

S3E42b Transcript

Coffee Break #23 with Katy Glenie

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.

Geoff Allix (45s):

Finally, don't forget to subscribe to the show on your favorite podcast platform so you never miss an episode. So, get your favorite drink ready and let's meet our guest. Welcome to Living Well with MS Coffee Break #23, where we are pleased to welcome Katy Glenie as our guest. As always, your comments and suggestions are welcome by emailing podcast@overcomingms.org. We hope you enjoy this episode's conversation with Katy coming to you straight from Taupo, New Zealand. So, Katie, welcome to Living Well with MS Coffee Break. We're very pleased to have you on our program and just to explain the purpose of this series is to better get to know some of the diverse members of our community from around the world. And today you're in the hot seat.

Geoff Allix (1m 26s):

You live in what sounds like an idyllic place. So, could you tell us a little bit about Lake Taupo in New Zealand?

Katy Glenie (1m 34s):

[unintelligible], Geoff. Thank you for having me on the program. It's lovely to chat with you. Yes, I live in the most beautiful place in the world, Taupo out there in New Zealand. So, we're on the edge of New Zealand's biggest lake and in the distance, some beautiful mountains on the edge of the lake. And that's one of the reasons that we moved to Taupo three years ago actually was to start doing a bit more mountain climbing, rock climbing, and I also love to swim and it's a freshwater lake and one of the cleanest lakes in New Zealand. So, it's beautiful swimming as well in the summertime. So, we were very lucky to live here.

Geoff Allix (2m 16s):

And when were you diagnosed with MS. And could you provide a bit of a backstory of that?

Katy Glenie (2m 23s):

Yeah, sure. So, I was diagnosed with MS around two and a half years ago. It was actually soon after we moved to Taupo, came as quite a shock as it will do for most people diagnosed. I have no family history of MS. We came to Taupo and we're really excited to start enjoying this wonderful outdoor lifestyle. We have a young daughter, so she would have been two at the time. And I had a, what I now know is a relapse. So progressively more and more pins and needles, numbness, loss of sensation on my right side.

Katy Glenie (3m 3s):

And eventually that turned into what I now know as the classic MS hug, so I was really struggling to breath doing anything more than very basic sort of day-to-day things. It took a really long time for me to get diagnosed through our public health system. So it was, it came eventually as a bit of a relief to have a name against what was happening to me, but it was also a huge shock. I imagined that I, within weeks might be in a wheelchair, which I now know is not the case, but I guess that's where my brain went and I thought, wow, how am I going to be a parent? How am I going to be a wife and a contributing part of a relationship?

Katy Glenie (3m 50s):

And how am I going to be able to engage in this beautiful outdoor lifestyle that we had come to Taupo to experience? So, it was a rough time.

Geoff Allix (4m 1s):

So, you've, you said you live in a beautiful but remote place. So, what are some of the challenges of having MS and living somewhere that's quite distant and remote?

Katy Glenie (4m 13s):

Yeah, thanks for asking that question, it is really challenging. And I hadn't realized that until I started to try and engage with the health system from a regional community. So, there's a lot of driving to appointments quite far away because our local hospital is really just very basic. The neurologist I see is just a visiting neurologist, he comes to the hospital at a town that's over an hour's drive from where we live and all of the services like MRIs and specialized testing and my infusions that I get are all done in another town.

Katy Glenie (5m 1s):

So, there's a lot of driving and there's a lot of sort of, I guess, stress around trying to find out if you're getting the right treatment, because there's no MS specialists anywhere near where I live or the specialists that we have around the main centers. So that's, I guess another complication.

Geoff Allix (5m 19s):

But you managed it well, do you get over those problems?

Katy Glenie (5m 25s):

Yeah. Yeah. I mean, everything's surmountable in the end, but it's just, you just kind of have to navigate your way through and try and find support where you can get it. So, for example, I found an excellent neurophysio who's based in Auckland and I've seen her through online sessions. And initially I thought, how do you see a physio online? Like, don't they have to see you doing exercises. But actually, most of the time we just talking about where I'm at, where I could go to next, what some of the challenges I'm facing might be.

Katy Glenie (6m 6s):

And then I just fly up and see her every sort of three or four months in person. And that actually worked really well. So, you sort of be a bit creative in that way. And the other thing that's, to be honest has been absolutely excellent are Overcoming MS tools and support that's available online, because that has been a huge source of inspiration and support for me on this journey.

Geoff Allix (6m 32s):

That's good. And one thing actually has been a good side of COVID is that actually the online ability to do things has gotten much better. I'm the same my-- I just spoke to my neurophysio last week, but although I can normally see her, that's very restricted because of coronavirus. But actually they, everyone has made real efforts to be able to do things virtually and you're right. Actually, I didn't need to physically see her. And it was easier just to do this, do it over Zoom, and we could have a conversation and actually get some things resolved and it was a good meeting. And I think things hopefully will stay like that because we've got this ability to communicate that's been improved because we had to.

Katy Glenie (7m 19s):

Yeah, yeah. I did notice that the, you know, like the webinars series that are in this, going through the different parts of the protocol and some sort of ideas and inspiration, you know, I feel like that might not have happened unless COVID sort of, or maybe sped things up a little bit and it, you know, I would have gone on a retreat if I could have, but that was all kind of closed down and with all the institutes not operating, so that option isn't there for me and being able to see all that stuff and engage with the little message boards and that, that's been really cool.

Geoff Allix (7m 60s):

And when did you come across OMS and why did you start, when do you decide to start to follow it?

Katy Glenie (8m 8s):

So, Dr. Google found me OMS, Dr. Google is an amazing resource. And I mean, I sort of had a look about, but it wasn't long until I found that. And then I know you've mentioned before on previous podcasts that you, you know, you like the idea that it's not selling you on a thing. And that appealed to me as well about really the research and that's quite genuine. So yeah, I came across it really quickly. And then I soon, you know, I started to see that people were having good results and I know, you know, the results on an individual level will be hugely variable depending on your situation and those sorts of things, but just having inspiration there, listening to people that I'm going to doing really well and that I encouraged them moving forward.

Katy Glenie (9m 1s):

That's been, yeah, it's been really good.

Geoff Allix (9m 4s):

And what are some of the challenges you've faced in implementing the OMS protocols?

Katy Glenie (9m 12s):

So first thinking about this before this conversation started, you know the hardest thing was I was not even vegetarian. I was a full meat eater; I had a lots of meat at every meal pretty much. And we, you know, I think we eat veggies here maybe once every three months and we had lots of cheese. So, it's kind of like, how do you cook without meat and cheese, is that even a thing? So that's been a real learning curve for us. We're kind of on a good record now, but that took a long time.

Katy Glenie (9m 52s):

And my husband was a very much a meat eater and he was like, well, when do I get to eat the steak? And I'm like, just put it on top. I just won't have those fats.

Geoff Allix (10m 2s):

I came from a very similar-- I say, in some many ways actually with your hobbies as well. So, I was into rock climbing and outdoor sports and might have by the case of surfing and very, very, very active, but my diet was terrible. It was very processed as well, as well as being mostly meat. There's a lot of pies. Yeah. There was a lot of fried food, a lot of cheese. And you wonder whether that contributed, I don't know, but I thought I was okay because I was so active. I was slim. And I thought, well, if I'm slim, then eating all that food is not doing me any harm, I'm burning it off.

Geoff Allix (10m 43s):

And you don't realize that there are other side effects to what you eat and, you know, heavily processed food is never going to be good. And yeah. Food with high fat.

Katy Glenie (10m 54s):

You know, [inaudible]. We're quite lucky in New Zealand, I mean, you know, everyone's a bit different, but our diet generally isn't that processed, but definitely a lot of meat. And, you know, fat, you know, I used to say to friends, fat's back, don't worry fat's back. You can eat as much as you like it's safe and you know, it keeps you [inaudible] So definitely, it was a big challenge. And the other thing that was initially a bit of a challenge, but it's now something I've come to love was the meditation. I mean, I own my own business. I have a young daughter and I'm very active in the community, and then the outdoors.

Katy Glenie (11m 39s):

And I was like, when do you fit this in? This is ridiculous. They're asking you to meditate every day, who does that? And then actually my physio said to me, as part of fatigue management, she said, you need to do something that rests your brain every day and you need to do it not right at the end of the day, when you're trying to go to sleep, you need to do it at a time when you really going to benefit from having your brain rested, which is the middle of the day. She said, you need to sit down, and you need to stop everything that's going on. All the stimulation, no reading, no listening to what's going on in the news. You need to just quiet your brain down.

Katy Glenie (12m 20s):

And I was like, geezers even the physio is telling me to do this, all right, I'll give it a go. And so, you know, put your Air Pods on and listen to this woman telling me to chill out. And after a while, I was like, this is amazing. This is, it's been a really, really beneficial change to my life adding meditation to the bag, and now I do it religiously every day.

Geoff Allix (12m 43s):

That was like my physio as well. And she said, my first neurophysio said, don't forget your mind, which I found really strange because I thought they would be, it's all about exercise and they would ignore all the other elements. And that would be their thing. But yeah, he said, no, you must think about your mind as well. And he was sort of talking about, you know, think about yoga and think about different things, but basically try and not get stressed out, calm your mind. And it was really interesting to get that from someone who's actually from a different field saying that they see benefits from people who practice mindfulness, stress relief, yoga, those sort of things.

Geoff Allix (13m 25s):

So, when did you start to see positive benefits from following OMS and what were these?

Katy Glenie (13m 32s):

Well, it's taken longer than I had thought, but it's been a slow progression of less symptoms. So, my symptoms have been mainly pins and needles and sort of lack of sensation. And then also I would get, I get problems around fatigue and heat tolerance. So, when I get too hot, I get really, really tired and all my symptoms, my pins and needles go a bit crazy. So, what I've noticed at the start, I didn't really notice anything, but over time I noticed that all the symptoms were getting less and less.

Katy Glenie (14m 21s):

So, I was still getting them, but I was getting them less frequently and they were lasting for a much shorter amount of time. But the thing that it really gave me, so that's obviously a benefit, but the thing that it really gave me was a sense of hope and a sense of focus. So, I knew I just needed to keep following the steps and keep working through it and it gave me some autonomy over my own health. I wasn't sitting and waiting to see if there was a new medication that was going to save me. I wasn't, you know, waiting to see if some amazing new neurologist was going to come into our town. I felt that I had that autonomy over my own health, and that has been probably the biggest benefit to the program.

Katy Glenie (15m 4s):

So, I have definitely seen improvements in my symptoms, but in terms of my outlook and my approach to life, that's where I've really benefited. And I feel that I've got much more confidence to continue to live a full life.

Geoff Allix (15m 20s):

And I think that the book talks about that. Having faith in there is actually, medically if people believe they're doing something and they know they're empowering themselves, and they're doing something to get better, that actually has a point of positive benefit. And there's an element of that in placebo effect. So, if you give someone a sugar tablet, but tell them it's the latest, greatest medicine, then the proportion of those people get better because they think they're doing something. And then your mind is so powerful that actually it can have an effect. And so, it's actually part of the program that you need to believe in the program, you need to read into it and understand it because that belief in itself is in itself a positive benefit.

Katy Glenie (16m 6s):

Yeah. And I've really experienced that. So, I mean, we'll come on to talk about it soon, but I guess taking on physical challenges and taking on things that initially I thought might not be possible for someone with MS, they just come through following the program. So, I just have belief that what I'm doing is helping my body for the long term and that I can go on to do challenging and exciting things that I might've thought were not possible.

Geoff Allix (16m 40s):

Well, talking about that then. So could you tell us a bit about climbing and how you got into climbing and how you balance your health needs with rigorous physical activity and dangerous physical activities.

Katy Glenie (16m 56s):
Manage danger, Geoff.

Geoff Allix (16m 59s):

Well, I don't know if I mentioned this on previous podcasts, but I've actually had a compound fractured tibia and femur of my right leg when I was 17 years old in a rock climbing incident and I couldn't walk for six months. There are some, sort of man-- it was managed because I'm still alive, so.

Katy Glenie (17m 24s):

Oh, all right. Yeah. So maybe there is an element of doubt. Yeah. So, and I guess in my sort of personal time, I love doing lots of things in the outdoors. And two of those things are rock climbing and alpine climbing and what I've sort of been working on it. So, I was recently the lucky recipient of a grant that will -- it's called the Mastering Mountains grant that's hoping to pay for a major go and take on a peak in southern New Zealand. So, I'm going to plan a 3000m peak at the end of the year.

Katy Glenie (18m 6s):

And that grant has, was started by someone with MS who went from a wheelchair to climbing a mountain, doing lots of, you know, focused work on diet and exercise and mindfulness. And that really inspired me reading that and I thought, okay, well if he can do it, I'm sure I can. And so, once I got the grant, I guess I've kind of publicly said to the world I'm going to do this peak. And then I bought, I don't know how I just write it down on the application form. So, then I thought, okay, I need to work out how to do this. And my, so I got in touch with the neurophysio that I mentioned before, and she's helping me on the program, on my sort of fitness program.

Katy Glenie (18m 56s):

And what I've done is I've just started out sort of with something that I think is achievable. And I've just, I've always done a lot of tramping that I think to the rest of the world is hiking. In New Zealand, we call it tramping, I don't know why. And so, I went on an overnight tramp, and I took a friend and I said, hey, can you carry most of my stuff? I just want to see if I can physically walk this far, but I want to be able to do it more than just a bush walk, like the neighborhood. And that worked, and then I thought, okay, well next time maybe I'll carry a bit more gear, that worked. And then the next time I thought, maybe I'll walk a bit further.

Katy Glenie (19m 38s):

And so, I've sort of taken it in stages like that without pushing too far, but each time pushing a bit further. And I just make sure I'm really listening to my body. So, I've got some great tips on what to do if my symptoms are a bit [inaudible], so, you know, take a rest, take some water, get something to eat, get yourself a decent rest, you know, 20, 30 minutes and then start again. Don't think I've just got to push through this you know, if your body's saying to stop that's okay, but that doesn't mean you have to turn around and go home. And then I've also recruited, I guess, some great friends who are helping me, so they know what's going on for me, they understand that sometimes I might want to walk slower or that I might want to rest a bit longer than they would normally rest.

Katy Glenie (20m 29s):

And they've all been really supportive with that. So, I guess it's about recruiting people to help you along the way, getting good knowledge and information about how to manage your symptoms when you're going through them. And also, just to not be afraid to push yourself a little bit further, you don't need to push yourself to the point of getting a relapse, but you do need to push yourself beyond just walking down to the litter box and back every day.

Geoff Allix (20m 55s):

You've mentioned Alpinism and climbing mountains, but for those people who don't know what alpinism is, and because it's a bit more than what you're saying is tramping and what mountain are you climbing? Because it's not, it's not a sort of like, yeah, it's not small hill.

Katy Glenie (21m 17s):

Yeah. Fair enough, yeah. So, I guess we aren't tramping because at the moment the snow hasn't come on yet. So, I'm waiting for the snow to come before I can start going on the mountain. And tramping is really good training for mountain climbing, but alpinism is when you are on the mountain and you have an ice ax in your hand, you have crampons on your feet. You have lots of warm gear on, and you've probably got a harness around your belly, and you're attached with the rope to someone else. So, entry level mountain climbing, you might not get ropes, but as you get better and on to the more technical climb then you're often roped to your climbing partner, and you would be off to climb something that might involve quite a steep slope, that might involve a bit of ice and snow and rock and a [inaudible] ideally you top out on some sort of summit.

Katy Glenie (22m 11s):

And that's what my objective is at the end of the year is to climb a peak called the Minarets, which is on the spine of the Southern Alps and the south of the South Island of New Zealand. And I'll be doing all those things, ropes and ice axes taking on some steeper slopes on a snowy peak.

Geoff Allix (22m 39s):

And on another subject, one of your other passions is caring for the environment and reducing consumption. So how do you put that into practice in daily life? And is there anything that could enlighten our listeners about this?

Katy Glenie (22m 55s):

Oh, I love that question. Awesome. So, I'm really, really passionate about looking after the land that we are so deeply connected to. And I guess for me how that works in daily life is I think a lot about reducing my consumption. So that's probably one of the easiest ways to summarize sustainability is that less is best. So, if you can buy less, if you can grow more of your own food, if you can buy things without packaging, if you can reduce your food waste, if you can drive less or drive-- we have an electric car, so we'd drive that, if you can share your ride with someone else that is less of you and different cars.

Katy Glenie (23m 44s):

If you can think about flying less, or if you can think about buying less things for your home, you don't need two TVs, you might need one. You don't need five sofas, you might need one, and it could be a sofa that's been used by someone else before it came to your house. All that sort of way of living is something that I really enjoy. And I liked the idea that through my actions, I can make an impact. And also, if I'm sharing those stories with other people, they can start to learn how they can also have a positive impact.

Geoff Allix (24m 21s):

Yeah. I noticed, I mean, we're very good at recycling, but we're now at a phase where someone said, you start off you need to recycle more and then you need to recycle less because actually there's an awful lot of stuff going to recycling and that's not necessarily a good thing. There's a huge amount, I mean, certainly in the UK, the amount of plastics in everything you buy and if you buy anything from Amazon, sorry, and other retailers are probably the same. I shouldn't just call them out, but if it comes in a box, in packaging, in another box. And it's like, sometimes you end up with three or four boxes to actually get inside the thing that's in the middle and yeah.

Geoff Allix (25m 3s):

The packaging and plastics and just buying food stuff, everything is covered in plastic.

Katy Glenie (25m 10s):

Yeah. And don't underestimate the power of one person because I think, you know, we're getting more and more understanding right now around the world on the issue and all those voices are getting louder and louder, you know? So, I would like to think that one day when you go to a UK supermarket, not every item, not every vegetable is single wrapped in plastic. Cause when I lived in the UK, hopefully it's different now, but when I lived over there, everything was individually wrapped because it comes from Ecuador or Argentina or something, that's like-- you know, limes aren't in season right now.

Katy Glenie (25m 51s):

So why are limes in the supermarket? [crosstalk]

Geoff Allix (25m 56s):

I would say there's less plastic now, but it still comes around the world and you can't explain it to your children, that you can't have an avocado this time of year because they don't grow. They're going to go, I want avocado, or I want strawberries, but it's December and they can get strawberries and that's the problem. Yes, they're from Peru or Kenya or, you know, they've flown them in an airplane. That's insane to do, but that's not-- I mean, I think it's a generational thing because when I was growing up, you ate what you could eat in season. And that was that.

Katy Glenie (26m 33s):

We did try to eat in season here. And I guess the other flip side of it, as, you know, the UK is kind of much more attached to a global economy. In New Zealand if the strawberries come from Argentina, they will be way too expensive for anyone to buy. So, no one will buy them. So we only buy strawberries when they come from New Zealand, because they're affordable and so I guess there's a bit of just that understanding that if you think every time you're wanting to buy something, just because it's something that you really need and if it is, try and buy second hand or try and buy it from a local supplier who might've made it locally or might be quite thoughtful about how much sort of [inaudible] and carbon dioxide has been involved in producing that item because it's, yeah.

Katy Glenie (27m 26s):

It's just being sort of a bit more thoughtful about your life.

Geoff Allix (27m 32s):

Okay, interesting perspective. So, if you tap into your-- back to MS. If you tap into your experience with MS generally and OMS specifically for a nugget of wisdom, what will help people adopt the OMS program?

Katy Glenie (27m 50s):

I guess for me, it's about that sense of community, that you're surrounded by others that are following the program and want you to do well and want to support you on that journey. And it's also understanding that even if you're not getting amazing results straight away, and you're not, you know, suddenly feeling better, it's a journey. And part of that journey is the belief that you're doing something that's positive for your health. And if you can kind of keep on that hopefulness and positivity, that will help you so much and your health and in your general wellbeing and outlook.

Geoff Allix (28m 36s):

And with that, I'd like to thank you very much for joining us, Katy Glenie.

Katy Glenie (28m 42s):

Thanks, Geoff.

Geoff Allix (28m 42s):

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Geoff Allix (29m 23s):

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