Coming up on Mayo Clinic Q&A, most people who have COVID-19 recover completely in a few weeks, but some people may have symptoms of the disease long after their initial recovery. These people are described as long haulers.

Unfortunately, we still have patients who are now suffering more than a year and a half out from their infection initially, it's not everybody. And I will say that most of those patients, they are doing better, but the recovery process is so slow. So, the long haul COVID name does really seem appropriate, unfortunately.

On this Mayo Clinic Q&A, we'll explore the treatments and the research being done to slow down the effects of long COVID.

I think with this impact that we're seeing, the long haul COVID, there's going to be more emphasis on getting this kind of research done, and frankly, more funding. I think once we have that, then we'll be able to develop things like a diagnostic test and then also have more definitive treatments other than a slow recovery.
Welcome, everyone to Mayo Clinic Q&A. I'm Dr. Halena Gazelka. While most people with COVID-19 recover completely, there are others who struggle to return to complete health after the virus. Sometimes these are called long haulers or long COVID. These patients can have fatigue, shortness of breath, brain fog, and other symptoms long after the time of their infection. Here to help us better understand long COVID is the director of Mayo Clinic's COVID activity rehabilitation program, Dr. Greg Vanichkachorn. Welcome back to the program, Greg.

Dr. Greg Vanichkachorn 01:34
Thanks again for having me. It's good to be back.

Dr. Halena Gazelka 01:36
Well, I'm so happy to have you back because we haven't really talked about this in a long time. And in terms of COVID it's been about forever as far as research keeps coming along. So, I'm excited for you to give us some updates.

Dr. Greg Vanichkachorn 01:49
Absolutely.

Dr. Halena Gazelka 01:51
And let's start right with what is the right thing to call this? We hear it called long COVID or long hauler's syndrome. What's the appropriate term?

Dr. Greg Vanichkachorn 01:59
Yeah, that's a great question, and it sort of shows an insight about where we are still with the research in this area. Even though it's been about a year and a half since our team first started working with patients with long haul COVID, we still don't have a name that we can all agree upon across the world. Some people call it long haul COVID, others call it post-acute sequelae of SARS-CoV-2, which is quite a mouthful, and we tend to use post COVID syndrome here. But as of right now, there just is no agreed upon name on this condition.

Dr. Halena Gazelka 02:33
All right. So, I was worried that I was calling it the wrong thing.

Dr. Greg Vanichkachorn 02:38
They all fit.
Dr. Halena Gazelka 02:39
That's a moot point right now. But can you tell us, do you know yet who is susceptible to this? Who is most likely to have a long COVID syndrome or post COVID syndrome?

Dr. Greg Vanichkachorn 02:50
Well, we see two different buckets. If individuals have a very severe acute infection, and these are the kinds of folks that ended up in the hospital, or maybe even in the ICU, if they have long haul COVID after that, they tend to have more severe symptoms. And this makes sense because we already know that patients coming out of the ICU for whatever medical condition can have a really long road of recovery after that. But on top of that, it seems like pretty much anybody else can get this condition as well, too. In fact, most of the patients that we've seen here in our program, 75% were not hospitalized as part of their acute infection. In fact, many of them just didn't need any medical care at all. They were able to take care of themselves at home. We also have not found any relationship with pre-existing health conditions like asthma, or high blood pressure, no relationship to depression, or anxiety, or fibromyalgia, or chronic fatigue. I will say that the patient population that we see in this condition tends to be younger than the patient population that we associate with severe acute infections. The average age is about 45.4 in our patient population, and for whatever reason, we tend to see more females than males, 68% of our patient population has been female. And this is a finding that's been reproduced in other studies, including another recent study that came out here at Mayo just this past month. More remains to be determined about what is leading to that. But other than that, it really is a condition that anybody can get.

Dr. Halena Gazelka 04:25
Interesting, what causes it?

Dr. Greg Vanichkachorn 04:27
This is another good question. Remember most of the research right now is trying to figure out what is the best name for this, and also how this condition presents across different socio-economic groups and patient populations. But that being said, there has been some scratching on the surface about what could be causing this condition on a chemical level, on a biochemical level. So, for example, we do have some research now that shows that some of the cells that are used to create immunity after an infection, they may be malfunctioning in this condition in patients with long haul COVID. We also now have some research that shows that patients with this condition can have antibodies against themselves, otherwise known as an auto-antibody, and this may be associated with the long haul COVID state. So, immune dysfunction and auto immunity, they may be at play here. We also now have some information saying that the neurological system may be more impacted by the acute infection than we previously thought. Now, these are all just initial research studies, and a lot is left to be done in this area, but there does seem to be a biological plausibility centered around the neurological system and the immune system that causes this long condition.
Dr. Halena Gazelka 05:44
Very interesting. Greg, do you know if there's preventative measures that can be used while the person is ill with COVID, such as monoclonal antibodies that help prevent this?

Dr. Greg Vanichkachorn 05:54
This is a question that we get quite a bit. And we've had a couple of patients receive monoclonal antibody and then go on to get long haul COVID. So, as promising as it sounds, we have not seen that be associated with improved outcomes and prevention of long haul COVID. That being said, it is an area that I'm really interested to see as part of future research when it comes to treatments. I will say that patients these days, they're coming in to be seen sooner than later. Early in the pandemic, patients were arriving three to four months out after their infection because they weren't certain what they were going through, and getting care was difficult. But now as this condition is more recognized and more programs are available, we're starting to see patients three to four weeks out from their infection, and if these patients do get long haul COVID, I will say that their courses tend to be less severe than what we have seen in the past, and they're getting better faster. Now, it kind of begs the question, is it the fact that we're seeing them earlier that's making them get better faster, or the fact that a lot of these people have been vaccinated? Too early to determine, but in any case, I do recommend that patients get care sooner than later.

Dr. Halena Gazelka 07:02
How long does it last typically?

Dr. Greg Vanichkachorn 07:05
This is the age-old question for something called long haul COVID. It's now more than a year and a half out from the start of this condition really, and unfortunately, we still have patients who are now suffering more than a year and a half out from their infection initially, it's not everybody, and I will say that most of those patients they are doing better, but the recovery process is so slow. So, the long haul COVID name does really seem appropriate, unfortunately.

Dr. Halena Gazelka 07:33
Greg, in our patient forum, Mayo Clinic Connect, there have been talks about loss of employment due to long haul COVID. Have you seen this concern with your patients?

Dr. Greg Vanichkachorn 07:45
Work has always been something that's been a focus of us here in the clinic being an occupational medicine clinic primarily. Because we always ask about work abilities and try to get patients back to their job, and unfortunately, that is not always possible. Because of the
prolonged nature of the recovery process many employers just can't wait, unfortunately, forever for these patients to get better. So yes, we have seen quite a few individuals who have not been able to get back to their normal work, or have been out of work completely and lost their job.

Dr. Halena Gazelka 08:15
Wow, that's difficult. How do you treat this? What is your program like for individuals who have long haul COVID?

Dr. Greg Vanichkachorn 08:23
Well, one of the first things that we do for patients in this is making sure first that nothing else is going wrong. There are some things that can happen after the acute infection like blood clots, or opportunistic infections, you know, bronchitis or pneumonia that comes in, that can really complicate the recovery. So, we want to rule out all of those kinds of life potentially life-threatening conditions early on. But after that the real main focus is helping patients recover in an appropriate fashion. Most people when they have COVID, no pun intended, they're really sick of being sick and want to get back to their normal lives. So, they try to do whatever their normal lives may be, whether it's going to work for eight hours, or training for a marathon. And with that, they resume their normal activities, and they have a flare of their symptoms, sometimes lasting for days. And this is kind of a hallmark feature that we see with long haul COVID. But then that unfortunately sets up this vicious cycle where they try something and they're tired, and then they're down and out, they become more deconditioned, then they try again, and so on, and so on, and so on until they're very deconditioned and very demoralized. So, very early on, if possible, we like our patients to visit with our rehab team, our team of occupational and physical therapists to help establish a proper rate of recovery and the proper recovery activities. Along those lines, we will often use medications and other treatments to help a lot of the symptoms. A lot of the symptoms like headache or nausea or dizziness, they can get in the way of patients trying to recover. And so, we treat those symptoms so patients can better rehabilitate more effectively. And then we walk along with them through this path. There tends to be a group of patients that gets better around four to six months. And then there's a group of patients that takes a little bit longer. The process is always too long though for everybody.

Dr. Halena Gazelka 10:14
That sounds incredibly frustrating.

Dr. Greg Vanichkachorn 10:16
Yeah, very much. So, our patients do deal a lot with some of the mental health issues that can come with being sick for a long time and losing function and work. And that's an important part of our treatment as well. Many patients by the time they come to us, they've been told some very unhelpful things about their condition like this is all in their head, or they just have depression and anxiety, or they just need to tough it out and be like the rest of us. And that's
very demoralizing for patients. They have a lot of guilt and self-doubt. So, one of the first things that we do for patients is simply just listen to them and let them know that their symptoms are not just all made up in their head, and that we're going to try to help them as best as we can get through this really mysterious condition.

Dr. Halena Gazelka 11:01
Greg, you mentioned earlier that you're all working together in the medical community on a name for this. But what else do you see as some of the most important research that's taking place? You mentioned some a little bit ago?

Dr. Greg Vanichkachorn 11:14
Yeah, you know, I really think that we need to get a better understanding of what is going on at a cellular level with this condition. And this is a condition that's very similar. I won't say that it is the same, but it's very similar to chronic fatigue and fibromyalgia. We've known about those conditions for decades. But just because of priorities and medicine, and stigma unfortunately, we haven't made a good headway about explaining what's going on in these types of conditions on a cellular level. I think with this impact that we're seeing from long haul COVID, there's going to be more emphasis on getting this kind of research done, and frankly more funding. I think once we have that, then we will be able to develop things like a diagnostic test, and then also have more definitive treatments other than a slow recovery.

Dr. Halena Gazelka 11:58
The other diseases you mentioned, chronic fatigue, and fibromyalgia, if I'm not mistaken, are also more common in women. Is that true?

Dr. Greg Vanichkachorn 12:05
Correct. Yes, we also see more autoimmune issues in women as well, too. I think there is a biological basis for this not just a socio-economic basis. Of course, both could be at play.

Dr. Halena Gazelka 12:17
Interesting. Thanks so much, Greg. Any last words you'd like to share today with our listeners?

Dr. Greg Vanichkachorn 12:22
You know, I tell patients that this really is a long haul condition, and it may take a while. Again, we do have patients now a year and a half out with symptoms still. But, that being said, I don't want patients to lose hope. We are still again at the very beginning of trying to understand this condition. Again, we don't even have a name that we can agree upon to call this. So, while things may be long haul right now, and it may be important to develop coping skills to manage
the symptoms, I'm hopeful that over the next year or two we're going to have a lot more progress in the science, and then we may have a cure or treatment that can fix this within a few weeks.

Dr. Halena Gazelka 12:59
Well, we hope with you Greg. And we look forward to hearing more when you come back next time.

Dr. Greg Vanichkachorn 13:04
Thank you again so much for having me. It's always been a pleasure.

Dr. Halena Gazelka 13:06
Thanks to Dr. Greg Vanichkachorn, the director of Mayo Clinic's COVID activity rehabilitation program for being with us today to talk about long haul COVID. I hope that you learned something. I know that I did. We wish each of you a wonderful day.

Narrator 13:22
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