

S4E47b Transcript

Coffee Break #28 with Claes Nermark

Geoff Allix (41s):

Welcome to Living Well with MS Coffee Break, a part of the Overcoming MS podcast family from Overcoming MS, the world's leading multiple sclerosis healthy lifestyle charity, celebrating its 10th year anniversary serving the MS community. I'm your host, Geoff Allix. Today, you'll meet someone living with MS from our global Overcoming MS community. Our Coffee Break series invites into the lives of each guest. They share their personal MS journeys and speak openly about their challenges and victories, large and small. We hope you find some common cause and a source of inspiration from the stories of these very special people. 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 or leave a review wherever you tune in to our podcast. Finally, don't forget to subscribe to Living Well with MS on your favorite podcast platform so you never miss an episode. Get your favorite beverage ready and let's meet today's guest on Living Well with MS Coffee Break. Welcome to Living Well with MS Coffee Break #28, where we are pleased to welcome Claes Nermark as our guest. Claes lives in Sweden, he is happily married to Malin, and they have three grown children.

Geoff Allix (1m 21s):

At university, Claes trained to become a physical education and biology teacher. In addition to teaching, he has added the following skills to his CV: software trainer, fitness and yoga instructor, event manager, sports club administrator, operations manager, vice-principal, and employee wellness manager. Claes, welcome to Living Well with MS Coffee Break. We're so pleased to have you on our program. The purpose of this series is to better get to know some of the members of the community from around the world, and today you're in the hot seat, so could you tell us a little bit about your day-to-day life?

Claes Nermark (1m 57s):

Well, of course. Great being here. Today, I'm doing the final training to become a personal trainer. Well, it's quite a bit of a study right now and starting up being a public speaker, doing the training at the same time. I have, in my days, been busy, starting up in the new year.

Geoff Allix (2m 22s):

When were you diagnosed with MS? Could you tell us a bit about that and how you initially dealt with it?

Claes Nermark (2m 29s):

Yes. Let's go back to May 2010, a very busy time in my life. I was transitioning from an administrative position at a huge sports club in Sweden into a startup in education about holistic health. For a couple of days, I was simultaneously doing more or less two jobs, commuting like an hour down south for meetings at my old job in Malmo, two hours in the car up north to meetings with my new managers, and an hour back home. Probably did some workout in the evening, and then next morning, down to Malmo and up north again.

Claes Nermark (3m 10s):

When I got into the car, I suddenly had double vision, but if I held my head on the ride, it almost narrowed it to one road. I was just three quarters of the one hour back home and two takeoffs from the freeway almost back home. Sitting at the dinner table, my wife said, "Well, you have to see the doctor. This is no good." I was like, "Well, I'm so busy, not tomorrow," and she said, "Maybe next week, but please call the advice line, at least." I did. I called the advice line and I said, "Hi, my name is Claes and I have this double vision out of nowhere."

Claes Nermark (3m 50s):

My wife reminded me before making the call to tell them you had a stroke eight years ago, so I said, "Okay, and I had a stroke eight years ago so what's your suggestion." They said, "I think you should call an ambulance and come in right away." That was quite different from my view of not having time to see the doctor the next day or the next week, but my wife took me there. They did all sorts of the regular neurological scans and a regular x-ray. I was a fully fit man, and they didn't find anything wrong with me. They said, "Well, you may stay tonight."

Claes Nermark (4m 31s):

You might get a return appointment for an MRI scan during the weekends." With my double vision, I realized I couldn't do much proper job the day after anyway, so I stayed at night. I got an appointment for an MRI scan, and it turned out I have active lesions in my brain. The doctor said, "This is one sign of multiple sclerosis, and we would like to make a number of punctures as well to rule out some other alternatives." I have that one down as well, and I found one out of two indicators for MS.

Claes Nermark (5m 12s):

I got the preliminary diagnosis and, straightaway, got onto intravenous cortisol. I stayed for a few days, got very tired, got back home, and slept for days. I was lucky because I didn't have any experience of knowing anyone with MS, so I didn't have any real picture of what MS really meant because I was so focused on getting into my new job. It was kind of, "Okay, let's fix these so I can get on with my life."

Claes Nermark (5m 52s):

"But my wife had quite another vision because her grandma ended her life in a wheelchair due to MS so that was her picture of having MS. Seeing me going down that route was not a future scenario for our family and things." She said, "Okay, you're not a good reader with your double vision. I'll scan what I can find, and I'll order some books." She got tons of books and started reading. Well, I was on sick leave as I couldn't do much. It was just tiring walking and doing things.

Claes Nermark (6m 33s):

If I just walked down the path, should I take the right or the left one with my double vision? Once in a while, I used the patch for one eye to ease off the double vision and things like that, but it was very tiresome, but luckily, I never got afraid of getting the MS diagnosis. We've been working a lot with mental training, doing visualization, things for sports events, and doing various things in life. That's one thing I used before, so my diagnosis was then in 2010, but looking in the rearview mirror, the stroke I mentioned from 2002 was another very hectic period in my life when I was working more than full-time as an event manager, trying to be the best dad and husband ever.

Claes Nermark (7m 34s):

At the same time, I ended up with optic neuritis, and back then they did all sorts of examinations, but it took like six or seven weeks until I got to do the MRI scan. When those results came back, they found one score or lesion, probably a score as it was weeks later, that was situated just before the optic nerve divided into each eye. My optic neuritis was very similar to before and they said, "Okay, we diagnose this as a stroke."

Claes Nermark (8m 15s):

But some years ago, I got to read all my old journals. In that journal from 2002, there was a little note, "Multiple Sclerosis?" As they found this scar and my vision was back to normal weeks later with no other symptoms, I got the diagnosis of stroke. Then again, between 2002 and 2010, I had others like numbness starting in my toes, slowly reaching just mid-thigh. Before it was turning back, I went to an acupuncturist to treat this weird thing.

Claes Nermark (8m 60s):

I had tingling in my hands and things like that during these years up to my official diagnosis in 2010. Officially, I was diagnosed in 2010, but probably I had my MS debut in 2002 with the optic neuritis.

Geoff Allix (9m 18s):

Then you probably never had a stroke.

Claes Nermark (9m 20s):

Probably not.

Geoff Allix (9m 21s):

That's fascinating when you say it because you look incredibly fit and I think that you don't look like someone who's had a stroke, but actually, that's amazing.

Claes Nermark (9m 35s):

Yes, I was just 40 years old having a stroke, being a fitness instructor didn't really come along with what I knew about fitness and health even though I now know a lot more. If I haven't got my MS diagnosis in 2010, I would most likely have had the opportunity to have a stroke or something similar later in life due to the lifestyle I had back then. I thought it was healthy, but wow, I've learned a lot since.

Geoff Allix (10m 8s):

Yes, likewise. I thought because I was slim and I could run a long way, I was healthy. I could eat anything as long as I burnt off the calories by doing exercise. That was my thinking. Anyway, when did you come across OMS and why did you decide to follow the OMS program?

Claes Nermark (10m 31s):

Well, luckily, one of the books, Marlin, my wife found when scanning the market was *Overcoming MS*, the big book by George. She started reading it and, we started it. I actually say "we" because she was on the same journey from the very beginning. We adopted most of it at once, but not most of it as she bought more books that were other alternatives. On top of the OMS program, we took gluten away and God knows what else we had to take away or adapt.

Claes Nermark (11m 13s):

For the first couple of months, we opened the fridge and said, "There's nothing we can eat," but slowly we realized, "Okay, probably the OMS program is 'the one' to trust." We went more and more into that one, even though there were some things. We've been into raw food for a while before my diagnosis, so we used a lot of cold-pressed coconut oil. We've read all about the benefits of that one, but then again, it's all fat fats, but we keep that one because we've heard from other sources that's a good thing, along with dark chocolate.

Claes Nermark (11m 59s):

With all the antioxidants, that's got to be good for you. We kept the dark chocolate. We were probably like 90+ percent into the program. As we've been in New Zealand for almost a year with the kids when they were small, Marlin found out about the retreat, mainly in Australia and New Zealand. We thought that was a good reason to go back to New Zealand. I wrote it down to the golden foundation, I think it's called. I asked, "Okay, when is the next retreat scheduled for New Zealand so I could see if I could get some funding from some grants or something here in Sweden to support the trip."

Claes Nermark (12m 46s):

I got some dates, but just maybe a month or so after I got an email saying, "Hey, you've shown interest in our retreat down under. We've just decided to set up the first in the Northern hemisphere, so you got another two weeks to decide whether you want to leave early bird applications." I just told them all, "Well, we just have to go. We can't miss this opportunity." In 2013, we were among the lucky ones getting into the Launde Abbey retreats.

Claes Nermark (13m 32s):

We referred to it as our second family that built up during that week. It was a week with George, <inaudible>, his wife, Sandra, a yoga instructor, and some other amazing people. I think we were about 35 people with MS, primary progressive, and like me, relapsing-remitting, and maybe 10 partners coming along as well. We actually lived the program for a week. When we had the retreat for ourselves, so they set up the menus and things like that.

Claes Nermark (14m 19s):

George went through everything from medications to meditations, and a lot of the research backing up all the claims in the book. I talked to George, and I said, "What about these coconut oils?" He said, "Well, it's saturated fats. I haven't found any studies separating animal or vegetable fats. As I haven't found any studies proving it's safe, I choose not to be the Guinea Pig." I was like, "Kind of a good point of view."

Claes Nermark (14m 59s):

Seeing George being so vital, fully fit, no signs of MS whatsoever, I realized, "Okay, let's drop the coconut oil." We actually dropped the chocolate at that point. From that retreat, we really have truly believed in the OMS program.

Geoff Allix (15m 24s):

Yes. It's true that the saturated fats from plant sources, we just don't know, do we? It's just one of those things that hopefully there'll be more research on because they know it is different. There are big chemical differences between coconut oil and meat fat, but like you say, do you really want to be the Guinea Pig to find out if it's okay or not? Maybe, in the future, we will be having coconut oil and we will be having chocolate.

Claes Nermark (15m 55s):

Yes. There were many nuts and seeds containing lots of fat as well, even though they've got other fats, but it's not fat alone. It comes in combination with other good things as well.

Geoff Allix (16m 9s):

I've had people actually have a very small amount of chocolate, very dark chocolate because there are benefits to chocolate. They weigh it up, but yes, it's very difficult. Hopefully, there will be, in the future, more research because the more I think it's becoming normalized that diet and lifestyle have a factor, then hopefully, there'll be more research done. It's difficult because the drug companies clearly aren't going to pay lots of money for it.

Claes Nermark (16m 41s):

Those kinds of studies, no, unfortunately.

Geoff Allix (16m 45s):

You mentioned you had a very stressful life. How do you manage stress now that you've been diagnosed?

Claes Nermark (16m 54s):

Well, in the beginning, I was just doing nothing for a while, but then I gradually managed to get into meditation. I think I managed to do that thanks to taking a Xi Gong course. My wife read an article about a guy saying now he dares to hold his daughter because he got his MS diagnosis when his daughter was born, and he got a malfunction in his arms, so he really didn't dare to hold his daughter. He went on to a Xi Gong course and got enormous benefits out of that one.

Claes Nermark (17m 36s):

I joined the same organization, went for a weekend, and started doing Xi Gong 20-30 minutes almost daily. That was one way for me to actually, more or less, do nothing even if you do some with very dedicated movements during the Xi Gong session. Before that, I had a hard time just sitting still for five minutes, but since then I've been adding it on, I'd say a couple of years now, I don't know when I really got into habits. I start my day by getting out of bed into my yoga or meditation sofa and sitting for 20-25 minutes before taking a glass of lemon water and taking 30-45 minutes morning walk, depending on the weather, before having breakfast.

Claes Nermark (18m 36s):

I start my day in a very relaxed way. With meditation, setting up myself for a stress-free day. I think this is the key to being so much more aware of where I am right now every day. Nowadays, I can so much earlier realize like, "Okay, there's a lot of things going on right now. How can I stop this stressful cycle from coming up?" Realizing, "Okay, yesterday I had my yoga class and then I had one meeting and then I should have my Sunday chat with my brothers, spread out in the world."

Claes Nermark (19m 19s):

I realized coming into the afternoon I don't have time for that meeting before meeting my brothers, so I just canceled that meeting. Actually, one thing, I've learned a magic word since my diagnosis. It's not a four-letter word. It's a two-letter word and it's spelled N-O. I've learned to say no to things, even though they're very exciting things. I really

have to see what's in my calendar. Could I add this one as well? I am an active person. I used to have a laser focus on my calendar way back when we all had paper calendars.

Claes Nermark (19m 59s):

Someone could ask, "Could you help out with this fitness class on Wednesday?" "Okay. What week?" "Next week," and then narrow down. "What date?" "Wednesday." "What time?" Then squared in the hour for the class. "Yes, there's nothing in my calendar. I could have like one class the day before, I had one class in the morning, and all other sorts of things, but no, that was perfectly fine. I could squeeze that in as well." Nowadays, I realized if I say no to some things, I can say yes to my health, I can say yes to my partner, I can say yes to my family. That is so much more important than pleasing everyone else because, that way, I will be here for the long run, and that way, I can please more people in the long run than pleasing everyone right now.

Geoff Allix (20m 47s):

That's a fantastic way of looking at it. I think it was actually my neurological physio who said to me a similar thing. He said, "You just need to consider that you're not an ambulance driver or a fireman. You can be late for things, or you can say, 'No, I'm not doing things,' and it won't actually cause a problem." If you don't do something, if you say, "No, I'm not going to do that," what's the worst that can happen? If you're five minutes late for a meeting, what's the worst that will happen? If you're doing something that's critical, like if you're an emergency paramedic, then yes, you need to do that thing right now, but you're not."

Geoff Allix (21m 28s):

Then you think, "Actually, yes," because there are people I know who are always late to things. You think, "They're always late," but it doesn't matter. They don't get stressed about it and you think, "Okay. Just don't get too stressed about things." So do you have any problems adopting OMS? What parts of the program did you have any trouble with?

Claes Nermark (21m 56s):

The problem, in the beginning, was actually that we did more than the OMS program. I was once, again, lucky because we attended the Unleash the Power Within seminar with Tony Robbins in London, 2007. The fourth day in that seminar is called living health. In the end, we got a 10-day challenge quitting, I think, meat and dairy for 10 days. I was definitely a meat eater and I love dairy, yogurt so it was a challenge for me, but my wife's been a pescatarian since before I think she was 16 or something.

Claes Nermark (22m 36s):

It was her almost everyday life, but it was a challenge to me. I said, "Okay, I can do this for 10 days," but after 10 days, I realized my stomach wasn't as upset and weird as it used to be. I didn't have this lack of energy in the afternoon having to have that afternoon snack or something. I thought, "Could this really be it?" For 10 days, I was not having meat or dairy, so I thought, "Well if it is, I'll try a little bit more." I haven't had meat since. I actually got back to having dairy when it was present in whatever kind of food you had out in the restaurant or seeing friends.

Claes Nermark (23m 24s):

I used to have some yogurt because I believe in beneficial bacteria in yogurt and things like that. I had taken huge steps towards the OMS diet in 2007. The diet thing wasn't that much of a giant step for me. It wasn't a total turnaround of my everyday diet. The most challenging thing I'd say was actually the meditation part. As I said, I had a hard time just being restful for more than a few minutes. I had to move around and things like that, but now, half an hour, no problem.

Geoff Allix (24m 4s):

When did you start to see positive benefits of the OMS program and what were those?

Claes Nermark (24m 12s):

I'd say, in a weird way, after about six months, my vision went back to normal like six to seven weeks. I was all fine until I think it was Christmas day or something. I got some weird senses in my eyes again. The day after, it was a full-

blown double vision. I thought, "No, this doesn't work." I went to the emergency, went to see a neurologist who said, "It was most likely a relapse so let's get you on intravenous cortisol," but we'd read the book and read about taking it orally in pills instead of intravenous, that way you could take it at night, adding onto the natural cortisol that your body's producing.

Claes Nermark (25m 4s):

I asked, "Well, is it possible to get it as pills as we had plans to go to see relatives before New Year in Stockholm?" She's like, "Well, if we have it," so she had to find out whether they had the option to give it as pills, but they did. I got the prescription for a five-day course. I took them at night, even though the prescription said, "Take them in the morning so it will not disturb your nighttime sleep," but I followed the suggestions in OMS. Went to Stockholm, was a bit discouraged about the OMS program not working as it was a full-blown double-vision like the diagnosis in May, but after three days, I thought, "I feel a little bit better today."

Claes Nermark (25m 55s):

We were out. The crazy in between Christmas and New Year shopping with all the sales and things. It was chaotic walking on the sidewalk with double vision. It's enough people caught on the regular day, but with the double vision, that was stressful. On the third day of the five-day course, it feels a little bit better but that can't be. It took like two months last time so now, it's just an illusion. The day after, I felt even a little bit better, like almost normal. The fifth day, we were driving back home or actually my wife was driving back home, but I felt like my double-vision has gone.

Claes Nermark (26m 42s):

I sat in the passenger seat pretending to be a driver, looking at the rear-view mirror. Could this really be? After an hour or so, we went for just a meal break and I said to my wife, "Well, you might not believe me, but my double vision is gone. Is it okay for you if I drive for a little while and make sure it's gone? Because I've been sitting here as a copilot for the first hour of the drive." She said, "Why don't we? It's just the freeway. You don't have to overtake anyone." I drove nonstop for two hours, nothing coming back, and double vision didn't come back. Then I realized, "Okay, the first time it took seven or eight weeks for my double vision to disappear. Now I've been on this program for six months and I'm taking those pills at night instead of intravenous, maybe that helped me to get back so much quicker."

Claes Nermark (27m 35s):

I took that as a true sign of there's something happening here. From that, getting the double vision again was really a backlash, but up to five days getting back to normal so quickly, I took it really as a sign that something is happening. I continue to have a few more relapses, a few issues with my sight, tingling in my hand, neglect that for about three years from diagnosis. During the year when we went to the retreat and I remember George saying, "It's usually between maybe two to four years before you see full results from being on the program because every single day or every single minute, you are renewing yourself."

Claes Nermark (28m 28s):

Sitting here talking, cells are dying in our bodies, and new cells are created, but if you feed them good building materials, they're not building out of old crap because you're building a new body with good, solid, proper, natural material that will not trigger things that might cause damage. I've now been relapse-free for almost nine years now so it's amazing.

Geoff Allix (28m 57s):

You're the ambassador for the OMS Circle in Sweden so could you tell us a bit about the OMS Circle there?

Claes Nermark (29m 6s):

I'm from this family of friends from the Launde Abbey retreat. I heard about their Circles and they're meeting people, but actually, I didn't meet anyone, and OMS wasn't present at all in Sweden. I said, "Okay, let's see what happens." During the pandemic, by a friend of a friend, got to meet a guy that was newly diagnosed. He was a carpenter, but also on sick leave. He was very low in energy. I'm just giving some starting advice on getting on to OMS on top of his

medication because he was, of course, on disease-modifying drugs like everyone else in Sweden as the first route of the treatment or rather the only route of treatment if you're not aware of OMS.

Claes Nermark (29m 52s):

I talked to him a couple of months later and he was just a new person. He was so full of energy and was so grateful for whatever advice I've given him. He was back to working half time and things like that. At that moment, they were talking about the OMS Online Circles. I was like, "Okay, we can actually meet online. We don't have to meet in person." I contacted OMS and said, "I'd like to be in a Circle, but I have to start up digital to spread it in Sweden. It's a big country, we're spread out, and there's not much knowledge about it."

Claes Nermark (30m 33s):

It started almost a year ago and I think we're about 10 people now. I've just met three of them in real life. Otherwise, we've just met digitally. One thing that I have to say in common, here, is you can get some hope compared with other Facebook groups or MS groups, you meet and discuss your problems. You never meet and discuss your opportunities. I'd say OMS is really an organization of hope and possibility.

Geoff Allix (31m 16s):

You contributed to the newly published Overcoming Multiple sclerosis Handbook. Could you tell us a bit about your contribution to that?

Claes Nermark (31m 27s):

Well, I got the honor to write my personal story about exercise. I was a lucky one because I was fairly fit when I got the diagnosis. When I got back from my relapses, I could fairly quickly get back to more or less normal fitness routines. I realized now becoming a personal trainer, the word exercise is, to many people, challenging. Now, when I think about it, it's sad. The chapter is called exercise instead of movement because what every person needs is getting out of an activity and that everyone more or less can move at their level.

Claes Nermark (32m 16s):

Even if you got MS sitting in a wheelchair, if you can push yourself around, do that because that will get your heart rate up a little bit and help push things around in your body that helps you heal as well. If you can walk, do the walk. If you can run, well, continue running or biking or swimming, whatever. Sometimes people say, "I have to exercise." Just the word, attitude, and exercise, it's not a good combination. Then they wanted so much, and they listened to so many others and it's a must and it becomes a stress.

Claes Nermark (32m 57s):

Stress is no good for, well, not anyone, especially for us with MS obviously. That way we should talk more about movement. My message is whatever you can move, keep moving it because our bodies are so exceptionally clever, they adapt to what you do and what demands you put on your body. If you put the demand on lying down on the couch, the body's clever, "I don't have to. I don't have to have this capacity to move around as I'm not moving around." Once you start moving around your heart and everything starts to adapt? There are healing processes of movement.

Claes Nermark (33m 41s):

Once you get into a decent amount of movement, maybe then you get enough energy to exercise as well.

Geoff Allix (33m 47s):

Thank you so much for being on Living Well with MS Coffee Break and allowing the community to get to know one of its own members a bit better. One last question before you go, we have a tradition to try and tap into your experience of MS and specifically OMS. Could you give a piece of wisdom to maybe help people who are newly diagnosed better adapt to the program?

Claes Nermark (34m 18s):

I would say I have two pieces of advice. First, I'd like to quote a quite famous sports brand and say, "Just do it," because in the Facebook group for the newly diagnosed, they come in and say, "Well, maybe I should wait for a little." Then people jump in, "Start right now," because the sooner you start, the sooner you will reap some benefits. As it will probably take a couple of years before you have a full-blown effect of whatever you do with the OMS program, so just do it. Get into it, but on the same note, do not do it all at once.

Claes Nermark (34m 59s):

That might be overwhelming. When you get newly diagnosed, just make sure you add good things like flaxseed oil and check your vitamin D levels. That way they can add good things without taking anything away. It's not a threat. It's not a turnaround of your life or anything like that. Becoming a trained health coach, they talked about crowd-outs. You add good things instead of focusing on taking things out. If you add good things and add good habits, suddenly the old bad habits are just crowded out of your life. Step-by-step, but just do it.

Geoff Allix (35m 39s):

Thank you very much for that. Claes, thank you for joining us on the Living Well with MS Coffee Break.

Claes Nermark (35m 45s):

Thank you. It's an honor being on the show.

Geoff Allix (36m 27s):

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