SO LONG COVID

Episode 2: Aha Moment

Reading version of the English subtitles

You're listening to the second of six episodes of the podcast SO LONG COVID. The six episodes build on each other. If you haven't listened to the first one yet, it's best to start there.

“Good morning, I hope you slept well. I slept well. I thought maybe it wouldn't be such a bad idea to send voice messages. You might find them a bit more pleasant to listen to than written messages.”

Jann, my partner, is in a rehab clinic for people affected by Long Covid. This is in the spring of 2024.

“How was your evening? Did you arrive safely?”

He has severe exertion intolerance, can only walk a few steps a day, and is sensitive to light and noise. Reading anything on a screen isn't really possible. That's why we communicate via voice messages as best we can.

“Hello Zita. I thought I'd make a voice message now, too. I think it's the first one I've ever made.”

It's very emotional to listen to these messages again today, two years later. I can hear so clearly in Jann's voice how weak he was and how bad he felt. So bad that he couldn't keep his appointments at the clinic. Strength training, occupational therapy, autogenic training, and so on.

He's given an ultimatum: one more week to try. Either he manages to attend enough therapy sessions, or he has to go home. I've had a pretty good day so far. It's been a rollercoaster, and every message I get makes me nervous.

“I'm sorry, but unfortunately, I have some bad news to share again. I'm just too weak again to keep these appointments and do everything they want. And yes, it's really important that I get back on my feet soon and can walk a bit longer. And I want that so badly... but somehow... yeah...”

Jann sounds a bit like a different person to me, and all of this sounds a bit like another life. Or as Jann said in the last episode: like something out of a bad movie.

I'm Zita Bauer, a social anthropologist and journalist and in this podcast, I tell stories like Jann's. Stories of people who fell ill with Long Covid and recovered. What can we learn from them? What was the turning point? How did they find their way back to life? This is SO LONG COVID, Episode 2: Aha Moment.

One of the tens of thousands of people in Switzerland who became seriously ill with Long Covid is Patricia Purtschert. It's a hot summer day, and we meet at a place that holds special significance for her.

Was the lecture in this building? Yes, exactly, in there. Patricia Purtschert is a philosopher and professor of gender studies at the University of Bern. We're standing together in front of the building where she was still teaching in the spring of 2022. And what kind of lecture did you give? It was a collaboration between gender studies and medicine, and I gave the opening lecture here with my colleagues, in this lecture hall, in this building.

The lecture hall, the building, belongs to Inselspital, the University Hospital of Bern. A year after the lecture series, in the spring of 2023, Patricia is back on these grounds. This time, however, in the ward building, as a patient. And then I was somewhere upstairs, I don't remember, on one of the higher floors. Maybe the 10th or 11th. Just like Jann, Patricia could only walk a few metres a day at that point.

Right, and the area between the old ward building and the lecture hall, I don't know either, that's... How far is that, I wonder? 150, no, I'm so bad at estimating, 200 metres. Yes, I would also say it's maybe 150, 200 metres. I couldn't walk the whole way. But I looked over here and realised how close together they are geographically, yes, these two different lives.

I look from the ward building to the lecture hall and back again. Back and forth between two different lives. How drastically can this illness turn everything upside down? Can I sleep tonight? Can I walk today? If so, how many metres? These are the questions Patricia, as a patient, asks herself. Questions that, just a year ago, were

completely self-evident. Back then, she would zip around the corner, park her bike with a flourish and run into the lecture hall.

I constantly thought about wanting to go back to that life, which is perhaps symbolically connected to the lecture hall. That life where I can move around independently and do the things I enjoy. So it was very present, but I just felt like... it was infinitely far away. I couldn't imagine how I could ever return to a life like that with a body like this.

Patricia's story reminds me a lot of Jann's. Both work at the university, both become seriously ill with Long Covid, and both are, at the lowest point of their illness, taken to a clinic in a wheelchair.

“Hey and... Yeah, this thing with... Long Covid... "Fuck my life"... This is really something right now...” A voice message to a friend. Sorry for the language. But I have to say: the phrase fits. The online Urban Dictionary says: Fuck my life: When something doesn't go as hoped. “And now, in the last two weeks, it's just gotten massively worse again. Yeah, and now it's really... bad, yeah. So... It's hit me hard. I've rarely in my life gone through something so... so difficult. Or am going through it. Somehow enduring that he's doing so badly, and... enduring that nobody knows how long this will last.”

It's precisely these stories you hear... about months, years... irreparable, incurable... Then I fall completely into a slump... Pacing like a world champion, energy management, all sorts of supplements, a low-histamine diet, absolute rest: we've tried so much. Nothing has really helped Jann. And even in the clinic, the big breakthrough hasn't happened yet. I went to visit him at the weekend. He could only see me very briefly.

Five hours on the train, fifteen minutes together. I knew he couldn't help it at all. It still made me sad, though. How is this supposed to go on? On the way home from Gais to Bern, I sit on the train and gaze absently out the window. Then I take out my phone. I've read so much about Long Covid online. In specialist journals. In forums for those affected. And on social media. It feels like a swamp of negative reports: about terrible fates, about care that is nowhere near enough, and the desperate search for solutions. I think it's important to report on the restrictions and the hopelessness. But at some point, it just depressed me. Add to that all the pseudo-medical offers where you're not quite sure: are they just making money from the despair of those affected and their families?

And in this quagmire, I suddenly stumbled upon an article. In the Guardian, the British daily newspaper. "If you have Long Covid, like I did, don't give up hope. Recovery is possible." I was sitting on the train, suddenly wide awake. This faint glimmer of hope really excited me. Hi, hi. I don't know why you can't tell from my voice, but I was really excited.

Maybe I didn't want to upset Jann too much, or maybe I didn't want to wake the neighbors. Anyway... I tell him about this article in the Guardian. The article is by an infectious disease specialist named Paul Garner. And Paul Garner talks about his own experience. He had Long Covid himself and has now fully recovered. Paul Garner has an explanation for Long Covid that I'd never heard before.

The nervous system is overactivated and therefore constantly sends out false alarms in the form of various symptoms. Nothing is actually damaged in the body itself. And he describes what helped him. He writes that he stopped constantly monitoring his symptoms. He stopped focusing on the symptoms. A plausible explanation for his condition changed everything for him. That's how he managed to get out of this terrible illness.

Hearing that gave me courage. But I also wondered whether this explanation was correct and whether it all really works. It worked for Paul Garner. He has fully recovered. I meet him for an hour-long interview via video call. And that would never have been possible during his illness. Nice to see you. Good to see you. Paul Garner is 70, an epidemiologist and public health expert.

We already talked about him in the first episode. He's one of the first to report on the long-term effects of COVID. He experienced the symptoms like a never-ending roller coaster. I really could not understand it, but I obviously interpreted all the symptoms that I had, that came and went, as directly attributable to this weird, mysterious virus that was causing such havoc in the country.

I mean, it was like a boom, it just bang. This strange virus had hit like a bomb. He simply couldn't explain his strange condition in the weeks after the infection. So he did what he does best as a professor of infectious

diseases: He approached his problem scientifically. He meticulously recorded in tables what he did, what he ate, and how all of that affected his condition.

Did you have one of these watches? Yes, yes, absolutely useless, completely useless. So... I mean, I had spreadsheets, what my body battery was, and what, you know, sometimes I woke up and my body battery was incompatible with life. I mean, it was sort of just... That nothing had happened. It was all over the place. He bought one of those pulse watches, just like Jann.

But he says it was completely useless. His observations made absolutely no sense. You can tell Paul Garner is someone who speaks his mind. That's also true about the moment that changed everything: It is a bit like a switch. It is an aha moment... There's even a scientific explanation for such aha moments. Apparently, there are thoughts in our unconscious that are circulating around, that we haven't quite put together yet.

And then occasionally things kind of fuse, and then the brain sends it up into your cortex, and you suddenly think: Aha! and it's associated with great pleasure, apparently. So I think we all need lots more aha moments. An "aha" moment occurs when our subconscious processes and recombines information. It happens in the background, before we consciously think about it. When a coherent solution is found, it enters our conscious awareness.

And that feels like a spontaneous realization. Happy hormones are released. We experience joy and relief. Paul Garner's "aha" moment was triggered by an encounter with a psychologist from Norway. She herself had recovered from ME/CFS. This encounter was a happy coincidence. And then this person asked me if I was open to the idea that there might be something to do with my brain being involved in this.

And I said yes. The person then gave me an explanation of neural pathways, fairly basic at that time. This person, this psychologist, explained: Your symptoms are real. But they aren't a result of physical damage; they're learned by the brain over time. And like everything we learn, this happens through new neural connections. The subconscious mind assesses situations as threatening, activates the nervous system, and sends physical signals like pain, fatigue, fever, increased pulse, flushed skin, and so on.

So, measurable symptoms. These processes happen automatically and unconsciously. We have no direct influence over them. Just like aha moments, which originate in the subconscious and which we therefore can't force. And then the psychologist got to the crucial point: Even though these processes happen unconsciously, you can unlearn these symptoms in the long term. You can get healthy again. And suddenly my world changed.

There was a way out. And that in itself, the explanation and the hope, started the process of getting better really quite quickly. The explanation and the hope that things could get better were the starting point of the recovery process. You can unlearn the symptoms that make your life a living hell. Not with medication, not by tracking your energy levels. But with new neural pathways, with conscious actions that influence the subconscious.

That's how it worked for Paul Garner. And there are other positive examples, too. Even in Switzerland. Shortly after I discovered the article in the Guardian, a friend told me about Patricia Purtschert, a professor at the Interdisciplinary Centre for Gender Studies. I immediately told Jann about it in a voice message. And that she had done exactly that, that she had outsmarted her brain...

Or perhaps "outsmarted" is the wrong word, but rather retrained it. And she, too, got out of it in exactly the same way. That had been a problem for a long time, that I couldn't imagine it... It kept getting worse, and I couldn't imagine how the body could ever recover. It was a mystery to me. That was in the spring of 2023. Patricia had been ill for many months.

She's at a loss. How will things ever get better? After it had been a downward spiral for a long time, which I couldn't interrupt, even though I really did everything conscientiously that I was told to do, really... So, with all the discipline and willpower I have, and it's not insignificant, it just kept getting worse. And then there was this turning point. And that's when I had the feeling that, although I'm still incredibly far from being back to normal, I somehow realised, okay, somehow I'm getting my feet back on solid ground.

While she's in the hospital, Patricia also makes a discovery that changes everything. As she's telling me about it, church bells start ringing somewhere. As if they wanted to emphasize how important what happened is.

Exactly, the crucial thing actually happened right here. It's a coincidence. Because in those few moments each day when I could access my phone or social media or the internet - which was very limited, also because of my...

...the slightest exertion triggers terrible symptoms. She can only be on her phone for a few minutes a day. And in one of those moments... I was on Altea - that's a network founded by health experts for those affected - I read a post from someone who had a very similar illness to mine and who recovered relatively quickly. And this person described it.

And that really was such a key experience. I read the post and realised: okay, this is like a new door opening. And I was desperate. I really realised... With every fibre of my being, I want to get back to life. It was good to realise that so clearly. There was absolutely no doubt that I would do everything I could. And in her post, she described it as if the nervous system had gone haywire.

That was her way of putting it. And she also pointed to several websites, articles, and especially websites with recovery stories. And that was very important. Because I'd always read so many negative accounts. So many frightening accounts. Accounts that basically say: the longer it lasts, the harder it is to ever get out of it. And so, in essence, the advice was: you really have to read recovery stories, you have to see how others got out of it. And especially the reference to the nervous system, that made perfect sense to me.

It really just clicked. And that was actually when I started to engage with these approaches. And I would truly say that's where everything changed. In the post Patricia is reading, several articles are linked. Among them is one from The Guardian. "If you have Long Covid, like I did, don't give up hope! Recovery is possible. It was shortly after my 30th birthday, in March 2024, when I learned about Paul Garner and Patricia Purtschert.

That was the week Jann got his last chance at rehab. It felt like a belated birthday present. I sent you lots of voice messages afterward, telling you about Paul Garner and then about Patricia. Do you remember what you thought about the ideas and approaches I told you about? Well, first of all, there were a lot of voice messages... Far too many for me to listen to all at once.

But I became very interested. Above all, I could immediately identify with it very strongly. We're listening to a voice message from that time together. "Hello, Zita..." That was a week later, because you somehow needed time to become familiar with these things. Then there was a day when you sent me a lot of voice messages. I don't remember that at all. You don't remember?

No. I think that was the day you saw Schubiner's video. Ahh... It was really good to hear that video again. And I'm totally convinced by this Schubiner. Howard Schubiner is a doctor and professor from the USA who has been treating patients for 20 years with the same techniques that helped Paul Garner and Patricia Purtschert. I remember feeling like something "switched" for you.

Like, you developed a different kind of confidence that it would all work out, or something like that. I think that's when I really understood what it meant. And I think I also understood its implications. That it's not at all specific to Long Covid, but that it 's a new way of understanding the body. Or how... how the body works. I think that's what fascinated me so much back then.

I remember being so happy that Jann had gained faith in the idea that things could turn out well, that recovery was possible. But at that point, he was still in the clinic. Seriously ill. And pretty much alone with this new information. A message from back then. There are always phases where you have doubts because it's really difficult. But now I'm 100% convinced that this is the way forward.

And I'm looking forward to taking this path. But somehow, here in the hospital, nobody is doing that... nobody even has this approach. Instead, it's always just assumed that you can't cure it at all. Long Covid as an incurable disease. This portrayal has held Jann back. He keeps hearing that it's primarily about accepting the illness and avoiding overexertion. Because otherwise it becomes chronic.

That is the dominant narrative. Not only in the clinic, but also in Long Covid consultations, in patient organisations and in many media reports. There are people who have suffered from ME/CFS for years, even decades. And now, these individuals are reporting that they have overcome this very illness. And not only that, People are also reporting a new explanation for these previously unexplained symptoms.

And these chronic symptoms, which can severely restrict life, can supposedly be unlearned. A complete recovery is possible. However, there is another perspective on this. One could also say: these are more claims circulating, like so many others. It is indeed suspicious that, for example, the specialized Long Covid clinic apparently knows nothing about this approach. I've also wondered if I'm falling for some kind of hocus-pocus.

When you're desperate and hopeless, you're particularly susceptible to dubious promises of cures. And that can get really expensive. There are plenty of tragic stories about that. So what's behind this explanatory model? Can it be trusted? And why aren't there more specialists working with it? We're simply not taught it. We doctors don't learn it during our studies. You can practice excellent pain therapy or medicine in general and still completely miss the latest findings.

That's what Antje Kallweit says. I was originally an anaesthesiologist, then completed my pain therapy training and now have my own practice in Hamburg. Antje Kallweit has been working as a pain therapist for about ten years and with these new methods for about four years now. And that came at just the right time for me because I was totally frustrated with my patients and felt like I could not really offer them what I would like to.

About five years ago, Antje Kallweit came across a podcast by a psychotherapist from the USA. Hello hello, how are you today? This is Nicole. You've reached my podcast, The Cure for Chronic Pain. Welcome, welcome... The Cure for Chronic Pain. - that was a title that, as a pain therapist, naturally caught my attention because I thought, "She can't possibly claim that. It doesn't exist."

Curing chronic pain. At that time, that simply didn't exist in the world of pain therapist Antje Kallweit. She became curious and listened to several episodes of the podcast. I remember it in the garden somehow, while weeding. There in the garden, weeding and listening to the podcast, she too had an aha moment. When I thought: wow, crazy, this is exactly what I experience in my practice, and she's presenting me with a tool, a way to approach it further.

And I realised that what she does in her podcast is only part of the whole truth. and that behind it there is a completely different, scientifically sound new pain therapy movement. The new pain therapy movement that Antje discovered is still relatively unknown in German-speaking countries. And then I applied it and realised: this is crazy, because it works incredibly well. And there are so many new things that still haven't arrived here in Germany and are not widely available.

What are these new scientific findings? And can it really be that there are promising findings that simply haven't reached a wider audience yet? I completely understand if scepticism arises at this point. It doesn't even have to be absolute conviction; nobody really has that when they start out. But an idea that somehow something doesn't add up. It often starts with just one story.

With another person saying, "Oh, look what happened to me and how it worked for me. And that's why these recovery stories are so incredibly valuable. Paul Garner came into contact with this Norwegian psychologist by sheer luck. Patricia Purtschert found a post by another affected person in a forum. And these two stories opened a new door for Jann. Hearing from others who have completely overcome this terrible illness gave him new courage and strength.

Until it then actually happened like in a movie. It happens exactly as Jann imagined. There's the plot twist where the story takes a new direction. And you then wrote your own recovery story, About six months after I came across the idea, Jann wrote his own recovery story. What was your motivation for that? It was like a coincidence that we stumbled upon this knowledge.

And that only happened because someone had written it down and shared it. So, that's something I wanted to share. And, um, also to know that so many other people are suffering from it. All the people I met and got to know in the clinic. That hopefully, many more people can experience the same thing. Paul, Patricia, and Jann aren't the only ones with recovery stories.

I came across so many during my research, including in Switzerland. Perhaps you know the story of the professional cyclist Marlen Reusser, who is back at the top of her game after recovering from Long Covid. I myself, as you said, experienced this illness. And I also encountered the narrative in Switzerland that it's very hopeless. That many people don't feel well for a long time. And that there's nothing you can do.

That you basically have to wait with your hands tied, hoping that you'll be lucky enough to recover somehow, or that you'll be one of the unlucky ones and simply have it forever. And that made me incredibly sad, incredibly hopeless. Until Marlen was made aware of the new approach from several sides. By her partner, her best friend, and: One way was that Jann and Esther told me about it.

Marlen also heard about this new understanding of illness from Jann, through a mutual colleague. The impetus for change, the access to this new knowledge, often comes from another affected person who shares their story in an article, a post, or a podcast. I mean, if I hadn't had people who introduced me to it, I never would have come across it. And suddenly, questions arise that you've never seriously considered before: Who can tell me where the boundary between body and mind is?

What exactly is behind this new pain therapy approach? And does it really make sense? It's science. This is just science. It's the science of the brain and how the brain works. And that brings us to the crucial question: And now you are saying that Long Covid or Post Covid too is a neuroplastic condition? More on that next time. It was a crazy week.

It was an insane week. And I think that week I changed my whole mindset about medicine and the world. This is SO LONG COVID, an independent production by Jann Zosso and me, Zita Bauer. If you enjoy the podcast and find the topic important, we'd be very grateful if you'd recommend it. And a rating in the app helps us get discovered by others.

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