SO LONG COVID

Episode 1: Incurably Ill

Reading version of the English subtitles

In the spring of 2020, exactly six years ago, we experienced something none of us had ever experienced before. This is an appeal from the Federal Council to the entire population: Take these measures seriously. Lockdown, distancing rules. Stay at home whenever possible. Today, it all seems a long way off. The pandemic is over. But not for everyone. There are people for whom Covid never ended. One of them is Jasna Cotting.

I'm Jasna. I'm from Fribourg, as you might be able to hear from my accent. I'm 32 years old and a resident doctor. So, I'm training to become a "real" doctor. Jasna started her first job as a resident doctor at a Swiss hospital in the autumn of 2020. I think that was right around the second lockdown... It was all a bit... ...I started working during a pandemic. And you know that. My GP always said: In the first few years when you work as a doctor, you're just always ill. Because you're exposed to these viruses all the time.

Makes sense. And it also makes sense that it was only a matter of time before Jasna caught Covid. For most people, the infection subsides after about two weeks. But Jasna simply does not fully recover. For weeks, and then months. And that is definitely no longer normal. I didn't feel healthy for a single day. And it was awful.

She has severe headaches, a sore throat, and feels completely drained. As if she constantly had the flu. Jasna used to go jogging a lot to balance out her work. That is no longer possible. I mean, if I had wanted to, I could still have run 10 kilometres. But afterwards I felt terrible. Those typical crashes they always talk about with this illness. So much so that by the winter of 2023/2024, I could barely climb stairs anymore. The athletic, vibrant Jasna can no longer climb stairs.

Then there are all the other symptoms. The brain fog is especially worrying. What kind of state is that? What does it feel like? Well, I was gaga. Gaga just means everything was in a fog. I had always felt quite quick and sharp in my head. And of course that was massively limiting. I was very afraid that I would never get my cognitive abilities back. That was really, really awful for me.

Sometimes Jasna has phases when she feels a little better. But only briefly. Even around a year and a half after her Covid infection, she wakes up yet again one morning and has a crash. She feels as if she has been run over. Then I really thought: Shit. Excuse me... Then it slowly dawned on me what I was suffering from. It had always been there in the background... My GP, and I too, had always had Long Covid in the back of our minds.

But I never really got it checked out, because I kept pushing it away. And then I really realised: Damn it, I am a chronic pain patient. I have chronic fatigue. I have this. Jasna has Long Covid. And then I went to the Long Covid clinic. They said: If it is nothing else, then that is what it is. Voilà. I am normally someone who can pick herself back up.

Yes, okay, fine. And now what do we do? And then came the answer - which I actually already knew, which is why I had put it off for so long. I did not want to go there. I did not want this diagnosis in my medical file. And then they told me: there is basically nothing you can do. At the end I asked: What are the prospects, or what has your experience been? Well, some patients are doing better after a year.

You just have to wait a little. And then I panicked because I did not know what to do. In Switzerland, there are an estimated 300,000 people with Long Covid, including children and teenagers. It is an elusive, diffuse illness. There are only hypotheses about its causes. And to this day there is no recognised treatment, no medication, no curative therapy. That is why Long Covid is currently considered chronic and incurable.

My name is Zita Bauer. I am a journalist and social anthropologist. And I wondered: Is the situation for people with Long Covid really as hopeless as it is often portrayed? Because there are people who recover. And not spontaneously or by chance, but with a new understanding of the illness and treatment methods derived from it. And, spoiler alert, Jasna is one of them. And perhaps you also know the story of cyclist Marlen Reusser.

After a severe case of Long Covid, she became world champion. I can now live a completely normal, joyful life again. And I have even been very successful in cycling since I recovered. Every day I noticed more and more that it was working and that it was the right path for me. And then it really did happen very quickly. It was astonishing. It was almost a little hard to believe, and even to talk about.

But it really did get infinitely better within weeks. Above all, I realised that I had actually been suffering for years from illnesses and chronic pain that did not really have to be there - things that can actually be cured. Marlen, Patricia, Jann and Jasna have something in common: Against all expectations, they all overcame Long Covid. And they are not isolated cases. This is not about either-or, or one single truth. It is about neurobiological findings whose application has enabled many people to recover.

It is about new methods from modern pain therapy. Promising for Long Covid. But not only for Long Covid: also for chronic back pain, irritable bowel syndrome, migraine, and many other conditions and symptoms that until now have been described as medically unexplained. We cannot find a cause. We are sorry. Unfortunately, there is nothing we can do. It is a real shift in perspective. And it offers incredible potential.

This is "So Long Covid". An independent podcast series by me, Zita Bauer, and Jann Zosso. With this podcast, we want to add to the current discussion around Long Covid - with recovery stories, well-founded knowledge and realistic hope. Episode 1: "Incurably Ill". I did not simply become interested in Long Covid out of nowhere. I came into contact with this serious illness involuntarily. Because Jann, whom we heard earlier, is my partner.

So let us start right at the beginning. How did it all begin? Well, Long Covid started with Covid, before it became "long", so to speak... That was in the winter of 2023. And your Covid was not extremely severe - a so-called mild case, right? Yes, I was pretty ill. But then I... The fever went away. The sore throat went away. But not the pressure on your chest - that stayed? It stayed for longer, yes.

A pressure in my chest and back. A kind of tightness, a very unpleasant feeling in the upper body. That could still have been normal. But over time it did become a bit frightening - the thought that something might be wrong with my heart. You hear stories about myocarditis that can develop. I remember that at first I was not too worried, because I thought sometimes it just takes a little longer to recover after being ill.

And also, somehow... you always have something, you know? Something always hurts, right? Yes, but usually it is something you already know. And if it is something new, it can be a little unsettling. That is true. And later, when it persisted, I did start to worry too. Just to understand Jann at that time a little better: he is in his early 30s, in the final stretch of his PhD in theoretical physics at ETH Zurich.

And he is one of the most athletic people I know. He plays ice hockey and badminton, and does yoga. He goes mountain biking in summer and cross-country skiing in winter. Relatively soon after your Covid infection, we went cross-country skiing in the Engadin. And you already noticed there that you were not as fit. Exactly, yes. I was tired - more tired than usual, even during the day. And there was always this pressure that would disappear and then come back again.

We did not really understand what was going on. And then we wanted to do the "Engadiner", the Engadin Ski Marathon. Of course you really want to be fit for that. But for me it was a bit of a stroke of luck that you were not as fit, because then we skied together. Exactly. Then you did not leave me behind. Exactly. Jann did not feel as fit, so he decided not to go full throttle.

Instead, he went a little more slowly. That was nice too. Yes, for one day. Yes. But overall it was already worrying. Yes, then I went on some ski tours that I had to cut short. And over time it became really worrying. That is when it started. Yes, you could say that. Jann keeps falling ill and develops diffuse, frightening symptoms: sudden dizziness and brain fog.

Especially things involving the brain, which were frightening. And not exactly ideal when you are trying to write a PhD thesis. Not ideal, no. Definitely not. Jann is not the first person to have such puzzling symptoms. A few months after the outbreak of the pandemic, the first reports appeared of people who did not recover after a Covid infection. One of the first to report this was the British infectious disease specialist Paul Garner, in May 2020.

He was affected himself and wrote in the British Medical Journal about headaches, muscle pain and total exhaustion. He described it as a roller coaster that simply would not stop. He never knew what would come next.

Symptoms came and went. He felt completely at their mercy. And no one could tell him exactly what the cause was. To be honest, we could not explain it. We simply observed that the patients were unwell,

says Iris Katharina Penner. She is Professor of Cognitive Neurology and Neuropsychology at Inselspital Bern. The cognitive changes were sometimes so pronounced that we really could not explain them. Nor could we explain the patients' extreme intolerance to exertion. Then there was this fog in the head that patients kept describing. This cluster of symptoms was something quite extraordinary.

Then the term Long Covid emerged. Long, as in longer Covid. And eventually the WHO definition of Post Covid followed. That means the symptoms have to persist for at least three months before the term can be used. Before Jann, my partner, became ill, Long Covid felt very far away to me. Somehow eerie. And above all extremely difficult to grasp. Many people feel the same way.

That is why, in this episode, we want to show what a diagnosis of Long Covid can mean. And it gets pretty intense. Iris Katharina Penner runs a clinic at Inselspital Bern and treats people with fatigue - a very typical symptom of Long Covid, and one that is also familiar from other illnesses, such as cancer or multiple sclerosis. It is completely different from normal tiredness. When we all go home in the evening, we are tired.

We may also be a little exhausted. But fatigue is something completely different. It really is this feeling of being so drained and depleted of energy that you cannot manage the day. Going shopping, cooking, meeting friends - things that used to be completely normal - become a challenge. Many people affected can only work part-time or cannot work at all. Long Covid in its most severe form is comparable to ME/CFS.

The abbreviation stands for myalgic encephalomyelitis/chronic fatigue syndrome. ME/CFS is one of the major unanswered questions in medicine. A scandal, writes the self-help organisation ME/CFS Switzerland on its website. It is an illness that existed long before Covid. The many Long Covid cases have brought hope that something will finally move: more research, and perhaps one day even an effective medication.

Recurring crashes are characteristic of ME/CFS and Long Covid. Crashes are insidious. You do something you enjoy, but maybe - just maybe - it will harm you. A short jog or dinner with friends. Anything can be too much. Yes, you feel it building up, and then, with a delay, a huge crash hits you and knocks you down, leaving you in bed suffering for a whole day.

Crashes usually happen with a delay. You only get the bill, so to speak, the next day. It is a kind of torture made up of unpleasant pain and sensations. Torture because you do not know when it will stop. And when that keeps happening - every time you feel a little better, or feel like doing something again - it really wears you down. And now it becomes even more insidious. It is said that crashes cause irreparable damage and make the illness chronic.

The longer you are ill and the more crashes you have, the harder it is said to become to ever recover. Over time it became so bad that it seriously restricted my life and was simply no longer okay. Jann's current state of health is this: Hmmm... he can basically only lie in bed and, on a good day, listen to audiobooks. On Friday, for example, he did go outside for a short walk.

And on the way home, which is about 500 metres, he had to stop three times to rest. Afterwards he was completely exhausted. That is the situation. In the winter of 2024, almost a year after the infection, Jann is diagnosed with Post Covid. Later the additional diagnosis ME/CFS is added. It is not unusual for it to take this long, because of the non-specific symptoms, the many medical investigations and the long waiting times. It is a diagnosis of exclusion.

If no other illnesses are found that explain the symptoms, then it is Long Covid - or, officially, Post Covid. For many people affected, receiving a diagnosis is initially a relief. That was true for Jann too. At last he had a name for his puzzling symptoms. And there were other people who had the same thing. But very quickly the question arises: What now? Then there is the question of treatment. And treatment is difficult.

Because there is currently no medication-based treatment for these patients. That disappoints many people. Of course you always think: now I will get a special pill, or something that can help me. But that does not exist. So ultimately we treat the symptoms, but not the cause. The cause behind the symptoms has not yet been established. There are only hypotheses, such as overactive immune cells or reactivated viruses.

Whether these hypotheses will ultimately lead to an effective treatment is uncertain. Current Long Covid treatment simply aims to relieve symptoms, says Iris Katharina Penner from Inselspital Bern. For example, we do energy management, prescribed through occupational therapy. Then pacing and managing breaks. Those are the classics. But that is almost it. People are strongly advised to take their limits seriously and avoid crashes as much as possible.

That is said to be the most important thing. One method is pacing: paying very close attention to the body's signals and acting accordingly. Jann buys a heart-rate monitor as a tool. He measures precisely how much strain different movements and activities place on his body. He tries to develop a sense of where his limits are and what is too much. And then I decided I would do the best pacing ever.

I wanted to be a world champion at pacing. And if that is what it takes - doing very little, I do not know for how long, and never going beyond my limits - then I will do it. I was fully motivated. I admired the way Jann approached it at the time. He analysed the situation, recognised what was needed, and carried it out precisely, conscientiously and purposefully. Just as he had always done.

But the plan - that he would gradually improve and recover - did not work at all. I searched the internet for anything that might still help. Once I went to the pharmacy and bought practically everything that might help - I do not even remember anymore - amino acids, vitamin D, zinc, all sorts of things. I came home with a whole bag full. We tried everything we possibly could, but nothing really worked.

It kept changing, and new symptoms kept appearing. In addition to severe fatigue, brain fog and muscle pain, there were now stomach problems, tinnitus, and a severe sensitivity to light and noise. And the intolerance to exertion kept getting worse, until I could no longer walk even 100 metres and could barely leave the house. Or, if I had gone out, I would have been completely laid up the next day.

Yes. I always tried to stay hopeful around Jann and encourage him. But the longer it went on, the harder it became for me to stay positive too. You could tell that medicine and science were groping in the dark. You were very dependent on help. You could no longer do much yourself. There was no place, no plan for what should happen in the longer term, or where you could be. You could not simply go to emergency care, because it was not an emergency.

Because it was a long-term, chronic condition. But at rehabilitation clinics, you did not meet the criteria for admission. It was a really intense experience of helplessness. Seeing him like that every day is devastating. And then the fear keeps coming back: how long is this going to last, and will it ever get better? But yes, I also have to allow that sometimes - accept it, be sad, be afraid, and then let it go again.

It does not help. I just have to take things step by step now. None of this is easy. For some people affected, pacing and energy management work and they improve a little over time. But if it does not work, the despair and frustration are huge. As they were for Jasna. I wrote down how exhausting each thing was for me. I mean, you fall into a hole, right? When it says: I can walk up one flight of stairs, but maybe not two.

And you are 30 years old. You fall into a hole, right? Jasna is full of energy. She is upbeat, quick-witted, and she gestures a lot. And when she does, you can see her muscular arms from all her sporting adventures. I find it hard to believe that just over a year ago, in the winter of 2024, she could barely climb stairs. With Long Covid, she is advised to see a psychologist.

I am absolutely in favour of psychotherapy. And it certainly helped me in some ways. And I love my psychotherapist. But it does not really address the core problem. Many people affected say they do not feel taken seriously. I felt that very strongly - being immediately put in this Post- or Long Covid box, with the suggestion that something was not quite right in my head. That you should not make such a fuss, should not be so hysterical, and should just get on with things.

Do not make such a fuss. Just get on with it. I can imagine that statements like these are also an expression of people's own helplessness. When I said I could not climb stairs and someone told me: just take the lift. That is not an answer to me. That happened to you? That happened to me, yes. And I thought: damn, I am 32. You cannot give someone an answer like that. And no one could help me.

Yes, then I became pretty desperate. At this point Jasna has been ill for a year and a half. She still works, sometimes at reduced hours, but otherwise she does not do much anymore. She no longer goes jogging or ski touring - a hobby she started a few years ago that became a passion. One of my big wishes was to take a ski mountaineering course. In the winter of 2024, she wanted to make that dream come true.

She had registered a year earlier. For a long time I did not know whether the hospital would approve my leave, whether I would get the time off. Then they said yes, it is fine, we moved a few things around, you can go. And I was incredibly excited. Jasna had hoped that she would be feeling better by then, that she could take the course. But that winter I realised I was so unwell that I had to cancel.

Of course, the mountains are not going anywhere. There will be another course. But at that point Jasna does not know when, or even whether, she will ever be able to go on a ski tour again. I was so disappointed. I was like: This has taken everything from me. The illness has taken everything from me, and now I cannot even go on this tour. This ski tour represents everything Jasna can no longer do because of the illness: no more cooking, no more eating with friends, no more climbing stairs, no more jogging, and certainly no ski touring.

And to be honest, at times I really thought: I do not want to go on living like this. If this does not go away, then I do not want to live anymore. I could still go shopping, I could still somehow function, but I would not have wanted to keep living like that. That was the point where I really thought: shit, if this continues, then that is it for me. I cannot do anything I enjoy anymore.

That sounds drastic. But Jasna is not the only person to have thoughts like these. Unfortunately, there have also been suicides because patients simply cannot bear it anymore. And I find that absolutely terrible - that people in our society become so desperate and feel so unsupported that they see no other way out. I always try to convey that there are still people there who can support them.

Iris Katharina Penner from Inselspital Bern. For people with Long Covid and those close to them, it is not always easy to believe that the medical system will catch them. For example, when you receive an appointment for the Post Covid clinic - and the appointment is five months away. I remember thinking: This cannot be right. Jann needs support now. That reaction is absolutely understandable. If I were affected, I would see it exactly the same way.

And I see it the same way as a clinician. We simply have far too few resources even to cope with the number of referrals. It is not that we do not want to do it; we simply do not have the resources. We did not get more staff just because Post Covid now exists. Post Covid was simply added on top. But no additional staff were added with it.

And I do think that is a flaw in the system. Care for Long Covid patients in Switzerland is currently inconsistent and, unfortunately, nowhere near sufficient. Not all hospitals offer a specialised clinic. And those that do, like Bern, have very long waiting times. There are physiotherapists and occupational therapists with expertise in pacing and energy management, but they too are often fully booked.

The same is true of psychotherapists who provide support in this very difficult situation. Then there are rehabilitation clinics with specialised Long Covid units. For Jann, one of these rehab clinics eventually becomes the only remaining hope. So we register him for a stay. It is almost exactly a year after the Engadin Ski Marathon. So much has happened in that year. Because someone else cancels, he unexpectedly gets a place very quickly, just three weeks later.

Together with his parents, we drive from Bern to Gais, in the Appenzell region. Jann sits in the passenger seat, which we have reclined so that he can lie down. He wears an eye mask and noise-cancelling headphones because external stimuli make his symptoms worse. There is fear and uncertainty, but also a sense of relief and hope. If there is one place where the staff and doctors understand what this means, surely it is there.

At first I felt very well cared for, and of course that gave me hope. His first day at the rehab clinic was exactly two years ago, on 15 March 2024 - International Long Covid Awareness Day. How fitting. Jann's big goal is that, after these five weeks, he will be able to walk more than just a few steps. He is motivated and hopeful, even on the second and third days at the clinic.

But there is pressure too, because there is a condition for him to stay at the clinic: he has to take part in the therapies - physiotherapy, autogenic training, nutritional counselling and so on. The first weekend is over. With

every day, my hope grows that things will turn out well. But then, on the fourth day, I receive a message. Jann has a major crash and has to cancel his therapies. After a week at the clinic, he is told: This cannot continue.

You have to go home. So the only place where I could be, and where I somehow felt: this is the place made for Long Covid patients, apparently was not the place for me - at least from their point of view. But with his last bit of strength, he manages to convince the senior doctor to let him try for another week. To try again, because I really wanted to, and because my family had only just started to recover after caring for me for months.

What if he has to go home? What do we do then? Where do we go? I have no idea what happens next. I cannot do this anymore. I think that was one of the lowest points for me, and for Jann too. It felt like a bad film. It was just crazy that I could not even walk up a flight of stairs, that I was stuck in my room and could not simply go outside whenever I wanted. I would actually imagine that one day, when I was healthy again, I would make a film about this time and this crazy situation in which they wanted to throw me out of the clinic because I was too ill.

But in that film I would somehow just manage to stay, and everything would turn out well. And it was sad to realise that life is not a film. But you had already thought of a title for this film? Yes. I liked the double meaning of the title "So Long Covid". In the end it did not become a film, but a podcast. This is the first of six episodes: "Incurably Ill".

And in the next episode, you will hear how things did, after all, turn out a little like in the film. And he is not the only one whose story takes a turn, where suddenly a happy ending becomes possible again. Not by chance, but with a new understanding of illness and methods from modern pain therapy and neurobiology. I then made a fairly radical decision: I am putting my faith in this. And that was when I started to feel - even though I was still incredibly far from it - okay, somehow I am getting my feet back on the ground.

I have to say honestly now: I really have my joy in life back. It is back. And for a while, you really could not say that. It is back. Even if I am not sleeping well now. Even if I still get headaches now and then. Then I just do not sleep so well. I am still sitting here with you. This is "So Long Covid" by Jann Zosso and me, Zita Bauer. It is important to us to draw attention to the realities of life for people affected and to highlight the gaps in care.

But we also know from research and from our own experience that a strong focus on the negative, like the one we had in this first episode, can make recovery more difficult. In the next episode we go one step further: What can we learn from those who have recovered? And suddenly my world changed. There was a way out. And that explanation, and the hope it gave me, set the recovery process in motion - quite quickly.

"So Long Covid" is an independent podcast series. We would be delighted if you recommended it to others. And please leave us a review. That helps other people find us. Original music: 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.

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Thank you so much. You can find all the information about the podcast at solongcovid.ch. And by the way: the next episode is already out.