

Long COVID

With Dr. Michele Longo

Diane (00:00):

What do you know about long-haul, chronic, or long COVID? Well, learn more on this episode of Vax Matters.

Clay (00:16):

Our topic today is a good conversation. It's about long COVID, also known as long-haul COVID, chronic COVID, or post-COVID condition. Now, while you may have heard a lot about the coronavirus, we'll help you understand the impacts of long COVID as well as what we can do to help prevent it. We're very excited to welcome Dr. Michele Longo to the show today. She is a clinical neurologist at the Tulane Center for Clinical Neurosciences at Tulane School of Medicine and currently runs the Tulane Neurology Post-COVID Care Clinic. How do we get all that on a business card?

Diane (00:55):

(laughs)

Clay (00:56):

We're so (laughs) grateful to have her here with us to talk about this. Doc, welcome, and, and let's begin at the beginning. What is long COVID or post-COVID condition?

Dr. Longo (01:05):

Okay, well, first I want to, uh, thank you for inviting me to talk about this, uh, about this condition and, and so let's, let's get started with, with answering that very important question, what is long COVID?

Clay (01:17):

Mm-hmm.

Dr. Longo (01:18):

You know, what we have come to understand is that most people who get sick with COVID are gonna get better within a week or a couple of weeks. But there are some people that will have symptoms either lingering from their, when they were acutely or when they were sick in, in that, that initial, um, infection with COVID. They'll have symptoms that will linger or new symptoms that may develop that will last for several months and, uh, will impact in their day-to-day function.

Dr. Longo (01:53):

And these symptoms can be, um, can come and go. They can, uh, what we refer to as intermittent, so there can be good days and bad days. And, uh, many different symptoms have been described. Some of the most common have been, uh, memory problems, or, or what, uh, people refer to as brain fog, which can be problems with focus or concentration. Uh, problems with fatigue, sleep

disturbances, shortness of breath, uh, gastrointestinal issues, dizziness. There, there, uh, have been over 200 symptoms that have been described-

Diane (02:33):

Geez.

Dr. Longo (02:33):

... in long COVID. So, we are trying to understand better what the working definition is going to be and, uh, there are multiple studies. Probably one of the largest ones, which we're a part of is called the RECOVER Study and this is the NIH or the National Institute of Health's, uh, study. Try to understand exactly what is long COVID? How do we define it? What is, uh, uh, to, to answer that real basic question that you, that you asked. We're still trying to formulate a scientific answer to that.

Diane (03:08):

You know, Doctor, I think that, uh, probably when you talk about COVID and long COVID, this is kind of a learning curve, not only for us, but for the medical field because, you know, well, let's face it. You know, COVID reared its ugly head, you know, back in 2019, so we're still, you know, relatively new into it, three, four years later. It's always gonna be around. You know, we know that it's always gonna be around.

Diane (03:34):

So, you know, I think my question is, when we first started with the people that had COVID and then, like you said, most people got better. In the medical field, was it kind of ... I don't know, surprising is probably not the right word to use, but when people would come in and say, "I'm lethargic. I have this brain fog. I feel like I'm not getting better like I should." Was there maybe a level of surprise or was that kind of expected along with this in trying to figure out what COVID is? 'Cause I know that, as I said, it's been tough to figure out the past four years.

Dr. Longo (04:11):

It, you know, I think, uh ... I, I don't think there's, that it's new that there could be lingering symptoms after a viral illness.

Diane (04:22):

Okay, okay.

Dr. Longo (04:22):

We know it is possible, especially as a brain and nerve doctor, there are other illnesses that we've seen that for. Take, you know, take polio, for example. We've seen people that may have, uh, symptoms long after that. Uh, that's, uh, I think that, that is not a novel or new thing that there may be some people that have, uh, lingering symptoms after a viral, uh, illness. But I think that the amount of people that we're seeing, that's a surprise. If, if I think back to, you know, the early years, uh, the, the early part of 2020, as a general neurologist, I was seeing patients with the symptoms that a general neurologist typically sees.

Diane (05:06):

Mm-hmm.

Dr. Longo (05:06):

Things like, uh, you know, headaches, and dizziness, and, and problems with, uh, brain fog, or with concentration, or focus. Um, but what I was seeing is that those patients were half the age of the typical patients (laughs) that, that I see with these conditions, so younger people. People that were not, uh, n- didn't necessarily have any medical conditions prior to COVID or particularly have, uh, a severe case of COVID were coming to the clinic with symptoms, which, that they, uh, uh, were being evaluated for. And I think that part, to me, was, uh, was different than what I would, what I was expecting or what I've seen in the past.

Diane (05:50):

Well, you know, when you said that, that some of the people that you saw, of course, the younger age, not fitting the profile of what you would normally see in your profession, you, you were talking about the, that they didn't really, some of them, didn't have severe COVID. I think that's something that I kind of assumed that only people that had severe COVID, that would make its way into the long COVID. I, I, I guess I just made that, that assumption and, I, I guess it's erroneous that even if you had just a mild case that you could still have long-term or long-haul COVID? Is that core- or experience?

Dr. Longo (06:26):

Yeah.

Diane (06:26):

Uh, see I did, I didn't realize that, Doctor.

Dr. Longo (06:28):

That, that, that's, that is correct and in fact, most of the people that we see had mild infections and-

Diane (06:35):

Really?

Dr. Longo (06:36):

... that's because most of the people that get COVID are, are not going to be, you know, especially with the newer variants, severe, you know, they're, they're not going to be severely sick with that.

Diane (06:46):

Uh-huh.

Dr. Longo (06:47):

But, uh, but by far, the majority of my patients were not hospitalized. In fact, you know, when I, when I see patients and I'm asking them about their COVID infection, I, I let them know that I understand that you had symptoms. You were sick. I'm asking if you were hospitalized but knowing that m- most of my patients were not and that doesn't invalidate the symptoms that we're about to talk about.

Clay (07:10):

How long is long COVID?

Dr. Longo (07:14):

Oh, that's a very good question. So, you know, that's a very good question that I, I, I can only have anecdotal, um, uh, responses to that question. I mean, I can tell you just this morning, I was, uh, um, uh, seeing one of my first patients that I saw with COVID, who, uh, is continuing to have symptoms and this is three years out.

Clay (07:39):

Wow.

Dr. Longo (07:40):

So, uh, there are people that are struggling for years.

Diane (07:42):

Hmm.

Dr. Longo (07:43):

Um, uh, there are people that get better in months, but, uh, but most people, it seems like the symptoms seem to be lasting more like between 12, 18 months.

Diane (07:57):

Really?

Dr. Longo (07:57):

So it's, uh, it's, it's not weeks to months. I, often I tell my patients, "You know, uh, we're vague in how we answer that question because we don't have the answer to that yet." We don't know how to define recovery and so until we understand better what does long-COVID recovery look like, it's a really tough question to answer, how long does it last?

Dr. Longo (08:23):

You know, I've seen many people that they, they, they thought they had returned to their previous level of h- health and then, you know, the symptoms come back. And we're kind of, uh, have to rethink the whole, the whole thing again. Uh, so w- so we don't know, but I tell my patients for most people, it seems to be more like months. It's not days, days-

Diane (08:44):

Mm-hmm.

Dr. Longo (08:47):

... to weeks. It's not weeks to months for most of them.

Diane (08:50):

You know, I know when COVID first came about, in hindsight, that was anything even close to what we were anticipating or thinking about. So, as you said, we are learning as we go and I think that's what's so important that people think, "Well, COVID, we're gonna look at this in the rearview mirror." We're never gonna be able to do that.

Diane (09:11):

It's always going to be around, so my question would be, when do ... When does your COVID infection, you know, when you have COVID, when does that turn into long COVID or is there a way to tell that? Is there a rule of thumb? I know everybody's different. Everybody's, you know, physiological makeup, their medical condition's different, underlying conditions, but is there some idea about COVID turning into long COVID when it happens?

Dr. Longo (09:42):

Uh, y- yeah. This, this is another excellent question, and it really depends on who you ask. And, and I'm talking about even, you know, among, uh, you know, well-respected sources like the CDC, the World Health Organization, NIH. Everyone has, uh, different, um, definitions right now of long COVID. We're, we're trying to change that with the information we're learning from RECOVER and other, other studies, but, um, but most people, uh, will say that s- that symptoms that are, um, interfering with day-to-day functioning, that are lasting somewhere between four weeks and three months.

Diane (10:21):

Mm-hmm.

Dr. Longo (10:22):

I think, um, you know, uh, anecd- anecdotally speaking from, from, um, the experience that I've gained over the past three years with the clinic. I tend to think that three months. But maybe, uh, uh, uh, a better number for us to use right now, really because if we say, "Hey, at four weeks you should start, you know, uh, seeking care." I think we'll see that a lot of people will im- improve in that time.

Diane (10:50):

Mm-hmm.

Dr. Longo (10:51):

But, uh, but, uh, but there are, y- you know, by the CDC, uh, definition, it's four weeks. If you go to World Health Organization, it's three months. So somewhere in, in, in there.

Clay (11:03):

Wow. So much information about this and (laughs) you said earlier about people, seeing the number of people who are still dealing with that. And Diane and I, uh, have done a number of these, these podcast episodes. And it does seem like the dialogue nationally is moving further and further away from COVID. And the precautions we should be taking in protecting ourselves and our families from it. W- what's your read on that? That, uh ... Do we need to talk about this more to make certain that this is still a very, very dangerous thing for all of us, adults and children?

Dr. Longo (11:40):

Well, you know, I think whenever there is something where your health is concerned that you can do something to lower your risk of being sick then-

Clay (11:48):

Right.

Dr. Longo (11:49):

... then we got to highlight that.

Clay (11:51):

Yeah. Hmm.

Dr. Longo (11:52):

And as everyone kind of struggles ... Well, uh, as everybody moves on past COVID, I mean, COVID fatigue's a real thing.

Clay (11:59):

Right, right.

Dr. Longo (11:59):

I mean, we, we see that, right? Well, there are some people that are still struggling and right now, uh, we don't understand all of the risk factors for being somebody that gets long COVID. So, uh, as I said, I see plenty of healthy, previously, you know, um, had no health conditions. I see professional athletes. I mean, uh, uh, we see all kinds of people that struggle with, uh, long COVID, but one thing that we're coming to understand is that if you can reduce your risk of being seriously sick with COVID or being reinfected, you may reduce your risk of long COVID. So anything that keeps you out of the hospital-

Diane (12:44):

Mm-hmm.

Dr. Longo (12:45):

... with, uh, with COVID, will potentially reduce your long-COVID risk. Anything that keeps you from getting COVID in the first place, like vaccinating, or, or, or masking, and doing, um, uh, these things when appropriate, uh, will reduce your risk of long COVID. So I think that message is still something that we need to make sure people are, are aware of and if you get COVID, to be, uh, to receive treatments that can reduce the risk of being hospitalized. So vaccine, uh, treatment of, uh, of COVID. Uh, avoiding, you know, um, through masking and social, uh, uh, protective measures are all still very relevant messages.

Clay (13:30):

Y- you know, there is a- as, as crazy as it may sound, there is some optimism in what you have said about long COVID. I happen to, to know some people who are still having symptoms very long after

having had the coronavirus and they're at a place where they think, "Well, I'm never gonna be able to get rid of this." They actually just may be dealing with the long-haul symptoms of COVID that may e- eventually go away, correct?

Dr. Longo (14:05):

Uh, yeah. But, but I, but I think it's important, just a caveat I want to make sure that is clear-

Clay (14:05):

Okay.

Dr. Longo (14:06):

... is that you ... That it's very important for people that are s- having symptoms that they're relating, you know, to a COVID infection-

Clay (14:13):

Sure.

Dr. Longo (14:13):

... that they continue care with the clinician that knows them best.

Clay (14:16):

Right.

Dr. Longo (14:17):

With their primary care doctor because COVID, long COVID is a mimicker of other conditions, so it's really important to, uh, uh, you know, to establish care with, uh, with a good primary care clinician.

Diane (14:34):

You know, my question too, when you're talking about long COVID, Doctor, can a person get COVID from someone who has long COVID?

Dr. Longo (14:44):

Uh, that's, that's an excellent ... Yeah, I'm glad that you asked that because, uh, no. When you have long COVID, you're not infectious.

Diane (14:52):

Okay, okay.

Clay (14:52):

Oh, wow.

Diane (14:52):

D- okay.

Dr. Longo (14:53):

So that's real, that's real, uh, um, important, uh-

Diane (14:55):

Right.

Dr. Longo (14:59):

... to know. So, um ... No. Long COVID is not contagious.

Diane (15:05):

Case closed. Bottom line-

Clay (15:06):

(laughs)

Diane (15:06):

... don't have to worry about it. Okay.

Dr. Longo (15:07):

Mm-mm.

Diane (15:08):

Okay. All right.

Clay (15:09):

Uh, so, so what are some of the more serious complications that can come from having long COVID?

Dr. Longo (15:16):

Well, y- you know, I think, uh, some of ... Long COVID, by its definition from the World Health Organization interferes with your daily function, which-

Clay (15:28):

Mm-hmm.

Dr. Longo (15:28):

... means it interferes with school, and work, and, and doing your chores, and taking care of yourself or others that you're responsible for. So that, that is, uh, that's a real issue with, uh, long COVID. Um, uh, it, it is a condition, um, that if it is interfering with, uh, you know, two or more a- areas of your life, it does, w- will, uh, qualify for disability.

Dr. Longo (15:55):

Or, uh, many of our, our patients do need accommodations at work or at school, so I think, so I think that, that's, uh, that's, uh, uh, a real serious consequence. If I look at the health consequences and you think that, you know, a lot of people that have long COVID, as I said, they're, they're, they're um, uh, they're at a time in their life where they're typically being productive. They're younger people-

Diane (16:21):

Mm-hmm.

Dr. Longo (16:21):

... a lot of them. Not all, but, but many and so this is i- i- interfering with, uh, with our workforce. We know that they just had a report come out of, uh, of, uh, the UK that there's a long COVID, uh, doctor group. And they believe that one out of five of their clini- of their doctors is not at work because of long COVID. It's interfering-

Diane (16:44):

Hmm.

Clay (16:44):

Wow.

Dr. Longo (16:44):

... with the workforce. But I want to point out, uh, something else that ... 'Cause my patients ask me, "Can I die from this?" Well, we need to make sure that this is, that long COVID is not mimicking another condition. And so that's real important to keep in mind, right? But the other part is, uh, i- there's, uh, there is a, uh, a, uh, mental health burden that goes along-

Diane (17:08):

Hmm.

Dr. Longo (17:08):

... not just with the pandemic and what we've been through, but also, with long COVID. It seems to, um, sometimes flare previous mental health conditions that were well controlled or, or we'll see new onset of mental health conditions like anxiety or depression in people that have never struggled with this. And I think there's a real concern for, uh, for suicide and people need to be supported, validated.

Dr. Longo (17:36):

They need to be, uh, h- heard. You know, um, this is, uh, uh, a dangerous time for isolation and when you're s- sick and you're ... And you have something that we refer to as an invisible disability, I think it really increases that risk of, uh, being socially isolated. And that, that's, that's not, that's not a good thing.

Diane (17:58):

Thank you, for bringing that up, Doctor, because that is just ... It just goes to the heart of the matter that with something like this, with long COVID you want to get well. You're trying to get well. You're not, you know, you're not just, you know, crying or whining about something, it's-

Clay (18:14):

Right.

Diane (18:15):

... real. It's symptoms. You don't want your friends or family to say, "Well, you know, you should have been feeling better by now." Oh-

Clay (18:21):

Yeah.

Diane (18:21):

... my gosh, why are you doing that? You need to be, as you said, supportive because that leads to, as you said, the anxiety, "Why am I not getting better? My mental health." Your mental health? That's critical because sometimes, you know, you keep thinking, "Okay, I'm sick. I'm sick. I'm sick." And it's, you know, your brain can do a lot, y- as you, as you know, your mental health can maybe kind of get you into this rut that you can't get yourself out of, that it's hard to even get yourself out of it, Doctor.

Dr. Longo (18:54):

Absolutely. Yeah, it's a very ... It's, uh, uh, you know, we ... There, there was a term that, um, that I first heard in my, uh, i- in my work with long COVID and that is a term that was called medical gaslighting.

Diane (19:08):

Oh, yes.

Dr. Longo (19:09):

And medical gaslighting-

Diane (19:09):

Gosh.

Dr. Longo (19:10):

... um, was, you know, people were coming to see me, and they were saying that they had the symptoms, but that they weren't believed. Weren't believed by their people at work-

Diane (19:18):

Uh-huh.

Dr. Longo (19:19):

... by their families, by their other, uh, um, by other medical professionals. I mean, um, uh, I see less of that than I think I did, you know, uh, a year and half or two years ago. Things like what you're doing h- here, when we get word out about long COVID, um, it, it, it helps not only for the patients to be believed, but for everyone else that hears about this. When Admiral Rachel Levine talks about long COVID, she always starts with, "Long COVID is real."

Clay (19:49):

Hmm.

Diane (19:49):

Yes, yes.

Dr. Longo (19:50):

That is so essential for, uh, not, not only for the patients, but also, for anyone in health care. All of us need to, to understand that, that, uh, that we need to believe what, what, what people are describing to us. That long COVID is a real thing. It's real.

Clay (20:08):

You know, you mentioned earlier some of the preventive measures that we can take to avoid contracting the coronavirus in the first place, but if someone has long COVID, what can they do to hasten its departure from their body?

Dr. Longo (20:22):

You know, right now, uh, our treatment for long COVID is treating the symptoms and, and a lot of that is, you know, i- is finding out what are the most bothersome symptoms for that individual and what can we do to, to treat those symptoms? There's not, there's not a, um, there's not a magic pill here. It's not something that you can walk in and treat, you know, uh, uh, all these varied symptoms with, with just, uh, uh, with just a capsule. So we, we try to first identify what are the most bothersome symptoms?

Dr. Longo (20:56):

For a lot of people, it is that they find that, that when they exert themselves, they're, they're worn out. They, they have post-exertional malaise and so first of all, it's important that we make sure that, that these, uh, patients have seen the appropriate specialists to rule out, you know, organ damage from COVID itself. I mean, that's, uh, you know, that's a very important thing. Once, uh, once we, we do that, then we start to, uh, look at interventions that can be helpful.

Dr. Longo (21:28):

Uh, we, uh, many of our patients have benefited from seeing, um, different therapists, like physical therapists that help them to understand, uh, how much exertion can they do before they, they get to the point that they need to stop? We want them to stop just short of having their symptoms. You don't want, you don't want to push somebody to, uh, be in, uh, to what the patients will refer to as a crash, which is, you know, like 12, 72 hours after they exerted themselves that they feel terrible, and all their symptoms have been flared.

Dr. Longo (21:59):

So sometimes, working with a physical therapist can help with that. Work h- helping patients. A lot of our patients have, uh, uh, sleep disturbances and we try to help with, um, with good sleep habits. And hygiene and doing sleep studies where necessary. We have, uh, uh, cognitive therapists that help patients that are struggling with, uh, brain fog. That have problems with focus or concentration to develop the skills that can help them to exert less mental energy in the activities that they're doing.

Dr. Longo (22:32):

And same with, with, uh, uh, um, occupational therapists that help our patients learn how to conserve energy, so it really is a team, uh, approach. These are some of the things that we're doing there. Uh, RECOVER is just beginning to do some clinical trials, so we'll learn more as we get more information, but right now, the treatments for long COVID are symptom-based.

Diane (22:59):

And I think that everybody that was listening earlier when you said there are ... Did you say 200 symptoms? Is that what you said?

Dr. Longo (23:07):

Over, over t- 200 symptoms have been described with long COVID.

Clay (23:11):

Wow. Who's, who's most at risk for long COVID?

Dr. Longo (23:14):

We are just starting to understand that. There have been multiple studies that have shown that, uh, certainly if you were severely ill with COVID, um, that's a risk for long COVID. If you, um, uh ... We think that's, uh, the p- that people that were not vaccinated, they get long COVID. Tend to have, uh, uh, a harder time with long COVID and be at a higher risk.

Dr. Longo (23:37):

There have been some studies that have cited other underlying medical conditions like, uh, obesity, or diabetes, or having other, uh, conditions like this as risk factors. Um, that's still being worked out, but I think that it is clear that the number one risk factor for long COVID would be, um, being someone that was severely ill with COVID.

Clay (24:01):

How does a vaccine impact long COVID?

Dr. Longo (24:06):

The, the vaccine impacts long ... Well, we, we understand that it decreases the risk of long COVID, and it seems like from our first studies that are coming out from the RECOVER Study, that, uh, people that are vaccinated may have, uh, a lesser long COVID. That remains to be seen, uh, be less symptomatic with it. But vaccine, um, reduces the risk and reduces it to ... And by reducing your risk of being seriously ill with COVID, um, e- even exponentially, so in that way reduces the risk of long COVID. Um, other things that, you know, we don't have, I don't have the science. I can tell you-

Diane (24:50):

Mm-hmm.

Dr. Longo (24:50):

... anecdotally speaking that I, um, early on heard from a lot of my patients that when they were sick with COVID, uh, they pushed themselves through that. They didn't get themselves rest. They didn't take the break. They were, uh, not in a job where they could take a break and so, you know, I see a lot of people that are coming from health care, from service industries. People that may not have been able to take the time, and rest, and recover from that initial infection. But I want to say again, that is anecdotally speaking. Uh, uh, we don't have the science on that observation.

Diane (25:29):

I'm thinking that sometimes too, that, you know, that when we were talking about the, uh, younger population that seemed to be so impacted by COVID and long COVID. And not just the older population because we know older folks had more challenges or the, the population that had the underlying y- underlying conditions. But I'm thinking too, that with the ones that have been healthy, oh, for a long, you know, forever, you know, their 30s, 40s, and 50s, they're thinking, like you said, "I can power through this. I can do this. This is just gonna be a little bit of an inconvenience." And then when it's not, it's like, "Uh, what do I do?"

Clay (26:05):

Right.

Diane (26:06):

"I am surprised. I am flabbergasted. I, I don't want to have to take ..." I think you said you could qualify for disability if you need to. I think, Doctor, so many times we're not used to taking care of ourselves. We just need to be good to ourselves. To give ourselves a break that, you know, that everything is good until it's not.

Diane (26:28):

Be careful and allow yourself to heal, as we were talking about with long COVID, about the fact that you get so disturbed and so discouraged. And so mentally depressed that you, you really, you m-make yourself go into a tailspin almost.

Dr. Longo (26:44):

Yeah. Absolutely. I think, you know, w- we ... Somewhere along the line of this pandemic, we got the expectation that if you were sick with COVID, you just worked from home, just as i- i- if you could, if you could do that. Well, that, uh, uh, many people couldn't do that.

Diane (27:01):

Mm-hmm.

Dr. Longo (27:01):

Um, a- and even people that could, you know, celebrities and, and political figures that would get COVID. And go on the national news and say-

Diane (27:10):

Mm-hmm.

Dr. Longo (27:10):

... that they were working from home. They had COVID. I think that gave this ... It contributes to this expectation that when I'm sick, I'm supposed to be working. And I think that when you are sick with COVID, i- i- i- you have to rest. You need-

Diane (27:24):

Yeah.

Dr. Longo (27:25):

... to let your body recover and the expectation should be that you are s- ... That you don't feel lazy or guilty for taking time-

Diane (27:34):

Exactly.

Dr. Longo (27:35):

... to recoup.

Diane (27:36):

Yeah.

Clay (27:37):

Wow. Uh, a lot of great information. Is there anything that we, we might have left out or not touched on?

Dr. Longo (27:43):

So I think it's important to keep in mind that long COVID is not a rare condition. The estimates are that about 10% of people that get infected with COVID, may go on to have long COVID. So it is very likely that you know somebody who is struggling with long COVID. If you s- if you, uh, have concerns about long COVID, you should e- e- either see the physician that know, or the clinician that knows you best or establish care with a primary care clinician that can then determine if, uh, specialty care is needed.

Diane (28:18):

And again, to be good to yourself and to not be discouraged. Not thinking, "Well, I should be well in a month, or two months, or a week, or two." Just to know that it's out there. That it's real. That it's legitimate and, as you said, to talk to your doctor. That's the important thing to have the conversation. So, Doctor, thank you so much for having this conversation with us today.

Diane (28:43):

It is going to impact many people, many friends, and many families on how they can have that same conversation with people that they love. So again, thank you. This has been w- another wonderful, and very informative, and important conversation here on Vax Matters. Thank you to our listeners for tuning in to this episode and we certainly hope you will join us again the next time.