



Airing Pain Programme 133: Sharing Pain – How Group Consultations Can Help Long COVID And Other Conditions

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How the symptoms of long COVID are being managed using group consultations and the many things long COVID has in common with other long-term conditions.

Paul Evans: At the end of July 2022, an estimated two million people in private households in the UK, that's over 3% of the population, were experiencing self-reported long COVID. With the highest percentages in Scotland and Northern Ireland and the lowest in Wales living with this potentially devastating legacy of their COVID-19 infection.

In this edition of ***Airing Pain***, we'll be looking at how long COVID is treated and how an innovative scheme developed for the management of other long-term conditions is now being used for the management of long COVID. So, at the time of recording this edition of ***Airing Pain*** in September 2022, what do clinicians know about this new disease, and what can be learned from established recommended treatments for chronic pain conditions such as fibromyalgia?

Dr Deepak Ravindran is Consultant in Pain Medicine working at the Royal Berkshire NHS Foundation Trust in Reading. He's the clinical lead for the pain medicine service in the secondary care hospital. He helped set up and leads the community pain service for Berkshire, and more recently, its long COVID service.

Deepak Ravindran: Right now, because long COVID is a syndrome, you know so many organ systems are affected and so many symptoms are there. We are making use of the existing knowledge and the existing symptom management techniques, but putting it together in a programme fashion, in a way that we can safely deliver it to patients who are struggling with this. We can't expect them to go to six different doctors or six different therapists in five different places to get seven different drugs. So, what a lot of clinics, and there are 90 such long COVID clinics in England, and they do have links with pain clinics, they are starting to develop links with other pain clinics and other specialities. Ours is probably unique in the sense that we are the first and still the only pain clinic to actually lead on the long COVID clinic as well.



So, what we are doing is taking that understanding of pain management programmes that we give for persistent pain patients, where we are able to provide information about many things in an integrated fashion. We are taking that same base model and then trying to apply it locally for our patients. So, what does that look like in actual practise? For example, let's take the example of maybe a forty-year-old woman who has got long COVID. Her typical symptoms would be pain, would be fatigue, would be brain fog, she would have chest pain, and shortness of breath along with palpitations, she would have stomach bloating, and she would have itchy skin, or sometimes a frequency to get more infections because immune system is not playing well, her dietary changes would be there. So, if this is a typical set of symptoms and she gets post exertional tiredness with any kind of activity, we speak to the cardiologists, and we are now comfortable in saying if there are palpitations or shortness of breath or heart related issues, we can investigate for that, and if there are major structural issues ruled out, we can think about medications that have been used for heart rate control, we can prescribe that, so that's one thing we can look after.

Similarly, for shortness of breath, we know that in previous times inhalers of certain kinds, steroid inhalers could be given, so we use that as a prescription there. We may have techniques for pain, so there are some nerve pain medications we can trial, so we could give medications as one go, as I support with. We can teach them interventions to retrain their breathing system, so that is a way of almost retraining the nervous system that controls the heart rate and breathing, and give them relaxation techniques or different ways of breathing, and we work with research projects to bring that together.

You may have symptoms of the GI – gastrointestinal – tummy symptoms. There is a suggestion that giving simple things like antihistamines can sometimes calm some parts of the immune system down, and so we can make suggestions of that to the GPs to trial. All these are relatively low cost, easy to do familiar techniques that GPs and doctors are familiar with so there isn't a harm in giving these for the patients. These are not experimental technologies, so it's safe to do that for patients, and then we combine it with giving them some information about pacing strategies, understanding how to pace your activities, so that you live within that energy envelope, we give them information about sleep techniques, nutrition is something very interesting because one thing we realise with fatigue management is the way I have been taught, and this is something I have learnt myself from



my therapists is apparently the virus can affect the energy factories in the cell, it happens in persistent pain patients as well fibromyalgia patients where fatigue occurs.

So, the energy factories in the cells are impacted such that, if you think of us as a mobile phone that can get charged to 100%, when your energy factories in your cells are affected, it is just like the battery capacity just can't charge to 100%. So, you are always left with being charged to 70%. And so, the reframe we have to have is, if all we had was getting up a seventy percent battery in our day, how are we going to spread our activities, such that we live within that energy *envelope* of 70%. And to have that conversation with patients, to have that discussion with them, to almost *increase* them and coach them to think about that capacity in a different way. That's a conversation we've had to have our own training with, that's been the learning we are taking back to our pain management programmes of how to deliver information about pacing.

And then, when we do a programme, we are able to combine this, so that's what we do in our programme at the Royal Berks hospital. It's what our community partners are able to deliver, that management of long COVID and all these symptoms together, and that's what our colleagues in primary care are also able to bring that to the primary care in the same way, so we've tried to replicate this and not just keep it in a secondary care specialised setting, but actually make it easier to give it for patients rather than making them wait long.

Evans: Dr Deepak Ravindran. Well, this all comes together in an innovative programme in which consultations are held with groups of patients, rather than on an individual basis. And rather than with a single clinician, say, a GP, sessions are taken by different members of a multi-discipline team of clinicians and therapists.

Dr Rupa Joshi, a driving force of the group consultation initiative, is a GP at the Woodley Centre Surgery near Reading in Berkshire.

Dr Rupa Joshi: I started setting up the group consultations back in 2017 as face-to-face pre-pandemic, and it is really because what I was finding with patients was that the ten-minute appointment just wasn't enough. There was so much more in-depth discussion that needed to be had, and we had our frequent attenders, they would be coming back again and again because we weren't really answering the question, and the question was really the



personalised care agenda, what matters to you, and I think we were really medicalising things, when perhaps patients needed more, they needed a holistic approach.

So, a group consultation is essentially having a consultation with a patient one to one, but in front of a group of other patients. So, other patients can then learn, and it may be questions they'd never even thought about. It may be, 'oh I always wanted to ask that but never really asked', and what we find when we do our group consultations is they are not really very medical. They are more about coping with the illness and getting advice from other patients, so it's not all about questions and answers. It's about bringing in the rest of the group and saying, 'Oh that sounds really interesting, what do you do about that kind of problem, how do you manage it?', and then the patients start sharing their own experiences, their own stories, their own support, and you end up with a support network, where they often speak to each other outside the sessions and take each other's numbers.

We had one group consultation where somebody said, 'I would really love to start going swimming again – I think that would help my exercise', and then two other patients said, 'oh I'll come with you', and then immediately you've got a group where people encourage each other and you go because you don't want to let other people down and you want to help them with their health conditions.

Evans: I presume it is not just one session, it is a series of sessions?

Joshi: Yes, it depends on the condition that you are managing, but particularly with these kind of conditions, one session is just not enough. We normally look at six or seven, and we like to have a group maybe every two weeks or monthly to get the momentum going. And then maybe we might meet up, maybe three months later, just to check in, or a month later. We ask the group, 'What is it you want to talk about?', 'How often do you want to meet?', and we go by the group and, 'When would you like to meet again?', just to touch base, and in those touch base sessions we don't even have to be here, maybe the patients can organise it for themselves.

Ravindran: This was very much an integrated piece of work as far as our area was concerned. We were lucky that our commissioners came to us and said they have some funding available to try some pilots on how to provide personalised care. How can we reach patients quicker and closer to their home? And so, we had this wonderful GP colleague of



ours, Dr Joshi, who was already doing this kind of technique called 'group consultations'. Even before COVID happened, she had a team in her practice who were supporting chronic pain patients, diabetes patients, by using this technique of group consultations.

It meant that she along with a counsellor, and a pharmacist and a nutritionist, were able to support these patients in the practice giving them access to information earlier, and my role, at those times, was to work with the primary care colleagues and actually talk to the patients as well and say that it doesn't mean that patients aren't being referred into secondary care, or should not be referred in as a cost cutting measure like some patients often think about it, like why isn't the GP referring them into hospital if they need it. This was more of a combined working strategy, wherein these patients might be waiting four to six months to see us in secondary care, but if I went out to primary care and I had this forum where I could reach ten or fifteen patients and tell them that if they needed medication advice, that could be provided. If they needed nutrition advice, if they needed some advice on breathing techniques, relaxation techniques, rather than waiting ten months to come and see us, they could get it within one month and they could get all of that stuff that they need, and if they needed some medication advice, then obviously the GP could discuss with me and between both us we would still have a plan that's faster and efficient for the patients.

Joshi: We have a facilitator, a non-doctor, and then we have a clinician who is an expert in that field and we also have plenty of other clinicians that come in, so we've got a health and well-being coach, care coordinators, mental health practitioners, personal trainer, diabetic nurse, pharmacists, we utilise the skills of everybody in our team, and invite them along for certain sessions. So, when we did menopause, our menopause doctor, women's health doctor came in and helped facilitate that session, but it's not even the control, it's all of us together. It's a group, and the clinician learns as much as the patients do, because I felt quite humbled with the chronic pain clinic, because I really understood how it must be for a patient with their day-to-day activities and how they cope, and it was a real eye opener for me, so everybody learns, everybody has the control within the group.

Evans: So, you are doing these group consultations for long COVID patients. How might that differ from doing it, say, for diabetes patients or COPD patients?

Joshi: With those kinds of conditions, you have a management plan in place, you know? You have your inhalers, you have your medication, you have lifestyle factors and nutrition,



and you sort of know what you are dealing with, whereas with long COVID, each patient has a different set of symptoms. Some of them might suffer with the fatigue more than the headaches, some might be suffering with the mental health side of things. Because it is a multi-system illness, everybody is different.

Evans: With all those differences, are there common things that can be addressed?

Joshi: Yes, it's the personalised care agenda. It's asking patients, 'What matters to you?', and developing different systems of support. So, we designed our long COVID clinic talking to the hospital, reading up, going on websites, finding out what the most common themes that patients are talking through, and we developed our programme of support. We asked Dr Ravindran to come in, to take our first session and called it: *The Science of Long COVID*, and we talked about the inflammatory processes that go on, why they go on, why do you have these symptoms, and what can we do to help. And for some of our patients, it was the first time they've met other people with long COVID, so they had felt what's happening to my body, what's happening to me, I don't understand this.

Ravindran: Our present understanding and this is something that has evolved with time. Initially we thought that people who've had very severe COVID and who needed hospital admission might struggle with the symptoms of the impact the viral infection had on their lungs, or on their heart, or on their muscles, and we thought that a lot of people with post COVID issues would be those that needed hospitalisation. We've now changed in the two years that we've lived with COVID now – we have seen that long COVID is now a new long-term condition. This is a condition that is predominately affecting people who have never been admitted to hospital, but very well may have suffered a COVID infection that they managed at home. It is a syndrome, meaning that it's not just confined to one or two symptoms. It is actually a condition that affects multiple organ systems and it can have multiple symptoms. So, one study from last year suggested that long COVID patients may have as many as ten organ systems affected, and they can report as many as two hundred symptoms affecting various parts of their bodies, and realistically that is what we are looking at: a new long-term condition characterised by multiple symptoms involvement and there is no association with how severe the acute infection was.

Evans: So, it falls into the chronic or persistent pain bracket, really.



Ravindran: It is one of those conditions where persistent pain is one of the most common symptoms that patients present with. Widespread aches and pains are a very common symptom, alongside fatigue which is again a very common symptom, then brain fog as well as new onset mood changes: *anxiety and depression*, then heart related problems like palpitations, shortness of breath, so these are the most common symptoms. Of course less commonly reported, but equally present, are skin issues, new onset stomach problems like nausea, bloating, weight gain of some kind, loss of appetite, loss of taste and smell, so these are all the other things that have been reported, but pain and fatigue are two of the most common symptoms.

Evans: Dr Deepak Ravindran. Caroline Mole has had COVID three times, and she's a participant in the group consultation sessions.

Caroline Mole: I didn't know what it was, you know, I'm a woman of a certain age, so you know, I guess there is certain things that you sort of put down to menopause or anything, and I realise that you know the chronic fatigue that I was feeling, the pain that I was in, I was vomiting quite regularly, that I probably phoned the doctors and it was at that point and I did a little bit of research myself online to see what long COVID looked like, just in case, and it sort of seemed to correlate with some of the things that were online, so I phoned the doctor and she said yea I think you are right, I think this is what it is.

Evans: How has it impacted on your life?

Mole: I have always been really energetic before, always been very fit and healthy. It's impacted my job, I've got quite a, what I would say is a, high-powered job and day to day that's been difficult, you know, just the brain fog maybe. Getting out of bed some mornings takes me half an hour sometimes because of the joint pain and things. The embarrassment of vomiting at work and having to stop a lot of the energetic stuff that I have always done. Even walking the dog has had its issues because he is a terrier, and if he is pulling a bit and I've got pain in my wrist joints, sometimes I can't even lift food out of the fridge to take it out and put it into an oven, because I live on my own, that can be quite difficult.

Ravindran: I have been looking after patients with chronic pain, fibromyalgia, chronic fatigue, ME like symptoms for a long time now, almost twenty years. So, when COVID happened, and I got a particularly nasty episode of the original variant of the virus back in



March 2020, and I struggled. I struggled for almost two weeks and I kept having symptoms for almost six or seven weeks before I fully recovered. And, I realised actually this is what my patients of fibromyalgia or chronic pain might be feeling every day of their lives, because for those first two weeks I was completely shattered. Just the sheer act of getting up and walking fifteen feet across to the bathroom and back would leave me breathless, in pain and tired, and I felt that there would be these kind of symptoms, and this group of patients, who would be having such a presence after their acute episode.

In fact, the previous epidemics that have happened in China, with the SARS epidemic in 2009, and the ones that happened in Hong Kong and Canada, there were studies, but much smaller studies, reporting that patients could struggle for two or three years after a SARS virus at that time. So, to me, if I felt very likely that after COVID, as well, we would have a big group of patients who might be struggling with pain and fatigue and other symptoms - and I'm very glad that, actually, in the UK, the government and the NHS took this really proactive step of releasing funding to set up a long COVID clinic because it felt that all the experience that I had of looking after patients with pain, fatigue and other symptoms – because, for example, in a condition like fibromyalgia, they do have stomach issues, they do have brain fog, they have fatigue, they do have issues of eye symptoms of blurring or tiredness, and all of them have a common factor that the nervous and immune system can be impacted, and stay impacted for a long time.

And we were already used to managing these patients in our pain clinics with pain management programmes, with the way we supported our patients, so it meant that when the funding for the long COVID clinics came in, our area here, my specialist pain physiotherapist, my fatigue physiotherapist here, my psychologist and myself, we felt fairly confident that, yes, we could look after a lot of these patients and provide them a more integrated experience based model for a lot of their symptoms, and for some of their symptoms like heart rate related issues or breathing related issues, we had really great colleagues that we could sort of seek the help of and get some experience from some of them, and as it proved over the last two years once the respiratory colleagues had done their X-rays or scans, most of them were normal, 99% of chest X-rays or lung MRIs or brain scans or heart scans, all came back as normal. And they felt that this was because the nervous system was being impacted by the virus, and so it meant that we were able to



support them with a lot of techniques that we had gained experience from in our previous work with fibromyalgia, chronic fatigue, ME and persistent pain patients.

Evans: What I find very interesting about that is that I have fibromyalgia and when the long COVID reports came out on television my wife says, 'that's you Paul, that's you Paul', and I say, 'no, no, no, same symptoms but there is organ damage with long COVID'. I'm wrong am I?

Ravindran: The research certainly shows that in some people, there seems to be a microscopic evidence of organ damage. So, there were a couple of studies that showed that there was lung changes when they did some really fancy form of MRI scanning, that there were possibly some brain changes in some patients who had very bad brain fog, and now we are having some research that is showing that in some people the immune complexes might be causing some clots – micro clots as their calling it in the social media and in the research papers, and there is us leaning towards saying that in many people who are struggling significantly there may be an element of vasculitis, meaning that the blood vessels could be affected and damaged by the viral infection.

It's two ways to look at it Paul. It's possible there is a group of people in which these kind of structural changes are happening, but the researchers themselves still don't know what the implications of that are. What does that mean for treatment because we don't have a drug or molecule or treatment, as such, that is evidence based and sustainable. The good side is, if it does turn out that the research into long COVID – now \$1.4 Billion of research money has been promised for long COVID in the US, up to 35 to 40 million pounds of research money has been looked into the UK research projects there – and if it does turn out in the next two to five years, we have a molecule or a treatment or some intervention, then I think that's a boon and a potential opportunity for existing fibromyalgia and chronic fatigue and ME patients because there are so many similarities we are noticing between these conditions. Why can't we offer those treatments for the fibromyalgia patients, and maybe we can turn back and tell a lot of our fibromyalgia and chronic fatigue patients that, yes, now that we have these investigations which showed some structural damage, maybe you had the same in your case as well, so it's a possibility.

Evans: Dr Deepak Ravindran. Caroline Mole again.



Mole: I've had a bit of a flair up recently, so I normally cook absolutely everything from scratch, but I thought to myself I got to make my life a bit easier, so I've just bought some ready meals to just go on with.

Evans: How did the flair up really affect you? Was it just a magnification of all the symptoms?

Mole: This time I've got a little bit of a different, I've got a real tightness in my chest this time, which I haven't had before, and I need to speak to the doctor to make sure it is not something untoward, but yeah, the aching joints just, I mean I call it a flair up, they're there pretty much all the time, but you learn to live with it, it's a lot more painful. The chronic fatigue is something you can't really explain to someone unless they've had it. I never knew and I probably would have thought, well, that's tiredness – until you experience it, and you know you can be in the middle of a conversation, like this, and all of a sudden, your words can't come out, and you need to just lay your head on the table and shut your eyes for a bit and things, so...

Evans: I have discussions with people about fatigue. All I can say is it is not tiredness, it's like being hit by a torpedo.

Mole: That's exactly it, and you know I can be at home and my family will have come to visit and all of a sudden, I don't realise but I'm fast asleep. You can start to feel it where your words start to slur, and as you say it does, it just feels like you've been battered and that's quite difficult. I think, when you've been quite energetic in life, and I love my job, it takes me in lots of different directions and sometimes you just sort of feel, wow, I've got to get through a day, and that's horrible to feel like you've got to get through a day, isn't it? It's a real negative feeling and I like to think I'm quite a positive person, so I have to try and turn that negative thought into a positive, and say, 'Actually, I can get through today.'

Evans: That's Caroline Mole who is a patient in the long COVID group consultation programme. Gregg Scott is a Cognitive Behaviour Therapist who works for *Talking Therapies*, a psychological service of the Berkshire Healthcare NHS Foundation Trust.

Gregg Scott: Talking Therapies has been an evolving psychological service since 2008. We started off seeing a range of conditions, primarily anxiety and depression, including health anxiety, which kind of ties into how I ended working with Woodley and the team here. So,



from 2017, there was a formal training started in long-term conditions – the jargon word. The basic conditions were diabetes, heart conditions, COPD. But as a team, we realised we had a very narrow focus, and that when we started to open our focus to include the physical and the psychological, and that more of a bio-psycho-social model, then we could start to see a relevance for what we were already doing. But, we also then saw that one of the difficulties is that if you have had a long-term pain condition, for example, you might not want to hear that you've got anxiety and that could be treated in a mental health service, even though it's a primary care mental health service. So, I've been in Woodley and Parkside, this site we're on since 2017, initially as a therapist, but working with Rupa, got very quickly involved with the consultation groups and then they became the virtual consultation groups.

But I guess the real thing for us, in terms of a response, is that we've been able to invite a group of people that we know have had long COVID, and some are recovering and some are going in, some have been diagnosed, into a virtual space, which by definition is safe in terms of not being re-infected, but we've also been able to bring people together with a range of professionals and the chance to ask a range of questions but also to hear other peoples' experience. It's been a real opportunity to have something that could touch a large group of people in an unobtrusive way into where they are living at home or working from home. So speaking with my Talking Therapies, head on, really wanted people to understand the things that we call anxieties and depressions are very common conditions. They're standard issue human conditions, they're not something that is wrong with you. If you've got those responses to your life circumstances it's normal and in some cases can be very healthy. So, getting people together and having a chance to discuss anxiety in the context, as opposed to hoping people might refer in to a separate service, or hoping people will understand that this is where the long COVID lies, and this is where the anxiety lies, or this is where your low mood is hitting in with your fatigue, etc. So, it has been an opportunity really to try and start those conversations with people, initially, in a kind of very friendly environment.

Fatema Hafizji: My name is Fatema Hafizji. I am a Health and Wellbeing Coach and I work for the Wokingham North Primary Care Network. So, we help to self-empower patients to get more control, get back in the driver's seat of their health and actually focus on what matters to them when it comes to their own health, so really asking those exploratory types of questions and very often we have a really lovely conversation about where their health is



currently at and where they'd like to go with it. What we tend to do as health and well-being coaches is really get to the specifics, so looking at SMART goals. People may have heard of that term, so really having a realistic goal.

Evans: SMART remind me is... It's Specific...

Hafizji: Measurable.

Evans: Measurable.

Hafizji: Achievable.

Evans: Achievable. Realistic.

Hafizji: Realistic.

Evans: And...

Hafizji: Timely.

Evans: And timely.

Hafizji: Yeah.

Evans: So, if someone, say if I came to you and said, 'Listen, I've been unwell, ill, feeling rotten for donkeys' years, I want to climb Everest.'

Hafizji: [laughs]

Evans: And that's what my goal is – I want to climb Everest.

Hafizji: Yeah.

Evans: That is not realistic.

Hafizji: Yes, so I will say oh well that's lovely to hear that you'd like to climb Mount Everest. Is there anything that you've set in place to help you to achieve that goal? And very often when I ask that question, it says, 'oh that's interesting, I haven't really thought about that', and then we say, 'oh, but actually, that is my long-term goal', and then it kind of opens the



doors to setting short-term goals to really getting to that goal of climbing Mount Everest. It might be a case of training, so you know going on walks and things, so the patient might say, 'Oh, actually, yes.' Going on walks is not something I would say and put those words, if you like, into the patients [laughs] head, if you like, but it would be a case of the patient actually coming up with the answers themselves and saying, 'Oh, actually, this is how I want to start.' And it would very much be around things like habit attaching with a lifestyle goal that we would want to achieve. It would be attaching whatever change we would want to make, attaching it to an existing habit. So, for example, if it was about fitness to help them to achieve climbing Mount Everest, it could be a case of their brushing their teeth, and after brushing their teeth they're doing two push-ups against the wall.

Evans: How do people react to being brought back from that *huge* goal to getting out of bed in the morning?

Hafizji: Yeah, that's a really good question. So, when a patient is coming to see a health and wellbeing coach, they have taken the step and they know that they want the help. So, when it comes to taking it back and how they react, from my experience so far, it's kind of, I want to say a light bulb moment, forgive the cliché, but it is. It really is that light bulb moment. And sometimes just having that reminder, even, and taking that step back because as you mentioned that example of Mount Everest, it can be huge in a person, and say, 'Oh my gosh that is an amazing goal that I want to achieve but how can I even get there?', if it is something that they are struggling with, pain or anything like that. But, it really is about having that positive talk around OK that's wonderful, but how can we break that amazing long-term goal into smaller chunks, so that eventually over time that person can achieve it. So I think when those conversations tend to happen, it really helps patients to kind of think positively, and say what's manageable for them, what can they do, especially if they are in pain. What can they do currently to help them achieve whatever goal it is that they want to achieve.

Kerry Doe: My name's Kerry Doe. I'm a personal trainer with the long COVID patients. I work on the physical activity, so going back to exercise, returning to exercise after long COVID, or during, you know, while suffering with long COVID. So, in that session we talk more about how people are coping with the current levels of exercise that they are doing and how they can go back to exercise, and lots of the patients when we first speak to them are struggling some days to do anything. They are not able to work, they can't exercise at all. It's



a real stripping back, lots of them did lots of exercise before, ran, did biking, was swimming, you know, very active people, so it's very hard for them to go right back to doing ten minutes' walk a day. They really have to strip completely back and do very slow increases but doing regular exercise. It's almost retraining again, retraining the body to exercise to be able to cope with exercising and exertion.

Evans: It's a real issue with mindset as well, isn't it?

Doe: Absolutely.

Evans: What is exercise? One person's exercise will be doing a 10K run.

Doe: Yeah.

Evans: Another person's exercise will be walking to the shops or even getting out of bed in the morning.

Doe: Yeah.

Evans: But when those people who've been used to doing the 10K run are reduced to the bottom end, I mean, how do you change a mindset, how do you get over that?

Doe: That's one of the most difficult things and it's really hard for people to accept, and there is an element of acceptance there that, for now, they fight against it. And what happens then, is that they over exert, and especially with long COVID, pushing yourself too much then will knock you out for two, three, four days. So, one of the first things we say, is when you're starting to come back to exercise, even right at the beginning, you need to monitor during and then after, but also the next day. That I often encourage people to keep a movement diary which really, really helps. Not only just to see when they've pushed too much but also it might seem silly doing an extra minute walk a day, if that's what we are beginning with. It varies, but it's very small increments, but over the course of a month, that might be the difference between doing a ten minute walk or a thirty minute walk and actually having that diary and being able to look back and say, 'This month I can walk for thirty minutes, and it's been slow, and it's slower than I'd like, but actually last month I could only walk for five minutes.' So being able to see that difference makes a difference, and then people are able to accept that they're going slower because they can see progress.



Evans: But pacing is very, very difficult.

Doe: Yeah.

Evans: Because when you feel good...

Doe: You want to push yourself.

Evans: You want to do everything.

Doe: That's the real difficulty, I think, and a lot of the patients said that once they were able to say no to things, social things, that was a big thing for a lot of people, they felt pressure with family and work and different parts of their lives, and being able to say the best thing for me is not to do that. Once they were able to do that, I think it changes a lot for people. They are putting themselves first, and lots of them are parents or they've got responsibilities with family and friends and things, and they're having to pull back and look after themselves as well. But once you see the benefit – it's starting, I think, getting started.

But also I think working with the group clinics, especially with the long COVID patients, them having people that are in the same situation and being able to talk to other people that felt the same was huge. And a lot of the sessions were very emotional, especially the early sessions because patients had felt that they were on their own, not so much early on, but some of the later patients knew a lot of people that had had COVID and they were back at work and they had recovered. It's difficult to accept. There's not always a reason why it's happened. That was difficult for people and they felt that colleagues, and family even, expected them to be better. And they had that pressure there that I do need to push myself because everybody is expecting me to be better, so them seeing other people that felt the same way, had the same symptoms. I think that was one of the most important things about the clinic actually.

Saira Mirza: My name is Saira Mirza, and I am an Advanced Physiotherapy Practitioner for long COVID and pain management.

Evans: So, what's the physiotherapist's role in the management of people with long COVID?

Mirza: We help to create a management plan and strategies to help them have more control over this. For example, with long COVID, some of the main aspects that people struggle with

are the shortness of breath, and it is very normal with this long COVID that people develop this abnormal breathing pattern disorder where you end up breathing into your mouth instead of through the nose, and that causes a whole array of different complications. So, some of the treatments that we do are trying to get back to that normal breathing pattern so it's a lot of breathing exercises, it's a lot of let's see if we can relax the system so that your diaphragm, your main breathing muscle, is working to the best that it can do to reduce the symptoms associated with that. And sometimes it's not always the shortness of breath that people experience with that – it can be a chronic cough, it can have effects on your fatigue, so it does have lots of other symptoms.

Evans: You may have noticed that as soon as I start talking about breathing, I've stopped slouching and my head has gone forward. So, just explain how you would help my breathing?

Mirza: So when people have any sort of virus, so for example just the normal cold virus, we have those symptoms where 'oh actually my nose is really stuffy and I can't breathe through my nose, so I'm just going to breathe through the mouth', and then our body corrects itself and it's able to breathe in the normal way. With long COVID it has almost created this habit of breathing in through the mouth, so what we like to get people to do, is be in a nice really relaxed position For the majority that is lying on your back. Some people feel that lying on their back increases their coughing or shortness of breath. That's fine. Just go into a nice relaxed position, and what we want to see is just you breathing as normally as you can, so when we are having this laboured breathing, as it were, sometimes you will find that your upper chest is rising a lot more than your abdomen, so that just lets us know that the accessory muscles, which are the muscles that assist with breathing are working a lot harder. These muscles also connect into the neck, so they are helping with the posture and they are helping with the neck movement. So, people might start to develop some neck tightness and as a result they can have headaches and so it kind of goes into this spiral, so if we can start to relax those muscles and focus on your abdomen that is getting us into the right position.

Ways that we can do this are almost having if you are in a seated position, sitting on your hands, so you're stopping your shoulders rising up too much, and if you're lying down, you can have your hands behind your head so you're almost stabilising that, and you're just making that diaphragm work a little bit more efficiently. Once we've kind of helped with that



balance between these muscle groups, what we then want to see is if we can breathe in through our nose that little bit more. Now when you're first doing it because it's been such a long time that you've almost got used to breathing in through your mouth, it's going to feel really unusual, you're going to find that maybe you can't take as many breaths through your nose as you used to. That is fine. This is a progression. What people tend to do is, they breathe in a lot through their nose. But taking that big deep breath can then introduce more coughing into the system. You can find where you're taking so much through your nose that you start to feel a little bit dizzy, so it's just a little bit too much if you are experiencing that. So, what you want to do is start to take some small breaths through your nose and then breathe out through your mouth, and you might only be able to do two or three of those at a time and then just go back to your relaxed breathing, and so, we are slowly introducing your breathing back to the way that we're used to, to see if we can normalise it again. So, in some people, it can take quite a while to get back into that way of breathing. Others, they can pick it up a bit quicker, so don't be disheartened if it does take a while. Don't panic, you're doing the right things, you just need a little more time to adapt to it. So, once we have done it in that nice relaxed position, whether that be lying or sitting, to make sure that we continue with this improved breathing, we want to change our position because as we are moving position to a more upright position that takes a bit more energy. It's a bit more of an effort, so you are going to find that your breathing might be affected and you might also feel that your fatigue gets affected with it as well. So, if you are doing a lot of these breathing exercises, you might feel tired afterwards and again because of the connection that's absolutely fine, so we are just building it up that way. The idea is that we change our position, so we go from sitting to standing, to doing some movements around the house, practicing this breathing exercise to try and progress it and build up your tolerance.

Evans: That's Saira Mirza, Advanced Physiotherapist Practitioner for long COVID and pain management with the Berkshire Healthcare NHS Foundation Trust. Before we go on, I'll just remind you that whilst we in Pain Concern believe information and opinions on ***Airing Pain*** are accurate and sound based the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. They are the only people who know you and your circumstances and therefore the appropriate action to take on your behalf. Do check out Pain Concern's website at: painconcern.org.uk, from where you can download all editions of ***Airing Pain*** and find a wealth of support and information material about living with and managing chronic pain. And from there, you can



also get details on how to order Pain Matters magazine, and of course there will be more information about this edition ***Airing Pain*** on the management and treatments of long COVID and group consultations. Now it is important for us at Pain Concern to have your constructive comments about these podcasts, so that we know what we are doing is relevant and useful, and we want to know what we are doing well and maybe not so well, so do please leave your comments on whichever platform you are listening to this on, such as Apple Podcasts, Spotify, Plenty More and the Pain Concern website of course, and that'll help us develop future editions of ***Airing Pain***.

So back to the long COVID group consultations with Caroline Doe, Drs Rupa Joshi and Deepak Ravindran to end this edition of ***Airing Pain***.

Doe: I remember talking at one and just being really emotional because all of a sudden you feel that you are not alone, because it's not a visible illness is it? It's not something that... and people are still learning about it. Just being able to have those conversations, I mean it was brilliant learning from all of the... and listening to all of the professionals. But the biggest thing that I got out of it was talking to others who were in the same situation and drawing on their experiences. And all of us were trying to draw on the positives of it, just so, 'What did you do to make you feel that bit better?' and being able to do that. I think that support group has really... did change things for me in a huge way.

Joshi: Every clinician has their area of expertise, so we're really getting everything with the whole group listening in, so everyone's learning and everyone's sharing. And we learn as well as clinicians from our colleagues, from our mental health practitioner, from our personal trainer, because everybody's got their niche of knowledge and skill and, so everybody learns, not just the patients. It should really be something that we roll out for everybody with long-term condition because it's so powerful. A hundred percent of patients say they would chose it again, that they would recommend it to family and friends, so everybody really benefits from that approach.

Doe: It turned my life around at a very difficult time. A time when you're trying to cope, with obviously schools were still open the whole time, so I was working throughout that time of lockdown of things, but when you're not feeling well and you're on your own and everything then builds doesn't it? And you sort of think am I going mad, is this just a result of being



stuck indoors all day or something? And the group just took that feeling of being alone in this illness, I suppose, or how you're feeling a way, and it was really, really great.

Evans: Glass half empty people who don't have long COVID, but have other conditions, that might think all this money is going into long COVID. Glass half full, all this money going into the long COVID, could, should help the management of all those other things.

Ravindran: Absolutely, that is my glass half full premise of looking at it, that every intervention and treatment strategy that comes out of our understanding of long COVID can be retrospectively applied, and I think should be applied or thought of for our existing fibromyalgia, chronic fatigue, ME and maybe other long-term post viral complications that many other patients are suffering from but we don't know.

Evans: If you're able to give advice to somebody with long COVID, what would you say?

Doe: I've really learnt to listen to my body, and if I have to say no that I can't do something that's not a failure, it's a really big thing because you are actually listening to your body and I don't think we do that enough.

End

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