

TRANSCRIPT OF “FILE ON 4” – “LONG COVID: MIND OVER MATTER?”

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MUSIC

ACTUALITY AT ROWING CLUB

SCHRAER: So, this is your boat, is it?

COUSINS: Yeah. That’s my boat that’s been sitting there for quite a while now, unused. You can see the dust. [LAUGH]

SCHRAER: In early 2020, Oonagh Cousins was rowing for Team GB, headed for the Olympics - the Olympics which didn’t happen because of the pandemic.

COUSINS: I love rowing this stretch of river, like rowing through London. It’s like one of the most peaceful places in London. It’s so nice, especially like really early in the morning.

SCHRAER: Oonagh started rowing at university. She'd be down by the river by 5.30 in the morning to get a training session in before lectures. When she graduated, she started training 30 hours a week.

COUSINS: I had just started my international career, you know, I'd been in the team for a year. Getting preselected for the Olympics was my first selection for a senior competition. I just really loved rowing, I really enjoyed it. I enjoyed the lifestyle. I could have seen myself doing it for many more years, and so there's a grief for kind of the life not lived. And also I worked very hard [LAUGH], I put in a lot of hours, I invested a lot of hours.

SCHRAER: But by the time the Olympics in Tokyo were rescheduled for 2021, Oonagh was too ill to take part. She'd contracted Covid at the very start of the pandemic and, like millions of others, her symptoms never really went away.

COUSINS: This word 'fatigue' is a bad word for what it feels like. It's nothing like tiredness, it's like a deep sickness. Exertion makes these symptoms worse. You wake up in the morning, like have a wave of nausea and you think, okay, like what am I going to be able to do today?

SCHRAER: Unlike most people though, Oonagh had access to private healthcare through her rowing team. She saw some very good doctors, but they couldn't offer her much. She took vitamins and did breathing exercises. Mostly though, all she could do was rest. We'll hear more from Oonagh later, because what happened to her next is what this programme is all about. I'm Rachel Schraer, the BBC's health and disinformation reporter, and in this episode of File on 4, I'll be investigating how our lack of knowledge around long Covid is opening up a space where unproven treatments can flourish.

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SCHRAER: There are some two million people like Oonagh with long Covid in the UK, and most of them - around one and a half million - have symptoms that interfere with day to day activities. Fatigue, breathlessness, heart palpitations and severe dizziness are just some of the conditions people experience. Currently there's no test for long

SCHRAER cont: Covid. But, according to one of the UK's leading long Covid researchers, Professor Danny Altmann, the medical community is learning fast.

ALTMANN: We've learned as much about long Covid in the last three or four years, probably as we've learnt about lupus or arthritis in the last hundred years. This is a very damaging virus that can get into many parts of the body in a way that you can see on things like an MRI and do direct damage. This is a real thing, disease with a real mechanism, with real things that we can measure.

SCHRAER: Researchers have found pockets of virus hiding in people's bodies. They can see damage to some people's hearts or lungs in scans. They can see changes in people's blood when they do specialist tests - tests that are generally not available at your GP. It could be years before we know for sure how best to treat long Covid. In the meantime, doctors can only try to alleviate the symptoms. But research is underway.

ALTMANN: If we think that some people have reservoirs of virus, let's do trials on antivirals. If we think they have blood clotting problems and micro clots, let's try them on anticoagulation therapeutics. We haven't agreed the guidelines, what drugs to give them, how to make them better, so I suppose to summarise the kind of clinical situation for people with long Covid as a sort of state of ongoing despair, where the lucky ones have bumped into a good doctor, who sees somebody with breathlessness or respiratory problems or cardiac problems or brain fog and use their knowledge of basic medicine to try and do something useful, which is absolutely better than nothing, but not where we should be at this stage. There are hundreds of thousands of dissatisfied, desperate patients who never get to meet any doctor, so our long Covid clinic coverage in this country and in other countries has become very uneven and a postcode lottery.

MUSIC

SCHRAER: The UK Government says it has invested over £300 million to care for people with long Covid, and more than £50 million into long Covid research. NHS England also told us it had invested significantly, setting up a network of ninety specialist post-Covid services.

ALTMANN: There was an initial tranche of money to look at it, and that led to funding for the first two or three or even four years of work, and that was very successful. After that, all funding bodies that I'm aware of absolutely lost interest in it, pulled down the shutters.

MUSIC

SCHRAER: File on 4 contacted all of the NHS trusts that run long Covid clinics in England, submitting Freedom of Information requests, asking for details about the services they provide. 58 trusts - about two-thirds of them - responded. The replies painted a picture of patchy services, with more than a third of long Covid clinics not being run by a doctor, and only one in ten even having one full time doctor on staff. What's even more concerning is that only one in five trusts could confirm their long Covid clinics will still be running beyond next year.

KANE: So, in terms of the main symptoms that are bothering you, David, what are the main things that you're struggling with at the minute?

DAVID: I get very tired easily and I get headachey and I get angry.

KANE: Okay.

SCHRAER: Dr Binita Kane worked with long Covid patients within the NHS in Manchester. She left the NHS service after feeling she couldn't treat people as she'd like.

KANE: And before you had Covid, what sort of things did you like doing?

DAVID: I used to do football and scouts, but I had to quit that because ...

SCHRAER: Now, she runs a private clinic in Liverpool, where she sees patients from all over the country. This patient - we'll call him David - is 12 years old. He and his family have travelled more than a hundred miles to see Dr Kane.

KANE: Sometimes people have been ill for three or four years and not had a proper physical examination. You know, a comment that I hear from a lot of patients is, when they come to this clinic, it's the first time they've really been listened to and validated, and somebody has taken their symptoms seriously, because there's a lot of patients whose symptoms are minimised or they're told that it's all in their head, and that is actually quite traumatising for people.

SCHRAER: David's mum was quite hopeful at first. She saw a helpful local GP.

MOTHER: She says, I'm going to put you in for a referral with the local long Covid clinic, so you think, oh great, there's all these special long Covid clinics. And you don't realise till you get to them, they can't really offer you anything, because they haven't got much funding. So, with our long Covid clinic, they'd only speak to us over the phone, they wouldn't even see us, which is bizarre, because you'd think, well, someone needs to examine him and look at him. They spoke to it to me over the phone about him and then they said, actually, all we can offer is just rest and time. That was about a year ago, and then we never, they haven't been in touch since, hence here we are.

MUSIC

SCHRAER: This struggle to get help is leaving some very unwell people desperate, and willing to try anything to get better. There are treatments to wash your blood, high pressure oxygen chambers normally used by deep sea divers, a rainbow of supplements, all with varying degrees of evidence. And, perhaps most strongly dividing opinion, programmes that claim to retrain long Covid patients' brains to stop their symptoms.

EXTRACT FROM ADVERT

PARKER: Using a range of brain training exercises, including visualisation, meditation and changing your language, you can set your brain in a new direction.

SCHRAER: This is Dr Phil Parker - an osteopath who previously practiced energy healing.

PARKER: So you can once again choose how you live your life.

SCHRAER: He founded something called the Lightning Process 25 years ago and he says it's helped more than 75,000 people. It now operates in at least 17 countries with a network of coaches, including at least 14 in the UK. He's not a medical doctor, but he has a PhD in the psychology of health

PARKER: Over the last few years, the Lightning Process has helped hundreds of people with long Covid to change their health and recover. So, what is the Lightning Process ...?

SCHRAER: In fact, it's currently being piloted by one NHS health centre in Scotland. The Centre for Integrative Care in Glasgow offers both conventional and alternative therapies, including homeopathy. NHS Greater Glasgow and Clyde said the Lightning Process was being assessed until this autumn, and a report would follow.

MUSIC

SCHRAER: The Lightning Process makes a seductive promise - that it can help people recover from illness by rewiring the brain, using techniques to influence physical changes in the body. There's no shortage of people who champion the Lightning Process, many of them sharing their positive experiences online.

WOMAN 1: I was stuck with long Covid and it just took three days of the Lightning Process to reset me totally. It was like taking a faulty appliance and pressing the reset button and suddenly I was

WOMAN 2: As a result of doing the Lightning Process, I'm 100% recovered and I've got my life back. Prior to that ...

WOMAN 3: I am about seven weeks on from doing the course. I literally feel like a different person to who I was back when I was ill. I am now

SCHRAER: But the programme has plenty of detractors too.

KANE: I don't have a problem with people focusing on mind body. I think that's a good thing. I do have a problem with people claiming that it can cure people without sufficient evidence and as a catch-all. There is a place for psychological support as part of a holistic treatment plan, which includes medication. This idea that you can just fix yourself by doing a, what is it, a three-day program that people are paying for? I'd raise serious concerns about that.

MUSIC

SCHRAER: So what should we make of it all? Is the Lightning Process the answer, at least for some people, or does it, at best, deliver false promises or, more worryingly, does it cause people to blame themselves for their illness, encourage them to push through and ignore their symptoms and potentially even make them worse?

ACTUALITY OF PHONE RINGING TONE

SCHRAER: Yeah, I just, I wanted to get a bit more information really. I came across the Lightning Process and
I called every Lightning Process coach currently working in the UK - fourteen of them.

ACTUALITY OF PHONE RINGING TONE

SCHRAER: Some of the stuff I have, I guess quite, like, physical, like my feet will go blue ...

ACTUALITY OF PHONE RINGING TONE

SCHRAER: I Just wanted to chat through to find out a bit more about how it works

ACTUALITY OF PHONE RINGING TONE

SCHRAER: Are those typical? What's the sort of typical result that you find that people

I gave a medical history based on interviews with several real sufferers. I also came up with a list of long Covid symptoms with long Covid researcher, Professor Danny Altmann.

EXTRACT FROM PHONE CONVERSATION

SCHRAER: I've had couple of seizures, muscle pains and post exertional malaise, they call it, so I wanted to find out a bit more about whether this is, I guess, appropriate for those symptoms and

Some of the coaches were cautious. A couple of them even advised me the treatment was not proven or officially recommended. But the majority made much stronger claims about what was causing the long Covid symptoms I'd described to them, and told me the Lightning Process could make me better within days. I'd gathered enough evidence to take my investigation a step further - to go undercover and secretly record a Lightning Process training course, so I could really understand what they were teaching people. I paid the coach £1,250 to take part in a 3-day course over Zoom.

ACTUALITY ON ZOOM

SCHRAER: Okay, joining.

COACH: Can you hear me?

SCHRAER: Hi, I can hear you.

COACH: I can hear you loud and clear. All clear your end?

SCHRAER: Yes, all good.

COACH: So welcome, welcome to day one.

SCHRAER: And that's how I found myself in my kitchen, standing on a piece of A3 paper in my socks.

COACH: Excellent. We're going to try one now. Each of these lines is designed to change your brain.

SCHRAER: This coach doesn't know she's being recorded.

COACH: Say your own things, whatever is affected, but these are really, really useful ...

SCHRAER: I follow a script I'm taught, and walk around that piece of paper, which is marked with symbols. They are labelled Stop, Present, Choice and Coach. This is the basis of the Lightning Process.

EXTRACT FROM TRAINING VIDEO

PARKER: When you start the process, you start in the Present. Move to the Stop and do the Stop gesture, then move ...

SCHRAER: First, I was shown a Lightning Process training video of Dr Parker doing the process and I followed along. The idea is, every time you experience a symptom or a negative thought about your symptoms, you say the word 'stop.'

ACTUALITY ON ZOOM TRAINING

SCHRAER: Stop.

PARKER: Then move to the Choice.

SCHRAER: You make a choice out loud to choose the life you love instead of the symptoms which they call the Pit.

SCHRAER cont: Do I want that or do I want this?

PARKER: And move to the Coach.

SCHRAER: And then you coach yourself.

Well done. You are on track, you are a powerful genius. If you can do that, you can do anything. I'm with you every step of the way.

PARKER: As the coach, you'll learn how to coach yourself, your trainer

SCHRAER: You say what you want - to be strong, to have energy, to feel comfortable in your body, and then you visualise a time you felt that way.

COACH: So it's changing that natural habits of brains that aren't that helpful sometimes. Every single part of it is designed to change a human brain, you know, scientifically proven, and a metaphor in nature is very powerful, but a metaphor of the you that you want to get back to is also very powerful.

SCHRAER: I want to be full of vitality, like I'm sparkling with light. How are you going to do that?

COACH: Whereabouts are you?

SCHRAER: On a beach in Spain.

COACH: Okay, so be there now on that beach in Spain with your friends. Feel the heat and the heat of the sun energising all your cells, recharging you like a long lasting battery.

SCHRAER: Dr Camilla Nord is a neuroscientist at the University of Cambridge. She studies the influence of the brain on the body and vice versa. She's helping me to evaluate some of the claims made by my Lightning Process coach.

NORD: Some of that, I would say, is pretty standard - things you might get in psychological therapy. Relaxation techniques, for example. And that can be a helpful process for many people, irrespective of the cause of their symptoms. The weird part about it is that it's giving people this kind of agency over their symptoms that I don't really think people have.

SCHRAER: Dr Parker told us a belief that long Covid is all in the mind is not part of the Lightning Process. Instead, he said it focuses on changing your brain to - quote - facilitate beneficial physiological changes in your body. But a core part of the teaching is that you can stop or improve your symptoms by changing how you think and talk about them.

COACH: You had the virus, you got ill, but your body did not get well, it got stuck in running the neurological pathways of fatigue, brain fog, because actually your body now, this timescale should now be being well. Your thoughts about your symptoms, your worry about whether it's ever going to go, that's what keeps the neurology going and alive.

SCHRAER: And that's what keeps the symptoms going?

COACH: Yes, exactly. Being in those kind of thoughts is what's maintaining your symptoms.

NORD: That's a big leap, but then there's another leap between if it's maintained by your neurology, then you can change it. Even in patients whose symptoms are largely or even entirely generated by some kind of cognitive process, that doesn't mean that they can just decide to change that. That would be great, I wish that were the case, but I would suggest that it is probably false hope, and also that it could lead patients not to seek other types of treatments.

SCHRAER: Not only did my coach say my thoughts were maintaining my symptoms, she also told me quite explicitly that there was nothing physically wrong with my body. That's despite having no apparent medical qualifications or requesting access to any test results.

COACH: They are physical, they're real symptoms, but they're not caused by a physical thing anymore, because it's your brain keeping them going, not the virus.

NORD: It's a wild claim that there's nothing wrong with your body. I would find that an impossible claim to believe. They're right that the brain can create symptoms of physical ill health, but I think it's a wild claim to say there's nothing wrong with your body and it's just, in every case, something that you can actively change. I think it's a really damaging assertion; it will absolutely be wrong about some patients.

SCHRAER: But while Dr Nord describes the Lightning Process as veering into pseudoscience, she doesn't think we should throw the baby out with the bathwater.

NORD: We shouldn't dismiss the possibility, I think the likely possibility that for many patients the brain, cognition, the wider nervous system plays an important role in their experience of symptoms. We know this to be the case across medicine.

SCHRAER: When your body is under stress, whether emotional or physical, it goes into a state called fight or flight.

NORD: Stress can have very profound physical consequences on gastrointestinal symptoms, on immunological function, on systems all over the body, so maybe it's one piece of the puzzle.

MUSIC

SCHRAER: So, she thinks there is a place for therapies that help to calm down your body, and those that help you to respond differently to your symptoms. It could even explain some long Covid symptoms in some patients. One of the most scientifically shaky claims we found Lightning Process coaches make is that using negative words can trigger symptoms, and using positive language teaches the brain to experience positive sensations. At one point, my coach seemed to be saying these positive and negative

SCHRAER cont: experiences - and the words to go with them - were literally housed in two different sides of the brain.

COACH: Let's get into the other side, the sparkly Disney side. It's coming up with the vocabulary for the sparkly side, because all of our vocabulary has been about feeling stuck, so it's coming up with words around body comfort, around energy, around clear head. So we're thinking on purpose in the Lightning Process, and we're thinking of the opposite thoughts to how we've been thinking and what's got stuck.

NORD: I'm afraid now we've strayed very, very far from neuroscience - what I would call neurobollocks, so it's a kind of abuse of neuroscientific terms in order to give quite simple psychological techniques, a kind of sheen of science about them.

MUSIC

SCHRAER: Oonagh, the elite rower we heard from at the start of the programme, missed out on the Olympics because of long Covid. After giving a TV interview about her condition, she was contacted by a Lightning Process coach and offered a free place on the programme.

COUSINS: I think they were hoping that I would have a positive experience and use my athlete platform to kind of advertise it to this new patient cohort that was appearing as a result of the pandemic.

SCHRAER: Instead, she told me she wants to help expose them for what she considers to be misleading claims about the process.

COUSINS: The way that they demonstrate that this is what's happening is by pointing out how bad your mental health is, and I objected to that because by the time I spoke to them, I had done a lot of work on my mental health and I'd recognised how important it was, and I came to, like, a place of acceptance around what was happening to me, and so the whole kind of premise of the course quickly fell apart.

SCHRAER: She gave up on the Lightning Process after two days. After the first day she complained, and was sent more stories of people who had recovered using the course.

COUSINS: This stuff makes me really angry, because it's exploiting the fact that a lot of people with chronic illness do have bad mental health, justifiably, and it's easy to exploit patients, because a lot of them will say, yeah, I do have bad mental health, so maybe it is my fault that I have these symptoms.

SCHRAER: At the end of the first day of the course, I was told to do the Lightning Process ritual you heard earlier, and then do a physical activity. Oonagh ignored this instruction when she did the course.

COUSINS: You quickly learn as an athlete that when you get sick, you stop and you have to rest to recover, and pushing through is just a really good way to make yourself more ill, basically. And so if people follow that advice, they definitely can do themselves harm and make themselves more ill. And then I also think, you know, the gaslighting and the kind of blaming patients for their symptoms and saying that it's their negative thought pattern that is stopping them from getting better, I think that's a dreadful thing to say to patients, and it makes people feel a lot of guilt and shame. And yeah, I think it has a lot of potential for harm.

MUSIC

SCHRAER: Long Covid doctors and researchers caution that increasing activity without medical assessment and supervision has the potential to worsen symptoms for some patients, and even prolong their illness. The recommended way of managing it is called pacing - basically a way of breaking up activities with rest to conserve energy.

COACH: We don't do pacing in the Lightning Process. No one ever gets well with pacing. Instead of pacing, so we always do the same, we do the Lightning Process and then do something, but a little bit stretching that you wouldn't have maybe done before.

SCHRAER: Dr Parker told us the Lightning Process does not encourage people to push through symptoms. And to be fair, my coach specifically told me not to do this, while also confusingly telling me not to pace myself. But it does teach that its ritual will give you a boost of energy which will allow you to safely increase your activity without crashing or becoming more unwell. Dr Binita Kane is dubious about it.

KANE: There are decades of evidence in ME to show that there is pathological reasons why there is energy limitation, that there is an underlying problem in the energy making factory of the body.

SCHRAER: ME is a condition also known as chronic fatigue syndrome, which has a lot of overlap with long Covid.

KANE: Oxygen is not getting into cells. Some of that might be due to micro clotting, inflammation of the blood vessels. Some of it might be due to autoimmune processes. This idea that people are just scared of exercise and it's all a fear-based response, I would say is complete nonsense. If you push exercise in a way that is not controlled, very, very carefully managed, you can actually make the underlying condition worse, so it really worries me that somebody who's not medically qualified would be asking patients to exercise, just on the idea that they've changed their mindset about it. To me, that sounds quite dangerous.

MUSIC

ACTUALITY AT GYM

JEWKES: I'm sat in my gym at the moment, which is in a double garage at the bottom of my garden. It's kitted out really, really well. I've got a treadmill, weights, loads of really, really good kit.

SCHRAER: Sarah Jewkes is a science teacher from the West Midlands.

JEWKES: And it's all not being used. It's a painful reminder, actually, of the person that I used to be and the life that I used to have.

SCHRAER: She's been struggling with long Covid for almost two years. Although not a professional athlete like Oonagh, she was also super fit and active before she developed long Covid. Now her gym houses her wheelchair.

JEWKES: I make sure that I take everything from upstairs that I need, because I can't manage the stairs very well, so I can only do one set of stairs really a day. I can't stand in the kitchen, because when I stand, it causes blood pooling, so my legs actually turn a bluey purple colour and my feet get really swollen, and the pain in my legs just from standing is horrific.

SCHRAER: Sarah thinks she's spent about £15,000 on treatments with varying levels of evidence and safety before trying the Lightning Process. She found it after going down a rabbit hole of recovery stories on YouTube.

JEWKES: The thought that perhaps my brain could be driving the symptoms was terrifying. It made me more anxious because you can't sit peacefully with your body and your brain, so it made me worse.

SCHRAER: Like Oonagh, and like I was when I did the course, Sarah was encouraged to do something she hadn't done for a long time after one day of doing the process.

JEWKES: So I thought, you know, I'm going to go and sit on the spin bike in my garage, my gym, and just, you know, have this different attitude, so I sat on the exercise bike and I very, very slowly pedalled for about five minutes, and my whole face was twitching, my eyelids were twitching. Whenever I do any kind of exercise or even just quite a low level of activity, I see quite immediate worsening of symptoms.

SCHRAER: Despite feeling worse when she tried to increase her activity, Sarah persisted with the Lightning Process for several months.

JEWKES: It didn't work for me, so I just tried harder. You do blame yourself, and you think you haven't done it right, so it just makes you feel completely even worse that you can't do anything to influence your condition positively.

SCHRAER: By now, she says she felt as if she'd been trained to ignore her symptoms.

JEWKES: I did the Lightning Process and then, about ten days later, I experienced two seizures, but because I'd recently done the Lightning Process and I'd spent a bit of time priming my brain, I just completely normalised and just ignored those really scary, horrible, terrifying seizures that I had and I didn't seek medical attention.

SCHRAER: Sarah doesn't know what caused her seizures - it's not clear whether they were related to long Covid, and there's certainly no suggestion they were anything to do with the Lightning Process. But her experience on the course led her to ignore them.

JEWKES: I just thought that that was part of/ the process, so I completely didn't seek any medical advice, whereas I should have.

MUSIC

SCHRAER: Lightning Process founder, Dr Phil Parker, said it was always disappointing when people didn't find benefit in a treatment, but that this was a possibility with all treatments. I put a series of questions to him about my findings. In an email, he told me he was too busy lecturing to speak to me, but he did send a written response saying that blame, ignoring symptoms and not seeking medical help were at odds with the central concepts of the Lightning Process. He also told me he believes long Covid is physical and that the Lightning Process is not about changing mindset. Instead, he said it is about using the brain to influence positive physiological changes in the body. I also asked him about specific claims made to me by Lightning Process coaches, but in his email he told me our questions were informed solely by the rumours and misinformation circulated by what he called anti-recovery activists. He referred us to what he described as peer reviewed evidence which supported the efficacy of the Process.

WHITFIELD: I knew that I was essentially well within the first two hours of doing the Lightning Process.

SCHRAER: Wow, that's quite extraordinary.
Rachel Whitfield is one of those people who says the Lightning Process worked for her. After a seemingly fairly mild Covid infection, she tried to get back to her usually busy life as a self-employed single parent. But she found herself developing strange symptoms - brain fog, exhaustion and purple toes. She tried to find more information from support groups online.

WHITFIELD: The first thing I posted was, does anyone recover?
And I remember this really clearly - I got no response. Nothing.

SCHRAER: This frightened her.

WHITFIELD: I got told if you had long Covid, then you were exercise intolerant, and I think every time I then tried to exercise, even if it was just sitting on a bike, I would get symptoms, and so I think I formed a conditioned response, basically like Pavlov's dog.

SCHRAER: After six months, she tried the Lightning Process.

WHITFIELD: When I then sat down and I did the Lightning Process course, very early on I said, of course I've got to pace, I've got to manage my energy, I've got to build up really slowly. And she said, Rachel, it's up to you what you do, but you have as much energy as anyone else. They call it the Pit, where you're so full of fear and expectation about this thing that you think might make you worse, that it actually starts to become reality. And something in that just clicked, and I realised that there were some things that didn't add up, like I could walk in my house, but not outside, and I just suddenly realised that my beliefs and my fears and my anxiety had just been keeping me stuck.

SCHRAER: She felt better almost immediately.

WHITFIELD: I went out and I rode my bike for ten miles, and then the next day I did a 5K run from scratch, having not done more than walk to the end of my street for seven months. Not everyone does that. Some people do. I'd done quite a lot of work before that in terms of thinking about how the mind and body are actually one system. I understood fundamentally the mind and the body and the impact of stress, so I'd already worked out that that was a huge factor for me.

MUSIC

SCHRAER: But the idea that anxiety about exercising is at the root of most people's post viral symptoms is an extremely controversial one, not least because of the large and growing body of evidence of physical damage in many people with long Covid. Part of the problem is long Covid is an umbrella term which might cover several different conditions. That's why long Covid specialists say people need a thorough assessment and access to a range of different treatment options, from psychological support to medication.

ACTUALITY IN CLINIC

EVANS: So, here on the left we've just come to our outpatient clinic. People will have blood tests literally just around the corner

SCHRAER: This long Covid clinic in Leicester offers exactly that. Dr Rachael Evans is a breathing doctor and a researcher who helps to run it. It's seen as one of the most comprehensive treatment programmes in the UK.

EVANS: Some people that are recovering but still have got ongoing symptoms, they might need more of a light touch approach. Other people have really severe symptoms and a very difficult time, and we have a much more complex approach. We've got a range of diagnostics - all types of imaging and physiology and blood tests that are all available.

SCHRAER: The Leicester clinic can prescribe a range of treatments from drugs to target symptoms to breathing rehabilitation. But it's not representative of the whole country. 40% of trusts responding to my Freedom of Information request said they had no ability to prescribe medication and almost 20% said they couldn't order tests or scans. Even Leicester's gold standard clinic can only do so much until further research points towards the best course of treatment.

EVANS: So, I think going through the service, people report that they feel better than they did at the start, but I do want to be cautious with that, because we're by no means curing people with these supportive measures, and we urgently need to find the real treatments of long Covid to stop this process in the first place, so we urgently need clinical trials to demonstrate which medications are going to be helpful.

SCHRAER: But, as Covid researcher Professor Danny Altmann is all too aware, those clinical trials take a fair bit of time - and money. And he says that's pretty much dried up.

ALTMANN: Why would you want to do 60 or 70 or 80% of the homework and then, you know, need the funding to get the other 20 or 30% to the finishing line to actually start making people better and getting them into the workforce and not be able

ALTMANN cont: to find anybody who'll even discuss it with you, because, they've lost interest. It seems incredibly shortsighted to me, but that's the nature of it.

MUSIC

ACTUALITY AT AIRPORT

SCHRAER: Unable to find much treatment at home, Sarah Jewkes has been accepted to take part in a Spanish trial of a new drug.

JEWKES: So, I'm here at Bristol Airport, ready to fly to Madrid for a clinical trial. I'm here with my mum, who's taking me, because I'm unable to walk or stand for long periods of time, I'm in a wheelchair. Feeling really exhausted already, but also really excited and really, really hopeful.

MUSIC

SCHRAER: She's hoping it might be a turning point in an illness that has already stolen two years of her life. Research is slow by nature. Even with the best will in the world, it could be years before we have an approved test or treatment. But in the rush to move on from the Covid pandemic, many still suffering its after effects feel they are being forgotten.

JEWKES: I do feel hope. I always have felt hope because this is a treatable condition for sure. The research is out there now. People are improving. I feel hopeful about the future, but I feel really frustrated and sad that it's going to take so long. People have been suffering for years and we need clinical trials now.