

Cllr Millard: Hello and welcome to episode 10 of talk Richmond, I'm your host, Jim Millard, and this is the final episode in our first podcast series. In this week's episode, I'll be talking to Caroline Hopper and Tracey Pretty about Long Covid. According to the World Health Organization, people typically recover from COVID-19 after two to six weeks. However, we are increasingly hearing about people who are experiencing a prolonged illness and who are not recovering to what their health was like before they contracted coronavirus. Tracey is a Whitton resident who owns a business in Twickenham. She joins us today to talk about her experience of long COVID and Caroline is Head of Physiotherapy at Kingston Hospital, whose clinical team have been treating COVID patients since March and she is here to offer advice. We should highlight that a lot remains unknown about the long-term effects of COVID-19 - there's no medical definition or one set of symptoms for long COVID. So, whilst Caroline will offer advice on how to deal with some of the symptoms involved, she won't be able to explain why symptoms persist or recur. So, having said that, without any further ado, a very warm welcome today, thank you very much for coming. Caroline, if you could kick things off please by telling us a little bit about your background, the work you've been doing looking after COVID patients at Kingston Hospital.

Caroline: Yes, well so well, thank you very much for having me. Lovely to have the opportunity to talk about a subject that is so close to my heart, I have to say. So I am the Head of Physiotherapy at Kingston Hospital and in that role I'm here to lead and support a large clinical team of physio staff to treat any patient that comes into the hospital, but specifically around Covid to ensure that we are here to give the best clinical care we possibly can. And just worth pointing out that although I'm a physiotherapist by background, physios can't do their job unless they work very, very closely with the whole range, it's a whole team effort, we work closely with the doctors, the nurses and all the other different allied health professions to ensure that each of those professions bring together a different set of clinical skills to provide the best care for the patient. We've really been working since March at a big team effort to ensure we are giving patients the best acute care we can and then ensuring that we follow patients up once they have been discharged as appropriate. so yeah, that's a part of what physios do, but obviously we're here to do more than that. We're also here to help keep people's breathing and help people clear their own secretions when they're ventilated, so that means when they're on a breathing machine.

Cllr Millard: I'm so sorry to interrupt, I was bursting to say that we spoke to Mark Sheen in our last podcast about his experience of being treated for COVID-19 in Kingston Hospital and he had the CPAP Hood on which is like a big plastic bag and he was he was in the prone position as well for a long time for a lot of the time exactly as you said. So that was literally just A to let people know who had listened and B a little plug for our last episode as well. Anyway, carry on.

Caroline: I was just going to say we get really stuck in when it comes to the rehabilitation of patients so that getting people being able to care for themselves again, getting our patients to wash themselves, dress themselves, stand up, walk, get back to the things that they used to be able to do before they came into hospital. And it's worthwhile pointing out that of course Kingston Hospital works across the boundaries. We work very closely with the boroughs Kingston and Richmond and the different health organisations in Kingston and Richmond to be able to provide that care.

Cllr Millard: So important. Thank you for explaining that to us. When did it first become apparent some people were suffering from long-term symptoms?

Caroline: I would say I'd say probably summer. The middle of the summer. As a group of clinicians, it became apparent that COVID really never has just been a respiratory disease - it's much wider than that. It's a multisystem disease that can affect all different parts of the body. And of course within that we need to remember that patients some patients are admitted to hospital with COVID, but many patients out in the community like yourself Tracey have experienced COVID but haven't necessarily been admitted to hospital, so it's not just an acute view, it's that really wide ranging view of patients out there suffering at the moment too.

Caroline: It's only really more recently that a formal definitions been agreed, so there's an organisation called NICE and they've only recently actually formally defined long COVID, it describes the signs and symptoms that develop during or following an infection consistent with COVID, but that but that actually continued for more than 12 weeks and with systems that are not explained by another diagnosis. It's quite a complicated syndrome, really for doctors to work out exactly what is a symptom of long COVID and what could be an exacerbation of another longer-term illness.

Cllr Millard: That is very interesting. Thank you so much for explaining that and I just wanted to bring in Tracey as well. You mentioned Tracey's experience, so it would be great to hear from you Tracey. Tell us about yourself.

Tracey: Love to. So, I'm Tracey. I'm 36 and I own a gift shop in Central Twickenham, so some people listening to this will probably know who I am and where I work, recognise the voice and I became ill with Covid back in March beginning of March so pre the first lock down. I'm previously healthy. I don't smoke, I don't drink excessively. I don't do drugs and I'm a very active person as well. So, you know, I walked from Whitton, Twickenham, and back every day. I have two dogs, I eat healthily. But the story goes that anyone can get this, and we still don't know why and how. And unfortunately, my journey is not been a very pleasant one with this horrible virus. It's been quite traumatic. I was poorly in bed for six weeks. I couldn't get out of bed and had an ensue of really nasty symptoms. So, what unfolded on my journey was, I think I've hit every symptom in the book with it. From an upset tummy and nausea temperatures and I had the breathing difficulties and still continue to have them. But the only thing I didn't have was the cough. So strangely enough and I think it was because I had so much pain across my ribs, I couldn't actually get an intake of breath to cough and I think I would have probably had it if I was well enough to have the energy to cough, which sounds horrific, but that's how nasty the virus is. Like with any illness you start to get sick, you hit your peak and then you start to get better. But with this I've gone on this rocky road of I don't know whether I'm relapsing, I don't know whether it's because I overexert myself. I don't whether it's just a very odd course that this virus takes, but I will have a good day and then the next day wake up and think I'm getting sick again, I can't get out of bed when crippled by tiredness. And odd symptoms still keep happening to me throughout the journey as well. It's a very strange course of events that's happened with long COVID.

Cllr Millard: Caroline. You're nodding vigorously that this doesn't sound familiar to you?

Caroline: I'm just desperate to ask you some questions, Tracey, if I may. On a good day, what do you do on a good day?

Tracey: So, I will get out of bed, get dressed and showered. I've actually did in the summer start to go back to work as well, so we're really good day for me is actually doing a day at work. But I'm fortunate that I own my own business, so I've cut my hours down. A day at work used to be 10

hours, I can only do five hours now and a good day would also be getting to the park and walking my dogs around doing one circuit. Whereas previously you know I'd walk from Whitton to Twickenham and be fine, so my good days now are nowhere near back to how I was at my best. But for me, compared to the bad days, I'm happy to be up and running.

Cllr Millard: Caroline does this sound familiar to you with experiences that you're hearing about?

Caroline: Yeah, very, very much so, yes. And I just want to say, the first thing is, I'm so sorry that you suffered in that way Tracey. It's just awful when we hear you know, people talk to us and run us through what they've been through, it's just awful. So I guess, just wanted to reassure you initially, and that at the moment, although, there's not a lot of clinical research gone into Long COVID at the moment because we're still at such an early stage of the disease, but at the moment some estimates suggest that there's about one in 50 people are probably suffering or will probably suffer from symptoms of long COVID, and there's about 10% of people would go on and suffer symptoms for something like 4 to 12 weeks, but it's about one in 50 that may go on to suffer signs and symptoms of Long COVID. It's really, in some ways not unlike something called chronic fatigue syndrome, in that the symptoms are similar. They're not exactly the same, but they are very similar as I know, there's been quite a lot in the press about this. I'm interested to know what happens on a bad day? You described having a bad day, what do you do then?

Tracey: So, I still have difficulties with my breathing. Regularly I wake up in the morning feeling like I've been punched in the ribs and on a bad day I will not be able to breathe properly, I'll be really sore, physically hurts, I feel like my body is cramped, headaches are still a problem, and loss of appetite is still a thing. I haven't fully got my taste back. I don't know if that's the common thing. I can taste, but things don't taste like they did before. I can't smell if the milks gone off. You know things taste different to me. Um, so on a bad day I'm in bed not feeling very physically poorly sore and not being able to move very well, but also mentally stressed because you've been through that trauma of having this virus and then it feels like you're getting the symptoms again, especially with the breathing you've had that trauma of not being able to breathe and getting out of breath. . And you know it's going to be alright but in reality, none of the doctors can 100% assure me that I will get back to normal and I am getting better. And worryingly you know there's all sorts going on with me. I'm having to have an MRI scan just to double check that there's nothing going on with my insides and I'm seeing a physio who is helping me to learn to breathe again. There's only so many times you can tell yourself you're getting better and you feel like today's a good day. And then you do something and then tomorrow will be an awful day or a bad day where you're feeling poorly again and this happens repeatedly for, well, eight months ago I fell ill now, so you start to lose positivity and start to lose hope. But hearing those figures and knowing that I'm not the only one, and now knowing that it's a recognised thing makes you feel less alone.

Caroline: You're absolutely not alone, because the symptoms that you described there are very much what we hear in the land of physiotherapy and what you know overall my medical colleagues would agree with me. But one of the most important pieces of advice that Physio can talk to you about is talking about graded exercise programs and pacing yourself because one of the big things one of the big challenges that a lot of our patients face is doing too much on a good day and then almost collapsing on a bad day. So, people wake up and feel super on a good day, a lot less pain and therefore they try to cram in all their activities, their shopping, their work and their trips to park on a good day. And what that can do is that can exacerbate the bad day because then you use the bad day to recover so you almost have peaks and troughs. Whereas for life to continue in a less in a less

painful way in a less up and down way if we can help you smooth out those peaks and troughs so you can keep going, perhaps at a slower pace for certain period of time, that can sometimes help with not only how you feel but your sense of achievement as to what you've done that day, but it is it is it is incredibly hard. Things like cognitive behavioural therapy can really, really help. I mean across Richmond and Kingston, you've got some fantastic services that can be accessed around the improving access to psychological therapy site and you can actually self-refer into that too. There's also there are also good websites available – the ME Association, so ME is another term that's used to describe chronic fatigue syndrome, and they have some really good local support groups. So that's another thing you can access but also want to just mention that across the NHS in London, work has begun to have conversations about setting up very specialist clinics for the assessment and treatment of Long COVID patients. It's in its infancy. I'm aware of that. But work is just beginning to help define the types of patients and the types of clinical criteria that you need to meet in order to be assessed in those clinics. But you know it comes right back to this is not just a respiratory disease, this affects many different systems of your body like you've described.

Tracey: Yeah, it's affected my eyes, my taste, digestion. My hair even started to fall out last month. , which is quite scary so it's comforting to know that clinics are being set up and it's becoming more of a recognised thing, both physically and mentally. I am having counselling. It was one of the first things they referred me to as well and unfortunately got diagnosed with – and I want people to know this because it's not just a virus like the flu, it has a massive mental impact on the trauma you go through – and they think I could be on the edge of getting PTSD from it because of what the journey entailed.

Caroline: the other thing about this horrible virus is that we already know the effect it has across all age ranges and predominantly it may affect vulnerable people. Vulnerable people in certain clinical categories and older people, but of course it can affect almost anybody from any walk of life, so nobody is safe from this virus and that's the really, really hard and piece of evidence to accept and that's why it's so important when you're out there, you know to wear a face mask to socially distance, to wash your hands, because as soon as that stops happening, this virus can very easily re-emerge and we just do not want that to happen at all.

Cllr Millard Can I ask, in relation to that Caroline, is there any sense that you know, do you have to have had a severe case of COVID initially to then suffer from long COVID or can it affect anyone?

Caroline: That's such an important question. No, this can really affect anybody. So, my brother-in-law at the moment is suffering a little similarly to you, Tracey. Examples is he says he's thinking professional choir, he can't sing, he can work, but he can't sing and he hasn't got that voice control or that capacity within his lung volume to be able to protect his voice with the tone he's used to and be able to sing so it really can affect everybody. I know that that's a small example of how it affects his hobbies, but of course life isn't just about getting to work, is it? It's about recognising that that health is about your physical health and your mental health. It's never just never just your physical health, and in order to get people back to 100% feeling fit, they need their mental health to be right up there with their physical health.

Cllr Millard: Thank you both so much. It's really been absolutely wonderful listening to you both talking to each other and almost having a live consultation, which I think I hope it's it feels like it's been a bit helpful to Tracey and she said it has been, and I hope that anyone listening who's going through the same thing finds it helpful as well. I wanted to say thank you so much to Tracey for

being so honest and describing what you've been through so well and sort of reliving it for us. Thank you so much to Caroline for your amazing knowledge and really caring and helpful suggestions and information. I mean, just to round up, quickly in a nutshell, what should listeners do if they think they're suffering from Long COVID?

Caroline: Yeah, just really important message that as a health professional I want to get across and that is if anybody out there is suffering from symptoms and their worrying about these symptoms. And they think that in normal time, so in pre COVID times, they would genuinely seek advice about these symptoms then do please go and seek that advice. Do not stay suffering at home. Go and seek advice from your GP or another professional. The NHS is open, we're here to help.

Cllr Millard: Thank you and Tracey do you have anything to say?

Tracey: Be kind to yourself. It goes without saying that if you're feeling, if you've been poorly, severely poorly, physical care is so important, be mentally kind to yourself as well and take each day as it comes.

Cllr Millard: Very wise words. As I say, there's been a lot of interest in this, and thanks to all those who got in touch. I hope this episode has been useful and answered some of your questions and concerns and thanks very much again to Caroline and Tracey for joining us. So, we will be going on a break after this episode and we would love to know what our listeners, what you, would like to listen to in the next series of Talk Richmond. If you do have an idea or a topic, please do email us at talk@richmond.gov.uk and make sure to subscribe so you don't miss the first episode of the new series. Thank you so much to everyone who's tuned in and listened to me over the last few months and all are wonderful guests throughout the series for being parts of Talk Richmond. I'm your host, Jim Millard. Thanks for listening.