

“Tired, sick people are seeking help from tired and sick people in a system in which there is very limited knowledge”

Australian academic Dr Pippa Yeoman speaks about her ongoing struggle with Long COVID

Richard Phillips
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In this video interview, Dr Pippa Yeoman, an educational ethnographer and a senior lecturer at the University of Sydney, speaks about her ongoing struggle with Long COVID.

Dr Yeoman, who is a member of the Long COVID Facebook community support group, also voices her concerns about the failure of Australian government to provide adequate support to Long COVID victims and the dangerous consequences for public health of the lifting basic COVID safety measures.

An edited text version of the video interview can be read below.

We encourage readers to share this interview widely on social media and to attend the forthcoming online public meeting by the Health Workers Rank-and-File Committee and the Committee for Public Education on Sunday, November 20 at 3 p.m. (AEDT).

Titled, “Unite educators and health workers: Oppose the ending of COVID protection measures! Lives before profit!” the meeting will outline a political perspective, including the building of rank-and-file committees to unify health workers, educators and other sections of workers, to fight for safety, decent wages and conditions, and the elimination of COVID-19. Register now: <https://bit.ly/3CRCuOh>

Richard Phillips: Thanks Dr Yeoman for your time. First of all, can you tell us a little bit about yourself, how you ended up catching COVID, and then Long COVID, and how you became involved in the support group?

Pippa Yeoman: Thanks for having me. I’m a university lecturer and as an ethnographer, I’m used to observing other people and what they do, so it’s quite different being in this space. I exist in this space as somebody who inadvertently ended up here, rather than as an object of research attention.

I got COVID in early March once we’d started moving back on campus. One of my sons came back with COVID and brought into the house. I got one case and got over that but then we were called back to campus to teach in person and got a second case. Two immunologists have told me that the two were likely to have been two different strains.

The hard thing was that I’d been keeping up to date with health advice and I’d had all my shots—two vaccines and a booster—and I’d been doing all the isolating and everything.

I ended up with two cases within a month, which was confusing because at the time New South Wales Health advice, when I phoned them, was

don’t worry about testing, you’ll be fine. You might test positive for a long time. I ended up testing positive by RAT tests for 31 days and so I went to the doctor. I was masked and she was masked—I’d phoned New South Wales Health twice and they said I could go—but the GP stood up and asked me to leave. I really understand this conflict because she had lived through two years of being on the front line. Her initial response was to move away from me and asked me to leave. Having done all the right things, and asked all the right questions, to have that as my first physical interaction with a healthcare provider was quite confronting.

I just never got over that second dose. I never managed to teach and be on campus from that point on. I limped along and because we were mostly allowed to opt to teach from home. I was sort of managing. But I was working really hard seven days a week per five workdays, and just exhausting myself.

That was March, April, and then in May, I just came undone. There’s just no way I could have carried on. Right from the start my symptoms were a mixture of orthostatic intolerance, which means I get dizzy really quickly and can’t stand up. Even now I’m sitting but my feet are up. I can’t sit with my feet down for very long.

There’s lots of dizziness and a fair bit of what people call brain fog. I find it a very disparaging term because quite often you can think thoughts, and you know what you want to say, but you can’t put the sentences together. This means you have to learn to speak differently to express yourself.

I teach in three-hour blocks, so I have to be able to cope with the cognitive challenges of organising my thoughts and expressing them for three hours.

You’re doing the mental toggling between all the equipment you’re using, where all the other people that you’re teaching in a team with and where all your students are. You’ve also got video interface and text interface, so it becomes quite challenging. It was too hard for me to do.

Although mine was a mild case—I was at home and wasn’t actually terribly sick but didn’t get well. I was left with—I never called it breathlessness—I always thought of it as a lack of oxygen. If I don’t take the medicines that help, I can’t talk.

If I don’t take the one medicine that helps me with my breathlessness, I can only talk on the out breath. This means I have the cognitive challenge

of organizing my thoughts and speaking on the out breath. It just makes it really, really difficult to carry on a life of thoughts or a life of speaking.

It has had an enormous impact on my ability to carry out my work, or at least a fair amount of my work. I didn't work for five months—May, June, July, August, September—but thankfully, I'm fully employed and have very good benefits for which I am grateful.

I know that there are a lot of people who are not in that position and a lot of casual workers who can't access those kinds of benefits. Whilst I'm grateful for the benefits I've had access to, I'm very conscious that this is a big privilege, which allowed me time, I suppose, to catch my breath.

I'm now trying to work one day a week in chunks. It's exhausting. I have a pulmonary embolism, adrenal insufficiency and all the orthostatic challenges and the brain fog. Taken together, it's not something small. The public messaging ought to warn people that if you take risks and you get this, you've got a 5 percent chance of ending up with something pretty crippling. There's no way I could function now, after nearly eight months, doing my job the way I did before COVID.

Individuals ought not to be forced to be the responsible people making decisions. This is a population-level challenge and ought to be dealt with as such.

If we are going to be individuals responsible for making our own healthcare decisions, then we ought to have good information on which to make those decisions. We clearly do not have that good information and part of that is that nobody talks about what it's like to have Long COVID and what that means personally.

I've talked about economic life and my work but in terms of your personal situation you end up with a really tiny life. You can do very little in a day. This interview, and one other social interaction, will be all I can manage this week.

In my downtime, I'm doing nothing that involves visual processing or social interaction, otherwise I can't cope. I might be able to sit and do research-based writing and stuff like that, but I can't interact, so that's a big change. If people are to be able to make individual choices, they ought to know that.

If I go out somewhere, I want to know how many people are infectious out there. If I have to make an informed risk assessment about going out there and not getting it a third time, how do I make that decision now? And why is it not safe to be in public transport or be out in an education institution. People should be wearing masks.

It profoundly impacts your personal life and your working life. If it is my responsibility to make decisions about how I go out and how I move about, I'm not able to make those decisions in an informed way if I don't have access to information.

RP: Everything you are speaking about here is at odds with the official messaging from the authorities, which is that it's all personal responsibility. As [Chief Medical Officer] Paul Kelly said, when they ["the National Cabinet"] announced that they were getting rid of mandated isolation, or his claim that Long COVID is not much of a problem in Australia because everyone was vaccinated.

The things you're describing here brings you into conflict with the official messaging. Presumably that's why the Facebook page was set up and why you're speaking to us today to alert people to what is actually going on.

PY: I'm not sure exactly when the Facebook group was set up, but it's been going for a while and grown hugely in the last couple of months. This refutes the statement that Omicron doesn't lead to high numbers of people with Long COVID.

When I joined in May, there were barely a thousand members, but we are nearly at 3,000 and most of those people got Long COVID from the

Omicron wave. So the Facebook group was set up to get groups of people together in the absence of anything else so we could share our experiences and knowledge. It works very effectively as a sort of peer support mechanism and a quick way to access knowledge of a sort of practical nature.

I can't give you the exact figures off the top of my head, but there are very few people in the group who were unvaccinated, and if they were unvaccinated, it was because it was pre-vaccine that they got COVID.

Is it okay that 5 percent of the people who get COVID, which is a big number because it is so infectious, have to live diminished lives for an extended indefinite period of time. Is that the price society pays for carrying on? I don't think so.

I hate the way we talk about being sorry for the healthy people who were vaccinated but got infected. But what about the people for whom life was already challenging before and then they get an infection, which just compounds the inequality...

The important thing for the people in the Facebook group to get information out there to express the nature of what it feels like to live with it, and to say that it's not okay for people to be making decisions in an information vacuum.

People's experiences of seeking help have not been universally negative. I'm doing the analysis at the moment and quite often you'll get a really, very distressing comment about some interaction with a medical service or medical provider. This is often coupled with a qualifier that says, "I know this person themselves is stressed. I know this person has lived through the pandemic. I know they've been at the front line, however, I'm the patient presenting, and this is the response I've got."

It is quite difficult because tired, sick people are seeking help from tired, sick people in a system in which there is very limited knowledge. Of course, very few people are going to feel well listened to, well cared for and well supported, because time and energy is in short supply.

There's a lack of knowledge for individuals in the public to make decisions about going out and the lack of being able to control the variables. I can put my mask on and choose where I'm going, but I can't do anything about what anyone else does. That's an uncontrollable variable for me as an individual.

When you start going into the healthcare system, you are somebody who is a confounding variable, who nobody knows what to do with. The medical system is set up to cope with highly qualified specialists who deal in parts, not wholes. It feels like there are very few people who care for the whole person and all the systems that are connected...

You go to the doctor and they say we have to exclude all these things and so you have all these tests done. I had an enormous amount of blood tests initially but the only thing that came back within some kind of caution about raised cholesterol and everyone focussed on that. But I couldn't breathe, couldn't stand up and couldn't do most things.

My cholesterol was not worrying me, and it wasn't what I was there for, but I saw three different cardiologists and each one of them gave me a perfect sticker. One even stood up and congratulated me and said, "I don't often send people from my rooms with a clean bill of health expecting never to see them again."

I did three rounds of cardiologists and got nowhere, which is time, money and resources. Those cardiologists could have been helping people with real needs let alone spending all this money. They seem incapable of acting outside of their wheelhouse.

I have Inappropriate Sinus Tachycardia [IST] and that shows up in event-based incidences. I've done 24-hour ambulatory blood pressure monitoring, two cardiac echoes, one cardiac stress echo, a cTCA [Coronary CT angiography] and one-month event monitor.

During those things you're supposed to record events, so you diligently

record your events saying what you were doing. Hanging up a load of washing or brushing your teeth ought not to raise your heart rate to 148 and blow-drying your hair ought not to raise your heart rate to 181.

You diligently record that information into an app and they come back and say it's all normal because the event didn't last for longer than X number of seconds. I don't know what normal is but to be told that blow-drying your hair with a heart rate of 181 beats of minute is normal and be expected to be able to function just on activities of daily living, we're not even talking about leaving the house.

Before I was put on beta blockers, I couldn't load a washing machine. The act of bending and sticking the washing in the washing machine would have me passing out.

I got these wonderful clean bills of health from all these cardiologists, but I couldn't function. I had this hideously reduced capacity for function and kept being told, "You're all good to go. I probably won't need to see you again. Cheers."

They wouldn't even prescribe beta blockers or consider it. A lot of patients with Long COVID have something called orthostatic intolerance but nobody knows how to diagnose it or nobody's willing to diagnose it.

Once you figure out that you definitely have it, they then say, "Well, why do you want to diagnosis it?" I explain that I want a diagnosis because I need to be able to manage my symptoms. Could we please rule it in or out and then I'll deal with it. I still don't have a diagnosis of Postural tachycardia syndrome [PoTS] although I have enough data to kill an elephant.

It was the respiratory physician who put me on beta blockers because he took my hand and put a pulse oximeter on it when I was sitting in his room. He said it's not normal for your heart to be doing 138 just sitting here talking to me.

I'm now on the tiniest dose of a beta blocker and it's quite confronting [important] to be able to tell you that it was a game changer. It turned my tiny miserable life into a tiny bearable life. Three cardiologists wouldn't prescribe or even think about prescribing a quarter of a beta blocker twice a day.

This has now created other problems. I've now got very low blood pressure, which is something I'll need to deal with. But there are simple things that can make an extraordinary difference to my level of functionality. It took seven months before I was prescribed a quarter of a beta blocker twice a day and I don't want someone else to live the seven months like I did. That's just wrong.

People living with Long COVID are doing a lot of reading. I don't want to be the expert in Long COVID and reading journal articles on it but in the absence of help from humans you go looking for help. We all know in the groups what we're dealing but we just don't how to fix it. I'm having great difficulty with cortisol levels. I can't function without cortisone prednisone. I was in a very bad stage when somebody picked that up and again it was a respiratory physician.

I still haven't had my initial consultation at the Long COVID clinic. I am scheduled to be there on December 5, and I'm looking forward to going. But any help I've had has come out of sheer persistence on my part and going private to get access to specialists.

RP: Presumably that's the experience of many members of the Facebook group.

PY: In about August people started getting texts saying that first appointments at the clinic would be in February or March 2023. It's like a big celebration when someone gets a text about their first appointment... I know of someone who recently went to an October appointment at one of the clinics but was turned away because they had misread the email. It was for October 2023, not October 2022. They pitched up a year early.

I know that the St Vincent's clinic is only operating two days a week and consists of a couple of people. They need resources and funding. They've got a model that works but why isn't funding being given to the people who are doing good work?

St Vincent's clinic is doing really well for a few very sick people but there's lots of people waiting a very long time to get help. Some people have applied to go there but been told they have to see someone in their location but there's nothing in that area. They must just go and see their closest hospital or something.

RP: What happens to people in states that don't have clinics?

PY: They have fly to Sydney and see the specialists here privately if they've got the money. If not, they do their best to cobble together their own treatment pathways.

When you get Long COVID, it takes you a while to realise that nobody's got any answers. In the beginning everybody's frantic because you think that someone's keeping the answer from you. You hit your head against the wall again and again and then you realise that no one's got really good answers for you and that there aren't good answers.

You then make a switch to trying to treat your symptoms and if you're lucky find somebody who can help you understand your system, your symptoms. If not, you stay at home, read journal articles, and talk to people on the Facebook group. There's a lot of lifestyle adjustments or simple things. For a lot of people antihistamines work to reduce certain symptoms but it's all hit and miss.

There's a group called "Emerge Australia" that provides support for people with Myalgic encephalomyelitis/chronic fatigue syndrome [ME/CFS]. They have been very generous in helping people with Long COVID and learning how to pace, and how to manage your daily living activities. Groups like that have been run off their feet.

RP: ABC News has just interviewed the head of Emerge Australia and she said that there was no money in the federal budget allowing them to maintain the support work that they're providing for Long COVID.

PY: That's a crime because they have been one group that has actually supported Long COVID patients throughout Australia. They are very generous. The way they synthesise and disseminate information for people with limited energy is extraordinary. The access that they've given all of us to a 20-minute consultation with a nurse has been unquestioning.

If there's going to be an agile response to something that's unknown, surely one of the clever ways to go about it is to see who's doing support well and helping them to support more people. Why do we have to go and have a new whole invention of something? Why can't we find the people who are doing good work and finance them to do more good work?

People are sitting out there. Well, no they're not, they're lying in bed or on the couch and not doing anything. When I am stressed, I cannot even stand to brush my teeth. I cannot wait for the kettle to boil. I cannot load a washing machine. I can't cook a meal. We haven't got time for people to go and dream up a solution.

Emerge Australia and the St Vincent's Clinic are doing good work and they are helping people. Why can't we help them help more people? Why do we have to have a new special something or other? I mean, if we need something new, that's great down the track, but right now it's too long. Seven months of living like this is too long, and there are people who've been living like this for two and a half years.

RP: As you said at the beginning, for a casual worker, for a low paid worker...

PY: They've lost their job, they've lost their income, and if they're paying a mortgage, they've lost their house. It's crippling and it is impossible.

The one thing that I find quite distressing is that amongst the Facebook group there's lots of classroom teachers and nursing staff. The difficulty those people are having getting ongoing support for long periods of time is really confronting.

These are the people that are out there and because of their jobs they're at risk. There's a spectrum. Some people who have been well supported. It's not all bad but for the vast majority of people, especially the casuals, who get stuck in this space, there is no backup.

You're so exhausted but can't even stand up to brush your teeth but you must go and fight for benefits so that you can keep your house or feed your children. Because more women in the age bracket of say 35 to 40 or 55 get it and are not only economically active but are raising small children. There's also a lot of single women who have not got permanent employment who are dealing with this.

The long-term health outcomes for those people, who keep pushing themselves, is horrible and crippling. They end up in wheelchairs, and nobody knows that, and they are so confronted and ashamed that this unknown thing has put them in a wheelchair. They're not really crippled, they can get up sometimes but not be up all the time and that's not ok.

The biggest thing for me is that it has been a squandered opportunity. We had an enviable degree of safety, which we have well and truly squandered for no good return. It is inexcusable that you can think so little of the risk to human life; that you can have a relative advantage and for no good return and you squander it. It is not just for 5 percent of us who are sick now, the risks to everybody are compounding and are huge.

You don't have to have Long COVID to end up with adverse health outcomes in the first year. We don't know how long, whether it will be in 5 years or in 10 years, in 12 years.

There is research that even if you don't get Long COVID, you've got a much higher risk of heart attack, stroke and diabetes. The fact that I have a pulmonary embolism and it's related to Long COVID is one thing, but I've got Long COVID so people can dismiss that.

The first thing people do when you get Long COVID is they try to understand what's different about you. Why were you the weak link that ended up with Long COVID? They want to understand how it is that they're not going to get it, and that they can go out there with no mitigation strategies time after time and get it but it's just the flu and they're gonna be all right.

They want to believe that, but public health messaging ought to be disabusing them of the fact that it is not the flu. The flu does not impact every body system or leave you vulnerable to all sorts of really unpleasant things. It's not nothing and public health messaging ought to take that into account.

Now that they've just scrapped everything, they think it helps everybody if we just don't talk about it. The Long COVID people, who are just 5 percent, should just stand to the side and stay at home on the couch.

You feel—because it's relapsing and remitting, that nobody understands Long COVID and there aren't any fixes and we're also tired—a sense of shame in how functionally incapacitated you are. Because you don't go out or insist on having a wheelchair to get you from A to B, and you really want to be back to normal but you're not, it helps people to paper over the cracks.

Short of us all going out and taking our couches and going and sitting somewhere. I'm not sure how we make people understand it—and I'm being facetious—but there's an enormous amount of hidden pain that's not being recognised...

And now I've lost my train of thought. If you spend any length of time with me you soon realise that I lose my train of thought. But I'm tired of apologising. I'm an academic and get paid to think for a living. I can't hold a line of thought for an hour and that's not living.

I think emergency departments must be really tired of seeing Long COVID patients because we are not gonna die today but we're pretty miserable and we're terrified that pain that we feel will kill us today. Emergency departments must be just swamped with, with people like me.

RP: If you could provide a short list of what should be done, what would be the essential items that you think need to be done?

PY: Mandatory isolation so people who are sick should not be in circulation. When you go out in public spaces, you ought to be masked.

If notification of an infection is no longer required, then that thing they do with the sewerage where they can tell by a postcode what the incidence is.

I want to have a dashboard that tells me by postcode. I don't just want to know whether it's going up or going down. I want to know in relation to when Omicron was at its peak that this postcode is now off the charts.

If I have to make a personal choice, then I want to be able to see the sewage thing and they can do that. They're doing it already because they are reporting weekly, but they just say up or down. If they were a bit more transparent with that data, those of us who want to be responsible can be responsible. We just can't get our hands on that data yet. So yes, people who are sick should stay at home.

All people in public spaces, if you can't be distanced, ought to be masked. It's not fun being masked. It's horrible teaching in a mask, but I'd rather not be getting it or passing it on. Notification of who's got it and when and tracking the money and where that's being spent and contact tracing. And that's not too hard. That's my practical list.

My not-practical list is clean air for everybody tomorrow. We can do that. We just have to have the money and the will to do that. Also support for people who are stuck at home—people who've lost their jobs and who need to rest.

Some of us need to rest for 12 months. Hopefully, when the research gets better, it won't be 12 months or two years, but if someone has three small children and a mortgage and they're the sole income owner, they shouldn't be on the street. They should be taken care of.

And proper funding for people doing good work. The people that are making a difference in the communities ought to be resourced.

We had the advantage on the 30th of September [when the National Cabinet met]; we had a chance to do things differently. We had an advantage and we have squandered it.

RP: And what are the social consequences for public health?

PY: We're not going to even begin to understand them for another couple of years and then we will be drowning.

RP: We're in an information war and we really have to step up the fight here. What this has demonstrated to us is that there's got to be a movement from below. It's not going to come from the powers that be, they are too bought and paid for, to put it in colloquial terms, and either party, who are just proceeding on the basis of the demands of big business.

So, it has to come as part of an independent movement of ordinary people, that's going to force change here. That's the basis on which we're taking forward this work.

PY: Thank you. The other thing is that one of the reasons this has been allowed to happen is because those of us with Long COVID are depleted. It's great when people who are not depleted in energy and resources are actually taking it up.

Whilst it might be invisible, it's very debilitating and doesn't leave you with extra energy to do this. Getting yourself organised in the morning is about as coordinated as I can get. So thank you and yeah it's really important. I'm sure there's lots of things I didn't say.

RP: Well Pippa thank you for your time because it's very difficult for you and we really do appreciate it.



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