

Cllr Jim Millard: Hello and welcome back to Talk Richmond with me, your host, Jim Millard. Today's episode is one that's very important. We're going to be talking about long lasting COVID symptoms, otherwise known as long COVID. And we're joined by Genevieve Bagge and Nicholas Newman from the NHS to talk about that. I'm personally dealing with long COVID, so I have a personal a deep personal interest in this subject and it's fantastic to be able to talk to you about it. And I think the the data from the Office for National Statistics tells us that currently 1.3 million other people in the UK are also dealing with Long COVID, and I'm told by clinicians that I've been talking to in Richmond that there may be as many as 3,000 people in Richmond Borough who are dealing with it and they're not all known to the NHS at this point. So, without further ado, I'm just going to say, welcome to Genevieve and Nicholas. To help us better understand Long Covid, we're going to discuss various long COVID symptoms, as well as what's being done to help people manage these symptoms. So, let's make a start with introductions. And could you tell us a bit more about what it is you do exactly, starting with you, Genevieve?

Genevieve Bagge: Oh, hello. Welcome everyone. I'm Genevieve Bagge. And I'm the Long-Term Health Conditions Lead for Richmond Wellbeing Service and also now Long COVID lead. I'm a Senior Therapist and Supervisor and particularly want to talk today about the devastating condition of long COVID.

Cllr Millard: Thank you. Thank you and Nicholas, welcome.

Nicholas Newham: Yeah. So, I'm an Occupational Therapist by background. And my current role is not related to this but back in March 2020, when things started kicking off, I was redeployed to work with COVID, long COVID wasn't spoken about at that time, and I was working with people who had been admitted to hospital and to intensive care or high dependency unit and supporting people to be discharged home and providing rehab in the home. And I've continued to work with people with long COVID whilst doing another role as well.

Cllr Millard: Thank you very much. So just to set some context before we get too much into it. When was long COVID first flagged Nic and is there any official definition for the illness?

Nic: So, for me it was first flagged when I when we started getting these different referrals through. I initially thought it was post viral fatigue, if I'm honest, this seemed to fit right. But then when I started to research and I came across an organisation such as long COVID SOS and they were doing a big campaign at the time which is called message in a bottle where they were really trying to make it known that there are lots of people experiencing these long COVID symptoms, but it's really around that time December and they were successful at campaigning at a parliamentary debate. And made it much more public, which was fantastic. So, it's really December.

In terms of definitions. So, we use the Nice guidelines, which is National Institute for Health and Care Excellence. They have broken the COVID definition down into three stages I suppose. So, you've got acute COVID-19, which is where there are signs and symptoms of COVID-19 up to 4 weeks. Ongoing symptomatic COVID-19, where there's signs and symptoms of COVID-19 from 4 weeks to 12 weeks.

And they've got post COVID-19 syndrome, where there's signs and symptoms that develop during or after an infection consistent with COVID-19, and they continue for more than 12 weeks and are not explained by an alternative diagnosis. But what they go on to say is that it usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. So that's quite a. Yes. A quite a quite a big definition, but so they essentially up to four weeks, 4 to 12 weeks, 12 weeks plus. Long COVID is more commonly described as signs and symptoms continue develop after the acute COVID-19. And from NICE's perspective, it includes both the ongoing and the post Covid. So, it's really from 4 weeks onwards and for me, I think that's probably a better way to look at it because if people think actually, they need to wait 12 weeks before they seek any support, that's already three months.

Cllr Millard: Well said. That's exactly what I did. I sort of thought, well, it's past four weeks, but it, you know, lots of people have ongoing symptoms, so you wait, you wait and wait and then you know, actually got worse over those over those three months. You can't just push through, and you have to take a different approach and we'll probably come back to this. Genevieve did you want to add anything on that point?

Genevieve: Well, just that it's interesting the thing about long COVID, who gets it doesn't link in with how bad you got the COVID in the first instance.

Cllr Millard: Yes.

Genevieve: And in fact, many of the people who developed this condition were not hospitalised at all.

Cllr Millard: No, indeed.

Genevieve: So that's a very interesting piece of data that submerging and also a lot of them are females aged between 30 and 60. So, we are discovering those. If you've had two vaccines and booster, you do reduce your risk of getting long Covid. Although I hear from you Cllr Millard that you did nonetheless get long Covid.

Cllr Millard: Yeah. Yeah. Yes, I absolutely. And I'm sure you know, I'm glad I was vaccinated. I know we heard in 2020 any of our regular listeners will remember the lady who joined us, and talk talked about being short of breath and experiencing significant fatigue, very severe fatigue, often racing heart. And she mentioned hair loss, body cramps, headaches, nausea, lack of appetite. There are a wide range as you say of overlapping things and as you said, it can affect any system in the body. And so, could you talk a bit more about what, what some of the more the most common symptoms are perhaps?

Genevieve: There's loads of symptoms, but the main and the most debilitating ones are still breathlessness, especially fatigue, they should put fatigue first, then breathlessness.

Cllr Millard: They should actually, yes, yes.

Genevieve: and then this thing called brain fog, which is where your mind. You feel befuddled. You can't think clearly. You're not like you used to be, or memory affected all of that, cognitive problems. And those are highly reported. And then on top of that, there are hundreds of others, especially loss of smell and taste, smell first and then taste sometimes. Problems with sleeping a lot of people get that and then heart palpitations, dizziness, whole range of things, from pins and needles to joint pain. The obvious depression and anxiety and mental health problems that come with this. Very important. And then things like tinnitus and earache. Feeling sick and diarrhoea. Stomach aches, loss of appetite. As well as high temperature cough. And headache, sore throat, rashes, you name it. There are lots more that I haven't mentioned, but those are some of the most common.

Cllr Millard: I feel quite emotional hearing you list out. Every time I speak to someone else, there's a fellow feeling that is very helpful actually. It's so it's so tough and I'd like to say anyone else who's going through this. You know, you're not alone. There are lots of us going through this and we can help support each other. Nic, did you want to add anything to that?

Nic: Only that, I mean I there was one large international study that suggested that there were identified over 200 different symptoms across 10 different organ systems, so it's incredibly difficult because there are so many. They fluctuate, they change.

Cllr Millard: It's extraordinary. I mean, it's such an extraordinary virus. I'm sorry. I'm kind of getting over excited and jumping in. You haven't finished your sentence, but it's such an extraordinary virus.

Nic: That's OK.

Cllr Millard: It's like a sort of jazz kind of thing. It's just going all over the place and doing unexpected things. And that's one of the hardest things. And I think, you know, I take my hat off to all the NHS professionals working on this because to have gone in the space of two years from knowing nothing about it, to having to sort of catch up with this, this crazy sort of presentation really is, is, is incredibly impressive and I'm very grateful of course personally, but also for everybody in the borough. And so Nic, while we're on that, I think Genevieve might have mentioned that there's a certain thing of women between 30 and 60 are perhaps one of the biggest groups, although obviously I I'm here to point out there are others - men in their late 40s. And anyway, who may seem

look younger. Nic are there any other patterns, do certain people suffer more from certain symptoms like brain fog or anything like that?

Nic: So, the the Office for National Statistics, they produce a monthly report of prevalence of symptoms. And this is based on a self-report survey. People don't have to have had a formal diagnosis to better complete this survey. So, it's a good insight into what people are experiencing and what from their last report, which was in March, they indicated that, from last week sorry, the prevalence of self-reporting on COVID was greatest in people aged 35 to 49. Females, people living in more deprived areas, those working in teaching and education, social care or health care. Or those with another activity limiting health condition or disability. So that's what's being found. But for me, I think we don't know. Is the honest answer and by that, I mean if you look at the two spectrums, children and young people, this is still being discovered. Older adults again and children presentations can be atypical – it may not be what we see with 35- to 49-year-olds. And they can be masked by other things, so with older adults it could be put down to frailty, deconditioning, other long term health conditions, and actually not recognised as being long COVID. This this self-report. This study, sorry, relates to people in private households, so it doesn't include people living in care homes, so we don't really know the impact on people in care homes. So, this is a snapshot, but I I don't think we've we truly know is the honest answer in terms of who it is affecting, how it's affecting people at this time.

Cllr Millard: It is and one of the things I'm very grateful for is just I'm aware there's a huge amount of research going on and all over the place, you know, just like with developing vaccines. Are there any recent developments that helped us to get a better understanding of long COVID?

Nic: I think one of the difficulties is that we're very limited understanding of the the biological mechanisms behind long COVID, which then makes finding treatments and creating tools for diagnosis really challenging. But as you said, there are lots of studies there. An example is the stimulate ICP study which is being conducted by University College London, UCL and this is going to be a large two-year study focusing on diagnosis, treatment and rehab. And in terms of developments, there's a couple of small stories that were published last year that offers potential mechanisms which are going to link into the to stimulate ICP study. One is a suggested link to the body's immune response and the overproduction of histamine via what called mast cells. So, people may have heard of mast cell activation. So, this is something that's being looked at. The other identified is for some people with long COVID, where was evidence of microscopic blood clots that were resistant to the body's natural ability to dissolve, and this could potentially impact on gas exchange in the lungs and also oxygen being able to get to the tissues when it's needed. As I said, these are both the initial studies, initial papers, very small samples. We're talking sort of 50 people in each. So, we don't know how representative it is to findings of the wider population.

I think another thing which makes it quite difficult with these studies, is that long COVID going back to a definition is, I think long COVID is seeing now as an umbrella term and actually under that umbrella there could be multiple syndromes or conditions which people are experiencing. So, it's very unlikely that long COVID is going to be one thing. So, there could be lots, lots of different clusters of symptoms, lots of different syndromes, which are affecting people which have different biological mechanisms. So, we need to explore anything that comes up like this. We need to explore,

but obviously we don't rush too early and start prescribing lots of medication because we don't know if it's going to have an impact, we don't know, it's going to cause any damage. We don't know. It just needs to be careful and so there are studies, thankfully, that are happening, as you said, which are going to be looking at things such as prescribing antihistamines, prescribing antiplatelet, anti-clotting medication to see if that will help if there are clots, but it's very much an evolving field. So hopefully I'm hoping that sort of within the next 12 months or something like that, that we will be moving closer to understanding more.

Cllr Millard: And that's very exciting and promising, isn't it? And I think with the micro clotting, those sorts of micro clots aren't picked up by the standard readily available tests that would be done for clotting, and I think before you get to an arrival at the sort of long COVID, you'll have been probably through loads of tests, you know, ECG's, blood tests, chest X rays and all those sorts of things. Where you're being told nothing is showing up. Which is part of what's so sort of difficult, and feeds into this little difficulty or in terms of wellbeing.

This brings me, as you know, we shouldn't. You have again very grateful for, The Richmond Long COVID service, can you tell us more about that, Genevieve?

Genevieve: Well, actually that's probably one for Nicholas.

Cllr Millard: It's one for Nic. Please tell us about it.

Genevieve: Do. Yes. And then we'll come and tell you what we do.

Nic: Do you want to go first? Genevieve, why don't you go first? Go for it.

Genevieve: OK. We have the Richmond Wellbeing Service and we have developed - really quite excited by these - groups for long COVID and they are eight-week groups and they're not huge, so it's very easily tailored to the individual within the group. But what we're finding is that at high intensity level, people who've experienced long COVID are coming in, and they're so isolated and they feel so at odds with the rest of the world because nobody else seems to really understand it. And then suddenly, there was a few people who've also got this, and it's incredibly reassuring for them. And we bring in a lot of help with the emotional distress. This sense of helplessness and isolation, and the physical symptoms too. So, it's a whole mix of looking at the symptoms, helping them with the brain folks that I talked about earlier and helping them to do what we call in Richmond Wellbeing, cognitive restructuring, which is really looking at negative thoughts, negative automatic thoughts and finding a way through them to increase, increase clarity and give you a different perspective, which is hard to do on your own. We've also got lots of exercises and they're very manageable. We're not expecting miracles for people. You know, it's very placed and very tailored to keep this ability, and we do some breathing control techniques which are very helpful for people who, you know, really struggle with their breathing or, you know, feel like they're panicking or going hyperventilating

And then a bit more specialised, but also included within the group, we do something called acceptance commitment therapy, which helps people who find it hard to come to terms with the fact that they used to be pretty fit and active and everything else, suddenly they're different, they've changed and it's coming to terms with that change, that change in self-identity, which can be quite difficult for them. And also, we do, well, I love doing the mindfulness, so I actually help out with the mindfulness because I find it just really give people relief from the physical symptoms. And the combination of all those things in eight weeks can really, really help people on their journey, not necessarily get them completely better. But some people have, and others are on the way. And then at the end of that, if anyone is really struggling because it depends on where they come into the group, if they've got more severity of symptoms than others, it may take longer. So, we then would offer individual treatment at the end for anyone who's still struggling.

Cllr Millard: That sounds absolutely fantastic, Genevieve. I'm sure that's extremely helpful. I really like the sound of that. I mean, do you self-refer to Richmond Wellbeing Service?

Genevieve: Yeah, you can self-refer. You literally pick up the phone and say I'd like to self-refer it's as easy as that or you can go to our website, or you can get your GP to do it for you if you prefer.

Cllr Millard: And Nic, you know what I am aware of is the Richmond Long COVID service which I've been referred to. So, I'd love you to tell the listeners more about that.

Nic: If it's alright, I just want to highlight one thing just listening to Genevieve speaking I think we missed earlier, and the fact is we spoke before about the medical symptoms. But I think it's incredibly important to highlight the wider impact this is having on people's lives. And by that, I mean. I mean it just from the the the office of National Statistics, stats I mentioned earlier, they've highlighted about 45% of people who have had or suspected to have had long COVID are describing that they've had symptoms lasting for 12 months or over, so this this for some people, this is not just a 12 weeks / three months thing, this is this is now starting to feel like a long-term condition. And the impact this is having on people in terms of work, finances, housing, relationships, social activities, caring responsibilities for their children and loved ones. The impact has on their roles, their identity, their ability to engage in, in meaningful and purposeful activity and the effects this has on their overall health and wellbeing is just it's just huge. So it's really important you take into account that it's not just about those presenting symptoms. But it it's much more than that and that's what's having an impact on people's lives.

But in terms of the Richmond COVID service? So, this formally started – we had a long delay, unfortunately, because of funding and getting funding - and this eventually became in existence around October, November last year. Our lead is Rasheen Hide and she's done a fantastic job actually with. And from our perspective, because we haven't got a cure yet as we've spoken about, we focus on supporting people with self-management of their symptoms because we know that we can help people to improve the management, their symptoms, which will then enable them to get back to doing the things that are most important to them in their life. And so, what we offer is that we provide an initial face to face holistic assessment, we provide group based, we provide individual one to one support that can be virtual, it can be in people's homes depending on what what's

needed and what will help them most at that time. But what I would have liked to say, and what for people who are listening, is think there's, as I said before, I think there's lots of people that we're not reaching at the moment.

Cllr Millard: Yes.

Nic: And I think there's a lot of people who probably have barely been managing, probably up to this point. And I imagine now they're pretty really start to struggle. And I think some people may not realise they have long COVID. Others may not know the services are available, others may not think they're eligible to receive support. But they are and you don't need to have been admitted to hospital. You don't need to have a formal diagnosis. You don't even need to be experiencing respiratory symptoms. I mean, some people think, COVID was all focused around a respiratory condition, but long COVID not necessarily. And so, what I would just say if you think, if this resonates with you and what we're talking about today, if you think you might have long COVID symptoms. And if it's impacting on your ability to do your usual activities, on your relationships, on caring responsibilities, on your mental, physical, social, health and wellbeing, then support is definitely available and accessible within the borough.

Cllr Millard: Absolutely. And you know, having experienced it, I've, I've, you know, had that initial consultation with Rasheen, she was amazing. It's an hour and a half. You sit down in, it's a very holistic approach to listen to everything you're going through and understand what you're experiencing and to use the techniques and approaches that so far, we've been able to get together based partly in what helps people with post viral fatigue and with, with ME, chronic fatigue and all those things. You know, understanding post exertional malaise, they call it you know how to pace yourself to you, to do the opposite of trying to push through it, which doesn't work. But to actually give yourself a chance for your battery to charge back up, as it were.

I've learned a lot from Richmond Long COVID service about how to how to sort of approach life a bit better actually. You know, a lot of us modern life as running around like, you know, headless chickens. Yeah, living on caffeine and adrenaline and cortisol and all those sorts of things that you can push yourself through. But actually, you know, sometimes perhaps that might make you more predisposed to getting a bit ill with things like this when something like a virus hits you, suddenly you're actually thinking. Well, I can't push through with, you know, honestly, everyone should do it. Do it now. Don't. Don't stop. Stop pushing yourself to the limit

Nic: Most people don't really think about how we recover from the daily stresses of everyday life. How we recover our mind, they recover our body, how we recover our energy levels. And so. What I started doing is working with people around energy conservation, so how can they use their energy, maximise the use of energy, but also looked at how people can recover.

I developed a model that called the restorative flower, and it includes a number of each petal is something different basically. And each petal focuses on restorative movement so what's the right movement for the individual at that time? So, it might be a 2-minute walk every day is what that person can do that doesn't trigger any exacerbation of their symptoms. It might be a one-minute

walk, but it's just making sure the body is still moving but moving to the right level. Another petal is restorative rest so before a lot of people have thought of rest as well, don't even think about really resting. So, end of the day they'd sit down and watch TV and that's their rest period. But actually, as you said there's other forms of rests that may be more beneficial to people at this time, such as mindfulness, such as the breathing exercises that Genevieve spoke about, gentle yoga, whatever it is that helps that person to activate the parasympathetic nervous system, clear the mind, and get in that calm, rest and digest state. Another one is restorative activity. So, finding activities that provide medium purpose in people's lives. And it might be a things like gardening, arts and crafts, baking, whatever it is that helps them to switch off, recharge and engage in something which has a purpose. Restorative thinking which links in with it the mental health side of things, becoming more aware of people's thoughts and feelings and what's actually helpful to them at the moment and and how they can change things which aren't helpful. Restorative nutrition. So, this is not about providing specific diets but focusing on strategies to help people so they can eat healthily even when they do have fatigue. And one of the biggest ones for me was this restorative sleep. And I think that's key. And by restorative sleep, what I mean, it's maximising your quality of sleep. It's not the length of sleep you could get, but the quality of sleep and and learning the difference between light, sleep, REM and deep sleep. Because these have different functions in terms of how the body and the mind recover. So, someone could be sleeping 13 hours a day, but they could be getting very light sleep and not actually helping the body or mind recover.

Cllr Millard: Sure. And I think it's really important for me, my experience I went to Richmond Long COVID service a few weeks ago now, and I'm already starting to see an improvement and I think that's important because we've said quite clearly that, you know, we don't have an evidential basis for understanding the mechanisms that are going on. And this is not officially a cure, but I would sort of counter that with you have had success in helping people.

Genevieve: Yeah, definitely. I mean, we've had really terrific recovery figures and I just want to read your quote by somebody who was really amazed by how she recovered, and she said the coping with long COVID course has been fantastic. It's helped me to turn around along COVID problems I was encountering and get me on a path towards better recovery. Several aspects of the course are life skills which will help me in the future, well beyond long COVID, and I feel exceptionally lucky to have been referred to this course. And then she felt so pleased with it all that she made a donation. We can't accept donations, but she made the donation to Richmond Borough Mind. So, thank you. So, I mean, she's just one of many, but she really, really got better. So, it's nice. That's what makes it so worthwhile, yeah.

Cllr Millard: It's wonderful to hear. It's amazing what you've done and I think you know we've touched on this, but I think I want to leave people with just this question. If anyone is listening to this and thinking they might recognise that they've got long COVID symptoms from what we've been saying, you know what, what should they do?

Genevieve: OK. Well, from our point of view, simply pick up the phone and dial Richmond Wellbeing Service. The telephone number is 0208 548 5550 and literally ask to want to self-refer. That's all you

have to do. And then the rest will be sorted for you, and you'll have an assessment and be welcomed.

Cllr Millard: And Nic, what about Richmond Long Covid Service?

Nic: So, for us the fastest route is through your GP, and the reason for that is because in terms of long COVID, it is about eliminating and making sure that there isn't something else going on which could be in fact impacting your symptoms. However, Rasheen would be more than happy to have a chat with you in the 1st place if that's what you prefer. And so, then the number for the Richmond Long COVID service is 0208 614 7380. And just to say, if it goes through to a voice message, please do leave a message, Rasheen does pick these up and we'll get back to you alternatively there is an email address, and we can put that on the notes of people prefer to email.

Cllr Millard: Yes. Fantastic. Thank you so much, Nicholas and Genevieve. All you've done for everyone and for taking the time to come and talk to me today.

Genevieve: Thank you.

Nic: Thank you. You're very welcome and I hope continued recovery.

Cllr Millard: Thank you very much. Yes. Thank you. Thank you, guys. Yes, much appreciated.

Genevieve: Come to us. We will welcome you!

Cllr Millard: I mean, gosh, it's been it's been quite emotional and very, very wonderful for me to be able to talk about this subject, which is obviously very close to my heart. And you know, I I look forward to meeting as many people who are going through the same thing as possible and helping each other to support each other.

Listeners, please do check the show notes for links to everything we've discussed, the phone numbers and such in this week's episode. If you've got any questions, please do email us, [talk@richmond.gov.uk](mailto:talk@richmond.gov.uk) and we will work with our colleagues at the NHS to answer them. It would be really great to hear from you. You know, as I say, really, really pleased to hear feedback from anyone else who's going through a long COVID and anyone who's previously gone through it and is feeling they've recovered anything you'd like to share with us. Talking of sharing. please do share this episode with any friends or family that you think it would help. And if you're on the sort of service where you can leave a review, please do feel free to leave five stars. As ever, I'm Jim Millard. Thanks very much for listening.