

Dr. Christina Wells (00:00):

Hello and welcome to another episode of Beyond the Needle. Today, we're going to be continuing our discussion of long COVID and we have back again with us Dr. Stephanie LaBedz who's going to be talking about her experience with long COVID. I'm Dr. Christina Wells. I'm a family medicine physician at the University of Illinois at Chicago, and I practice at the Miles Square Health Center. And Dr. LaBedz, can you tell us who you are and where you practice? And thank you again for joining us today.

Dr. Stephanie LaBedz (00:34):

Thank you so much for having me back on the podcast, Dr. Wells. My name is Stephanie LaBedz. I'm a pulmonary and critical care physician at the University of Illinois at Chicago. And I've had sort of a unique experience in this pandemic, not only being a doctor who cares for patients with long COVID, but also as somebody who has suffered from long COVID myself.

Dr. Christina Wells (00:57):

And I know we're going to be discussing that experience today, and so I'm thankful that you're able to come on and talk to us about that experience. I wanted to put out something that I had been reading about lately, and in my studying of long COVID, I came across the post COVID-19 functional status scale. And it is a questionnaire that physicians or providers can use to give to patients that can assess their functional capacity after having COVID-19. And it may be a tool that can help to understand if a patient may be presenting with symptoms that are suggestive of long COVID. And as we talked about in a previous podcast, we know that symptoms of long COVID can be very, very non-specific. But we just wanted to give you a little opportunity to tell us what was your experience like with long COVID and how did that help you in how you approach patients with long COVID because of your own personal experience, and what other things you think that we as family physicians should understand and know about long COVID.

Dr. Stephanie LaBedz (02:18):

Absolutely. So I had COVID-19 in the spring of 2020, and I had seemingly recovered from it, but weeks after my infection, I started to develop some sort of unusual symptoms. And when I say unusual, I mean unusual for me. The first thing that I noticed was that I started getting headaches on a regular basis, and I'm somebody who would only have a handful of headaches a year. I'm not a headache person, but I started to develop headaches every day, which was very unusual for me. Around that same time, I also started to develop symptoms that I would call more cognitive symptoms or what a lot of people refer to as brain fog. And for me, those things were difficulty concentrating, difficulty processing information, difficulty remembering things that would oftentimes come along at the same time as my headaches. And I would start the day out feeling totally normal, but as the day went on, I would start to develop these symptoms.

(03:22):

I also had sleep disturbances that were new. I found myself waking up every single night, which was a totally new symptom for me. I would wake up and I wouldn't be able to fall back asleep, and that was something that I had not experienced prior to having COVID-19. I also had very strangely had some sensory abnormalities. I was very, very sensitive to noise, which is something that I haven't read much about and I couldn't explain, but it was like somebody who has a migraine when they're very sensitive to light or sensitive to noise. I would hear things on the other end of my house that I would normally not be able to hear and just every noise was very jarring to me. So I started to develop these symptoms that were new and unusual for me.

(04:09):

And as a pattern started to emerge, it became apparent to me that something was going on. And you have to keep in mind, this was spring, early summer of 2020 and long COVID was not really a thing at that time. So I was in this unusual position recognizing something was going on with me but not really knowing what it was and not really having heard about long COVID. But it wasn't long before I became convinced that this was related to COVID-19. These were not things that I had experienced before, and I had no other explanation for it. So I went to my primary care physician and was referred to a neurologist, and I explained to these doctors, "Hey, this is new. I don't know what's going on."

(04:57):

And unfortunately, I had a similar experience to a lot of people. I was kind of written off and was told, "Oh, this is probably from something else." And I was a little surprised and disheartened by that, because I knew at that stage this was from COVID. There's no other reason for it. These are new things that I had never had before and nothing else had changed in my life except for having COVID-19. So it began a months long journey to try to find help with this. And unfortunately during that period of time, my symptoms worsened to the point where I was pretty disabled from them.

(05:30):

I had a lot of these post exertional fatigue, post exertional malaise, and that was not only with physical exertion, but actually in my case, mostly mental exertion. So I would start my workday feeling, but the more sort of brain power I exerted, the worse my symptoms got. And by mid-afternoon or the end of the day, I would essentially be not functional anymore. I would have such a debilitating headache or debilitating fatigue that I couldn't do anything. And that's even normal everyday activities. I couldn't make dinner for myself. I couldn't fold my laundry and things that I needed to do just to get by every day. That's how disabling my symptoms were.

(06:15):

My symptoms got worse, I would say, over the course of about six months, and I won't forget it was the week of the 2020 election. I couldn't get off the couch for an entire week. I felt like I had on a hundred pound bodysuit. My arms and legs felt so heavy I could barely get off the couch, I couldn't move around my house. And it was just a very stark low point in my long COVID journey. But I'm happy to say after about six months, things did slowly start to turn around, although there were ups and downs in my course of recovery, I did eventually recover, although I would say that I had long COVID for over a year, probably closer to 15 months. And over that 15 months, I would say that I was essentially disabled for about eight of those 15 months.

Dr. Christina Wells (07:12):

Now, you said that you were eventually recovered. Was there anything in particular that assisted you in your recovery?

Dr. Stephanie LaBedz (07:22):

I was very, very fortunate to get connected with a neurologist at Northwestern who I think started the first long COVID clinic in the city of Chicago and I imagine one of the first long COVID clinics in the country. He was somebody I think that was on the forefront of recognizing that there were many patients who were having these disabling symptoms from COVID-19 and decided to start a long COVID clinic. And so I was very fortunate to get in to see him, and he prescribed me a medication that's often used for migraines. And I think that for me started my path to recovery. I took that medication for

several months and noticed a dramatic improvement in my headaches and then a more slow improvement in my other symptoms in particular the cognitive issues that I was having and the fatigue.

(08:24):

Now that being said, I may have recovered without being on that medication at some point, but for me, that was a clear time point that I started to turn around. And I will say though that my recovery was not a linear process. And I think this is something that I've really tried to stress to the patients that I see with long COVID is that they're going to have good days and bad days. And one of the mistakes that I always made was when I'd have a good day or two, I thought to myself, "Oh, I'm getting better. I'm going to go back to doing things." And then I would pay for it because I would overexert myself and I'd be right back where I ended up. And so it's really important I think to recognize that the recovery is not a linear process and people are going to have ups and downs, good days, bad days, good weeks and bad weeks, but if the overall trajectory is on the up and up, that's a really encouraging thing.

Dr. Christina Wells (09:25):

Yeah, it's interesting listening to you and your experience and you mentioned some of the symptoms that you were having after being diagnosed with COVID and having this long COVID. I was reading about things such as something you mentioned earlier about post exertional malaise as being a hallmark of long COVID and being very, very disabling where people can't do the simple activities that they used to be involved in. And I was also reading about fatigue also being a really big symptom related to long COVID and maybe similar to what we see in people who experience chronic fatigue syndrome. And so I know that that long COVID is also bringing to the forefront chronic fatigue syndrome and allowing us to look into that a little bit more about that pathophysiology and how we can manage that.

(10:21):

I was also reading about POTS, which is postural orthostatic tachycardia syndrome that also can commonly occur in COVID where patients can have things like abdominal pain, bloating, blurry vision or tunnel vision, constipation, loose stools, dizziness, fatigue, lay out blood pressures, lightheadedness, night sweats, nausea amongst other symptoms. And so there are a lot of things that people can present with that we may not always know that it's related to long COVID, but again, going back and thinking about a good history and physical to put with the symptoms to be able to help patients understand what their presenting symptoms may be related to and considering that these symptoms may be related to long COVID.

(11:17):

I know you also mentioned treatment and we know that there is no overriding treatment for long COVID, but it may be symptomatic and it may be dependent on what the patient is presenting with and directing treatment toward the symptoms or the conditions that patients are presenting with. We also know too that healthy lifestyles in general are important. So encouraging our patients to maintain a healthy diet. I always like to tell my patients, make sure they're eating lots of fruits and vegetables because that always helps them to minimize that chronic inflammation that can also be occurring. And then also encouraging our patients to stay active when they can, but also understanding their limitations and being okay with that. And then providing our patients with support and also remembering to provide our patients with mental and emotional support and referring them when needed to specialists like yourself or other specialists where we can have other resources to help our patients.

(12:30):

And so are there any other lessons or things you've learned and also even today now, can you tell us again how long it's been since you first had COVID and then also are you experiencing any symptoms

now or are you completely back to your baseline where you were before COVID? And are there any other suggestions or thoughts that you have for us as family physicians as we treat patients who may be presenting with symptoms suggestive of long COVID?

Dr. Stephanie LaBedz (13:06):

So I had COVID in the spring of 2020, so it's been about two and a half years since I had the infection. I felt close to normal about I would say 12 to 15 months after I was sick with COVID-19. So it was a long road to recovery for me. I feel that I am close to a hundred percent back to normal, although I do find that I have subtle differences in my ability to concentrate. I find that on days where I'm doing a lot of reading and writing that I maybe can't sit and do that sort of work for the same amount of time that I could before. But I think it's pretty subtle. It's one thing that I think maybe will never go back to normal. I also found that my sleep disturbances took much longer to recover than the rest of my symptoms.

(14:06):

I was about two years after I started having long COVID symptoms where I wasn't consistently waking up in the middle of the night. So I do feel at this point that I'm more or less recovered, although there may be some very, very subtle differences at this stage that may never go back to normal, but there are certainly things that I can deal with and are not really impacting me in a functional way in my day-to-day life.

(14:33):

I'm really glad that you brought up chronic fatigue syndrome or what's also known as myalgic encephalomyelitis. I learned a lot about this and sort of my efforts to understand what was going on with me. When I started to have long COVID, it was not really described. I think I had seen a few things in the news about it, but it was not a widely accepted condition at the time that I started having symptoms. So I'm sure many doctors, I spent a lot of time searching on PubMed or UpToDate or all these other medical resources just trying to find an explanation of what was going on with me because like any of my patients, I thought I was going crazy.

(15:17):

I'm a very active person and at that point I could barely do anything, and I felt like, am I just lazy or is there something really wrong with me or am I going crazy? I can't think straight anymore. I can't remember things. So it was really distressing for me and I channeled that distress I think into doing a lot of research. And the first thing that I found that really validated to me that something was really wrong with me was information about chronic fatigue syndrome or myalgic encephalomyelitis. When I read the most recent diagnostic criteria for it, I thought to myself, "Aha, this is what's going on with me." All of my symptoms fit, even the noise sensitivity, which to me was the strangest symptom that I had. That sensory sensitivity is one of the symptoms of chronic fatigue syndrome. So it was a very enlightening moment for me because it validated, "Okay, I think this is what's going on. This might actually be the same thing, and it's a recognized disease, so I'm not going crazy. This is actually something that other people experience."

(16:27):

And what it was even more helpful for me in terms of just dealing with this new condition and new disability that I was going through was I learned about this concept of the energy envelope or staying within your energy envelope. And the idea behind it is that people who have chronic fatigue syndrome, they may have a fixed amount of energy that they're able to expend on a daily basis, and so they have to be very cognizant that they stay within their energy envelope, if you will, or that they don't overexert themselves because the end result of that is crashing. If you deplete your energy stores within that day

or the next day or a couple days, if you totally deplete your energy stores, they won't be able to function. And that's kind of what I refer to in the previous episode as being that crash.

(17:19):

When I describe it to my patients, I tell them it's kind of filling up a car with gas, but the gas tank has a leak and it's always dripping gas. If they don't rest and fill up that gas tank and that gas tank keeps on leaking, eventually that gas tank's going to go to empty and the car's going to break down and they're not going to be able to do anything. So they have to be very, very cognizant of not overexerting themselves.

(17:46):

My personal experience was that I would tend to get this ... I'm just going to call it a funny sensation in my head. It wasn't a headache at that point, but I felt weird. I felt off, and still to this day, I can't describe what it was, but for me, that was the first symptom that I had where I started to recognize, "Okay, this is the precursor to the headache. This is a precursor to the brain fog. If I don't stop or slow down now, if I keep pushing myself, I'm going to be in bad shape later. I'm going to have a full on headache. I'm not going to be able to think straight." So at that point when I recognized it, I would stop working and I would rest, and I found that I would be able later in the day if I stopped and I rested, I might be able to get some stuff done, but if I keep pushing it at that point, I won't be able to do anything and I'll crash, and I may not be able to get out of bed the next day.

(18:40):

So one of the things that I tell my patients is they really have to be cognizant of any of their physical symptoms that they're having and try to recognize the very early stages of these things going on, and when they do recognize that they have to stop. And I think that's really hard for people. I know it was hard for me, and I'm sure you can relate to this, Dr. Wells. Physicians, we tend to be people who work really hard, maybe even workaholics. We're people who used to pushing through when we're not feeling well. We're notorious for coming into work when we're sick or just working through when we're not feeling good. And that's how I had lived my life up until this. If I wasn't feeling good, I would just work harder and I would eventually get it done, but I couldn't do that anymore.

(19:28):

It was physically impossible for me to sort of push beyond my symptoms, and in fact, it would make things much worse to the point where I couldn't function the next day. So I really had to be very cognizant of staying within my energy envelope and not overdoing it. And if I did start to feel symptoms come on, I had to stop what I was doing and give it up for a few hours in the hopes that I would get anything done the rest of the day. And there were many days where I couldn't at that point.

(19:57):

Also, just the distress of not knowing you're going to get better, if you're ever going to get better. What an awful feeling that is to progressively get more and more disabled and not know what it is or if you're ever going to live a normal life again. I think that was just one of the hardest parts for me. Yeah, it's just a really difficult thing I think for anyone to go through being a normally functioning person to sometimes getting a cold and then months later not being able to do day-to-day activities and not understanding why either.

Dr. Christina Wells (20:30):

Thank you for sharing that. I'm so glad that you have recovered. It's different when you're the patient, then you can really understand where patients come from.

Dr. Stephanie LaBedz (20:41):

Absolutely.

Dr. Christina Wells (20:42):

And that will allow you to be able to empathize with them and then also really in reality, walk in their shoes to some extent.

Dr. Stephanie LaBedz (20:53):

I have found my patients are very grateful to hear about my experience, because I can relate to what they're going through. Literally every patient that comes to me with long COVID, I tell them all about what I went through. And I think it's one very validating for them to hear that, yes, you have a problem. I always tell them, we're going to put a name to this. You have long COVID. And I think it's validating because they have all these symptoms that there's no diagnosis to it. And to have a name put to it say, "Yes, you are sick. Yes, you have long COVID." I think it gives them permission to be sick and to be kind to themselves and not be hard on themselves when they feel like they can't do something.

(21:40):

Even things that are just basic day-to-day activities, they're very disabled and it's hard to explain to people, yeah, I can't do things just even very simple basic things, they just can't do it. And so I think it's good to hear, but I think also just being able to relate to them is really, really important. I've had patients in near tears in my clinic just hearing about my story because it's I think a much different experience to have a doctor who has also gone through the same thing and understands how disruptive it can be and disabling for them.

Dr. Christina Wells (22:22):

Are there things that you think, as we wrap up here, that would be helpful? I know we talked a little bit earlier about encouraging patients to maintain a healthy lifestyle by eating healthy. Some patients experiencing things like the chronic fatigue. Are there advice that you would still tell physicians that they can give patients and how they can still maintain some sort of physical activity? I know you mentioned about staying in their envelope, but are there other things that you could say that would be helpful so that we don't cause another disabling condition because they're not active at all?

Dr. Stephanie LaBedz (23:03):

I think it's a fine balance, unfortunately, and it's going to be something that you have to determine on a case by case basis. We all know physical activity is really important, and as physicians, we are always recommending our patients to stay active because that is important for a healthy lifestyle, but we don't want to push it. And that's where it's really difficult to know how much activity is good and what the threshold is from going from a good amount of physical activity to potentially disabling amount of physical activity. And it's really hard. I struggled with this myself for months to know how much I could do and when I was pushing myself too far, and there are many days where I didn't realize I was pushing myself too far until the next day when I couldn't do anything.

(23:55):

And so I think that it's going to be really difficult for any physician to give advice in terms of how much anybody can do. I always tell people like, "You have to listen to your body to know what the right amount is." I always encourage my patients to stay active when they can, but I also really, really emphasize that they need to rest and they need to recognize when that point is that they're going to

overdo it. I have been a very big advocate for my patients actually to take time off of work and to let their body heal. And so I would encourage anyone listening to really, if their patient wants to take time off work, to be the person who fills out the disability paperwork for them or the worker's compensation paperwork, whatever you can. I've done that for many of my patients because I do feel it's really important for people to take the time to heal.

(24:57):

And I think that really means resting for many people, although we are so accustomed to encouraging people to be active. I think this is sort of a double-edged sword with long COVID because physical activity can be very detrimental. It can be the thing that puts people in the crash where they can't do anything, and it's better to do a little bit of activity every day than overdo it and not be able to function for days at a time.

Dr. Christina Wells (25:30):

Great. So I think what my takeaway from that is that we have to be mindful and whatever recommendations we give, we need to target it and tailor it to the individual patient.

Dr. Stephanie LaBedz (25:42):

There's no way to know really what's going to be the right solution for every person. I think the patient is going to be the best person to tell you what the right amount of physical activity is. So what I do is I ask my patients, "What do you think you can do now?" And I listen to them. If they feel like going back to work is too much for them, I say, "Okay, well, let's give you more time off of work. Or if you don't feel like you're ready to do these things yet, then don't push yourself." You really need to listen to the patient and what they tell you that they're ready to do.

Dr. Christina Wells (26:17):

Right. Well, thank you so much for sharing your story today. It's been so enlightening to listen to it. We hope that this information has been helpful and to be able to understand what a physician's personal experience has been. And as we approach our patients with long COVID, we can hopefully get a better light and be able to understand what they may be experiencing as well. Although we know there's a myriad of symptoms that people with long COVID may be experiencing, this will give us a little bit of insight into what we can look for, some things we can suspect when patients present to our clinic. Thank you again for being with us, Dr. LaBedz, and for sharing your story with us. We really appreciate it.

Dr. Stephanie LaBedz (27:03):

Thank you so much for having me, Dr. Wells. It was a real privilege to be here today.