AK    Hello, good afternoon, good morning or good evening from the World Health Organization headquarters in Geneva. My name is Aleksandra Kuzmanovic and today I'm joined by Dr Janet Diaz, who is WHO COVID-19 Clinical Care Lead. We will talk about post-COVID condition or so-called long COVID, that many people who have been infected with the virus are affected with the post-COVID condition as well.

We're also joined by Jani Savolainen, who is a representative of the Long COVID SOS group. Good afternoon, Janet and Jani. Thank you for being with us today and for your time. I would just remind viewers to send us their questions using the hashtag #askWHO if they're watching us on Twitter. If you're watching us on other platforms please submit your questions via the comments section.

Janet, maybe we can start with you as WHO published a clinical case definition of post-COVID condition last week. Can you tell us what's the definition, why it was so important for us to get that definition and how it will help people to get the right care?

JD    Thanks so much, Aleks, for the question and good afternoon, good morning, good evening, colleagues out there listening. It is very important that we publish the clinical case definition of post-COVID-19 condition, what is also called long COVID, as you described. I'm going to read it out because it's important to just say it.
It occurs in individuals who've had a history of probable or confirmed COVID-19, usually three months from the onset of the COVID-19 symptoms with symptoms that last for at least two months and that cannot be explained by an alternative diagnosis.

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Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally do have an impact on everyday function. The symptoms may be new in onset following the initial recovery of the acute COVID-19 episode or they can persist from the initial illness. Symptoms sometimes fluctuate or relapse over time.

Why is this important? This has been a big global need to improve the recognition of patients who are experiencing living with post-COVID-19 condition and so a standardised definition allows that people get recognised so that the clinicians, the health workers, the community workers or the patients themselves or their families can recognise better that the condition may be existing if you have some of these symptoms lasting, as I've described.

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So it helps clinicians then identify patients or patients identify themselves and go seek care and then patients can be started on the appropriate care and treatment pathways.

It also will help us, I think, understand the magnitude of how many patients are living with post-COVID-19 condition so understand the prevalence globally. Finally also we want this to promote more standardised research so with a single definition we can try to synergise the global research efforts and improve our understanding of this condition. Thank you.

AK  The definition. We worked with different groups and patients who are affected with post-COVID condition and today we have, as I mentioned, Jani, who is a representative of the Long COVID SOS group. Jani, good afternoon and could you please share your experience with us since you got infected with COVID and then with your post-COVID condition?

JS  Hello from Finland. I'm Jani Savolainen. I was healthy before the COVID hit me last March, 2020. My initial illness was quite mild but it was nothing compared to mild [sic] because the acute phase lasted over three months and I was previously sick.

Even though I was not hospitalised with the COVID in the acute phase I had an [unclear], I had an [unclear] with my lungs and
[unclear] with my muscles and a lot of different symptoms that I hadn't had in any disease before in my life.

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After 19 months I'm still having the relapses and some weird symptoms still come back every now and then. Usually they came back in the acute phase in around one-month cycles and you knew in the morning when you woke up that this month would not be a nice day because there were some symptoms coming back.

Now, 19 months on from the acute phase I'm still feeling the symptoms. The symptoms are neurological and chest pain and pain in the legs and pain in the fingers and pain in the toes. Some symptoms are new, which I didn't have before in long COVID and some are still the same, like bone pain and a fizzing sensation in your head, fizzing pain in the temple area, around here.

Some of the symptoms are usually on the other side of the body and some are in different parts of your body. It has been quite a long ride with ups and downs. Everybody is feeling the ups and downs and relapses and so on so it has not been a nice time.

**00:07:14**

AK Thank you so much, Jani, for sharing your experience with us. This is also a wide range of symptoms that you, as one patient, are experiencing. Janet, maybe you can tell us, what is the range of symptoms that we know so far that people with post-COVID condition may have?

JD That's a complicated question because there are many different reported symptoms that have been described from studies and from patients' experiences. We chose through our Delphi process... The way we made our case definition was to do a consensus process.

We surveyed people from around the world on what symptoms we should say specifically in the case definition and there we came up with some of the more common symptoms such as fatigue, shortness of breath and the cognitive dysfunction which may be troubles with memory or may be troubles such as brain fog.

But we do know that's just three common symptoms and it's not all the symptoms so people, as you just heard from Jani, can have very different kinds of symptoms. They can have chest pain, they can have neurological symptoms, they can have
trouble with their smell and taste so the types of symptoms can be wide-ranging, affecting different systems in the body.

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So I would say if you have had COVID-19 and you're experiencing either symptoms that don't get better after three months, which is what we wrote in our case definition, or you develop a new symptom that you hadn't had before and you're just not sure what that's from then go to seek care from your provider and have them evaluating you, see what's causing this and could it possibly be the post-COVID-19 condition or long COVID.

AK    Thank you, Janet. Is there a treatment for post-COVID condition?

JD    Right now there's no one drug for post-COVID-19 condition. As you know, for COVID-19 itself, for the acute phase of the disease we're just now starting to find new therapeutics, which is good. But for the post-COVID-19 condition we do not have one drug.

What we do have though is care pathways, meaning that if you have, let's say, functional limitations such as fatigue or shortness of breath or the cognitive, the brain dysfunction then when you go to seek care what we are recommending is that the care centres have integrated care, multidisciplinary care, rehabilitation interventions so that interventions can be done.

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There's more we're learning about this and if you're interested we'll have the webinar we had last week on the website maybe in the next couple of days - it's not live yet - with the various presentations of different rehabilitation interventions and care models that can be done to care best for the patients that are experiencing such symptoms that are affecting their lives.

AK    Thank you so much, Janet. Jani, we actually haven't spoken much about the Long COVID SOS group. We just mentioned that you represent it but maybe you can tell us a bit about the group and how you as patients with post-COVID condition are supporting each other.

JS    About the Long COVID SOS, I think everything comes back to one year ago. Last July or August members of Long COVID SOS made a huge video on YouTube and they presented there. Then they started to message, I think, Janet who was the main contact at WHO.
Then we had the first meeting with WHO last August regarding long COVID and I was part of that meeting. Long COVID SOS is bringing the people together who had COVID and now have long COVID and trying to help the patients through support groups and so on.

We are doing the same in Finland. I was the creator or I made some YouTube videos from last March to December, recording the COVID symptoms. Then I created the Facebook support group for the COVID survey version [?] last April and now there are over 5,000 people on that group.

People are getting help from that support group because nobody knows what this is or what this sickness is doing to us. That's from the Long COVID SOS and from Finland.

Thank you so much, Jani. Janet, here is a question from Veronica Douglas, watching us on Facebook. What policy does WHO have in place to help front-line healthcare providers battling post-COVID in various countries?

Thanks for the important question. What do we have in place to back up healthcare workers that are caring for patients with post-COVID-19 condition? That's the question that I understood.

We have in place right now a few important documents. The first one is the clinical guidelines so back in December of last year we published our update to the clinical guidelines and that included one chapter on the initial guidelines for the clinical management of patients with long COVID or post-COVID-19 condition.

In there you can see we do recommend, one, recognition, two, an integrated approach, as I've already described, for care and that those should be put in place into the health system.

Now most recently, as you can see, we've published the clinical case definition so we do hope member states and policymakers can use that now to both do better surveillance of this condition as well as implement the appropriate resources into the health system in order to ensure that these patients can be cared for in this integrated, comprehensive way.

Then third my colleagues in the rehabilitation group that helped deliver that webinar last week are right now working on an update to the rehabilitation guidelines for post-COVID-19
condition and are right now assembling the experts and patients together to write those guidelines and we do hope that that is available towards the end of this year.

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AK Thank you so much, Janet. One of our viewers is asking, can post-COVID condition affect children?

JD Again a very good question. The information on children... We do know children are less likely to get severe illness, severe and critical COVID-19 from the acute perspective. However the prevalence of post-COVID-19 condition in children, I think, still needs to be further described but we do know it is happening in children as well. We just don't know if it is as common in children.

In adults we do know that people can get post-COVID-19 condition regardless of the initial disease severity. We have seen that so, as Jani described, even if someone was managed as an outpatient and considered mild or not needing acute hospitalisation, the symptoms can develop and they can cause significant limitations in daily functioning.

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So more information and more research needs to be done on the paediatric population, on smaller children to see how much they will experience a post-COVID-19 condition. Also I just want to highlight the definition we have right now, we know, may have some limitations potentially in children where it may be harder to elicit some sort of symptoms from children.

So we are working with paediatrician research working groups in order to see how to adapt to the definition for children.

AK Thank you so much, Janet. You mentioned we are working with different groups so maybe both you and Jani can explain to us how we are working with groups of post-COVID condition patients like long COVID SOS and others. Maybe, Jani, you want to start.

JS Yes, I can start. I think we can work together so that we have the information shared around the world and throughout the VSO and throughout the different patient groups around different parts of the world and making that [unclear] this disease and how it's moving forward in us.

Because some people are not recovering in any states because the persistent illness is still coming back and still nobody knows why.
AK  Thank you, Jani. Janet, any comment from you on collaborations?

JD  Sure. I just want to acknowledge what Jani said at the beginning. The first interactions we had with Long COVID SOS were to bring this to WHO's attention and to actually set the initial strategies of what we were going to work on so that was definitely a partnership with Long COVID SOS and with patients that were living with long COVID.

That helped us set up the three R approach, which is what we began with, which was the recognition - so getting this case definition - the research aspects and I want to highlight again what was just said, that the need to understand the mechanisms of disease, what's causing this, what's causing the different types of symptoms, is it the same thing, is it different mechanisms so that we can better understand how to treat it and actually develop more targeted treatments.

I think that is an important piece of work that still is ongoing. We know many people are working on this but it needs to continue so that we can find an answer.

Then rehabilitation so those three Rs were what we started with and that was from the initial collaboration. The definition we developed was developed alongside patient partner groups, the webinars we've had, the three that we just finished, also working with colleagues, clinicians, researchers, policymakers and different public health organisations and patient groups, patients themselves and also patients who are researchers or patients who are clinicians so maybe coming from those two perspectives.

So for us, as we do with everything at WHO, we like to work with groups from all regions of the world and so the Long COVID SOS group has provided us with a lot of good colleagues from different parts of the world as well.

AK  Thank you so much, Janet. We've got a question from one of the viewers asking, what is the main mental health problem that people with post-COVID condition may have? Are we aware of some mental health conditions?

JD  I'll start to answer that but maybe Jani also wants to answer that. I think the symptoms that have been described that
are mental health symptoms are anxiety and depression. Those two symptoms have been described in the various researches that have been published.

Again since we don't fully understand the mechanism of the condition it is complicated to put the whole picture together but those are two mental health aspects that have been described in patients with long COVID.

As well, I think, mental health problems in general during the pandemic in those with post-COVID and those who have post-COVID has been highlighted and the importance for mental health care also highlighted here at WHO.

AK: Thank you, Janet. Jani, any examples from the group?

JS: No, I don't have anything to add because that was well-said because it really can affect your mind, the whole diseases. When the symptoms don't end it also affects you, if you are not getting any help for those symptoms and they're continuous it affects daily things so well said, Janet.

AK: Thank you, Janet and Jani. Here's a question from Nino Bukiya. When is a good time to seek care? Sometimes long COVID symptoms might not be getting in the way of daily activities so patients might not think they need to seek care but might actually need to. How to make the judgment when to seek care?

JS: That's a really good question because those symptoms can be very weird sometimes. I think if you have some neurological issues, that you are not seeing quite clearly or you are having issues when you are speaking or something is not correct and your family notice that then I would suggest that you seek care as soon as possible.

AK: Thank you, Jani. Janet, do you have anything to add?

JD: I agree. I think everyone knows themselves the best but if you're not recovering from your acute disease, if you knew you had COVID and you're not recovering, there's a symptom that's lingering or you're not feeling just like yourself yet I think it's good to get care and to talk to a health professional, to describe the symptoms.

AK: Thank you, Jani. Janet, do you have anything to add?

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with someone alongside of you to see, to monitor the symptoms and see how they're evolving, if they're coming and going, if they're relapsing, if they're fluctuating, if they're persistent, those sorts of things.

I think alongside a healthcare provider that type of relationship can help make the diagnosis sooner and also if interventions need to be done get those interventions started sooner rather than later.

AK   Thank you, Janet. We also got a question about post-COVID condition in pregnancy. Do we have any particular advice or information that it can affect pregnant women?

JD   That's a good question. I don't have a specific answer for that. I think that's still something that we need to better understand in that sub-population of pregnant women so thank you for raising that. I think it's an important thing to raise on this talk but I don't have any further information on that but that's something that we will bring back to all the information that we're trying to synthesise.

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What we try to do with all these publications is to put it all together and make sense of it so that we can share this with the community at large so that is an important point. Thank you.

AK   Thank you. Janet, I'm aware that we don't have much time left but maybe the last question that you can answer is about vaccines, whether they prevent patients from getting post-COVID condition or help to reduce symptoms. There was quite a lot of comment around vaccines and post-COVID condition so what do we know about these two?

JD   Again another great question. The vaccine's ability to prevent post-COVID-19 condition, we believe, depends on its ability to prevent infection in the first place so again number one is prevention of COVID-19 and all those vaccination, all the other public health interventions that help prevent transmission and prevent you from getting sick in the first place are important.

However we do know that vaccines mostly are very effective in preventing severe disease and death but sometimes someone can still get infected so if they get infected is there some protection to developing long COVID in those patients that are breakthrough infections?

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That we're not so sure yet. There are some studies that are looking to see, if you were vaccinated and then you got infected and, let's say, you had symptoms, how long did your symptoms last and are the symptoms persisting or are they shorter than other people's?

I think that's where there's some interesting research that's being done to quantify if patients who've been vaccinated but then develop infection will be less likely to have long COVID and we just don't have the answer yet.

AK  Thank you, Janet. Jani, what is your advice for people suffering from post-COVID condition?

JS  Seek care when you need it and take it day by day. Don't stress too much and seek the support groups because you will get help from the other patients who are suffering in the same situation. That has helped a lot of people in Finland. That's my advice.

00:24:48

AK  Thank you so much, Jani, for your advice and for sharing your experience but also for what you do with the group to support others. It's very much appreciated. Janet, any final advice from you for people suffering from post-COVID condition?

JD  I echo what Jani said. Take care of yourself and if you notice... Again early recognition is key, seeking care is key and engaging with the healthcare system, I think, is very important so I think with patients that's important, to monitor yourself, that your symptoms do resolve if you get acute COVID, that if they don't resolve within the right time frame or if they're bothersome in some way, if you're concerned then seek care and get an opinion.

Get a healthcare worker to be your partner in trying to sort this out with you and then for those of you that are out there doing clinical research on treatments, on understanding mechanisms of disease, it's a really important piece of work to continue and advance our understanding of the post-COVID-19 condition so that we can prevent it and treat it better and hopefully find ways to resolve it so it doesn't continue to affect people's lives.

AK  Thank you so much, Janet, for your time and sharing with our viewers what we know at the moment. I'll just use this opportunity maybe to ask those who are still in good health to be careful and follow all the measures. Wear a mask over the face, keep your distance, make sure you're in a well-ventilated space
or open windows, clean your hands and avoid crowds and get vaccinated when it's your turn.

I guess those measures to prevent infection are the best way to prevent post-COVID condition as well. Please stay tuned for more information and updates from us. As Janet mentioned, there is more information to come in the following months, hopefully before the end of the year on this subject.

Until next week, stay safe. Thank you.

JS    Thank you.
JD    Thank you. Bye.

00:27:07