't know. You know what I mean? But I mean, I very quickly figured out which doctors were incompetent and which ones weren't, and I stayed with the doctors that were.

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Audie Cornish

What's the difference between the two? What kind of things do they say? What does it feel like?

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Alexis Misko

I think on the most very basic level, right? Did they have some awareness of the research that's coming out with long COVID? Do they have the ability to, I guess, be humble enough to say, 'I don't really know what to do about this, but we'll figure it out.' Right? That's the most basic thing.

00:23:32

Imani Barbarin

Yeah. And I think the gaslighting really depends on what your presentation is as a human being. You know, I'm fat, Black and disabled. If I walk into the doctor's office saying I am, 'I'm having trouble breathing, I'm having fatigue, all these things,' again, they're going to just tell me to lose weight. Like they don't they're not going look any further than that. But if you're somebody who is thin, who looks healthy, who looks fit, that questioning might sound completely different.

00:23:57

Alexis Misko

I mean, I'm sure that it does. But in my personal experience, like I, you know, I went to, the first doctor that I went to who is my PCP, who had been my PCP before I got sick, who knew me a little bit, you know, I was like, I'm blatantly declining. Right? Like a month ago, my husband and I hiked over 100 miles, like in the span of a few weeks. And now I can't hold my head up. I can't hold a spoon. And she just was like, 'Well, let's get you some antidepressants.' And it's just like, that's not that's not going to work.

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Audie Cornish

Whoa. That is not...

00:24:30

Alexis Misko

And also, it doesn't matter. It does it matter if I was in shape, you know? If I was disabled before and I was in a wheelchair, but I could do certain things and now I can't do them anymore, that's still a really big deal. It's all about like what was normal for you and quality of life and people's quality of life has just declined. It's so frustrating.

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Audie Cornish

This is a question for both of you because there's going to be listeners who have questions here. They're likely some people listening right now who have long COVID or who think they might have long COVID. They might be kind of, you know, maybe coming to this realization that they're disabled. What advice would you give them?

00:25:13

Imani Barbarin

The advice that I have for people is to pace yourselves. This system has been underfunded and neglected for years and people have made an effort to actively make it better. And that there's advocates there. But it's still going to be very difficult for you to navigate it. Also, rely on the disability community. A lot of the answers that you are seeking, disabled people themselves have been seeking for decades. And some of us have found answers. Some of us have found remedies to the stress that we are under.

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Alexis Misko

Yeah, I totally agree with that. So I just want to also say that, you know, there are people that have been doing this work for decades. Really listen to them. Seek them out. Have gratitude for what they've done. Like all these diseases have just been so underfunded and under, just neglected. And so we really need to build off of the information that's already there.

00:26:19

Audie Cornish

That was Alexis Misko, a former occupational therapist with long COVID. We also heard from long-time disability advocate and activist Imani Barbarin. And you can find her on most social media as Crutches & Spice. That's it for this episode of The Assignment. New episodes drop every Thursday, so please listen and follow wherever you get your podcasts. And if you like the show, leave us a rating and a review. One more thing — if you have an assignment for us and that means a story you want to hear more about or one that is affecting your community, give us a call. Leave us a voicemail. You can do that at (202) 854-8802. Or you can record a voice memo on your phone and then email that to us at TheAssignmentCNN@gmail.com. The Assignment is a production of CNN Audio. Our producers are Madeleine Thompson, Jennifer Lai, Lori Galarreta, Isoke Samuel, Allison Park and Sonia Htoon. Our senior producers are Haley Thomas and Matt Martinez. Editing assistance from Rina Palta. Mixing and sound design by David Schulman. Dan Dzula is our technical director. Abbie Fentress Swanson is our executive producer and special thanks to Katie Hinman. I'm Audie Cornish. Thanks for listening.

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