SO LONG COVID

Episode 5: So Long, Cohen

Reading version of the English subtitles

You're listening to the podcast "SO LONG COVID." Episode five of six. These six episodes build upon each other. If you haven't listened to the first one yet, it's best to start there.

Good evening, dear passengers, we'll be arriving at Basel SBB station on platform 11 in a few minutes. Exit on the left-hand side in the direction of travel. Today, I'm visiting the University Hospital Basel.

Now I think I'm in the right place... I'm standing in front of a large metal door. You could almost call it a gate. How do I get in here? I don't see a door handle or a switch. And then, suddenly, it opens by itself. I meet Katrin Bopp, a specialist in internal medicine and senior physician at the medical outpatient clinic. She and her team established one of the first Post Covid consultation services in Switzerland in 2021. They had a good laugh when we sent the interview request.

It was because of the podcast's name. What's the story behind it? That we actually gave our last lectures under that title. And of course, I found it absolutely fascinating that there's now going to be a podcast series with the same title. As head of the Post Covid consultation service, Katrin Bopp regularly gives lectures for other professionals. Under the same title: "SO LONG COVID."

The story behind it is that I spent some time studying Leonard Cohen. And there's a podcast about Leonard Cohen. And the title? There was a picture of Leonard Cohen and it said "SO LONG COVID"... At least, that's how I read it. And then my brain perked up. Something's not right here. Why is there a picture of Leonard Cohen and Covid? And then it dawned on me: For a split second, what I've been doing all along - dealing with Long Covid - my brain simply read the letters it recognised.

Even though it said something completely different. It said, of course, "So long, Cohen." Katrin Bopp's brain turned "So Long Cohen" into "SO LONG COVID." That's something that happens to us humans all the time. We already talked about this in the third episode: The mechanism is called "predictive processing" or "coding." It's due to evolution. Our brain consumes a relatively large amount of energy, and this is essentially an energy-saving mode.

If it doesn't have to finish every thought from scratch, or constantly analyze every sensation, we save energy by predicting. Secondly, we can protect ourselves better if we 're always one step ahead of a potential strain or danger. Our brain constantly tries to predict what we'll see, hear, or even feel next, based on our experiences. And mistakes do happen in the process. This is precisely what happens with neuroplastic symptoms.

The brain anticipates danger and sends out symptoms, even though the bodily signals sent to the brain are actually harmless. Because predictive processing is central to her work with Long Covid patients, Katrin Bopp incorporated this little mix-up between Cohen and COVID as an anecdote into her lectures. We then incorporated that into our lectures to show where this is happening. And simply to include the meaning of this phrase, because it has something of a farewell, "so long," and something of "it is sooo long."

And it also has something of "So, Long Covid." Now let's talk. This is "SO LONG COVID." An independent podcast series. I'm Zita Bauer, a social anthropologist and journalist. You are listening to the fifth episode: "So Long, Cohen." So, Long Covid. Let's talk. And for that, we're going to the office of Rainer Schäfert, professor and head physician for psychosomatics at the University Hospital Basel.

Because Long Covid is so complex, they work interdisciplinarily at the University Hospital. And that's precisely why Rainer Schäfert and Katrin Bopp wanted to do the interview together. Because of their close collaboration across departments. Especially regarding the Long Covid consultation and, by now, more generally, for fatigue patients. This is a very important collaboration for us, in which we are also conducting a joint research project on Long Covid.

The team in Basel is part of a large-scale European research project: Horizon Europe Long Covid. This is a consortium of different research groups: virologists, researchers working with mouse models, experts in blood coagulation, and so on. And as a consortium, we have really investigated these Post Covid syndromes from all angles. And I expected we would find something. And I am still surprised that we have found almost nothing biomedically.

So no clear, unambiguous explanatory possibilities. There is no single physical cause for Long Covid. The most important news is that, to this day, there isn't a single pathomechanism that can be measured in any way. Neither in imaging nor in blood tests. There are countless antibodies that have been studied, but which also occur in healthy individuals. Or whose elimination doesn't eliminate the symptoms.

And I believe this contextual information is very, very important for those affected, who have to navigate a sea of information. And that's practically impossible without someone who knows the subject. To categorize and evaluate all this information from reports and studies requires expertise and experience. The clinical pictures of Long Covid are diverse. Up to 200 symptoms are associated with this disease. Those affected experience an average of twelve of them.

This makes it even more difficult to assess one's own condition. Then there are the different histories. In our consultations, we see patients whose history includes depression, trauma, anxiety, autism, ADHD, burnout, sleep disorders, and pain. But we also see those who don't have these issues. There are always multiple aspects to an illness and its recovery. In addition to physical factors, psychological and social factors can also play a role.

For example, loneliness or financial worries. This is true for every illness. Even with a broken leg, the course of recovery depends on our overall health and whether we have any additional stressors. Considering all these factors is a fundamental insight in medicine. This is known as the biopsychosocial model. And we've noticed that in patients whose depression improved over time, the symptoms often persist.

We've also had patients who lacked any of these factors, which we call vulnerability factors, and yet still experienced symptoms. Although no structural abnormalities were found in Long Covid patients, simply treating the psychosocial factors wasn't enough, explains Katrin Bopp They were still missing a piece of the puzzle. And you can imagine what it was: new knowledge from neurobiology and modern pain therapy. That was a crucial piece of the puzzle for us.

The neuroplasticity of the brain is closely linked to the theory of predictive processing or coding. And pursuing this further, acquiring more knowledge in this area, was a crucial factor for us in developing our explanatory model into what we can now explain in our consultations. They worked on the aforementioned EU research project, exchanged ideas with international colleagues, read countless scientific papers, attended conferences, and learned from patients.

And with all of this, the team at University Hospital Basel arrived at the same conclusion as the experts we heard in the last episodes: that in a large proportion of people affected by Long Covid, neurobiological mechanisms play an important role. The brain and nervous system have learned disease symptoms. And "learned" in this context doesn't mean I learned vocabulary, I actively made this symptom appear.

Rather, there are people in whom neural networks in the brain persist after an event - in the case of Long Covid, the Covid infection - even though the acute situation is over. This seems to be particularly true for people who learn well, whose brains make connections quickly. And they don't choose this; it simply happens. Their neuroplastic, biopsychosocial explanatory model is proving effective.

You are convinced of it and are continuing with it. Yes, absolutely. We see, we are hearing a lot of feedback on this from those affected, and we are convinced that it plays a very, very, very large and relevant role. Yes. Patients in the Post Covid consultation in Basel are already hearing very early on: Recovery is possible. At the same time, it is very important that no feelings of guilt arise if recovery doesn't go as the person affected imagines.

It's not about not doing well enough, about not succeeding. It's about walking this tightrope together and enduring it. You can't force recovery. And fundamentally, every recovery path is different because everyone's starting point is different. There are patients who develop COVID-19 and then Post Covid symptoms even though

they were in very good health. But a large proportion of patients had already had significant burdens in their lives beforehand.

And that makes it more difficult. They need more specific support, which is precisely what we try to provide in this multidisciplinary, interprofessional team. And not everyone receives the same thing. The therapy is tailored to each individual. But for everyone, the first step is to strengthen safety and trust. This includes differential diagnostic assessments. Ensuring that nothing has been overlooked. Building trust that the body itself isn't damaged.

A stable relationship between the healthcare professionals and the patients is also crucial And therapy then takes place on this foundation. In Basel, this approach encompasses pretty much the same points we presented in the last episode. First and foremost, it's about education - informing people about how neuroplastic symptoms develop. Then it's about reinterpreting the symptoms. For acute symptoms, Rainer Schäfert also recommends Somatic Tracking: observing the symptoms with curiosity and an open mind.

And then it moves more towards taking action. Often, there are ingrained avoidance or protective behaviours, stemming from a desire to protect oneself, to take good care of oneself. But these can actually exacerbate the symptoms. And once this is understood, the next step is to dismantle these avoidance and protective behaviours. Since the beginning of the year, they've offered their patients group therapy where they all work on this together.

The goal is to teach themselves, step by step, that the symptoms aren't dangerous, to gradually resume doing things, and thereby conveying to the brain, "You are safe, you can trust." Taking new actions, doing something different - that's the most powerful message you can give your brain to effect change. When I truly do something new, the brain begins to rethink its processes. For almost two years, they have been studying neuroplasticity and predictive processing at the University Hospital Basel.

Over time, it became increasingly clear to them what an important role these play in Long Covid symptoms, and also how much research already exists on the subject. These findings have increasingly been incorporated into consultations and therapies. Today, Katrin Bopp, Rainer Schäfert, and their team understand and treat Long Covid. as a neuroplastic symptom complex. This is pioneering work in Switzerland. So far, it's still a relatively small group of people working with it.

However, we're hearing from various sources that these findings are gaining traction. Besides Basel, we know that the Lucerne Cantonal Hospital has integrated neurobiological insights into its treatment concept. Lara Diem, head of the Post Covid consultation, writes in response to an inquiry: she is very familiar with the neuroplastic approach and considers the treatment methods scientifically plausible. Brain retraining, i.e., the reinterpretation of symptoms, is a component of their therapy.

Other hospitals have already heard of it, find it interesting, and see it as a potential solution. However, they lack the resources to work with it seriously. For example, I heard this from Iris Katharina Penner at Inselspital Bern. She was featured in the first episode of the podcast. We simply don't have the staff currently available to do this with patients. But if I had more staff, I would certainly do that.

Other hospitals declined to comment. At the moment, it's a matter of chance whether you find a doctor who integrates findings from neurobiology and pain therapy into their treatment. Katrin Bopp, head of the Post Covid consultation at the University Hospital in Basel, is also aware of this. We know that there are still very different approaches, which makes it very, very difficult for those affected when some doctors still talk about a serious, incurable illness, and others come up with a different concept.

And I think at the moment we can only observe without judging. We can offer what we know and can do. And we can explain it in a well-founded way. But it's true that the landscape isn't uniform. How can this be explained? Why is the approach, which seems to work for so many, only spreading hesitantly? Why, on the contrary, does it sometimes encounter strong resistance?

Why aren't we listening more to those who have recovered? These questions occupied me throughout my research. And I also asked them to numerous interviewees. Okay, so now we are coming to that question: Why these neuroscientific approaches... from the field of chronic pain haven't made their way through. Not yet. Why is

that? What's the situation in Switzerland? Why isn't it mainstream yet? It's like an onion, you have to peel it a little bit.

You haven't heard this voice before. This is Monica Greco. She's a professor of sociology at the University of Bath in England. Her research lies at the intersection of sociology, history, and philosophy, with a focus on psychosomatic medicine. Her answer to my question: So the most immediate answer to that question could be that there is a lack of education and training in medical schools around this.

That the knowledge is simply not addressed enough in medical studies. Where physical medicine and psychiatry are very separate, these conditions really fall in a no man's land. Because physical and mental health are often viewed separately, these insights fall through the cracks. I do wonder a bit, what have we actually learned? Because I never listened with that filter the way I would today.

The cyclist Marlen Reusser, who studied medicine in Bern. There was always a clear distinction made between purely physical illnesses and those that actually originate in the mind and have an effect on the body. I would say - and I might be corrected by others, I'm very open-minded - but I would fundamentally differentiate them that way. And I wouldn't actually endorse that distinction anymore today.

New ideas always take time to permeate medical training. And the knowledge about the neuroplastic origins of symptoms is also relatively new in the history of medicine. Silje Endresen Reme spoke in the last episode about five years since the paradigm shift occurred: the shift from simply talking about symptom relief to increasingly about recovery. Pain therapist Antje Kallweit also mentions this relatively recent development.

It was only in 2017, nine years ago, that the International Association for Pain Research (IASP) introduced a new pain category: nociplastic pain. It's that new. In medicine, that is no time at all. From the first term and its appearance in official guidelines to today... it's no wonder that it's still completely unknown to many people. Nociplastic means practically the same as neuroplastic. It's a bit confusing with all these terms: mind-body, neuroplastic, and nociplastic.

This is simply due to the fact that the knowledge isn't yet widely established. And then there are also the terms psychosomatic and functional disorder. These have been around for a while and describe physical symptoms without structural damage. However, they are broadly defined and sometimes misunderstood. Today, we've moved a step further and can describe it more precisely based on neurobiological findings, using the terms neuroplastic or nociplastic.

And the crucial point is that there are concrete therapies that build on this new knowledge with the prospect that recovery is possible. But enough of this digression on terminology. We were actually discussing why this knowledge about neuroplastic or nociplastic symptoms is spreading so slowly. One answer is that there aren't that many studies on the subject yet. And medical professionals, for very good reasons, prefer a large number of studies.

There aren't that many yet because this knowledge is still relatively new. That's one reason. Another, almost more important one, is the complex clinical picture of Long Covid and ME/CFS. The effectiveness of a pill is easier to test than the effectiveness of a combination therapy tailored to individual symptoms and a person's unique life context. The design of medical studies is generally better suited to clearly measurable physical problems for which a single intervention exists, such as a medication.

And then there's also the question of research funding allocation. Iris Katharina Penner from Inselspital Bern: It must be said that behavioral research - that is, research that isn't about cell research but rather about behaviour or these invisible symptoms - receives far, far less funding, including from the Swiss National Science Foundation (SNSF) and other institutions. And I don't think that is justified. All of this brings us to the general understanding of illness that we have as a society.

The dominant paradigm, the dominant set of assumptions, are still biomedical. We're back to Professor Monika Greco's explanation: The dominant paradigm is still biomedical. This means that illnesses that can be measured and localized are culturally valued more highly and are more socially accepted. A heart attack or a broken leg, for example. People say: "Aha, you've broken your leg. Of course, you can't work."

Illnesses that are less tangible, that can't be measured, where you don't have a cast on your leg, are taken less seriously. People are more likely to say: "So you can't, or you don't want to?" And these ideas are ingrained in all our minds. Marlen Reusser: Ultimately, the patients, like me, are the problem. If a doctor had told me earlier: "Your symptoms are learned and you can get rid of them by reprogramming your brain" - then I would have said: "Yes, I'm sick, you'd better help me!"

Then nobody feels taken seriously. I believe that if we could integrate into our culture, into our understanding, the idea that this is just as real and just as present, regardless of the cause or the chicken-and-egg situation, but if one doesn't feel diminished because of it - why does it always have to be the broken leg? Not all illnesses are judged the same. If you don't have a measurable cause for your symptoms, you're not really ill.

You're somehow partly to blame. You're stigmatised. Monica Greco: The moral burden, the stigma associated with them and so on, is almost as bad as the symptoms themselves. And certainly, again, if we go along with the brain-based explanations, we have to assume that this stigma and so on feeds into the processes that aggravate the symptoms. And the stigmatisation only makes the symptoms worse.

With doctors, in contact with disability insurance, or even with employers, patients often have to prove that they are really ill. And culturally, "really ill" tends to be something physically visible. There is some wonderful research by Nordic anthropologists who have studied interactions in clinics. They have also studied the way patients talk about their symptoms when they are outside the clinic. Studies show that in a medical context, patients emphasize the purely physical aspects of their illness, hoping to be taken more seriously Because they think that's the only way they will be taken seriously by the doctor.

When they go home, they might talk to the rest of their family using very different vocabulary. At home, they talk about it quite differently. Monica Greco quotes a fitting statement by Nortin Hadler, an English rheumatologist: If you have to prove you are ill, you can't get well. It's because all your energy goes into demonstrating your illness, indulging in your illness and staying in your illness, rather than going into getting better.

If you have to prove that you are ill, you cannot get well. All your energy is focused on being ill instead of getting well." The stigmatisation of symptoms that don't have a structural cause is deeply ingrained in our minds. I wish our culture would quickly accept that this isn't worse, just different. And that when a doctor suggests this therapy, people don't think: "They are not taking me seriously," or "This will not help anyway."

Preconceived notions of what constitutes illness and what doesn't can lead to a situation where only purely structural explanations count, and everything else is devalued. This is particularly evident on social media. For example, on Marlen Reusser's Instagram profile. She received a lot of negative comments on her video, which we listened to in the third episode. People were saying things like: "I didn't even have Long Covid," or "I couldn't know," and just all sorts of things like that, and some of it was really not great.

The private messages, on the other hand, were very positive, as she'd already mentioned. And even now - a year has passed - people write that they started doing it afterward because of it, and that they're now cured and feeling better. A lot of people write to me like that, but it always comes as a private message, and then I think there's definitely a bias there.

I've also spoken with people who have recovered and who would have liked to share their experiences with others, to offer encouragement and show a possible path forward. But they didn't. Because they didn't dare to post anything. For example, in the Facebook group of the association "Long Covid Switzerland." They had the justified fear that their illness and their recovery path would be dismissed, or even that they would be portrayed as traitors.

The harsh tone of this debate also troubled me from time to time during the podcast's production. And there were moments when I really thought: Come on, let's just give up. And then I asked myself: What's the problem? If this approach can help even a single additional person, then it would be legitimate for me to share that. And I found that very unfortunate.

Some of the comments were also below the belt, very thoughtless. People who speak out publicly, like Marlen Reusser, become a projection screen. For all the frustration and anger about the lack of recognition, the inadequate care, inconsistent information, and their own despair. Paul Garner, whom we heard in the second

episode, said he even received death threats. And the outrage from a segment of the affected community is then picked up again by the media and also by the medical establishment as the "voice of the affected."

Marlen Reusser is certain: The knowledge about the neuroplastic development of symptoms will be fully integrated into clinical practice in a few years. It's simply unbelievable. These days, all I can do is shake my head at us. It's just a gap. It's something whose importance hasn't yet been grasped. Something that's often still completely ignored. Monica Greco sees the change already underway. The cultural shift, we are beginning to see it happening.

You know, 20 years ago, we couldn't have had this conversation. Twenty years ago, we wouldn't have been able to talk about this topic in this way. She observes that we, as a society, are in the process of developing a vocabulary around neurobiological explanations and the dysregulated nervous system. The topic is becoming increasingly visible. For me, this also includes the founding of Mind Body Switzerland, an association for the treatment of neuroplastic symptoms.

Their very first meeting was on a sunny Friday afternoon in early March, two days before we released the podcast. And I was there. I warmly welcome you all. It's so cool that you're here. Four people met in the Länggasse district of Bern. Among them was Daniela Knup, who had the idea to found this association. Daniela studies health sciences. And I myself contracted Long Covid two and a half years ago.

I somehow stumbled upon the mind-body approach and recovered as a result. I've now written my master's thesis on this topic and networked with people. And that's how the idea arose to found the association with Alexandra. Alexandra Burki has been a craniosacral therapist for 25 years and is a trained Pain Reprocessing Therapy therapist. With the neuroplastic approach, she was able to almost completely cure her own migraine symptoms.

I searched for therapists and doctors in German-speaking countries who work with this approach. And there are still very few. And based on this, I then tried to bring together those who already exist. Together with other affected individuals and therapists, Daniela and Alexandra launched the association. The association's goal is to create a website with compiled information in German. They also want to connect therapists and those affected.

And they already have a concrete idea for that: peer support. People could ask questions, like how those who have recovered did it, and whether they can offer any tips. Another idea is perhaps group meetings. Offering a monthly group meeting where those affected can exchange experiences, share their stories, and realise that everyone is going through the same thing, everyone experiences setbacks, everyone has doubts, and it's not a linear process.

We all know that social contact with like-minded people, with people who have the same symptoms but also the same knowledge, offers a great opportunity. It shows that healing and recovery are possible within this context. Even the hope of a possible recovery can in itself contribute to an improvement in symptoms, as they themselves have experienced. There's nothing worse than losing all hope. It will still take some time until the association has set up the website and peer support mentioned above.

They are doing all of this on a voluntary and part-time basis. However, they already have a domain and an email address, which we have linked in the show notes. It is those affected, their relatives, and dedicated professionals, like those at University Hospital Basel, who are moving this work forward despite all the resistance. These initiatives also include the websites chronischbesser.ch by Serena and neurojackpot.com by Adrian and Samira.

Swiss websites that have been sharing knowledge about chronic pain since 2021 and 2022, respectively. And almost at the same time as our podcast was released, another website specifically for Long Covid was launched: cfs-hilfe.ch by Cédric. Change is happening. But it takes time. Those affected need perspective and support now. That's why these websites and the podcast you're listening to exist. There are ferments of counterculture happening in between spaces, not necessarily in the official spaces.

Hope arises in the in-between spaces. In the interstices, in the vernacular, in the places where people self-organize, and do things for themselves. And that's where the hope is. In the places where people organize

themselves. Where they take matters into their own hands. That's where hope is. There is a crack, a crack in everything. That's how the light gets in. You can add up the parts. You won't have the sum.

You can strike up the march. There is no drum. So Long, Cohen. The fifth episode of the podcast "SO LONG COVID." And the next episode is the grand finale of this podcast series. It will be released in two weeks. Jann and I are going back to Gais, back to the place where he was admitted two years ago, seriously ill. Crazy, right? Yeah, it is.

When you arrived, we just had to drive up there and then get the wheelchair. Yeah. You can't even imagine it anymore. We hear how the neuroplastic approach has improved the lives of Jann, Jasna, Marlen, and Patricia beyond Long Covid. For years, I suffered from chronic neck pain. And with the same techniques, I was able to combat and unlearn these symptoms. To realise that possibilities for recovery and for returning to life were truly opening up for me inside.

And that's exactly what happened. It was an incredible feeling. That week, I was truly myself. I was finally the cheerful person again. Yes, and now we're going I don't know, swimming in the Aare again. And we're asking ourselves, what's needed now? What needs to change? And what does this new knowledge mean for medicine? It points to a revolution, a small, quiet revolution in medicine that's brewing little by little, bubbling up little by little.

And there's no doubt in my mind that this will happen. This will become mainstream. Whether it happens in my lifetime or not, I don't know, but it will happen. The last words of this episode from Howard Schubiner. "SO LONG COVID" is an independent podcast series by Jann Zosso and myself, Zita Bauer. If you enjoy the podcast and find the topic important we would be delighted if you recommend it to others.

A rating in the app helps us be found by others. We listened to an excerpt from "Anthem" by Leonard Cohen. The rest of the music was composed by Janos Mijnssen and Moritz Widrig. Mastering, mixing and sound design: Christina Baron. Dramaturgical consulting: Franziska Engelhardt. Editorial support: Stella Bollinger. Voice direction: Irene Müller. Recording studio: Radio RaBe. Host and editing: Zita Bauer. Production, concept and editorial: Jann Zosso and Zita Bauer.

You can find all information about the podcast on our website: solongcovid.ch.