

S3E43b Transcript

Coffee Break #24 with Lieza Vanden Broeke

Geoff Allix (1s):

Welcome to Living Well with MS Coffee Break, a part of the Overcoming MS podcast family made for people with Multiple Sclerosis interested in making healthy lifestyle choices. Today, you'll meet someone living with MS from our global Overcoming MS community. Our guest will share their personal perspective on the positive and practical lifestyle changes they have made which have helped them lead a fuller life. You can check out our show notes for more information and useful links. You can find these on our website at www.overcomingms.org/podcast. If you enjoy the show, please spread the word about us on your social media channels. Finally, don't forget to subscribe to the show on your favorite podcast platform so you never miss an episode.

Geoff Allix (47s):

So, get your favorite drink ready and let's meet our guest. Welcome to Living Well with MS Coffee Break. In this episode of the Coffee Break, we welcome Lieza Vanden Broeke. Lieza is the OMS Ambassador for Christchurch, New Zealand. Lieza grew up in Belgium and lived there for 12 years until her family decided to move to Christchurch, New Zealand. In her teenage years and early twenties, Lieza was a competitive horse rider. Because of her studies she gave up horse riding and took up running as a way to de-stress from university. In 2015, while studying for her PhD, Lieza was diagnosed with Primary Progressive MS at the age of 25.

Geoff Allix (1m 28s):

In October 2019, Lieza went to work and lived in Hong Kong for one year. Thanks to Facebook and a fellow OMSer this is where her OMS journey began, and when she realized that Overcoming MS was a possibility. Lieza returned to Christchurch, New Zealand and in October 2020, she experienced her first bout of optic neuritis. Since then, Lieza has regained her sight, returned to full time work, and seen improvements in walking, and even made progress with her running. So, to start off with, could you describe your life before your MS diagnosis?

Lieza Vanden Broeke (2m 3s):

So, in my early twenties, I used to be a runner and I did two half marathons and three full marathons. And when my dad and I used to practice on our trail runs, I'd fall over a tree root, over tree roots sometimes and we'd just laugh about it and say, "Oh, how clumsy". But then during my last half marathon, I noticed some strange symptoms. I had blurry vision while I was running and I couldn't judge distance or depth very well and I slurred my words, and I'm finding it hard to concentrate and my legs and feet feel heavy.

Geoff Allix (2m 50s):

So how did you find out that you had MS? That was MS [unintelligible].

Lieza Vanden Broeke (2m 57s):

Yeah. So, during my last half marathon when I was feeling all these symptoms, I had completed 18 kilometers kind of fine. I was doing it with my sister, and then the last three kilometers-- oh, I'll get to that. So, after 18 kilometers, I could no longer run straight or see properly, and my sister had to hold my hand to help me run in a straight line. And the people on the course ended up stopping me because they noticed something was wrong and they gave me lollies and water and told me to sit down, and they were going to call the ambulance for me, but the ambulance was actually busy somewhere else on the course.

Geoff Allix (3m 47s):

So how did that-- So from 18k, that's near the finish, isn't it? So, like what's the half? Because to us 13 miles would be a half marathon. So, 21 is a whole distance? So, you're really close to the end then?

Lieza Vanden Broeke (4m 1s):

Yeah. I was very close to the end. And so, the ambulance was busy somewhere else on the course and because I was so close to the end, I ask them can I just finish by walking and finish their half marathon. And so off I went with my sister, they let me complete or continue. And I walked for a bit then I started running again and the same thing

happened. So, we went back to walking and then, because I didn't want to walk through the finish line, I ran the last hundred meters for the finish line, but that was the last time I ran.

Geoff Allix (4m 42s):

Right. So, with full-on symptoms, but you just, I have to run just to get, just because it looks better. I've only done one marathon, but I had, it was-- and I didn't, well, I may have had some minor MS symptoms at the time, but completely unknown to me. And that was pretty hard to run through the finish line then actually, just to do it. Yeah, that's yeah quite amazing persistence. Just to think I'm going to run it anyway. So, what went on from there?

Lieza Vanden Broeke (5m 12s):

So that was in June of 2016. And then of course after the way the things that had happened to me, I wanted to-- well I spoke to my GP and she referred me to lots of specialists and I got lots of tests done, but no answers. So, my family finally paid for a private neurology, neurologist appointment. And then when I met with the neurologist and explained my symptoms to him, he mentioned something about Uhthoff's phenomenon, but that was all.

Lieza Vanden Broeke (5m 52s):

And of course, I asked Google and I found out that people who experienced Uhthoff's phenomenon don't necessarily have MS. So that's what I was hoping for, that I didn't have MS. But so, in November of that year, I was supposed to get my MRI scan. And then, so I got my MRI scan, a few weeks later I saw my neurologist again and he said, I think you have MS. But in New Zealand, I don't have friends like this everywhere.

Lieza Vanden Broeke (6m 32s):

You need to, they need to confirm your MS diagnosis with a spinal tap. Like the MRI by itself is not enough. Is it the same in the UK?

Geoff Allix (6m 44s):

That's the same here. It does differ, I think not everyone in the UK has, we call it a lumbar puncture now. I actually prefer spinal tap because it's one of my favorite films.

Lieza Vanden Broeke (6m 54s):

I didn't even know it was a film.

Geoff Allix (6m 58s):

Oh, you need to watch it. Separate conversation. Yeah. So yeah, it's normally confirmed. I think that there's some bands that they can spot in the lumbar puncture. But certainly, I mean, I was definitely told that basically you have to confirm MS by ruling out everything else that it could be. So, there's no blood tests for MS. They can't just say, "Oh, yep. Give me some blood test. You have MS." They have to basically go through endless things to rule out. So, there's, we have to have tests on our eye reaction times. So that's something they can use. So, they use like a body of different things to try and say, well, it's clearly not lupus or other things it could potentially be so yeah.

Geoff Allix (7m 45s):

Similar, but yeah, we call it a lumbar puncture normally.

Lieza Vanden Broeke (7m 49s):

Yep. So, four days before Christmas, 2016, I got my lumbar puncture and then shortly after I got my diagnosis of Primary Progressive MS. So, a merry Christmas to me. So, I was 25 at the time.

Geoff Allix (8m 10s):

So, what was it like then after that? I mean, especially coming to Christmas, what was it like after your diagnosis was confirmed?

Lieza Vanden Broeke (8m 17s):

Well, my symptoms weren't really bad. Like I couldn't run, but I could pretty much do everything else. So, I thought, you know, not the end of the world and I just continued living my life. So, at the time I was diagnosed, I was in my first year of my PhD in Medical Physics. So, it never even crossed my mind to quit and escape going on. And as I mentioned before, you know, I'm very stubborn and I like to live my life on my own terms. So, after my diagnosis, I traveled to many different countries because I love traveling.

Lieza Vanden Broeke (8m 59s):

So I went to China, I went to two weddings in India. I travelled through India and Nepal. I visited my family in Belgium because that's where I was born. Went to Lithuania. I have some family there. I went to a conference in Sweden, and I finished my PhD. So yeah, I could walk fine, but I couldn't run anymore. And then fast forward a year and a half to 2019, October 2019. And I got to go to Hong Kong for one year, to live and work there.

Lieza Vanden Broeke (9m 43s):

Kind of the same thing, I was doing my PhD in New Zealand, but just continue it as a post-doc in Hong Kong. And I loved Hong Kong. The temperature and humidity are very different to New Zealand, so I guess my system was in a bit of shock. But when I arrived there, it was autumn. So, it wasn't actually too hot. So, I hadn't experienced their summer. But then January 2020 on Chinese New Year, we found out about the coronavirus outbreak in Wuhan which was the center of the outbreak was 900 kilometers away from Hong Kong.

Lieza Vanden Broeke (10m 38s):

So, it's kind of scary.

Geoff Allix (10m 39s):

So how did that, I mean, as much as anything apart from MS, how did the pandemic affect you being in Hong Kong?

Lieza Vanden Broeke (10m 50s):

Well, I was diagnosed, so I couldn't run anymore but I still loved being active. So, I used to go to a gym to do strength training, but of course COVID shut down all the gyms so I can't go to my gym anymore. And my walking deteriorated really bad, was probably partly due to the stress of COVID as well, not just the lack of gym. So, walking 500 meters from my apartment to the bus stop was a real, real struggle.

Lieza Vanden Broeke (11m 32s):

Walking downhill was awful. My legs would shake, and they would feel like jelly. Yeah. So, stress and everything made my MS symptoms all of a sudden worse.

Geoff Allix (11m 45s):

And how did you come across Overcoming MS then from there?

Lieza Vanden Broeke (11m 52s):

So, at [inaudible], when my symptoms started getting worse in Hong Kong, I was alone. So, I didn't have anyone, I kind of felt hopeless. I was experiencing something that I'd never experienced before. So, I turned to Facebook, MS support groups on Facebook for help and advice. So, I joined quite a few of them, but I found them really depressing. And they were negative, you know, people complaining about their symptoms and saying, "Oh no, my life is awful." So yeah, that made me feel even more hopeless.

Lieza Vanden Broeke (12m 35s):

And I just thought my life was downhill from there. And then Facebook actually suggested a group called Overcoming MS to me and I joined not fully knowing what it was. I just liked the name. So, Overcoming MS, so I was like, I want to overcome MS. And the first few posts that I read had people being really kind and helpful. So, I was hooked. And then, soon after I actually met up with a member from the Overcoming MS Facebook page, who also lived in Hong Kong, and she explained the seven step Overcoming MS Recovery Program to me.

Lieza Vanden Broeke (13m 27s):

And she had been following OMS since her diagnosis. And she told me that she'd managed to shrink some of her lesions, and I thought, cool. I want to shrink my lesions so get me into that. So, after meeting her, I followed the diet part of OMS 100% straightaway, a few hours after meeting her. I was taking 50,000 IU of Vitamin D a month. So not enough, but I exposed myself to the sun as much as I could because UV indexing in Hong Kong is quite high.

Geoff Allix (14m 12s):

Yeah. I mean, that's the thing with not enough from 50,000 IU sounds low. If you're in New Zealand or the UK if you're in Hong Kong, and potentially, you might not need to take any. Cause you could just get, you know, a half an hour of sun in Hong Kong and most days would probably be as much as us taking 10,000 a day? Because I'm currently in cold indoors, getting zero minutes from the sun. So, yeah. So, I think, and that's the thing between people always say how much, it's different for everyone, Isn't it? So--.

Lieza Vanden Broeke (14m 47s):

Yeah. That's so true.

Geoff Allix (14m 47s):

You probably just need to get yours checked to what your levels are, but yeah. So sorry. Yeah, go on. And you were saying, what else you were doing?

Lieza Vanden Broeke (14m 56s):

Yeah, so I also bought some resistance bands, and I did some resistance training in my tiny apartment. I had bought some flaxseed oil, so I was taking two tablespoons of that a day. And my friend that I met on the OMS Facebook page made me go to yoga with her. Yeah. So originally, I wasn't really seeing any changes from OMS, but from everything my friend had told me is that I could expect it to take a really long time, like even years.

Lieza Vanden Broeke (15m 37s):

So, I just kept going.

Geoff Allix (15m 38s):

Yeah. They say it's like turning around an oil tanker. You can't, oil tankers don't turn around instantly. This is a very slow process. And that's definitely the way I saw it at first, yeah, I'm not expecting anything. If I exp -- for something you take a tablet and then instantly you'll see a change, but I knew that that wasn't going to happen. I think you have to have faith that that's not something that's going to happen. It's going to be slow, incremental changes.

Lieza Vanden Broeke (16m 8s):

It's easier to have something fast and instant.

Geoff Allix (16m 11s):

Yeah, yeah. You take the tablet that stops the headache, and the headache stops. So, from there, was it all plain sailing and improvements onwards?

Lieza Vanden Broeke (16m 23s):

So, I was still in Hong Kong at this point, but I had declined an offer to extend my contract because my health was more important, I thought. So, I went back to New Zealand and at this stage and in Hong Kong, everything was just a struggle. Every move that I made had to be calculated, like, was it worth it? Am I going to have to pay for it for the next couple of days? I remember even buying like souvenirs for my family. That was, even that was awful.

Lieza Vanden Broeke (17m 2s):

Like I didn't have to go far, but I just, I couldn't do it. So yeah, I was happy to go back to New Zealand because I'd have my family and my boyfriend. So, in New Zealand, if you, oh, during the coronavirus coming into the country, you can only come in if you're a resident or a citizen and you had to do two weeks over of hotel isolation. So, I thought, oh, that's okay. I'll get two weeks of rest.

Lieza Vanden Broeke (17m 42s):

And I deepened, you know, organized all my meals to be OMS friendly. I'd ordered some flaxseed oil from the local health food store. So, I thought life was going to be really good. And then I completed one week of my hotel isolation, and now I was waiting in my room and the vision in my left eye started to go blurry. And a few minutes later, I couldn't see anything with my left eye. So, I was experiencing, I didn't know it at that point in time, but my first bout of optic neuritis.

Lieza Vanden Broeke (18m 28s):

So optic neuritis is often associated with an MS relapse, but I was diagnosed with Primary Progressive MS. So, I'm not meant to have relapses or so I thought. So, I was given a five day course of oral steroids.

Geoff Allix (18m 45s):

So, you're still in isolation at this point? You're in a hotel room on your own? Okay.

Lieza Vanden Broeke (18m 50s):

And no one can touch me. So, a neurologist, I had to call one over the phone and she prescribed me the steroids. And I ended up getting some vision back in my eye within a few weeks. So, at this stage I was back at home, I'd finished a mandatory isolation. I was at home with my family, my boyfriend, and my eye recovering more every day. And I thought, yay, I'm through the worst, but yeah MS has other plans, very unpredictable.

Lieza Vanden Broeke (19m 31s):

So, before the steroids, I could walk, well looked like normal, so downhill, was a struggle, and not for a long time. And after the steroids, I couldn't walk in a straight line, my balance was all over the place. And my legs felt even more like jelly, and I had a limp. Yay. So, I'm not blaming the steroids, it was just probably the natural progression of my MS. But yeah, it was awful.

Lieza Vanden Broeke (20m 13s):

I don't feel like myself, but as I told you earlier, I'm very stubborn.

Geoff Allix (20m 20s):

So, things continued to get worse and decline as well?

Lieza Vanden Broeke (20m 28s):

So nearly everything that I've read and heard about MS is that once you start getting worse, there is no way to get better, at the level we used to be. But I really trusted OMS. So, I kept following OMS and I followed it even more closely. So, I upped my Vitamin D, because I was back in New Zealand in Christchurch, not in Hong Kong. So yeah, I, upped it to 10,000 a day, instead of my 50,000 a month. I started supplementing with magnesium.

Lieza Vanden Broeke (21m 12s):

I started meditating and I went back to the gym. So, in Hong Kong I had a personal trainer. So, I used what I had learned from him, and I started training myself. So, I did strength training mostly by myself, but I like doing checks every once in a while, to see if my MS is improving or not. So, what I would do is at the end of my session, I would walk on the treadmill. And when I first started walking on the treadmill, treadmills are very narrow.

Lieza Vanden Broeke (21m 52s):

So, I had to hold the sides with both hands, and I walked five minutes or even less. And then eventually I moved on to doing one hand for one minute, another hand for another minute, I did that for a few months. Then I did one finger with one hand, one finger of the other hand, did that for a few months. And now I can walk without holding on to anything for five minutes. So that took about six months for me to see the difference.

Lieza Vanden Broeke (22m 33s):

And then once I came back from Hong Kong my eye recovered, I started working full-time at a medical imaging company that I had worked for prior to moving to Hong Kong. And parking's kind of bad where I work. So, because

there at the university there are lots of students that steal my carparks. So, I had to walk one kilometer roughly to work every day and one kilometer back. So don't forget that I had a limp at this point, and I couldn't walk straight, my legs felt like jelly.

Lieza Vanden Broeke (23m 15s):

So that one kilometer was awful. My limp was so noticeable. It used to really upset me walking to my car and to work because I thought everyone was looking at me, you know, judging me, wondering what was wrong with me. And then so after I'd finished my job for the day, I'd go to the gym, I went three times a week. I didn't feel like going, but I did it because I knew that it would be good for me. And then I'd come home after work and gym, and I'd cook myself an OMS friendly meal.

Lieza Vanden Broeke (23m 58s):

I was exhausted by the end of the day. And I used to ask myself like, is it really worth it? Everything that I'm doing? But after a few months, my limp walking to work was gone. I don't know where it went, but I was happy to see it go. So, I'd gone back to walking like a normal person for a few hours, at least. And then my limp would be gone in the morning and over lunch, so it would only come back in the evening.

Lieza Vanden Broeke (24m 38s):

And then a few months later it would be gone completely. And now I don't have a limp at all. And I walk five kilometers a day.

Geoff Allix (24m 48s):

Wow, that's amazing. So as a final question, how do you think then that Overcoming MS has affected you overall?

Lieza Vanden Broeke (24m 58s):

Well, I remember when I first joined the Facebook page, I read this quote that said, "the day you plant the seed is not the day you eat the fruit." And that is something that has always stuck with me. So, one thing that OMS taught me is that recovering from MS is possible. It takes a lot of really hard work, and you have to be determined, you have to plan everything, and it takes a lot of resilience, but it is possible. So, OMS in my opinion, has been and will continue to be for the rest of my life 100% worth it.

Geoff Allix (25m 44s):

Thank you very much. That is an incredibly inspiring story. And thank you for joining us on the podcast, Lieza Vanden Broeke.

Lieza Vanden Broeke (25m 54s):

Thank you.

Geoff Allix (25m 55s):

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Geoff Allix (26m 37s):

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