Dr. Christina Wells (00:00):

Hello everyone and welcome to another addition of Beyond the Needle. And today we're going to be talking about long COVID. We know that we have been hearing and probably many of us have had patients who are experiencing long COVID symptoms. And so today we wanted to address that topic and get more information to help primary care physicians be more equipped to dealing with patients who present with long COVID symptoms.

(00:34):

Today we have some special guests with us who are going to talk to us about their experience with long COVID. We have Dr. Heather Prendergast who is an ER physician at the University of Illinois at Chicago, and we also have Stephanie LaBedz who is a pulmonary and critical care physician also at the University of Illinois at Chicago. And I'm just going to give them a moment to just briefly introduce themselves. Dr. Prendergast.

Dr. Heather Prendergast (01:07):

Hi, thank you so much Dr. Wells for an opportunity to be a part of this podcast. As you mentioned, I am an emergency medicine physician. I've been at the University of Illinois for over 25 years. And as we are winding out of the pandemic, we are really now starting to see a lot more of these long COVID cases, so I'm really excited to be a part of the conversation today.

Dr. Christina Wells (01:32):

Thank you and welcome again. And we also have, again, Dr. LaBedz.

Dr. Stephanie LaBedz (01:39):

Thank you so much for the introduction, Dr. Wells. My name is Stephanie LaBedz. I'm a pulmonary and critical care physician at the University of Illinois. I've been practicing for almost a decade now and have had sort of a unique experience in the pandemic, both being on the front lines in the ICU, taking care of patients who are critically ill with COVID-19, but also seeing the aftermath of long COVID in my pulmonary practice. I've been taking care of patients now for over a year, almost two years with long COVID symptoms so I've seen quite a bit of it in my time. So I'm pleased to be here to share my experience and insight.

Dr. Christina Wells (02:20):

Wonderful. And I'm Dr. Christina Wells, I'm a family medicine physician at the University of Illinois at Chicago as well, and I practice at the Mile Square Health Center. And so we're going to jump right into our discussion today on long COVID. And we're first going to start off with a definition of, what is long COVID? Now, we know that there is really no universal definition, but the Center for Disease Control and Prevention defines long COVID as symptoms persisting a minimum of four weeks after an individual has been infected. The World Health Organization describes it as unexplained symptoms beginning within three months after being infected with COVID and that lasts at least two months. And we're going to talk about what those symptoms may be and how patients may present. And so either Dr. Prendergast or Dr. LaBedz, can you tell us a little bit about what has been your experience in how patients have presented with long COVID?

Dr. Heather Prendergast (03:34):

I can start with this because often a lot of times patients have no idea what is going on. They've had COVID and in some cases the symptoms have persisted, in some cases they have gotten better, and then some weeks thereafter began having symptoms again. And so oftentimes when we see patients in the emergency department, it's for these persistent fatigue or oftentimes they have not really been able to really communicate it out to their primary care physician. In fact, they're just not quite sure what is the etiology of it. And so it's not until, part of my role in the emergency department, I see myself as putting the pieces of the puzzle together, trying to inspect a gadget, kind of looking to get all of the clues.

(04:25):

And when you start to talk to patients and you see that they've had a diagnosis of COVID and then you kind of try to explore the onset of these symptoms. And oftentimes we find that patients are like, yes, they're not making the correlation. And I think when you said one of the questions was what should I know as a family physician? I think there needs to be a heightened sense of suspicion. Because it presents in so many different ways. So a lot of these non-specific symptoms and patients don't always know how to communicate or just having trouble concentrating. So the more that we can communicate out the different symptoms that are associated with long COVID, I think it'd be easier to make the diagnosis because we know that about one in five adults that have COVID are at risk for developing long, and let Dr. LaBedz chime in as well.

Dr. Stephanie LaBedz (05:22):

Sure. As a pulmonologist, I am typically referred patients who have long COVID who are experiencing shortness of breath or breathlessness. So my interaction with patients with long COVID is a little bit skewed towards the sort of cardio respiratory symptoms. That being said, almost everyone that I've seen with long COVID has other symptoms as well. And I kind of put people into different buckets. I see very predominant sort of cardiorespiratory symptoms. I will see a sort of pattern of neurologic symptoms. And then there's sort of the third bucket, which is anything else.

(06:01):

And that anything else bucket I think can be very long in terms of the symptoms and sometimes sort of unusual things. I've heard people report hair loss, sort of skin rashes, so things that you may not expect from long COVID. But if you search online, the list is very long and I'm sure things are going to be added to it as time goes on. But I tend to think of long COVID as very much being sort of cardiopulmonary or neurologic symptoms. But then there's also a long list of other things that people have experienced in the weeks to months after COVID-19 that they have no other explanation for.

Dr. Heather Prendergast (06:40):

One thing that I can add on to that is that sometimes when we think about long COVID, we think about onset of symptoms directly after having a COVID illness. That often delays the diagnosis in a lot of folks because we also now know that individuals can have relatively mild courses or even be pretty much asymptomatic and still develop symptoms associated or consistent with long COVID. So again, that's where having that really broad differential and listening to the patients when they say, "Something doesn't feel right," and being familiar with the whole consolation of symptoms, as Dr. LaBedz mentioned, they are pretty wide, but we are starting to see some patterns, definitely neurologic, fatigue, brain fog, cardiopulmonary issues, but then there's also musculoskeletal. So there is again keeping that differential very broad.

Dr. Christina Wells (07:39):

Right. And I think for myself as a family medicine physician, some of the things that I've seen have been similar to what you guys have just mentioned. I've had patients who after COVID have reported that they've had extended loss of taste and smell. I've had patients who were not previously on oxygen. I have one patient now who continues to need oxygen and cannot get off of it. I had another patient who was on oxygen temporarily for a few months but was finally able to get off of it. Had patients with blood clots, fatigue. And so some of these things are some symptoms that sometimes can actually, they'll be confusing because sometimes you ask yourself, well how do I know if this symptom is related to long COVID or is it related to something else? And so is there any sort of methods that you have found yourself using to help differentiate whether or not the symptoms that the patient is presenting with is related to long COVID or it's related to something else or it's a combination of the two?

Dr. Stephanie LaBedz (08:54):

I think it's really difficult to differentiate symptoms of long COVID from something else because the symptom list of long COVID is so long. I think the sort of temporal relationship between when the symptoms developed and the COVID-19 infection for me is sort of the biggest clue, particularly with people who have underlying health conditions that may have overlapping symptoms. What I often find is we'll say, "Well, this was sort of stable before and now it's changed," or, "It's a new symptom that I've never had, even though it could be attributed to something that I have already. I never really experienced that before and now I'm having it." So I think that to me is a major clue that the symptom could be from long COVID.

(09:40):

Another thing that I found, and I'm reminded of this from a patient that I saw this week is one thing that I find rather unique about long COVID is that people have these crashes that I can't attribute to anything else. So they may have symptoms of shortness of breath, for example, might have something like asthma and they're not really sure if their shortness of breath is from asthma. If they tell me that they're experiencing these episodes where they crash from overexerting themselves in some sort of activity that would not lead to what I call a crash. And my sort of loose definition of a crash is if you can't get out of bed or off the couch for a day or two days, that's pretty unique in my experience to long COVID.

(10:23):

So if I'm seeing somebody who comes in and they have some condition that may have symptoms that overlap with long COVID, but they're also telling me, "Yeah, I've been finding that I crash, I can't really get out of bed," that really makes me start to think this is long because I think that's a rather unique aspect of the disease.

Dr. Christina Wells (10:41):

It's interesting that you mentioned that because I was just reading about post-exertion malaise, which is a hallmark of long COVID, and it's a disabling condition where there's often delayed exhaustion that's disproportionate to the effort exerted. So like you said, someone who can't get off the couch because they're just so exhausted from those simple activities. And so it's a very interesting phenomenon. Dr. Prendergast, have you noticed anything as well?

Dr. Heather Prendergast (11:17):

In the emergency department, we have really a small snapshot of what's going on with the patients. But for patients I always look for a key to, in my mind, is something different from their baseline and that's not easily explained. And so along with what we were just talking about, it's not only just a physical exertion, it is the mental. We've had someone say, "You know what? I sent a couple of emails and then

all of a sudden it just totally wiped me out. It was just mental." So it's also physical and mental and those things again raise the flag. And so my approach now is to refer patients to our long COVID clinic. So essentially if they're having pulmonary issues or to make sure to refer them so that they can get some further workup around this.

(12:08):

And right now most of the treatment is really symptomatic and so it's really getting them to someone who can follow up on their symptoms. Because I think that that's very important because this is very disabling for patients to have these symptoms and is very frustrating to not be able to get answers. And so I always tell patients right now we have treatments for COVID, but we don't really have anything necessarily for treatment prevention, so to speak of long COVID. So right now we're really just still being reactive, but there are treatments available. It's really more symptomatic, but definitely making sure that I get them to the right place.

Dr. Christina Wells (12:50):

Wonderful. It's great that you mentioned that. Before we talk a little bit about that, I wanted to also ask you guys, had you seen any differences in presenting symptoms between adults and children? I know I was reading where some children were presented with more psychological symptoms, although they weren't sure whether or not those symptoms were also related to the isolation that children experienced during COVID. But have you guys seen similar, different, almost the same type of symptoms in adults versus children that present?

Dr. Stephanie LaBedz (13:31):

I only treat adults, so I can't really comment on that.

Dr. Heather Prendergast (13:35):

I have not really seen a lot of these symptoms in our pediatric patients. Definitely we see it a lot in the adult population, but I can't say that I've referred any children to our long COVID clinic or had any real suspicion of that in our pediatric patients.

Dr. Stephanie LaBedz (13:54):

I'm curious to know your experience, Dr. Wells, sort of contrasting the presentation in adults and children.

Dr. Christina Wells (14:02):

Even for myself as a family medicine physician, I haven't as well seen as many children. I can't even really think of a case of a child that I've seen with long COVID symptoms. Or maybe there may be, again, this is why we're doing this podcast because maybe I have seen a child who has symptoms, but I haven't attributed those symptoms to long COVID. And so this is why this is important because maybe there are children who are presenting to us and they're having symptoms, but we're not really going back in that history and thinking about is this something that's related to long COVID or at least is COVID a contributing factor to these presenting symptoms?

(14:47):

So I haven't seen either, but I think that this podcast will help us to be able to have our eyes open to be able to look for those symptoms when patients in particular when children present to the clinic. So thinking about that, are there any sort of red flags or anything that family physicians you think should be

looking for? And are there any sort of specific workups that we should be doing as family physicians when patients present to us and we think that they have symptoms that may be related to long COVID?

Dr. Stephanie LaBedz (15:24):

That's a great question and it's a question that I don't know the answer to and I really struggle with in my practice how to work this up and what to do about it. I have searched and have not found really any agreed upon recommendations in terms of the workup for symptoms. And I know my colleagues who also see patients with long COVID and myself, we tend to order very sort of routine testing for shortness of breath things such as a chest x-ray, in some instances a CT scan of the chest, pulmonary function testing is pretty standard. I often will order other tests depending on the symptoms that a patient reports to me, things like an EKG, an echocardiogram. I'll also go through if they were hospitalized or if they've seen another physician look at their laboratory work and see if anything sort of stands out to me that could be followed up.

(16:18):

So I think these are pretty routine tests that I would imagine many family physicians are also ordering for their patients. There are some circumstances where I may go as far as ordering a cardiopulmonary exercise test depending on the degree of disability that the person's experiencing and the longevity of their symptoms and if I'm finding anything else on any of their other testing. But if I'm being honest, most of the testing that I order for patients is totally normal, which is extremely frustrating for myself and the patient because I know that they're very distressed from their symptoms. They're oftentimes very disabled from their symptoms. And when the testing's negative, I can't really provide them any explanation as to what's going on with them. And so it's very frustrating and I think very invalidating sometimes for the patients because they want an answer. And unfortunately a lot of the testing that we can do is either not sensitive enough or we're not really on the right track at picking up what's going on with them.

Dr. Heather Prendergast (17:18):

Yeah. And one thing that I would add to that, I agree, and my approach is quite similar in the emergency department in terms of obviously we want to make sure that within that symptom that there's not an acute life threat. And so I think that as a family physician, you still want to get these tests. If someone has shortness of breath, you want to get those standard tests. And although it is very dissatisfying, I agree, as physicians we want to provide our patients with answers. We want to be able to help them with their conditions. But then when things come back negative, it sort of actually adds more weight to this person perhaps suffering from long COVID. And then there's some additional options that are available to them, obviously symptomatic treatment. But then if this is really becoming very disabling now, we know that is now recognized by as a disability.

(18:15):

And so if this is to the point where it is it severely impacting their ability to live their life, whether it's just the basic ADLs, there's now some support that can also come from that. So that's why I think it is still important even though we want to give our patients answers, if the tests come back negative, then it actually helps to build a case. And then one thing that I think that is important to do is really to proactively think about who is at risk for developing long COVID. And that list is growing but it's not as long as it could be. And so there is still some tangible things that we could take away from that.

(18:54):

So we know that individuals who have had more severe cases of COVID-19 are more likely at a higher risk of developing long COVID. Obviously individuals with underlying health conditions. Our unvaccinated patients, there's a lot of data coming out now showing that there is really a tangible difference in that patients who are at unvaccinated and do the coronavirus do have a higher likelihood or risk of developing long COVID. And so these are just some of the things to also keep in the back of our mind if we know this information and then it kind of helps us to also put the pieces of the puzzle together for our patients a little quicker.

Dr. Christina Wells (19:39):

It was interesting you mentioned about vaccination. I was just reading in the Lancet where it showed that vaccination was associated with reduced odds or risk of long COVID with the preliminary evidence suggesting that two doses were more effective than one dose. And so we know that studies are showing that patients who have been vaccinated with, especially as this study pointed out, with two doses at least were having less risk of getting long COVID. And you also mentioned Dr. Prendergast, that they're there are specific or maybe there are some conditions that are associated with increased risk for also getting long COVID. Are there any specific chronic conditions that either of you have seen more than others that particularly may be putting people at risk for getting long?

Dr. Stephanie LaBedz (20:42):

I have not seen any sort of patterns in my practice. I've seen long COVID in people who are young, people who are older, people who are highly active, people who are maybe less active and more sedentary. So I think it is sort of a non-discriminating illness and I'm not aware at least anecdotally or based on any empirical research of any particular underlying condition that puts anyone at higher risk.

Dr. Heather Prendergast (21:14):

And I agree, I can't really say that I tend to see it in this particular constellation of individuals with a certain underlying condition. But I do know that the studies reported that patients who experience multi-system inflammatory syndrome with their COVID illness appear to have a higher risk of developing long COVID. But that's again with their actual COVID infection. So like I said, definitely that at least that's been shown in the data, but I can't say that there's just one particular group that I've noticed because really it is actually all over the place. And really just the fact that they have underlying health conditions can be a factor, but it's not the only factor because some people who have no underlying health conditions can also develop long COVID. So I want to make sure to communicate that out as well.

Dr. Christina Wells (22:10):

Maybe this is another question too, although we know that people without chronic conditions can develop long COVID, do you think that chronic conditions may worsen the symptoms of long COVID, exacerbate them, or maybe people just have to deal with now two chronic conditions and that just worsens their outcomes?

Dr. Stephanie LaBedz (22:35):

That's really interesting. I think that because the symptoms of long COVID are so varied, what you may see is that patients have an underlying condition that's a distinct disease process, but the end result might be a symptom that is the same as something with long COVID. For example, if you see somebody who has COPD who at baseline is short of breath and then they get COVID and their shortness of breath gets worse, they may have a separate disease process from COPD that's caused by long COVID, but both

are contributing to shortness of breath through different mechanisms. So I'm not sure that the COPD or some other underlying health condition in itself will make long COVID worse, but that they may have a separate sort of pathophysiology that's also contributing to sort of overlapping symptoms but by a different mechanism.

Dr. Christina Wells (23:30):

Right. You mentioned earlier about diagnostic testing and I was reading a little bit about some of the similar things that you guys mentioned that most of the time there's nothing specific doing the basic laboratories or imaging tests that you would do in a patient who would present with whatever presenting symptoms they're coming in with. And so really following similar protocols to what we do in our everyday practice is important. So at what point do you think a family physician should consider referral to a specialist for a patient with long COVID?

Dr. Stephanie LaBedz (24:11):

I think anytime you are unsure of what's going on or you need help, that's a good time to refer to a specialist just for a second opinion or an extra set of eyes on things. I often find the family physicians do a really good job at evaluating patients. And when they refer somebody to me, it's when they're not really sure what's going on or they think that it could just use another set of eyes or they're not really sure how to help their patients. I don't know that I have any expertise in this area beyond what a family physician would have. So I don't know that I can offer anything that a family physician couldn't other than one, maybe ruling out something else that could be going on and two, corroborating the family physician sort of diagnosis that they've come to that this is long COVID and not something else.

Dr. Heather Prendergast (25:05):

I would agree with that. And I think that in addition to getting another set of eyes or just assistance with managing the patient and managing their symptoms, there's also the opportunity to take advantage of other resources. So if this does turn out to be long COVID, there are a lot of support groups out there for patients. Because I think one thing about referring the patient out, particularly if there is an opportunity to refer them to a center that's looking at long COVID, it provides a more holistic approach to managing the symptoms. Because also there's the physical symptoms, but then there's the emotional symptomatology that comes with just not being able to do what you used to do. And I think that one of the things that is often under reported is around the anxiety and depression, although we're seeing more of it now, but we know that these patients who develop long, it's not just the physical symptoms, there's some emotional baggage that is coming along that adds to the disability.

(26:09):

So that's another reason that I think that it's really great to refer these patients to get a second opinion and to just get more resources available to the patient that we have available to us. And one thing that I want to add at this point is that this long COVID, we're still trying to understand why certain people get it. As time goes on, we're accumulating more and more understanding of risk factors, but there's still much more to know about why different individuals develop long COVID. And so I think that that is not only at a national level through the NIH and through the CDC. Locally there are a lot of different researchers looking at this.

(26:55):

And one thing that I want to mention at this point, there's a recover study, and this is something that's national. It's not just here. It's at University of Illinois. We are participating in the trial, but it covers the entire state of Illinois and there are other institutions across the entire country that are participating in

this recovery study. And it's really designed to help us understand why some people experience long-term effects after having COVID, and most importantly, what can be done to speed recovery and prevent it? So right now we don't have the answers, but it's a lot of attention and it's a need to try to understand why this is happening to people. So that's another resource for family physicians as well.

Dr. Christina Wells (27:45):

So thank you for that information. Dr. Prendergast. Can you please tell us a little bit about how a family physician could refer a patient to the recovery study? There's also a long COVID clinic at the University of Illinois. Can you tell us a little bit about how that clinic works?

Dr. Heather Prendergast (28:08):

And so what we do actually depends on the patient's symptomatology. So we have physicians such as Dr. LaBedz, that if we have a patient that's having shortness of breath and we suspect based on their history that this may be long COVID, we can refer them for follow up with her as part of the long COVID clinic. And so this way it allows us to kind of tailor. So someone is having neurologic symptoms, it's more we are able to refer to a neurologist who is seeing patients as part of this long COVID clinic. This way it allows us to cast a wider net and provide more options for patients in managing some of these symptoms.

(28:50):

Regarding the recovery study, if you're in Illinois, we have a website, but if you just go and do a simple Google search for a recovery study, it will tell you all the sites and which one is near to you. And then there's contact information. And really it's an observational study in that it's really trying to understand we're not giving patients medications, but it's really trying to understand and to direct patients to resources to kind of help them.

Dr. Christina Wells (29:18):

Wonderful, wonderful. This has been so informative as we wrap up here. I wonder if either of you have any closing comments that you think would be important for family physicians to know about long COVID?

Dr. Stephanie LaBedz (29:33):

I would say what is really important to me, and I know the patient that I see, is for physicians to believe them. I've heard many, many times patients tell me that they feel like they're going crazy. They don't know what's wrong with them. They look normal on the outside. Every test that they get is normal. But they are sick and they're experiencing often very distressing and disabling symptoms. And I know that a lot of times people are written off and they feel that they're not believed when they go to their doctor and say, "Listen, I have been experiencing this and I don't know what's wrong with me." And it can be very invalidating and discouraging to them.

(30:18):

And so I think the most important thing is just to believe them. Even though we can't find something objectively wrong, doesn't mean that there's not something going on. I think one of my big takeaways from this pandemic and my experience treating patients with long COVID is to be much more empathetic for these sort of silent or diseases that you can't find anything wrong and you can't see something wrong, but they're still sick. So that would be sort of the takeaway message or the last message that I would like to leave everyone with.

Dr. Heather Prendergast (30:52):

And I would just echo that. I think the biggest thing is that we can listen to our patients, and Dr. LaBedz summarized it quite well. I think that that's so important because I have seen patients completely break down in tears when even just making the suggestion that, "You know what? This may be a part of your COVID," at least giving them hope that, okay, this is not in my mind. I am not going crazy. There is something wrong. So I think listening to our patients and validating them and saying, you know what? Let's figure out what this could be and then sharing, we'll do these tests. This is what it may be. And just so that you can actually see the weight fall off of them in terms of just understanding that, hey, someone is listening to me.

(31:37):

And then I think we need to keep long COVID in our differential so that people are thinking about it. Because that's one thing that we've seen with the recovery study that we have these patient groups and people just, wait a minute, I have those symptoms. You mean this could be? And so it's like the light bulbs go on. And so I think that that's the first thing. If you really want to diagnose something, you have to have an awareness.

(32:03):

I think that I really want people to understand that even the way people present with long COVID is not traditional in that they can present along different spectrums of that illness. It could be resolved and then weeks later. And I think that that's the next thing that I would say, listen to our patients. And that COVID is teaching us something new every day. And although we're now seeing more acute cases again, but three years into this, now that we're seeing more patients with long COVID, we have to make sure and just know that we don't know everything there is to know about long COVID yet, so always just have a heightened index of suspicion that this patient, they're presenting symptom or symptomatology associated with long.

Dr. Christina Wells (32:51):

Yeah, I think what you both have said has been wonderful. I think that we have to help patients to understand that we don't know everything and this is a work in progress. But we can listen, provide, support, and do the best that we can. And I think that is the best position for us to be in as physicians to really help our patients to be able to get through things such as long COVID. I thank you both, Dr. Prendergast and Dr. LaBedz for being with us today. This was a wonderful opportunity to discuss long COVID, and we hope to have you back on another episode. Thank you.

Dr. Heather Prendergast (33:32):

Thank you so much.

Dr. Stephanie LaBedz (33:33):

Thank you for having me. This was a pleasure.